An exploration of the potential benefits of a read-aloud program to the wellbeing of cancer patients undergoing treatment: A mixed methods study.

by

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Dedication

This research is dedicated to the memory of some amazing women: my mum, Irene Wells, who read for as long as she was able; and my cancer pin-up girls, Jane and Lynne, who taught me how to find happiness in the midst of diagnosis and treatment.

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Glossary and Abbreviations

ASRA Adult Survey of Reading Attitude.

Bibliotherapy "the use of reading as therapy" (HarperCollins, 2021, Definition 1). Various forms of bibliotherapy exist, using fiction and non-fiction, and independent, guided or group sessions.

BoP Books on Prescription schemes, using self-help books (often based on cognitive behavioural therapy) endorsed by health professionals which may be prescribed by treating physicians or obtained via self-referral for their therapeutic content.

Cancer patient is the term used here to denote a person affected by cancer who is currently undergoing treatment. Recognising that some health professionals prefer the term 'survivor', even from the time of diagnosis, it is not the preferred term of the researcher and many others who have been affected by cancer because it carries connotations of battle and the logical conclusion that those who did not survive their encounter with cancer lost their battle, which in turn carries other implications, such as perhaps they did not fight as hard as those who survived. Additionally, in the researcher's experience, referring to everyone diagnosed with cancer as a survivor when some people are already late-stage and palliative when diagnosed, seems like a cruel misuse of a label for the people who will clearly not survive. Like many others who have experienced cancer, the researcher is uncomfortable with the term cancer 'survivor' (American Society of Clinical Oncology (ASCO), 2024; Bell & Ristovski-Slijepcevic, 2013; Berry et al., 2019; Cancer Council NSW, 2021b; Fitch, 2019). This study targets cancer patients and those who have had a cancer diagnosis and are within a year of receiving treatment.

CBT Cognitive Behavioural Therapy.

CRCI Cancer-Related Cognitive Impairment, commonly known as chemo fog or chemo brain, or more recently, cancer fog or cancer brain.

DASS-21 Depression, Anxiety and Stress Scale (short form).

EORTC European Organisation for Research and Treatment of Cancer.

Existing readers those who regularly read for pleasure.

HRQoL Health Related Quality of Life.

IFLA International Federation of Library Associations and Institutions.

Integrative oncology to complement conventional cancer therapies and assist in the management of symptoms and side effects of both cancer and treatments, patients are offered therapeutic interventions like music and art therapy, yoga, exercise classes, mindfulness and massage, to heal and support the whole person (mind, body and spirit). Also called Supportive Cancer Care.

LIS Library and Information Science.

New readers those who have reading ability but do not regularly read for pleasure.

PLV Public Libraries Victoria.

Psychosocial (in medicine) associated emotional, mental, spiritual and social effects of a disease; “some of the psychosocial effects of cancer are changes in how a patient thinks, their feelings, moods, beliefs, ways of coping, and relationships with family, friends, and co-workers" (National Cancer Institute, n.d.).

Psychosocial oncology addresses psychological, emotional, behavioural and social issues experienced by cancer patients and their families.

QoL Quality of Life.

RA Readers’ Advisory.

RAYS Reading and You Scheme (also known as Reading and You Service), group bibliotherapy approach originally established in Kirklees, UK in 2000, which by 2018 evolved into **Words in Mind**, developed from the bibliotherapeutic approach of reading any fictional or poetic material (including sensory resources, visual imagery and songs), chatting about books and sometimes also involving some participant writing, for mental health support including mild to severe mental health problems and dementia (Brewster & McNicol, 2021). Tailored for group members and therefore considered an approach rather than a single model of bibliotherapy (Brewster & McNicol, 2019).

RCT Randomised Controlled Trial

Read-aloud program and **intervention** mean the same thing in the context of this research and the terms are used interchangeably.

RfW project Reading for Wellbeing project was launched in northeast England in 2020 by author Ann Cleeves in recognition of the solace that stories have always given her.

Community Reading Workers facilitate access to books and support reading for pleasure to improve wellbeing, often with people experiencing loneliness, ill-health (physical or mental) or with caring responsibilities, providing one-to-one support and tailored reading suggestions when needed (Reading for Wellbeing, n.d.-b). Their motto seems to be "finding solace in stories" (Reading for Wellbeing, n.d.-a).

RR given to mean rural or regional participants in this study.

SLV State Library of Victoria.

SR Shared Reading program/model developed by UK charity The Reader (also known as The Reader Organisation or TRO), beginning in 2002. Group reading sessions with a facilitator. Only literary fiction (also referred to as serious literature, classic literature, literary canon or great literature) or poetry is read. The works are read aloud by the facilitator, with pre-determined points for pausing to check understanding and allow discussion of personal issues that may have arisen during the reading. The program was previously known as Get into Reading (GiR) (Davis et al., n.d.).

TA Thematic Analysis. Reflexive TA was used in this study.

UniSA University of South Australia

Wellbeing "The state of being or doing well in life; happy, healthy, or prosperous condition; moral or physical welfare" (Oxford University Press, 1989). Various definitions around the number of dimensions of wellbeing exist, for instance the model of eight dimensions lists them as intellectual, physical, social, occupational, emotional, financial, environmental and spiritual (Thrasher, 2015). All the definitions or approaches share an emphasis on a positive state of life (not merely an absence of dysfunction), including concepts of psychosocial functioning, flourishing, happiness and satisfaction (National Center for Complementary and Integrative Health, 2021).

WEMWBS Warwick-Edinburgh Mental Wellbeing Scale.

Yarn Australian yarn (also known as Aussie yarn). Fictional short story of any genre but is often humorous. Yarns are generally rich in setting and/character descriptions, always involve some kind of adventure and are generally very engaging. They are written in a chatty style and always set in Australia. Australia is considered a storytelling nation, perhaps because of the rich storytelling tradition of the First Nations peoples, for whom yarning is telling a story that may be of any length (much like a piece of yarn).

Abstract

"Reading is what connects us … reading opens the doors to whole new worlds … we know that reading, particularly reading for pleasure, has an impact on people's life outcomes."
-Sarah Hall, Jonathan & Alix Langley (The Reading Agency, 2022, 1:50-5:48)

Reading and bibliotherapy are known to improve wellbeing and mental health. Bibliotherapy, or reading for therapy, comes in many guises, and the tools generally employed are cognitive based therapeutic self-help books or fiction and poetry. However, the joy and therapeutic benefits derived from reading can be elusive for those undergoing cancer treatment. People with cancer often experience cancer related cognitive impairment (CRCI). CRCI can mean concentrating sufficiently to read to oneself can become frustrating then impossible. People diagnosed with cancer may also experience distress, physical, emotional, familial and financial pressures, all of which are exacerbated by treatment and associated side effects. Reading may be one way of providing distraction or positive experiences during this difficult time.

This research explored a read-aloud program and its impact on the emotional wellbeing of people undergoing cancer treatment and their families. It was an exploratory study, using an experimental pre/post design and a mixed methods approach. The research was phenomenological, using a participatory worldview. Thirty-eight people currently undergoing or within 12 months of cancer treatment were recruited for the six-week read-aloud intervention, which was delivered weekly, one-on-one at participants' homes, local libraries or online for rural, regional and interstate participants. The Depression Anxiety Stress Scale – Short Form (DASS-21) and Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) were administered, and standard statistical analyses were conducted on the pre- to post-intervention wellbeing scores: one-sample t-tests for normally distributed data and Wilcoxon Signed-Rank Tests for skewed data. Interviews with participants and family members were conducted following the conclusion of the intervention and reflexive thematic analysis was performed to identify themes related to their experience of the program.

The intervention resulted in statistically significant reductions in self-reported stress (p = 0.004), anxiety (p = 0.000) and depression (p = 0.015), and increased wellbeing (p = 0.001). Qualitative feedback was overwhelmingly positive. Key wellbeing themes were relaxation, mood lift, increased self-efficacy for everyday activities, "time out" and feelings of warmth/special/treat. Distraction and escapism was reported to benefit mood, pain relief and

relief from nausea. Individual tailoring and delivery of the intervention was important to participants, as was their sense of connection to the reader. The intervention reportedly provided comfort and/or respite for family members. With an emphasis on recruiting both metropolitan and regional/rural participants, it was hoped that comparisons could be made between the two populations, however the small number in the regional/rural group and subsequent low statistical power resulted in outcomes being assessed across the entire cohort rather than by geographic location. A future study could focus on recruiting more regional/rural participants.

The emotional wellbeing of cancer patients undergoing treatment and participating in a read-aloud program has not been previously examined. The original contribution of this piece of research is the combination of psycho-oncology and bibliotherapy, acknowledging that cognitive impairment is a common accompaniment to cancer that can prevent reading. This research provides support for the implementation of read-aloud programs in integrative cancer care, cancer centres, hospices and as part of community palliative care programs to improve patient wellbeing.

Declaration

I declare that:

this thesis presents work carried out by myself and does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; to the best of my knowledge, it does not contain any materials previously published or written by another person except where due reference is made in the text; and all substantive contributions by others to the work presented, including jointly authored publications, is clearly acknowledged.



13/12/2024

Elizabeth Wells

[Signature] [date]

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Chapter 1. Introduction

"A miraculous alchemy occurs when one person reads to another, transforming the simple stuff of a book, a voice and a bit of time into complex and powerful fuel for the heart, brain and imagination." (Cox Gurdon, 2019, back cover)

1.1 Background and Rationale

A cancer diagnosis carries connotations of illness, hospitals, pain and death, and for many is shocking and overwhelming. The treatment journey, despite the best medical care, can be arduous and the destination cannot be predicted. The uncertainty is enormous as is the emotional burden for individuals and their families (Cardy et al., 2006; Galway et al., 2012; Lewis, 2010; Matthews et al., 2003; Rossman & Shrock, 2009). Opportunities to improve emotional wellbeing and quality of life are sought-after and people with cancer are using art, music, mindfulness, movement and touch therapies to help (International Psycho-Oncology Society (IPOS), 2024; McDonald et al., 2022), but bibliotherapy, despite the plethora of studies supporting its usefulness, does not exist in many integrative oncology regimes.

Holistic cancer treatments recognise the importance of treating psychosocial (emotional or mental health, social effects and spiritual wellbeing) as well as medical needs. Bibliotherapy, long recognised for its therapeutic benefits but not widely known, can help improve emotional wellbeing (Billington, Longden, et al., 2016; Davis et al., 2016; Helfgott, 2017; Malyn et al., 2020). Health care staff working with people affected by cancer should be aware of effective adjunct therapies, and bibliotherapy could be considered as part of that toolkit. However, chemotherapy, radiation, hormones or other interventions, combined with the body's own response to tumour growth, frequently decreases cancer patients' ability to concentrate (Winocur et al., 2018), which has the potential to limit or eliminate their ability to read for education or pleasure. Therefore, possible benefits of read-aloud/listening programs for improving the emotional wellbeing of cancer patients undergoing treatment requires exploration.

Cognitive impairment in cancer patients (called Cancer-related Cognitive Impairment or CRCI) during and after chemotherapy and other cancer treatments is a common occurrence (Ahles & Root, 2018). This impairment has been seen in some people diagnosed with cancer prior to the commencement of treatment, however, treatment exacerbates the condition (Winocur et al., 2018). CRCI affects memory, attention, processing speed and high-level cognitive functions such as planning and performance monitoring (Joly et al., 2015) and as a

result it can frequently deny avid readers their reading habits and enjoyment, yet the link between oral reading programs and cancer patients remains unexplored. A read-aloud program may benefit the emotional wellbeing of cancer patients undergoing treatment, whether by reconnecting them to their love of reading, or helping new or lapsed readers connect with, and hopefully delight in, reading and all its benefits.

Studies indicate the importance of holistic treatments to improve the physical and emotional health of people affected by cancer, and adjunct therapies such as exercise, psychotherapies and artistic therapies are recognised as an important part of the modern cancer treatment regime (Bardia et al., 2009; International Psycho-Oncology Society (IPOS), 2024; McDonald et al., 2022). Oral or storytelling traditions have occupied an important place in many cultures for hundreds, even thousands, of years and hearing a story affords us the opportunity to immerse ourselves in a setting, characters and plot, and connect to both the story and the teller. Therefore, linking these two ideas to produce a read-aloud program as a possible complementary therapy for cancer patients was considered worth exploring.

This research topic arose from the researcher's experience, particularly as she worked in small public libraries in central Victoria. Noticing avid readers amongst family, friends, and the community lose their ability to read for pleasure during cancer treatment was the impetus for this study. Despite suggestions of large print books, magazines and audiobooks, many of these readers still could not enjoy reading and were thus losing the therapeutic benefits reading can provide. This prompted an interest in why this was occurring and ways to rectify it if possible.

Research continues to identify benefits of reading and bibliotherapy for physical and mental health, even showing a relationship with increased longevity (Bavishi et al., 2016); yet there are few studies examining bibliotherapy with cancer patients, and even fewer concerning read-aloud programs where the only expectation is listening. Reading for wellbeing has been explored across a variety of disciplines: library and information science (LIS), creative arts, and health sciences, including medicine, nursing and psychology. The aim of this project was to undertake an exploratory study to investigate the potential of a read-aloud program to improve the emotional wellbeing of cancer patients undergoing treatment.

This research was undertaken from an advocacy/participatory perspective, within a pragmatic paradigm, using a mixed methods framework in an experimental pre/post design and an exploratory sequential approach. The intervention involved reading aloud to cancer patients for six weeks either over the course of their treatment, or within their first year after

treatment. Fiction, poetry and narrative nonfiction, including Australian yarns, was read. Audiobooks were not utilised, as the research was underpinned by the benefits of social support and human interaction that are achieved by face-to-face connections, and also with the intent of not burdening people in the midst of their cancer-related cognitive impairment (CRCI) by asking them to try and operate audiobook technology. Throughout this thesis, the term *read-aloud* is given to mean oral reading, or reading aloud, and in the case of this research, the oral reading was done by a dedicated person (the *reader*) while participants listened to stories read aloud in real time for their pleasure.

To determine if the intervention improved the emotional wellbeing of participants, wellbeing was measured using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) and stress, anxiety and depression were measured using the Depression Anxiety Stress Scale short form (DASS-21). These instruments were administered prior to the commencement of the reading intervention and then at the conclusion of the program to facilitate comparison of pre-/post- intervention scores and perform statistical analyses on the differences. As a secondary measure, participants' attitudes to reading were measured using a condensed Adult Survey of Reading Attitude (ASRA). Individual semi-structured interviews with participants and family members were conducted and analysed thematically. Mid-point surveys were administered to determine enjoyment (or otherwise) and elicit any ideas for improvements that could be implemented in the remaining sessions. Observations were systematically collected throughout intervention delivery to inform future choices of reading material and to triangulate with interview data.

1.2 The Cancer Context

The number of cancer cases in Australia rose from 47,462 cases in 1982 to 131,452 cases in 2015 (Cancer Australia, 2019). Last year, an estimated 165,000 Australians were diagnosed with cancer (Australian Institute of Health and Welfare, 2023a, para. 2). Currently, in excess of 1 million Australians live with or beyond cancer (Australian Institute of Health and Welfare, 2021), and this is expected to rise with a projected 4.56 million new diagnoses between 2020 and 2044 (Cancer Council NSW, 2021a; Luo et al., 2022). Although cancer is a leading cause of death worldwide (National Cancer Institute, 2024), survival rates are improving. The overall five-year cancer survival rate was 53% in the early 1990s, yet it increased to 71% by 2015-2019 (Australian Institute of Health and Welfare, 2023b, para. 7). As people live longer following a cancer diagnosis, the need to intervene to promote quality

of life and ways of coping with treatment side effects (such as CRCI) becomes more compelling.

A cancer diagnosis often elicits a plethora of feelings: anxiety, nervousness, fear, depression and distress (Aldaz et al., 2017). However, numerous studies show doctors significantly underestimate their patients' psychosocial distress (Adler & Page, 2008). In the wake of King Charles' recent announcement about his cancer diagnosis, Maggie's Cancer Care Centres (the pioneers of cancer wellness centres (McDonald et al., 2022)), issued a statement including advice about getting support following diagnosis because "the emotional impact of a cancer diagnosis can be as hard to deal with as the physical impact" (The Maggie Keswick Jencks Cancer Caring Centres Trust, 2024, Importance of support after a cancer diagnosis section). Cancer treatments can be physically and emotionally exhausting. However, by addressing psychosocial needs, morbidity is reduced (Adler & Page, 2008). This research is intended to determine whether bibliotherapy is an appropriate additional tool for the oncology psychosocial toolbox.

1.3 Research Problem

In the way that education seeks to embrace the whole child, modern cancer treatment needs to embrace all aspects of patients' lives. "Whole person medicine" is an underlying principle of integrative oncology (Abrams & Weil, 2014, p. 2) and it was the psychosocial impact of cancer that led to the establishment of the field of psycho-oncology, with emphasis on the emotional, spiritual and psychological impacts of both the disease and associated treatments. Unfortunately, despite the proven benefits, psychosocial support is frequently not offered to cancer patients (Lally et al., 2020; Zebrack et al., 2016). However, a number of low-cost support options, including bibliotherapy, exist. The problem is reading is not linked to cancer support in Australia, nor does it seem to appear in overseas integrative cancer centres. This could possibly be due to a lack of strong evidence of its benefits in this population – a gap this research seeks to explore. Bibliotherapy could offer some respite for cancer patients and minimise the impact of CRCI on reading ability. Delivering stories audibly may be a feasible path for bibliotherapy implementation.

1.4 Research Aim

The aim of this research is to explore the role of a read-aloud program as a mode of bibliotherapy aimed at improving the emotional wellbeing of cancer patients undergoing treatment. The intention is to empirically test whether listening to stories for pleasure, despite

difficulties with concentration and reading, benefits the emotional health of people undergoing cancer treatment through human connection and storytelling.

Hypothesis: The read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment, as indicated by increased self-reported wellbeing and decreased symptoms of stress, anxiety and depression, and will provide a positive experience for those involved.

1.5 Research Questions

1. What impact does regular participation in a read-aloud program have on the emotional wellbeing of cancer patients currently undergoing treatment?

2. What are the perceived psychosocial effects of a read-aloud program from the perspectives of patients and families?

1.6 Significance of the Research and Contribution

Despite ever-increasing cancer treatment options and improved survival rates, scholars and clinicians also need to continue searching for ways to support cancer patients in mind and spirit. The benefits of reading on mental health have been widely documented. The significance of this research is that it acknowledges the impact of cognitive impairment and seeks to draw together the concepts of improving wellbeing and reading, to inform the implementation of a read-aloud program in integrative cancer care.

This research contributes to the current bodies of work on bibliotherapy, integrative oncology and psycho-oncology. It is an original contribution demonstrating bibliotherapy through read-aloud programs can sit alongside other evidence-based complementary therapies aimed at improving the emotional wellbeing of people affected by cancer. Bibliotherapy, CRCI and the unmet emotional needs of people affected by cancer have all been individually documented, but no studies have explored the intersection of cancer patients and reading in individually tailored programs, with potential wellbeing effects resulting from regular read-aloud sessions as a bibliotherapeutic intervention.

Exploring read-aloud bibliotherapy using creative literature for people affected by cancer has not been studied before and therefore represents new knowledge in the fields of bibliotherapy and integrative cancer care.

1.7 COVID-19 Impact

Research began early in 2021, at a time of fear of COVID-19, when daily infection and death rates appeared in news bulletins, and border restrictions between Australian states existed, as did quarantines and lockdowns. Participant recruitment occurred late 2021 and throughout 2022, when COVID-19 was still extremely active, with new strains emerging. Mask-wearing was still mandatory in South Australia and quarantining after potential exposure was still required. Throughout this thesis, this time will be referred to as *during COVID-19*.

Conducting this research during COVID-19 meant justifying the need for a face-to-face intervention and the creation of a COVID-19 protocol; and it had an impact on participant recruitment and intervention delivery (as discussed in Chapters 3 and 6).

1.8 Thesis Structure

With a focus on the real life problem of the rising incidence of cancer diagnoses and the often unmet need for psychosocial care of people living with cancer, this chapter (Chapter 1) has introduced the context in which the research topic arose, the research problem and research questions, the significance of this cross-discipline research and the impact of conducting this research during the COVID-19 global pandemic.

Chapter 2 presents a review of the literature on the benefits of reading (to both physical and mental health), a brief historical overview of bibliotherapy, descriptions of the types of bibliotherapy in practice, and a review of studies reporting the therapeutic effectiveness of bibliotherapy. Arguments are presented for storytelling in the modern era as a reinstatement of ancient traditions. A review of the psychosocial needs of people undergoing cancer treatment, rural and regional impacts and the prevalence and impact of CRCI are presented, to further set the scene for this study. This chapter is presented as a narrative review due to the scarcity of literature on bibliotherapy in a cancer context.

Chapter 3 outlines the pragmatic approach for this mixed methods, phenomenological exploratory study, including justification of the chosen epistemology and ontology. The research design, intervention details and the theoretical framework for analysis are described, including an account of the implementation of reflexive thematic analysis.

Chapters 4 and 5 report the outcomes of the program. Quantitative findings are presented in Chapter 4. These findings indicate statistically significant reductions in stress, anxiety and

depression, and increased wellbeing, across the participant group from pre- to post- the bibliotherapy intervention.

Chapter 5 presents key qualitative findings from observations and the mid-point surveys, and detailed results from the interviews with participants and family members. Themes include improved wellbeing, the value of distraction and escapism for relief from treatment side effects and for improving mood, the value participants placed on the intervention design and human interaction, and effects on concentration.

In Chapter 6, key ideas and implications arising from the triangulation of qualitative and quantitative findings are discussed, including the importance of intervention customisation, some rural/regional, Zoom and gender differences, the role and possible effects of CRCI on reading, the strengths, limitations and learnings from the current study, the role libraries could play in implementing reading programs in cancer and palliative settings (as well as implications for current library staff in readers' advisory roles), and implications of the decision to use in-person reading in contrast to audiobooks and simple social contact.

Chapter 7 concludes the thesis with a summation of key findings and discussion of implications – both for future research and application to existing integrative oncology and palliative settings, with possible connections to public libraries and LIS education.

Chapter 2. Literature Review

As there is so little literature directly about difficulties reading while undergoing cancer treatment, and none found about bibliotherapeutic interventions aimed at circumventing these difficulties to provide holistic benefits, this chapter seeks to draw together relevant topics and their associated research, much like putting together pieces of a jigsaw puzzle. Firstly, the benefits of reading are examined, including the effects of reading fiction. Bibliotherapy can be a confusing term, and the reasons for this are explained. A brief history of bibliotherapy is presented, as well as a discussion of the main ways it is currently delivered. It is relevant to consider how bibliotherapy is currently used internationally, and to also explore attempts at instigating bibliotherapeutic programs and research in Australia, before looking at the evidence of the impact such programs can have on their participants, especially in the context of wellbeing. Storytelling is a vast topic, but only the subcategory of reading aloud as a mechanism for storytelling is examined.

In this phenomenological study, all participants had a lived cancer experience, and so cancer and its associated implications are considered. Cancer statistics, including rising rates of both diagnosis and living beyond treatment, are relevant in light of the need for psychosocial help, and this sets the scene for the need for research in this area. Anecdotally, it seems that cancer-related cognitive impairment (CRCI) may be a little-known phenomenon in the general community, and even among many people with cancer, yet it was this phenomenon that led to the discovery of the reading problem and gap in the research. Therefore, studies of CRCI are reviewed, particularly with respect to its impact on sufferers and likely mechanisms in the brain for this impact. There were no studies identified that combined bibliotherapy and CRCI, however there were some studies of bibliotherapeutic interventions for people with cancer, and these are examined.

This literature review pieces together evidence about reading in general, different bibliotherapy models, the need for additional emotional supports for people with cancer, the impact of CRCI, and existing research of bibliotherapy in cancer settings. Although these topics may initially appear disparate, their analysis and the subsequent synthesis of key ideas was crucial to the development of the intervention studied in this project.

2.1 Benefits of Reading

> "Reading is to the mind what exercise is to the body."
> -Joseph Addison (Addison, 1831/1710, p. 270)

The benefits of reading for our mental and physical health have been documented in many studies (Malibiran et al., 2018). Reading can physically strengthen our brains: reading is associated with a 32.3% reduced rate of deterioration of memory (Wilson et al., 2013, p. 316) and higher levels of cognitive reserve, which may provide physical protection to the brain from a number of harmful events, including from lead exposure (Bleecker et al., 2007) and from the development of dementia (Spitznagel & Tremont, 2005). Functional magnetic resonance imaging (fMRI) studies show reading is associated with significant increases in brain connectivity (Berns et al., 2013) and increased connectivity is associated with an improved flow of information between different regions of the brain, potentially improving cognitive, emotional and social functioning (Tompson et al., 2018). Reading fiction has been associated with greater empathy, social skills and vocabulary (Cain & Oakhill, 2011; Kidd & Castano, 2013; Mar et al., 2006). In addition to cognitive and social skills, reading has benefits in terms of stress reduction. Spending half an hour reading provides the same notable reduction in stress as half an hour of yoga, including reduced blood pressure and heart rate (Rizzolo et al., 2009). Researchers from the University of Sussex, commissioned by Galaxy Chocolate (who have also sponsored The Reading Agency's 'Quick Reads' program for many years, effectively showing their support for reading), found similar results: reading for just six minutes is sufficient to slow heart rate and ease muscle tension, leading to a 67% drop in stress, with listening to music coming in as the second most relaxing activity they studied (with a 61% stress reduction), more than walking (42% reduction) or having a cup of tea or coffee (54% reduction) (Galaxy, 2009, p. 2). Although this is innovative research that supports the health-related benefits of reading, it has not been peer-reviewed so results should be interpreted with caution. However, it has been shown that reading books is associated with a boost in longevity, regardless of education, gender, health or wealth (Bavishi et al., 2016).

Loneliness is frequently described as a huge problem in many countries and its devastating effects include decreased longevity and increased risk of depression and dementia (Czaja et al., 2021), yet reading has been shown as an effective tool to combat loneliness (Hilhorst et al., 2018; Rane-Szostak & Herth, 1995). When reading, a fictional world can become a person's social world, with characters serving in-part as real-world friendships, easing feelings of aloneness and increasing feelings of belonging and connection (Broom & Wagner,

2023; Troscianko, 2018). Functional MRI studies have indicated there is little distinction between the representation of real-life friends and favourite fictional characters in terms of the brain activity of lonely people (Broom & Wagner, 2023), and emotional attachments to fictional characters can be formed (W. J. Brown, 2015; Cohen, 2003) opening the door for fictional characters to influence beliefs, behaviours and attitudes (Broom et al., 2021; Cohen, 2003; Djikic & Oatley, 2014; Shedlosky-Shoemaker et al., 2014) as well as reducing loneliness.

In 2015, The Reading Agency (UK) commissioned a review of current findings on the non-literacy impacts of reading for pleasure in the general adult population and in adults with health needs. They found recreational reading had a number of positive effects, including expanded knowledge (meeting the desire to learn about new things), increased relaxation, a sense of escapism, and sheer enjoyment, in both groups; while the adults with health needs also showed fewer symptoms of depression and dementia after participating in reading interventions (BOP Consulting, 2015). The following year, a report on adult readers found that reading empowers people (by increasing confidence or inspiring action), provides comfort, reduces stress, offers an avenue for escapism, allows people to discover different people/places/times/cultures with the side-benefit of making readers more interested in the world and feeling encouraged, offers new perspectives, and teaches acceptance and empathy (Billington, 2016).

Reading has been shown to be an enjoyable and immersive activity for both adolescents (Wilhelm & Smith, 2016) and adults (Porteous-Sebouhian, 2022). Some people facing mental health issues praise reading for its positive effect on their wellbeing: “reading has been an absolute lifesaver for me … sometimes reading is the only thing that keeps me going” and “if you’d had a difficult day and all you want to do is just lay down and escape from the world, I think reading offers you that chance” (The Reading Agency, 2022, 2:52). Investigating the idea of reading for pleasure as potentially beneficial for people with mental health issues, The Reader Organisation found approximately 74% of regular readers in the UK believe reading impacts their mental health positively, and 77% say reading helps them “feel relaxed and happy” (Porteous-Sebouhian, 2022, para. 4). They attribute the positive effects to the “in the moment collective experience” (Porteous-Sebouhian, 2022, para. 4), leaning on the warmth of human connection that is a part of their Shared Reading model. Drawing on research to sum up the benefits of reading, the CEO and directors of The Reading Agency, as well as an Arts Council England board member, described what reading can do:

> We change lives through the proven power of reading … real evidence of its impact over a long period of time … reading is what connects us … reading opens the doors to whole new worlds … we know that reading, particularly reading for pleasure, has an impact on people's life outcomes. (The Reading Agency, 2022, 0:25-5:48)

2.1.1 The Special Role of Fiction

Writers themselves point to the healing nature of reading. Looking back at writers of yesteryear, Cicero, in a letter to Varro, famously wrote that we have everything we need if we have both a library and a garden, and told Varro "I've reconciled myself with my old friends – my books!" (Cicero, 46 BCE, as cited in Zeiner-Carmichael, 2014, p. 51). Shakespeare provided another good example when he extolled the virtues of reading in Titus Andronicus, "Come, and take choice of all my library, And so beguile thy sorrow" (Shakespeare, n.d., Act IV, Scene 1, lines 34-35), and likewise D.H. Lawrence, in a letter he famously penned to Arthur McLeod on 26th October 1913, wrote "one sheds one's sickness in books – repeats and presents again one's emotions, to be master of them" (Lawrence, 1962/1913, p. 234). Although none of these writers made the distinction between fiction and non-fiction in their declarations of the importance of reading, some notable contemporary writers praise the power of stories. For instance, Blake Morrison is an advocate for stories and the difference they can make: "great therapeutic power of literature - it doesn't just echo our own experience, recognise, vindicate and validate it - it takes us places we hadn't imagined but which, once seen, we never forget" (Morrison, 2008, para. 23). The idea of transporting readers to other places, to offer distraction, is relevant to this study, and is echoed by other writers: "I could just transport myself away from my circumstances and dive into this incredible mystery" (Alex Wheatle in The Reading Agency, 2022). Similarly, Raymond Tallis (geriatric specialist, poet and author), when interviewed, suggested fiction gives us an enjoyable means to escape and "the ability to distance one's self from one's own circumstances" (Morrison, 2008, para. 16).

The voices of writers have been included here to set the scene for this section about the special role of fiction, as writers have the gift of beautifully crafting words to tell a story, and that is appropriate for this section about stories. This ability to paint a picture with words is certainly evident in the words of British author Neil Gaiman (2013), who is passionate about the role fiction can play in taking care of our emotional wellbeing:

> I'd like to say a few words about escapism. I hear the term bandied about as if it's a bad thing. As if "escapist" fiction is a cheap opiate used by the muddled and the foolish and the deluded, and the only fiction that is worthy, for adults or for children, is mimetic fiction, mirroring the worst of the world the reader finds herself in. If you were trapped in an impossible situation, in an unpleasant place, with people who

> meant you ill, and someone offered you a temporary escape, why wouldn't you take it? And escapist fiction is just that: fiction that opens a door, shows the sunlight outside, gives you a place to go where you are in control, are with people you want to be with (and books are real places, make no mistake about that); and more importantly, during your escape, books can also give you knowledge about the world and your predicament, give you weapons, give you armour: real things you can take back into your prison. (para. 21-22)

Similarly, although many librarians see their reference role as the mainstay or most important part of their occupation, others understand fiction is what keeps library patrons returning, as librarian David Wright (2010) describes in the American Library Association's readers' advisory guide:

> It is almost impossible to overstate how important Story is to people, and to libraries. Story is what makes us human. We think in terms of narrative: it is how we make sense of our lives and our world. Hardwired for creating and interpreting stories, our dreaming minds spin tales even in our sleep. Despite the library profession's habitual (over) emphasis on Information, it is Story in its myriad forms and formats that keeps our doors open and the lights on. (pp. 131-132)

Corroborating the importance of stories, a recent analysis of public libraries found that more reading is done for enjoyment than learning (Coates, 2020). In Australia, the most recent library borrowing statistics show fiction occupies 18 spots in the list of the top 20 most-borrowed books, with the other two being narrative memoir and biographical (Civica, 2022). Clearly, Australians love their stories.

The mechanism by which fiction draws us in, to even provide transformational experiences, is the subject of much hypothesising in both the psychological and philosophical arenas. Although it is universally acknowledged that we are drawn to stories, precise motivations remain unexplained (Slater et al., 2014). It could be that we experience an intimate connection with another's thoughts, feelings and actions in a way that is impossible in real life, or it could be that we are temporarily expanding our own experiences and narratives (Slater et al., 2014). When we read fiction, we can put aside our sense of self and vicariously experience another way of seeing the world, or at least particular situations, and experience different thoughts, emotions and behaviours. This can be transformational, but when a reader re-engages with the story or characters after the book is closed, personal growth happens (Pogosyan, 2022). Reading literature provides the opportunity for us to engage in cognitive and emotional simulations (Oatley, 2012). A comparison of reading a literary text as opposed to the same facts presented in a documentary style, showed significantly greater emotional changes when reading the artistic literary form (Djikic et al., 2009). It is possible this occurs because imaginative literature allows readers to imagine what is possible rather than what has been, an idea originally proposed by Aristotle (Aristotle cited in Oatley, 2012). Positive

emotions contribute to psychological wellbeing (Croom, 2015), and reading, with its ability to change emotions, and its benefit to mental health and wellbeing, is relevant. Shrodes, who will be discussed more below, describes this well:

> Through the centuries the philosopher, the critic, and the artist have attributed to the imaginative writer not only intuitive understanding of man's motives and his nature but also power to influence his thinking, to move his heart, and even to alter his behavior. (Shrodes, 1960, p. 311)

The emotional response fiction generates is known as the paradox of fiction: that the reader can be emotionally moved by that which he/she knows to be fictitious (Radford & Weston, 1975). This paradox was first discussed by Radford and Weston (1975), and has been discussed in ontological circles since. Aristotle (again) had much to say about the effects of fiction: "(T)he plot [of a tragedy] must be structured … that the one who is hearing the events unroll shudders with fear and feels pity at what happens" (Aristotle cited in Walton, 1978, p. 5). Stated simply, "real people can, and frequently do, have psychological attitudes toward merely fictional entities, despite the impossibility of physical intervention" (Walton, 1978, pp. 5-6). However, some critics of this theory propose that what is experienced are in fact quasi-emotions, a physiological/psychological state, or that the fictional narrative generates a make-believe truth that draws the reader into acting his/her part in the narrative, and the readers' reactions are triggered by an awareness of the quasi-emotion sensations generated (Walton, 1978). Another critic, Stecker, proposed that readers feel "something akin to an emotional response" (Stecker, 2011), yet thought theorist Lamarque purported readers only need a representation of an evocative experience to feel a real emotional response (Lamarque, 1981). Numerous studies have explored the relationship between fiction and the affective arousal valence network, specifically that overlapping sections of the brain are stimulated whether reading about an experience or participating in it, and brain regions corresponding to emotional arousal are engaged when reading fiction (Adair, 2019), showing emotional responses to fiction occur.

Readers know stories have the capacity to affect emotions (Adair, 2019; Radford & Weston, 1975) – we (i.e., readers) cheer for our heroes in stories and cry at the tragedies. It can be as though we are in the story ourselves, through the eyes of the characters. Given the response in our brain is as though what is happening on the page is actually happening to us (Speer et al., 2009), it is unsurprising that this engagement with stories is thought to lead to increased empathy (Bal & Veltkamp, 2013) and sees scores of people around the world as regular members of book clubs or book discussion groups. It is no coincidence that organisations like

The Reading Agency regularly construct lists of "Mood-boosting Books" based on reader recommendations (The Reading Agency, 2021c). These lists have become a resource used by readers and librarians around the world, as stories are powerful and it is natural to want to share our experiences with them. Canadian author Gwen Tuinman says written stories remind her of possibilities:

> Movies and episodic television provide the viewer with images that direct us to feel predetermined emotions… a book invites us to interpret words in order to make our own meaning and allows our minds the pleasurable task of generating images to match the story. (Tuinman, 2021, para. 16)

One study exploring reasons for reading fiction found that people read it for relaxion, to improve literacy skills, to learn about the world, to help make sense of their lives (including affirming their own beliefs and attitudes) and to escape loneliness (Usherwood & Toyne, 2002). In that study, all manner of escapism was mentioned repeatedly by study participants and comments like "I move into another world when I read fiction ... I just get completely absorbed" (Usherwood & Toyne, 2002, p. 35) were common. It is this activity of immersion in a story that allows readers' minds to become occupied with another reality, and this was described as mindfulness in a recent interview with clinical psychologist Caitlin Sopp by *The Sydney Morning Herald*: "when you're absorbed in a good book, you're not worried about what happened earlier in the day, you're not stressing about what's coming the next day … reading is a form of mindfulness" (Lewin, 2021, para. 9). Numerous studies show the benefits of mindfulness on mood, stress, fatigue and QoL in cancer patients (Carlson & Garland, 2005; Carlson et al., 2003; Fish et al., 2014).

Reading fiction allows readers to step into another world – one that the author helps create in the imagination, where they experience times, places, adventures or encounters they may never be a party to in real life (Alexander, n.d.; Gaiman, 2013; Morrison, 2008; The Reading Agency, 2022). The relationship between the story and the reader is the basis of reader-response theory, where the development of a reader's response is the key to not only understanding a story, but also for producing intellectual and emotional participation in it (Mart, 2019). Rosenblatt (1982) is considered the earliest exponent of the reader-response theory and she explained it simply as "a transaction" (p. 268) between a reader, with all their life and language experiences and memories, and a text, which may be read visually or listened to. She proposed that non-fiction texts are interpreted in an efferent way - the reader focuses on what information is to be taken away from the text; whereas a reader of imaginative works turns the experience of reading inwards, and senses the story or poem in

an aesthetic way (Rosenblatt, 1982). Regardless of whether texts are interpreted or sensed, the experiences a reader brings to their side of the transaction affects the reading experience (Rosenblatt, 1982). In simple terms, this means reading is not a passive consumption of words that authors have recorded, but rather it is an activity that involves readers actively assembling the story for themselves. Without using the term *reader-response,* Shrodes (1961) pointed to the "interaction between the personality of the reader and imaginative literature" (p. 22) which addresses the crux of reader-response theory as part of her own theory about evoking an emotional response to literature, which is important for her premise of identification / catharsis / insight described in section 2.2.2.

The way people can become engrossed in a story, focussing only on it, leads to distraction from worries and ultimately to relaxation (James & Römhild, 2023). This immersion is referred to in a number of ways by researchers: escapism (Brewster, 2016), transportation (Bal & Veltkamp, 2013; Green, 2008), involvement (Moyer-Gusé, 2008), enchantment (Felski, 2008) and when interviewed by researchers recently, bibliotherapist Nina Killham described it as a "book trance" (James & Römhild, 2023, p. 5). This is an important consideration for a reading program whose participants are likely to be experiencing distress. One of the researchers in a University of Sussex study on reading and stress reduction, David Lewis, is quoted in their press release as saying: "Losing yourself in a book is the ultimate relaxation ... It really doesn't matter what book you read, by losing yourself in a thoroughly engrossing book you can escape from the worries and stresses of the everyday world" and he explained this idea as "more than merely a distraction but an active engaging of the imagination as the words on the printed page stimulate your creativity and cause you to enter what is essentially an altered state of consciousness" (Galaxy, 2009, pp. 1,3). Although his comment is linked with his study's findings, given the lack of peer-reviewed papers on this topic, it would be advantageous to see this replicated in future research. This is especially relevant as distraction is recommended as an intervention for dealing with distress (Mansell et al., 2020), with studies citing improved mood (Webb et al., 2012). While distracted, multiple positive neural pathways are engaged, including the reward pathway, which increases resilience to distress and also has an anti-depressant effect (Tabibnia, 2020). Synthesising the findings of these studies could indicate fiction's potential as a drug-free intervention for reducing distress and depression. An example of using fiction to decrease distress can be seen in the aftermath of the 1999 Venezuelan mudslides when the 'Read for Your Life' project was established to distribute bags of books: novels, picture books and

humorous books (Douglas, 2002), to help the disaster victims cope. The words of author Anne Fine's characters sum this up well:

> Helen: I'm all right. I feel much better. ... Kitty's been telling me a story.
> Mrs Lupey: She spins a good yarn ... that is the power of the story-teller for you ... Living your life is a long and doggy business … and stories and books help. Some help you with the living itself. Some help you just take a break. The best do both at the same time. (Fine, 2019/1989, pp. 192-193)

2.2 Bibliotherapy

> "Bibliotherapy attempts to open up that world of pleasure to the people it works with, to make their lives richer, and allow them to pass on their own pleasure and enjoyment of the things they have read to others." (Duffy et al., 2009)

2.2.1 History of Bibliotherapy

It is generally believed bibliotherapy began in ancient times: ancient Greeks and Egyptians carved inscriptions above library entrances that are variously attributed as "Healing for the soul" (McLaine, 2010b, p. 141) or "Medicine for the Soul" (McDaniel, 1956, p. 585). Aristotle's name appears repeatedly in the literature for his ideas regarding books and reading as beneficial to one's health (for instance Bankar & Patil, 2021; Harvey, 2010; McCarty Hynes & Hynes-Berry, 2011). The origin of the word bibliotherapy is from the Greek word for book "biblion" and healing "therapeia", although putting the words together to create the term "bibliotherapy" is credited to an American minister, Samuel Crothers, about 100 years ago. He first coined the term in a 1916 article in *The Atlantic Monthly*, where he described stumbling upon a "bibliopathic institute" that his GP friend, Dr. Bagster, ran in a church vestry (Crothers, 1916, p. 291). Bagster apparently told his friend:

> During the last year I have been working up a system of Biblio-thera-peutics. I don't pay much attention to the purely literary or historical classifications. I don't care whether a book is ancient or modern, whether it is English or German, whether it is in prose or verse, whether it is a history or a collection of essays, whether it is romantic or realistic. I only ask, "What is its therapeutic value?" .... A book may be a stimulant or a sedative or an irritant or a soporific... A book may be of the nature of a soothing syrup or it may be of the nature of a mustard plaster... Bibliotherapy is…a new science. (Crothers, 1916, p. 292)

The benefits of reading have been acknowledged and extolled for centuries. For instance, the act of reading aloud was considered beneficial exercise, on par with walking, during the Middle Ages, when reading stories were seen to offer solace and act therapeutically on mood and emotion, and so their role as "medicine of words" was widely accepted (McCann, 2015, p. 53). Prior to the Middle Ages, the "lectio divina" or "divine reading" occurring in

monasteries (comprising lectio [reading], meditatio [meditation], oratio [speaking] and comtemplatio [contemplation]) influenced reading practices and was derived from Saint Augustine's embracing of the biblical concepts of Christ as healer/physician and Christ as scripture/the word (McCann, 2015, p. 55). In his recent book, *Literature and Consolation*, Pieters (2021) emphasised the role of both Christian and secular fiction in bibliotherapy and used the terms console, comfort and solace frequently and interchangeably.

By the end of the 1700s, the majority of the "better mental hospitals" in Europe had libraries, and reading for recreational purposes was popular (Weimerskirch, 1965, pp. 510-511). Reading was "second only to physical exercise" as a prescribed therapy in the early 1800s (McMillen & Pehrsson, 2004, p. 74) and Benjamin Rush, among the first in America to recommend reading for the ill, defined two types of recommended reading: for entertainment (especially travel books, to raise the spirits of those confined to hospital) and for knowledge (for which he recommended moral, religious and philosophical texts as well as newspapers) (Weimerskirch, 1965). Additionally, Rush recommended fiction to cure melancholia, in part due to the "constant employment" (Weimerskirch, 1965, p. 512), which could be translated into today's vernacular as absorption in a story, and he found reading aloud and listening to be of importance (Weimerskirch, 1965, p. 514). Freud was another proponent of bibliotherapy, using creative literature during sessions with patients and acknowledging storytellers as "valuable allies" in psychotherapy (Freud, 1922, p. 113). The patient libraries established in major hospitals were to distract patients and give them a "positive focus" (McMillen & Pehrsson, 2004, p. 74).

Bibliotherapy developed and matured with the collaboration between doctors and librarians during World War I, when it came to prominence for a time as a valid therapy both at the front line and in hospitals (Haslam et al., 2018; McDaniel, 1956; University of London - School of Advanced Study, 2018). In a touching article written by hospital librarian Sadie Peterson-Delaney (1938), she described the important role of books specially selected for each patient based on their diagnosis, treatment and interests, in a veteran's hospital in Alabama. She described a number of case studies where the hospital's bibliotherapy unit prescribed reading (including books, newspapers and audiobooks on records, intended for both entertainment and information), ran the library press club, debating club, philatelic club and taught Braille to blind veterans with astoundingly positive results despite these men being "broken in body and spirit" (Peterson-Delaney, 1938, p. 306). She wrote:

> The library service to the bed patients is most important. This consists of the librarian's daily visits to the bedsides on the various wards with a library book cart

> filled with carefully selected reading material and pictures. This gives the patient who must spend long hours in bed, an opportunity through books, to build up hope, relieve his mental tension, absorb his worries and alleviate his pain. (p. 305)

These hospital librarians played an important role in the rehabilitation of returned WWI servicemen (Pittman, 2017).

Although bibliotherapy has since been used in a variety of settings including hospitals, schools, community centres, prisons, aged care facilities and libraries (McLaine & Mackenzie, 2013), it is little known in Australia. The UK has the good fortune to have a number of reading organisations, including The Reading Agency who partner with Literature Wales and Verbal (in Northern Ireland) for some of their programs such as Reading Friends (The Reading Agency, 2023b), The Reader Organisation, ReLit, Reading for Wellbeing (RfW) project, the medical humanities projects at the University of Oxford (University of Oxford, 2018) and the long-running Kirklees public library bibliotherapy initiative (Reading and You Scheme - RAYS), which has evolved into the Words in Mind program (Brewster & McNicol, 2021). With all these initiatives, the UK appears to be leading the world in the field of reading for wellbeing. However, bibliotherapy appears to remain little-known outside the UK (discussed more in section 2.2.3) and does not even elicit an entry in the *Encyclopedia of Library and Information Sciences* (McDonald & Levine-Clark, 2018), considered an authoritative and up-to-date reference in its field. Other researchers have also noticed the modern-day absence of bibliotherapy, and from a hospital or health perspective, report that adult patients are generally provided only with didactic literature about their illness while emotional needs remain unaddressed, yet it is realistic to expect people facing a health burden today will still experience the same uncertainty, fear, loss of control and vulnerability as the patients of yesteryear who were given books for solace (McMillen & Pehrsson, 2004).

The COVID-19 pandemic brought a few bibliotherapists to light, with some programs made freely available by libraries such as State Library of Victoria (SLV), seeking to ease some of the isolation and anxiety of those caught up in the extended lockdowns (SLV, 2021). Also during the COVID-19 pandemic, the *New York Times Magazine's* "The Decameron Project" revived the storytelling ideals of Giovanni Boccaccio's *The Decameron,* which was set during the Middle Ages at the time of the plague, and was intended to offer solace, "using storytelling ... not merely a source of distraction but a means of survival ... to soothe and contain the anxious mind" to aid both the storyteller and the listener (Downes & Römhild, 2022, pp. 45-46).

In summation, bibliotherapy has a long history of providing comfort and solace, from ancient times to the recent COVID-19 pandemic. The following section will consider the different forms and ways in which bibliotherapy has been implemented.

2.2.2 Types of Bibliotherapy

A review of the literature reveals a variety of descriptions and delivery methods under the umbrella term bibliotherapy, but at its core, bibliotherapy is simply about reading for its health-related benefits. Terms commonly seen include prescriptive or clinical bibliotherapy, which is in clinical settings using workbooks and/or self-help books to supplement information from a therapist (Canty, 2017); books on prescription, utilising self-help books endorsed by health professionals which may be prescribed by treating physicians or obtained via self-referral (National Association of Primary Care (NAPC), 2016); and creative or affective bibliotherapy, which uses imaginative works, often delivered in a group setting (Bruneau & Pehrsson, 2017; Glavin & Montgomery, 2017). Developmental or community-based bibliotherapy refers to the use of self-help books, often in a group setting, facilitated by a librarian, teacher, bookshop owner or other non-health-professional (Cook et al., 2006; De Vries et al., 2017; Pehrsson & McMillen, 2005; Sevinç, 2019). Cognitive behavioural bibliotherapy also utilises self-help books (Axelsson et al., 2018), and depending on the presence or absence of a therapist guiding the process (reading, interpretation and attempts to put ideas presented into practice), this would come under one of two types: clinical bibliotherapy or books on prescription. Other terms seen in literature include cognitive bibliotherapy, which uses self-help books or literature with characters going through similar circumstances and reaching effective outcomes where the underlying problem, such as fear or sadness, is explicitly mentioned (Betzalel & Shechtman, 2010); client-developed bibliotherapy, which involves writing responses as well as reading (De Vries et al., 2017); and hero's quest bibliotherapy, for therapists treating people with adjustment disorder (Duffy, 2010).

When looking at different types of bibliotherapy, the needs of the reader have also been used in definitions. For instance, Czernianin et al. (2019) describe the application of bibliotherapy with a variety of groups including those with mild intellectual disability, those with emotional disorders, people with low self-esteem, individuals who are deemed socially maladjusted, and those with limited mobility. How the groupings were derived is not adequately described and compared to the bulk of literature on the types of bibliotherapy, they appear to be anomalous classifications.

A review of bibliotherapy literature would be incomplete without mention of Caroline Shrodes, who played a seminal role by providing a detailed theoretical framework for the emotional benefits of bibliotherapy. In her ground-breaking 1949 dissertation, she recognised the place of both didactic and imaginative literature in a bibliotherapeutic role; however, she went on to further study the role of imaginative literature, insisting this type of literature holds more power for creating change (that is, "effective therapy") due to its ability to produce an emotional response (Gillespie Hendricks et al., 1999, p. 120). Shrodes (1955) explained the role of the "vicarious experience" (p. 24) in affecting a therapeutic change through literature by way of identification with a character or a situation, catharsis and insight. Anecdotal evidence of such break-through moments when reading (i.e., the classic "ah ha" moment when a new concept is grasped) abound, but this idea of breakthrough was clearly shown in a study focussed on a group of girls enrolled in a program to treat obesity: the intervention group read a novel about a similarly overweight girl who developed confidence in her ability to change her behaviour and improved her health as a result, and subsequently the study participants in the intervention group reduced their body mass index (BMI) dramatically in comparison to the control group (Bravender et al., 2010). Functional magnetic resonance imaging (fMRI) studies support the theory that while reading, the brain responds as though the situation had been a lived experience (Speer et al., 2009).

Not all researchers support Shrodes' theory of identification and breakthrough while reading. For instance, Troscianko (2018) suggested there is a lack of supporting data. Observational studies linking fantasy, science fiction and non-canonical literature to important therapeutic effects could also undermine Shrodes' similarity and identification theory. A recent study by Pettersson (2023), for instance, supported the use of fantasy and other popular genres rather than material traditionally used in bibliotherapy, such as classics and illness narratives, which can be complicated and unhelpful (Brewster, 2018). Similarly, a recent study by Brewster (2016) highlights the role of crime fiction, fantasy, science fiction, narrative non-fiction and children's books in therapeutic reading for the benefits that arise from escapism rather than from Shrodes' theory of identification / catharsis / insight. Brewster's studies of bibliotherapy in the UK have led her to classify four models of reading for therapy: emotive, for catharsis, empathy or emotional validation; escapist, to disconnect from problems, including health problems; social, via bibliotherapy groups such as SR or RAYS; and informational, mostly using self-help books which may or may not be based on cognitive behavioural therapy (CBT) (Brewster, 2011; Brewster, 2016).

An early hospital librarian's advice is relevant: specific bibliotherapy is not needed by most (90%) general hospital patients (Jones, 1939, p. 13), with the implication that the benefit of reading can come regardless of what is read, that is, the distraction, pleasure and relaxation that comes from immersing oneself in reading a book is sufficient for producing favourable results. However, she implored other hospital librarians to pre-read story selections for appropriateness, citing the existence of potentially harmful material for various conditions (e.g., graphic accounts of painful cancers). She described her experience and advice about story selection:

> The great desire is for fiction - romance to brighten the dreary hospital round, detective stories to sharpen the wits, stories of adventure to widen the walls … divert their minds … if only for a few minutes at a time, make them think of something normal, happy, and outside themselves. (Jones, 1922, pp. 535-536)

This pre-dates but supports the finding of The Reading Agency that an aspect of reading for pleasure is just escapism, leading to relaxation (BOP Consulting, 2015), aligning with comments by Gaiman (2013) (refer section 2.1.1). Other research has found similar support for the value of reading for distraction and escapism from problems (Brewster, 2011; Brewster, 2016; Toyne & Usherwood, 2001). There are many potential applications of bibliotherapy, however, as described above, escapist reading to provide respite from problems is eminently relevant to health and wellbeing.

Bibliotherapy researchers today describe the flexible nature of using imaginative works because of their suitability for tailoring to a variety of audiences, delivery methods, settings and facilitators, to meet a variety of needs (Brewster, 2016; James & Römhild, 2023). Contemporary authors and bibliotherapists Ella Berthoud and Susan Elderkin were interviewed about the origin of the field: "bibliotherapy, if it existed at all, tended to be based within a more medical context, with an emphasis on self-help books (but) we were dedicated to fiction as the ultimate cure because it gives readers a transformational experience" (Dovey, 2015, para. 7), and they describe bibliotherapy as "the art of prescribing fiction to cure life's ills" (Berthoud, n.d., para. 1). In 2013, Berthoud and Elderkin co-authored a humorous book of reading prescriptions for many everyday ailments and afflictions, using everyday language. Instead of listing book prescriptions under, for instance, "grief", the reader is referred to "broken heart; death of a loved one; sadness; widowed, being; yearning, general" (Berthoud & Elderkin, 2013, p. 290), making imaginative bibliotherapy accessible to the masses. They describe the effects of their novel prescriptions as "Some treatments will lead to a complete cure. Others will simply offer solace, showing you that you are not alone. All

will offer the temporary relief of your symptoms due to the power of literature to distract and transport" (Berthoud & Elderkin, 2013, p. 10).

Some bibliotherapists argue for the inclusion of media other than books. For example, Arleen McCarty Hynes, an early pioneer of poetry therapy, purported the benefits of bibliotherapy result from the interactive process between the triad of participant, literature and facilitator, and that benefits do not come from the reading but rather from the discussion that comes afterwards, and also that literature consists of anything with language, so it could include a film, an advertisement or a song (McCarty Hynes & Hynes-Berry, 2011). Similarly, wellness educator Debbie McCulliss described bibliotherapy as a tool for mental health professionals and not only included films and other audiovisual material, but also art activities, writing, virtual reality and gaming software in her description (McCulliss, 2012). However, recent research by Horowitz-Kraus and Hutton (2018) used fMRI imagery to assess functional brain connectivity at rest, during reading time and screen time, and found that screen time was related to less connectivity between the seed area (i.e., area of interest, in this case the visual word form area) and regions associated with cognitive control and language. In simpler terms, this means less neural networks are activated when watching a video compared to listening to a story read aloud or reading oneself, so one could argue in favour of the written or spoken word for having greater impact. Bibliotherapy researcher Detrixhe (2010) states that grouping books and films together without stating exactly what was read or watched is problematic, which it is, and he is critical of suggesting that books and films invoke the same processes (for change) and produce the same results. However, he compares vastly different genres of film with each other to illustrate this, yet the same point could be argued about different genres of books producing different results. Further, in the face of technological advancements, including sophisticated computer games, artificial intelligence and virtual reality, and advancements in telecommunications that allow people to send each other texts of seemingly unlimited length, coupled with social media and other applications for posting comments, some proponents of bibliotherapy are delivering interventions using means other than books, and indeed other than reading. The lack of definition about what exactly constitutes bibliotherapy and the labelling of the non-reading interventions as 'bibliotherapy' adds to the confusion about what materials constitute bibliotherapeutic materials.

A prominent feature of bibliotherapeutic research has been its focus more on self-help books (including specialised workbooks) rather than imaginative literature. This appears to be changing, but the old focus may help explain why prescriptive or self-help bibliotherapy is now national policy in Wales (Brewster et al., 2012), and about 80% of libraries in the UK

offer NHS-endorsed (self-help) Books on Prescription (NAPC, 2016, p. 16). A recently created library in a residential drug and alcohol rehabilitation centre in the USA, where staff successfully use a CBT-based books on prescription model and an affective model, using fiction for identification/catharsis, provides an example of how both self-help and imaginative literature can be combined to provide bibliotherapeutic activities for the residents "where healing is the catalyst" (Shereff et al., 2017, p. 46).

In this section, it has been shown that there are many types of bibliotherapy and also many delivery methods, which may or may not involve facilitators, prescriptions by medical professionals or librarians, worksheets, journal-writing, group discussions, and variations involving silent (lone) reading or reading aloud (by a facilitator, actors or participants) in a group setting. When the term 'bibliotherapy' is used, there may be an assumption that it is one particular model or delivery method: "one thing … [but] in practice it is not although the general premise-that solace can be found in books-is broadly agreed" (Brewster & McNicol, 2021, p. e12). Bibliotherapy research, especially using creative literature, is still limited (Troscianko, 2018) and there have been no studies to-date comparing delivery methods. Therefore, it was surprising to see one librarian's definition of bibliotherapy explicitly exclude individual reading and the use of texts in individual consultations with therapists, stating that bibliotherapy is strictly a group activity (Rubin, 1978). Béres (2018) similarly defines bibliotherapy as a facilitated group activity, but with self-reflective writing an as essential component. These are both in stark contrast to the evidence pointing to the effectiveness of, for instance, the Books on Prescription program in the UK (NHS Wales, n.d.) which is an individual reading activity, as is the reading recommended by mental health professionals around the globe in their interactions with patients (Pehrsson & McMillen, 2005). These contradictions abound and emphasise the lack of consensus about what bibliotherapy comprises.

With so many different descriptions and models of bibliotherapy and the lack of consensus in the literature concerning terminology and delivery techniques, confusion about what constitutes bibliotherapy can result (Jack & Ronan, 2008). Researchers in Lithuania surveyed public library staff and found 73% regularly delivered "accidental cases of bibliotherapy": librarians regularly recommended literature to provide "aid" (mostly emotional support) without realising the applicability of the term *bibliotherapy* (Janavičiene, 2012, p. 169). However, as recently as a decade ago, a study found, despite all the models of bibliotherapy on offer, the current models fail to meet all the needs of those with mental health issues (Brewster et al., 2013). The literature illustrates the bibliotherapeutic techniques used in

modern research are deliberate, measured, and found to be of benefit, and some themes such as escapism and relaxation have appeared regularly since the time of early studies. In summation, regardless of the way bibliotherapy is delivered and categorised, at its core remains the central concept of therapy using books, that is, feeling better as the result of reading.

2.2.3 Bibliotherapy in Practice

Bibliotherapy in Practice: International

Bibliotherapy is widely used in the UK and is reportedly growing rapidly as a profession (Morrison, 2008; Pehrsson & McMillen, 2005). Bibliotherapy is widespread across Wales (via their Book Prescription Scheme and Literature Wales), and numerous programs exist in England (refer Table 2.1). Although this section appears UK-centric, that is simply because the UK is currently leading the world with its variety and quantity of bibliotherapy initiatives. This section is not intended to be a complete account of all bibliotherapy initiatives around the world, but rather is intended to serve as a snapshot.

Table 2.1

Reading Programs in Britain

Organisation / program	Population	Description
The Reading Agency	Over 2.4 million people during 2023-2024 (The Reading Agency, 2024).	Numerous reading initiatives, including Reading Well book prescription scheme, mood-enhancing booklists and themed booklists, summer and winter reading programs, reading challenges, World Book Night, Reading Friends program, book clubs and 'Quick Reads' books. Numerous statistics, including 71% of Reading Friends experienced increased self-efficacy and 68% felt less lonely; the Reading Well collection was helpful for 85% of adults using it (The Reading Agency, 2024).
The Reader	Over 350 SR groups meet each week; reaching 19,500 readers each year (The Reader, 2024).	Group sessions delivered by trained facilitators. Numerous statistics, including 95% of readers in SR groups declared the reading sessions made them "feel better" (The Reader, 2024).
Reading for Wellbeing (RfW) project	Initial pilot study with six local authorities. Number of participants is unclear. It is still funded in some areas whilst RfW activities are incorporated into some library services (Sirisena et al., 2024).	Community Reading Workers go out into north east England to engage with both avid and lapsed readers, providing support, encouragement and resources (such as facilitating audiobook access via library apps for people struggling to read visually or hold physical books) and they also hold reading groups (Reading for Wellbeing, 2023). RfW has facilitated the establishment of positive connections, improved attitudes about self-care and increased self-efficacy (Sirisena et al., 2024).
ReLit – recently relocated their base from the UK to the USA, maintaining a presence in both locations	Over 50,000 participants in their 'Reading and Mental Health: Reading for Wellbeing' course (ReLit, 2021).	Bibliotherapy using poetry. Initiatives include workshops, online courses, poetry competitions, and poetry publications. Limited studies, including Holland (2017) with mixed results, and Helfgott (2017) who found bibliotherapy using poetry improved wellbeing.
Reading and You Scheme/Service (RAYS) – now called Words in Mind	Total number of participants is unclear; 31-47 groups participated in a recent study (Brewster & McNicol, 2021).	A directed group chat model to discuss all manner of fictional books and book-related issues (Duffy et al., 2009). Focus is on enjoyment, relaxation and social support, rather than being framed as a therapy. Some key themes: solace, social connection, improved mental health, and escapism was valued (Brewster, 2016).

While the Reading and You Scheme (RAYS) was marketed as being a normal, fun, flexible activity, tailored for group members, it has been studied in a mental health context (Brewster,

2011) and for people with dementia (Brewster & McNicol, 2019). The Reader's Shared Reading (SR) model has also been studied in a variety of settings, for instance with clinically depressed people at both a GP clinic and a mental health drop-in centre (Dowrick et al., 2012) and with people experiencing chronic pain (The Reader, 2016). Similarly, as researcher Patricia Neville points out, bibliotherapy via book prescription schemes have been successfully evaluated in the UK and Ireland, although the Irish scheme has also been criticised for its role in government cost-saving measures which perpetuates their apparently "substandard mental health service" (Neville, 2013, p. 33). Despite all these bibliotherapy initiatives in the UK, a recent study by Brewster and McNicol (2019) found *bibliotherapy* is generally an unfamiliar word, accounting for the lack of practical support encountered at program venues such as aged care facilities.

In the USA, People and Stories/Gente y Cuentos began in 1972, using literary-quality short stories read aloud in groups followed by "rigorous discussions" (People & Stories/Gente y Cuentos, 2023, para. 1) in prisons, homeless shelters, youth centres, halfway houses and low-income seniors' homes. Although their format appears very similar to the SR program, this program had a greater focus on adult literacy and positive interpersonal engagements. More than 40,000 people have participated in parts of the USA and South America, in English and Spanish (People & Stories/Gente y Cuentos, 2023, para. 5). In 2016, a short film was made about the program and participant comments focussed on a newfound love of reading and the ability to express opinions on important matters they may not have considered before, while staff comments reflected the founder's desire to educate, liberate and empower people (StateoftheArtsNJ, 2016). Veterans' reading support groups and private bibliotherapy services for general wellbeing also exist in the USA (Glavin & Montgomery, 2017).

Researcher Natalia Tukhareli developed bibliotherapy programs in South Africa for people affected by HIV/AIDS (based on both the SR and RAYS approaches), before launching the Read to Connect program in Canada, based on the SR model, targeting disadvantaged members of the community (Tukhareli, 2018). Although most bibliotherapy research and literature appears to originate from western Europe and North America, there is some evidence of bibliotherapy research in eastern Europe. For instance, Hungarian researcher Judit Béres has studied bibliotherapy in a variety of settings, albeit not cancer settings: juvenile prisoners (Béres & Csorba-Simon, 2013), disadvantaged youth (Béres, 2015), young parents (Béres, 2014) and women (Béres & Csorba-Simon, 2015); while researchers Daniela Popa and Dana Popa (and their colleagues) have researched bibliotherapy in Romania, with

Dana conducting a systematic review of bibliotherapy in a clinical context (Popa & Porumbu, 2017) and Daniela studying perceptions of bibliotherapy (Popa et al., 2018).

Bibliotherapy via the SR model reached New Zealand in 2015, with the establishment of The Reading Revolution (The Reading Revolution, 2022). However, despite the best efforts of some Australian advocates, bibliotherapy remains little known in the Australian public library sector and seems unheard of in the general Australian population. Bibliotherapy in practice in Australia is described in the next section.

In summary, although bibliotherapy initiatives had been trialled on almost every continent, there is a predominance of western nations represented both in the published research and in active programs. Currently, the UK leads the world with the breadth of its bibliotherapy programs and participant engagement. Given the benefits of bibliotherapy (refer section 2.2.4), hopefully it will become more commonplace.

Bibliotherapy in Practice in Australia

A recent study by James and Römhild (2023) described creative bibliotherapy as "gaining momentum since the 2010s" but they also went on to state that bibliotherapy in Australia is "in its infancy" (p. 2). Their second statement is more accurate: numerous programs have been trialled in Australia with varying degrees of success.

In 2008, an article appeared in *Australasian Public Libraries and Information Services*, where the author and library manager, Bernice McSwain, described the components of the 'Salisbury Reads' program, which included a number of pre-literacy programs, family reading centres within libraries and a book prescription program, "Prescribe Books", in the northern Adelaide suburb of Salisbury (McSwain, 2008). Unfortunately, other than baby and pre-school storytimes, the other components of the 'Salisbury Reads' program have long since stopped running due to reasons ranging from lack of funding to lack of interest as the branch libraries moved and changed (N. Cooper, personal communication, March 13, 2024) and unfortunately the book prescription program was in fact never adopted (B. McSwain, personal communication, March 18, 2024). In 2010, the 'Book Well' pilot program commenced in Victoria - a collaboration between the State Library of Victoria (SLV), VicHealth and Public Libraries Victoria Network (PLVN) based on the SR model (McLaine, 2010a, 2010b). That year, The Reader sent staff to Australia to train 20 people (mostly library staff from a variety of library settings) in the delivery of the SR model and although some of the trained staff implemented the program it appears that problems acquiring delivery

partnerships hindered the ongoing uptake of program delivery (McLaine, 2021), as did lack of ongoing funding (Freeman-Greene, 2011). Also in 2010, another Victorian librarian, Jennie Bolitho, went to the UK to train as a SR group facilitator, and on her return, she set up a SR group in a Melbourne aged care hostel as part of a 12-week trial that was considered so successful, the hostel agreed to fund it for the remainder of the year and through the following year (Bolitho, 2011), however, the program did not continue. A more successful but modest enterprise, Shared Reading NSW was formed in 2014 as an outreach targeting social isolation and it remained a small part-time charity until grants recently allowed it to expand (C. Smith, personal communication, October 19, 2021; March 6, 2024). Other attempts at establishing bibliotherapy programs in Australia include a pilot Books on Prescription scheme (modelled on The Reading Agency's scheme), launched in 2016 by the Central West Libraries of NSW, but this initiative suffered lack of funding and support from health care providers before being discontinued (Fitzpatrick et al., 2018). Also in 2016, an article appeared in the Melbourne edition of *Time Out*, encouraging readers to book a session with bibliotherapists Nina Killham and Sonya Tsakalaki at The School of Life (Crawford, 2016). However, searching The School of Life website at the time of writing this thesis revealed a variety of therapies but bibliotherapy was not among them (The School of Life, n.d.). Killham and Tsakalaki were also profiled in the recent James and Römhild (2023) article, but only Tsakalaki appears to still offer bibliotherapy sessions via her private practice (Tsakalakis, n.d.). Thus far, the numerous attempts at instigating bibliotherapy programs in Australia have met significant challenges.

During 2020 to 2022, in the face of the COVID-19 pandemic, Victorians endured some of the longest lockdowns in the world and the widespread fear and uncertainty in the community formed the basis of predictions of an imminent increase in mental health issues. SLV, along with bibliotherapy advocate and then-PhD-candidate Susan McLaine, partnered to produce two recorded series of bibliotherapy podcasts aimed at assuaging listeners: "Each episode will focus on a different feeling or experience to use the healing power of literature to nourish and comfort us during this challenging time" (McLaine, 2020a, para. 2).

There are a few ongoing and new bibliotherapy programs and studies in Australia. McLaine holds group bibliotherapy sessions with prisoners (Rosenbaum, 2015) and is director of Bibliotherapy Australia, which has started offering bibliotherapy training courses branded as "heart-centred bibliotherapy" (Bibliotherapy Australia, 2024), presumably with its foundations in the SR model as McLaine trained in, and has advocated for, the SR model (James & Römhild, 2023). A recent study by Roemhild and Turner (2023) involved running

five pilot SR groups in metropolitan Melbourne, with a total of 27 participants, who reported positive effects on self-confidence, self-understanding and relating to others. At around the same time, LaTrobe University media staff interviewed Roemhild and colleague James, to produce a statement about reading with other people to help with social confidence as the state emerged from the pandemic, and they promoted SR groups, saying "We're running Shared Reading groups in a range of settings and locations across Victoria" (La Trobe University, 2022, Join a Shared Reading group section) but it is unclear whether these groups were actually the pilot SR groups from their study (Roemhild & Turner, 2023), which were Melbourne-centric. Shared Reading programs in Australia have reportedly been well received and there are ongoing studies to assess whether they have benefits for mental alertness, cognition, and management of chronic pain (Roemhild, 2024, personal communication).

A new major Australian initiative is the Australia Reads project, which has been accumulating Australian and international data, including the 2021 National Reading Survey (Australia Reads, 2023b) and advocating for the many advantages of reading. Their mission is to make Australia "a reading nation" (Australia Reads, 2023a, para. 9).

In summary, numerous programs have been trialled in Australia, including 'Salisbury Reads' in South Australia (McSwain, 2008), 'Book Well' in Victoria (McLaine, 2010a, 2010b), a Books on Prescription scheme in New South Wales (Fitzpatrick et al., 2018) and not-for-profit organisation Shared Reading NSW. Nearly all of these have been discontinued. However, some Victorian academics have recently undertaken studies based on the SR model. Additionally, although it has been anecdotally observed, Australia Reads appears to be becoming more prominent in circles that include Australian LIS researchers, librarians, authors and publishers, which is an encouraging sign. Although bibliotherapy is more commonly practiced in other parts of the world, there are some promising programs indicating increased interest in Australia.

2.2.4 Therapeutic Outcomes of Bibliotherapy

Over the last two decades, a plethora of studies and reviews have demonstrated the benefits of bibliotherapy for many common mental health conditions. In addition to articles in discipline-specific journals, three books have been published in the last few years about the link between reading and improved mental health (Billington, 2019; Davis & Magee, 2020; McNicol & Brewster, 2018), and a fourth book addresses it in part (Hilger, 2017). Incorporating all these studies is beyond the scope of this review, but the diversity of conditions, both physical and mental, that have benefitted from bibliotherapy will be

described, with an emphasis on those most relevant to adults with cancer: anxiety, stress, sadness and depression, posttraumatic stress, anger, loss of control, loneliness (Cancer Council NSW, 2021c) and pain.

The conditions most studied in relation to bibliotherapy are mild to moderate stress, anxiety and depression (Chamberlain et al., 2008; Floyd, 2003; Frazer et al., 2005; Gualano et al., 2017; Gusmao & de Souza, 2020; Macdonald et al., 2013; Pettersson, 2018; Reeves & Stace, 2005; Taleban et al., 2016). Looking beyond the mild to moderate label, Driessen et al. (2010) conducted a meta-analysis that included bibliotherapy as a treatment for depression, and found people with more severe depression experienced greater effects from treatment. More recently, bibliotherapy was used successfully with people experiencing severe mental health problems at a rehabilitation unit in the UK, and participants reported enjoying the weekly group program (Sharp et al., 2019). In another evaluation of bibliotherapy for people with severe depression, some participants experienced a reduction in depression scores, but causality could not be inferred because the reduction in depression scores may have been due to the passage of time rather than the bibliotherapy program (Billington et al., 2010).

In addition to addressing depression and anxiety, bibliotherapy has regularly been used to address a wide variety of conditions. It has regularly been used to assist with loneliness, grief and trauma, and has been found to improve quality of life, self-esteem and boost overall emotional wellbeing in the presence of these problems (Billington, Longden, et al., 2016; Davis et al., 2016; Helfgott, 2017; Malyn et al., 2020). These interventions have been implemented in heterogenous settings. An example of the wide range of applications and settings can be found in a pamphlet produced as a guideline for GPs referring patients to the UK's Books on Prescription program, recommending the program for those suffering from common mental health disorders, including depression, anxiety disorders (including health anxiety), eating disorders, sleep problems, self-esteem issues, stress, worry and chronic pain (NAPC, 2016). In Wales, the national 'Book Prescription Scheme' addresses these mental health problems via CBT-based self-help books (NHS Wales, n.d.). This scheme is based on a trial in Cardiff, where a massive 1600 book prescriptions were filled during the first six months (Frude, 2003). Research evaluating the effectiveness of the program surveyed prescribers, dispensers and users of the program, and although the survey response rate was poor, the 37 health professionals who had prescribed books reported that the program was helpful (Grundy, 2005). In that study, although all users reported the books were helpful, the sample size was too small to draw conclusions. An evaluation of the English arm of the program found that of the 99 users of scheme included in the general analysis, almost all

(98%) found their books helpful or very helpful (Trier et al., 2019, p. 32). Of particular relevance to this study, 96% of the 43 participants with (or caring for someone with) mental health needs reported their books to be helpful or very helpful, while 84% tried implementing the advice they offered (Trier et al., 2019, pp. 32-33). These are promising figures, but there appears to be a lack of direct evidence about the effectiveness of book prescription programs, although it is likely that collecting either qualitative or quantitative pre- to post- intervention data would be problematic, not least because some people 'dip into' their books over time while others read them cover-to-cover. Despite this, it has been found that most people engage with their books to a considerable depth and many follow the advice offered within the pages, suggesting they are coping with their health needs more successfully than prior to reading their book (Trier et al., 2019). In summary, bibliotherapy has been beneficial in the context of a wide range of mental health problems.

Another common concern that significantly impacts quality of life is chronic pain, which presents many challenges, including with daily living and reduced enjoyment of activities (Holmes et al., 2013). Stories abound of individuals reading to soothe physical and emotional pain, and the literature contains some powerful quotes about the role of reading and chronic pain:

> Reading pushes the pain away into a place where it no longer seems important. No matter how ill you are, there's a world inside books which you can enter and explore, and where you focus on something other than your own problems. (Morrison, 2008, para. 5)

> I read constantly to escape from my aching knee, from my room, from the real world.... While previous treatments—painkillers, physiotherapy, acupuncture, hyperbaric oxygen therapy—have failed, the self-prescribed reading cure works … books have been my only medicine. (Sautter, 2010, para. 2)

Reading for escapism and solace are common themes for chronic pain; the same themes which also surfaced in our communities recently during the psychological distress of the COVID-19 pandemic and lockdowns (Hepworth, 2020; Stip et al., 2020). It is known that "stories and identification with story characters provide a means individuals may use for temporary relief from the task of self-regulation and from the limitations of individual personal and social identities" (Slater et al., 2014, p. 439) by way of transporting readers out of their own reality and into a narrative world (Strange et al., 2002). Reading thus presents an effective way to be liberated from thoughts and feelings associated with difficult circumstances, whether they are physical or emotional.

The time and expense involved in running any program is important, and bibliotherapy has been shown to be an effective, low-cost (Reeves & Stace, 2005), low-impact (Körner et al., 2019) option suitable for stepped care approaches (e.g., Baraitser, 2014; De Vries et al., 2017; Jarrett, 2016; Moccia, 2014). Stepped care utilises a hierarchy of interventions, starting with the least intensive, according to individual needs. Additionally, where mental health problems co-exist with physical illness, bibliotherapy is an effective, low-cost intervention (Czernianin et al., 2019).

When considering the methods used in bibliotherapy studies, the collection and analysis of quantitative data was necessary when it was desirable to demonstrate statistical significance or non-significance. This was especially relevant given past attitudes about the credibility of qualitative analysis (Maher et al., 2018; Sarantakos, 2013). Although it may not always be the case, when studies lack participant voices, there may not be enough information to understand the mechanism through which an intervention made a difference (or not), in what way the difference was made and what was important to participants. Anecdotal stories abound of the difference reading has made to people's lives in a variety of situations, but there is a lack of mixed methods studies which may make it difficult to understand how and why an intervention worked (or not), and in turn may make it hard for researchers to build on previous bibliotherapy studies.

A wide range of reading material has been used in bibliotherapy studies. Accounts written by hospital librarians during wartime and in the years that followed, described providing patients with all manner of reading material for the purpose of distraction and something cheerful to focus on, as well as for vocational education (Jones, 1939). Since then, however, studies seem to have mostly used various forms of didactic or classic texts. The literature frequently contains warnings about choosing bibliotherapeutic materials with sensitivity, however, no contraindications for bibliotherapy were found, except in the instance of reading for some eating disorders (Troscianko, 2018). Recent studies have demonstrated the usefulness of books to assist people with managing mental, emotional, social and physical issues and "together with other comparable services, for example, music therapy, art therapy, play therapy, dance therapy and poetry therapy, bibliotherapy underscores the idea of healing, consoling power of art through its various methods" (Zanal Abidin et al., 2023, p. 124).

In summary, when looking at the literature, the lines become blurred between evidence that reading is good for you, and evidence that bibliotherapy is good for you. While undertaking this review, it initially appeared that studies used the term *reading* when it is self-directed, as

opposed to *bibliotherapy* when a book or poem has been suggested specifically to an individual, obtained via a recommended list, or read via a group activity. However, as the examination of literature continued, it became obvious the terms are frequently used interchangeably. Book clubs, popular all around the world, the UK's The Reading Agency and The Reader, all extol the benefits of *reading*, yet the Welsh national policy of reading to benefit mental health, the RAYS program and reading/listening for solace during COVID-19 are all referred to as *bibliotherapy* in the literature. Regardless of the terminology used, the literature provides countless examples of the benefits of reading (and bibliotherapy), irrespective of the setting and the way in which a book came to be in a reader's hand. Throughout this thesis, the definition adopted is that which is central to all bibliotherapy models: reading for its health-related benefits.

2.3 Storytelling: Giving Stories a Voice

> 'Story is living and dynamic. Stories exist to be exchanged.
> They are the currency of human growth. Stories conjugate.' (Houston, 1987, p. 96)

Evidence abounds of our early attempts to tell stories – from pictographs in caves to hieroglyphs in pyramids to scrawls on parchments. People have been finding ways to tell each other stories for eons. This need to communicate stories is embedded in us: reliance on stories over thousands of years have ensured human brains think in terms of stories and story structures (Haven, 2007). Stories are therefore part of the fabric of human connection. Oral storytelling is part of cultural traditions around the world. It is the oldest form of teaching and not only passed down knowledge but also helped bond communities (Darici, 2023). Different faiths around the world have storytelling traditions, for instance Jesus told parables to teach, the Hindi have passed down the epic tales of the Mahabharata and the Ramayana, the Sufi use the stories of Nasiruddin and the stories of the prophets are foundational in Islamic culture (Garlock, 2018).

Storytelling is an art (Del Negro, 2021; National Storytelling Network, n.d.). Modern storytellers are akin to actors, skilled at carrying their audience along on the wave of their story (Australian Storytelling Guild NSW, n.d.; MacManus, 1963, as cited in Del Negro, 2021). You cannot help but be enthralled. When one thinks of storytelling, it is generally in the context of telling cultural stories, or contemporary actors and poets giving performances, but one could also think of the way many people read to children from a young age. Reading a story to youngsters at bedtime as part of the nightly routine is generally considered a

mutually enjoyable time. This was exemplified in a recent survey of UK parents initiated by the team at Ladybird. Most parents surveyed felt reading to their children was important (93%) and an enjoyable experience (88%), with 68% citing bonding as a key motivator for reading together (Ladybird team, 2023, para. 3-4). The pre-literacy and literacy skills children gain from a regular bedtime reading experience are routinely acknowledged, but it is also a time of comfort and connection, as these figures show.

Authors and poets intimate using the voice to enjoy the written word. Author Margaret Atwood laments the present-day absence of routinely reading aloud and advocates for its return: "every written story is … a score for voice … I'm not arguing for the abolition of the eye, merely for the reinstatement of the voice, and for an appreciation of the way it carries the listener along with it" (Atwood, 1989, p. 71). The power of stories is such that both the reader and the listeners are transported to other lands and other times in the wonderful world of imagination (National Storytelling Network, n.d.). Bibliotherapists Berthoud and Elderkin (2013) prescribe fictional works to cure life's ills and advise "sometimes the remedy is best taken as an audiobook, or read aloud with a friend" (p. 10). Poet William Sieghart, who has compiled books of poetic prescriptions, referring to them as poetry pharmacies, advises "it's the reading aloud that will allow you to properly hear it; that will make you understand the rhythms, cadences and musicality of the words and phrases" (Sieghart, 2019, p. xviii). Storytelling and shared stories via the reading aloud of stories and poems is a valid alternative to reading to oneself, and the connotations of warmth, comfort and human connection that accompany these practices are imperative to this study.

Storytelling can be an intimate one-on-one experience or shared as a group. In fact, reading was a social activity prior to the late seventeenth century, with texts routinely read aloud rather than silently (Jajdelska, 2007). Author and philosopher Jean Houston links modern lifestyle to the demise of family storytelling:

> We must restore story. It is a shame that so many grandparents have moved to sunnier climes and are no longer available for the telling of stories. In this era of radical mobility, we have no hearth for storytelling, so we have lost the pattern of connection … No hearth, no heart. Nowadays, the hearth has been supplanted by the television set. (Houston, 1987, p. 95)

Houston goes on to describe storytelling in the presence of serious illness, including cancer, and the importance of stories near death. In line with the Buddhist tradition of reading aloud their funerary text, she suggests a shift in storytelling when appropriate near end of life, and describes her own telling of stories preceding the death of a loved one (Houston, 1987). Other traditions include Muslim people believing that reading the Quran aloud can impart a sense of

peace to the dying (Cheraghi et al., 2005), while Christians often read from the Bible to those near end-of-life (Kemp & Bhungalia, 2002). It is commonly said dying people can still hear (Blundon et al., 2020), and when at the bedside of a loved one close to death, talking, reading and music are generally encouraged by health professionals (Cancer Council NSW, 2023; Heart to Heart Hospice, n.d.; Hospice of the Red River Valley, 2024). The only academic studies found about reading near end-of-life were undertaken with the intent of addressing spiritual needs and focussed on religious texts or other inspirational material (for instance, Hermann, 2007; Kemp & Bhungalia, 2002; Kim & Choi, 2022). The internet has many suggestions about what to read to a loved one at this time, from both religious and secular viewpoints, and although written as an anecdotal comment, the advice of an end-of-life counsellor is relevant: "Why wait until someone is on their deathbed to start reading out loud with those you love?" (McCann, 2016, para. 13).

Cultural storytelling still has a role to play. Indian-born UK psychiatrist, Kedar Nath Dwivedi, editor of *The Therapeutic Use of Stories: Handbook for Professionals*, described storytelling growing up in India, in his family, at school and in his village (Dwivedi, 1997). He also described how storytelling was used to bridge the gap between traditional practices and the introduction of Western medicine, resulting in cooperation between the advocates of each. Although the stories utilised appear to parallel Shrodes' ideas of the way fiction holds therapeutic value via identification, catharsis and insight (as discussed in section 2.2.2), the effect was achieved via the oral telling of myths, stories and legends.

The term *storytelling* is a vast topic and this review does not seek to explore it in depth, but rather focuses on the narrow application of storytelling in the guise of reading aloud to adults. Interestingly, in recent years, storytime sessions have been held for the general public in libraries in parts of Australia (City of Burnside, 2024; Lang, 2016), New Zealand (Christchurch City Libraries, 2024) and North America (A. Scott, personal communication, April 23, 2021; S. TerBeest Berhow, personal communication, May 21, 2021), and for people with disabilities in one instance in the USA (M. Wright, 2017). To assist in planning adult storytimes, a chapter of a renowned readers' advisory book is devoted to the topic, following the success of David Wright's 'Thrilling Tales' adult storytime sessions in Seattle library (Wright, 2010). Although research exists to show the mental health benefits of individual reading (fiction, non-fiction and directed workbooks), to the author's knowledge, none exists for adult storytimes (i.e., read-aloud programs for the simple joy of listening to a story). The closest link to this is the research around the UK's Shared Reading (SR) program, delivered via the charity The Reader, with its pre-determined pause points to check for understanding

and allow reflections to be shared by group members. Proponents of the model say “being read to is part of the nurturing experience” (Bolitho, 2011, p. 89).

Adult storytimes, in contrast to existing group bibliotherapy sessions, are simply reading and listening, taking delight in the story, sometimes with a discussion at the end for those who want to contribute. Feedback from the storytimes in Melbourne showed all participants enjoyed the program, with 72% indicating an improvement to their wellbeing because of attending the sessions (Lang, 2017, p. 4). Of relevance, a regular attendee of the Melbourne program, called Story Lounge, was a cancer patient visiting Melbourne from the country to receive her chemotherapy treatment. She confided that her concentration was affected by her treatment, and although she found solo reading difficult, she found the stories read aloud were accessible to her – she was able to listen and concentrate, and she found the sessions therapeutic (Lang, 2016). This later formed the basis of their outreach Story Lounge program at Peter MacCallum Cancer Centre, which ran until the hospital was faced with relocating to a purpose-built facility at the end of 2015, at which point the program was suspended, but unfortunately it has never restarted. As the program was held in the patient waiting area of the hospital, it was difficult to collect attendance numbers or feedback, but facilitator Lisa Lang reported a positive experience for patients and their carers (L. Lang, personal communication, April 22, 2021). Also of note were the regular attendees at the library-based program who were recovering from conditions such as chronic fatigue and brain injury, who also experienced an inability to concentrate on reading for themselves (Lang, 2016). Lang attributed the reason the program resonated so well with cancer patients and those with chronic illnesses (with the common ground of impaired cognition and focus) was the experience of the “human voice in real time” (L. Lang, personal communication, April 22, 2021).

A large-scale study of reading aloud began in Britain in 2017: the Reading Aloud in Britain Today (RABiT) project (University College London, 2021). The study found people read aloud for various reasons, including to help them understand a complex text, follow instructions, meditate, pray, enjoy poetry, within meetings, to children and to share a text within a family group - showing a diversity of purposes and texts, and acknowledging that adults do read aloud (Duncan, 2020). The role of reading aloud also varies according to neurodiversity: there are some people who understand texts much better if read aloud to them, while for others they understand more when they read aloud to themselves (Duncan, 2020). With radio, television and internet commonplace, shared reading experiences within families and communities may be dwindling despite the acknowledged social dimension of

reading (Duncan & Freeman, 2020). This dimension of reading has been described as "social connection and communion … as a thoroughly transformative and deeply social process" (Radway, 1994, p. 278). Reading aloud for educational purposes has been extensively studied, but studies of adults reading aloud for other purposes are few (Duncan & Freeman, 2020).

Reading aloud to oneself aids remembering what is read. The process provides our brains with more information about what is being read, and it is this extra information that helps with retrieval, since by speaking aloud people *produce* what is read – hence the term the *production effect* (MacLeod et al., 2010). While this effect is strongest for self-production (i.e., reading aloud to oneself), it is still present when material is presented by another person (Macleod, 2011). These studies are not mentioned here with the idea of testing the comprehension of read-aloud program participants, but rather to support the concept that listening to stories is a meaningful activity, and participants are likely to engage with the story being read.

The visual or auditory cortex take information to our semantic system, based on whether a story has been read or heard (Davis, 2018; Moisala et al., 2015) and the semantic system is invoked regardless of the way the words are received (Davis, 2018; Deniz et al., 2019). It is this latter finding that may be useful to those for whom silent reading is difficult, legitimising the option of listening to books to assist with comprehending and remembering. Comprehension of a text is no different for the different input modes (Rogowsky et al., 2016). Therefore, listening may be a useful approach for those with cognitive or other health conditions making reading difficult.

The value of listening to stories as a way to recapture the love of reading has been documented. For instance, numerous participants in a study of The Reader's programs commented on their depression or impaired concentration making independent reading too difficult, the subsequent loss they felt and the importance of reinstating the ability to read: "the return to reading was part of the sense of recovery, including the recovery within reading of more innocent or joyous experiences that seemed to have been irrevocably lost after trauma or breakdown" (Davis et al., 2016, p. 45). Previously avid readers repeatedly tell of their experience of being unable to read when struck down by illness, but nevertheless able to listen to stories (e.g., Sheffield, 2022; Wheeler, 2023). The concept of reinstating the ability to read by listening to stories is pivotal to this research.

Yarns, tales, stories, narratives, sagas, fables, fairy tales – people are "drawn to stories" (Pehrsson & McMillen, 2005, p. 51), capable of being immersed in them, and distracted from worries for a time. Despite advancing technology, which has made a vast number of audiobooks available via a variety of delivery methods, they cannot replace the in-person telling of stories; stories that still teach, heal and connect us "in a way nothing else can" (Nelson & Sturm, 2018, p. 4444). Researchers from the University of Warwick (2016) suggest reading aloud is a sensory experience, resembling being massaged with words, corroborating that there is indeed "something beautifully soothing about being read to" (Freeman-Greene, 2011, para. 38).

2.4 Cancer Specifics

> "The wonders of high-tech cancer care are best complemented by the humanity of high-touch care. Simple kindnesses can help to diffuse negative emotions that are associated with cancer diagnosis and treatment-and may even help to improve patients' outcomes."
>
> (Berry et al., 2017, p. 744)

2.4.1 Psychosocial Effects of Cancer Diagnosis and Treatment

Cancer treatments are physically and emotionally exhausting (Kirshbaum, 2010). About half of all people diagnosed with cancer are not offered any help for emotional distress (Chapman, 2016). Asking about their feelings and experiences with cancer is an important component of ascertaining their perception of their own health and wellbeing, and can be done using purpose-built questionnaires, called patient reported outcome measures (PROMS). These are designed to assess quality of life (QoL), symptoms, how they function on a daily basis and other health and wellbeing aspects (Australian Commission on Safety and Quality in Health Care, 2019). Collecting patient-reported outcomes (PROs), has been found to increase health related quality of life (HRQoL), decrease the number of emergency department visits and hospitalisations in patients undergoing chemotherapy, and to also extend lives (Basch et al., 2017; Basch et al., 2016; Gotay et al., 2008).

The term *distress* in the cancer context is preferred by some over precise clinical terminology, such as anxiety and depression, because it encompasses numerous mood disorders and is useful for oncologists and lay people alike, yet does not carry the stigma that mental health diagnostic labels still carry (Carlson et al., 2012; Howell & Olsen, 2011). Untreated distress is linked to a reduction in QoL, reduced compliance with scheduled clinical treatment (DiMatteo et al., 2000; Greer et al., 2008) and increased risk of mortality (Pinquart & Duberstein, 2010; Satin et al., 2009). Significant distress is experienced by up to

75% of people diagnosed with cancer (Cardy et al., 2006, p. 13; Galway et al., 2012, p. 1). A recent study looking at women diagnosed with breast cancer, found 30-60% of them suffered "significant cancer-related distress" yet less than 30% of these distressed patients received psychosocial care (Lally et al., 2020, pp. 2163-2164). There is consensus that distress is common for both patients and their caregivers (Linden et al., 2012; Zabora et al., 2001).

It is understandable and frequently documented that anxiety, nervousness, fear, depression and distress frequently accompany cancer diagnoses and treatment (Aldaz et al., 2017; Bultz et al., 2011; Korfage et al., 2006; Lewis, 2010; Linden et al., 2012; Lunevičiūtė & Masteikienė, 2014; Rankin et al., 2015; Schuurhuizen et al., 2015). Literature documenting the distress associated with cancer diagnosis abounds. For instance, in Canada, where a psychosocial oncology program dedicated to addressing "social, psychological, emotional, spiritual, quality of life and functional needs of patients and their families" exists (Cancer Care Ontario, 2018, p. 2), cancer-associated distress is recognised as the "6th vital sign" (Bultz et al., 2011, p. 463). Distress is similarly recognised in Australia, yet in many cancer settings screening for distress is not undertaken routinely (Carlson et al., 2012). Where the presence and treatment of cancer are accompanied by chronic pain, a further consideration is the elusive nature of effective pain treatment and the comorbidities of depression, anxiety and cognitive impairment (Grégoire et al., 2017; Moriarty et al., 2017; Wang et al., 2021).

For people affected by cancer living in regional and rural areas, lower survival rates than their counterparts in metropolitan areas are the norm (Clinical Oncological Society of Australia, 2012; Coory et al., 2013; Fox & Boyce, 2014; Hoon et al., 2009; Murphy et al., 2015; National Rural Health Alliance Inc., 2021; Pascal et al., 2016). Despite the Australian federal government allocating funds more than a decade ago for regional cancer centres (RCC), their use today is somewhat different than intended as the complexity of chemotherapies and immunotherapies necessitates specialised staff to deliver them – staff who are not located in regional and rural areas. Thus, the cancer experience in rural areas is impacted by lack of local services, necessitating the need to travel for treatment and generally rely on self or informal supports for psychosocial needs (Pascal et al., 2015; Pascal et al., 2016). For those able to access their treatment locally, they are likely to find their nurses, who in rural areas are expected to deliver many facets of care including emotional support, unable to adequately deliver psychosocial care because of their own emotional exhaustion (Kenny et al., 2007). It had been widely thought that rural cancer patients are at much higher risk (than metropolitan counterparts) of serious psychological distress, however, recent research has demonstrated that although rural cancer patients have "unique unmet psychosocial needs relating to

rurality", these unmet needs are now no greater than those experienced by their urban counterparts (van der Kruk et al., 2022, p. 1). This may have been achieved by the initial uptake of RCCs and more recently the increasing use of telehealth and digital healthcare options. However, rural patients continue to face additional, different problems, largely related to travel (van der Kruk et al., 2022). Rural people have been found to value psychosocial supports when they are made available (Gunn et al., 2013). It would, therefore, be remiss to exclude them from research aimed at improving psychosocial outcomes.

Despite the widespread acknowledgement of the prevalence of cancer-related distress, a disparity still exists between the need for psychosocial care and the frequency with which it is offered or delivered (Zebrack et al., 2016). This may be because in the past, extending life was the primary focus and now that physical outcomes have improved, psychosocial issues have come to the forefront. In 2010, the International Psycho-Oncology Society (IPOS), the multidisciplinary organisation responsible for psychological, behavioural and social issues in cancer care, created an "International Standard of Quality Cancer Care", which they revised in 2014, and which states:

> Psychosocial cancer care should be recognised as a universal human right;
> Quality cancer care must integrate the psychosocial domain into routine care;
> Distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain. (IPOS, 2014, para. 2)

Person-centred care ensures individuals, with their needs, preferences and values are at the centre of their health care decisions and plans, rather than the disease being the primary focus (Australian Commission on Safety and Quality in Health Care, 2024). Studies show that a person-centred approach in palliative settings reduces isolation and increases social support (Bradley et al., 2011), so it follows that a person-centred approach is appropriate for addressing psychosocial needs.

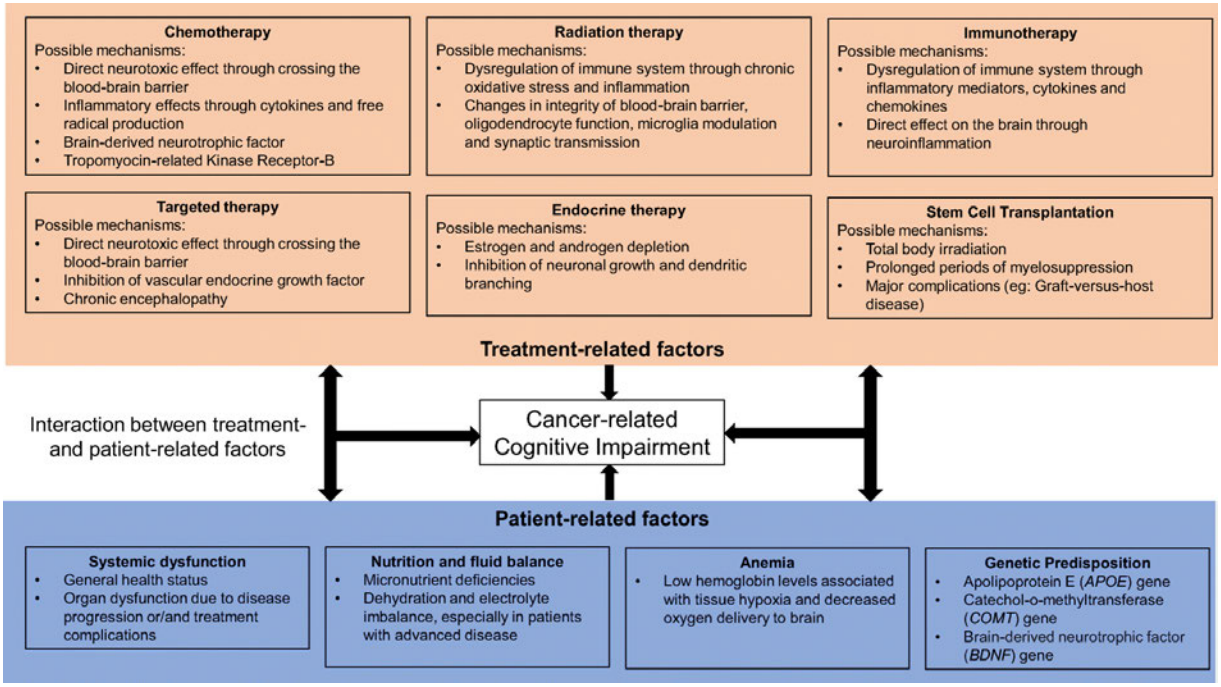
2.4.2 CRCI

Cancer-related cognitive impairment (CRCI) and cancer-related cognitive dysfunction (CRCD) are terms for the same condition, commonly known as cancer brain, cancer fog, chemo brain and chemo fog (Cancer Council, 2023b). It is a commonly reported occurrence, affecting more than half of cancer patients during (and often after) their chemotherapy, radiotherapy, immunotherapy and hormone therapy treatment. The most impaired functions are memory, attention, processing speed and executive functions (Ahles & Root, 2018; Joly et al., 2015; Lange et al., 2019; Wefel et al., 2015). The prevalence of CRCI varies according to different studies, each looking at different types of cancer, with the highest occurrence

seen as 75% for breast cancer patients who received chemotherapy (C. G. Brown, 2015, p. 204). With breast cancer now the most frequently diagnosed cancer in the world (ANZ Breast Cancer Trials Group Ltd, 2023a), it is reasonable to imagine CRCI will become more prevalent. Although precise mechanisms for the primary cause of CRCI are unknown, recent research indicates the body's own response to tumour growth may be one cause and cancer treatments worsen it (Winocur et al., 2018). A complex array of possible factors contributing to CRCI exists (refer to Figure 2.1).

Figure 2.1

Contributing Factors of Cancer-Related Cognitive Impairment



Note. Figure from Mayo et al. (2021). Reprinted with permission.

Historically, doctors did not believe, or they minimised, patients' claims of cognitive impairment, even when those patients reported losing the ability to recall words, read and make decisions (Boyer, 2019). With the recent ability to demonstrate that cancer and its treatment (especially chemotherapy) can result in physical changes to the brain, three separate anatomical changes have been identified with CRCI: inflammation in the brain's nervous system resulting from the release of cytokines in the body's attempt to inhibit tumour growth; impaired production of new brain cells in the regions associated with memory as a consequence of chemotherapy; and impairment of the learning and memory regions of the brain resulting from the combined effect of chemotherapy and tumour development (Winocur et al., 2018). These cause changes to the hippocampus, which is important for memory

(Apple et al., 2018); to the frontal areas of the brain (Castaneda et al., 2007; Kendler et al., 2018; Richardson & Adams, 2018), with reduced grey and white matter volume and density shown pre- to post-chemotherapy (Lycke et al., 2017; Winocur et al., 2018); as well as to the complex networks throughout the brain (Lycke et al., 2017; Menning et al., 2015; Zhu et al., 2024).

These brain changes relate to difficulty reading. Although the occipital lobe, responsible for visual perception, is located at the rear of the brain, the prefrontal cortex is involved in maintaining attention or focus, which is necessary for reading to oneself; and with visual memory also located in the prefrontal cortex (Funahashi, 2017), it is also affected by these cancer-related changes. Additionally, chemotherapy patients have been found to have inflammatory markers suggesting a relationship between inflammation, CRCI and compromised visual memory (Williams et al., 2018). However, located laterally in the brain, the temporal lobes process auditory input before projecting it to a wide region of the prefrontal cortex for processing by the working memory, allowing different networks to trigger and even shift, according to attentional needs (Plakke & Romanski, 2014). When comparing silent reading and listening, it is important to note that CRCI affects the temporal lobes less than the prefrontal cortex and so listening to stories may be easier than reading for people affected by cancer.

Research demonstrates decreased connectivity in the brain is also associated with CRCI (Dumas et al., 2013; Phillips et al., 2022). This is relevant because reading has been shown to increase brain connectivity (Berns et al., 2013). As an example, Welsh miners in a lead exposure incident had a level of protection from the cerebral effects of lead exposure if they were regular readers, but their non-reading peers did not (Bleecker et al., 2007). Other studies have shown reading both strengthens existing neural pathways and builds new connections (Temple et al., 2003).

Aside from the traditional notion that CRCI occurs while actively undergoing treatment, and recent studies showing it can occur prior to treatment, there is also a subgroup of cancer patients who experience a delayed onset of cognitive decline (Ahles & Root, 2018). Additionally, CRCI may still be present 10 years (de Ruiter et al., 2011) and even 20 years after cancer treatment (Koppelmans et al., 2012). Furthermore, other factors can influence cognitive outcomes. For instance, distress can also impair cognitive function (Castaneda et al., 2007; Kendler et al., 2018; Richardson & Adams, 2018) so the potential exists for distress to also play a role in the prevalence of CRCI (Lycke et al., 2017; Winocur et al., 2018).

Likewise, it is widely accepted that pain and fatigue impact cognitive function, and for people with cancer, associations between chronic pain and CRCI, and fatigue and CRCI have been found (Lycke et al., 2017; Menning et al., 2015; Zhu et al., 2024).

Although CRCI can affect people in different ways, there are commonalities reported of the impact it has on people's day-to-day lives, such as difficulty with reading, driving, navigating, losing the thread of conversations, losing things and forgetting appointments (Myers, 2015). Not surprisingly, this takes an emotional toll on patients, adversely affecting self-confidence, QoL, ability to self-care, and causing workplace and relationship challenges (Ahles & Root, 2018; Lange & Joly, 2017; Mayo et al., 2016; Myers, 2012; Wefel et al., 2004).

The importance of social connectedness is a recurring theme in many cancer studies. Loneliness also ranks among possible potentiating factors of CRCI, along with insufficient sleep and exercise (Hartman et al., 2015; Jaremka et al., 2014). Exercise is widely acknowledged for its myriad benefits across the continuum of cancer treatment and survivorship, including the palliative phase (Toohey et al., 2023), yet fatigue and CRCI can affect the motivation to engage in physical activity, as can loneliness (Hawkley et al., 2009) so there is a vicious circle at play. Myers et al. (2022) found their cognitive rehabilitation program both improved cognitive functioning and decreased loneliness. Among the acknowledged impacts of loneliness in the general population, are increased cancer incidence and poorer survival rates (Kraav et al., 2021), so there is a place for programs to help ease the loneliness burden. Reading has been shown to reduce loneliness (Hilhorst et al., 2018; Rane-Szostak & Herth, 1995) and is therefore worth considering as a potential mitigator of CRCI linked to loneliness.

Mental health benefits are a widely recognised consequence of reading (Billington, 2019; Davis & Magee, 2020; McNicol & Brewster, 2018). However, when experiencing CRCI, reading can become challenging, and even exasperating (Cancer Council NSW, 2020; McCrossin, 2020-present; Myers, 2015). Losing the reading habit or being unable to start it, can add to the distress experienced by people with cancer. This impact is described repeatedly in non-academic sources, however research about it is scarce and does not elucidate participate comments. Although not part of an academic study, this description given to staff at Cancer Council NSW by someone impacted by CRCI, humanises research findings about difficulties with memory and concentration:

> My head would get foggy, you can't concentrate. I'm an avid reader, I couldn't read more than two or three paragraphs because "what did I just read?" I had to go back and read it again. That was hard, so I kept on doing crossword puzzles and word puzzles or whatever to try and exercise my mind, of course, to just try and get the sharpness back. (McCrossin, 2020-present, para. 15)

Like many others, this person's capacity for reading for pleasure deteriorated while experiencing CRCI. Considering this, a bibliotherapeutic program that provides opportunities for simply listening, face-to-face with a competent reader with an attitude of caring, may restore the therapeutic benefits of reading within a warm environment, potentially leading to a more relaxed and emotionally uplifted state of mind (in line with known reading benefits).

2.4.3 Impaired Concentration and Reintroducing the Joy of Reading

The International Federation of Library Association and Institutions (IFLA) has identified the need for, and provided guidelines concerning, easy-to-read material for those with reading disabilities (IFLA, 2010), which one could argue includes cancer patients with CRCI. The World Health Organisation (WHO) has identified three dimensions in their definition of disability: impairment (of physical function or structure or mental function – examples include loss of vision, limb or memory); activity limitation (examples include trouble walking, seeing or problem-solving); and restrictions on participation in "normal daily activities" (examples include engaging in recreational or social activities) (Centers for Disease Control and Prevention, 2020, para. 3). As discussed in section 2.4.2, memory, attention and executive function (which are associated with reading) are all impaired with CRCI, so it can be argued that all three WHO dimensions are impacted: cognitive (including memory) impairment, problem-solving and navigation difficulties, and impacted daily activities including reduced social activities because of the difficulty keeping up with conversation and reading (Cancer Council, 2023b; Myers, 2015). Therefore, CRCI fits the WHO definition of disability.

The researcher's observations in libraries, coupled with cancer patients' narratives (Lang, 2016), and the known effects of CRCI (as discussed above), point to many people affected by cancer losing the ability to read for pleasure. Australian journalist and activist, Julie McCrossin, recorded a podcast series called "The thing about cancer", and in her episode about CRCI, people with a history of cancer related their experiences of being unable to read a novel during and for years after treatment, as they were unable to concentrate sufficiently to keep abreast of characters and plots (McCrossin, 2020-present). IFLA (2010) proclaims the

democratic right of all people to have access to "culture, literature and information – and in a comprehensible form", and emphasises the link between reading and quality of life:

> Being able to read gives a person a tremendous amount of self-confidence, by enabling him/her to expand his/her view of the world and take control of his/her own life. Through reading people are able to share ideas, thoughts and experiences, and to grow as human beings. (p. 3)

Studies confirm that reading is difficult for people affected by symptoms of illness, such as concentration difficulties and fatigue (Brewster, 2011; Mårtensson & Andersson, 2015; Pettersson, 2018; Robinson, 2008), including for people who have experienced CRCI (Cancer Council NSW, 2020; McCrossin, 2020-present). A read-aloud bibliotherapeutic program may provide the comprehensible format needed. Pairing participants with a competent reader verbally delivering stories may help them return to a happier and more relaxed emotional state.

2.4.4 Bibliotherapy as a Holistic Cancer Treatment

Holistic cancer care includes a variety of adjunct treatments and can include counselling or psychotherapy (individually or group CBT-based), exercise programs, nutritional guidance, artistic and musical therapies, mindfulness and other meditation, massage, acupuncture, Shiatsu, social programs and bibliotherapy. It is unclear from the literature how often bibliotherapy is made available as one of these treatments for cancer patients. Certainly, from the researcher's experience in Victoria and South Australia, and reviewing relevant literature, it has not been an available option.

Towards the end of 2022, Australia's leading cancer centres published a white paper about integrative cancer services (McDonald et al., 2022). The cover of the report has pictures of many complementary therapies, including yoga, art, music, massage, exercise and bibliotherapy, although bibliotherapy is the only one of these therapies not mentioned in the report. Bibliotherapy using imaginative literature shares attributes with music and art therapies, and as such a brief discussion of commonalities is presented in section 2.4.5. According to the authors of the white paper, "More than 50% of Australians with cancer will use complementary therapies to take control of their own healing, to cope with side effects, improve their long-term outcomes, and because they align with their culture and their values" (McDonald et al., 2022, p. 2). They also noted that these therapies can be accessed in a number of ways, but people who are able to choose to have their treatment in Integrative Oncology and Wellness Centres do so because of the person-centred care offered, which allows them to be actively involved in choosing treatments to improve their QoL. This report

also describes the frequent need for urgent treatments, which can be debilitating, and can leave patients seeking "comfort, distractions and ways to cope" (McDonald et al., 2022, p. 5). Reading is one approach to improve emotional wellbeing, as bibliotherapy has been seen to offer comfort (Cohen, 1994; McLaine, 2020b; Pieters, 2021) and distraction/escapism (Brewster, 2016; James & Römhild, 2023; Pettersson, 2023; Walwyn & Rowley, 2011)

Integrative oncology services are growing: in Australia, about one quarter of our healthcare organisations offer integrative oncology services (Smith et al., 2018), and evidence for its value and uptake are growing (McDonald et al., 2022). Bibliotherapy is known to be an effective, low-cost intervention (Axelsson et al., 2018; Frieswijk et al., 2006; Gualano et al., 2017; Monroy-Fraustro et al., 2021), and given funding constraints, low-cost therapies may have more chance of being adopted than costly ones. Dr Jimmie Holland, considered the founder of psycho-oncology, started the Vintage Readers Book Club, whose members read and discussed classic works, leading to discussions on other topics considered important to members (Grisham, 2018). This is bibliotherapy in action with people affected by cancer, instigated by a leading figure in cancer care, but unfortunately its effectiveness was not evaluated.

Many clinical research studies show the effects of bibliotherapy on the broader population (refer section 2.2.4), but only very few randomised controlled trials (RCTs) measuring the effectiveness of bibliotherapy on mental (or emotional) health in an adult cancer context exist. When searching for studies of bibliotherapy interventions in adult cancer settings, some studies were excluded because they had a focus other than assessing the effectiveness of bibliotherapy on emotional wellbeing. For instance, Bálint and Magyari (2020) used culturally appropriate fiction, poetry and folk tales with likely parallels to the lives of participants, read aloud, with guided group discussions to reveal spiritual needs, and to address some of these needs (such as death anxiety), but there were no measures to indicate how successfully these needs were revealed and addressed. Similarly, Huang et al. (2023) also focussed on spiritual wellbeing. Interestingly, they defined bibliotherapy as a group activity using self-help books, but developed an intervention that electronically sent articles about Taoism, Confucianism and Traditional Chinese Medicine to participants each day and encouraged them to post comments about their reading on an online chat forum. Nevertheless, their pre- and post-intervention measures (the Spiritual Attitude and Involvement List) determined the intervention group had a significant increase in spiritual health scores, compared to a control group, which adds to the body of evidence supporting bibliotherapy for spiritual health. Spiritual health is an important part of a person's overall

wellbeing, however, research on emotional wellbeing is more directly relevant to this research.

Thirteen studies of bibliotherapy with adult cancer populations were identified as relevant. Ten used the bibliotherapy intervention as a didactic experience: as a vehicle for delivering cognitive behavioural therapy (CBT) (Carpenter et al., 2014; Semple et al., 2009) or problem-solving therapy (Krebber et al., 2016), for learning more about cancer as a disease and care options (Schulman-Green & Jeon, 2017), or about how to deal with the side effects of anxiety, depression and the ability to cope (Allison et al., 2004; Angell et al., 2003; Beatty, Koczwara, et al., 2010; Beatty, Oxlad, et al., 2010; Körner et al., 2019; Roberts et al., 2016). Two of these studies utilised the same psycho-educational workbook intervention (*NuCare)* 15 years apart, with one targeting head and neck cancer patients (Allison et al., 2004) and the other including participants with any type of cancer (Körner et al., 2019). Both studies by Beatty and colleagues (Beatty, Koczwara, et al., 2010; Beatty, Oxlad, et al., 2010) utilised an Australian version of the workbook created by Angell et al. (2003), which the researchers first used with breast cancer patients after finishing treatment. This first study found no measurable effect (Beatty, Oxlad, et al., 2010), which the researchers surmised may have stemmed from the timing, so it was repeated with a group of breast cancer patients following diagnosis, with positive results (Beatty, Koczwara, et al., 2010). Interestingly, participants in Roberts et al. (2016) study who received a workbook aimed at improving coping skills, suggested they would have preferred the workbook in audiobook format. Only three studies used imaginative literature: two poetry (Daboui et al., 2018; Tegnér et al., 2009) and one fiction (Hammer et al., 2017).

In 11 of the 13 studies, the usefulness of the interventions for improving patients' psychosocial wellbeing was established (or suggested, in the case of pilot studies) using a wide range of psychometric tests. Participants reported improved coping skills (Roberts et al., 2016), sense of empowerment (Körner et al., 2019), quality of life (Allison et al., 2004; Körner et al., 2019; Semple et al., 2009), being emotionally supported (Angell et al., 2003), improved self-efficacy (Carpenter et al., 2014; Schulman-Green & Jeon, 2017), and physical and social functioning (Allison et al., 2004; Semple et al., 2009). Studies reported decreased distress (Körner et al., 2019; Krebber et al., 2016; Schulman-Green & Jeon, 2017), posttraumatic stress (Semple et al., 2009), feelings of helplessness/hopelessness (Beatty, Koczwara, et al., 2010), cognitive avoidance (Beatty, Koczwara, et al., 2010), depression (Allison et al., 2004; Semple et al., 2009), fatigue (Allison et al., 2004), anxiety (Semple et al., 2009) and uncertainty (Schulman-Green & Jeon, 2017).

For the studies using imaginative literature, anxiety and anger were significantly reduced for the participants in one poetry intervention (Tegnér et al., 2009), while increased hope and reduced stress were reported by participants in the other poetry intervention (Daboui et al., 2018). Participants in the only study using fiction, listened to audiobooks while completing a walking program and attending a supervised book club (Hammer et al., 2017), which may be too demanding for people undergoing cancer treatment. The participants reported that the chosen audiobooks were too depressing, and the study had a high dropout rate. Nevertheless, it did reinforce the idea of fiction as an immersive experience (Hammer et al., 2017), which would be positive given the right reading material.

Two of the studies had very high drop-out rates. The Krebber et al. (2016) study had a 60% dropout during the bibliotherapeutic component, which was delivered as a self-help intervention via the Internet or a booklet (p. 1756). The main reasons cited for dropout were lack of motivation, finding the program too stressful or difficult, or lack of concentration; noting however that 17% of those who dropped out did so because they started feeling better (Krebber et al., 2016, p. 1756). The Hammer et al. (2017) study of fiction-based bibliotherapy had a 53% dropout rate, and the most common reason cited for leaving the program was the choice of literature (pp. 474-475). Cancer patients with CRCI frequently do not have the focus to complete assigned reading tasks on their own and they lack the energy to persist with tasks that are not enjoyable, which could include reading or listening to books they find distasteful. That study provided audiobooks for six intervention sessions, based on a list of ten alternatives, chosen especially for the program by a modern literature expert. However, a cancer patient who dropped out after only one session stated “you have to try very hard to find positive things in life … so it can be a bit difficult to cope with books involving numerous suicides or characters who are sick of life” (Hammer et al., 2017, p. 476). Such a comment, coupled with the high dropout rate, leaves one wondering about the appropriateness of their book choices, and if in fact they added to the patient distress burden.

Psychoeducational booklets, workbooks, audiobooks and picture books were found to be beneficial to the mental health of adult and child cancer patients in an appraisal of existing evidence, which included four of the 13 studies described above (Malibiran et al., 2018). Reading for cancer therapy is also a theme with the UK’s national cancer charity, Macmillan Cancer, who provide cancer collections at libraries. Also in the UK, cancer patients have contributed to the production of dedicated lists of books especially chosen to recommend to other cancer patients because of their positive effects on mood (The Reading Agency, 2021a, 2021b). Of particular note is that these lists contain mostly fiction, and almost all are not

about cancer. Likewise, the concept of "Quick Reads" (The Reading Agency, 2021d) has the potential to play a role in delivering accessible reading material to cancer patients: "great stories and not very long, they are perfect for anyone without much time and … for people who face problems such as anxiety, impaired concentration and the side effects of medication" (Turner, 2008, p. 58).

Cancer can trigger components of grief (for many reasons – lost opportunities, loss of lifestyle, one's own mortality) and sometimes trauma, and whilst research has been done on the effectiveness of bibliotherapy in this context, these focus predominantly on children and families (e.g., Baraitser, 2014; De Vries et al., 2017; Jarrett, 2016; Moccia, 2014), and so more research is needed in adult cancer settings. Nevertheless, with bibliotherapy shown to be a useful therapy when physical and mental health conditions coexist (Czernianin et al., 2019), it may relieve some physical and emotional symptoms typical of cancer diagnosis and treatment.

Although the bibliotherapy studies involving cancer patients are small in number, they present an overall positive correlation between bibliotherapy and reduced distress, anxiety, depression and stress, and increased QoL. This supports the real possibility of positive results emerging from read-aloud programs.

2.4.5 Art and Music Therapies as Holistic Cancer Treatments

Art, music and literature are all humanities steeped in creativity and imagination, therefore it is worthwhile looking at the proven positive effects of art and music as therapies, as potential indicators of the effectiveness of literature when also used as a complementary therapy in the cancer treatment arena. Literature has been defined as a creative art form on numerous occasions, including by Oatley (1999) who defines art as the "creative expression of an emotion in a particular medium such as words" (p. 104).

The effect of art and music therapies in cancer care have been studied. A systematic review of 12 art therapy studies, involving 587 participants, found that anxiety, depression, fatigue and QoL all improved by attending facilitated art therapy sessions, delivered in a variety of ways (varying duration, frequency, length and group versus individual delivery) (Jiang et al., 2020). Monti et al. (2006) found mindfulness-based art therapy with accompanying reading recommendations to support the program produced significant positive changes to anxiety, depression and sleep.

Music therapy has long been used in a variety of settings. The history of its use is similar to bibliotherapy's: its use for healing dates back to ancient times, an acknowledgement of its psychotherapeutic usefulness really developed after WWII and it is recognised for its impact on physical and mental health (Köhler et al., 2020). A systematic review of music therapy within a cancer context, involving 30 studies and 1875 participants, reached different conclusions based on whether the participants were undertaking curative treatment or were in a palliative setting (Köhler et al., 2020). The findings during treatment phase are relevant to this research and they show music therapy had a positive effect on depression, anxiety and intake of pain medication (Köhler et al., 2020). Similarly, COVID-19 lockdowns were also a time of uncertainty and isolation, and during this time music was shown to help with loneliness, decrease anxiety, improve mood, provide escapism and aid relaxation (Cabedo-Mas et al., 2021).

Art and music therapies are recognised evidence-based complementary therapies used in a variety of settings, including in cancer settings. Music and art therapies are offered by some Australian cancer centres. The Olivia Newton-John Cancer Wellness and Research Centre in Victoria offers both therapies, while the Chris O'Brien Lifehouse in Sydney offers music therapy alongside other evidence-based complementary therapies such as mindfulness and yoga. The Cancer Care Centre and Flinders Cancer Wellness Centre (both in Adelaide) offer art therapy, as does the Peter MacCallum Cancer Centre and Royal Children's Hospital cancer centre (both in Melbourne) and Bloomhill Cancer Care (on the Sunshine Coast). This is relevant because the Australian, New Zealand and Asian Creative Arts Therapies Association (ANZACATA) includes therapies such as visual arts, dance, music, drama, creative writing, poetry, narrative and storytelling under their banner, and they describe the effectiveness of creative arts therapies as arising from the concept that "creativity enhances the well-being of all people and is a natural aspect of all cultures and human experience" (ANZACATA, 2021, para. 1). Imaginative literature, encompassing fiction, poetry and plays, "could be considered parallel to the creative practices of arts therapies which use emotive visuals, calming or motivating music, and contemplative poetry" (McLaine & Mackenzie, 2013, p. 8). With a similar uptake to bibliotherapy, creative arts therapies have been established internationally (particularly the UK, USA and Europe) since 1940s but are still seen as emerging but growing professions in Australia (ANZACATA, 2021).

Creative arts therapies engage the imagination, which can be especially important at a time when so much of a person's life feels out of their control, such as when diagnosed with cancer and undergoing treatment. These therapies are generally seen as pleasurable and can

form the basis of new interests and hobbies "which are vital for ongoing self-support" (ANZACATA, 2021, para. 5). In addition, the contact with another person, whether that is an arts therapy facilitator or someone simply reading aloud, offers a social connectedness in a non-threatening environment – the focus is on the art, music or literature rather than on the individual. Social connectedness is widely acknowledged as an important component of wellbeing, but in a cancer context where the focus is generally on treatments and tests for their effectiveness (or otherwise), which can be daunting, having a different, enjoyable focus offers a reprieve. As Hodge et al. (2007) found, reading together acts as a "powerful [socially] coalescing presence, allowing participants a sense of subjective and shared experience at the same time" (p. 102). Their study interviewed participants in programs run by The Reading Agency, and comments collected support this finding, such as

> It's nice to have somebody read to you. I don't think there's anything nicer than sitting there listening to somebody reading to you, I find that really relaxing. It's as though you can just let your mind wander and y'know you get all your imaginary pictures of how certain characters are, I think that enhances it. It's as though, I don't know, a different part of your brain is involved again. It gets you thinking a bit more 'cause you're listening. (Hodge et al., 2007, p. 102)

A "new and rapidly expanding field of research that is aimed at the intersection of psychological aesthetics, biological mechanisms, and human evolution" is neuroaesthetics, which shows how "music, art, theater, dance, literature, landscape, and media have the power to help treat any number of disorders and improve one's quality of life" (Dana Foundation, 2019). Neuroaesthetics researcher, Susan Magsamen, argues that people have an inbuilt, evolutionary need for the arts – that it is more than a predilection, that they are necessary for our wellbeing because of their role in helping people connect and communicate (Magsamen, 2019). Furthermore, IFLA recently stressed the importance of culture and cultural expression for building resilient, literate and informed societies, noting that "culture and the arts help connect people to the past and to one another. Arts like the written and spoken word move, inform, and enable action … a testament to the power of words to move and to change outlooks" (IFLA, 2021, para. 9).

Art, music and literature have been found to make life more meaningful and happier, and they are consistently found to improve wellbeing (Westgate & Oishi, 2022). This is important because treatment is not always undertaken with a curative intent, instead some therapies, such as yoga, dance and massage serve a physical purpose and also improve emotional wellbeing, that is, they make people *feel* better (Falkensteiner et al., 2011; Selman et al., 2012). The intent of a reading program is to help improve emotional wellbeing while

undergoing cancer treatment; for when you feel better, you are better able to cope with whatever else is happening in your life (Folkman & Moskowitz, 2000; Fredrickson, 1998; Fredrickson et al., 2003; Lazarus et al., 1980).

2.4.6 Benefits to Others

Psychological distress accompanying cancer diagnosis and treatment can also affect the family and friends of patients (Lewis, 2010; Matthews et al., 2003). It is possible that those close to the cancer patient receiving complementary therapy sessions will also be influenced. In the case of a bibliotherapeutic intervention, it may be via the calming influence of being read to (if they choose to be present during delivery of the program), or by experiencing some respite from caring duties, or simply by the reassurance their loved one is experiencing a pause from the focus on their illness. A recent Australian study found carers have lower levels of wellbeing than the general population, with many expressing they lack time for their own pursuits, including exercise and self-care (Mylek & Schirmer, 2023). Carer wellbeing is enhanced by being able to take a break from caring duties (Måvall & Thorslund, 2007; Wylie et al., 2021) and a bibliotherapy program for their loved one would provide some time of respite from caring duties.

Ongoing distress of cancer patients also causes distress for oncology teams (Lunevičiūtė & Masteikienė, 2014) so it would be reasonable to correlate that cancer ward nursing staff are affected too. Nurses caring for distressed patients may experience some respite or joy seeing their patients participate in a psychosocial program. When considering others who may also be involved in the care of people affected by cancer, volunteers have potential for some activities. The sense of purpose and satisfaction that result from volunteering is a long-established well-documented concept (Volunteering Australia, 2011, 2022). If volunteers help with delivering psychosocial interventions, they may experience a sense of fulfilment from their role in the program.

2.5 Summary and Conclusions

> "Literature helps us find a way forward. It creates enjoyment and human connection."
> -Helen Cook (Jeynes, 2022)

This literature review draws on evidence for the benefits of reading and bibliotherapy for the general adult population, as well as to specific groups within our communities, to propose that bibliotherapy is a relevant therapy for individuals with cancer. By also drawing on literature examining psychosocial impacts of having cancer, CRCI, and storytelling in the

context of reading aloud, it is possible to analyse each of these pieces of the ‘reading during cancer treatment jigsaw puzzle’ with a view to putting them together to make a positive difference to the wellbeing of cancer patients.

Reading is beneficial, whether it is for pleasure or learning (Hollis, 2023). Bibliotherapy comes in many guises. It is given a variety of names, and it is delivered using many different vehicles – there is no consensus and even other researchers describe the definition of bibliotherapy as lacking “conceptual clarity, consistency of terminology” (Cohen, 1994, p. 428), “challenging” (McMillen & Pehrsson, 2004, p. 73; Shereff et al., 2017, p. 44) and “not well defined” (Brewster & McNicol, 2021, p. e12). However, the main methods are silent reading of prescribed self-help books or imaginative literature (with or without intervention from a health or library professional), or group sessions with a facilitator reading aloud that include targeted discussion of the text and issue being addressed. At its core, bibliotherapy is about using books to improve wellbeing and all techniques have produced positive outcomes for participants, whether measured by quantitative or qualitative methods. These outcomes are especially relevant in the context of individuals who may be anxious, depressed or isolated.

Distress is commonly experienced by people with cancer, but it remains vastly under-addressed (Chapman, 2016). CRCI is also now acknowledged as a real condition affecting huge numbers of cancer patients, impacting their lives in many ways. One of these impacts is a reduced ability to concentrate, which is both frustrating and disabling, and can rob cancer patients of their ability to read for pleasure or education, or to even partake of some everyday activities such as successfully following a recipe or directions (Boyer, 2019).

Art and music therapies share some commonalities with bibliotherapy, especially when using creative literature, and while both art and music therapies are accepted in integrative cancer settings, the role of bibliotherapy for cancer patients has received a little attention. Findings range from tentatively positive to qualitatively or statistically significant (Malibiran et al., 2018), although the focus has been generally on self-directed CBT-based bibliotherapeutic interventions. While bibliotherapeutic studies have tended primarily towards qualitative outcomes in the past, they are becoming increasingly quantitative or mixed methods. Studies utilising a read-aloud delivery are limited and none exist in a cancer context.

Storytelling has always played a role in human connection. Listening to texts read aloud offers an alternative mechanism for understanding a written text and it may be the solution to providing access to those with cognitive impairment. Reading aloud and listening are likely

to be a useful vehicle for restoring or introducing reading, and all the accompanying therapeutic benefits, to those suffering CRCI (Plakke & Romanski, 2014; Williams et al., 2018). Reading aloud offers human connection and is more accessible than lone reading when cognitively impaired.

The concepts of distraction and comfort appear regularly in literature about relieving distress and also in relation to reading or bibliotherapy using imaginative works. Authors, librarians, bibliotherapists and doctors all extol the benefits of immersing oneself in fictional reading, and more recently, science has been able to confirm not only the benefits of reading such works to brain health (Wilson et al., 2013), but has also been able to explain some of the cognitive networks invoked when processing these stories (Berns et al., 2013).

The literature illustrates an increased interest in bibliotherapy over the past decade. Bibliotherapy appears to be widely recognised and practiced in the United Kingdom, and whilst there is some evidence of its implementation in other European countries and the USA, it still appears little-known in Australia (James & Römhild, 2023). Australian Cancer Councils produce excellent pamphlets to help those newly diagnosed, undergoing treatment, or just finished treatment (and their families) but there are no references to either bibliotherapy or read-aloud programs and their potential benefits. Therefore, it is important to provide evidence within the Australian setting for the inclusion (or not) of bibliotherapy. There is a research gap in investigating read-aloud programs as an adjunct to existing holistic cancer treatments, where the sole aim of these programs is to boost the emotional wellbeing of cancer patients undergoing treatment.

Whilst the individual issues of CRCI, self-administered bibliotherapy and the (generally unmet) emotional needs of patients during cancer treatment are documented, there is no literature to support the interaction of readers and cancer patients, and the possible effects bibliotherapy through regular read-aloud sessions can have on emotional wellbeing. Read-aloud programs for cancer patients may provide benefits to mental health and improve emotional wellbeing, and that is the essence of this exploratory study.

Therefore, the research presented in this thesis addresses the following research questions:

- What impact does regular participation in a read-aloud program have on the emotional wellbeing of cancer patients currently undergoing treatment?
- What are the psychosocial effects of read-aloud programs from the perspectives of patients and families?

More specifically it is hypothesised that a read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment, as indicated by increased self-reported wellbeing and decreased symptoms of stress, anxiety and depression, and will provide a positive experience for those involved. This research will fill a gap in the literature regarding the effectiveness of individually tailored bibliotherapy on the emotional wellbeing of people undergoing cancer treatment.

"More than at any other time, when I hold a beloved book in my hand my limitations fall from me, my spirit is free. Books are my compensation for the harms of fate. They give me a world for a lost world, and for mortals who have disappointed me they give me gods." (Keller, 1929, p. 313)

Chapter 3. Methodology and Methods

"It was more than simple escapism. Gran didn't care for horror or thrillers or crime sagas because she'd seen enough unhappiness in her life … Why wouldn't she choose to surround herself with love and happiness?"

-Phoebe Chapman, *Love Me Do* (Kelk, 2024, p. 241)

This chapter outlines the methods used to collect and analyse data to explore the impact of participating in a regular read-aloud program on participants undergoing (or recently completed) cancer treatment. The theoretical underpinnings to support the selection of methods are also presented. An approach involving multiple types of data and collection points was selected to understand the impacts of the intervention on participants and their families. The intention was to collect quantitative data that could be analysed statistically, as well as qualitative reflections about participants' experiences, in order to construct a rich description of the reading program experience.

3.1 Design

Design theory

This was an exploratory study, with an a priori hypothesis, using an experimental pre/post design. The emotional wellbeing of cancer patients participating in a read-aloud program while undergoing treatment has not been previously examined.

A mixed methods study is "more than simply the ad hoc combination of qualitative and quantitative data in a single study" (Halcomb et al., 2009, p. 3); it embraces the intentional collection of various data sources, for instance, observations, interviews and surveys from individuals, families and organisations. The analysis and mixing of this qualitative and quantitative data within a single study (or series of related studies) to understand a research question or problem results in "new understanding of the phenomena under study" (Klassen et al., 2012, p. 378). By capturing participants' voices along with associated quantitative measures, an exploration of the research problem extends beyond what numbers alone could describe by adding the meaning participants ascribe to any changes or lack thereof associated with the intervention. A mixed methods research framework is ideal for cross-disciplinary work (Creswell, 2009; Hesse-Biber & Johnson, 2015) like this, where an understanding of both emotional wellbeing and bibliotherapy were necessary. After completing the wellbeing instruments, interviews would provide an avenue for rich, detailed feedback. A mixed

methods approach is also ideally suited for health care issues (Creswell, 2009). Qualitative approaches pursue an understanding from participants' viewpoints (Vaismoradi et al., 2013), which was necessary to inform the content of the intervention, specifically the choice of reading material. Measuring emotional wellbeing was essential to achieve an objective measure of change, before returning to a qualitative approach that gathered detailed data about the experience of the intervention from participants, their families and nursing staff (if any had been involved).

Table 3.1

Research Decisions

Paradigm (Ontology & Epistemology)	*Design*	*Methodology*	*Methods*
Pragmatism	Experimental pre/post	Mixed Methods	Enrolment questionnaires Pre-/post-intervention instruments Mid-point survey Observation Interview

The broad research design decisions foundational to this study are presented in Table 3.1. A pragmatic paradigm was most suitable given the intervention was a practical one built from participant input (that is, human experience as an input to the construction of the study) with outputs that sought to bring relief to people undergoing cancer treatment. Positivism, with its reliance on reason, logic and mathematical proof is well-suited to quantitative methods, while constructivism stems from a belief that individuals construct their own ideas of reality and is well-suited to qualitative methods, however a pragmatic approach "embraces the two extremes and offers a flexible and more reflexive approach to research design" (Kaushik & Walsh, 2019, p. 6). Pragmatism is a paradigm or worldview, through which research can be conducted, and thus it can be considered as both the ontological and the epistemological stance (Maarouf, 2019). Adopting this stance, the most appropriate research design and methodology for addressing the research questions were chosen reflexively, evolving from a desire to objectively quantify the outcomes of the program, paired with the richness of qualitative findings gathered from participants and their families to explain the impact of the

intervention from their perspectives. Embracing plurality of methods also addressed a fundamental tenet of a pragmatic paradigm. Although CRCI has some common characteristics across the population it impacts, it can affect people in different ways and so the inadequacy of a single data source and the synergistic combination of quantitative and qualitative research to create a result "greater than either approach alone" (Creswell & Plano Clark, 2018, p. 58) was embraced. Additionally, with the potential importance of real life applications resulting from this research, and pragmatism's focus on actions and potential to empower marginalised communities (Kaushik & Walsh, 2019), in this case considering those undergoing cancer treatment as somewhat marginalised, pragmatism was eminently suitable.

Table 3.2

Study Design Summary

Data Collection Implementation	*Qual:Quant Priority*	*Integration of Qual & Quant Findings*	*Theoretical Perspective*
Exploratory Sequential	Equal	During interpretation / discussion	Advocacy / Participatory

The underlying study design decisions are summarised in Table 3.2 and explained below. This research was undertaken through the lens of an advocacy/participatory perspective (Creswell, 2009). Advocacy research gives participants a voice, which is important in the cancer context where help with distress is frequently an unmet need (Chapman, 2016; Lally et al., 2020). More specifically in this context, an advocacy/participatory approach is a collaborative method, which was appropriate because participants helped choose the reading material – either directly by specifying specific titles or indirectly by supplying information about favourite genres, authors, films or books they enjoyed as children. Additionally, participant feedback was sought at the midpoint, when the program could have been adjusted for them and reading choices altered. However, using an advocacy/participatory approach held potential challenges for recruitment, including prospective participants feeling obliged to enrol because the researcher belongs to the same phenomenological group. Therefore, as a precaution, no individuals were approached to enrol and the researcher was previously acquainted with only one participant, although she found the study independently.

This research is phenomenological by nature: all participants have a lived cancer experience, as does the researcher. While it is deemed impossible to keep subjectivity out of qualitative research (Walkerdine et al., 2002), there are two approaches for dealing with it: epoché,

where an attempt is made to ignore existing ideas and assumptions; and reflexivity, which generally involves reflection and introspection (Finlay, 2009). By embracing a reflexive approach, the researcher was able to embrace her own experiences that place her into the same phenomenological group and so there was no need to allocate time for extensive contact with the participants at the outset in order to understand the impact cancer can have on people. Refer to section 3.3 for a description of the researcher's position. Additionally, the researcher's ongoing contact with others affected by cancer, through the sport of dragon-boat paddling which attracts and retains a large population of people affected by breast cancer, broadened the researcher's assumptions about emotional and physical impacts of cancer. While acknowledging not all cancer experiences are the same, understanding and empathy with participants was a natural consequence of this association.

Data collection

An exploratory sequential approach to data collection was used (Creswell & Plano Clark, 2018; Fetters et al., 2013) with quantitative and qualitative data collected at different stages of the read-aloud program. As part of enrolment in the study, participants were required to complete a demographic survey in addition to completing a questionnaire about reading habits and preferences, and also complete their pre-intervention Adult Survey of Reading Attitude (ASRA). This initial qualitative data impacted the delivery of the intervention, as the books chosen to be read aloud to participants were based on this initial data. It was possible for participants and the researcher to collaborate with choosing reading material. Book selection was an important component of the intervention, and unlike the Books on Prescription scheme or the SR model, these book selections were tailored for the enjoyment of each individual.

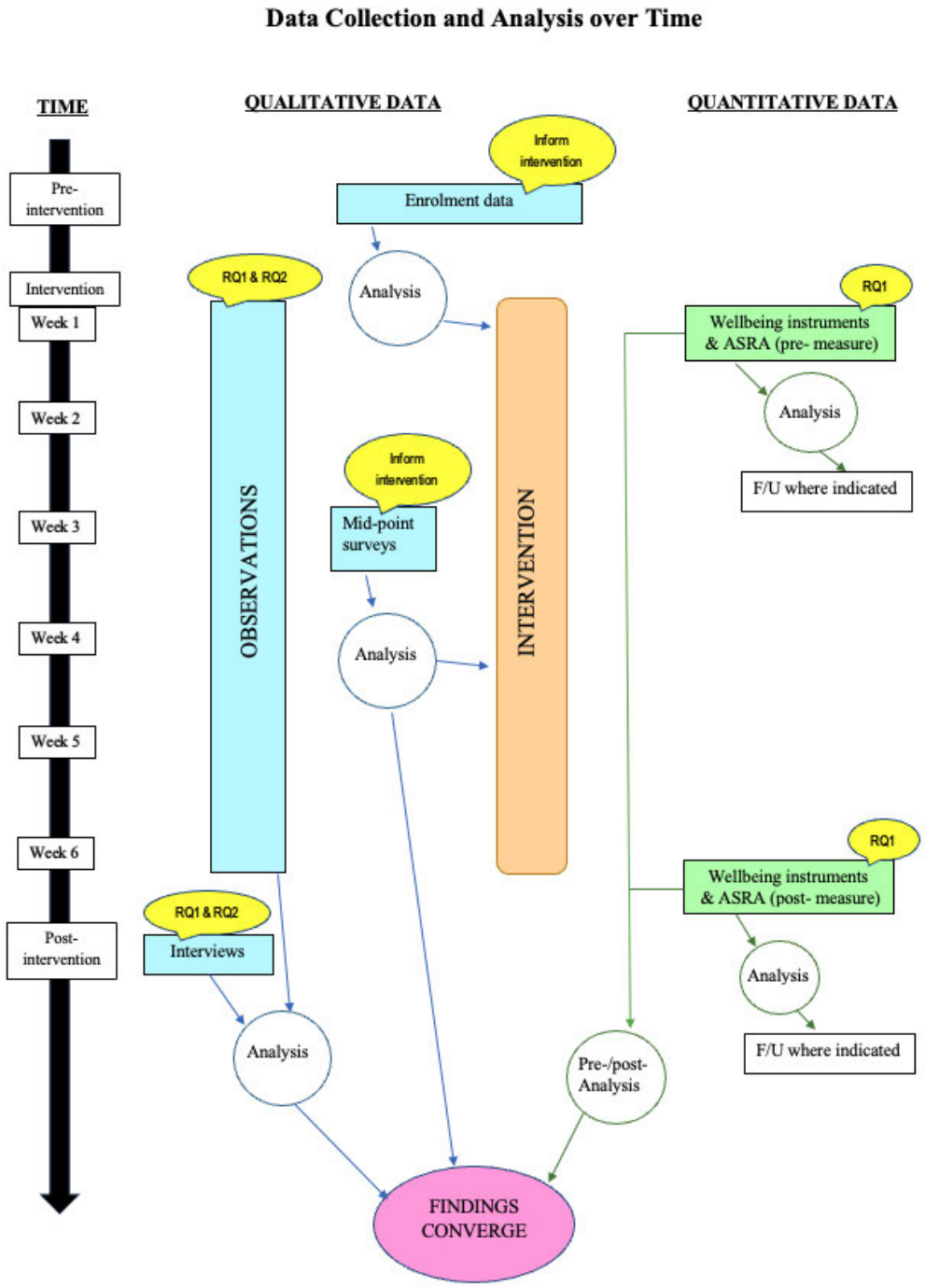
At the commencement of each participant's first reading session, pre-intervention quantitative data were collected as a baseline: the wellbeing instruments (as detailed in section 3.8.2) were administered. Ongoing qualitative data was collected, with the reader systematically recording observations of each intervention session with each participant, guided by STROBE's checklist for conducting and disseminating observational research (STROBE, 2024a). STROBE is an acronym for STrengthening the Reporting of OBservational studies in Epidemiology (STROBE, 2024b). Participant observation (along with informal or formal interviews) is considered one of the qualitative researcher's tools for understanding "the nature of phenomena" in a naturalistic setting by researchers observing and/or taking part in the activity of the people being studied (DeWalt & DeWalt, 2011, p. 2).

Gathering data in this way, that is, participating (as the reader) while observing then explicitly recording those observations assisted with the development of the more structured part of data collection, such as interview questions (DeWalt & DeWalt, 2011). Certainly, information gathered via observation assisted with deeper questioning during interviews, which were based on the semi-structured interview questions. Other bibliotherapy studies, for instance Billington et al. (2010), Brewster (2011), Dowrick et al. (2012), Hodge et al. (2007), Pettersson (2023) and Robinson (2008), found the collection of observational data helpful and valid.

A short qualitative survey was administered mid-way through the intervention to gauge enjoyment of the reading material, before the quantitative data collection at the conclusion of the intervention. This was followed by interviews, which yielded rich conversations. When a family member was available, willing, and gave consent, interviews were arranged directly with the family member. These were usually conducted over the phone. With qualitative data informing the development of the intervention and the existence of multiple data collection points, the utilisation of an intervention mixed methods framework is intimated (Fetters et al., 2013). The data collection steps are represented in Figure 3.1.

Figure 3.1

Data Collection and Analysis Over Time



Note. This fits the experimental methodology for intervention trials as described by Creswell et al. (2009). Key: 'F/U where indicated' refers to a follow-up letter written by one of the clinical psychologist project supervisors, with participant permission, to their GP to report DASS-21 and WEMWBS results where scores were severely abnormal.

Equal weighting was given to both qualitative and quantitative data collected, with a mixing of data at the interpretation stage. An inductive approach was used when analysing the interview data, which is discussed further in section 3.10.2. It had been intended to explore

the perspectives of staff and volunteers via interviews, however no participants were in-patients at the time of taking part in the program and volunteers were ultimately not needed to help deliver the program (refer section 3.7).

Absence of control group

People affected by cancer are notoriously hard to recruit for psychosocial research studies (Custers et al., 2023; Hulbert-Williams et al., 2019; Lankveld et al., 2018; Rabin et al., 2013), therefore the study design did not include a control group. Maintaining a waitlist control group was considered but there were implications with rural and regional (RR) participants potentially being sent home while still on the waitlist and potential complications with some sessions in-person and some via Zoom, with the possibility of some participants becoming unable to complete the program because of limited (or no) Internet capacity at home, or no desire to finish the program via Zoom. An additional complication was the ethical issues associated with control groups involving sick people who would like to engage in an intervention and denying them intervention enrolment. As discussed in Chapter 2, although unproven in a cancer context and via read-aloud delivery, bibliotherapy has nonetheless been repeatedly shown to be beneficial for a range of mild to moderate mental health issues, chronic pain and loneliness. It is deemed unethical to withhold treatment of a therapy with proven benefits (Louro et al., 2023).
help deliver the program (refer section 3.7).

Individual versus group delivery

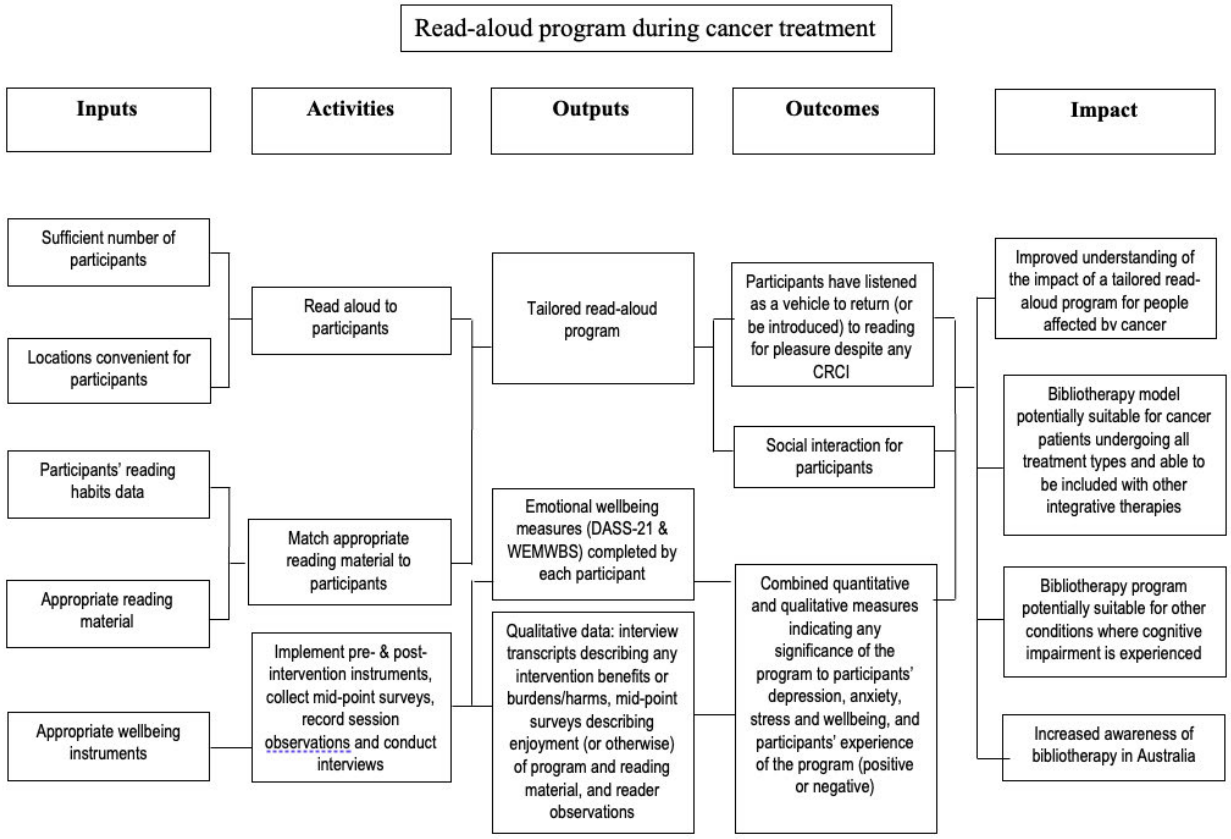
Although social contact is generally perceived favourably in terms of mental health benefits (supporting arguments for group activities), some cancer patients prefer one-on-one programs (Semple et al., 2006). One study delivered their individualised intervention in people's homes one-on-one and experienced a dropout rate of only 4% from the experimental group (Semple et al., 2009, p. 380). Similar studies with groups of cancer patients have up to 15 times greater dropout rates than this, hence the choice of a one-on-one intervention here. Studies also indicate that the shorter the distance between participants' homes and intervention venues, the greater the participation rate (Chaudhari et al., 2020; Lankveld et al., 2018). Participant burden is perceived as low if the intervention is delivered in their home, and moderate if they need to travel to participate, which led to the development of this intervention as a home-based program to keep the burden as low as possible: less stressful because of no travel expectations, no associated travel or parking costs, achievable in the midst of cancer-related fatigue, and thus with an anticipated low dropout rate.

Design Summary

To summarise the program design, considerations when constructing it, and desired results, a logic model for the study is contained in Figure 3.2.

Figure 3.2

Results Chain: Input-Activities-Output-Outcome Logic Model



3.2 Ethical Considerations

This study received ethics approval from the University of South Australia HREC (approval number 204027). Approvals were also received from St. Andrew's Hospital HREC (project number 139) and Southern Adelaide Local Health Network (SALHN) HREC (application number 128.22 LNR), in addition to approvals from Breast Cancer Network Australia (BCNA) and NeuroEndocrine Cancer Australia. Given this research involved cancer patients undergoing treatment, sensitivity to any potential additional distress to the participants was of the utmost importance. The researcher had current first aid and mental health first aid training, and personal experience interacting with people affected by cancer. Participants

were provided with contact details for the Cancer Council 13 11 20 Helpline and Lifeline at the commencement of the study. To allow for the remote possibility of any issues occurring during a reading session, a distress protocol was developed, and co-supervisors and clinical psychologists, Dr Amanda Hutchinson and Dr Kate Gunn, were available by telephone to assist. All books were chosen with a mood-enhancing element in mind, unless the initial reading habits questionnaires of individual participants indicated they had other specific reading preferences.

All participants were over 18 years of age and were provided with an information sheet outlining the program. Participants were required to give their consent to participate in the intervention.

Using an advocacy/participatory approach raised potential ethical challenges, such as power dynamics, community representation and the blurring of boundaries (i.e., intertwining researcher and participant roles). To address the power dynamics challenge, potential and enrolled participants were always listened to, their input was utilised, participants were given the space and opportunities to withdraw or reschedule whenever needed, and attempts were made to avoid socially desirable responding (refer section 6.5.1). Community representation was attempted through an initial collaboration with the Cancer Council regarding the involvement of their lodges, then via cancer support groups with their members reaching out to others in their network. To avoid blurring boundaries, especially when using reflexive TA (where the researcher is a tool in the process), it was necessary for the researcher to frequently consider the role of empathy and remain vigilant to fully analysing data. It is important for researchers to acknowledge their background and beliefs (see section 3.3 for positionality statement), but there is the need to keep researcher and participant voices separate.

3.3 Positioning / Reflexivity statement

Acknowledging my background and position as researcher is important in reflexive thematic analysis (TA) and this is discussed further in section 3.10.2. It is this personal and professional background that led to the desire to find a way to reinstate the therapeutic benefits of reading to those struggling to read as a consequence of their cancer diagnosis or treatment, and discovering the gaps in current research in relation to this phenomenon (as described in section 2.5). This statement is needed because the reflexive nature of this study demands that I acknowledge my role, which includes bringing my background, beliefs, experiences and assumptions to bear, as they affect the research process.

I am a first-generation Australian woman from a working-class, English-speaking family. Reading was important to my mother, but not to my father, although he supported the love of reading that my mother fostered in both my brother and me. Now in his mid-50s, my brother continues to be an avid reader of printed books, defying statistics and stereotypes that women read more than men. My employment experiences, particularly teaching at secondary school level and being able to influence disengaged teenage readers to once again embrace reading, followed by my years working in the public library sector, where I took joy in matching books and audiobooks to readers, frame the way I view reading as an amazing source of entertainment and companionship. My library experience was invaluable for the readers' advisory (RA) skills needed for this research and the development of questionnaires. Further, teaching and library work are essentially service-providing activities, which influenced my decision to use a pragmatic paradigm with an advocacy/participatory theoretical perspective.

With a personal cancer diagnosis and treatment approximately six years ago, I hold an insider status to my participant group. My previous cancer experience was not kept secret from the participants. It is important for researchers to own their perspectives (Elliott et al., 1999) and I sit with the group of 75% of people diagnosed with cancer who experience distress (Cardy et al., 2006, p. 13; Galway et al., 2012, p. 1) and the half who were offered no help with their distress (Chapman, 2016), which is a strong position of empathy with the phenomenological group in this study. Additionally, my cancer experience in regional Victoria gave me experience of the difficulties encountered when seeking practical and psychological support in regional and rural areas, which were a stark contrast to the opportunities available in metropolitan Melbourne. However, I saw fit to revisit my position regularly throughout the research process to acknowledge that people's reactions to diagnosis and treatment can vary. Particularly during the collection of qualitative data, I was aware of the need to keep the voices separate; not to influence or overlay my voice onto what the participants said, or to blur boundaries between us (Berger, 2015). I remained well aware of the possibility that my experience could block other voices (Cloke et al., 2000) or that I could assume the participants and I had the same experience, and thereby not really hear or understand what they were telling me (Finlay, 2002; Pillow, 2003), and so while I probed during interviews if I needed more detail or clarification, I tried to stay self-aware and did not express any of my own opinions. When compiling observational notes, I tried to do so as an outsider looking onto the scene.

My experience working in my local regional community palliative care unit just prior to moving to South Australia to commence this research project enabled me to embrace the

enrolment of palliative cancer patients in this study and cherish the reading experiences at the bedsides of those near end of life. I believe in the truthfulness of what participants told me, and believe in presenting the findings as objectively as possible, while acknowledging my role in the qualitative analysis method, reflexive thematic analysis (reflexive TA), which is discussed in section 3.10.2.

Although I was not aware of experiencing any CRCI myself, I witnessed the upheaval it caused in the lives of family, friends and community members affected by it. In particular, I saw a pattern of readers, first my mother during her cancer treatment, then library patrons at the small country library where I worked, lose their ability to read for pleasure, and thus lose the friends lurking between the pages of books at the very time when those friends were needed. I saw the frustration then sad resignation when they could no longer read in a meaningful way. I was aware my lack of personal CRCI experience could potentially pose a barrier to some participants, however through helping others with coping tips, I had an in-depth working knowledge, which was unfortunately put into practice when I experienced Covid Fog during the PhD.

3.4 Recruitment and Selection

Eligibility criteria were established to determine participant suitability for enrolment.
Participant inclusion criteria:

- People over 18 years old
- Fluent in English
- Currently undergoing, about to undergo, or completed cancer treatment in the last 12 months.

Exclusion criteria:

- People affected by cancer not receiving any active treatment or not within 12 months of treatment
- People under 18 years of age
- People without a good level of English comprehension and unable to read/write English (some reading/writing accommodations were possible – see below).

The inability to read/write English exclusion criterion was based on participants needing to be able to complete wellbeing instruments. Cognisant of vision impairment, dyslexia or physical disability impacting either the reading or filling out of the instruments, accommodation could be made in the form of the researcher reading these questionnaires

aloud and ticking responses as directed by the participant. When this was required, a reminder about the confidential nature of the study was forthcoming because sharing details about the state of their emotional wellbeing could be embarrassing for some participants when the relative anonymity of using a paper questionnaire was not possible.

Although CRCI can occur independent of treatment or result from any treatment type, for the purposes of this research, the focus was on patients actively receiving or recently completed treatment. At the research proposal stage of this project, emphasis was put on recruiting participants who had undergone, or were undergoing, chemotherapy, however, including all treatment types allowed for anticipated participation by rural and regional (RR) residents of the Cancer Council lodges. In some cases, South Australian RR people affected by cancer may be able to travel to Adelaide for only initial chemotherapy infusions then low risk infusions may be administered at their closest regional cancer centre, but the majority need to travel to Adelaide for at least a day (and two nights) every few weeks to access infusions and other specialty scans and appointments. Contrastingly, RR people attending Adelaide hospitals for radiotherapy generally stay for eight weeks, and seek the comfort of things to do, and companionship, during this time away from home. Participating in a reading program had the potential to fill some of those gaps. The research was limited to competent English-speaking participants, in order to keep the scope of the research manageable.

Recruitment involved contacting Cancer Voices SA, Cancer Council SA (regarding Greenhill and Flinders Lodges, as well as their general social media presence), Cancer Council Victoria, the Cancer Care Centre (approval pending and later withdrawn), UniSA research volunteers webpage, the many cancer support groups that meet in-person in SA as well as those that exist solely online, numerous cancer-specific organisations (such as Breast Cancer Network Australia (BCNA), Leukaemia Foundation Village Adelaide and Myeloma Foundation Australia), Australian Library and Information Association (ALIA) and Public Libraries SA, as well as posting advertising flyers on public, library and university noticeboards, and utilising social media (such as Facebook, Gumtree and LinkedIn). The researcher gave numerous presentations (refer to Appendix A for a full list of media engagements) while seeking to recruit participants. Speaking at cancer support group meetings was the most effective way to recruit participants.

Recruitment was very difficult. Given cancer is statistically more likely to occur as people age, flyers were sent to each state's Returned Servicemen's League and Country Women's Association. ALIA's weekly newsletter featured two calls for public libraries to support

participant recruitment and Public Libraries SA also emailed public libraries in the state. However, most SA library staff, when approached, were unable to advertise this reading program because they were constrained by rules issued by their controlling local governments. This is discussed further in section 6.8.

Given the prevalence of CRCI, and the acknowledged difficulties finding instruments subtle enough to measure it, this study addressed the issue of CRCI by asking participants questions around self-reported cognitive impairment during recruitment, and also via the inclusion of the two European Organisation for Research and Treatment of Cancer (EORTC) cognitive questions alongside the DASS-21 and WEMWBS instruments. This study did not attempt to objectively measure cognitive impairment of participants nor use the presence (or absence) of CRCI as inclusion or exclusion criteria.

Most cancer treatments in SA are delivered in Adelaide, so regional cancer centres were not approached for recruitment. RR participants were able to receive the intervention online via Zoom in their homes and it was anticipated they would also be able to receive it in-person at either of the Cancer Council SA supported accommodation facilities: Greenhill Lodge or Flinders Lodge. It was thought that participating in the program might also ease some of the discomfit associated with staying in the city, away from their usual supports. However, some recruitment avenues were cut off when new COVID-19 variants reached Adelaide (including Cancer Council SA lodges) and other potential recruitment agencies withdrew support without indicating reasons.

The target sample size was 20 metropolitan participants and 20 RR participants (40 in total). This was a reasonable target sample size considering other studies involving interventions for cancer patients generally had an initial sample size around 40-60 (Carlson et al., 2003; Körner et al., 2019; Semple et al., 2009) and the WEMWBS guideline is for a minimum sample size of 30 individuals (Warwick Medical School, 2021, para. 1).

Potential participants were screened by phone to ensure they were eligible, and to have the study described to them. A telephone script was created to assist with this. If eligible and interested, a participant information sheet (PIS), demographic questionnaire, reading habits questionnaire and consent form were sent (by email or post depending on email capabilities of participants) (see Appendices E – G).

Participant recruitment occurred most effectively when presenting in-person at cancer support group meetings and through articles published in their newsletters and magazines. Regular

readers, lapsed readers and non-readers were all invited to participate. As most strategies yielded only a few participants, a wide variety of approaches was required to reach recruitment targets.

3.4.1 Participants

In total, 38 participants were recruited: 24 metropolitan and 14 RR. One (rural) participant withdrew (due to deteriorating health) and one (metropolitan) participant was unable to complete the intervention as he died mid-way through the program. Further details about participants are presented in section 4.1.

3.5 Intervention

While this intervention does not directly fit the current bibliotherapy models described in Chapter 2, it nevertheless uses books as therapy – reconnecting cancer patients to their love of reading or helping them discover the joy of reading during their cancer treatment journey, with the intention of boosting their emotional wellbeing in the process. This intervention is grounded in theories of reader response and the role of escapism/distraction for providing solace and respite from some of the physical and emotional impacts of cancer and cancer treatments. There are many names for many different styles of bibliotherapy. Perhaps this can be considered a new style of bibliotherapy, with a name along the lines of ‘reading for wellbeing’ or ‘real-aloud for wellbeing’. The details are described below.

3.5.1 Program Design

The frequency of the intervention (i.e., reading sessions with each participant) was weekly given new brain connectivity remains for about a week after reading fiction. Berns et al. (2013) report on a functional MRI (fMRI) study in which networks of brain activity associated with reading increased each day while reading a novel and then dissipated after finishing the book. These functional networks that occurred while reading fiction persisted for approximately a week (Berns et al., 2013). Although the nature of these long-term effects was unclear, one week was also chosen as practical and achievable (balancing participant burden with beneficial outcomes) for the current intervention and likely to be within the life of neural connections built by reading the previous week. This is consistent with previous bibliotherapy research that indicates the need to plan the frequency of sessions according to participant illness and symptoms of illness (Pettersson, 2018).

The duration of intervention sessions was anticipated as 30-40 minutes, with flexibility to cater for participant fatigue; however, it was generally closer to an hour to allow for greetings and a wellbeing observation, reading stories and often discussing them, then time for booking a session the following week. Accurately estimating the time to read a story aloud versus reading it silently was a skill that needed to be developed and the researcher found that timing the reading of an entire page of a given story, then multiplying it by the number of pages in the story generally worked, except for illustrated books such as an illustrated Jeffrey Archer short story book (which was popular and used frequently).

Intervention sessions were held at convenient locations. Most intervention sessions were conducted in participants' homes. Some were conducted in public libraries near their homes. Sessions could have been conducted within the recruiting hospitals if any in-patient participants had been recruited, or if others had requested sessions in the chemo suites or the Flinders Cancer Wellness Centre. UniSA's clinical trials rooms at City East campus were available if needed. Some RR participants and all interstate participants participated using Zoom. The Cancer Council lodges were originally organised as the intervention venue for RR participants staying in Adelaide for treatment. However, the Omicron variant of COVID-19 sent the lodges back into lockdown, and they did not re-emerge. This meant any participants staying at the lodges needed to travel to the closest library. With this extended lockdown at the lodges, the promised promotion of the program by the social workers there also did not happen. A poster was placed in the kitchen at Flinders Lodge and of the three people who saw it, one did not complete enrolment because her treatment regime changed and she was sent home following surgery, and R5 completed the reading program over Zoom when she arrived home from Adelaide, with R2 as the only participant who had no option other than to travel to sessions because of the changed conditions at the lodges. At the first session at the closest library, it was quickly apparent that it was not viable to continue meeting there because of noise, drafts and lack of out-of-the-way space to sit together. We conducted the remaining sessions at a library a little further away then via Zoom when he left Adelaide at the end of his treatment.

Some RR participants were within acceptable driving distance from Adelaide. Up to an hour's drive was considered acceptable when the journey could be combined with visiting other RR participants in the general vicinity. One RR participant met the researcher at a public library halfway between her home and Adelaide in order to participate in-person. At the request of three RR participants who enrolled together, and were within reasonable driving distance from Adelaide, sessions were initially held (individually) at a café of their

choosing but it was too noisy and after two sessions a joint decision was made to meet two of them (individually) at the local library and one in her home. Finding quiet places to read in public spaces could be haphazard as there was not always time to visit and assess the environment prior to the first session.

The mode of the intervention was one-on-one (one reader and one participant present). Consideration was given to individual versus small group delivery. Due to the logistics of coordinating small groups (people with different availabilities and different reading interests) and the findings of the Semple et al. (2006) study indicating a preference for one-on-one programs during cancer treatment, one-to-one program delivery was chosen. Some situations arose whereby small groups were suggested by groups of potential participants: a regional Young Women's Christian Association (YWCA) Encore group, a regional walking group, and two friends in the Adelaide Hills, but for consistency the program remained one-on-one. Participant feedback overwhelmingly supported this decision (refer Chapter 5).

The duration of the intervention was similar to other studies with cancer patients, which have generally delivered their interventions over 5-8 weeks: bibliotherapy over six weeks (Körner et al., 2019; Roberts et al., 2016); music therapy, "optimal intervention duration of 1–2 months" (Li et al., 2020, p. 1121); art therapy for five weeks (Archer et al., 2015); poetry for 6-8 weeks (Daboui et al., 2018; Tegnér et al., 2009); while eight weeks appears to be the standard course of mindfulness programs according to the multitude of studies on mindfulness programs and cancer patients. Two meta-analyses point to psychosocial interventions (specifically interventions involving coping skills, social support and counselling) exceeding 12-weeks duration as being notably more effective than those of shorter durations (Kalter et al., 2018; Rehse & Pukrop, 2003). However, a 12-week intervention was beyond the scope of this exploratory study. This intervention ran for six weeks which was consistent with the aforementioned studies that nevertheless achieved benefits to their participants. The researcher took the position that the ideal intervention delivery was often enough to make a difference, but not so lengthy as to tire the participants or have them lose focus during sessions, or to lose the motivation to continue, and to deliver the sessions at a location that kept the participant burden as low as possible.

All projects have practical considerations. The key factors with this project centred on the logistics of visiting participants, determination of accurate reading times for stories, and COVID-19. In the interests of providing a resource for future implementation of read-aloud programs, the practicalities of delivering the program are described in Appendix B.

Whether to prescribe audiobooks or to read-aloud in person was a consideration when planning this study. This was such an important design decision that it is described in detail in section 3.5.2 below and the impact of this decision on the participants is discussed in section 6.6.

3.5.2 In-Person Reading

When considering the merits of in-person reading versus audiobooks, confidence was derived from storytelling traditions to create a read-aloud program, where human connection and intervention personalisation could make a difference, rather than supplying pre-recorded books. Further inspiration was gathered from the adult storytimes around the world, particularly Melbourne's Story Lounge, and the UK's Shared Reading (SR) and RAYS programs. The recognised benefits of social connection to health, of which numerous studies exist, including Czaja et al. (2021); Holt-Lunstad et al. (2010); Holt-Lunstad and Steptoe (2022); Martino et al. (2017), also influenced choosing this method of program delivery.

Audiobooks can be great company at those times when escaping into a physical book is not feasible (for instance, when holding a book is difficult due to impairment, or when performing simple tasks like weeding or washing the dishes) and they tell stories that help keep drivers awake on long trips. However, using audiobooks in this study was decided against, in favour of individual personalisation and the warmth of human contact for the following reasons:

- The bibliotherapeutic studies with the highest retention rates (refer Appendix N) generally involved extensive in-person contact (and no travelling required for participation).
- There was a huge drop-out rate in the only existing study about listening to imaginative literature (refer discussion of Hammer et al. 2017 in section 2.4.4) and they used audiobooks.
- Difficulty operating technology when experiencing CRCI is not uncommon (Nelson, 2017; Nova Scotia Health, 2022). This was an issue the researcher first saw in her mother during her cancer treatment and was a cornerstone of the design decision to deliver the reading in real-time rather than ask participants to use audiobook technology.
- The lack of short stories available in audiobook format would have hindered the program. Additionally, when pre-reading story collections to find appropriate material for the intervention, there was never a collection where every story was suitable. This

was the other main practical reason for not choosing an audiobook intervention delivery.

- Lack of confidence in keeping participants involved, stemming from the reduced motivation that often occurs during CRCI, as well as reduced energy during and for some time after, cancer treatment was an important consideration. During interviews with participants, as described in Chapter 5, lack of motivation for undertaking or completing tasks was common - potentially resulting from the frontal lobe impact of chemotherapy (refer Chapter 2) as well as the fatigue associated with all treatment types.
- The warmth of human contact has been shown advantageously in repeated studies. For instance, "people perceived as warm and competent" consistently bring out positive emotions and behaviour in others (Fiske et al., 2007, p. 77), which is of particular importance to this study of emotional wellbeing. Additionally, the trait of warmth dominates competence, with people judging it in others based on the perceived motives of the other person (Fiske et al., 2007) and it would be reasonable to assume the motives of someone undertaking a time of sharing stories would only be good.

During interviews, rather than directly asking if participants preferred in-person reading to listening to audiobooks, they were instead asked to compare the two experiences in order to reduce socially desirable responding. More details about in-person reading versus audiobooks from the viewpoint of participants, and the impact of choosing in-person real-time reading is discussed in section 6.6.

3.5.3 Book Selection

As bibliotherapy researcher Detrixhe (2010) noted, book selection is dependent on therapeutic goals. The intention of this intervention was not to educate patients about their disease or treatment, nor to use self-help books to directly address emotional issues, but rather to use fiction (an already acknowledged bibliotherapeutic tool and storytelling mechanism) to engage the participants' minds and facilitate the reading benefit of transportation away from current emotional difficulties. One of the geniuses of our time, Albert Einstein, famously said in an interview in 1929 "imagination is more important than knowledge" (Einstein quoted from 1929 interview in Morgenson, 2005; Nilsson, 2010). Although unclear whether the oft-touted famous advice about making children intelligent by reading them fairy tales, then making them more intelligent by reading them more fairy tales

can in fact also be attributed to Einstein (Winick, 2013), the value of stories has withstood the test of time via our storytelling traditions, the practices of early hospital bibliotherapy (Jones, 1922, 1939; Peterson-Delaney, 1938) and the recommendations of modern bibliotherapists such as Berthoud and Elderkin (2013).

Studies of The Reader's SR program support this preference for fiction, and one study involving people with chronic pain, where both the condition and the treating drugs could impair concentration, found the reading program (consisting of short stories and poems read in weekly sessions for 12 weeks) resulted in decreased pain and improved psychological wellbeing (Billington, Humphreys, et al., 2016). Participants noted the choice of literature was paramount, not self-help and not about their medical condition, they favoured the more complex stories and poems, as making sense of them proved absorbing which was a great distraction from their pain (Billington, Humphreys, et al., 2016).

In consideration of text length, studies by Pettersson (2018) and Brewster (2011) involving participants with mental illness, found concentration difficulties arose from participants' illness. In a study by Pettersson (2023), she noted that texts needed to be short enough to be read by participants in their entirety prior to the session. Pre-reading is in direct contrast to this intervention, however, using shorter texts to enable reading complete stories at each session was pertinent. Brewster (2016) noted the importance of children's literature, genre fiction (including crime stories, fantasy and science fiction) and narrative non-fiction, with Pettersson (2023) confirming the usefulness of fantasy and other popular genres for producing bibliotherapeutic effect. Immersion in a story may offer the opportunity for release from some of the burden of cancer diagnosis, treatment and side effects and the disorientation of CRCI. Yet, recommended lists of books for providing information about health conditions and for managing mental health conditions exist, and so the effectiveness of these is known, but there does not appear to be any research about the best texts to use when engaging in bibliotherapy using imaginative literature.

As discussed in Chapter 2, fiction can play a special role in bibliotherapeutic terms, and was thus the reading material of choice in this study. As author Philip Pullman (2015) wrote,

> The meaning of a story emerges in the meeting between the words on the page and the thoughts in the reader's mind. So when people ask me what I meant by this story, or what was the message I was trying to convey in that one, I have to explain that I'm not going to explain. Anyway, I'm not in the message business; I'm in the "Once upon a time" business. (para. 2-3)

With fiction as the chosen type of literature, supplemented with some narrative non-fiction and poetry, the specific choice of reading material was informed by the reading habits questionnaires completed during enrolment. It was appropriate to include yarns, anecdotes, folklore, Australian wit/humour and other narrative non-fiction because of the way they retell (mostly) true stories. Tailoring reading material to individual participants was very important – under the premise that it must be enjoyable to be effective (to provide an immersive, escapist experience). Personalisation was indicated by Cohen (1992b; 1993) and she suggested "you want as close a fit as possible" (1992b, p. 57). In this study, personalisation was also a consideration to reduce potential dropout. However, unlike Cohen (1992b; 1993) with her recommendation of escapist reading only when patients were too unwell for illness narratives, the intention of this intervention was not to entice patients to identify with characters going through a similar disease experience, but rather to boost emotional wellbeing by redirecting them to positive experiences and thoughts: to show them fictional "sunlight" (Gaiman, 2013, para. 22).

The importance of using appropriate reading material was highlighted by the findings of Hammer and colleagues (2017), which had a high dropout rate with feedback linking the dropout to the chosen reading material, which was out of participants' control. Conversely, the study of CBT-based bibliotherapeutic interventions based in participants' homes was tailored to individuals, and the dropout rate was calculated at only 4% (Semple et al., 2009). This corroborates the importance of individually tailoring the intervention. Retention is discussed further in section 6.5 and Appendix N.

With weekly reading sessions, short stories and stand-alone chapters from novels or narratives were good options, requiring no recall of previous sessions. Additionally, this allowed for complete reading of texts in individual sessions, to facilitate a sense of achievement or accomplishment, and it has been shown that accomplishments can promote psychological wellbeing (Croom, 2015).

The reading material crossed gender and genre barriers. For instance, a Maeve Binchy (2020) Christmas story (women's fiction genre) was read to everyone enrolled towards the end of the year, and without exception, everyone enjoyed the tale that was spun about the nature of relationships in families and between friends, and the humour it contained. Thus, the reading list produced as an output of this project intentionally contains a wide variety of genres and will hopefully be a useful resource for people affected by cancer looking for a good story. Personal reading preferences play a huge role in the selection of reading material and not all

stories will be enjoyed by all people. Catering to personal taste is intrinsic to reading customisation. The importance of sourcing enjoyable stories for each person is of more value than attempting to read them material dictated simply by expectations associated with demographics, for instance gender differences (Statista Research Department, 2015), or any pre-conceived notions of the value of one style of literature over another. Two of Ranganathan's laws of library science were applicable delivering this intervention: "Every reader with his or her book" and "Every book its reader" (Ranganathan, 2006/1931, pp. 280, 299). There really are stories suited to everyone.

Story selection was complex, drawing on both logical choices such as stories by participants' favourite authors, and creative choices with stories similar to their indicated favourites, but sometimes a bit different to promote interest. The intricacies of story selection can be found in Appendix C. The care and attention given to choosing stories, and its time-consuming nature, can be a common tenet of bibliotherapeutic work (James & Römhild, 2023). However, all the time and effort devoted to story selection was worthwhile given the value participants placed on stories chosen just for them (refer section 6.1).

3.6 Output – Story Guide

Hundreds of stories were assessed for suitability to read to participants. Lists were created, by genre, of stories appropriate to read aloud to people affected by cancer (with caveats on their inclusion where warranted) and stories deemed inappropriate. These lists are not exhaustive but have been collated to form a reading guide to assist others when choosing stories to read to people undergoing cancer treatment, people who have completed cancer treatment but are still experiencing CRCI, or to people in palliative situations. Appendix D contains the guide.

3.7 Volunteers

A read-aloud program is eminently suited to trained volunteers assisting with reading and it was intended that reading volunteers would help deliver this intervention. The researcher had planned to process all the enrolment questionnaires and source appropriate reading material for each participant and for volunteers to assist with reading aloud. The researcher was to meet with each volunteer to discuss issues around reading aloud, recognising participant fatigue, personal safety and to attempt to instil a sense of the lived cancer experience.

Just prior to the hospitals' HREC approvals, in anticipation of an influx of participants greater than the researcher could manage to read to herself, the university's Performing Arts

department was approached, looking for student volunteer readers. This was done on the basis that these students in particular would be great at delivering stories. Some responses were received, but difficulties with establishing contact, ensuring potential volunteers were fully COVID-19 vaccinated and lived in the vicinity of potential participants resulted in being unable to utilise them with intervention delivery.

Various ways of getting reading material to volunteers were considered, such as ordering books for them to collect on their own library cards from their nearest public library, or sourcing e-Book versions. However, the main reason volunteers were not utilised was the logistics of getting tailored reading material to them, with a secondary concern of the need to assess the suitability of individual volunteers (regarding personality, empathy and reading aloud skills) and the human resource management skills of how to tell unsuitable people they were not required, especially with the added complexity of limited face-to-face contact due to COVID-19. The advantage of the researcher doing all the reading herself was that she was able to collect observations of each session and see participants' reactions, which informed decisions about what to read next. Often, a small selection of suitable books was taken to reading sessions, to choose from spontaneously according to participant mood and wellbeing. Being able to choose and being prepared to swap books is a skill which would need to be taught if/when the program is rolled out on a larger scale.

3.8 Development and Implementation of the Testing Protocols

The demographic and reading habits questionnaires were sent to participants to complete prior to enrolment. As its name suggests, the mid-point survey was used as a program health check half-way through the delivery of the intervention. The wellbeing and reading attitudes instruments were given to participants to complete prior to commencing the intervention, and at the completion of the intervention. Semi-structured interview questions were developed for use in the post-intervention interviews. These are all described below.

3.8.1 Demographic and Reading Habit Questionnaires, and Mid-point Survey

The participant information sheet (PIS) (refer Appendix E) and participant consent form (refer Appendix F) were created on UniSA proformas. The demographic questionnaire (refer Appendix G) was developed to enable reporting based on demographic variables, which is the standard seen in other studies of this nature. Self-reported medical data was collected: cancer type and stage, and treatment type and stage. This questionnaire was based on enrolment questionnaires used in similar studies, with the addition of three questions about

self-perceived cognitive impairment, which are relevant to this study. These questions were based around the two EORTC QLQ-C30 cognition questions (refer 3.8.2) which address concentration and memory, but these distinguish between cognitive changes since diagnosis versus since treatment, and ask about the impact of any such changes to daily living.

The reading habits questionnaire (refer Appendix H) for existing readers was based on typical home library questionnaires whilst for new readers it sought out limitations that may have prevented participants from reading and explored any prior reading habits and current interests to form the basis for choosing reading material. During enrolment, new/non- reader participants were also asked about their television and film preferences. This questionnaire was developed from the researcher's experience working in public libraries, including her delivery of home library and other outreach services, and her LIS supervisor's experience.

A brief mid-point survey (refer Appendix I) was developed to gauge participant enjoyment of the material being read to them. This is consistent with other multi-week creative interventions, for instance Clark et al. (2006) and Skingley et al. (2014). It was developed based on questions that ought to be asked regularly of home library recipients (from the researcher's library experience). As such, the mid-point survey comprised only three short questions.

All participant forms are contained in the appendices.

3.8.2 Instruments

Depression, Anxiety and Stress Scale short form (DASS-21)

The DASS-21, with its Australian norms and no licence issues, was a logical choice to assess stress, anxiety and depression. It has high internal consistency and validity in a variety of settings (Antony et al., 1998; Lovibond & Lovibond, 1995).

The DASS-21 is the shortened form of DASS-42, with only 21 questions instead of the original 42 questions. Participants respond on a 4-point Likert scale ranging from 'never' to 'almost always' to assess symptoms of depression, anxiety and stress among adults via seven items in each of three subscales. The subscales have excellent discriminative, concurrent and convergent properties; can be useful for measuring both current state and changes over time and have been validated with cancer patients (Coker et al., 2018; Healthfocus Clinical Psychology Services, 2018; Singh et al., 2015). The DASS-21 has Cronbach's alpha values of 0.94, 0.87 and 0.91 for each of the subscales (depression, anxiety and stress respectively) (Antony et al., 1998, p. 179), indicating excellent internal consistency and reliability. For

scores outside the normal range, the higher the score, the more severe the disorder. Conversely, using the DASS-21, the lower the scores are, the higher the emotional wellbeing. As the DASS-21 exists in the public domain, the Psychology Foundation of Australia makes it freely downloadable via the University of New South Wales website (https://www2.psy.unsw.edu.au/dass/).

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

The WEMWBS is a measure of positive wellbeing in the sense of the degree of flourishing, happiness and satisfaction with life and the version used in this study consists of 14 items. Responses are provided on a 5-point Likert scale ranging from 'none of the time' to 'all of the time', presented in a visual format for ease of completion. The 14-item version measures the respondents' mental wellbeing via both feeling and function items (Warwick Medical School, 2020b). It is scored from 1-5 for each item, with a total possible score from 14-70. Scores less than or equal to 40 indicate probable depression, 41-44 indicate possible depression, 45-59 indicate average mental wellbeing and scores of 60 or higher indicate high mental wellbeing (Warwick Medical School, 2021, para. 6). The higher the scores, the higher the levels of mental wellbeing. It has been validated in a variety of clinical settings; and "covers key aspects of psychological functioning: optimism, autonomy, agency, curiosity, clarity of thought and positive relationships; and positive affect (feelings): confidence, feeling relaxed, cheerful, having the energy to spare" (Warwick Medical School, 2020c). A licence to use WEMWBS is free of charge for non-commercial use and was obtained from https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/using/non-commercial-licence-registration/.

The WEMWBS has been comprehensively validated in adult, adolescent and minority populations (Warwick Medical School, 2020a). It has been found to be reliable and responsive to change at both an individual and group level including with breast cancer patients (Maheswaran et al., 2012), rural cancer patients (Shaheed et al., 2019), in an interactive psychosocial support study for cancer patients (Whiteman et al., 2015) and has been used as a bench mark for measuring the effectiveness of other instruments in cancer studies (Moschopoulou et al., 2021). The WEMWBS has been successfully tested against the Centre for Epidemiological Studies Depression Scale, the Edinburgh Postnatal Depression Scale, the Patient Health Questionnaire and the Association of University and College Counselling Scale (University of New South Wales - School of Psychology, n.d.). It is used to measure and monitor mental wellbeing rather than specific mental health issues

(University of New South Wales - School of Psychology, n.d.), and was therefore ideal for this study. The WEMWBS has good content validity and internal consistency, with a Cronbach's alpha score of 0.89 (student sample) and 0.91 (population sample); its test-retest reliability has been calculated at 0.83 which shows high reliability (Tennant et al., 2007).

European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30

With permission from the Executive Assistant of the European Organisation for Research and Treatment of Cancer (EORTC), participants were asked the two EORTC questions relevant to CRCI symptoms. The EORTC QLQ-C30 is a 30-item instrument for measuring QoL in cancer patients (EORTC, n.d.). The two EORTC QLQ-C30 questions (questions 20 and 25) relating to cognition were utilised, since self-perceived cognitive difficulties are relevant to this study. The two questions are:

- Have you had difficulty in concentrating on things, like reading a newspaper or watching television? (not at all / a little / quite a bit / very much)
- Have you had difficulty remembering things? (not at all / a little / quite a bit / very much) (EORTC Quality of Life Group, 1995)

Adult Survey of Reading Attitude (ASRA)

A shortened Adult Survey of Reading Attitude (ASRA) was also administered to capture attitudes around the experience of reading. The ASRA was developed in 1988 by M. Cecil Smith as part of a longitudinal study of reading skills, habits and attitudes from childhood to adulthood, based on a 1977 children's reading attitude survey created by Wallbrown, Brown and Engin (Smith, 1990a). The original survey comprised 92 items across eight subscales, whereas Smith identified five meaningful and appropriate subscales for adults: activity and enjoyment, social reinforcement, reading anxiety and difficulty, reading modes and assisting others (Smith, 1990a). It was designed to accurately portray adults' reading attitudes, behaviours and feeling (Smith, 1991). The ASRA has been shown to have good reliability, with Cronbach's alpha score of 0.93, test-retest of 0.87 and reasonable construct validity across groups of adults of different ages, education standards and reading abilities (Smith, 1991, 1992a). It has been used in multiple studies (in either its complete or a shortened form) where measures of adults' attitudes to reading were required (e.g., Ahmed, 2016; Annamalai & Muniandy, 2013; Anugrah, 2019; Asif & Gouqing, 2023; Ho, 2016; Laurier, 2017; Mahato, 2016; Remark, 2017; Smith, 1992a, 1992b). Some studies, however, used such an altered version of the ASRA that its effectiveness becomes questionable. For instance, Ahmed (2016) only used the subscales of activity and enjoyment, and reading anxiety and

difficulty, yet he split Smith's subscale of activity and enjoyment into his own separate subscales but presented the questions (to participants) for each of the subscales consecutively, which could undermine the effectiveness of the scale. Likewise, Ho (2016) incorrectly credited the ASRA questions to more recent researchers, such as Annamalai & Muniandy (2013), rather than the ASRA's creator, and created his own subscales. It is worth noting that in some studies, such as those by Ho (2016), Mahato (2016) and Remark (2017), the researchers did not score the ASRA responses correctly. Their scoring of some questions was counter-intuitive (i.e., they assigned the same numerical value to both positively and negatively framed questions), and correspondence with the ASRA's creator resulted in confirmation that was incorrect so this research could proceed with full knowledge of how to score ASRA responses (M.C. Smith, personal communication, September 13, 2021).

When undertaking reading work with adults it is advantageous to be aware of their reading attitudes (Smith, 1990a), and so the ASRA was administered as a secondary outcome measure. Overall scores for the ASRA range from 40 to 200 indicating poor/negative attitude to good/positive attitude to reading (Smith, 1990b). Considering the participant group in this study, with their likely fatigue and cognitive impairment, only questions from the reading enjoyment and anxiety subscales were administered to reduce participant burden and because these subscales display the highest reliability coefficients (Smith, 1992a).

3.8.3 Semi-structured Interview Questions

The purpose of the semi-structured interviews was to examine the success (or otherwise) of the program from a 360-degree perspective: participant, family, nurse (for any in-patients) and reader/volunteer. Questions for family members, nurses and volunteers were created to explore the benefits of the program as they saw them to the participants, as well as any impacts the program had on themselves. Semi-structured interviews with open-ended questions allow for more flexibility than either quantitative instruments or closed questions and aim to understand the participants' perspectives and experience.

The questions were developed by the researcher in consultation with the research team, to gauge the effects of the program on the participants and their families. As exploratory research, there were no sources to draw upon from prior studies of read-aloud bibliotherapy programs in a cancer context. However, considering interviews as "purposeful, directed conversation" (Singh, 2014, p. 792) with the goal in this case of discovering what it was like to experience the read-aloud program, questions were constructed to open up conversations

about various aspects of the intervention while allowing for follow-up of spontaneous comments and questions from either the interviewer or interviewee.

The interviews were conducted soon after the program concluded and were in-person where the intervention had been in-person, as that continued the warmth and meaningfulness of face-to-face interaction. Zoom interviews were conducted with the RR and interstate participants who received the intervention via Zoom. In-person, Zoom or telephone interviews were all offered as alternatives for family member interviews. Most family members were interviewed over the telephone while some were face-to-face.

Although there was a social component to this intervention, measuring the perceived level of social support experienced by participants was beyond the scope of this research. Mindful of this, the interview question "How do you think human voice and presence contributed to your enjoyment of the program?" was included to encourage participants to explore and explain any social impacts they felt.

The participant interviews were expected to run for 30-45 minutes (less for family members) and were recorded. In reality, interview times varied significantly, with a range of 9 minutes (for the participant with aphasia) to 51 minutes, and a mean of 23 minutes. Rather than using purposive sampling to invite participants to interviews with the intention of getting a spread across cancer type, age, gender, marital status and different living arrangements, given recruitment was staggered, all participants who completed the intervention (except one) were interviewed. All family members who were willing and contactable were also interviewed. Refer to Appendix J for both participant and family member interview questions. Questions were also developed for use with reading volunteers and nursing staff; however, volunteers were ultimately not used to help deliver the intervention and no participants were in-patients at the time.

3.9 Data Storage

A data management plan was constructed for the management, storage and disposal of data. Privacy and confidentiality was achieved by assigning identification codes to participants and storing this information separately: electronically on the university's research data storage (RDS) server in a private folder as well as in hardcopy. All audio files and transcriptions are stored and backed up according to University of South Australia's policies and the ethics protocol. All hardcopy consent forms and questionnaires are stored in a locked cabinet in D2-08 at Mawson Lakes campus.

3.10 Analysis / Statistical Analysis

Twenty-four metropolitan participants enrolled in the program (including interstate participants who lived in metropolitan areas), and all except one completed the program. One participant died part-way through so there is no post-intervention quantitative data for him, but his spouse generously gave some written feedback, which has been included (with her permission) in the qualitative analysis. Therefore, pre-/post- quantitative data exists for 23 and qualitative data for 24 metropolitan participants.

Fourteen RR (including interstate regional) participants enrolled in the program, and all except one completed it. One withdrew due to deteriorating health. Additionally, one participant from the RR cohort completed the 6-week program but was unable to complete the post-intervention measures and interview due to severe anxiety. His pre-intervention DASS-21 indicated severe anxiety and his WEMWBS indicated probable depression. He declined the offer of a letter from the project's supervisory team to his GP about this. His feedback on the mid-point survey was positive and his spouse was interviewed after the conclusion of the intervention. Her feedback was included in the qualitative analysis. Overall pre-/post- quantitative data therefore exists for 12 RR participants and qualitative data for 13 RR participants.

In total, pre-/post- quantitative data exists for 35 participants. Additionally, 52 interviews were conducted: 35 with participants in the intervention and 17 with family members.

Refer to section 4.1 for participant details.

3.10.1 Quantitative Data Collection and Analysis

Quantitative research collects and analyses numerical data to measure relationships between variables, which can include behaviours and attitudes. The primary purpose of the quantitative component of this study was measuring change to emotional wellbeing as a result of the intervention. The minimally important difference (MID), first defined by Guyatt in 2002, then revised by Schunemann in 2005, is the standard now used for interpreting changes in HRQoL (King, 2011). The revised definition of MID is "the smallest difference in score in the outcome of interest that informed patients or informed proxies perceive as important, either beneficial or harmful, and that would lead the patient or clinician to consider a change in the management" (Schünemann et al., 2005, p. 82). However, given the small participant group and the exploratory nature of this study, trends in the pre- and post-intervention scores, rather than MIDs, were sought. Additionally, given MIDs can vary by

context and population, and depend upon participants' baselines (King, 2011), standard statistical tests were instead performed using a p value < 0.05 to indicate significant movement. These tests were one-sample t-tests for normally distributed and Wilcoxon Signed-Rank for non-parametric pre- and post-intervention data. An initial descriptive analysis of the data was undertaken, using Minitab software, to generate means, standard deviations and ranges of scores for each of the instruments administered, prior to undertaking the aforementioned tests for statistically significant change. Details of the analytical methods used can be found in sections 4.2.1 and 4.3.1.

Using quantitative methods to measure change to emotional wellbeing necessitates an acknowledgement of potential issues. These issues included being limited by the instruments; however the chosen instruments have been validated in a cancer context (refer section 3.8.2). Another issue could have been the degree to which participants understood the questions in the instruments, but confidence can be gained from the fact that the DASS-21 and WEMWBS were created by psychologists, are proven in a cancer context, and they continue to be used in their capacity as good measures.

3.10.2 Qualitative Data Collection and Analysis

Qualitative data were collected at three junctures in this research, as well as via observations throughout intervention delivery. At enrolment, participants were required to provide details about their reading habits. These details informed the choice of material that was read aloud during the intervention. At the mid-point of the program, participants completed a very short survey as a program health check: checking whether or not participants were enjoying the material being read and affording an opportunity to adjust reading choices. At the conclusion of the read-aloud program, participants were interviewed, as well as family members where possible. Interviews were also planned with nursing staff and reading volunteers if applicable.

Observations made by the reader were systematically recorded after each session with each participant. In order to best understand the week-by-week intervention experience and use the observations to inform future choices of reading material, the observations focussed on:

- participant mood/comments during greeting
- reactions to stories read (including body language and comments)
- anything participant said that could influence choice of future reading material
- mood at the conclusion of the session if different to mood at greeting
- any indicated pleasure or displeasure of the intervention thus far.

Although there was not a second observer with which to confer, observations were triangulated with data collected at enrolment to inform the ongoing selection of reading material, and with interview data at the conclusion, thus increasing their rigour. Refer to Figure 3.1 for a visual representation of the data collection.

Thematic analysis is appropriate for this study because it was more relevant to analyse for themes and patterns reported by participants from their perceptions, experiences and the meanings they attribute to those experiences, than the exacting content analysis of who said what. Thematic analysis is now considered the most widely used method for analysing qualitative data (Liamputtong, 2019, p. 20) and it has been widely used to analyse perceived advantages of interventions within the framework of identifying and interpreting key features of data as directed by research questions (Clarke & Braun, 2017).

Semi-structured interviews provided in-depth feedback on the program, which was combined with any spontaneous feedback provided over the course of the intervention (and recorded in weekly observation notes). This data was analysed using Braun and Clarke's (2006, 2019, 2021a, 2021b, 2023a) approach to reflexive thematic analysis. This is an interpretive method of analysis – to get the lived experience of the participants going through the intervention - using an essentialist epistemology. An essentialist approach is objective, it is what can be seen, it is observable and measurable, taking participants' comments at face value and reporting experiences, meanings and the reality of participants; rather than a constructionist epistemology which examines participants' experiences and meanings in light of societal discourses (Braun & Clarke, 2006). Although there are limitations with this approach, including over- or under-reporting feelings or experiences, these limitations were minimised by interviewing family members, resulting in qualitative triangulation. The orientation to the data was experiential with the belief that the experiences, feelings and thoughts of the participants reflected their realities, rather than a critical orientation in which language used by participants is examined for meaning beyond explicit meaning.

The analysis was performed using a predominantly inductive (bottom-up) approach because it was exploratory research, and thus a deductive approach (with pre-conceived theories or themes to prove) was not applicable. As such, codes that were descriptive and reflective of the content of the data, free from any pre-conceived theories or coding frameworks were generated. This open-coding best represents the meaning communicated by participants (Braun & Clarke, 2013). However, Braun and Clarke (2023b) acknowledge the difficulty of using one approach exclusively, and note that in reality, one approach is used predominantly.

In this case, a predominantly inductive approach was used, with open-coding and an emphasis given to participant meanings based on (not derived from) content. However, some deductive analysis occurred when ensuring the open-coding produced themes that were relevant to the research questions. The analysis was performed reflexively, driven by the data itself, using semantic coding because searching for hidden meanings or interpretations (latent coding) were not applicable to this study. Participants spoke directly about their experience of the reading program and the analysis was conducted on the basis that what was communicated was what the participants intended to convey about their experience.

Braun and Clarke's (2006) original steps to reflexive thematic analysis (TA) have been further explained and updated over the years and their current six-phase approach to reflexive TA (Braun & Clarke, 2023b) was adopted:

1. Data familiarisation
2. Data coding
3. Generating initial themes
4. Reviewing and developing themes
5. Refining, defining and naming themes
6. Producing the report.

Although 52 interviews were conducted, there were 53 interview files. This was because 51 were verbatim transcriptions from audio recordings, one was notes made during a family member interview where recording was not possible due to a technology limitation at the time, and one resulted from contact from the spouse of the participant who died mid-way through the program. It felt inappropriate to contact her for an interview, but she spontaneously gave her feedback (which was used with her permission) which has been included with other interview data. Transcription software was used to generate initial transcripts based on the audio recordings. With the need to manually correct major transcription errors, then to fine-tune and check their accuracy, the interviews were listened to in their entirety a minimum of three times. Interviews ranged in length from approximately 15 minutes to a little over an hour. This repeated listening and reading/correcting transcriptions provided the opportunity for the researcher to immerse herself in the data, as per phase one of reflexive TA.

Immersion in the data led to noticing common ideas that were descriptive of participants' experiences, thoughts and feelings. Some initial ideas about potential codes were apparent after completing phase one of the TA process, for example, participants found the program

relaxing, nurturing and they really valued the one-on-one, personalised approach. Continued reading of transcriptions led to more relevant excerpts and the generation of more codes, as per phase two. Given the large volume of interviews, NVivo software was used to highlight researcher-generated codes in the transcriptions, then combine the codes into themes (Braun & Clarke, 2006, 2019). Early in phase three, with the generation of initial themes, the researcher met with the supervisory team to discuss codes and themes. A fundamental tenet of this reflexive method is the researcher playing an active role (Braun & Clarke, 2021b) and while there is no need for consensus on themes between members of the research team as meaning is produced "through the researcher's active engagement with their data, and their interpretive skills" (Braun & Clarke, 2023a, p. 14), discussion of generated codes and themes provided opportunity for feedback from more experienced researchers. Using the open coding methodology of reflexive TA, rather than codebook TA with its pre-set codes, the reflexive practice "developed and modified the codes" while working "through the coding process" (Maguire & Delahunt, 2017, p. 3355). Reviewing and developing the themes, phase four, occurred as a result of reviewing code characteristics and groupings, and generating theme names to accurately encompass the groupings. This recursive process was aided by the ability to group codes as children of generated themes in NVivo.

A fundamental tenet of reflexive TA is it relies on researcher interpretation, and as such, researcher biases are acknowledged (refer section 3.3). The researcher's strong position of empathy with the phenomenological group in this study helped with identification of codes related to any relief from distress. This was relevant throughout but was especially pertinent in phase four (reviewing and developing themes).

Some codes, for instance relaxation, and the importance of personalisation / choice of reading material, appeared in most if not all transcripts. However, the frequency of a code does not determine its importance regarding criteria for a theme. Rather than count the number of individual code occurrences and use the most frequently occurring, it is more important that the codes and subsequent themes communicate something meaningful to answer the research questions (Braun & Clarke, 2013).

To add dependability, at phase five (refining, defining and naming themes), the codes were reviewed by the researcher with each of two supervisors individually (KG, clinical psychologist, experienced qualitative researcher, no personal experience with cancer but has worked extensively supporting those with cancer as a clinical psychologist and DV, LIS specialist, experienced qualitative researcher, experience supporting family members with

cancer), not to identify additional codes or themes, but rather to assist with their groupings in relation to the research questions. The reflexive nature of such reviews, with the researcher examining and explaining each time, added further credibility to the examination of interview transcripts, generation of codes and subsequent generation of themes.

Phase six (producing the report) consisted of the creation of Chapter 5 of this thesis, which was written as an iteration of revisiting the research questions, hypothesis, code list and theme definitions. The researcher's positioning and role in shaping the research was apparent in this phase, with her natural tendency towards storytelling being her preferred way to report these findings. Documenting the findings in relation to the research questions and hypothesis opened the synergetic relationships between themes and led to the creation of the visual representations in section 5.4.

Most times, interpretation of data was empathic, that is, the focus was on what participants said or did, or their reactions, and no hidden meanings were sought. As a phenomenological study, with the researcher in the same phenomenological group, the *why* of a comment or behaviour was already understood, and thus the *how* of the participants' experience of the reading program could be the focus of interpretation. However, while phenomenological research is necessarily empathic in nature, there is an "interplay between 'empathy' and 'suspicion' in the search for understanding" which is "the driving force behind the hermeneutic circle through which all interpretative activity must move" (Willig, 2017, p. 276). Accordingly, suspicious interpretations of some interview responses did occur – for those that were contradictory or sufficiently short to be dismissive of explanation, and in a quest to deepen understanding at interview-time, the researcher probed for additional information to respectfully and with curiosity, aid understanding. When looking at the hermeneutic circle as a way of understanding, researchers recognise and admit to "the impossibility of approaching a phenomenon without adopting a particular perspective in relation to it" because in order to find meaning in what is encountered, "we need to draw on some ideas and assumptions in order to begin to make sense of it" (Willig, 2017, p. 276). For this study, the perspective adopted was that of the participants experiencing varying levels of distress, as it is known distress frequently accompanies cancer diagnosis, and it reflected the researcher's position within the analysis. From this perspective, the ideas and assumptions centred on attempting to relieve some of this distress.

Quantitative researchers have tools that include the use of reliable and valid measures, and these tools can give confidence that results can be replicated or assessed for generalisability,

rigour and accuracy (Alele & Malau-Aduli, 2023; Polit & Beck, 2010). However, qualitative researchers have not enjoyed the same reputation for rigorous data analysis. Concerns typically centre on the nature of analysis using interpretive, subjective methods (Maher et al., 2018) and the variety of methods and standards (Sarantakos, 2013). The quantitative research measures of reliability, validity and objectivity are not applicable to qualitative research and alternative characteristics to determine quality, rigorous, trustworthy qualitative research are typically used instead: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985, p. 219).

Credibility is achieved by undertaking activities likely to produce credible findings and interpretations, such as external checks like peer debriefing, iterative redefinitions of working hypotheses as data collection and analysis continue, the ability to check preliminary results against archived data, testing the findings and interpretations against the study participants and "prolonged engagement, persistent observation, and triangulation" (Lincoln & Guba, 1985, p. 301). In this study, engagement with participants commenced from the time of initial enquiry, continued with the exploration of their reading habits and then continued through the six-week intervention until the concluding interview (i.e., prolonged engagement). Regarding the other criteria for establishing credibility, observations were recorded after each intervention session and debriefing with the supervisory team occurred at regular intervals. This is the first study of its kind so there was no archived data to compare against. However, the researcher was able to determine if later participants agreed with feedback from earlier participants. Credibility has also been defined as measuring "what is intended and is a true reflection of the social reality of the participants" (Maher et al., 2018, p. 3) and verbatim participant quotes have been used for this purpose. Triangulation of the interview data, mid-point surveys, observations and quantitative wellbeing scores add to the credibility of this study.

Transferability in qualitative research involves supplying the data to enable "potential appliers" to make transferability judgements (Lincoln & Guba, 1985, p. 316) and as qualitative research is context-specific (Maher et al., 2018), only descriptions (rather than absolute statements) can be given to aid others in making decisions about transferability (Lincoln & Guba, 1985, p. 316). When triangulating the results and considering their implications, opportunities for transferability were considered, which will be discussed in section 7.4.

One way to demonstrate dependability is by replicability (Lincoln & Guba, 1985, p. 317). The research design used in this study utilises standard paradigms, approaches and methods. Problems encountered and limitations have been described, as have the components of the intervention. This transparency around the research process makes it possible for others to replicate the study.

The technique for demonstrating the confirmability of a qualitative research study was originally that of conducting a confirmability audit or inquiry audit (Lincoln & Guba, 1985, pp. 318-319). However, it has more recently been described as attempting "to show that the findings and the interpretations of the findings do not derive from the imagination of the researchers but are clearly linked to the data" (Liamputtong, 2019, p. 12). Using reflexive TA places the researcher as a tool in the process of analysis (as discussed in Chapter 5), however, acknowledging this role and the biases that come with it, helps negotiate and mitigate effects. The researcher was aware of her own cancer experience while living in a regional area, and the lack of both practical support and support for the psychological distress she experienced. She acknowledged it was necessary to put aside some of her own assumptions. The desire and need to maintain an ethical and empirically rigorous course led to embracing a trustworthy approach to data collection and analysis. The attributes of credibility, transferability, dependability and confirmability are discussed further in Chapters 5 and 6.

Reading aloud to an individual, sharing stories, is a warm, intimate experience. With an intervention aimed at boosting the emotional wellbeing of listeners, hearing the participants' own stories of what the experience was like for them is a natural expectation. The qualitative component of this research study was necessary to hear and interpret these stories:

> Qualitative research is uniquely positioned to provide researchers with process-based, narrated, storied, data that is more closely related to the human experience. One can learn so much from another's experience, and from a good story. Yet, the degree of trust one has in the person telling the tale has much to do with the degree of trust attributed to the telling. (Stahl & King, 2020, p. 26)

3.10.3 Integrating the Data

Data was integrated using a combined embedded and sequential framework (Creswell & Plano Clark, 2018): qualitative data informed the content of the intervention, quantitative instruments were used to take a baseline then measure changes over time, and additional qualitative data was collected throughout via observations, mid-point surveys and finally interviews with participants and family members.

Quantitative and qualitative data were analysed separately, converging for the discussion of the themes generated, research questions, hypothesis and implications for future research and potential implementation. These separate analyses were underpinned by the theoretical perspectives discussed in section 3.1 then findings were integrated to reach conclusions. Integrating findings at the interpretive stage is the recommended approach for exploratory sequential research (Creswell, 2009). Quantitative findings are presented in Chapter 4, qualitative findings are presented in Chapter 5 and the integration of findings is presented in Chapter 6. This methodological triangulation improves the reliability and validity of findings (Bekhet & Zauszniewski, 2012).

Chapter 4. Quantitative Findings

"The books have kept us going during a really tough time. Sometimes, when Lola has been too tired to read herself, I've read aloud to her."

-Laura, *The Other Bridget* (Johns, 2024a, p. 17)

The purpose of this study was to explore associations between involvement in a read-aloud program and the wellbeing of people undergoing cancer treatment. The mixed methods study design saw quantitative data collected pre- and post-intervention. Quantitative findings are presented in this chapter. These findings were merged with the qualitative findings on the impact of the reading program (presented in Chapter 5) and are discussed in Chapter 6.

Restating the study's hypothesis: The read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment, as indicated by increased self-reported wellbeing and decreased symptoms of stress, anxiety and depression, and will provide a positive experience for those involved.

4.1 Participants

Participant characteristics are described in Table 4.1 for the N = 38 participants. Aside from the characteristics listed, no participants lived in supported accommodation, no participants identified as transgender or non-binary, three participants spoke English as their second language, and most participants' treatment regimens involved multiple facets (combinations of surgery, chemotherapy, immunotherapy, radiotherapy, stem cell therapy and hormone therapy). Additionally, most participants reported symptoms of CRCI (discussed further in section 6.4).

Table 4.1

Participant Characteristics

Participant characteristic	freq.	%
Age (years)		
18-34	0	0.0%
35-44	1	2.5%
45-54	8	21.1%
55-64	8	21.1%
65-74	13	34.2%
75+	8	21.1%
	38	100.0%
Gender		
Female	28	73.7%
Male	10	26.3%
	38	100.0%
Ethnicity		
Australian	24	63.2%
British	8	21.1%
European	3	7.9%
Indigenous	1	2.6%
Asian	1	2.6%
New Zealand	1	2.6%
	38	100.0%
Marital Status		
Married or partnered	27	71.1%
Divorced	6	15.7%
Widowed	3	7.9%
Never Married	2	5.3%
	38	100.0%
Living arrangements		
Lives with family	28	73.7%
Lives alone	10	26.3%
	38	100.0%
Education level		
Some High School	2	5.3%
High School	12	31.6%
Trade	3	7.9%
Diploma	2	5.3%
Bachelor	11	28.9%
Post Grad.Dip	2	5.3%
Masters	5	13.1%
PhD	1	2.6%
	38	100.0%
Employment status		
Employed full-time	3	7.9%
Employed part-time	7	18.4%
Employed sick leave	3	7.9%
Retired	20	52.6%
Disabled	2	5.3%
Not employed; not looking	3	7.9%
	38	100.0%

Table 4.1 (continued).

Participant characteristic	freq.	%
Cancer type		
Breast	21	55.3%
Myeloma	5	13.1%
Brain	2	5.3%
Prostate	4	10.5%
Bowel	1	2.6%
HeadNeck	2	5.3%
Other cancers: H.Lymph, Renal, Vulvar	3	7.9%
	38	100.0%
Cancer stage		
Stage 1 or 2	13	34.2%
Stage 3	6	15.8%
Stage/grade 4	13	34.2%
Myeloma	5	13.2%
stage unknown	1	2.6%
	38	100.0%
Participants currently receiving treatment		
Current treatment	31	81.6%
Within a year of treatment	7	18.4%
	38	100.0%
Self-reported CRCI symptoms		
Memory or concentration difficulties	36	94.7%
No memory or concentration difficulties	2	5.3%
	38	100.0%
Nominated intervention venue		
Home	21	55.3%
Closest public library	7	18.4%
Zoom	7	18.4%
UniSA	3	7.9%
	38	100.0%

Note that the different cancer types represented reflect the cancer support groups that welcomed presentations about the reading program and call for recruitment; these were especially breast cancer groups (most notably, the YWCA Encore programs around Adelaide and Fleurieu Peninsula, and informal support groups organised by women with a breast cancer experience), the Myeloma Foundation (locally and via their Myeloma Month webinar, newsletter and magazine) and the Head and Neck cancer nurse-practitioner-led support group. Perhaps the large number of participants with breast cancer in this study is unsurprising also because “breast cancer has now become the most commonly diagnosed cancer worldwide, with around 2.3 million people diagnosed with the disease globally each year. In Australia and New Zealand, it is the most commonly diagnosed cancer in women” (ANZ Breast Cancer Trials Group Ltd, 2023b, para. 1). Women are far more likely to be

affected by breast cancer than men, and women are more likely to participate in research studies (Geller et al., 2011; Saphner et al., 2021) perhaps because “women might be more likely to prioritise quality of life and psychosocial oncology research than men” (Wakefield et al., 2017, p. e163). Additionally, previous studies have found women have higher scores on reading attitude assessments than men (Mikulecky et al., 1979; Smith, 1990b) and regardless of age, Australian women read more than Australian men (Australian Bureau of Statistics, 2024), which could be another reason why more women than men expressed interest in this study.

The age of the participants is also typical of research studies. Nearly all participants in this study were over 45 years of age. Participants are usually older than 55 years in studies involving cancer patients (Shah et al., 2022), and Geller et al. (2011) reported people affected by cancer aged 60 to 79 years old were most likely to participate in research. Although clinical trial participants are getting younger (Becze, 2019), participation across all adult age groups in psycho-oncology and QoL research is declining, perhaps due to increasing numbers of studies, less free time and less interest in research (Wakefield et al., 2017). Considering the different cancer types and stages, age, education levels and employment status of participants, the participant group was a relatively heterogeneous one. The extent to which participants reported depression, anxiety, stress and wellbeing on validated self-report questionnaires is presented in section 4.2 below.

4.2 Wellbeing Instruments

When scoring the DASS-21 instruments, the three scales (stress, anxiety and depression) are scored and reported separately. Participant scores are classified as indicative of normal, mild, moderate, severe, or extremely severe depression, anxiety and stress as recommended by Lovibond and Lovibond (1995).

The WEMWBS is scored as a single value, indicating an overall mental health score. Wellbeing is categorised by score ranges (refer section 3.8.2) with the general rule of higher scores indicating higher levels of mental wellbeing (Clarke et al., 2011).

4.2.1 Statistical Analysis Methods

Twenty-four metropolitan participants enrolled in the reading program but with the death of one participant, there was pre- and post-intervention wellbeing instrument data for n = 23 metropolitan participants.

Of the 14 RR participants, 13 completed the 6-week intervention. However, of those 13 participants, one was unable to complete the wellbeing instruments and ASRA post-intervention due to mental health issues. This means there was pre- and post-intervention wellbeing instrument data for n = 12 RR participants.

Statistical analysis software, Minitab, was used to perform the statistical tests which were performed on the difference between pre- and post-intervention test scores for both the DASS-21 and WEMWBS (N = 35). When performing tests on the DASS-21 stress, anxiety and depression scores, the null hypothesis was that there was no difference in the pre- and post-intervention scores, that is, the difference between them was zero (H_0: $\mu = 0$), while the alternate hypothesis was that the difference was less than zero, that is, the scores were less after the intervention (H_1: $\mu < 0$). When performing tests on the WEMWBS scores, the null hypothesis was that there was no difference in the pre- and post-intervention scores, that is, the difference between them was zero (H_0: $\mu = 0$), while the alternate hypothesis was that the difference was greater than zero, that is, the scores were bigger after the intervention (H_1: $\mu > 0$). Whenever $p < 0.05$, the null hypothesis was rejected, and it was concluded that the alternate hypothesis was true. That is, significance was at the $p < 0.05$ level.

The probability plots for each DASS-21 scale and WEMWBS scores were generated. Where the plots showed normal distribution ($p > 0.05$), one-sample t-tests were performed to compare pre- and post-intervention scores. For data that were not normally distributed, skewness and kurtosis indicators were assessed. A skewness value greater than 1 or less than -1 indicates a highly skewed distribution. A value between 0.5 and 1 or -0.5 and -1 is moderately skewed. A value between -0.5 and 0.5 indicates the distribution is fairly symmetrical. For skewed data, the non-parametric Wilcoxon Signed-Rank Test was appropriate.

4.2.2 Metropolitan

Pre- / Post – intervention movement on the DASS-21 and WEMWBS scales

The distribution of metropolitan participants in the normal, mild, moderate, severe and extremely severe ranges of the DASS-21 subscales, and the WEMWBS ranges at baseline and post-intervention are detailed in Table 4.2. While more participants presented in the normal ranges rather than other ranges, the proportion increased pre- to post-intervention, indicating upward shifts in wellbeing across this cohort. Descriptive statistics for metropolitan participants' DASS-21 subscales and WEMWBS are presented in Table 4.3.

Table 4.2

Subscale Breakdown for Metropolitan Participants

DASS-21 subscales	Baseline		Post-intervention	
Stress				
- normal	15	65.3%	19	82.6%
- mild	3	13.0%	1	4.4%
- moderate	2	8.7%	3	13.0%
- severe	3	13.0%	0	0.0%
- extremely severe	0	0.0%	0	0.0%
	23	100.0%	23	100.0%
Anxiety				
- normal	10	43.5%	21	91.3%
- mild	3	13.0%	1	4.3%
- moderate	6	26.1%	0	0.0%
- severe	3	13.0%	0	0.0%
- extremely severe	1	4.4%	1	4.4%
	23	100.0%	23	100.0%
Depression				
- normal	13	56.5%	17	73.9%
- mild	6	26.1%	1	4.4%
- moderate	3	13.0%	5	21.7%
- severe	1	4.4%	0	0.0%
- extremely severe	0	0.0%	0	0.0%
	23	100.0%	23	100.0%
WEMWBS	Baseline		Post-intervention	
High mental wellbeing	1	4.4%	3	13.0%
Average mental wellbeing	11	47.8%	15	65.3%
Possible depression	8	34.8%	3	13.0%
Probable depression	3	13.0%	2	8.7%
	23	100.0%	23	100.0%

Statistical significance

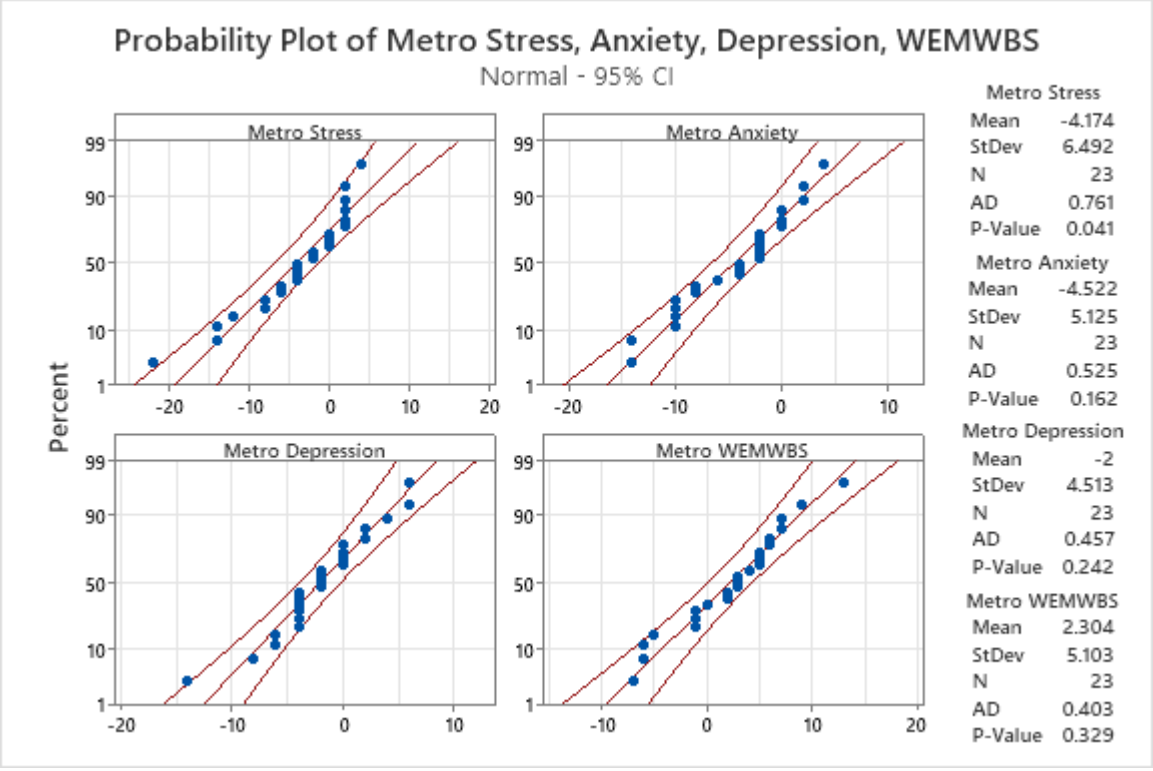
Table 4.3

Descriptive Statistics for Metropolitan Participants

Measure	N	Mean	StDev	Median
Metro Stress	23	-4.17	6.49	-4.00
Metro Anxiety	23	-4.52	5.12	-4.00
Metro Depression	23	-2.00	4.51	-2.00
Metro WEMWBS	23	2.30	5.10	3.00

Figure 4.1

Probability Plots of Metropolitan Wellbeing Instrument Scores



The probability plots (refer Figure 4.1) have $p > 0.05$ for anxiety, depression and WEMWBS, therefore they were all normally distributed. The stress scores were not normally distributed.

STRESS

Descriptive statistics for metropolitan participants' stress scores are presented in Table 4.4, and combined with the histogram (refer Figure 4.2), it can be seen the data were skewed.

Figure 4.2

Metropolitan Stress Scores Histogram

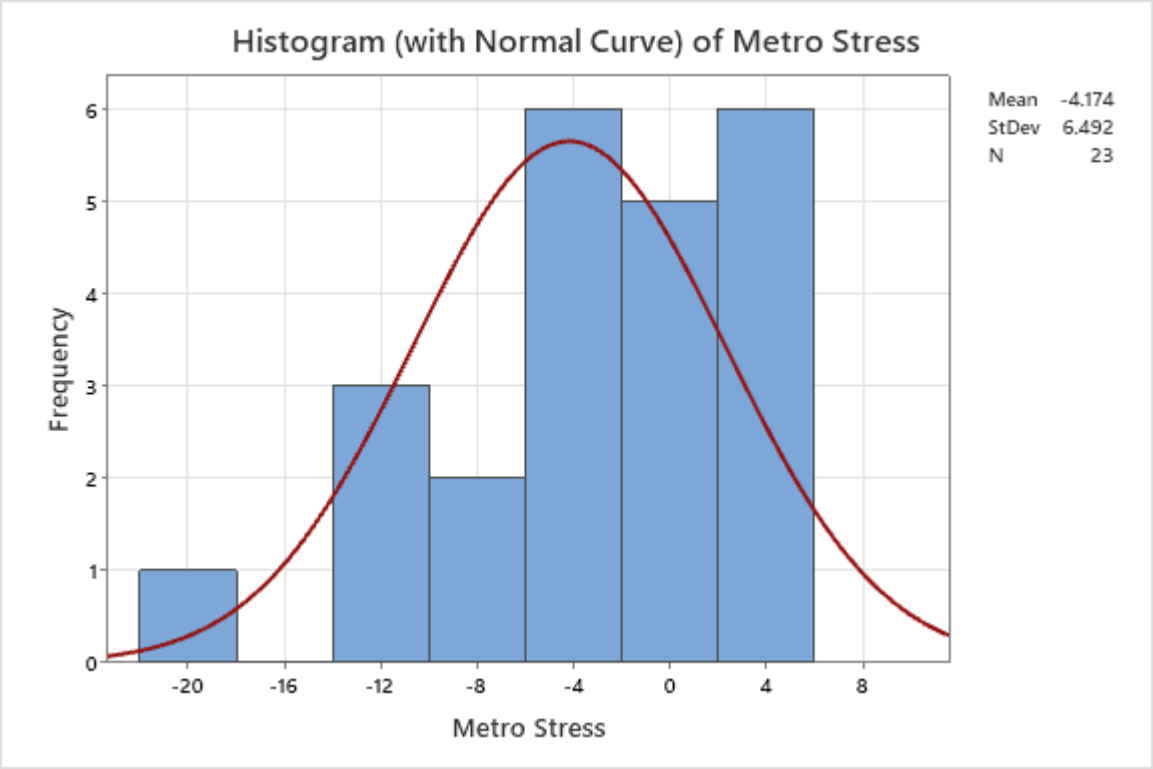


Table 4.4

Descriptive Statistics for Metropolitan Participants' Stress Scores

Measure	n	Mean	St Dev	Min	Q1	Median	Q3	Max	IQR	Skew-ness	Kurtosis
Metro Stress	*23*	*-4.17*	*6.49*	*-22.00*	*-8.00*	*-4.00*	*2.00*	*4.00*	*10.00*	*-1.13*	*1.13*

The Wilcoxon Signed-Rank Test was performed with H_0: $\eta = 0$ and H_1: $\eta < 0$. Metropolitan participants reported decreased stress scores (M = -4.17, SD = 6.49, η = -4.00) as measured by the DASS-21, W = 30.00, p = 0.003. This supports the study hypothesis: participation would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

ANXIETY

Results of a one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu < 0$ demonstrated metropolitan participants reported decreased anxiety scores (M = -4.52, SD = 5.12) as measured by the DASS-21, $t(22) = -4.23$, $p = 0.000$, which supports the study hypothesis: participation would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

DEPRESSION

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu < 0$ demonstrated metropolitan participants reported decreased depression scores (M = -2.00, SD = 4.51) as measured by the DASS-21, $t(22) = -2.13$, $p = 0.023$, which supports the study hypothesis: participation would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

WEMWBS

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu > 0$ demonstrated metropolitan participants reported increased wellbeing (M = 2.30, SD = 5.10) as measured by the WEMWBS, $t(22) = 2.17$, $p = 0.021$, which supports the study hypothesis: participation would be associated with increased self-reported wellbeing.

4.2.3 Rural / Regional

Pre- / Post – intervention movement on the DASS-21 and WEMWBS scales

The distribution of RR participants in the normal, mild, moderate, severe and extremely severe ranges of the DASS-21 subscales, and the WEMWBS ranges at baseline and post-intervention is shown in Table 4.5. Initial scores for the two RR participants who did not complete the post-intervention testing were not included in the data analysed. While more participants presented in the normal ranges rather than other ranges, the proportion increased pre- to post-intervention, indicating upward shifts in wellbeing across the RR cohort. Descriptive statistics for the RR participants' DASS-21 subscales and WEMWBS are presented in Table 4.6.

Table 4.5

Subscale Breakdown for RR Participants

DASS-21 subscales	Baseline		Post-intervention	
Stress				
- normal	7	58.4%	10	83.4%
- mild	1	8.3%	1	8.3%
- moderate	3	25.0%	0	0.0%
- severe	1	8.3%	1	8.3%
- extremely severe	0	0.0%	0	0.0%
	12	100.0%	12	100.0%
Anxiety				
- normal	5	41.7%	9	75.0%
- mild	3	25.0%	1	8.3%
- moderate	3	25.0%	2	16.7%
- severe	1	8.3%	0	0.0%
- extremely severe	0	0.0%	0	0.0%
	12	100.0%	12	100.0%
Depression				
- normal	6	50.0%	8	66.7%
- mild	0	0.0%	0	0.0%
- moderate	3	25.0%	3	25.0%
- severe	1	8.3%	0	0.0%
- extremely severe	2	16.7%	1	8.3%
	12	100.0%	12	100.0%
WEMWBS	Baseline		Post-intervention	
High mental wellbeing	0	0.0%	2	16.7%
Average mental wellbeing	7	58.3%	7	58.3%
Possible depression	1	8.3%	1	8.3%
Probable depression	4	33.4%	2	16.7%
	12	100.0%	12	100.0%

Statistical significance

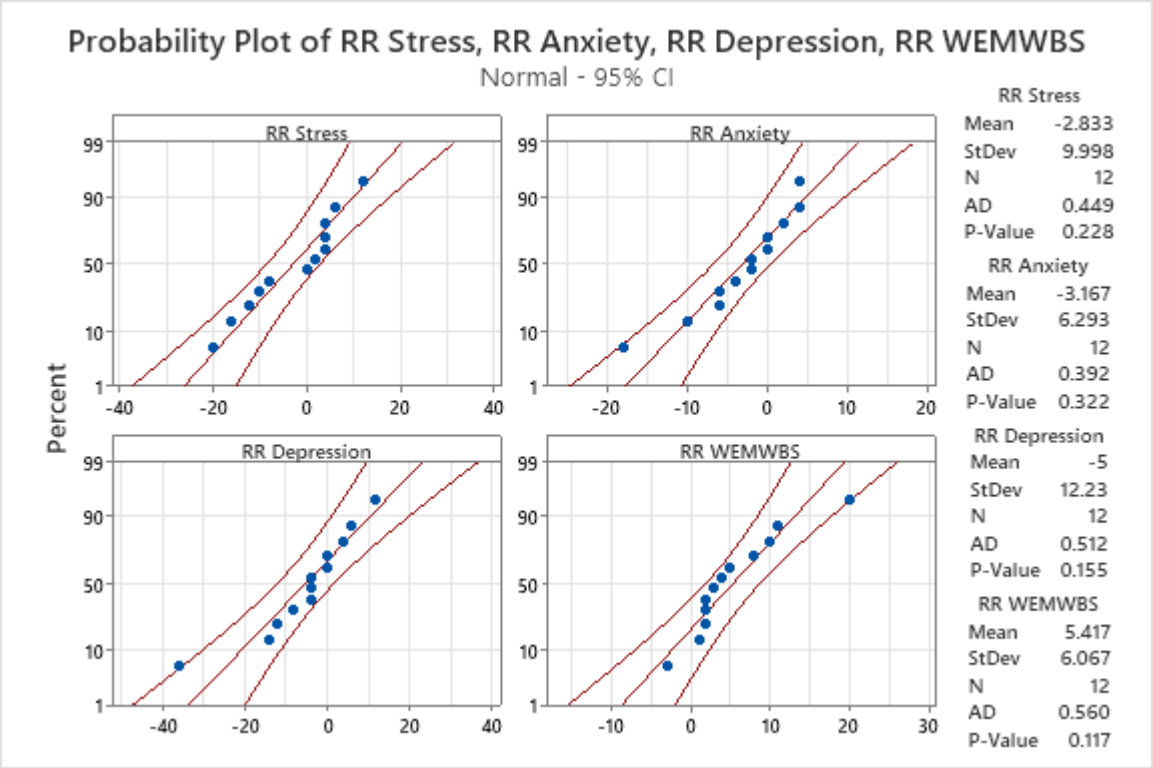
Table 4.6

Descriptive Statistics for RR Participants

Measure	n	Mean	StDev	Median
RR Stress	12	-2.83	10.00	1.00
RR Anxiety	12	-3.17	6.29	-2.00
RR Depression	12	-5.00	12.23	-4.00
RR WEMWBS	12	5.42	6.07	3.50

Figure 4.3

Probability Plots of RR Wellbeing Instrument Scores



Probability plots (refer Figure 4.3) indicated all data sets were normally distributed.

STRESS

A one-sample t-test was performed on the differences between the pre- and post-intervention stress scores with H_0: $\mu = 0$ and H_1: $\mu < 0$. RR participants did not report decreased stress scores (M = -2.83, SD = 10.00) as measured by the DASS-21, $t(11) = -0.98$, $p = 0.174$, therefore the intervention did not change stress scores for the RR participants.

ANXIETY

Results of a one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu < 0$ demonstrated RR participants did not report decreased anxiety scores (M = -3.17, SD = 6.29) as measured by the DASS-21, $t(11) = -1.74$, $p = 0.055$, therefore the intervention did not change anxiety scores for the RR participants

DEPRESSION

Results of a one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu < 0$ demonstrated RR participants did not report decreased depression scores (M = -5.00, SD = 12.23) as measured by the DASS-21, $t(11) = -1.42$, $p = 0.092$, therefore the intervention did not change depression scores for the RR participants

Although not statistically significant, the mean differences in stress, anxiety and depression scores were all negative, indicating reduced scores. Confounding factors may be present, which will be discussed in Chapter 6.

WEMWBS

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu > 0$ demonstrated RR participants reported increased wellbeing (M = 5.42, SD = 6.07) as measured by WEMWBS, $t(11) = 3.09$, p = 0.005, which supports the study hypothesis: participation would be associated with increased self-reported wellbeing.

4.2.4 Overall Participants

Finally, all the metropolitan and RR data were combined into one data set for analysis. Although it was important to separately analyse any measurable effects on wellbeing, as indicated by the DASS-21 and WEMWBS, on the metropolitan and RR cohorts individually, because their needs and coping mechanisms can be different (refer section 2.4.1), it was also important to consider the study outcomes for the sample as a whole, particularly given the relatively small sample sizes. Movement in the DASS-21 subscales and WEMWBS ranges pre- to post-intervention are shown in Table 4.7. Descriptive statistics for the overall group's DASS-21 subscales and WEMWBS are presented in Table 4.8.

Statistical significance

Table 4.7

Subscale Breakdown for Overall Participant Group

DASS-21 subscales	Baseline		Post-intervention	
Stress				
- normal	22	62.9%	29	82.8%
- mild	4	11.4%	2	5.7%
- moderate	5	14.3%	3	8.6%
- severe	4	11.4%	1	2.9%
- extremely severe	0	0.0%	0	0.0%
	35	100.0%	35	100%
Anxiety				
- normal	15	42.9%	30	85.7%
- mild	6	17.1%	2	5.7%
- moderate	9	25.7%	2	5.7%
- severe	4	11.4%	0	0.0%
- extremely severe	1	2.9%	1	2.9%
	35	100.0%	35	100.0%
Depression				
- normal	19	54.4%	25	71.4%
- mild	6	17.1%	1	2.9%
- moderate	6	17.1%	8	22.8%
- severe	2	5.7%	0	0.0%
- extremely severe	2	5.7%	1	2.9%
	35	100.0%	35	100.0%
WEMWBS	Baseline		Post-intervention	
High mental wellbeing	1	2.9%	5	14.3%
Average mental wellbeing	18	51.4%	22	62.9%
Possible depression	9	25.7%	4	11.4%
Probable depression	7	20.0%	4	11.4%
	35	100.0%	35	100.0%

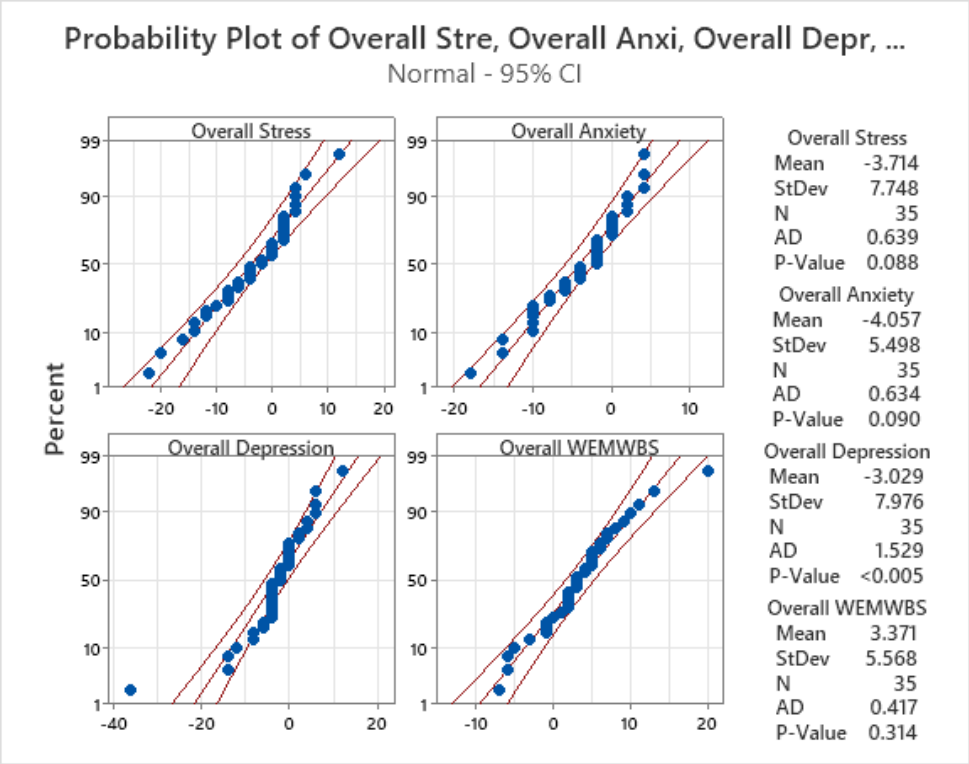
Table 4.8

Descriptive Statistics for Overall Participant Group

Measure	N	Mean	StDev	Median
Overall Stress	35	-3.71	7.75	-2.00
Overall Anxiety	35	-4.06	5.50	-2.00
Overall Depression	35	-3.03	7.98	-2.00
Overall WEMWBS	35	3.37	5.57	3.00

Figure 4.4

Probability Plots of Overall Wellbeing Instrument Scores



Probability plots (refer Figure 4.4) indicate stress, anxiety and WEMWBS were all normally distributed, whereas the overall depression scores were not normally distributed.

STRESS

A one-sample t-test was performed on the differences between the pre- and post-intervention stress scores with H_0: $\mu = 0$ and H_1: $\mu < 0$. Overall, participants reported decreased stress scores (M = -3.71, SD = 7.75) as measured by the DASS-21, $t(34) = -2.84$, $p = 0.004$, which supports the study hypothesis: participation would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

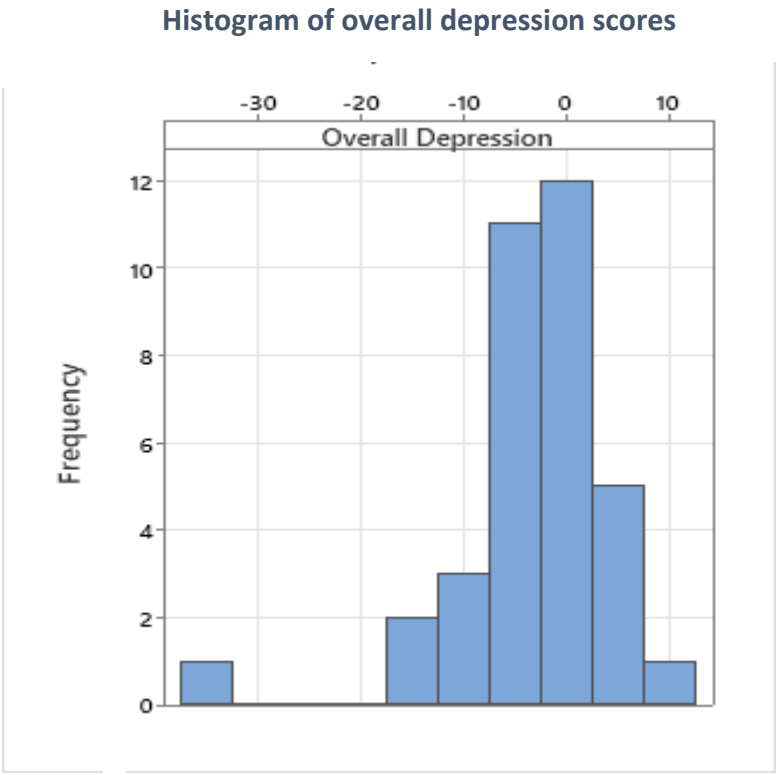
ANXIETY

Results of a one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu < 0$ demonstrated that participants overall reported decreased anxiety scores (M = -4.06, SD = 5.50) as measured by the DASS-21, $t(34) = -4.37$, $p = 0.000$, which supports the study hypothesis: participation would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

DEPRESSION

Figure 4.5

Overall Depression Scores Histogram



The histogram for the depression scores across the group (refer Figure 4.5), clearly shows the data were skewed. This was confirmed by descriptive statistics for the depression scores (refer Table 4.9).

Table 4.9

Descriptive Statistics for Overall Participants' Depression Scores

Measure	N	Mean	St Dev	Min	Q1	Median	Q3	Max	IQR	Skew-ness	Kurtosis
Overall Depression	*35*	*-3.03*	*7.98*	*-36.00*	*-4.00*	*-2.00*	*0.00*	*12.00*	*4.00*	*-2.02*	*7.96*

The Wilcoxon Signed-Rank Test was performed with H_0: $\eta = 0$ and H_1: $\eta < 0$. Overall, participants reported decreased depression scores (M = -3.03, SD = 7.98, η = -2.00) as measured by the DASS-21, W = 116.50, p = 0.015; the intervention lowered depression scores for the overall group of participants, which supports the study hypothesis: participation

would be associated with lower symptoms of anxiety and depression pre- to post-intervention.

As the RR and overall depression scores had outliers, in addition to the non-parametric tests, the outliers were omitted and a one-sample t-test was run on the remaining data. The result was the same as the non-parametric test.

WEMWBS

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu > 0$ demonstrated that overall participants reported increased wellbeing ($M = 3.37$, $SD = 5.57$) as measured by WEMWBS, $t(34) = 3.58$, $p = 0.001$, which supports the study hypothesis: participation would be associated with increased self-reported wellbeing.

4.3 The ASRA

The shortened Adult Survey of Reading Attitude (ASRA) was administered as a secondary measure in the study. ASRA scores provide an indication as to whether or not participants value the experience of reading more or less as a result of participating in the study. Scores for the ASRA range from 40 to 200 with low scores indicating poor/negative attitude and high scores indicating good/positive attitude to reading (Smith, 1990b). Although not hypothesised, increases in reading attitude scores could indicate additional benefits of the reading program, with participants attempting to read to themselves, or listen to audiobooks, for those who were able.

4.3.1 Statistical Analysis Methods

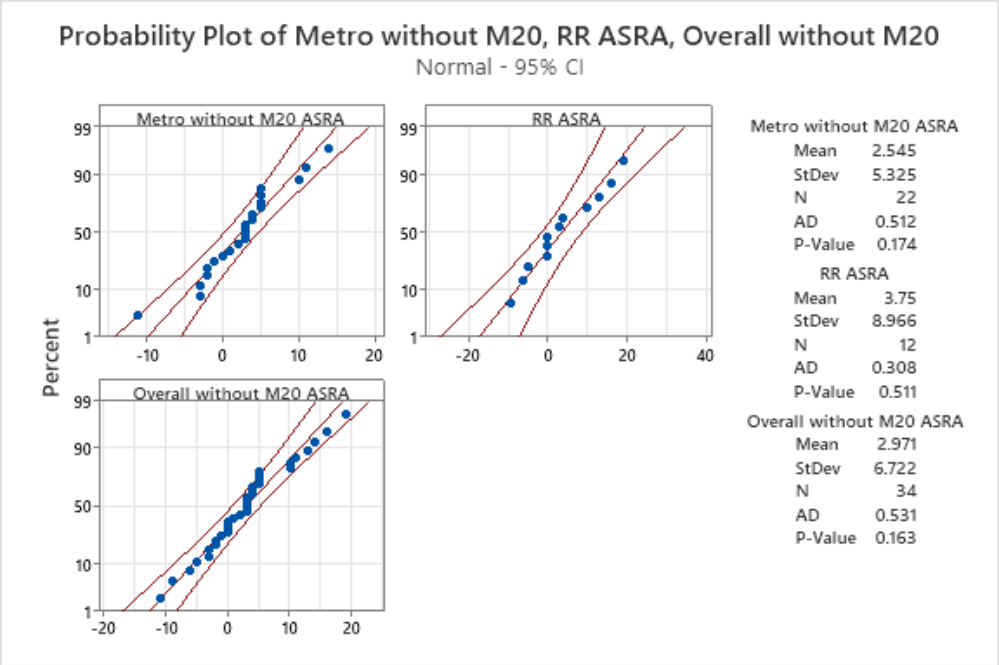
The number of pre-/post- intervention ASRA results mirrors the wellbeing instruments, as described above in section 4.2.1: pre- and post-intervention ASRA data available for n = 23 metropolitan participants and n = 12 RR participants, a total of N = 35 participants. One-sample t-tests were used to determine whether ASRA scores changed over time. Significance was at the $p < 0.05$ level.

M20's results were excluded from the analysis because her aphasia had not been disclosed by either herself or her spouse (who had completed all the enrolment forms for her, including her initial ASRA, and she only had to sign). Given her pre-intervention ASRA was completed with the assistance of someone other than the researcher and the answers indicated severe inconsistencies, especially in light of aphasia and current inability to read, it was reasonable to conclude M20's pre-test ASRA was not an accurate reflection of her reading attitudes at

that time, and her ASRA results were therefore removed from the analysis. ASRA data for n = 22 metropolitan participants were analysed.

Figure 4.6

Probability Plots of ASRA Scores



The probability plots (refer Figure 4.6) indicate each data set was normally distributed and so one-sample t-tests were appropriate.

4.3.2 Metropolitan

A one-sample t-test was performed on the differences between the pre- and post-intervention ASRA scores with H_0: $\mu = 0$ and H_1: $\mu > 0$. Metropolitan participants reported improved reading attitudes (M = 2.55, SD = 5.32) as measured by increases in the ASRA scores, $t(21)$ = 2.24, p = 0.018, which supports the potential that the intervention raised the ASRA scores for metropolitan participants.

4.3.3 Rural / Regional

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu > 0$ demonstrated RR participants did not report improved reading attitudes (M = 3.75, SD = 8.97) as measured by the ASRA, $t(11)$ = 1.45, p = 0.088, which indicates the intervention did not raise the ASRA scores for RR participants.

4.3.4 Overall Participants

A one-sample t-test with H_0: $\mu = 0$ and H_1: $\mu > 0$ demonstrated participants in the total sample (N = 34) reported improved reading attitudes ($M = 2.97$, $SD = 6.72$) as measured by the ASRA, $t(33) = 2.58$, $p = 0.007$, which supports the potential that the intervention raised the ASRA scores for the participants overall.

4.4 Family Member Interviews – Quantitative Component

The family member interview questions were constructed by the researcher in consultation with the broader research team (see section 3.8.3 for details on question development), in order to get a richer picture of the effects of the intervention on the participants, and also any effects of the intervention on their family. Family member interviews were primarily qualitative, however, the interview also comprised five statements and family members were asked to indicate whether they agreed or disagreed with each, in relation to their loved one participating in the reading program. Additionally, there were four questions to which they could respond yes, no or unsure.

Seventeen family member interviews were conducted, including partners (n = 15) and adult children (n = 2). R2 was the participant unable to complete the post-intervention wellbeing instruments and ASRA, yet his spouse kindly agreed to an interview, and her results are included here. See Table 4.10 for the quantitative component of the interviews.

Table 4.10

Results of the Quantitative Component of Family Member Interviews

Question / statement	**Yes**	**%**	**No**	**%**	**Unsure**	**%**	check total
Do you think these apply to (participant name)'s experience of the reading program:							
• Being able to enjoy stories again because cancer fog was interfering with reading?	12	70.6	2	11.8	3	17.6	17
• Discovering new stories?	12	70.6	0	0.0	5	29.4	17
• Having another person there reading i.e. the warmth of this type of contact?	16	94.1	1	5.9	0	0.0	17
• It was a good distraction from the cancer treatment?	13	76.5	0	0.0	4	23.5	17
• It gave another topic of conversation for (participant name)?	13	81.2	3	18.8	0	0.0	16
Do you think (participant name) enjoyed the reading program?	17	100.0	0	0.0	0	0.0	17
Family-reported CRCI?	16	94.1	0	0.0	1	5.9	17
Do you think (participant name)'s reading interests were catered for in the program?	14	82.4	0	0.0	3	17.6	17
Do you think there was anything (participant name) didn't enjoy?	1	6.3	15	93.7	0	0.0	16

All family members interviewed felt their loved ones enjoyed the reading program. Almost all (94%) felt in-person delivery made a difference, most (82%) felt their loved-one's reading interests were catered for and three-quarters of respondents (76%) felt the intervention was a good distraction from cancer treatment.

Two questions proved too difficult for all family members to answer. During the interview with M5's spouse, she was unable to answer the question "It gave another topic of conversation for (participant name)?" because, although she felt this would apply to her husband if he could speak, she had no way of answering beyond assumption. During the interview with R14's spouse, she was unable to answer the question "Do you think there was anything (participant name) didn't enjoy?" because she was confident if there was something her husband had not enjoyed, he would not have told her. However, during the interview she

expressed confidence in the opinion he had really enjoyed the program, because he made time for it in his busy week (working full-time in a managerial role while still undergoing treatment, family commitments, travel to/from work and personal interests).

According to family members interviewed, only one participant experienced something they did not enjoy in the program. Qualitative data revealed R2 enjoyed the intervention until travelling to sessions became difficult due to exhaustion and treatment side effects. This is discussed in section 6.2.

4.5 EORTC Questions

Assessing any change in self-reported CRCI pre- to post-intervention was undertaken as a secondary analysis. Movement in these scores was never a measure of success for this study, however, they provide additional information that is relevant in the context of people undergoing cancer treatment.

Responses to the two EORTC questions (refer section 3.8.2 for details) were treated separately. In each case of metropolitan, RR and overall cohort, the data were either normally distributed or sufficiently symmetrical to warrant one-sample t-tests. Testing for the possibility that scores were lower post-intervention, one-sample t-tests with H_0: $\mu = 0$ and H_1: $\mu < 0$ were conducted and led to the conclusion that the intervention did not improve the concentration or memory of the study's participants, which is as expected:

- Metro concentration was unchanged ($M = 0.22$, $SD = 1.13$) as measured by EORTC Q1, $t(22) = 0.93$, $p = 0.818$
- Metro memory was unchanged ($M = 0.17$, $SD = 0.49$) as measured by EORTC Q2, $t(22) = 1.70$, $p = 0.948$
- RR concentration was unchanged ($M = 0.50$, $SD = 0.91$) as measured by EORTC Q1, $t(11) = 1.91$, $p = 0.959$
- RR memory was unchanged ($M = 0.58$, $SD = 0.79$) as measured by EORTC Q2, $t(11) = 2.55$, $p = 0.986$
- Overall concentration was unchanged ($M = 0.31$, $SD = 1.05$) as measured by EORTC Q1, $t(34) = 1.77$, $p = 0.957$
- Overall memory was unchanged ($M = 0.31$, $SD = 0.63$) as measured by EORTC Q2, $t(34) = 2.95$, $p = 0.997$

Changes to memory and concentration were not hypothesised, and the results of this secondary analysis help with understanding the value of this reading intervention for targeting emotional wellbeing.

4.6 Quantitative Results Summary

In this chapter, the results of the analysis of the quantitative data collected have been presented. The instruments used to collect the data were reliable and they were administered responsibly and ethically. The summary table (see Table 4.11) shows that scores on all wellbeing instruments moved in the direction of improvement. Statistically significant movement occurred on all wellbeing measures across the total participant group, supporting the study hypothesis. Additionally, ASRA scores improved over time; and family interviews yielded strong support for the program. Chapter 6 will present a synthesis of these findings with the qualitative findings to present a picture of the full effects of the reading program on the study participants.

Table 4.11

Summary of Descriptive Statistics for All Administered Instruments

	METRO		RR		TOTAL	
	Mean	Std.Dev.	Mean	Std.Dev.	Mean	Std.Dev.
DASS-21 Stress	-4.17	6.49	-2.83	8.98	-3.71	7.75
DASS-21 Anxiety	-4.52	5.12	-3.17	5.77	-4.06	5.50
DASS-21 Depression	-2.00	4.51	-5.00	11.06	-3.03	7.98
WEMWBS	2.30	5.10	5.42	6.29	3.37	5.57
ASRA	2.55	5.32	3.75	8.97	2.97	6.72

Chapter 5. Qualitative Findings

"Books turn people into time travelers, shape shifters, body switchers, mind readers, and immortals, and therefore books are the last great alchemy of our age." (George, 2023, p. 73)

Presented in chronological order of collection, this chapter presents observations from the intervention sessions, spontaneous feedback given during the implementation of the mid-point survey and the post-intervention interviews with participants and family members. These qualitative findings will be merged with the quantitative results (as reported in Chapter 4) in Chapter 6, to give a full account of the psychosocial effects of participating in the intervention, including any measurable improvements in emotional wellbeing.

Although qualitative data were collected during enrolment, this was to inform intervention delivery and did not form part of the analysis presented here. Aside from observational data collected over the course of the intervention, there were two distinct time points for collection of qualitative data for analysis: mid-point surveys and final interviews. Mid-point surveys were intended simply as a program health check, to check participants were enjoying the choice of reading material and to offer an opportunity for other suggestions (either reading-related or general suggestions), however, many participants used the opportunity to provide spontaneous feedback. Observations recorded by the reader immediately following intervention sessions contained invaluable insights about the way the program was received by participants from week to week and were useful as context for the other data sources. Including the mid-point survey data and the observations adds to the rigour of the research with regard to a continuation of themes across all data inputs.

Key interview themes are presented: program enjoyment, improved wellbeing, value of program design, value of human interaction, value of distraction and escapism, and effects on cognition and executive function, particularly concentration. These themes addressed both research questions: 'what impact does regular participation in a read-aloud program have on the emotional wellbeing of cancer patients currently undergoing treatment?' (RQ1) and 'what are the perceived psychosocial effects of a read-aloud program from the perspectives of patients and families?' (RQ2). They demonstrate the impact of the program on emotional wellbeing and also the psychosocial effects of the program from the perspective of both participants and family members. Consistent with reflexive TA, first-person language is used for the entirety of this chapter.

5.1 Observations

Observations were important to assess participants' reactions to the current reading material, to the environment (especially relevant when reading in libraries or on campus) and participant discomfort (several participants were palliative and on pain medication for symptom relief). Watching reactions to stories was important for informing future reading choices. The very nature of humanity is that we are each individual, and I saw different reading preferences, different senses of humour and even different ways of listening. For example, some participants listened with their eyes closed, some watched me and others focussed on something in the room.

Observations were recorded shortly after the conclusion of each reading session. There were a few stand-out observations that illustrate the value of the program to participants in different ways. For instance, when greeting me at the front door for our second session, M1 greeted me with "I've been thinking about that crocodile story all week!" M1 had recently started the chemotherapy colloquially known as Red Devil by those affected by breast cancer. She had been extremely unwell due to side effects and had spent some days in hospital in an effort to control these effects, so it was incredible that she had been thinking about a story we read together the previous week, on our first session together. Written by her favourite author, it told the tale of a lady on a first date in far north Queensland who visited a crocodile farm, but her insufferable date was accidentally eaten by a crocodile. The plot sounds dreadful, but the story is superbly written and very funny in places. Using an empathic interpretation to make sense of this, M1's comments, in light of her experience that week, illustrate the escapist nature of stories and highlight the extent to which the story distracted her from the unpleasantness of her treatment side effects. This observation helped answer RQ1, showing the impact the reading program had on M1's emotional wellbeing that week.

Another powerful observation came from R7, a regional participant who had disengaged from reading about six months earlier, potentially as a result of CRCI. During the course of the intervention, his doctor started suspecting his (already advanced) cancer might be spreading, and he was understandably very anxious about upcoming tests. I read him a 'Jack Reacher' short story during our second session together, and he became excited because he had not realised that his favourite 'Jack Reacher' films were based on some of the 28 novels in the series by Lee Child. At the next reading session, we read other action/adventure stories, while in the background I scrambled to obtain and pre-read more 'Jack Reacher' short stories. We then read one each week. However, he took it upon himself to go to his local library and

borrow some ‘Jack Reacher’ novels. He started reading these outside of our time together and on the day of the much-anticipated tests at the hospital, which generally involved waiting time and anxiety, he took his then partly read novel with him, finished it, and started the next one. At our next session, he told me the books distracted him on the day, and his anxiety was reduced. This is a powerful example of the hypothesised benefit of the program in action – improved emotional wellbeing in the face of adversity associated with cancer treatment. Some months after reading together, he contacted me to thank me for the reading program, said some tests had been inconclusive but he was due to see his oncologist soon; and also, that he was still reading ‘Jack Reacher’ novels. This is a fantastic illustration of the power of stories to transport us in the face of anxious times.

Finally, the reactions of M4, M13 and R8 each week as they greeted me at their front doors and we started our sessions, are worth noting. All were palliative, yet all exhibited gaiety at seeing me and enquiring about the stories I had brought with me. They will be discussed further in section 6.9 but are mentioned here to highlight the obvious pleasure they experienced during reading sessions, including enjoyment of the story selection, which was deduced from their delighted greeting and anticipation. They demonstrated feelings of positivity towards the reading program, which (as they each told me over the course of our six weeks together) they did not always feel day-to-day.

The observations indicated themes of program enjoyment, improved wellbeing (via reduced anxiety and mood lift /excitement) and the value of distraction and escapism. These themes are analogous to the themes generated from the interview data (see section 5.3), illustrating the credibility of the analysis and findings.

5.2 Mid-point Surveys

The mid-point surveys comprised three short questions:

1. Are you enjoying what we’re reading?
2. Any suggestions for other items to read?
3. Is there anything we could improve?

5.2.1 Importance

Using a participatory lens, the mid-point surveys were necessary as a program health check half-way through the six-week intervention period, to ensure participant needs were being met. They provided an opportunity for participant feedback in a non-confrontational/non-embarrassing way – for instance, if a participant had not been enjoying the stories, or there

was some other problem, this was an easy way to bring it to my attention without fuss. As noted in Chapter 2, it was considered vital that participants enjoy the reading material in order for the intervention to be effective, both for escapism and immersion in the story to occur and also to reduce drop-out. These short surveys were simply a vehicle for informing the choice of reading material for each participant moving forward, and as such, each survey was analysed on a case-by-case basis with respect to the material already read, and ideas for suitable material for the second half of the intervention.

While some participants simply wrote "yes" or "no" on their surveys in response to the three questions, others chose to provide additional feedback. Some comments reinforcing the choice of reading material are presented in Appendix K.

5.2.2 Early Feedback

These surveys allowed the opportunity to get early feedback on participants' enjoyment of the intervention and meant I could tweak, or make significant changes, if necessary. It provided an opportunity to gauge enjoyment of the program to-date, and another way to view the experience through the participatory worldview: to seek participant feedback so changes could be made if needed. Comments such as M8's "Sure brilliant!" in response to Q1 and M13's comment "I'm really, really enjoying it" were reassuring that participants' needs were being met. The survey results indicated high acceptability of the intervention and illustrated some psychosocial impacts of the program which are relevant to RQ2 via the themes of the value of program design (especially through the story selection), program enjoyment and improved wellbeing (relaxation and mood lift, as seen by the words "happy", "fun" and "not stressed"). These are a subset of the interview themes and therefore show consistent feedback through mid-point surveys and post-intervention interviews, which lends credibility to the analysis process and findings.

Surveys revealed most participants preferred the researcher chose the stories, as they enjoyed abdication of effort around choosing, as well as the surprising nature of the program when delivered this way: "I like the surprise!" (M17). Some participants, however, did make some special requests at the mid-point, such as "More humour" (R8) and "I would enjoy some more Maeve Binchy" (R10). One participant critiqued my voice when reading aloud. On reflection, this may have been due to CRCI presenting as difficulty paying attention or following along because she experienced other CRCI symptoms such as confusion over our meeting times and self-reported difficulties with reading and concentration. However, it may

also have been a cultural difficulty due to my Australian accent. All comments were reflected on, and story requests were actioned.

5.3 Post-intervention Interviews

In total, 52 interviews were conducted: 35 with participants and 17 with family members (mostly partners but also a daughter and a daughter-in-law).

Interviews were analysed following the six phases of reflexive thematic analysis (Braun & Clarke, 2006, 2019). See Chapter 3 for a detailed description of the methodology. In accordance with Braun and Clarke's directive that because the researcher themself is a tool in the analysis, the writing phase (Phase Six) should be written using first person language (Berger, 2015; Braun & Clarke, 2023a), this section continues that advice and also uses an "analytical narrative" (Braun & Clarke, 2006, p. 93) to argue the findings answer the research questions and support the hypothesis.

The themes generated are presented in Table 5.1 and will be discussed in turn.

Table 5.1

Interview Themes Generated

Theme	Sub-theme	Codes
Program enjoyment		• Enjoyed the program in general
Improved wellbeing	Feeling valued	• Me time or treat • Nurtured • Warmth and feeling special
	Mental health benefits	• Relaxed • Family noticed loved one is more relaxed • Sleep • Mood lift - happier • Mindfulness • Time out
	Self-efficacy	• Self-efficacy
Value of program design	Importance of story selection	• Enjoyed story selection • Added to known or liked books and or authors
	Being read to	• Enjoyment of being read to • Less effort than reading to self • Entertained
	No expectations	• No expectations on participant
	Personalised	• One-to-one contact – tailored - personalised
	Recommended situations	• Valuable program for others
Value of human interaction	Companionship	• Company • Connection with a person • Human presence – in general
	Story discussion	• Discuss stories
	Human presence valued by family members	• Family – allowed time away from carer's role • Family pleased that loved one is getting some pleasure or help or company • Other family reactions
	Personal qualities of the reader	• Enjoyed voice of the reader • Personality and warmth • Flexibility • Pets tolerance
Value of distraction and escapism	Escapism	• Distraction from cancer or other worries • Escapism – immersion in story
	Distraction effects continuing	• Anticipation – looking forward to sessions • Effects continuing outside session time • Conversation topic
Effects on cognition and executive function – concentration		• Concentration difficulties • Helping with concentration or understanding • Human presence effects on concentration

5.3.1 Program Enjoyment

"Did you enjoy the reading program?" (Researcher)
"Oh, no. I've *loved* the reading program." (R8)

Program enjoyment was a theme running through every interview, with both participants and family members. Although frequency of occurrence is not considered a measure of importance in reflexive TA (Braun & Clarke, 2006) it is interesting to note that general enjoyment of the program was frequently mentioned, separate from enjoying the story selection, the warmth of human contact, the personal qualities of the reader, or other specific areas of enjoyment. This indicates that at the very least, the program was a pleasurable experience for those who participated, which was also evident to family members. This is an important theme in support of the hypothesis, specifically illustrating a positive experience for all involved. Comments like "The whole thing's been wonderful" (M16); "Each week, it's been really good – really enjoyable" (R17); and "I loved it … it's all been really good and enjoyable" (M20) illustrate this theme well.

Despite the difficulty in getting people to enrol in the program (even among people who met the eligibility criteria), once enrolled, every participant reported enjoying the intervention. Comments such as "You know, there was nothing I would have changed to be honest. I really enjoyed it" (M3), to "(I) enjoyed it more than I thought I would … I enjoyed the whole program" (M9) showed an enjoyment of the program that was somewhat unexpected because as adults we are not accustomed to being read to, and therefore unsure what a read-aloud program would entail, and how we would feel participating in one.

Some participants became emotional when trying to explain what the one-on-one visits and shared stories meant to them. Emotional responses centred around the view that the program was so good because someone made an effort to do this just for them, that is, someone cared just for them: "I think that's probably the essence of it all, that you would come to my home, you would care enough, [indecipherable], that you would do that for me [indecipherable – teary and upset]" (M15). This was a cross-theme response and arose not only from program enjoyment but from sub-themes of feeling valued, the importance of story selection, being read to and companionship. Although this was a more common reaction among those participants who lived alone, it was not confined to them. For instance, M9's comment: "I'm sad that it's coming to an end" was one of many in this vein; likewise, "I shall miss you" (R5) and "I always looked forward to it. I'll miss it" (M4). When R8 was asked if anything in the

program had a negative effect on her, she replied “Yes, because you finished … you left too soon, Liz”.

Enthusiasm for the program was reinforced during interviews with family members. For instance, R14, who was a RR participant and took part via Zoom said “I loved it. It was fantastic” (R14) and this was echoed by his spouse:

> For him to like carve out and make time in his busy schedule for this, he committed and that was fine, but for him to actively look forward to it, regardless of whether he's driving or whatever, I mean, that was big.

Family members repeatedly spoke of the enjoyment their loved ones experienced by participating in the reading program, for instance "Ah, (she) loved it! Yes, I mean, she looked, really looked forward to you coming each time" (M1 spouse).

The effect on family members knowing their loved ones were finally able to enjoy something in the midst of their cancer diagnosis (and often in the midst of treatment) was verbalised beautifully by M3’s partner: "It's just good to see her enjoying anything really or just like, anything to have sort of a positive impact". All family members interviewed spoke of the comfort or pleasure they felt knowing their loved one was being cared for. Other effects on family members will be discussed in section 5.3.4. If any in-patients had enrolled in the program, nursing staff would also have been interviewed.

When participants were asked if there was anything they found negative about the program, the overwhelming response was that the only negative was that it was ending - which is a positive comment about the intervention and supports the positive experience aspect of the hypothesis. Given the exploratory nature of the research, it was reassuring to find, at the very least, the reading intervention was universally enjoyed by the participants, which would have contributed to retention rates and resulted in referrals from one participant to another.

"I didn't know I was going to enjoy it as much as I did … I really loved (it), I shall miss you." (R5 with intervention via Zoom)

5.3.2 Improved Wellbeing

"It changed my whole attitude for the day." (R15)

"More than enjoyed it, I've loved it. I love it … the feeling of being nurtured. It's a very nurturing feeling. It takes you to another world. It's lovely to listen to someone read. And yeah, it's a beautiful … it's a gift. Really, it feels like a gift." (R8)

Table 5.2

Improved Wellbeing Sub-themes and Codes

Theme	Sub-theme	Codes
Improved wellbeing	Feeling valued	• Me time or treat • Nurtured • Warmth and feeling special
	Mental health benefits	• Relaxed • Family noticed loved one is more relaxed • Sleep • Mood lift - happier • Mindfulness • Time out
	Self-efficacy	• Self-efficacy

Improved wellbeing included three sub-themes, presented in Table 5.2, and described below.

Feeling valued

Participating in the reading program led to most participants experiencing feelings of warmth, and a sense of being nurtured or feeling special. I had not anticipated this, but such feelings are associated with feeling valued and are intrinsically linked to an improvement in wellbeing. From participants' viewpoints, comments like "decadent" (M13), "luxury" (M15), "a privilege" (M8) and "an indulgence" (M23 and R4) show how they viewed our time together as a special treat. R10 likened the feeling after a session to the feeling of being pampered by a beautician:

> I feel like it's been a real treat for me. Like almost like if I've gone and had a, my nails done or something, that I've walked out of here feeling like, oh I've had something nice done for myself. You know, it's been a real treat.

Approximately half the participants mentioned feeling special or nurtured. When R11 tried to think of the right word to describe how the reading program made her feel, she came up with "warming and nurturing" which suits the tone of all the comments perfectly. These comments

illustrate the warm, nurturing feelings the reading program invoked – a very positive psychosocial effect.

Many participants said reading together reminded them of happy times when they were children, either with their parents or teachers reading to them: “my mum spent days reading to me and so it's a caring, nurturing … so it was harking back to that I suppose, and the comfort feelings” (M1); “I loved, first of all, the novelty of it. It took me back to reading to my children, but it took me back to my childhood, of teachers reading to me, and how good it feels” (R8). Likewise, R13 fondly remembered teachers reading to her at school, and she was reminded of that during our reading together, preferring an “actual person” in contrast to a recording – note here that I do not say in contrast to face-to-face in-person because R13 participated via Zoom. This shows the value participants placed on a person reading tailored material to them in real-time:

> Some of my favourite memories from primary school was having the teacher sit at the class and read the book. Yeah, that in your lesson or daytime, or whatever, or your, you know parents reading to you, or I remember reading to our children and yeah, and, you know, just how much, you know “Another story!” You know, they beg you for another story (chuckling) You’d be exhausted. But no, definitely there's a plus for the actual person. (R13)

Others also shared how reading together prompted happy memories of their youth: “Today I was thinking of my dad … that atmosphere, you know, those feelings when I had, when I was, when I was young, that was the same now. … It brought back those nice, warm, family feelings” (M17). Repeatedly, participants mentioned that reading together reminded them of when their mothers, siblings or teachers used to read to them, triggering warm memories.

Family members perceived the reading sessions as bringing “comfort” (M13’s family member) and some well-deserved “me-time” (M24’s spouse) for their loved ones. Comments about feeling “important” (M12’s spouse) or receiving a metaphorical hug (M13’s family member) show their understanding of the value of the reading program to their loved ones.

R10’s words provide a perfect summary for this section about feeling valued, warm, special and perhaps like having received a treat:

> I've always felt really calm whenever I've walked out of here. I felt like I've been, actually walking on a cloud whenever I've walked out of here. Yeah, just super, super relaxed. Just … honestly, I felt like I've been to the beauty therapist. (laughing) I honestly do, like when I've walked out of here, (chuckling) and I haven't had to pay the exorbitant fees of the beauty therapist.

Mental health benefits

References to relaxation appeared repeatedly across interviews. Most interviewees referred to being relaxed at least twice during their interview. This means we are spoiled for choice when it comes to quotes about relaxation resulting from the reading intervention. However, the general tone of the comments is like these: “It was very calming. There's something comforting about it. It did make me feel, at, when you're being read to, it does make you feel very relaxed, and it does lift your mood" (M24); “I actually think it’s a lovely treat to be read to. I can completely relax. I don’t have to think about what I’ve just read. I can just be relaxed. It really is such a treat” (R3 – mid-point survey) and “I was relaxed. The reader made me relaxed” (M6). This last comment also speaks of the value of the personal qualities of the reader (discussed in section 5.3.4). The use of fiction for generating participant relaxation was also reported by Dowrick et al. (2012), Walwyn and Rowley (2011), Usherwood and Toyne (2002) and Brewster and McNicol (2019), while Brewster (2016) found that reading for escapism went “beyond relaxation”, allowing people to enter a “safe world” (p. 176). The fact that participants overwhelmingly found the reading intervention relaxing is important, as relaxation is a recommended integrative oncology therapy, charged with being beneficial for anxiety, nausea and vomiting, depressive symptoms and improved mood (Greenlee et al., 2017).

Family members also noticed their loved ones were more relaxed after reading sessions. M4’s spouse’s comments are typical of comments about relaxation from family members, “after you’d left, and during the reading, she found herself in a rather tranquil place”. Similarly, M13’s family member stated, “I've spoken to her a couple of times, you know, when she has been read to and she's really calm.” M13’s loved one elaborated: “There's been a bit more peace for her ... She says she loves that feeling of someone reading to her like it's, yeah. It's just, it's a calm feeling.” With M13’s reliance on a drug trial for some improvement in her health, and with her disclosing that she gets anxious the night before each weekly treatment, discovering the intervention left her more peaceful and calmer shows a clear impact of participating (as per RQ1) and given her loved one saw this, which in turn brought comfort, shows positive psychosocial effects for both patient and family (as per RQ2). A more relaxed state (i.e., reduced stress) is recognised widely for its role in mental and physical wellbeing, and this supports both RQ1 and RQ2.

Relaxation was potentially a trigger for improved sleep. Sleep is fundamentally important for both physical and mental health (National Institutes of Health - U.S. Department of Health and Human Services, 2013). Some participants mentioned sleep during their interviews. Most

comments centred around improved sleep, which was likely due to being relaxed. Some participants appeared to experience more dramatic effects to their sleep than others:

> After the first read, I knew instantly that that had had an effect. Like I walked out from being read and was just yawning and yawning and yawning. All afternoon, I continued to yawn and had the deepest, most refreshing sleep I've had in, oh, years after that. … And those sort of, for want of a better term, the symptoms of having been read to, that continued the next day, but not as strong as the first day. And then repeated each week, for the six weeks that I was read to. (M7)

Interviews with family members also produced comments on sleeping difficulties and how the participant's sleep improved during the intervention: "She's had a lot of trouble sleeping lately and I know the last two or three sessions she's actually had a good night's sleep the night that she's had the reading … it helped her obviously relax and get some sleep" (R11's spouse). This is a lovely indicator of the program's effectiveness spilling over into physical wellbeing, because of the link between sleep and both mental and physical wellbeing. Improved sleep after reading is supported by Finucane et al. (2021) and sleeping after group bibliotherapy sessions was found by Steenberg (2016) – attributed to the intensity of the experience, which could also align with the participant experience in this study (i.e., because of the intensity of the effort to concentrate in the midst of CRCI). Improved sleep after listening to stories was also found in a study of intensive care patients, where researchers deemed it an effective low-cost, non-pharmacological intervention for improving sleep quality (Mermer & Arslan, 2024).

In contrast, a couple of participants felt increased energy listening to stories. For instance, the first couple of R4's sessions were held when she would normally be napping, but she said: "sometimes I was very tired, but I felt perked up so I always felt refreshed afterwards". Feeling refreshed is also a positive consequence and an indicator of improved emotional wellbeing.

Mood lift, feeling happier, was regularly reported by participants: "I have noticed that I have been feeling more positive, and I don't - I put it down to the interaction with you" (R6) and "I feel so light-hearted now, I feel so much, so much better" (R15). However, R10's words about improved mood directly answer both research questions, and support the hypothesis that the intervention resulted in an improvement in emotional health:

> It's made me feel super - like really super. And I don't know, what other word I can use to describe how I felt when I've walked out of here. And for the rest of the day, and, you know, even into the following day, but it's not just a fleeting feeling. You know, it's like, it's been a lasting feeling that I felt … umm … That, you know, even that, the rest of that night, I've had a good night's sleep. Yeah, it's made me feel really, really good.

Family members were asked if they observed any effects of the reading program on their loved ones and although descriptions varied, the commonality was mood lift, which M24's spouse described as a sense of excitement:

> Because you can tell when she has talked to us at mealtime around the book and you know, you can see um the mood change slightly, because she's recalling something that she's enjoying doing. … She sort of explains a few things and what she did and, and you can tell just in the way that she's talking, there's that little bit of excitement there, and rather than the normal sort of chatter. (M24's spouse)

Family members noticed positive effects on their loved ones while participating in the reading program, which both supports the hypothesis and contributes to RQ2.

Also beneficial to mental health, mindfulness was mentioned by many participants and some family members. M7 likened the reading experience to the mindfulness of her regular yoga practice. Others alluded to mindfulness without using the exact phrase, for instance: "Enjoy the moment. Enjoy it" (M17); "I think it was just relaxed, sitting back listening and relaxing. And being present in the moment" (R6) and "it's like when I'm doing my meditation I try to focus and be present. It's like you're doing that, it's being present in the story" (M19); "it's like a form of meditation" (R14). Another bibliotherapy study also found fiction had the effect of taking participants' minds off their problems and resulted in "intense absorption ... meditation" (Dowrick et al., 2012, p. 17). In a cancer context, meditation is recommended for improved QoL, as is yoga, which is additionally recommended for improving sleep (Greenlee et al., 2017). As discussed in Chapter 2, half an hour reading has the same beneficial effects as half an hour of yoga (Rizzolo et al., 2009), therefore, although not tested empirically, we can suggest reading has the potential for producing those same effects: improved QoL and improved sleep.

The concept of time out was mentioned repeatedly. It was referred to in various ways, as time out, permission to simply stop (work or thinking about what medication or exercises they should be taking/doing), or time to switch off and allow the time and mental space for enjoying the escapism offered by the stories:

> I think it made me stop and just take some time out, which I've struggled to, my recovery, to do. Umm and I think that's probably been the hardest part of my recovery is just to take some time out for myself, so I think that it made me do that … time to just not be thinking about 500 things or what stretches I should do or what medication I should be taking or whatever else is going on in the world. (M3)

The idea of time out was generally associated with simply a guilt-free pause to the day, which all appreciated. Nobody said the time out was an intrusion in their day.

Self-efficacy

Many studies have shown increased self-efficacy to be an indicator of improved mental wellbeing, and more than half of the participants exhibited increased self-efficacy related to everyday activities. Some examples of this increased self-efficacy could be seen, for instance, in M4 going to her local library and enrolling in a computer course and how she felt after two lessons: “for the first time in a long time, I felt a little bit sort of empowered, it was good.” M16 also joined her local library as a consequence of the program, while M22 felt more motivated to do tasks at home and much to his wife’s disgust, this included jobs involving climbing ladders. M21 felt motivated to start a detox program and enrol in an exercise class and R12 felt inspired to create a special flower-filled spot in her garden to enjoy reading when she feels able to tackle reading to herself again and she was also keen to volunteer to read aloud to children at her local primary school (with no expectations of them around comprehension, just as I had placed no expectations on her – she was profoundly affected by this). M7 had started knitting after feeling that if she could focus on a story being read, then she could focus on following a knitting pattern, and she also reported feeling more confident in conversing with others:

> But I have noticed, I've been able to hold a conversation with people, like previously I could only sort of do one or two words, and I'll be, you know, my mind would be blanking out. Whereas now, I can pretty much, maybe 15-20 minutes, I could hold a conversation quite easily, I think.

M5’s spouse was pleased that the reading program inspired her husband to consider volunteering at the library where we met for sessions, and this empowerment carried over into doing more things together again, which had diminished since his surgery:

> He was happier. He was picking up books and trying to get through them, and getting enjoyment from them. And now thinking about volunteering at the library. It has given him a bit of confidence…. He was more motivated and turned on.

Regarding activities they could enjoy together again: “He’s starting to initiate outings again – concerts … He’s starting to do more again, like we used to do. I was so glad he was involved with the 6-week program and I think it has helped” (M5’s spouse). Her statement represents a powerful example of psychosocial effects on both participants and families.

One of the best pieces of feedback about self-efficacy concerns M20, with her aphasia, and the increase in confidence she was starting to experience with understanding and speaking. She said the reading program helped her “by understanding, or trying to understand a little bit more, when you’re reading” and she enjoyed “Laughing about some of the different things”. It is hard to determine who experienced more joy from the interactions with M20 - her or me – because whenever she reacted to a plot twist or laughed at a funny part of a story, I knew

she had understood, and that was a joy for me. It was apparent from the interviews with both M20 and her husband, that they both valued the opportunities for interaction, listening and comprehension in an environment without pressure or expectation.

> "So, how did you feel being read to?" (Researcher)
> "Ah well, you want to hear it? I felt like a king!" (M8)

5.3.3 Value of Program Design

> I didn't expect to get such joy out of being read to again. I knew I enjoyed it, but I didn't realise I'd look forward to it so much … I think that's probably part of the joy of being read to, that you also makes you feel loved and, and cherished in a way. (M13)

Table 5.3

Value of Program Design Sub-themes and Codes

Theme	Sub-theme	Codes
Value of program design	Importance of story selection	• Enjoyed story selection • Added to known or liked books and or authors
	Being read to	• Enjoyment of being read to • Less effort than reading to self • Entertained
	No expectations	• No expectations on participant
	Personalised	• One-to-one contact – tailored - personalised
	Recommended situations	• Valuable program for others

The value of the program design was commonly referred to in interviews, under the key ideas represented by the sub-themes and codes presented in Table 5.3 and described below.

Importance of story selection

As previously noted, although frequency is not necessarily an indicator of importance in reflexive TA, having 134 references to the code *enjoyed story selection* cannot be ignored. The importance of getting the story selection right for each participant was clearly a huge part of participant engagement and retention. As M7 said: "There wasn't one that I didn't enjoy … they were all good; it was a mixture. The short stories were good", while M15 went so far as to comment on the quality of the authors: "all those stories were well written, which is what I

like. … They were light and yet they were real!"

In her interview comments, R8 reflected on the way reading material had been carefully chosen for both appropriateness and enjoyment:

> You gave me the option halfway: "do you want me to bring in something else?" And I said, "no, no, what you're doing is perfect". So, I think humour, for me, is a good thing. And that gives you that sense of wellbeing … and happiness anyway. I wouldn't like to have been read something very heavy or confronting, umm, and challenging, and something that requires too much thinking, as well.

With the participatory lens of the study, collecting participant reading preferences at enrolment time was necessary to develop the tailored program for each person and it was valued by participants:

> Your book choices were great - lots of variability. Thanks for asking at the start because you asked me what I like and whatever. And that was really good. That's really good, because I would imagine some of these programs potentially, not so much reading, it could be anything, there might be some that make the mistake of not asking, and just launching into reading and it's, it's great to be asked. The second bit is, yeah, the great variability, Ah, good sense of humour, a bit of quirkiness, a bit of darkness. A bit of everything. A bit of murder. It was good. (R14)

The overwhelming success of the story choices indicates the need for an experienced library professional (or similar) to choose the material. Another bibliotherapy study also found the choice of reading material was a key aspect, positively affecting psychological wellbeing (Pettersson, 2018). Short stories suited the program, allowing participants to enjoy an entire story without needing to remember characters and plot from one week to the next. M15 was one of many who pointed this out: "It was nice that they weren't long. Whereas when I'm reading a book myself, it's longer. And it's the effort of doing that".

Story selection was also important for my three participants for whom English was their second language. M8 expressed his enjoyment of the selection tailored expressly for him:

> So it's actually, you were able to choose good stories, yes. So good stories which I don't know, which was good to get authors you don't know or stories you don't know. And, why the diversity of good English language, which, so for coming from non-English background yeah, so it's something I appreciate.

And regarding humour, he said: "I always appreciate a good story … Oh, well, to get someone to do a grenade with a fuse and then the dog, so that's kind of completely crazy … So that's really hilarious" (M8 – referring to 'The Loaded Dog' by Henry Lawson (1995/1901)). M8 was not the only participant to thoroughly enjoy this Australian classic.

Most participants liked it best when I chose the stories, which supports this element of the program design. This was in fact a recurring theme among most participants, and R3

expressed it well:

> Well, I love stories. So I enjoyed the stories. I actually enjoyed that you were picking the stories, and I wasn't. Because it meant that I didn't know what I was gonna hear that day, and there's always that curiousness, that open curiousness about, well, where's this story gonna lead? … What's gonna happen? And I liked not having to have the responsibility of picking the stories.

Historically, R17 had no success choosing fiction for herself, so she was delighted I would choose for her, which was one of her main motivations for enrolling in the study. Although the first few intervention sessions felt like a bit of hit-and-miss, her interview responses told a different story:

> Just the stories and the variety that we had and … better than what's on television … I could read a whole range of things really and enjoy them, but I think that the things that you chose for me, were well-chosen and I thoroughly enjoyed them. I perhaps wouldn't have chosen some of those things that you chose but I found I really did enjoy them.

This is consistent with previous research showing bibliotherapy widens literary horizons (Hodge et al., 2007).

Corroborating the idea of the crucial nature of story selection, some participants made comments indicating that they would not have enjoyed it as much if the story selection was not to their liking. One participant even said that if I had brought along a genre she did not enjoy, she would have had to bring her own book for me to read instead:

> I think if you just rocked up with sci fi (laughing), okay, I'd have to say no, it's not going to benefit me in any way. (laughing) … I might have to bring my own book along (laughing) and say, "can you please read this instead?" (laughing) (R10)

Tailoring the stories for participants, away from the genres they did not like, and most importantly, away from their illness and treatment, reflects the findings of the Pettersson (2023) study about using "genres that have not traditionally been used for bibliotherapy, such as fantasy and realistic fiction that thematize issues other than the participants' own problems or health concerns" (p. 56).

Stories with a twist and humorous material played an important role in the intervention. Humorous stories were enjoyed by existing and new readers alike, although it was a favoured choice for new readers. Participants regularly commented on their enjoyment of stories with plot twists, both during intervention sessions and during the interviews, showing congruence between these two data points. Illustrating this for instance: "And I always got the twist to it – there was some sort of twist in the story. And also to be able to laugh at something" (M7); and "that sense of quirky fun. I found I really enjoy those funny little twists and turns. … I really, really enjoyed it. Really enjoyed them" (M13). This is consistent with story selections

for the popular adult storytime at Seattle Public Library: “that is what I wanted my storytime to be: fun, captivating, a bit dangerous, and unexpected in all the expected ways” (Wright, 2010, p. 133). From my perspective when choosing reading material, although sometimes difficult to match type of humour to participant, that matching was successful more often than not, and I always tried to include a story that had at least a little laugh along the way. For M6, who enjoyed the combination of humour in the stories and the lack of effort on his part: “You know, quite a few funny ones and umm yeah, yeah, that's what I enjoyed about it. I just had to, you know, sit back and let it happen”. The importance of humour or at least a lightness and a twist in the story was commonly reported, for instance:

> You know, maybe it might have been different if the, if the stories were a little bit morbid but I don't think any of them were, I think they were all, kind of had a bit of a giggle or something in them somewhere. … The little twists, yeah, the things you kind of didn't really expect sometimes. (R11)

When I saw a participant laughing, I felt as though I had in some way won a prize, that I had succeeded, because if they were laughing, they were getting relief from cancer treatment and worries, and lightening their mood. Again, this is supported by the adult storytimes at Seattle Public Library, where the storyteller said, “I know I’ve succeeded when I hear a murmur of realization spreading through a crowd, a sudden gasp, or the laughter of surprise” (D. Wright, 2017, para. 4). The most dramatic example of the role of humour in lifting mood occurred with R15 (refer section 6.9). Humour seemed to cause the dramatic shifts in mood she experienced on more than one occasion, and thus it is mentioned here. Studies have shown the value of laughter to individuals facing adversity (Crawford & Caltabiano, 2011) and a cancer diagnosis is certainly an adverse experience. Participants in a humour intervention showed decreased stress, anxiety and depression (Crawford & Caltabiano, 2011). In this study, participants’ reports on the effect of humour during reading sessions show an overwhelmingly positive impact on them, with dramatic mood improvement consistent with enjoying humour, and it was mirrored in the positive impact family members reported from hearing the participant’s laughter.

Sometimes humour was the tonic and sometimes intrigue was the tonic. For instance, for R16, who loved to figure out the back-story and even emailed me once with his reflections and interpretation of ‘who dunnit’ in a story we read together said:

> The ones that are funny, just kind of yes, they are, they are funny. I enjoy the comedy. Not quite so much, I suppose. … I’m a problem solver. Yes. Yeah, I enjoy the challenge. And I liked the variety, the odd comedy and ah, yes the different authors.

Of course, what could be considered as appropriate and funny for one participant, can be

entirely unsuitable for another. It was vital to be able to 'read' (i.e., have an awareness or perception of) the participants to gauge this.

M5's spouse's comment really highlights the joy the right story can bring: "You were organised and assessed his reactions to stories; choice of stories. After the sessions, when I asked, 'Did you enjoy it?', he had a face of delight, he was like a little boy, and said yes, he did." The success of choosing enjoyable reading material for each participant was apparent in the interviews: "You'd come and you'd bring maybe three, but there wasn't a dud" (M15). This reinforces the intervention design of personalising the program for each participant. It highlights how vital it was that participants enjoyed the reading material, as that was the route to getting the benefits of reading, including relaxation and distraction from pain.

Being read to

Many participants voiced uncertainty about what to expect, or what it would feel like to be read to as an adult, but all participants quickly settled into enjoying being read to. For instance, M9 said "I was apprehensive about how I would feel about being read to but, I actually enjoyed it", and R11 said:

> I think probably the first session. I was probably a little ... maybe a little nervous because I just thought, well, this is really weird because I'm an adult, and I'm having someone read to me, which is something I'd normally do myself. But I found within that first five minutes, I felt relaxed.

Those participants with initial reservations, without exception, later said the reservation or concern about being read to only lasted a few minutes into the first session, and then they focussed on the reading and relaxed, with subsequent sessions being relaxed from the outset.

A few participants already knew they enjoyed the experience of being read to: "I love being read to. So that's what was most enjoyable. And the choice of books was great" (R5). However, M13's words sum up the warmth being read to can evoke, most poignantly:

> I didn't expect to get such joy out of being read to again. I knew I enjoyed it, but I didn't realise I'd look forward to it so much …. I think that's probably part of the joy of being read to, that you also makes you feel loved and, and cherished in a way.

Regardless of demographics, cancer stage, personality, or in-person versus Zoom delivery, all participants enjoyed the experience of being read to. Common feedback was that being read to was relaxing and/or entertaining. Some participants, both male and female, mentioned the fun of live reading, which had not been considered directly during the design phase of the program, but which added to the feeling of having a positive experience: "listening to stories is always good fun, I reckon" (M6).

A number of participants mentioned being read to brought back happy childhood memories, some of which we saw in relation to feeling valued in section 5.3.2, but also sometimes in relation to simply enjoying the experience of being read to, as R11 explained:

> I enjoyed being read to ... because, I guess it's a bit of a, it comes back to a bit of a childhood thing. It's just, I don't know what it is. I don't know the right way to explain it. But there's just something that feels quite warming about it.

While R17 said "aah, it made me feel like a child again, 'cause my sister used to read to me when we were small children, and I used to really enjoy her reading to me", other participants said it reminded them of happy schooldays.

A couple of participants valued the opportunity to undertake a simple, non-demanding, quiet task while listening. For R17, this became the key to her relaxing into listening. Whilst for most participants, the reading sessions afforded an opportunity to do nothing other than relax, for a kinaesthetic person, sitting doing nothing can be torturous. After a couple of sessions, R17 asked if I minded if she did mending while listening, which of course I did not, and she was visibly so much more relaxed that she saved mending and simple sewing tasks for my subsequent visits. She described this transition from:

> I found it harder to begin with, I was just restless, but I ummm, when I was trying to sort of work out, you know, just sitting there … I felt as if I had to sit and listen like a good student

to:

> When I realised I needed to focus on something else, that wasn't intellectually at all at demanding, like the mending, or sewing, I found it a lot easier, yeah I could really concentrate on umm … in spite of the dog (laughing) … concentrate on what you were reading, better when I was doing something that was occupying my hands.

R17 went on to report really enjoying and valuing the program: "Each week, it's been really good – really enjoyable", and as already seen, the highlight for her was the exposure to humour. This suggests that when implementing read-aloud programs, carrying a stress ball, adult colouring book or simple sewing task that does not detract attention from the reading but allows a degree of movement may be important to neurodiverse people and people deemed to be kinaesthetic learners. Figures around the proportion of learners deemed to be kinaesthetic learners range from 5% (Knowledge Network for Innovations in Learning and Teaching (KNILT), 2020 para. 1) to 18.1% (Lujan & Dicarlo, 2006, p. 14), and are even as high as 45% (National Math Foundation (NMF), 2023; Tranquillo, 2008), while neurodiverse adults comprise approximately 15-20% of the population (Doyle, 2020, p. 112), so this could be an important initiative for future bibliotherapy programs.

Listening to a story is less effort than reading to oneself

Although under the sub-theme of being read to, this sub-theme cropped up often, not just among those participants who had previously abandoned reading, and is therefore reported separately here. For instance, M5, an avid reader, was having trouble keeping track of characters when reading to himself. He had started to use an iPad to make brief notes he could refer to. He always listened intently to our stories - the ease of listening to stories held real meaning for him.

Another vivid example of this was M1, who had only recently commenced chemotherapy, and she said: “It was nice to be just immersed in the story without the effort of reading umm and feeling tired, I could just concentrate on the story, and let it wash over me.” When discussing M1’s chemotherapy cycle, and her recent infusion and subsequent unpleasant side effects, I asked if she was able to read for herself when feeling unwell. She said she could not manage to read at those times, even though she had been an avid reader in the past, and she ended up watching television when feeling sick. She asked me: “Why is it, that even for a reader, reading to yourself is more effort?” Given the known impact of CRCI to the frontal lobe (Ahles & Root, 2018; Conroy et al., 2013; Miao et al., 2016; Myers, 2015), where visual processing is located, and the known difficulties with reading, navigating and other visual tasks (Myers, 2015), M1’s difficulties may be associated with her cancer treatment, especially as her combination of breast cancer and chemotherapy puts her in the 75% likelihood of CRCI as reported by C. G. Brown (2015, p. 204).

Participants repeatedly spoke of the accessibility of listening to stories being read to them during the program, as opposed to the difficulty of reading a book, visually, to themselves: “whatever you read, I was quite intrigued with it. It wasn't arduous” (M7); and “I could just sit, I didn't have to do any of the reading myself. … I didn't have to … Oh, no effort. I didn't have to put in any effort. I could just sit and listen” (M17). Among the many who considered listening and concentration, M9 described it as being an easier task because less concentration was required: “Just enjoy listening, ability to listen to stories rather than to have to, you know, concentrate”. These comments all illustrate the feasibility of listening to a story as a viable alternative to reading (visually) to oneself in the midst of CRCI.

Listening to reduce the effort of reading was especially important to M20, a participant with brain cancer and aphasia who could no longer read to herself but kept a couple of books on her coffee table that she wanted to be able to read. She described how listening to someone read worked so successfully for her: “being able to like listen and just relax and listen. … Just

being able to sit and relax and not have to try and worry about the words and stuff that I was doing". Based on her comment, the reading program was suitable and useful for people affected by brain cancers, not only for improving emotional wellbeing but also for providing a stress-free environment to practice concentrating and interacting to help improve confidence.

Participants expressed a freedom from concentration resulting from the ease of listening, which aided distraction and escapism: "Well, just enjoyed going into those different spaces. You know, with you, reading to me I was, I didn't have to concentrate on the reading part of it. It was the listening part. And I was able to escape into those spaces and visualise things that you were reading about" (R6). Likewise, M9 spoke about a reduced need for concentration when listening, making the stories accessible in a way they no longer were when trying to read to herself: "Just enjoy listening, ability to listen to stories rather than to have to, you know, concentrate and the stories that were chosen were really quite quirky and interesting."

Participants found listening easier, not just from the perspective of impaired concentration, but also for other reasons. For instance, R14 spoke of the physicality of visual effort and how it is not only impacted by, but can add to, the burden of treatment side effects. However, for him, being read to was a wonderful way to restore the benefits of reading:

> Reading is still some effort. … If I was lying in hospital, the last thing I wanted to do was read because you're feeling squeamish. So when your eyes follow the words, it can make you feel like vomiting. I didn't read anything. I don't think I ever read in all the days I was in hospital. If I did, I can't remember it. So being read to is massively different. Now reading is wonderful. So when you start to feel a little bit better, absolutely, you can read yourself, but I think being read to is something, you think about it, how many adults have been read to in the last two thirds of their life? No one.

With participants classifying listening as less effort, and therefore more accessible than reading to oneself (visually), it could be expected that participants would embrace audiobooks. However, with a few exceptions, this was almost universally not the case. Referring back to the decisions around methods and program delivery (in Chapter 3), audiobooks were not chosen as the delivery mechanism due to the very thing causing difficulty reading (i.e., CRCI) likely to make operating technology difficult, which I saw first-hand prior to undertaking this research and was one of the prompts for this study. This difficulty combined with research showing the importance of interpersonal warmth, firmly established the groundwork for this study being an in-person read-aloud program. Aside from the recognised warmth of human contact, considering the demographics of our cohort, with

55% of participants over the age of 65, as M8 said: “being as old as I am, yes, means that I still prefer face to face and still prefer live people than rather than technology”. The dichotomy between in-person reading and audiobooks encountered during the design process was detailed in section 3.5.2 and its impact on the participants’ experiences of the program will be discussed further in section 6.6.

No expectations

There were no expectations placed on participants. Metropolitan participants could take part in the intervention from the comfort of their own homes, their local library or a UniSA campus. A Zoom option existed for those with concerns about COVID-19 exposure. The lack of travel was appreciated: “It was very easy. The easy part of it was you coming here” (M21). The lack of any expectations was a highlight for many participants. For instance, M15 found the absence of travel, preparation and need to offer hospitality a positive:

> And there was no expectation: I never offered you a cuppa or anything. So I didn't have to clean the house or you know, any of that. … That’s just amazing. I didn't have to do any effort to get anywhere.

Of the 14 enrolled RR participants, seven were within a reasonable driving distance of Adelaide, providing trips were combined to see multiple participants in approximately the same geographical area on the same day. This meant participants who would not have taken part if it had only been offered to them via Zoom, were included. One participant who was beyond reasonable driving distance, however, R12 was not keen on a Zoom delivery, so we compromised, and she drove halfway to Adelaide, while I drove halfway to her area, and we met at a public library with good facilities for reading together relatively undisturbed. Only R2 had no choice but to travel to a public library near the Cancer Council Lodge, then we continued the last couple of sessions via Zoom after he left Adelaide. This need for him to travel added to his cancer treatment burden and impacted his enjoyment in the latter part of the program. Although discussed further in Chapter 6, the need to travel when in pain tainted his enjoyment towards the end of the program. This reinforces the need to make it as easy as possible for people affected by cancer to participate in wellbeing programs.

Most participants were reminded at the start of the first few sessions that they did not have to remember anything about the story – I would not be testing their comprehension. At the end of the first couple of sessions, M17 wrote down the names of the stories we had read together. I initially thought that was because she had enjoyed them so much, but in fact she was anticipating that I would ask her what we had read at a subsequent session, and she knew

she would not remember the titles from one week to the next. By session three, she had stopped writing down titles and was more relaxed: “I could just sit, I didn't have to do any of the reading myself”. She had chosen to have her reading sessions at a nearby UniSA campus, and so a room near the public library was always booked so our reading location would be easy to find by someone external to the university. I always waited for her outside the nominated building, as the room booked could vary according to availability and I wanted to keep participant burden as low as possible. Her daughter suggested that was part of the appeal to her mum: “probably the relaxing part, that she could just go and not have to worry about anything and be read to”.

The lack of expectations around both what was required during reading sessions and not being obliged to travel were important:

> To have an interaction where there's no … nothing is needed from that person, it's just presence, whereas often, people who have life-challenging situations or illness, it's a medical appointment, it's a this, or tell me, or this and that - there was nothing that was needed. It was just pure presence. (R8)

For R12, this lack of expectations allowed her to relax and enjoy the stories in a way she had not expected:

> When we started, I was very appreciative of you saying, I won't ask you any questions, there'll be no onus on you to recall anything or remember anything. So it allowed me to relax and really visualise, really make pictures in my head about what you were reading.

The absence of placing expectations on participants, such as allowing them to choose to discuss stories or to simply listen, was also a feature of Robinson’s (2008) study with neurological patients, some of whom also experienced physical and cognitive (including speech) difficulties, and was in direct contrast to the SR model that prompted his research but nevertheless showed benefit to the patients involved.

Personalised

The personalisation was really appreciated by participants: one-to-one reading sessions, reading locations chosen to suit them, and the paramount personalisation of reading material chosen especially for them. Adjustments made for individuals in the delivery of the stories, “actually live person, reading to you at a pace which kind of is adjusted to a specific person” (M8), was also important. The specifics of this were encapsulated well by M8:

> And also, I think that the reader, you as a reader, if you see, you actually see my reaction, that means you adjust the pitch, the speed, and whatever, the reading itself, to what you see, maybe consciously, maybe subconsciously, but you adjust the performance to the audience, to some extent, so which audio can’t … If I would be

> too tired, asleep, yes, so maybe raise your voice a little bit or ask me a question or something like that yeah. So what is means is that's all the difference.

Throughout the sessions, participants were monitored for reactions so their impressions of stories could be gauged, as well as obvious fatigue or pain.

While reading, I shared the humour with participants. A number of participants and I had similar senses of humour, for instance R4 and I would often laugh our way through any humorous stories I had chosen for her. During her interview, she referred to her own laughter: "I thought I'll, you know, I'll mute myself because I'd be distracting you and then I realise, well no, it's better for you to know, to have that interaction from your side as well rather than me just sitting there mutely" (R4).

When considering the concept of a personalised program, M8 described it in some depth in his interview, so it clearly resonated with him, and he spoke as though he appreciated both the way in which the stories were chosen, and the thought given to expanding upon the reading habits information supplied at enrolment time:

> The personalisation is also in that we had a few chats and about literature and stuff. And that, I'm ready to bet, that influenced your choice of actually readings … So that means that that's another aspect of it, that after one or two sessions, the reader actually adjusts the reading to what I would say the 'readee' … interesting, because there are stories I may never come across, if I would be just seeking stuff somewhere on audiobooks. So what that means is that you brought in some new perspectives, and some fresh stuff ... if you have a very depressed person, try to find actually stories the person can relate to. As you did with me, and so as you found some funny stories … So it is a personalisation aspect which, and human contact, which is increasingly important in this kind of cool, technocratic society.

This modern-day utilisation of technology instead of human interaction (that M8 referred to) is done for efficiency, but at the cost of human contact and empathy, even though it is known patients treated with kindness and empathy have better outcomes and higher recovery rates (Institute of Health and Nursing Australia (IHNA), 2022). The one-to-one contact in this intervention gave participants the gifts of kindness, empathy and time – time for someone to tend to their emotional needs, to nurture them, to make them (and their reading choices) feel important and valued. This was a recurring theme mentioned by participants. R8 said it beautifully:

> To me, it's like a gift. Because you're taking the time. So we're obviously creating time for ourselves to do so … it's a beautiful gift to be given ... not only to feel relaxed, but to go into another world and it's beautiful.

This idea of a connection between people who share a story read aloud and the gift that is, is echoed in other studies. For instance, a participant in a study by Duncan (2015) said "it feels

as if you are being given a bit of a gift, I think, when somebody reads to you. They are giving you time, they're acknowledging you and giving you something quite special really" (p. 89). Other participants in that study spoke of reading aloud as a way to simply be present with another person, and for establishing and sharing a bond. The time to simply let one's mind wander from current stresses can also be a gift. It seems all the creative therapies allow the time and space for letting this happen, which is perhaps necessary for the therapeutic benefits to occur; while other integrative oncology approaches, for instance meditation, yoga, tai chi and massage, directly target both mind and body (Ben-Ari, 2022; Gentile et al., 2020; Melbourne Integrative Oncology Group, 2023).

Further to the concept of the gift of time, it was important to always have time to chat about a story if participants wanted to, and almost all wanted to. Likewise, it was important to not rush into and out of sessions, but to allow the participants to talk about the stories, things the stories reminded them of, or to talk about what was coming up in their week if they wanted to. It was also important to sense, according to participant fatigue or liveliness, when to conclude the session. This allowed the session to finish on a natural high and added to the feeling of being cared for, which was important for emotional wellbeing, and was another aspect of personalisation.

The personalised delivery was beneficial in making participants feel valued:

> I think it becomes, for me, it felt more personal. So it wasn't like a … you know, you weren't reading to a group. It was just me you were reading to, so I think, you know, that made me feel, it's another word that I'm not going to be able to think of, maybe important or valued. (R11)

Aside from the notion of feeling more valued as the person receiving the gift of time and the benefit of the story, there were issues around the ability to be more relaxed with nobody else there to observe them:

> And I didn't have to worry about, you know, other people and how, you know, I might react to a particular maybe part of the book that you might have, you know, read - there was a couple of funny ones there where I had a bit of a giggle. You know, maybe if there were other people around, I might be more aware if there were other people around whereas I didn't need to be, I didn't need to think about my surroundings. I just, I could just listen to the story. (R11)

When looking at studies of many modern bibliotherapy initiatives, especially the popular SR program, one of the key positive aspects of such programs is reportedly found in the interaction of the group when responding to facilitator prompts about the text, even to the extent of repeating, almost or completely verbatim, another participant's comments (Dowrick et al., 2012). Contrastingly, comments from participants in this study emphasised the value

they placed on the intervention not being a group activity, which is consistent with Semple et al. (2006) findings that cancer patients prefer individual programs. This aspect of the program design clearly meant a lot to many participants and two participants explained its importance to them: “it makes a huge difference because it’s a person who's interested in you and they're focusing on you and caring for you, and doing something special for you, and it's really a lovely thing” (M13) and “I think that’s probably the essence of it all, that you would come to my home, you would care enough, [indecipherable], that you would do that for me [indecipherable – teary and upset]” (M15). The philosophy and science of caring was considered central to Jean Watson, who developed her Theory of Human Caring in the 1970s, which is still considered at the core of nursing (Watson, 2008). Her theory was built on ten “carative” factors (Watson, 2008, p. 32) and the tenets most relevant for the delivery of this intervention were loving kindness, nurturing, authentic listening, balance (addressing individual needs), minister (emotional needs) and open (to mystery and miracles – after all, anything is possible with stories) (Sitzman & Watson, 2014). That participants felt cared for through the experience of sharing stories is not a new emotion in the reading space: "One of the most important aspects of reading aloud to the hospitalized child is his knowledge that someone who cares about him is near - someone who cares enough about him to share a book" (Anderson, 1992, p. 47).

Family members also appreciated the personalisation, with regards to the ease of participation and an appreciation of a thorough assessment of appropriate reading material for their loved one. For example, M5’s spouse valued the choice of venues and opportunity for participant input when choosing reading material:

> I think you went to quite a bit of effort for it to happen in an appropriate place. We suggested Burnside Library and you phoned back quickly and had it sorted out. Organisation – you were organised and assessed his reactions to stories; choice of stories.

When I asked her if she thought her husband’s reading interests had been catered for, she replied: “I think so, he was quite happy and *very* happy when asked for his feedback and suggestions”. That families noticed the personalisation of the reading program adds to our knowledge of their perception of it and how it influenced their loved ones and supports RQ2.

Recommended situations

Participants’ own enjoyment of the program led them to believe it would be valuable for others. Twenty-two participants reflected on their own experience of the reading program and made recommendations for future uses of the program. The general consensus amongst those

who had finished the bulk of their treatment, was that the program would be most beneficial to those currently receiving treatment, especially chemotherapy and radiotherapy: "earlier might have even been better - when you're in treatment" (M15). This is in direct contrast to bibliotherapy studies of a didactic nature in a cancer context: Angell et al. (2003), with their workbook-journal intervention based on supportive-expressive group therapy principles, found their program would be better suited to patients nearing treatment completion, while Keenan (2021) with her book-based acceptance and commitment therapy (ACT) intervention, found her intervention would be better suited to people who have completed treatment.

Some participants felt reading during chemotherapy infusions would be ideal, which is something I also saw as a potential future application, and particularly relevant for RR cancer patients who come to the city alone for treatment:

> Going to the chemo sessions … you're just sitting there for an hour, two hours. So yes, we talk or we just read, you know, to ourselves really. … but you could read to the person there … It'd also make the time fly too I think as well, because there is a lot of that, just waiting around. (M21's spouse)

R3 reiterated the idea of reading in the chemotherapy suite: "when you're sitting there for hours it would be lovely to have, you know, an hour of reading". The feedback from participants in the midst of active treatment (and associated side effects) about the value of distraction at this time (refer section 5.3.5), lends weight to the idea of the most beneficial timing for the program being during active treatment.

"For people that are going through a similar thing with cancer treatment, especially older people who don't have other people in their lives" (R11) was an interesting recommendation when considering three-quarters of participants did not live alone, but still claimed to have benefitted from the intervention. In today's society, with our acknowledged loneliness pandemic (Demarinis, 2020; Ending Loneliness Together, 2023), it is not only older people who might not have others in their lives. This is consistent with this program being appreciated by all participants regardless of their living arrangements. In R14's enthusiastic words: "I really hope that this becomes part of people's recovery because it'll bloody well help them for sure".

5.3.4 Value of Human Interaction

"Just to listen, and to immerse yourself in a world … it was also nice to share the humour response with you too. Yeah, that you were obviously enjoying reading to me." (R8)

Table 5.4

Value of Human Interaction Sub-themes and Codes

Theme	Sub-theme	Codes
Value of human interaction	Companionship	• Company • Connection with a person • Human presence – in general
	Story discussion	• Discuss stories
	Human presence valued by family members	• Family – allowed time away from carer's role • Family pleased that loved one is getting some pleasure or help or company • Other family reactions
	Personal qualities of the reader	• Enjoyed voice of the reader • Personality and warmth • Flexibility • Pets tolerance

The value of human interaction included four sub-themes, presented in Table 5.4, and described below.

Companionship

Although company was undeniably important for some participants, that indefinable sense of *connecting* with someone was significant to participants considering the value of human interaction. Connecting with the reader was mentioned as a program highlight in most participant interviews. Participants repeatedly spoke of the value of human connection: the value they placed on feeling important/valued/worthwhile because someone was taking the time and making the effort to come and read to them and connect with them – individually. The significance of connecting with others is omnipresent in programs targeting loneliness, and the idea of connecting through books or libraries is a theme across studies undertaken by perceptive library services and the UK reading organisations. It is not just participants in this study who have placed value on connecting with another person. Umberto is a 92-year-old member of Yarra Plenty Regional Libraries (YPRL) in Victoria, and he said: "At 92, I live

each day one by one, because you never know what to expect, but I am always telling everyone, 'Go to the library, it is where you learn and it saved my life'" (Stella, 2022, para. 21). YPRL CEO, Jane Cowell, added: "Simply put, Libraries Change Lives as they provide an inclusive forum and support for expression, creativity and cultural identity no matter which postcode you come from. And they provide a place where human connection is promoted which saves lives" (Stella, 2022, para. 21).

For participants living alone, some of them expressed an appreciation of the interaction with respect to spending time with someone. For example, "Well, I live on my own, so of course, somebody coming is always great" (M15) and "(I felt) cared for. It's like that, because I live alone, it was like a nurturing for me" (R6). Three quarters of participants lived with family, so there was no overall sense of craving company across the group that motivated them to participate, which illustrates this valuing of human connection even more poignantly, that is, there was no sense that participants took part simply because they were lonely and wanted some company. As humans, we value connections with other caring people (Watson, 2008). As mature individuals, we know intrinsically that we cannot get all our needs met by the same individuals (i.e., family simply do not always meet all our emotional needs), so "Having active conversation, you know, friendliness, coming in, and a conversation then reading" (M9) was also important to participants living with family. The interviews demonstrated that although company was important, genuine connection with a person (not just company for the sake of not being alone) was highlighted as most important.

Having cancer can leave a person "a bit socially isolated at times" (M4), which was heightened by COVID-19 and the physical distancing required, particularly by immune-compromised people such as those undergoing cancer treatment. This meant "the fact that you know someone's coming and spending time with you" (M1) took on even more meaning. One interstate participant had been living apart from her family, although under the same roof, to try and avoid exposure to COVID-19. Participation in the reading program led her to realise that she did not need to feel so isolated and could connect with friends over Zoom like she had been connecting with me:

> I really enjoyed the social contact ... I think because I'm in a space where I'm isolated to a degree because of the pandemic, and not wanting to pick up influenza as well. So I've also thought on about that, maybe I need to start asking a friend every now and then, "can we do a Zoom call?", to try and fill that space. (R3)

The increased use of telehealth during the pandemic had obvious benefits, but it was also to the detriment of personal contact, which is generally considered necessary to feeling cared

for. M3's comments about this highlight the problem and the way the reading program filled a gap for her:

> And I think that is just about having someone actually, personally come in, rather than all the other bits and pieces I'm using, or strategies I'm using, to kind of get through, which is all things I can turn off ... throughout the whole process, I haven't actually had much personal contact. I've found that my care team have been quite standoffish anyway. So I haven't actually seen a nurse or, apart from a doctor every now and again, I haven't actually seen anyone personally, so I think this has just provided a bit of personal contact.

Other comments affirmed the value of human presence in the reading program, and these comments were for both in-person and Zoom delivery. For R15, the reading program made a huge difference to her day on a number of occasions, and so she "looked forward to having you come, I'm thinking, how can I make you come a bit more?" which resulted from a combination of in-person delivery, the personal qualities of the reader and the story selection. For many participants, the program was a release, some escapism, and a reminder of the joy of reading.

Participants' comments demonstrate the value placed on companionship rather than just company. It is useful to clarify these terms, as I have used *company* in the sense of casually spend time together, whereas I have used c*ompanionship* to imply a closer relationship – a connection or feeling of closeness - which did transpire from sharing stories together. The one-on-one nature of the program meant that closeness was fostered quickly as we shared reactions to stories. This meant some participants placed enormous value on our reading sessions and were upset at the program ending, which will be discussed in more detail in section 6.1. This further illustrates the psychosocial impact of the program in participants' lives.

Story discussion

Discussing the stories was not an expectation placed on participants. However, I routinely asked participants if they enjoyed a story, especially on the occasions when their facial expression left me wondering (which was the case with a few participants). It was important to understand their level of enjoyment, because the choice of reading material was participant-led. Additionally, given the vast majority of participants wanted the reading material to be chosen for them, it was vital to understand their preferences and reactions. On those occasions when I suspected a participant may have missed a twist in a story (generally suspected from a lack of reaction), I gently recapped the twist, using phrases like, "wasn't that unexpected when …?" This is an important skill for future readers, so that these types of

comments are not intrusive, not pointing out any inadequacy they may be feeling from fatigue or CRCI, but instead serve to add to the experience by helping them understand the plot if they missed a bit – the intention being to add to their enjoyment which must have worked because nobody indicated any intrusive questioning about the stories in their interview responses.

About a third of participants mentioned enjoying discussing the stories during their interviews. Many contrasted the opportunity to read together then discuss stories with listening to audiobooks, which will be examined in section 6.6. Participants valued the opportunity to chat about the stories or unpack storylines. M5 told me that chatting about the story was a highlight of the reading program for him, even though those 'chats' were done via his 'etch-a-sketch' because he did not have a larynx: "better than reading solo because of the ability to discuss the reading content with someone else". Similarly, M24 was an avid reader prior to her treatment and had been struggling with reading since shortly after commencing her chemotherapy, with this struggle continuing into her radiotherapy, yet she enjoyed the opportunity to discuss the stories with me as a way of re-engaging with stories and reigniting her passion for reading:

> I liked being read to by somebody in the room that you can then discuss what it is you've read with that person. And they can then give you another, different, an added insight into what they saw in the story as well as what you were already thinking. … And I think there's just from that whole, I mean, there's the whole aspect of being able to discuss it with you afterwards. I enjoyed that. (M24)

Another previously avid reader, R3, enjoyed "delving into" the stories with me after hearing them, and many participants enjoyed hearing my brief introductions to stories, which generally just consisted of the title, author, sometimes why I had chosen that story for them, and sometimes some details about the setting, including the era if relevant (especially if it was set in a bygone Australian era, or used older language like P.G. Wodehouse's language, or contained names of foreign places that I could only pronounce as best I could). One of my interstate participants, who was a problem-solver by nature, loved stories that gave him the opportunity to try and puzzle out the plots, and he found that these discussions were the way he experienced additional comfort from our sessions: "to think that we were going to discuss it a little bit before and then sometimes afterwards. Yes, that certainly provides a feeling of warmth" (R16). During intervention sessions, we became a reading community of two. Although our reading environment was different, the feeling of community was nevertheless reminiscent of Australian academic, Rose Michael's comments about "the sense of

community that coalesces around bookstores and the connection between people books can be a conduit for" (Michael, 2023, para. 5).

Human presence valued by family members

Although family members did not experience the program for themselves, which was not through deliberate exclusion but rather just as a result of the nature of the program (i.e., there was no need or expectation for family members to be present and it afforded them the opportunity to be otherwise engaged in their own activities knowing their loved one was being cared for), they did express understanding of the effects of human connection on their loved ones. "The social bit, ah, the fact that it made her feel better after the reading, more relaxed and that" (M4's spouse); "interaction with people for (R5) is one of the most valuable things" (R5's spouse); and "having someone here with him and doing something for him here" (M6's spouse) are examples of family member comments about valuing a human presence, noting these comments came from both metropolitan and RR family members, including some of whom had family receiving the intervention over Zoom. From the perception of families, in response to RQ2, we see they believed their loved ones experienced positive psychosocial effects as a result of participating in the reading program.

The reading program was a positive experience for family members in a variety of ways. Some family members were comforted:

> So knowing that there was just this option of something that was just for her, to be read to, you know, just a moment where she didn't have to think about anything else, anyone else, or be burdened by anything was really, yep, that was comforting for me. (M13's family member)

While others felt relief: "It made me feel relieved that she found something to do that she enjoyed and that she was doing it for herself and actually relaxing. She doesn't do that very often" (M17's family member), and increased mood themselves: "Well, anything that makes her lift her spirits, a bit, always makes me feel a lot more positive" (M20's spouse). Family comments were overwhelmingly of the nature that they were happy knowing their loved one was happy, and this comment from R5's spouse is typical of those received: "Anything that's good for (R5) is good for me, and makes me feel positive."

For those who filled a carer role in the lives of their family member with cancer, the time their loved one spent in the intervention was time they could have some respite from their role, and some time for themselves. This was seen in interviews with a number of spouses. Sometimes they appreciated the time to themselves, as with M6's spouse: "Well, I just was able to get on with the things that I needed to do, and probably, or wanted to do"; and R5's

spouse “it just for a period took away my need to be constantly on duty. And that's so, it’s valuable not just for the person being read to”, while others could indulge in hobbies (like watching the motor sports on television – M1's spouse) or simply having a nap (M22’s spouse). We know caregivers also suffer distress (Linden et al., 2012; Zabora et al., 2001), so the ability to provide comfort or respite is immense and supports the hypothesis.

Personal qualities of the reader

The quality of the interaction between the participant and the reader was vitally important. In order for that all-important connection with the reader, which was mentioned repeatedly by participants (as we saw above) a rapport had to exist between us, and thus the personal qualities of the reader were crucial.

The warmth and personality of the reader was important to participants: “a friendly person” (M9) or “a person who's interested in you and they're focusing on you and caring for you” (M13) were important, while “you're a lovely person to talk to” (M21) and the ultimate praise for warmth of personality, “You're a special soul, Liz” (R8) all show the significance of a caring personality. M16 said, “you've been wonderful”. Many participants (both in-person and via Zoom) commented on the value of sharing the emotion in stories; that together we could “laugh at certain things in a book, or to express a sadness about certain stories” (R5).

R6’s social anxiety meant “there are times when, you know, you want to run away and hide and you don't feel safe. But I haven't felt that at all” and she went on to confide “I must have felt that rapport with you. Even when you first came, I didn't want to run away”. Comments made during interviews show that it was important to the participants and thus the success of the program, that the reader had a personality that put them at ease and allowed them to feel comfortable and relaxed. This was reiterated by R12 who was very conscious of her ongoing CRCI, which affected her word-finding during conversations, and yet she enjoyed our pre- and post-reading conversations and was unconcerned about her perceived slowness when speaking with me. Giving participants the time and space they needed to speak was obviously important and effective: “the conversations that we've had before, after have been just so enjoyable. … I don't care about speaking slowly to you or waiting for words because I know you understand” (R12).

Some participants, both metropolitan and RR, both male and female, when asked what they enjoyed *most* about the reading program, said it was “you”, referring to me, the reader. This was expressed by R8’s words: “I think what has been lovely, is the connection we've

fostered." It was easy to build connections with most of the participants. Even though they were going through some terrible things, they were receptive to sharing stories, and for them, having a calm, empathetic person appearing weekly, made a difference, as R15 said:

> I looked forward to you coming. I looked forward to whatever you were reading to me. You're a very relaxing person to be with. You've got a lovely personality and you're always smiling … You always smile and that is so important. It costs you nothing to smile. You know, you use more muscles frowning than you do smiling. Researcher: I've read that. ...I read a book once (both laughing) and it said (laughing) R15: See look, you know, the smile's there. It changes the whole atmosphere in the house.

The quality of the reader's voice was also important. Participants expressed this in a number of ways, for instance:

> Well, it's a bit like touch isn't it, you know, human touch? And especially tone, you know, like … the spoken word … Like if somebody's saying something to you, it's the tone and all of that, that … that you take from it: calm and peace and tranquillity and, and all of that, that makes you feel good within yourself. (R10)

Being "a good reader" (M7) was necessary to hold the participants' attention and interest; as M6 said, there is "an art to reading". Other voice qualities that were important to people were speaking clearly, using intonation and inflection, managing names from different nationalities, being expressive and altering the speed (and sometimes volume) for my audience: "The way you read the stories … was the most enjoyable thing. The way you put intonation and made the story come alive" (M13). The speed was especially relevant to those with severe CRCI, like R12, who said the reader's voice was "Absolutely easy to listen to - clear and slow enough for me to process."

As noted in section 5.2, there was one participant who expressed negative feedback about my voice at the mid-point survey and provided an impromptu voice coaching session. During her interview, it was anticipated she would raise this as a problem again, but instead she was effusive in her praise of the program, and only made this comment about my voice:

> I think the thing that I didn't enjoy in the first one was the problem which I told you about. And you corrected, was the, you know that the nasal tone can become penetrating and annoying and you, you dealt with it. So I think that was very good. You got 10 out of 10 for thinking about that. (R5)

In the interviews, participants said the personal qualities of the reader should include a warm personality and an appropriate level of reading aloud skills. These personal qualities echo the teachings of Arleen McCarty Hynes (who established a biblio/poetry therapy training program at a hospital in Washington): those of empathy (and the ability to communicate it), ability to accurately perceive a participant's experience during a session, respectful, mature,

genuine, self-aware, adaptable, responsible and has integrity (McCarty Hynes & Hynes-Berry, 2011, pp. 94-103). The participants' experiences of the reader have been presented here; the reader's experience is described in Appendix L.

> "You've got a lovely clarity with your voice, Liz … Yeah, it's perfect, because, you know, your expression is there, and it flows and, yeah, you can picture the characters. So when you're reading to me, I'm picturing all of these things, just as I would be reading, but it's so lovely to hear *your* voice, and what comes through too and yeah. No, it's beautiful." (R8)

5.3.5 Value of Distraction and Escapism

> "If anyone needs the escapist magic of books right now, it's Laura."
> -Bridget Jones, *The Other Bridget* (Johns, 2024a, p. 45)

> "I think (it) gave me just a distraction from stuff that, all the stuff that's going on. So especially the last couple of weeks when I've felt a bit low. And just knowing that you're coming is like, yes, I've got, I've got something to look forward to, you know what I mean – it just gave a boost." (M24)

Table 5.5

Value of Distraction and Escapism Sub-themes and Codes

Theme	Sub-theme	Codes
Value of distraction and escapism	Escapism	• Distraction from cancer or other worries • Escapism – immersion in story
	Distraction effects continuing	• Anticipation – looking forward to sessions • Effects continuing outside session time • Conversation topic

The value of distraction and escapism included two sub-themes, presented in Table 5.5, and described below.

Escapism

During interviews, most participants indicated the distraction afforded them by the stories we read together provided relief from pain, treatment side effects, cancer worries and everyday worries. As we saw in Chapter 2, studies show reading can bring comfort to those in pain. Additionally, Brewster (2011) found in her study that informational content about the diagnosed condition can be too difficult to read when distressed, and reading for escapism can be a better choice. As M1 said, "What did I enjoy most? … The distraction and the stories". M1 started her chemotherapy just prior to our reading sessions commencing. She

had awful side effects to her treatment, some of which saw her back in hospital for a few days to manage them. Therefore, for her to experience distraction during the program (especially to the extent that she described it as the most enjoyable part of the intervention for her) is immensely important: “it's just, taking my attention off how I'm feeling and onto the stories, just washing over me, better than watching television frankly” and “if I was feeling a bit queasy which has been the case sometimes, it took my mind off it” (M1). Her spouse corroborated this with his comments: “I don't know what (laughing) expectations (M1) had, but I do know that she used to come away being much more relaxed, less affected by … all the horrible things that were happening to her body”. Like M1, M13’s comment in the mid-point survey reiterated the value of distraction: “I find it so relaxing … You can escape the reality of thinking about cancer all the time”. M3 also compared the escapism effects of reading to watching television, but found reading was superior:

> M3: I guess it's just the escapism for a bit, without I mean, I've been in bed for a long time, so I've watched enough television and Netflix to kill enough brain cells, so it's nice to be able to get that same distraction and escapism without having to watch television.
> Researcher: Nice. Can you think … do you think there's a bit of a distinction between the TV and the books?
> M3: Yeah, I feel like your brain switches off more. Well, I think for me... umm... I get, I guess a bit more relaxed with the reading because there's not so much stimulation.

Pain is a very personal experience. Observations during reading sessions led me to believe several participants were in chronic pain. Reading for distraction from pain was mentioned by some participants, but it was a huge part of R8’s experience:

> So after, a few weeks after radiation, where I was, you know, it was high end pain, I mean nine out of 10, or, initially 10 out of 10 pain. So it took a few, you know, three to four weeks, to really, starting to feel more myself. So when you were coming to me ... yeah, I was having regular, every four hour intervals, pain, pain management. So, there was one day ... I didn't take medication at the time I should have, and I was aware of it, but I was so comfortable. And so instead of focusing on pain, I was focusing on the story, and what you were sharing with me, so it became a lovely, pointed distraction, to take me away from pain. And yeah, and I think that, that is a wonderful benefit for anyone who's … has challenges in their life to, that's the beauty of the ... of what you're doing.

M8 was also going through chemotherapy during our time together. He spoke about the distractive value of our sessions: “it's something pleasant to look for, rather than be grumpy about the next cycle of chemo” (note English is a second language for M8, and whenever he said “look for” he meant “look forward to” - this was clarified in the interview). During a chemotherapy cycle, when side effects emerge following infusions, the drugs used to treat the

side effects can affect mood as well as the chemotherapy drugs themselves affecting mood (Kelly, 2023; Whitford et al., 2020). Studies show that the most reported cognitive complaints during chemotherapy are depressive symptoms, memory deficits and sleep problems (Palmer et al., 2020). Chemotherapy is tiring and can make it hard to get out of bed, but the anticipation of enjoying a pleasant reading session could make a difference:

> Get out of bed, backside up, as we say in my country … So actually, reading, it's something to look for, yeah. So get to the uni yeah. So, get this kind of session. It's quite useful. ... Oh, it's a good distraction; it's a good mood lifter, as I said, it's something to look for. (M8)

Once participants were part-way through the intervention and had enjoyed their sessions, they looked forward to repeat experiences, which was really important not only for study retention but also for improved mood. R14 vividly described how the distraction of the stories worked for him:

> I find, um, it's like you're in a movie because you're reading it to me, I find it more visual and descriptive in my brain. So I could, I can see the characters and it's like I'm watching it. So that's, for me, even more distracting than reading a book.

Yet R14 was not the only participant who spoke about the more imaginative and internally visual nature of the reading experience when listening to being read to. Visualising stories unfolding was a component of the experience, which only added to the escapism value of the story being read: "I was thinking too of the Jeffrey Archer one, visualising this, this little village and all the goings on with it. So yeah, it's not just passive in the sense I'm listening to the words - your brain's working on visualising" (R4). Others described similar experiences:

> So it allowed me to relax and really visualise, really make pictures in my head about what you were reading. It was almost like … ah, the pictures that I was getting was creating the story as much as the words you were reading. And as that went on, over the weeks, I then thought maybe I can learn to read differently, like more visually, than um about words. (R12)

Visualisation leading to distraction is a known phenomenon. A recent study used virtual reality (VR) to provide a visual and immersive experience (much like participants in this study described) to achieve pain relief for people with cancer (Groninger et al., 2024). The idea of visualisation and escapism providing a safe place away from anxiety is reminiscent of Neil Gaiman's (2013) words in section 2.1.1 about escaping into the sunshine and is another aspect of the impact of the reading program on emotional wellbeing. Participants expressed this well: "I can move out of a space and move into the book. So I can disidentify from what, you know, if I'm anxious then I can go into another nice safe place too" (R6).

The value of distraction and escapism through stories worked effectively on current and lapsed readers and non-readers alike. For instance, I introduced R7 to the Lee Child *Jack Reacher* series, and he noted that it was "something to take my mind off other things and 'oh, I wonder what Reacher is up to next?'" Some participants found the value of distraction started with their anticipation of the reading sessions. M24, for example, had just started chemotherapy when she enrolled in the program and she found the distraction and mood-boosting effects also existed outside of our reading sessions:

> I think it just took me away from my own. … took me out of thinking about what was going on for me. … I was struggling at the end of chemo. And then I'd struggled, the start of radiotherapy. And so this just gave me that, that hope, and something to, you know, be positive about. … It's not gonna, this week is not just going to be all "bleurr". That you're coming, and you're going to help me feel better, about myself and about life and the future and everything, you know, even though it's just us, you're just reading stories, it's not like we're having a counselling session (chuckling) but it just gives you that positive boost of "Yes! Yeah". Take your mind off what's really going on and focus on something else.

Some participants linked the escapism directly to the experience of being read to: "I felt by you reading to me was giving me permission to do nothing and just immerse myself in the story" (R14). This melding of themes – the value of program design (i.e., the reading aloud, individually, in-person with tailored reading material) and the value of escapism and distraction - show how interconnected the themes are and how important it was to get this right in order to have these positive effects on participants.

Distraction effects continuing

For some participants, the distractive effects of the stories were present only during the session (such as with M22: "when you're here and reading, I was focused on that") while for most others, the effects lingered, either through thinking about the stories outside of sessions or anticipating what we might read at our next session. The concept of anticipation, looking forward to sessions, was common. For instance, M6 described his experience: "Yeah, I used to look forward to it, it was an hour or so a week that was enjoyable, something to look forward to" and "leading up to it, I might wonder a little bit about what you'd chosen to read. And afterwards, I would certainly recall the stories". That participants looked forward to the reading sessions was noticed by family members: "it was something I looked forward to each week" (M1) which was reiterated by her spouse, "she was always looking forward to you coming". Among the participants who spoke of thinking about the stories outside of our reading time, was R17, who was so affected by enjoying fiction again after many years away from it, that her thoughts of the stories led her to her local library to search for books by the

same authors, and she did this because, “it does take you out of yourself and into that world that you’re ummm, you’re reproducing for me through the book. And it’s a nice distraction”. Looking forward to sessions was common, as was wondering what we were going to read next. While participants were looking forward to sessions and thinking about stories, they were less focussed on worries, illness and pain.

For some participants, the anticipation was for time out each week:

> The fact that it was an hour out of life. You just stop your life. Stop being on a roundabout. You go round, round, round and for an hour we got off the roundabout, sat on the grass and did something else (chuckling) … I knew that there was that hour each week put aside for that. So, it's not a goal thing, but you know that it's coming, you know, so I've looked forward to it. (M18)

While for other participants, the anticipation centred around both my visit and thoughts of what we might read together:

> I've looked forward to having you come, I’m thinking, how can I make you come a bit more? … my anticipation of what you were going to bring the next week kept me thinking about different authors or different stories I'd read, you know, like the surprise that you brought in the book that day, that was my husband's favourite … Jeffrey Archer. There's no way on earth I would have thought you'd bring that book for me. Because that was my husband, my late husband's book, author. And when you, I actually enjoyed it. … I looked forward to you coming. I looked forward to whatever you were reading to me … I think, “Are we going to have a romantic one, like the train ride one or? (laughing)” (R15)

Many participants spoke about the lingering effects from immersing themselves in the stories. These persisting effects were described in a number of ways, but they stemmed from thinking and talking about the stories, especially their favourites:

> I've recounted the story. That 100-year-old story, half of the world knows that and how good that it was. And often do recount some of the short stories to friends. So yeah, that did bring a positivity outside of the reading time. (M13)

The length of time the effects lasted varied: “At times, two or three days later, I'd try and remember back: how did that story end?” (M7); “For the rest of the day, and, you know, even into the following day, but it's not just a fleeting feeling” (R10); while R5’s spouse, a music therapist, said:

> The thing about music and stories and the arts is that they don't just last for the period it's actually happening. It lasts for days, weeks, months afterwards. … The effect that you had was much longer than just the period of interaction. That's the value. … it doesn't stay with you just for the reading. It stays with you in the thinking process.

For a number of participants, a cancer diagnosis was not the only challenge they were facing. Some were facing other huge issues in their lives, and yet still found value and comfort from our reading sessions, especially via the mechanisms of descriptive language and humour:

> Like good escape stories, you know, that, and just good, fun stories as well. So yeah, I think they were a good distraction, because I could just, for a whole hour, I could just totally switch off from everything. And because, you know, not only am I going through the recovery of cancer, I'm also going through the process of grieving. You know, the death of my father, and dealing with the estate and helping my mum and all of that. So for me, this was like an hour where I could just walk away from everything. Not just the cancer, but everything, I could just come here, switch off, and escape everything, and just immerse myself completely in the stories. And I did – I did completely immerse myself in those stories. And you know, those two stories in particular, was the dog with the explosion (chuckling) the explosives and *Yellow Jacket Jock*, particularly those two, where I could just, you know, picture myself there and seeing these things happening. You know, these Australian larrikin yarn-type stories. (R10)

Comfort and distraction were urgent needs identified by the recent Australian integrative oncology white paper (McDonald et al., 2022, p. 5), yet both were experienced by participants in this study. The role of humour in distraction did not go undetected by participants either:

> The Michael Caine book made me laugh. And when you're concentrating on a book and you're taking in what somebody else is telling you about their life, then you're not thinking about your own life. It's, you're completely coming out of your life and stepping into somebody else's. So all the problems in your own life are not there for a while. (M18)

Likewise, when personal interests and humorous stories intersected, that seemed to be a very effective combination:

> For some reason, because I'm a mad keen fisherman, I've thought about the barramundi, because it was so short and so funny and so Australian. I love those. I love those. Those stories have appealed to me since I was a kid. (R14)

It is worth noting that R14 was still talking about the barramundi story weeks later.

Some participants still worked part-time or even full-time, and some were also still raising their families while coping with their cancer treatments and work schedules. It is not hard to imagine how difficult that must have been, yet the stories provided enchantment for them too, including beyond session times:

> It was a good distraction from, you know, the treatment, but also away from everything else that I've got going on in my life as well (chuckling). So it really did make me stop thinking about work or, you know, school pickups, drop offs, you know, dinner, what's for dinner, like it really did actually make me focus on and listen to the books. (R11)

Family members reiterated this: “it helped her obviously relax and get some sleep and … I think just to, you know, another outlet to distract her from what she's been going through in life. I think, you know, it's definitely helped” (R11’s spouse).

Almost all participants noted the value of distraction, from R8's simple observation: "just to listen, and to immerse yourself in a world ... and I loved the books you selected"; to R4's direct association between health-related discomfort and the benefits of reading, "sometimes I was tired, other times I'd be in pain, or you know, there'd be issues, health issues and they just went because I was sitting back enjoying things. … it was a tonic".

A cancer diagnosis is often accompanied by fear and anxiety (Aldaz et al., 2017), yet a number of participants spoke of the way the stories distracted them specifically from these things, for instance: "I think it gave me a space in which I wasn't thinking about myself. And worrying. So that was a nice little digression from concerns" (R5); and "If you're focused on the story, and you're enjoying the story … I suppose it takes you away from feeling the pain or feeling anxiety" (M19). Anxiety or fear was mentioned by participants with both early and advanced stage cancer. Among people who have experienced a cancer diagnosis, 33% to 96% experience fear of recurrence or progression (Koch et al., 2013, para. 3) and for many, this fear never goes away (Koch et al., 2013) therefore it must be managed. Along with participants' comments about the reading distracting them from what was happening with their bodies, the researcher can attest to these fears and the role of reading for distraction from them. Among the participants, R6 described this distraction from fear of recurrence perfectly:

> You're present. You're in the moment. So you're not worried about … like I worry about it - is this pain happening again, because of, you know, is it going to present itself again, because of? When you're here, I'm concentrating on what you're saying, what you're reading, rather than getting into the fear.

Escapism and immersion in the stories we read was a recurring theme in interviews, including with families noticing the way the stories provided a distraction too: "I think it put her in a different state of mind for a while … Takes her mind off things" (M4's spouse); "the escape from everything else going on in her mind … just that release, and that, you know, a small opportunity to help recharge the batteries and focus on something else" (R11's spouse); and M17's daughter felt the distractive value of the stories was directly responsible for her mother's improved mood:

> I think before, she was really … a bit glum about everything … And then she found the reading program and then she picked up a little bit. You know, always talking about that, and she's like, "I look forward to being read to - it's something that I can distract myself with, from other things that are happening."

The value placed on the distraction of loved ones undergoing cancer treatment, as a way to relieve some of their emotional distress or treatment side effects, was commonly mentioned in family interviews and clearly important.

Participants spoke of the distraction from pain, treatment side effects and anxiety. All these comments add to the evidence of positive psychosocial effects before, during and after reading sessions. Nobody indicated that they dreaded the sessions or were unhappy or bored during them. Equally, nobody expressed ambivalence. Aside from the reading recommended to distract patients stuck in hospitals of yesteryear (as discussed in Chapter 2 and so poignantly expressed as to "relieve his mind from his malady and worries" (Peterson-Delaney, 1938, p. 305)), reading for escapism has emerged as a key theme in some recent bibliotherapy research, albeit not in a cancer context, for instance Brewster (2011), Brewster (2016), Usherwood and Toyne (2002), and Pettersson (2023). Brewster (2011) noted "participants did not always engage with emotions via their reading, and instead they used literature to escape from negative experiences" (p. 206), whereas Billington et al. (2010) found "the intense absorption was closer to meditation than 'escapism'" (p. 30). Participants in the current study also likened the escapist experience to meditation: "I tried to, yeah, imagine, it's like when I'm doing my meditation I try to focus and be present. It's like you're doing that, it's being present in the story" (M19). Radway (1983) studied rural female romance readers, and found their reading offered escapism and fantasy, which was needed when the readers' real life was a disappointment to them. Usherwood and Toyne (2002) found the experience of escapism occurs via three mechanisms: escape through active involvement in "another world", escape by association (for instance, an earlier time in their life or a familiar place) or escape via the aesthetic beauty of fiction (p. 36). Whatever the mechanism, escapism clearly has a positive role to play in the lives of people affected by cancer.

Also relevant to distraction and escapism are the Community Reading Workers in the Reading for Wellbeing (RfW) project in England, who support access to books (including audiobooks) for lapsed readers, disadvantaged communities and socially isolated people (especially in the wake of COVID-19 when some people were afraid to rejoin their communities), and they support people as they join book groups (Reading for Wellbeing, 2023). Research into the impact of the pilot program was positive and analysis of feedback from service users not only illustrated how the program positively influenced the important issues of loneliness, book-driven discussion and friendship, it also focused on the value of respite and escapism through reading (Sirisena et al., 2023). Although data is not available

from this study, a selection of participant comments appear on the Reading for Wellbeing website. It is not clear under what conditions these comments were collected, so they may be anecdotal, however one comment in particular mirrors those of the participants in this study: "something else to think about... instead of going to bed thinking of all the bad things that's happened you're thinking of the book and it just makes it so much easier to switch off from real life" (Reading for Wellbeing, 2023, para. 6). Their comment is included to show commonalities with other sources. Participants in this study experienced respite from physical and mental symptoms for varying periods of time around the reading sessions, and this supports the improved emotional wellbeing of RQ1 and also proclaims (along with the family comments) another positive psychosocial effect of the program from the perspectives of both participants and families in answer to RQ2.

In Chapter 2, bibliotherapy was paralleled alongside other arts therapies like art and music therapies. A cornerstone of both music and art therapy is distraction and escapism (Cabedo-Mas et al., 2021; Robb-Dover, 2021; Uttley et al., 2015) and our participants also spoke about the distraction and escapism produced by the reading sessions. Bibliotherapy's effects mirror the art and music therapy effects of decreased anxiety, depression and pain, improved mood and increased sleep (refer section 2.4.5). Additionally, the benefits of escapism and distraction arising from fiction's ability to draw readers into becoming emotionally invested in the stories (Broom & Wagner, 2023; W. J. Brown, 2015; Cohen, 2003; Oatley, 2012; Radford & Weston, 1975; Troscianko, 2018) could be a key to removing the focus on unpleasantness in life (for instance, a cancer diagnosis, treatment and side effects): "books are an escape, certainly; but for that reason they are also therapy for living" (Bayley, 1999, p. 23). To further support this, these positive effects were reported by our participants during their interviews.

> "I think, immersing yourself in the story so much; just the escaping. Escaping from what you're going through in the outside world, you know, just you can just take you away and relax, and you can just forget about everything else." (R10)

5.3.6 Effects on Cognition and Executive Functions - Concentration

"I've read about the chemo fog and all that sort of stuff, but I think it is quite real." (R13)

Table 5.6

Value of Effects on Cognition and Executive Function Codes

Theme	Sub-theme	Codes
Effects on cognition and executive function - concentration		• Concentration difficulties • Helping with concentration or understanding • Human presence effects on concentration

The theme of the effects on cognition and executive function (concentration) was generated from three codes, presented in Table 5.6, and described below.

Unsurprisingly, given 95% of participants reported experiencing concentration or memory problems typically associated with CRCI, these were issues repeatedly mentioned by participants of their own accord during interviews. Improving memory, concentration and executive functions was not the aim of this study, and therefore these were not assessed nor asked about during interviews. However, the fact that almost half the participants mentioned these issues during interviews illustrates how important they were and how they were impacting their lives. Participants commonly commented on memory and concentration; some also commented on language (typically word-finding ability during conversation which was also clearly a huge issue for my participant with aphasia).

Without prompting, the impact of cognitive and executive function difficulties on participants' lives was described during reading sessions and interviews in a variety of ways, but there were commonalities with their descriptions, relating to motivation, concentration and memory, summarised by these two comments:

> I had a really flat day. Physically – all I could do was roll about. (chuckling) And I thought "you could be reading"; "nup, you couldn't be". (M15)
> Because it, the motivation, just wasn't there? (Researcher)
> No motivation, no concentration to do it; no energy to do it. (M15)

> After my cancer treatment, especially, I noticed that, reading, even just newspaper articles or magazine articles, was something that I couldn't manage. … I just had this brain fog and this, this inability to concentrate … But even just flicking through a magazine was difficult for me, to even just flick through and look at, even just the images in a magazine. You know, it, that was hard for me to focus on as well really. (R10)

R10 was three years past her surgery and radiotherapy, but still on hormone therapy. These CRCI problems were still ongoing for her and impacting her QoL. This ongoing impact is consistent with de Ruiter et al. (2011) and Koppelmans et al. (2012) findings about the persistence of CRCI following breast cancer treatments. Towards the end of the intervention, she started choosing audiobooks from the library, and we discussed her choices, other suitable material and the willingness to choose another one if struggling with a selected story.

Some participants were searching for ways to improve both cognition and executive functions. Of the family members interviewed, 94% noticed CRCI in their loved one, with 6% saying they were unsure. No family members indicated an absence of CRCI. Generally, participants lacked an understanding of CRCI, and clearly had not received much guidance about it from their medical team, as seen in this comment by M1: “Why is it, that even for a reader, reading to yourself is more effort?” The participants who had treatments other than chemotherapy had not attributed their cognitive and executive function difficulties to CRCI. Although the read-aloud program was never intended to be an educational resource, the link between all treatment types and the potential for suffering CRCI was part of the usual speech I gave at cancer support group meetings as part of the recruitment drive. Discovering that all cancer treatments (and tumour growth itself) can lead to CRCI, gave several participants hope. For instance, M18 did not receive chemotherapy as part of her breast cancer treatment, but her lack of concentration and subsequent feeling that she could no longer perform her job to the same standard as prior to her diagnosis and treatment, made her retire early. She did not understand the potential cause of what she was experiencing:

> I didn't realise that cancer fog could be the result of radiotherapy and hormone tablets - I thought it was just for chemo. So once I'd learned that, and a lot of things fell into place about my own lack of concentration and lack of motivation and I could tie the two up, then I wanted to know how reading would affect it. (M18)

Numerous participants mentioned forcing themselves to concentrate during sessions, but said that was a positive experience for them because they were able to prove to themselves that they were able to concentrate for short periods in order to immerse themselves in the story. About half of the participants who mentioned concentration difficulties also mentioned a relationship between having a person reading to them in real time and improved concentration, as M7 said simply: “It contributed to me being attentive”. Participants overwhelmingly reported listening was easier than reading to themselves (refer section 5.3.3), and so the interconnectedness of listening as an easier process and the need for less concentration allowed participants, who were previously frustrated with their efforts to read,

to concentrate enough to listen to stories and be able to immerse themselves in them. For instance, M4 was surprised but pleased to find she could concentrate sufficiently this way to enjoy the stories: “I was a bit surprised that I was able to, and pleased … that I was able to focus on it and enough to concentrate on the story and enjoy it”. Steenberg (2016) also found that listening to texts read aloud encouraged and supported concentration. This shows the validity of the data collected around listening to stories as a way to reinstate the benefits of reading while experiencing CRCI.

Some participants drew a parallel between the presence of a person and bringing their focus back to the story we were sharing if it wandered away, as a sign of respect for the reader: “out of respect, you’re fully in tune and concentrating on what the reader is saying. Whereas with the audio, my mind does tend to wander” (M7). Others had a feeling of being a stakeholder in the shared experience:

> I guess with an audiobook, it's like, you switch it on and you listen, you switch it off, you know, sort of not that, you've got a human voice, but I'd have to probably go back and start listening to them to just sort of know that. I don't know. And I guess it's because - that's probably it, because you're humanly there, I'm invested. You're invested. So, if it was an audiobook, I might not be, I wouldn't be as invested. I might think, “Oh, I can't do this, because I need to do something else”, you know, or I just sort of listen because I want to get through the story and not because I'm taking “me time”, I guess. So that human investment seemed to be important. (R3)

Participants also shared the notion that having a person with them, whether in-person or via Zoom, meant they could not just stop the story if they got distracted (like they could with an audiobook). For instance, “ a live person who can interact so not just switch them off or on as you can do with an audiobook” (M8) and you cannot replay a real person like you can with an audiobook: “it's easier to go back because you can just replay the recording. … whereas with face-to-face, I have to be present because somebody is reading to me” (M19). Participants found it a sanctioned time to concentrate on a story, which they would not have done if the reader was not there with them:

> If you’d had said to me, “read this book for half an hour a week”, I would have just gone, “yeah, yeah fine, okay”, and I would not have done it. Because I just would not have put time aside to do it. It's a bit like exercise when you’re told “exercise” - so you stand in front of the TV. Do you do it? Well, no, not really. … And that's a bit the same with the reading, I think. If you just said find half an hour, I would never have got round to it. But the fact that you've come here, sat here, the phones have gone off, and we're actually concentrating for that hour. It's on my calendar. That's the time given over. … So I looked forward to the novelty of that, and for a shared past-time, with you, and taking an hour out of life to concentrate on something that was, not quite real, in a book, a story. (M18)

For M20, with aphasia, concentrating during our sessions together was an important part of her experience, as she found them great opportunities to practice listening and understanding: “Just being able to listen, when you were reading and like trying to understand ... what you were reading … I really enjoyed it” and she went on to explain: “Just being able to sit and relax and not have to try and worry about the words and stuff that I was doing”. These comments indicate the opportunity to concentrate without pressure (e.g., of responding to stories or during conversation). Her spouse valued the program for the contact it afforded his wife, and the opportunity it gave her for trying to concentrate and understand words without the effort of trying to read to herself, which she could not do at all at that time: “With understanding words again, and people when they're talking, and just understanding, you know, a book without having to concentrate too hard on actually reading it” (M20’s spouse). He was so pleased that she enjoyed the sessions, embracing the experience to practice listening, understanding and speaking as part of her recovery, which led to her feeling encouraged. Positive cognitive effects were also mentioned in M17’s daughter’s statement: “Her overall demeanour, I think, is a little bit different now. She's still just generally forgetful. But she's doing a lot better now. Which is great.”

Did the program improve participants’ concentration or memory? That was never a goal, and so it was not measured. I felt concern when sometimes participants (either at enrolment time or during reading sessions) expressed their belief that participating in the program would ‘fix’ their CRCI, and I always quickly dispelled that, reminding them of the study’s aim. Participants reporting that the reading intervention helped with their concentration is consistent with some other research findings: people suffering from depression attending SR groups reported improved “powers of concentration” (Billington et al., 2010, p. 81); reading increases neural connections (refer section 2.4.2); and it is also consistent with the message of the doctors who founded the Reach Out and Read program for children in the USA, stating reading to children improves cognitive development (Reach Out and Read, 2023). Many participants felt inspired to read for themselves towards the end of the program, which was fantastic, but is not proof of improved CRCI: “I've reconnected with the fact that I enjoy a book” (M18); “you've opened up my eyes to, just reading again, not my eyes, my heart to reading again … what I've enjoyed the most is just reigniting that passion for reading again” (R10).

As there was no follow-up with this study, we were unable to determine how many reconnected readers continued with their reading efforts. Even for those who may have tried but abandoned their reading again, a number of factors would be contributing, including but

not limited to, trying to read (visually) to themselves, which we know is potentially hampered when affected by CRCI, and choice of reading material. We read short stories together, which were manageable chunks, but towards the end of the program, some participants showed me novels, and not always uplifting, that they had chosen for themselves at the library based on the blurbs on the back cover. It would be great if library staff were trained to help choose material for people experiencing cognitive difficulties, and people affected by CRCI could ask for assistance.

"I noticed he didn't read yet he had always been an avid reader and he was forgetting things." (M5's spouse)

"And, you know, I have had to concentrate on the words. Yes, part of it has been concentration, but I think most of it has just been a relaxation." (R10)

5.4 Interplay Between Themes: Thematic Summation

The diagrams presented in this section visually summarise the qualitative findings.

Figure 5.1

Contributing Factors to Improved Participant Wellbeing

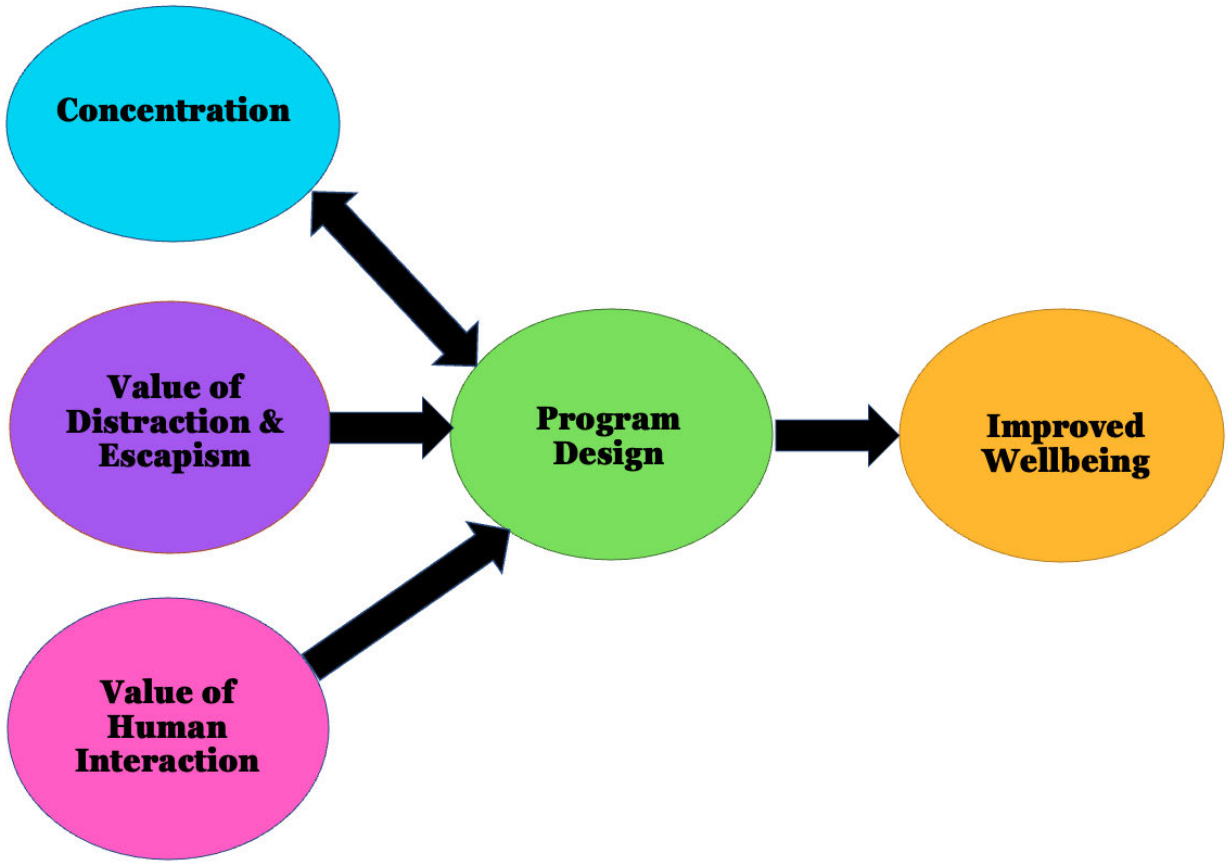


Figure 5.1 represents how improved wellbeing was arrived at: the value of distraction and escapism, coupled with the value of human interaction were considered intrinsic to the value of the program design (i.e., they fed into the program design), which produced improved wellbeing. It is possible to look across the themes and see each contributed to producing the positive outcomes described by participants.

In the diagram, concentration has a two-way relationship with the value of program design because some participants felt that the program enticed or forced them to concentrate (i.e., the reading program impacted concentration), while the choice of reading material and absence of comprehension tests catered for impaired concentration (i.e., concentration impacted the reading program). The program was designed as read-aloud rather than reading (visually) to oneself, to help ease the stress of concentrating while suffering CRCI, which is another aspect

of the concentration-program design link. Causality is not suggested between the reading program and changes to concentration, just that some level of concentration was required.

Figure 5.2
Relationships Between Key Themes

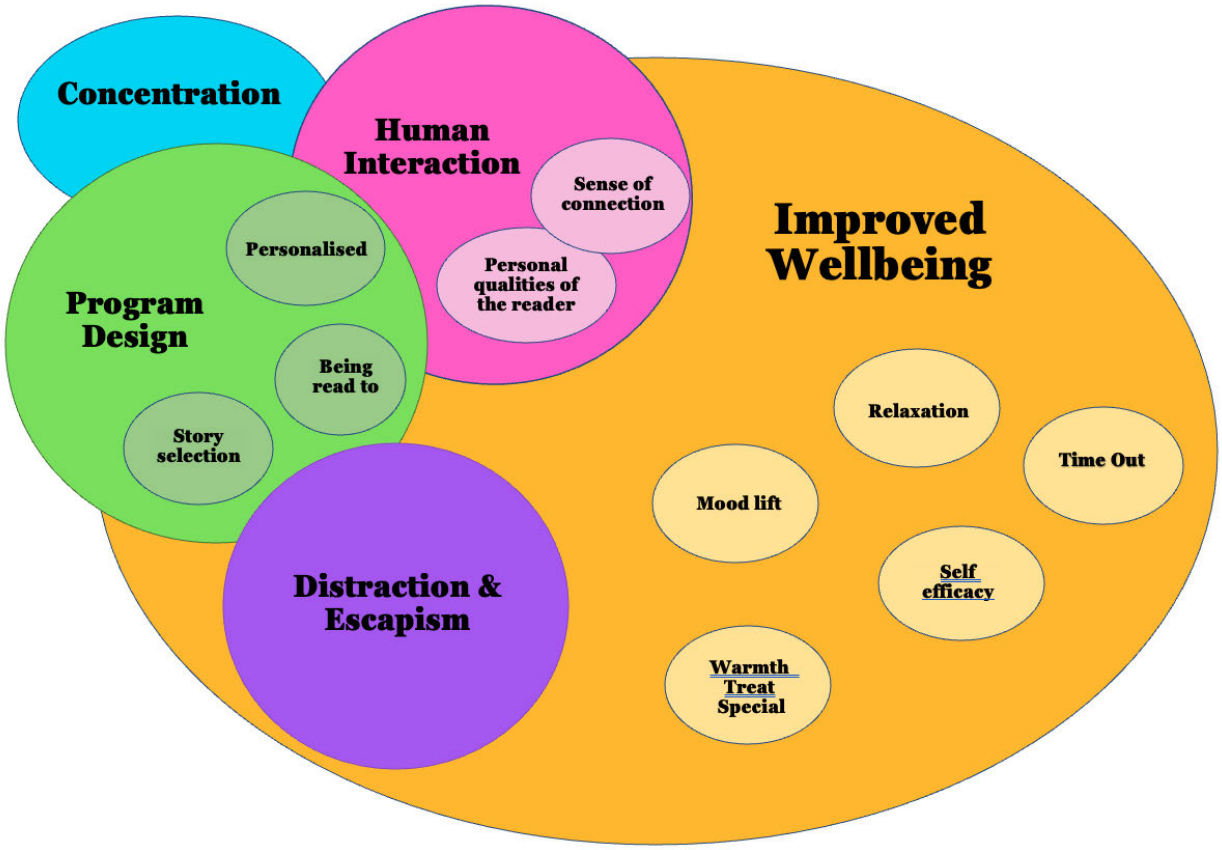


Figure 5.2 represents the relationship between the key themes as discussed by participants. Relaxation, mood lift, time out, self-efficacy and feelings of warmth/treat/special were the driving forces for improved feelings of wellbeing. Sitting completely in the domain of improved wellbeing, is the value of distraction and escapism, because this brought respite from thinking about cancer, cancer treatments, side effects and everyday worries, and resulted in improved mood. Improved mood was evident in observations and interviews, and can also be seen when looking at the results of the wellbeing instruments with reduced stress, anxiety and depression, and increased wellbeing. This will be discussed in Chapter 6.

In this diagram, the value participants placed on human interaction is also represented. During the interviews, participants reported that the in-person sessions could not compare to listening to an audiobook, for a variety of reasons, including the ability to adjust the delivery

for the individual, the opportunity for discussion about the stories and also the human experience of connecting with another person and often sharing a laugh together. This is discussed more in section 6.6.

The diagram shows an overlap between human interaction and concentration because even the ‘foggiest’ participants managed to concentrate, albeit sometimes with conscious effort, out of respect for the reader. However, the overlap between concentration and program design reflects the fact that concentration can be a struggle when impacted by CRCI, which is the very reason the program was listening rather than reading to oneself. Improving concentration was never a goal of the intervention, and thus it is external to improved wellbeing in the diagram.

Distraction/escapism overlaps with program design because of the conscious choice of fiction, narrative non-fiction and poetry in order to achieve distraction and escapism, yet it sits wholly within improved wellbeing because of its association with improved mood and reduced pain and nausea. The overlap between human interaction and program design is because of the choice of in-person reading rather than audiobooks, and the huge impact that had on participants, particularly with respect to valuing the warmth and other personal qualities of the reader, and the sense of connection with the reader. Ultimately, the program design (including delivery method and the qualities of the reader) produced distraction, escapism, enjoyment and something to look forward to. This in turn led to improved mood, increased self-efficacy for everyday activities and a sense of relaxation, all of which answer both research questions and support the hypothesis.

In this chapter, I have told the “analytic story” or “overall guiding story” (Braun & Clarke, 2023a, p. 13) of the participants’ experiences taking part in the intervention. The distraction and escapism participants experienced led to reduced feelings of pain, treatment side effects and worries, and thus were integral to improved wellbeing. This improved wellbeing addresses RQ1 regarding the impact of the program on emotional wellbeing, which was positive in all cases. The individual, face-to-face delivery of the reading sessions, coupled with the warmth of the reader, led to participants feeling nurtured and relaxed, with these feelings themselves linked to improved wellbeing. Family members were able to confirm these effects on their loved ones as well as share their own experiences of respite from their role as carer, or simply feeling comfort with the knowledge their loved one with cancer was being cared for, and this answers RQ2 regarding the psychosocial effects of the program from the perspective of cancer patients and their families.

The themes of program enjoyment, improved wellbeing, the value of program design, the value of human interaction, the value of distraction and escapism, and the effects on cognition and executive function (concentration) were generated from the interview data, and were consistent with the observations and mid-point surveys. This data triangulation promotes the credibility of these findings. The themes support the role of bibliotherapy for supporting emotional wellbeing in people with cancer. These themes will be integrated with the quantitative findings in the next chapter.

Chapter 6. Discussion

"She could not recall a time when reading had not been both a comfort and a refuge."
-Mary Bennet, *The Other Bennet Sister* (Hadlow, 2020, chap. 4)

With the problem of people undergoing cancer treatment frequently suffering CRCI, and with many unable to read effectively, thereby losing access to reading for boosting mood and alleviating loneliness and chronic pain (refer Chapter 2), the purposes of this study were to explore the effects of a tailored read-aloud program on the emotional wellbeing of participants and examine its psychosocial effects from the perspectives of both patients and families. This chapter draws together the findings from the quantitative and qualitative components of this study and examines them in relation to literature on bibliotherapy, CRCI, psycho-oncology and integrative cancer therapies (such as art and music therapies). This methodological triangulation, that is, the use of more than one method (in this case, quantitative and qualitative) strengthens the findings and invites a deeper understanding of the participants' experiences of the intervention, in addition to the effects of the intervention on the participants.

The findings presented in Chapter 4 and Chapter 5 individually support the hypothesis that the intervention was associated with improvements in emotional health and was a positive experience for all involved. Chapter 4 showed the intervention resulted in significant improvements in wellbeing symptoms pre- to post-intervention: reduced stress, anxiety and depression and increased wellbeing among participants following the intervention. However, when combined with the qualitative findings presented in Chapter 5, the themes of pleasure, relaxation, nurturing and escape from pain and the side effects of treatment, as well as the intervention being a way of providing comfort and respite to family members, the nature of the intervention's impact on the individual participants and their families is better understood.

There are no other studies of read-aloud programs for people affected by cancer, but the results of studies of poetry or workbook therapies, as well as art and music therapies, support the role of complementary therapies, including bibliotherapy, to improve emotional wellbeing during cancer treatment (Angell et al., 2003; Hammer et al., 2017; Jiang et al., 2020; Köhler et al., 2020; Körner et al., 2019; Krebber et al., 2016; Monti et al., 2006; Roberts et al., 2016; Semple et al., 2009; Tegnér et al., 2009).

This chapter is organised around the topics and questions that arose from not only the coalescence of the previous two chapters, but also from a reflexive examination of the tenets of the program that were most important to participants and in existing literature. The intervention design, especially the customisation, became a cornerstone of the study success – participants considered it important above all else – and so it is discussed first. Next, some examination of the metropolitan versus RR and Zoom delivery, as well as gender differences are discussed. CRCI prevalence and effects underpinned the program design and delivery, and so they need discussion too; before study limitations, strengths and challenges are presented, including community and participant reading attitudes and the nil drop-out rate in this study. Some salient questions arose over the course of the research project and these are addressed:

- Why read aloud - why not just give people audiobooks?
- How do we know the improvements were not just a result of social contact?

Strategies for implementing a reading program in cancer centres and hospices are considered, including:

- What part can libraries play?

These are such big questions and so important to the very framework of the program design, they are discussed in this chapter to highlight their significance. Finally, the way this program made a positive difference in lives of palliative and end-of-life patients (and their families) is presented.

For clarity, the hypothesis and research questions are restated as follows:
Hypothesis: The read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment, as indicated by increased self-reported wellbeing and decreased symptoms of stress, anxiety and depression, and will provide a positive experience for those involved.
RQ1: What impact does regular participation in a read-aloud program have on the emotional wellbeing of cancer patients currently undergoing treatment?
RQ2: What are the perceived psychosocial effects of a read-aloud program from the perspectives of patients and families?

6.1 Intervention Design, Including Customisation, Reflected in the Study's Themes

Chapter 2 showed the term *bibliotherapy* is used to mean a variety of things, and is an umbrella term encompassing various reading dictates and delivery methods. Additionally, it illustrated the high incidence of cancer-related distress and the low rate at which assistance is offered for that distress. Bibliotherapy is a low-cost intervention (Monroy-Fraustro et al., 2021) with proven benefits for a range of mental health conditions (refer section 2.2.4), and so finding a way to deliver these benefits despite CRCI (and its potential impact on reading), became a design challenge. Customisation or personalisation was therefore the key concept for attempting to initiate or maintain interest and engagement with reading in a way that could be possible in the presence of cognitive impairment. Participants valued the design, especially the personalisation, and this was expressed across the qualitative findings.

Looking briefly at each of the themes, participants and their families expressed the first theme of 'program enjoyment' reflecting an overarching sense of pleasure from the reading program, separate from any of the more specific themes that followed. This is consistent with the idea that creative therapies are a natural, enjoyable component of the human experience (Australian New Zealand and Asian Creative Arts Therapies Association (ANZACATA), 2021), in keeping with philosophies that therapies should make people feel better (Falkensteiner et al., 2011; Selman et al., 2012). Even putting aside all other aspects of the intervention, the pure enjoyment of reading has been reported in other studies (Wilhelm & Smith, 2016), likewise the enjoyment of participating in other reading programs has also been reported (Brewster & McNicol, 2019; The Reader, 2024; Tegnér et al., 2009).

The second theme, 'improved wellbeing', encompassed all the signs and symptoms of enhanced wellbeing that occurred before, during and after reading sessions, like mood lift, improved sleep, increased self-efficacy for everyday activities, and feeling relaxed or nurtured. In keeping with the many studies detailed in section 2.1 and section 2.2.4, this theme and the statistical significance of the improved wellbeing and decreased stress, anxiety and depression of participants align with known benefits of bibliotherapy; including reduced stress (Rizzolo et al., 2009), increased relaxation (BOP Consulting, 2015; Brewster & McNicol, 2019; James & Römhild, 2023; Usherwood & Toyne, 2002) and improvements in many mild to moderate mental health conditions (Billington, 2019; Chamberlain et al., 2008; Czernianin et al., 2019; Davis & Magee, 2020; Floyd, 2003; Frazer et al., 2005; Grundy, 2005; Gualano et al., 2017; Gusmao & de Souza, 2020; Macdonald et al., 2013; McNicol &

Brewster, 2018; Pettersson, 2018; Reeves & Stace, 2005; Taleban et al., 2016).

In our modern 'self-serve' society, the next theme was unsurprising, that of the 'value of human interaction', where participants and their families not only valued companionship and the opportunity to discuss stories, but the personal qualities of the reader were important for feeling cared for and for families to feel comforted by the reader's presence. Studies have linked individual reading with reduced loneliness (Hilhorst et al., 2018; Rane-Szostak & Herth, 1995; Usherwood & Toyne, 2002) but more importantly, other shared reading interventions have linked the experience of reading together with a revaluing of human connection and nurturing (Bolitho, 2011; Brewster, 2011; Brewster & McNicol, 2019; Porteous-Sebouhian, 2022; The Reader, 2024).

The fifth theme, the 'value of distraction and escapism' reflected a common viewpoint among participants and families regarding shifting the focus away from cancer, treatment and other worries to ease stress, pain and nausea, which is consistent with other bibliotherapy studies (including Anderson, 1992; Bal & Veltkamp, 2013; Billington, 2016; BOP Consulting, 2015; Brewster, 2011; James & Römhild, 2023; Jarrett, 2016; McMillen & Pehrsson, 2004; Pettersson, 2014; The Reading Agency, 2022; Usherwood & Toyne, 2002). The ability of stories to transport readers to another reality (Strange et al., 2002) and free them from their own identity (Slater et al., 2014), is particularly relevant when considering that for someone affected by cancer, being themselves in their reality of treatments and medical appointments is hard, and some escape could be welcome. Understanding stories allow *self* to be left behind is pivotal to understanding their role in this research study: reading to relieve the psychological distress that often accompanies cancer diagnosis and treatment.

Other studies support the value of distraction in a palliative care context. Distraction is an important theme among people attending specialist palliative day care because of opportunities for relaxing and chatting, and the "change of scenery", providing a diversion to illness and side effects, which results in increased feelings of self-worth (Bradley et al., 2011, p. 217). Additionally, Fisher et al. (2008) found that people with palliative disease do not want to talk about their illness with family and friends, and argued "palliative day care provides a day off for patients from thinking about, and being concerned about, the future, and a day off from being perceived as a bounded 'patient'" (p. 124). Likewise, in his bibliotherapy study of patients in a neurological rehabilitation centre, Robinson (2008) found that talking about a subject other than their health and the meals served was vitally important to his participants. This idea of distraction and escapism for palliative patients is echoed by

Hopkinson and Hallett (2001) and is important to this study because of the way reading can provide distraction and escapism.

The sixth theme, ‘effects on cognition and executive function – concentration’ arose separately from any implied causality, rather participants spoke of impaired concentration and relearning to concentrate (sometimes in new ways such as by visualising stories) in order to enjoy the reading. CRCI and its effects are now widely documented (refer section 2.4.2). Difficulties with concentration and the joy of listening to reinstate reading is consistent with findings from studies of the SR program (Davis et al., 2016) and the RAYS program (Brewster, 2011).

These themes of the participant experience (pleasure, relaxation, nurturing and escape from pain and the side effects of treatment) were a consequence of the intervention design, including the distraction/escapism afforded by stories and the warmth of human interaction, and they resulted in the significant stress, anxiety, depression and general wellbeing improvements that were measured using the pre- and post-intervention instruments. This leads us to remember the third theme, ‘value of program design’, which was generated from the plethora of feedback about the things participants found most important about the program: personalised story selection and reading, the pleasure (and reduced effort) of being read to and the absence of expectations on participants. Bibliotherapy has been seen to improve mental health but it has not been studied via a personalised read-aloud delivery in a cancer context and yet this study demonstrated that an in-person, personalised approach was very important to participants, and is thus viewed as the source from which the benefits flowed. In fact, each of these themes has been found in separate (and sometimes disparate) studies, and so the uniqueness of this study means this is the first time they have appeared in combination in a cancer context.

The design process for this intervention produced a one-on-one program, tailored in all respects. Although bibliotherapy schemes currently being practiced with creative literature tend to be group-based, often with prescribed styles of texts (as discussed in Chapter 2), there is a significant history of individual reading for therapeutic purposes (L. J. Cohen, 1992a; Coomaraswamy, 1975; Levin & Gildea, 2013; McDaniel, 1956; McMillen & Pehrsson, 2004). Post-WWI hospital librarians felt the importance of selecting reading material for each patient so keenly they even went as far as creating scrapbooks based on individual patients’ interests in order to whet their appetite for reading: “what is good for one person might be detrimental to another, therefore, this careful and intelligent selection of reading matter for

each individual is of great importance" (Peterson-Delaney, 1938, p. 305). Likewise, post-WWII hospital librarians felt "reading material needs to be considered, evaluated and matched for the characteristic needs of patients" (Coomaraswamy, 1975, p. 30) and some bibliotherapists today offer individual reading recommendations (Berthoud & Elderkin, 2013; Tsakalakis, n.d.). Bibliotherapy researcher Sarah McNicol found that although the effectiveness of bibliotherapy has been demonstrated in a variety of settings, the mechanisms of "*how* it works" is more difficult to determine, especially with consideration of the differences between readers and the way in which bibliotherapy may be more or less effective for those different readers (McNicol, 2018, p. 23), which supports the concept of personalisation in bibliotherapy. Tailoring reading material to each participant needs to be a key consideration in the delivery of future programs for people undergoing cancer treatment, yet this is not a trivial component of a reading program, as indicated by the personal interaction between a reader/listener and a text (as described by reader-response theory and discussed in sections 2.1 and 3.5.3). Researchers studying the impact of bibliotherapy when participants were able to choose their own books found that "the right book fit leads to the most impact" and participant input into book selection led to feelings of empowerment (Bruneau & Pehrsson, 2017, p. 255). Similarly, in a study of music therapy for patients experiencing chronic pain, both pain and depression symptoms were reduced more when patients chose the music rather than the researcher (National Center for Complementary and Integrative Health, 2023), illustrating the importance of tailoring interventions to participants, thus ensuring they are person-centred. Although most participants in this study were glad to relegate the task of choosing stories to the researcher, choices were carefully made according to participant preferences.

In contrast, some bibliotherapy models (such as the SR model) focus on the text rather than choosing reading material for the particular people who will be listening to it, which of course is complicated by having a group of people present rather than an individual. In fact, Dowrick et al. (2012) studied SR groups and found three key factors: "literary form and content", "group facilitation" and "group processes" (p. 15). The way in which many current bibliotherapy programs focus on the text rather than the participant has also been noticed by other researchers, such as Brewster and McNicol (2021). In a cancer context, treatment side effects and fatigue, combined with possible presence of CRCI, would soon make interest wane if a program was not appealing or suiting participants' needs, hence having a person-centred approach is crucial. As detailed in Chapter 5, participants repeatedly indicated the importance of having reading material chosen just for them. This is supported by Brewster

(2011) who found her study participants questioned the ability of someone to recommend a book without knowing the intended person, and they spoke strongly about the concept of reading being a highly personal activity. Indeed, reading a book is a personal communication between the words and the reader, so the experience will be different for different readers, which is the foundation of reader-response theory (refer section 2.1.1). Individual support and reading recommendations are also a cornerstone of the RfW project (Reading for Wellbeing, n.d.-b). The need for connection between the reader and the text is important but it can only occur with the right combination of reader and text.

With the common cancer (and treatment) side effect of fatigue, people with cancer are advised to prioritise where they expend energy (National Cancer Institute, 2008), which is another reason to design the intervention with care to not only provide an enjoyable experience but also to not tax them unduly. When evaluating aspects of the program design, participant comments were relevant, including those indicating that if they had been asked to attend group reading sessions then they would not have been as engaged or relaxed. Group settings would have made tailoring reading selections difficult or impossible, yet personalisation and customisation were key ingredients for participant satisfaction with the program. Walwyn and Rowley (2011) noted in their (group) study that although participants were happy for facilitators to choose texts, some participants were "unenthusiastic" about book choices (p. 311). For programs like this, the choice of reading material is important, necessitating becoming well-acquainted with the reading and/or viewing preferences of participants and having experience with a wide range of genres, empathy for people affected by cancer (or other life-changing disease) and an understanding of what would be both appropriate and enjoyable for each person. Choosing reading material is not a quick or trivial activity, but it has been explained as close as possible in section 3.5.3, with examples and further explanations in Appendix C.

Although great value was placed on story selection as a program design decision, including humour per se was not a deliberate choice, but rather an evolution of systematic observation of participants. Humour became an integral component of the program. Further to the section 'The Importance of Story Selection' in Chapter 5, the impact of humour on many participants was palpable – visually (people smiled or laughed, and looked happier) and aurally (people chuckled, laughed, exclaimed and always wanted to comment on the stories with humour, especially humorous plot twists). Given the obvious enjoyment of the humorous stories among the majority of participants, it deserves further attention in future studies. Ian Gawler, meditation advocate and contributor to the contemplative studies centres at both Melbourne

and Monash universities, wrote in support of a new book on the role of humour during cancer treatment: “When you laugh, there is no room for anything else. Laughter brings its own natural mindfulness” (Ben-Moshe, 2017, p. i). This comment is steeped in research: using fMRI scans, Nummenmaa et al. (2023) found that laughing and crying use different neural networks, and so laughter allows a shift in perspective by stopping distressing emotions when they exist, a concept supported by Yim (2016) who reported laughter positively affects cortisol, dopamine and serotonin levels.

The role of humour during cancer is a little-known area and Sebastian Gendry, laughter wellness coach, also wrote in support of this new book: “Laughter is an untapped science. We didn’t really know until now how to use it as a reliable therapeutic tool, but we do now and the results are amazing” (Ben-Moshe, 2017, p. iv). Studies show existential anxiety and fear of death are reduced when humour causes people to view life in an amused way (Raviv, 2023). Clown doctors, not only the prerogative of paediatric patients, have positive effects on self-reported pain, anxiety and the effectiveness of some treatments, and also enliven the workday of medical staff (Gomberg et al., 2020). Although studies of humour therapy and laughter are small in number, humour has been correlated with improvements in QoL, resilience, sleep quality and increased happiness, with reduced stress, anxiety and depression (Bennett et al., 2014), and reduced pain (Adrián et al., 2018; Bennett et al., 2014) - all factors that contribute to emotional wellbeing. Interventions that induce laughter have been found to positively impact mental, physiological and physical health outcomes (Stiwi & Rosendahl, 2022). In a discussion of the role of books for paediatric patients in hospitals, author Dapier Jarrett (2016) tells of his own time in hospital as a child:

> The experience of being read to by people who loved me, of hearing Dr. Seuss's tale of screwball rhymes and feline tomfoolery, entertained, soothed, and distracted me. It conveyed something of home, comfort, and care. I was safe while I listened to Dr. Seuss being read to me by someone I loved. (p. 24)

Long-time children’s hospital librarian Marcella Anderson used her experience to stress the importance of humorous stories for her young patients: "Studies show that humor helps to reduce stress and to release endorphins, the body's natural pain blockers that lower pain levels and contribute to a sense of well-being. Also, humor helps patients to relax by the diversion it offers" (Anderson, 1992, p. 14). The use of humour for escapism and distraction from illness, treatments and side effects is valid for both children and adults. The value participants in this study placed on humour is consistent with previous research on the use of humour in alleviating pain and distress and improving quality of life. Future research could focus on the specific role humorous reading material plays in bibliotherapeutic programs.

The melding of themes is a natural consequence of the way aspects of each are interconnected. For instance, 'value of program design', 'improved wellbeing' and 'value of human interaction' are associated with the idea of the reading sessions being 'a gift'. This came out repeatedly in interviews and appeared to be a direct consequence of the personalisation, specifically tailored reading choices, individual delivery, and a gift of time. The notion of *time* is important: "Acceleration spares no one … If it affects each and every one of us so much, it is because it deeply governs the structures of Western societies. To the point of making us lose sight of what is essential" (Rosa & Vettraino, 2016, para. 1). Sociologist Hartmut Rosa became intrigued with where time goes, considering the way we use appliances and technology to conserve time and prioritise urgent tasks over important ones (Rosa & Vettraino, 2016). Taking time out from the cycle of cancer-related appointments and treatment for some self-care or psychosocial care is important for those affected by cancer, increasing QoL, which results in reduced visits to hospital and increased treatment compliance (DiMatteo et al., 2000; Greer et al., 2008). Personalised reading sessions offered the opportunity to decelerate and set aside time to 'just be'. As many participants noted in the interviews, they could not pause a person reading to them in real-time to go off and answer work emails or finish a chore – the reading sessions equated to a self-imposed stop and an opportunity to relax, which is so desperately needed during the stress and distress of cancer treatment.

The impact of tailoring the intervention and the gift of time led to some sadness at the program ending, which was observed on a number of final sessions with participants (refer section 5.3.1). The emotional interview responses and the sadness expressed at the end of final sessions indicate the value people placed on this weekly interaction just for them. Whether it was the pain relief component, relief from nausea, distraction from the anxiety of diagnosis and treatment (or other worries), a lightening of mood or simply the relaxation or 'time out', some people did not have a substitute for this weekly time slot and were anticipating feeling a loss. Ideally, in cancer centres, hospices and as part of community palliative care programs, tailored reading programs with no fixed end-date or pre-determined program length would mitigate this problem.

This program does not exactly fit any of the models of bibliotherapy currently in use (refer Chapter 2), but it has reading for improving wellbeing at its core, which is the fundamental principal underlying all bibliotherapy models. The description of the Kirklees bibliotherapy program, even though their model and group delivery was quite different to this program, is in fact a rather apt description of the essence of this read-aloud program too:

> As an inherently flexible and adaptable approach … best defined by its ethos, rather than a prescriptive list of its activities, as is the case for many alternative approaches to bibliotherapy. It is an approach to bibliotherapy which is person-centred; avoids value judgements of texts and responses to them; is often co-produced with group participants; is about making a contribution (in a variety of ways); and emphasises social connection. This separates it from other current models of bibliotherapy … and demonstrates how it may be tailored. (Brewster & McNicol, 2021, p. e12)

The personalisation of the reading program was important to all participants. The sub-themes of 'feeling valued' and 'mental health benefits' resulted from the one-to-one, tailored approach, so the interplay between the themes of 'value of program design' and 'improved wellbeing' work together to fit the axiology of improving emotional wellbeing – the crux of the study. This is an important finding, and we can conclude that through the change in pre- to post-intervention wellbeing scores and the themes of program enjoyment, improved wellbeing, value of program design, human interaction and distraction/escapism, and the effects on concentration, that the program contributed to emotional wellbeing. This data triangulation illustrates the credibility of the findings. Therefore, in answer to RQ1, we see regular participation in a customised, individually delivered read-aloud program impacted cancer patients by increasing their emotional wellbeing and relieving some of their treatment side effect burden.

6.2 Some Rural / Regional and Zoom Differences

Analysis revealed the intervention did not result in statistically significant improvements in stress, anxiety and depression scores within the RR participant group, yet statistical significance of all DASS-21 domains and the WEMWBS was evident in the *overall* participant group. The small RR group (data for n = 12 RR participants) resulted in low statistical power, calling into question the value of looking at the quantitative findings for the RR population in isolation. It was hoped comparisons could be made between the two populations, however the low power of the RR group resulted in searching for meaningful findings measured across the entire cohort rather than by geographic location.

Qualitative interviews with RR participants identified additional stressors for the RR participants: over the course of the 6-week intervention, six of the 14 RR participants needed to travel to Adelaide for treatment or for tests, both of which involved the need to be away from home and disruption to routine. This was especially relevant in relation to R2 experiencing an aspect of the program that he did not enjoy: travelling to intervention sessions. At the mid-point survey, R2 indicated that he was enjoying the reading choices and

he had no suggestions for improvement. However, according to his spouse, “I think the effort of getting there … that is the difficult part … towards the end because he had, he was in a lot of pain … and then perhaps it got a bit of a chore, the last couple, because he was just a bit over everything”. This travel requirement echoes the reported cancer experience in rural areas: impacted by the need to travel for treatment and therefore generally relying on self or informal supports for psychosocial needs (Pascal et al., 2015; Pascal et al., 2016).

Significant distress is experienced by up to 75% of people diagnosed with cancer (Cardy et al., 2006, p. 13; Galway et al., 2012, p. 1). In addition, different problems faced by rural/regional people affected by cancer has previously been reported (Gunn et al., 2013; van der Kruk et al., 2022). It is possible that among the RR participants in this study, the need to travel and be away from home impacted their emotional wellbeing. However, the small sample size (data for n = 12) and reduced statistical power was the likely reason a statistically significant change was not detected in the RR subgroup.

Delivering the intervention over Zoom came about as a way to reach rural and regional people affected by cancer and to increase study enrolments. This was extended to include interstate participants when recruitment expanded to help reach target participant numbers. Being exploratory research, and being conducted during times of COVID-19, an online delivery mode was a sensible pragmatic option to increase participant safety and access to the intervention. The researcher did wonder if the nature of the interpersonal relationship would be affected when the reader and participant had screens between them. However, the qualitative data was reassuring. The easy acceptance of participating via Zoom was reflected in some participants’ comments: "The only expectations I had is I thought I will probably enjoy it anyhow. And I did." (R16) and "It became more of a ‘Oh, on Tuesday, I've got Liz reading to me. That's tomorrow. That'll be good’ (chuckling)” (R3). R4 was an interstate participant, but in her comment below it can be seen that the Zoom delivery was convenient and fitted well into her working day:

> I would be working and the sessions were coming on, and I thought, oh, you know, I wouldn't really want to stop, but I thoroughly enjoyed it. There was never any “Oh, I should be getting back to my work”. I just went along with it and really enjoyed it. And that was, I wasn't expecting that. I thought sometimes that it might be “Oh, golly, you know, this has been intrusion into my work” and it wasn't, I really enjoyed them.

However, some would not have participated if they had to do so via Zoom, and as one RR participant said “Had it been online, I wouldn't have enjoyed it as much because I like to have that one–on-one, yeah. Rather than online, I feel it's very impersonal. And this is very personal” (R6). There was a potential regional participant who did not enrol in the program

because she was unwilling to participate via Zoom and it was too far to drive for only one participant. The ability to offer different modes of delivery was a strength of the program from the point of view of participant satisfaction and recruitment.

To see if the program's effects were different according to delivery method rather than geographical location, the DASS-21 and WEMWBS scores were split into two alternate groups, according to in-person versus Zoom delivery, and analysed; with H_0: $\mu = 0$ and H_1: $\mu < 0$ for the DASS-21 subscales, and with H_0: $\mu = 0$ and H_1: $\mu < 0$ for the WEMWBS. The analysis showed that the in-person delivery group experienced statistically significant improvements across all DASS-21 subscales (stress $p = 0.001$; anxiety $p = 0.000$; depression $p = 0.017$) and the WEMWBS (wellbeing $p = 0.000$). However, no improvements were found in stress ($p = 0.625$), anxiety ($p = 0.128$), depression ($p = 0.286$), or wellbeing ($p = 0.428$) for the Zoom delivery group. The sample size was very small for the Zoom-only group (n = 7) so this analysis was underpowered, although the qualitative data was encouraging. All participants, including those who participated via Zoom, spoke highly of the program, and valued their time participating, with valuable comments like this one:

> I guess with an audiobook, it's like, you switch it on and you listen, you switch it off, you know, sort of not that, you've got a human voice … I guess it's because - that's probably it, because you're humanly there, I'm invested. (R3)

showing connections can still be formed between the reader and participant when the delivery is remote. The fact that it can be harder to feel a sense of connection when sessions are online (Glazier, 2021) may imply the best results could be produced when the program delivery is in-person. Researchers at Massachusetts Institute of Technology found face-to-face is the "most valuable form of communication" (Pentland, 2012, p. 65), and experienced corporate consultant, Paul Axtell, favours in-person meetings over online meetings because of the sense of empathy, intimacy and connection that is hard to replicate in online meetings (Axtell, 2015). However, a recent study showed RR people affected by cancer value human interaction and connection and are accepting of both face-to-face and telephone intervention (Gunn et al., 2021), with telehealth becoming common practice during COVID-19 (Legge et al., 2023). Irrespective of his online delivery, R14 felt he really benefitted from the program:

> It redirects your brain, redirects your brain away from feeling off. So you know that you feel off, but your brain goes somewhere else and I would bet that then once you get off this, it's like a form of meditation Liz, once we close down the video and you're off the screen, I would bet that I'd feel better because my brain's gone down a different path.

and his scores showed meaningful improvements across all domains. Different delivery modes could be tested in future research, noting that adequate statistical power is required to determine whether in-person delivery of a reading program is superior to online delivery.

For this study, it was intended to try and find local readers regardless of the region the participant was located, so this is something that could also be explored in a future study. A partnership with SA Libraries could facilitate this, with local public libraries recruiting and supporting reading volunteers in their area. However, the importance of continuing care with the same service provider, as mentioned by Gunn et al. (2021), equates to a need to match volunteers to participants for the duration of any future programs. This was another underlying consideration for design and delivery of this study, acknowledging the importance of continuity of care to ease any social anxiety, establish a rapport and get to know individuals sufficiently to note their reactions to reading material chosen for them. As M8 said, when considering what the reading program might be like with different readers, "you get to know their preferences", which for him was positive because it resulted in enjoyment of the reading material chosen and (for many) feeling valued as a result of the personalisation and continuation of care.

Although in-person felt like the best delivery method because a sense of companionship seemed to flow more quickly this way, when it was not possible because of distance issues, the Zoom delivery was observed to still generally be good from a reader perspective and from participant feedback. The one-to-one nature of the intervention afforded the opportunity for connection between the reader and the participants. The facility of shared stories set the scene for a shared stress-free experience which helped establish rapport. Regardless of delivery method, the stories still served as escapism/distraction, there was still rapport between the reader and participants, and a sense of human connection was expressed in interviews.

In total, three RR participants who received in-person intervention delivery indicated they would not have taken part in the program if it was online. One regional participant with the choice of in-person or Zoom delivery said she preferred online delivery. The youngest participant, a mother of school-age children, working full-time and receiving active treatment, did struggle to make time for in-person delivery towards the end of the 6-week program, and although the venue had already changed from on-campus to her home, the last two sessions were conducted via Zoom. Considering the different intervention delivery methods, I experienced a strong sense of camaraderie with a few of my Zoom participants, and it was almost like being face-to-face.

The importance of the reader seeing the participant at the other end of a Zoom session cannot be overemphasised. On two occasions, participants could not be seen during sessions. The impact of this was an inability to gauge valuable participant responses - vital for determining speed, pauses and volume while reading, as well as for informing future reading choices. Additionally, the opportunity to make eye contact and observe facial expressions and body language was lost, and the reader felt disconnected from the participant when reading that way. Likewise, feedback indicated that participants valued being seen by the reader because it made them feel as though the experience was just for them:

> I felt like I was being communicated to. I felt like the book was being read *to me*. Ah, you do something with your eyes, which is really good – you flick your eyes up at the screen, whether you know it or not, about every 30 seconds … Which is really good. Not just head down reading. So you do feel as if it's been directed at yourself. (R14)

In-person delivery was preferred because it was easier to build warmth, but participant feedback indicated that online delivery did not preclude a flourishing connection around shared stories and the ability to transport the listener to another place, far away from cancer diagnosis and treatment.

Combining quantitative and qualitative findings showed both in-person and Zoom delivery led to enjoyment of, and positive psychosocial effects from, the reading program for RR participants, however some in-person participants would not have taken part if their only delivery option had been online, and one participant preferred online delivery. Literature referenced in Chapter 2 indicates higher study retention rates when interventions are delivered in-person without the need for participants to travel, however, the COVID-19 pandemic made online and telephone communication generally more acceptable, including between health professionals and patients, and this can be the most efficient way to provide services to RR people. Based on that, these findings continue to illustrate acceptance of a one-to-one program, delivered in real-time and this is important for future studies and/or the implementation of bibliotherapy programs in cancer centres and hospices.

6.3 Gender Differences

Women are more likely to participate in research than men (Curtin et al., 2000; Singer et al., 2000), and this study is consistent with those findings with a higher proportion of females than males participating: 28 females participated (18 metro and 10 RR) and all completed the program; 10 males enrolled to participate (6 metro and 4 RR) and 8 males completed the program.

Gender differences were evident in self-reported CRCI and in differences between information shared by male participants and their female partners. At enrolment, 82% of women and 70% of men self-reported CRCI since diagnosis, and 85% of women and 60% of men self-reported CRCI since treatment. These figures contrast with the answers to the EORTC questions (refer section 6.4). The pre-intervention EORTC answers show 97% of women and 60% of men self-reported concentration difficulties and 100% of women and 80% of men self-reported memory difficulties. These figures show clear differences between the genders, which is consistent with studies showing sex-based differences in treatment side effects, with women more likely than men to experience them (Unger et al., 2022; Winstead, 2022). However, all the male participants were married or partnered at the time of enrolment and spouse interviews illustrated a different story to that told by the men. While the men were not admitting to CRCI or downplaying it, interviews revealed their partners were seeing clear signs of it, especially regarding memory difficulties. The men in this study may have been downplaying difficulties, which is consistent with findings showing men are often unwilling or lacking motivation to seek, read or understand health-related information (Ek, 2015; Lee et al., 2015).

Men in this study tended to downplay other aspects of their cancer. For instance, M5's interview comments suggested he was not much impacted by his cancer: "I don't think I needed a distraction as my cancer is not immediately life-threatening and does not bother me greatly", yet he had no larynx! It is difficult to understand if/how this attitude can be true, or whether it was simply bravado. In contrast in his wife's interview, she was in tears, saying she was looking to give him reasons to want to live, and she was thrilled he was taking part in this study:

> He was more motivated and turned on. There's a lot going on in his head, regarding treatment; immunology now; it's in his lung too; he's realised things will never go back to normal ... I felt happy because it's good to see him going out doing something and enjoying it [crying and the researcher calming her] ... Anything to get him to thinking life is worth living and taking initiative. It was a good reminder of what he's still able to do and enjoy.

Her distress was not mirrored in her husband's DASS-21 or WEMWBS, nor in his interactions with the researcher. M5's spouse also revealed that whenever she questioned him after reading sessions, about what it was like, his face always spread into a grin, and he was delighted "like a little boy".

The intervention was inclusive of all genders. In the researcher's reader advisory experience in libraries, the reading interests of men and women can be different, but as reading material

for the intervention was personalised for each participant, personal preferences were catered for. However, there can be perceived gender differences in other ways too, for instance on the priority given to relaxation, as seen by this comment by R2's spouse:

> I can see that it would suit a lot of people. I think women would might enjoy it more because women are always busy and to have someone sit and read to them, I think they would enjoy that. That's just my view. ... Because we're always so busy that you don't, looking after everybody else, you don't often have the chance to just sort of sit and relax.

There are clear differences between the processing of illness and self-care between men and women. This phenomenon is widely acknowledged in both studies and clinical trial organisations. Around the globe, men are less likely than women to seek medical advice for cancer symptoms, resulting in poorer outcomes (Fish et al., 2022), and they are also less likely to seek out general medical help (Trialy, 2022). Furthermore, men are less likely to seek help for mental health issues:

> Depression and anxiety can happen to anybody, but men are less likely to reach out for help. That's because men generally put off getting help for health problems, especially when the issue is with mental health. (New Zealand Government, 2023, para. 1)

This may also explain why men are less likely to participate in psychosocial research (Geller et al., 2011; Saphner et al., 2021; Wakefield et al., 2017) – simply because they think they do not need it or because it is harder for men to seek help. Additionally, the association of reading with solitary or anti-social activity (Radway, 1994; M16), luxury time (Australia Reads 2021, 2023; R14), or waste of time (M17) may also be at play here, because studies show (in general) that women read more than men (Australia Reads, 2023b; Australian Bureau of Statistics, 2024). However, Australia is currently seeking to bolster the number of people of all genders who read, to "build a reading nation" through initiatives such as Australia Reads (Australia Reads, 2023b, p. 1).

Some of the women in the study mentioned an intimacy about the shared reading experience, for instance describing it as "an intimate experience" (R3), "this is very personal" (R6) and "it's so personal" (R8). It could be the men felt uncomfortable or embarrassed using this word, or this idea, with a female reader, or men may have perceived the intervention differently to women, or may have had less confidence in their abilities regarding emotional intelligence (Fischer et al., 2018). Regardless of gender, a sense of rapport and a sense of intimacy (as the women said) could be felt, especially when chuckling along to a funny part in a story or exclaiming at a surprising part. Sharing their pleasure was a lovely part of the reader experience and is no doubt what led to the connections.

The qualitative evidence in this study supports improved emotional wellbeing for both men and women following the intervention. Other studies show men tend to present different symptoms to women when dealing with depression and anxiety (Healthdirect Australia, 2021; Möller-Leimkühler et al., 2022; Streb et al., 2021) and are slower to admit to a problem and seek help (Ek, 2015; Lee et al., 2015; New Zealand Government, 2023; Trialy, 2022). A study by Unger et al. (2022) showed women are more likely to experience severe cancer treatment side effects than men, and Fultinavičiūtė (2022) and Daitch et al. (2022) showed women have historically been under-represented in clinical trials. This has been to their detriment because of biological differences resulting in potentially different effects when the treatments studied in men are generalised and implemented in women. These studies illustrate the changing nature of gender norms with greater acceptance of difference. The findings of this project, however, show that regardless of gender, participants enjoyed and benefitted from the program.

6.4 CRCI

At enrolment, 79% of participants self-reported CRCI symptoms via the demographic questionnaire. Additionally, self-reported CRCI was measured using the two EORTC items related to CRCI. Across the overall participant group, at pre-intervention, only 13% of participants reported no difficulty concentrating (EORTC Q1) and only 5% of participants reported no difficulty remembering things (EORTC Q2), that is 95% of participants indicated they were having trouble with their concentration and/or memory. As seen in Chapter 2, the prevalence of CRCI varies across different studies, cancer types and treatment types, with the most frequent occurrence seen of 75% for breast cancer patients who received chemotherapy (C. G. Brown, 2015, p. 204). Given our group of mixed cancer types and treatment types, it could be reasonably expected therefore that about 30% of participants might report no CRCI symptoms. Instead, only 5-13% did not report symptoms. This high rate of self-reported CRCI may be because people suffering CRCI were more attracted to participate in this study than those without CRCI because they were the people struggling to maintain their reading for pleasure. A contraindication to this supposition, however, was that not all participants were regular readers: only 58% of metropolitan and 57% of RR participants were habitual readers for pleasure prior to enrolling in the reading program. Cognitive tests continue to be unreliable for diagnosing CRCI (Henneghan et al., 2021; Maeir et al., 2023; Pendergrass et al., 2018) and so its incidence is most often self-reported. Rates of self-reported CRCI can vary widely, even for the same cancer type (Ho et al., 2024). Considering the high percentage

of self-reported CRCI symptoms in this study, perhaps it appears more frequently than is generally reported, however the sample size of this study is too small to draw any conclusions about this.

Observations and interviews revealed that for some participants, participation in this project produced feelings of validation stemming from recognition of CRCI - legitimising their experience of CRCI, especially for those who had treatments other than chemotherapy. It is widely accepted that acknowledgement and validation of another person's feelings provides support and justification of those feelings. Knowing there is a likely cause for the cognitive difficulties legitimises recent experiences and thus can result in relief and hope. A recent Australian study about health professionals' knowledge of CRCI had some alarming results, with more than half of the participating health professionals having "low knowledge … of the relationship between CRCI and cancer" (He et al., 2022, p. 4731) and few health professionals discussed CRCI with their patients unless the patients raised the issue. Health professionals cited lack of screening tools and clear pathways for treatment of CRCI as reasons they chose to not initiate conversations with their patients about it (He et al., 2022). Although beyond the scope of this study, initiatives to promote discussion of CRCI with all people with a cancer diagnosis may improve practice in oncology.

Improved emotional wellbeing was the primary outcome for this study, despite a number of participants saying the program had helped with their concentration and/or confidence around their actual or self-perceived slow speed of processing and/or speech. Improving cognition was never the outcome, that is, one hour of reading each week was never intended to fix CRCI. Statistical analysis of the pre- to post-intervention responses to the two EORTC questions related to CRCI showed no effect (refer section 4.5), as expected. The lack of change in pre-/post- intervention responses to the EORTC questions supports the idea that the improvements seen in wellbeing were not just the result of the passage of time but were associated with the intervention. That is, the target of the intervention, wellbeing, improved but cognition did not. Additionally, qualitative data indicated the program appealed to those with attention and memory concerns and gave them hope about cognitive improvements.

Inability to read as a consequence of disease or treatment has also been reported by people experiencing mental health problems, where a desire to read was present but so were difficulties and frustration (Billington et al., 2010; Brewster, 2011; Steenberg, 2016). This is analogous to the CRCI experience and shows reading aloud to people thus affected has a real and compassionate role to play.

6.5 Limitations, Strengths and Challenges

Reading volunteers

Although making use of reading volunteers was originally intended, problems appeared when attempting to incorporate them into the delivery of the program. Creating interest in becoming a reading volunteer occurred quite naturally as people responded to participant recruitment posters. For a significant period of time during recruitment, there were more potential volunteer readers than participants to read to. However, problems existed with utilising the potential volunteers: UniSA ethics approval was contingent on creating a COVID-19 policy and the policy stipulated that all volunteers had to be fully vaccinated against COVID-19; the researcher also had to be confident the volunteer was a clear speaker and had empathy; the volunteer needed to live sufficiently close to enrolling participants or be willing to travel; and the researcher needed a way to deliver reading material to the volunteers. A partnership with local public libraries, with their existing volunteer bases, could alleviate these concerns for future studies or implementation. Additionally, such partnerships could facilitate local reading volunteers for regional and interstate participants so that in-person reading could be an option for participants living beyond reasonable driving distance of metropolitan resources. In this study, many of the RR and all of the interstate participants had no choice other than to participate using Zoom. Having only one reader for this exploratory study could also be considered a strength in terms of the consistency of approach and delivery, thereby reducing the introduction of extraneous variables that could affect the study outcome. In addition, this provided the opportunity for the researcher to become intimately acquainted with participant reading preferences, thus facilitating the planning of each participant's sessions.

6.5.1 Limitations

Rural and regional participation

In this study, a read-aloud program was implemented and explored for its impact on the emotional wellbeing of cancer patients undergoing or within a year of treatment. The overall sample size was acceptable for an exploratory study and was in the order of the recruitment target, however, the number of RR participants was lower than hoped for. Future research which targets rural and regional participants will result in a clearer picture of the impact of the reading program on their emotional wellbeing and facilitate comparisons between metropolitan and RR participants.

Participants receiving other support

As part of the enrolment data collected for this study, information about whether participants were seeing a psychologist, undertaking an exercise program or other intervention with a known impact on mood was also collected. These additional sources of support may have contributed to improvements in wellbeing pre- to post-intervention. However, this was not a controlled study, but rather a real-world study, and these additional supports participants were availing themselves of are a typical and accepted part of life following a cancer diagnosis. Future research could attempt to distinguish between those receiving extra support and those who are not.

The reader was also the interviewer

Given the researcher was the reader and the interviewer, there was some risk of socially desirable responding, but with a single researcher and no opportunity for anonymity using interviews, it was not something that could be entirely mitigated. Participants were asked to compare in-person reading to listening to audiobooks in an effort to depersonalise the question about the enjoyment of the particular reader and to try to gain an understanding of their experience of being read to in general. Some participants had been regular audiobook listeners, while some had not; all reported enjoying in-person reading in preference to listening to audiobooks (refer sections 5.3.3 and 6.6). Asking participants how they would compare the two experiences (that is, listening to a person reading versus an audiobook) rather than directly asking which they preferred, was a way to reduce socially desirable responding. Another way to counteract potentially skewed participant responses was by interviewing family members, with whom the reader/researcher had no relationship and, in most cases, had never met. Family member interviews confirmed participant enjoyment, as did the systematic weekly observations: it is unlikely that participants would pretend to be excited when greeting the reader and asking what would be read that day.

Control group

This study had no control group. Given the difficulty recruiting participants in this phenomenological group, the study design was to forgo a control group of people with cancer who did not participate in the intervention. Although this would have controlled for changes in emotional wellbeing due to factors other than the intervention, with the added difficulties associated with COVID-19, it would have been difficult to recruit any further participants. A wait-list control group was considered, but in anticipation of recruiting rural/regional participants via the Cancer Council Lodges, where people either had a short stay every few

weeks for chemotherapy or extended (up to 8-week) stays for radiotherapy, putting people on a 6-week wait list was not feasible and therefore it was not done across the cohort. Future larger studies with more statistical power should include a control group or comparison group undergoing usual care or an alternative intervention.

Follow-up

Given the focus on improvements in emotional wellbeing over the course of the six-week intervention, a follow-up with participants to reassess emotional state after a given period would be of interest. If the effect of the reading program, as R5's spouse proclaimed, "lasts for days, weeks, months afterward … The effect that you had was much longer than just the period of interaction", it would have been interesting to see if the statistical significance of decreased stress, anxiety and depression scores, and increased WEMWBS scores persisted over time. If not, it may be an indication that ongoing participation in a reading program is the key to maintaining the benefits, which would be a reasonable assumption given the goal of restoring the therapeutic benefits of reading via listening. If a future study does a follow-up, it would also be interesting to see which of the participants who felt inspired to try reading again for themselves were still doing it, given the difficulties imposed by CRCI.

Technological issues

Internet speed was occasionally problematic for a couple of the regional and interstate participants. Two participants were intermittently impacted, and it is potentially a limitation for RR and interstate participants without access to local reading volunteers in future studies. At the reading end, a fibre-optic connection to NBN was utilised so there was nothing that could be improved at the delivering end while internet speeds at the receiving end were beyond the control of the project. All that could realistically be done to mitigate this was to encourage participants to stop the reader if they missed something being read. Access to, and familiarity with, appropriate technology may be a limiting factor for rural and regional people, and also metropolitan people who are time-poor or isolating to avoid potential COVID-19 or influenza exposure. As an example of this, one potential RR participant, with Internet capability only on his phone, could not be encouraged to participate using the computers at the library in his closest town. However, in Australia, between March 2020 and July 2022, 19 million patients received 118.2 million telehealth services (Australian Digital Health Agency, 2023, para. 1). In order to participate in a telehealth appointment, patients require either a telephone or capability for a video call, so people are becoming increasingly familiar with both the terminology and the technology. Delivery of a reading program via

phone is not a preferred option because of the inability to see participants and thus gauge reactions, which are so important for keeping reading selections tailored appropriately for each person.

Intervention venues

The study design was deliberately set up to eliminate travel unless a participant chose a venue other than their home or Zoom for the reading sessions. However, one participant (R2) had no choice but to travel. Although this was a limitation due to the COVID-19 lockdown at the Cancer Council Lodges, it was beyond the control of the research team. Some participants elected an alternate venue for their reading sessions (a public library or UniSA campus) and while most were happy to continue with this arrangement, M3 did switch to a Zoom delivery in order to fit in with her busy family and work life. For R2, however, as he became increasingly more fatigued, in pain and unwell from his treatment, travelling to a public library close to the Cancer Council Lodge became a chore and although the sessions did switch to Zoom when he left Adelaide for a break in his treatment, according to his wife, he was "over *everything*" by this point and had enough of everything associated with "the whole cancer treatment stuff". This reinforces the design decision to reduce or eliminate travel wherever possible for the person undergoing treatment.

Special consideration: Gender-specific participant comfort

The nervousness of some participants with regard to having a new person visit their home for the first reading session is noteworthy; likewise, their willingness to nevertheless experience this initial anxiety, which in all cases lasted about five minutes into the first session. Although at one time there was a local volunteer for some regional participants, and he did have ready access to collect any books that were ordered for him from his local library, the female RR participants in his area elected to have the female researcher read with them instead, which resulted in the male volunteer not being used. This was a shame given he was one of the university's performing arts students, with a beautiful voice. This highlights a potential consideration for future studies in relation to choosing readers: a reader of the same gender may be required for participants living alone or likely to be alone when the reader visits. Participant comfort is paramount, therefore the ability to choose the gender of the reader they feel most comfortable with is ideal. This is consistent with the findings of Walwyn and Rowley (2011) about the appropriateness of single sex groups for some people.

6.5.2 Challenges

Participants' reading attitudes

The relationship between reading habits and bibliotherapeutic results is a subject of discussion among researchers (Pettersson, 2018). While Cuijpers (1997) and Nordin et al. (2010) proposed that participants who are experienced readers with sufficient concentration and motivation to complete reading tasks have more success with bibliotherapy, Brewster (2011) and Hodge et al. (2007) found that good results can occur for people with a wide range of reading experience. This is an area still open to debate in the absence of further research to support either conclusion. Of note, this intervention showed significantly improved wellbeing results for participants across the spectrum of reading habits, noting that most readers had lapsed with diagnosis and/or treatment. Lapsed readers were able to nominate preferred genres and/or authors during program enrolment, while non-readers were asked additional questions about film and television viewing, childhood reading interests and barriers to reading – both strategies enabling personalisation of reading material. Perhaps it was the appeal of stories suited to their interests that held their attention and produced the bibliotherapeutic results rather than any association with reading ability and concentration/motivation.

It is unrealistic to expect this intervention suddenly turned non-reading participants into regular readers, despite the enjoyment the stories gave to all participants. However, many felt encouraged to try reading again (or persist with reading efforts), because they reported feeling such a mood lift during and after each session and wanted to keep enjoying stories, and continue with times of relaxation and distraction from pain or worries. The improvement in attitudes to reading, based on the pre- and post-intervention ASRA scores, was statistically significant (as reported in Chapter 4), however, there were some problems with this measure, as detailed in Appendix M. These problems raise concerns about its reliability and validity, both in modern society (remembering the ASRA dates back to 1988) where what constitutes reading is ambiguous (regarding social media, listening to audiobooks, etc.) and in health-challenged groups. Furthermore, CRCI may have impacted reading ability and/or motivation making interpretation of the ASRA questions too difficult. Participants may not have understood the questions and they may have been confused about current reading habits versus pre-treatment habits. Unlike the DASS-21and WEMWBS, which were created by psychologists and are proven in a cancer context, the ASRA was created by a teacher of adult learning and has not been proven/tested in this population.

There are no other studies of this nature that measure reading attitudes and habits among people undergoing cancer treatment, including those suffering CRCI, and the triangulation of qualitative and quantitative findings here suggest the sole use of instruments to assess reading attitudes and habits in people undergoing cancer treatment may not be worthwhile because the ASRA has been seen here to be unsuitable and there are currently no other measures to consider for this adult population. Despite this, the qualitative findings show people affected by their cancer and/or treatment were receptive to listening to stories chosen for them and read to them individually, in real-time and many felt compelled to try and replicate the positive experience and continue their improved wellbeing by trying to read again for themselves.

Community perceptions of reading

The reading attitudes of participants was discussed above; however, participant recruitment was impacted by widespread perceptions that reading, in the words of one of this study's participants, is "a waste of time" (M17). Despite M17's initial view about time spent reading (visually) being a waste of time, she did listen to audiobooks because they allowed her to multi-task, and she could thus feel productive. This time-wasting perception about reading appeared to be a common issue when trying to recruit participants into the study (see section 3.4 for more about recruitment and recruitment strategies). The popular and humorous concept that retired people no longer have time to undertake new activities because they are simply too busy with other pursuits also comes into play here, for when people in their 80s and 90s cite the reason of being too busy to enrol in a study taking only one hour a week, with no need to travel, it seems likely there are other reasons present. Are some people closed to the idea of reading to feel better, because people are generally less interested in reading? In Australia, fewer children now read for pleasure and more spend increasing hours with screens (Naylor, 2023), which does not bode well for our next generation of readers, while fewer adults are reading now too (Australia Reads 2021, 2023). One study looking at the reasons for preservice primary school teachers not reading, found participants reported boredom, dislike, lack of time, eye strain, and a preference for mobile phones and computers as reasons for not reading (Babayiğit, 2019). This is consistent with anecdotally reported trends of reading "because they are told they must for school" (University of the People, 2024, para. 2) and popular opinions such as "for many of us these days, reading has been reduced to the occasional clicked-on article showing up on our Facebook or Twitter feed, GPS directions, and the monthly bills" (Hampton, 2018, para. 1) abound. Our National Reading Survey 2021 found 29% of Australian readers find time for their reading while on holidays, with "less

demands on their time from daily life" (Australia Reads 2021, 2023, p. 2). Do people view reading as a luxury they do not really have time for, or boring, or irrelevant to modern life as the studies and surveys above indicate? An interesting question but beyond the scope of this study.

So many stories, so little time!

The researcher read hundreds of stories in preparation for delivering the reading program, yet thousands of short stories exist, and so many more may have been suitable but were not used. Likewise, the list of material deemed inappropriate is limited, and stories on this list may be enjoyed by some people affected by cancer, even though the researcher judged them as inappropriate given their potentially depressing content or use of offensive language. The reading list which is an output of this study is necessarily limited by the number of books and stories that could be feasibly read while developing the intervention.

Recruitment

Recruitment was extremely difficult (refer section 3.4). When recruiting, some organisations, like the Myeloma Foundation, BCNA and YWCA's ENCORE program, were very supportive, while others were not at all interested. Some people in this phenomenological group are research-fatigued, for example the people in the BCNA research recruitment group: very few enquiries were received following advertising and the few conversations/emails that resulted were very negative about doing wellbeing questionnaires and committing to a six-week program. Myriad posters, flyers and emails were distributed to cancer support groups and organisations, and public spaces. Despite obtaining ethics approval from two Adelaide hospitals, putting up posters in their chemotherapy suites and speaking at staff meetings, these strategies resulted in only two new participants. The researcher was interviewed on television, radio, newspaper, a community magazine and a podcast; and all these avenues yielded an additional two participants. Speaking at cancer support groups was consistently the most effective way to recruit new participants.

Library involvement

Metropolitan Adelaide public libraries were unwilling to support the program by advertising for participant recruitment in their library spaces, nor would they offer meeting rooms as quiet places to read without cost to the researcher and this sometimes resulted in less-than-ideal reading conditions. Some public libraries had quiet reading nooks, which were marvellous and were eminently suitable, however, others were noisy places with no offers of

somewhere quiet to read unless a meeting room had been booked and paid for by the researcher. A future study with a bigger budget would be able to book meeting rooms in public libraries or perhaps be able to secure commitment from the local councils that control the libraries, thus securing support for a reading program. This project lacked the resources to contact all Adelaide metropolitan councils to secure their support. The project had the support of ALIA and the SA public libraries network, but that was insufficient for individual greater-Adelaide public libraries to provide their support. Although the researcher had anticipated public libraries would advocate for this research project, with the majority of SA public libraries unable to promote it, no participants were recruited this way. See section 6.8 for the potential role of libraries in bibliotherapy programs and RA for people affected by cancer.

Participant fatigue

Participant fatigue was an inherent challenge and needed to be considered both in terms of enthusiasm for potential travel and overall ongoing attendance. Cancer patients undergoing treatment found some days were easier than others, depending on where they were in their treatment cycle, therefore a willingness for the researcher to reschedule intervention appointment times was necessary. Although participants had many medical appointments, exercise programs and holidays to work around, intervention sessions were never rescheduled due to fatigue, perhaps because all participants anticipated and enjoyed them. However, fatigue from lack of sleep due to medication side effects and anxiety did occasionally present a challenge when a few participants relaxed sufficiently during a session to become sleepy. This is discussed in more detail in section 5.3.3, however, tailoring the delivery of the story kept all except one exhausted participant awake. Maintaining the flow of program delivery in the face of illness, holidays, COVID-19 exposures and infections (both participants and researcher), and treatment and prognosis distress (resulting in mid-intervention breaks for two participants) was a challenge. Only some participants completed the intervention in six consecutive weeks.

Participant reading and writing ability

Another challenge existed with perceived versus actual ability to read and write English, which was a prerequisite for participation, with provision for vision impaired people and those with dyslexia or physical disability. Some conditions, such as brain cancer and/or its treatment, may leave affected people unable to read and write for themselves, yet able to comprehend when read to. This situation was encountered on a few occasions. When

forewarned or encountered extemporaneously, it was catered for by reading instruments aloud to participants, which was also done for a vision-impaired participant.

Cross-discipline work

The dichotomy between library and information science (LIS) and psycho-oncology was also challenging at times. Although the cross-disciplinary work was rich and meaningful, the differences in language, and reporting and writing styles were challenging. Examples of this dichotomy include the extremely succinct psycho-oncology writing style versus the narrative LIS style, writing in third person versus first person, and terminology like pilot study versus exploratory study with all the implications those terms invoke. Some chapters in this thesis were written using a phenomenological, social sciences voice, while others are presented in a scientific style, with a multi-disciplinary discourse. Where the writing differs from one style to another, it is indicated to aid the reader, and the interchange was kept to a minimum. The positive aspects of this interdisciplinary work far outweighed the challenges, but they existed for both the researcher and the supervisory team.

COVID-19 impact

Recruitment was impacted in a number of ways by COVID-19. Many support groups were not meeting in-person, so a visit to talk to them about the study and advertise the need for participants was not possible, and many of the support groups solely operating via social media had strict rules prohibiting study recruitment notices. However, the biggest impact was the Cancer Council lodges locking down with new strains of Covid. They had previously advised that their social workers would promote recruitment and readers would be allowed on-site to deliver the intervention to people staying there. When they locked down, there was enormous impact on RR recruitment. Speaking in-person at support groups that still met in-person was the most effective recruitment strategy.

COVID-19 impacted the delivery of this intervention as a face-to-face program in many ways. A COVID-19 protocol was constructed in order to get HREC approval. This protocol incorporated Australian COVID-19 requirements at the time, such as maintaining 1.5m social distancing, doing a RAT if the researcher felt unwell and time away from the program if either the researcher or a participant was a contact of someone with COVID-19 or had contracted COVID-19 themselves; as well as university and industry standards, such as maintaining up-to-date COVID-19 vaccination status (this requirement impacted the recruitment of some potential volunteer readers), and disinfecting book covers and pens. In

addition, the RR participant staying at one of the Cancer Council lodges had no choice but to travel to a nearby library to participate because of the lockdown of the lodges. Another way COVID-19 impacted the study was the change in some participants' reading habits: not travelling to work or not going on holidays resulted in some participants no longer reading for pleasure and this added to the confusion with the ASRA. On a positive note, with all the telehealth appointments the participants were attending, many participants commented on the extra value the in-person delivery of the intervention provided.

6.5.3 Strengths

Retention

Recruitment was hard, but once people were recruited, retention was high – 100% (refer Appendix N). Participants valued the personalisation of the weekly reading sessions and the connection with a competent reader with empathetic qualities. The common participant experiences of program enjoyment and subsequent relaxation (detailed in Chapter 5) stemming from a variety of factors, including the very important story selection, likely forms the crux of the reason for the high rate of program completion. In previous studies of psychosocial interventions for people affected by cancer, as detailed in Chapter 2, the personalised programs where participants were not required to travel had the highest retention rates. These findings support the rollout of individual bibliotherapy sessions, held at locations convenient to participants, as part of psychosocial care for people affected by cancer.

It is reasonable to argue that retention is linked to enjoyment, which further supports the second half of the hypothesis (a positive experience for those involved); as well as RQ2 with the psychosocial effect being the inclination to continue with the program and continue receiving the regular social contact and therapeutic benefit of reading.

Effect sizes in retrospect

During the design phase of this study, a power analysis was not conducted because there are so few studies of bibliotherapy in a cancer setting, and more specifically studies of bibliotherapy using imaginative literature in a cancer setting, to know what effect size to expect. Additionally, with this being an exploratory study (often referred to as a pilot study), there is evidence that they are traditionally underpowered (Lee et al., 2014). Furthermore, many pilot studies do not conduct effect size calculations at all, and Amy Whitehead and colleagues, who have conducted research into pilot studies, including sample sizes, significance thresholds and effect sizes, determined that effect sizes are not applicable

(Whitehead et al., 2014). However, Cohen's *d* was retrospectively calculated for overall stress, anxiety and the WEMWBS. Since the depression scores were non-parametric, the standardised test statistic from the Wilcoxon test (*z*) was used to calculate effect size *r* (Cohen, 2013; DATAtab Team, 2024). A medium effect size was detected for stress (Cohen's $d = 0.52$), a large effect size was detected for anxiety (Cohen's $d = 0.78$), a medium effect size was detected for depression ($r = -0.29$) and a medium effect size was detected for the WEMWBS (Cohen's $d = 0.43$). According to Cohen (J. Cohen, 1992), for power at 0.80 and $p = 0.05$ (i.e., the p-value previously used in both the one-sample t-tests and Wilcoxon Signed Rank Test), the sample size needed to detect a large effect size is N = 26, and for a medium effect size N = 64. The calculations using this study's data revealed both medium and large effect sizes, even though the study was underpowered for medium effects (i.e., having fewer participants should have made this harder to detect). This is strong support for a larger, adequately powered study.

Universal

Strengths of this study include it being accessible to all English-speaking adults without hearing impairment, regardless of location, education level or prior reading ability. The individual tailoring and delivery was deemed a huge strength by participants, as was the lack of expectation on participants. The ultimate strength of the study was stories made people feel better, and it is known that feeling better has flow-on effects to improving other areas of life (Folkman & Moskowitz, 2000; Fredrickson, 1998; Fredrickson et al., 2003; Lazarus et al., 1980), which is also supported by UK reading studies (as seen in Chapter 2). This supports RQ1 by stating that participants felt better as a result of participating in the read-aloud intervention.

6.6 Why Not Just Give People Audiobooks?

The frequency of CRCI and potential difficulties maintaining concentration while listening to audiobooks, as well as cancer-related fatigue and/or CRCI potentially rendering the operation of audiobook technology difficult, were factors contributing to the in-person read-aloud design decision. Other factors that were considered were described in section 3.5.2.

Participant feedback that crosses themes (program enjoyment, value of program design and value of human interaction) is presented here to illustrate in-person reading in real-time was a good choice for the participants for a number of reasons:

- People loved that the reading program was just for them – tailored reading choices, delivered one-on-one (as discussed in section 5.3.3).
- Real-time, in-person delivery meant the story reading could be personalised – for instance, a louder voice at times, inserting pauses, laughing together - there were many interview comments about this, even from people who like audiobooks (refer section 5.3.3).
- Not everybody likes audiobooks: “I don't like audiobooks” (M9).
- Participants appreciated the effort involved with choosing and reading stories just for them:

> Oh they [audiobooks] are great, but they're not real pepe (sic), well, they're not people sitting here making an effort to read out of a book to you.… it was the fact that someone puts in an effort to try to make me feel better. So that's always a nice feeling, I think. (M13)

- Using technology could trigger unpleasant treatment-related side effects, like headaches:

> Because, because of my migraines sometimes, listening to tapes and actually having to get on, especially phones, the actual thing of looking at your phone and what it does to wiring in your brain can trigger a migraine sometimes. So just having someone just come into the house and normal and talk to you is quite different to looking at an app. (M4)

- The in-person delivery fostered a connection with the reader, which was important: “I think the podcasts are, you know, they're great if you're listening to them, you know, whilst you're driving your car. But it's just, it’s not quite the same. It's not quite, you don't get that connection” (R11).
- Reading with a person rather than a recording brought back happy memories of being read to by parents or teachers: “some of my favourite memories from primary school was having the teacher sit at the class and read the book” (R13).
- As participants pointed out, they would not have been able to talk about the story afterwards with a recording. Although they were not questioned about their comprehension of a story, which has already been shown to be a positive part of the experience for many participants, this story-discussion was a feature of the intervention they particularly enjoyed (refer section 5.3.4).
- Participating in the reading program ensured some dedicated time for relaxation whereas audiobooks allow the listener to pause the recording and undertake chores or “wander off” (M19): “I love audiobooks. I'm not for a moment going to pretend I don't. But it’s different, it's different. It's more connected. ... I can't pause you, I can't

… A human's more effective, no doubt" (R14), and participants related the mindfulness of listening in real-time to relaxation:

> If I have something on an audio I'll get up and do things, and not listen to it attentively. So with you it was more like I was in the moment listening. And not in the moment when I'm listening to an audiobook. I'm not present, like I am with you. (R6)

- Sharing stories with another person was seen as an authentic interaction that is impossible to get by listening to a recording:

> Throughout the story, if there's been a funny little bit, we've both had a little bit of a giggle along the way as well, which you don't get that with an audiobook. So an audiobook would be fine, but I think just having that interaction, personal interaction with the reader along the way. (R10)

> Well, a talking book doesn't stop to laugh at certain things in a book, or to express a sadness about certain stories. So having this real, you know, you being real, is I think very different from a book being, being read professionally, when the reader can redo things if the reader doesn't like it. (R5)

- Issues around the suitability of the reader's voice become less of an issue for an in-person reading in contrast to a recording, perhaps because listeners have higher expectations of recordings because they are often performed by voice actors:

> It was definitely more personal ... I don't enjoy talking books very much. I've only listened to a couple … and the James Patterson one I listened to, the person who was reading it, didn't have the voice I expected the … narrator to have … I expected it to be Morgan Freeman's voice, because that's who I picture in the James Patterson books. And it wasn't his voice, so I just couldn't listen to it. Whereas your voice fitted all of the stories. (R9)

At enrolment, participants were required to indicate if they read books or listen to audiobooks. However, some participants completed their enrolment forms based on their previous reading habits, which had changed (reduced or ceased) with their cancer diagnosis and/or treatment and/or COVID-19 impacts. Nevertheless, 45% of participants indicated they listened to audiobooks or podcasts for pleasure. However, when the topic of audiobooks came up in interviews, participants stated they preferred the in-person reading to listening to audiobooks in all instances (refer section 5.3.3).

The reduced energy and motivation that often occurs during cancer treatment, irrespective of the presence of CRCI, resulted in a lack of confidence in keeping participants involved if audiobooks were chosen as the delivery mechanism for stories, and this was considered while designing the intervention (refer section 3.5.2). During interviews with participants, as described in Chapter 5, lack of motivation for undertaking or completing tasks was common -

potentially resulting from the frontal lobe impact of chemotherapy (refer Chapter 2) as well as the fatigue associated with all treatment types. Yet, participants stayed engaged with in-person reading.

The way the delivery was personalised for each participant, and the value they placed on that, which cannot happen with a recording such as an audiobook, was expressed by participants during interviews (refer section 5.3.3). M8 not only expressed the value he placed on this personalisation, but also added his reflections about why personal contact rather than utilising technology can be important, and these reflections are likely relevant for many of the participant cohort:

> It's probably the live contact, because obviously now the internet is full of audiobooks, so it's not a problem to listen to an audiobook. Some of them are very professionally made. Yeah, so with professional actors reading it and acting it to some extent, audiobooks with actually added noises and squeaky doors and, and all those kinds of things but it's one side of, I would say experience, the other side of experience is actually live person, reading to you at a pace which kind of is adjusted to a specific person … And a live person who can interact so not just switch them off or on as you can do with an audiobook … so being as old as I am, yes, means that I still prefer face to face and still prefer live people than rather than technology, so I grew up in a situation where I had maybe not that many but real friends of flesh and bone and when we wanted to meet somewhere we had to go somewhere and do things together, rather than sit on Zoom … so, it's cultural path as well. … it's very important too and I think in the future, becomes even more important as well, because people are becoming so distant from each other because of the technology. The technology which is supposed to join us actually, it makes us more distant, so it means, that leads people to believe that I don't need anyone because I can watch the video on the app, I can listen to an audiobook and I don't need to talk to someone because the AI will talk to me. … As a society we developed a situation where people don't have enough human contact anymore.

Participants expressed their enjoyment of personal interaction in the face of dwindling human contact (so eloquently expressed by M8 above), which is supported by studies such as Mitchinson et al. (2021) which found COVID-19 caused reduced in-person interaction in healthcare settings, which negatively impacted patients, their families and health professionals. The Institute of Health and Nursing Australia (IHNA) (2022) has found the small size of Australia's healthcare workforce coupled with increasing costs has resulted in shorter patient consultation times and the loss of clinical empathy. "Healthcare professional–patient relationships are key to ensuring the preservation of adequate human connections" (Soler-Gonzalez et al., 2017, p. 1) and despite the COVID-19-induced (and busyness-induced) reduction in connection between health professionals and patients, participants in this study valued the connections made with the reader.

The way supermarkets and department stores are increasingly removing staffed checkouts and converting to entirely self-serve checkouts is another example of the loss of human contact in modern society. Airports have more self-serve check-in devices than staffed counters and fast-food outlets in Australia appear to have removed the ability to order a snack from a person – having replaced staff with ordering and payment machines at their entrances. Another example is the UniSA libraries, having removed all staffed desks, so to speak to a librarian, even within a library, a phone handset needs to be used. Numerous studies have shown social isolation is a formidable risk factor for mortality from all causes, including cancer (Adler & Page, 2008), comparable to the risks associated with smoking, high cholesterol, hypertension, obesity and lack of exercise (House et al., 1988). This researcher laments the use of self-service loan kiosks in libraries because they create distance between library patrons and staff, and a subsequent disconnection from patrons' reading preferences, resulting in lost opportunities for informal reader advisory services, as well as reducing opportunities for human connection. Likewise, a senior LIS academic, Michael Stephens, spoke about the need for human contact in libraries when interviewed about the role of AI in libraries:

> Now more than ever, folks want human contact, and they want to feel like they belong. I don't see that delivered by artificial intelligence, but I do see it delivered by thoughtful information professionals that create spaces—both in-person, physical space and online—that welcome people in and engage with [them] in a human voice. (Affelt, 2023, p. 40)

Some people in our communities can now go days without interacting with another person as a result of all the self-service technologies, and so interactions which could serve as informal wellbeing checks have ceased. The dwindling of human connection is beyond the scope of this study, but it is relevant to studies like this that look to impart some warmth of human contact.

In section 6.1, it was shown that personalisation / individualisation was highly valued, and this would not have occurred simply by giving people audiobooks. Additionally, with focus and problem-solving potentially negatively impacted by CRCI, the ability to operate audiobook technology may be beyond the scope of some (or many) people with CRCI. Reading in-person allowed connections to be fostered and enabled discussions of stories, which is similar to the uptake of RA services during the pandemic when library staff noted "readers turn to us for the joy and necessity of stories and for human connection" (Lockley et al., 2021, p. 188). Based on that, these findings show people really enjoyed and valued real-time in-person reading and may not have persevered with the program if it had been

audiobook based. This is important because the known benefits of reading can be denied while suffering CRCI when reading is suspended or abandoned, but some benefits (in particular, boosted emotional wellbeing) were restored by shared read-aloud stories, so this combining of social contact and sharing stories supports the hypothesis.

Reflecting on the interactions between the reader and each participant, the multi-dimensional nature of social support becomes relevant, comprising instrumental/practical support, informational support and emotional support (Adler & Page, 2008). The dimension of emotional support involves the "verbal and non-verbal communication of caring and concern" while "listening, 'being there', empathizing, reassuring, and comforting" (Helgeson & Cohen, 1996). This is consistent with the nature of interactions experienced during the intervention sessions, as described by participants during interviews, and supports the improvements found in the emotional wellbeing of participants. Further supporting the effectiveness of the reading-aloud being done in real-time, The Reader Organisation assessed the intrinsic values of their SR program, and discovered the first value was "liveness" that is, texts being read aloud in the group rather than being read by group members prior to each gathering, which added to participant feelings of pleasure, enjoyment and "absorption/immersion" (Davis et al., n.d., p. 9).

To summarise, although audiobooks are good, it would be unrealistic to give people a pile of audiobooks and expect the same results for several reasons: motivation to put them on; with CRCI impacting concentration, people becoming easily distracted would likely result in going to do other tasks while listening – therefore no mindfulness and relaxation components; audiobook technology can be too hard to operate; difficulty choosing what to read/listen to; not the right speed for everyone (especially considering impacts of CRCI), which can be altered when using audiobook apps and newer Playaways, but not when using CDs or older Playaways; some audiobooks are like radio plays, which some people enjoy but the sound effects are too distracting for other people; and the value of interaction, laughing together and chatting about stories read. The words of journalist and author Meghan Cox Gurdon are apt to end this section:

> A superb audio recording is a work of art, a creation not so different in certain aspects from a marble bust or a portrait in oils. Yet as with such works, the relationship between the adored and the adorer is one-sided. Unlike a live reader, a recording has no idea who is listening. It doesn't care what you feel. A recorded story does not spring to life in the moment, in that unpredictable, fugitive communion of voice, ears, and text. The machine won't ... engage you in any way. It will keep playing until the story ends, or you switch it off, or the battery runs down. (Cox Gurdon, 2019, p. 37)

6.7 How do we Know the Improvements Were Not Just a Result of Social Contact?

Social support plays an important role in cancer survivorship, with higher levels of support linked to reduced anxiety and depression and improved overall wellbeing, regardless of the type of support received, providing positive social interaction and distraction in the form of "someone to take their mind off things" (Haviland et al., 2017, p. 2281). The read-aloud intervention provided both positive interactions and distractions.

This study did not have a control group or an alternate social-only intervention to rule out social contact as the mechanism for improvement in emotional wellbeing, however, participant interviews revealed some key concepts supporting the argument that any improvements in emotional wellbeing and pain relief were linked to bibliotherapeutic effect in combination with social contact, as detailed below with participant statements that cross themes and are therefore presented here to support the importance of the role of bibliotherapy in intervention sessions:

- There was no pressure to participate during reading sessions, specifically, there were no expectations on participants. Interviews revealed participants valued this complete lack of expectations. For instance, there was no need to make small talk, or talk about medical issues: "I don't have to do anything. It's, someone's reading to me, and umm yeah, I can just relax and take it all in" (R13) also echoed by R8, "It's just presence, whereas often, people who have life-challenging situations or illness, it's a medical appointment, it's a this, or tell me, or this and that - there was nothing that was needed. It was just pure presence" and expressed succinctly by R14, "You just close your eyes and listen."
- Participants said that without the story they would otherwise have felt awkward or nervous because they did not know how the sessions would have progressed:

  > Maybe a little nervous because I just thought, well, this is really weird because I'm an adult, and I'm having someone read to me, which is something I'd normally do myself. But I found within that first five minutes, I felt relaxed. (R11)

- Participants loved the process with the focus on the story; they could just be relaxed because they knew the focus was on the story, not on them, and perhaps with so many medical appointments, all about their health, where the focus is on them, this was nice because of being such a different interaction to their usual ones:

  > The fact that it was a story and there was a process, that meant that I relaxed into it. There was no nervousness about, "what are we going to talk about today?"

> You know, that sort of thing. It was a process. So it was relaxing into that process became quite easy. (R3)

This is supported by comments made during an interview with Mersey Care mental health trust project leader, Judith Mawer, who noted the difference that exists between reading groups and quilting bees, knitting groups or modern-day men's sheds, because the focus on a story adds another dimension to the gathering (Morrison, 2008).

- Observations (particularly of the greeting the participants gave the reader each week) showed many participants routinely expressed excitement along the lines of "What are we going to read today?" This indicated an eagerness to hear the stories, and it was echoed in participants' interview comments, with many people mentioning the anticipation of reading sessions with comments such as "I looked forward to you coming. I looked forward to whatever you were reading to me … I think, 'Are we going to have a romantic one, like the train ride one or … ?' (laughing)" (R15)
- Some participants were self-conscious about conversation and their memory because of their CRCI and the focus on enjoyment of the story took the pressure off: "I was very appreciative of you saying, I won't ask you any questions, there'll be no onus on you to recall anything or remember anything" (R12).
- The stories brought distraction and humour – this was emphasised repeatedly in the interviews. For instance, R4 said "I just, I want to know how they end!" while R14 colloquially emphasised the effect of humour on him: "I was peeing myself. It was awesome." For R8, the real value of distraction and humour (which she favoured) came in the form of pain relief: "instead of focusing on pain, I was focusing on the story, and what you were sharing with me, so it became a lovely, pointed distraction, to take me away from pain." Further examples of the value of the stories for their distraction and escapism are in section 5.3.5.
- The intimacy of a shared story was important to many, like R3:

> It was the in-depth reading social contact that, and that is an intimate space to be in, because I guess most of us experience reading with our children, like we read with our children, and when you become an adult, like you say, no one reads to us like this. And, and so I think it was that social, the human connection - that might be better. … Yeah, human connection through the process.

The points mentioned above are unique to bibliotherapy and different to just a social visit, so it supports the powerful combination of human warmth and the difference reading can make, but to be certain, a RCT would need to be conducted (with three groups: read-aloud bibliotherapy, social visit and audiobooks).

Systematic observations and interview feedback indicate the powerful combination of in-person, real-time reading aloud and well-chosen stories made a difference to participants. If we were to try and separate the delivery mode from the mechanism (i.e., bibliotherapy), and state it was the bibliotherapy alone that produced these findings, then audiobooks would have been sufficient, but as described in section 6.6, it was the *combination* of the intervention ingredients that participants valued, and which led to producing these positive results. As in this study, participants in Words in Mind (previously RAYS) groups commented on "the use of words to drive discussion" (Brewster & McNicol, 2019, p. 19), where the "words" they refer to are in fact words from the shared texts, and "instead of just making conversation, you've got the book as an intermediary" (Brewster, 2011, p. 196). Brewster (2011) describes two of the benefits of reading aloud as relaxation and establishing camaraderie "using literature as a focus for discussion" (p. 244). These studies add to the argument that for people affected by cancer, there is the potential for greater benefits when there is no pressure on them to contribute to conversation and the focus during a social interaction is on an activity (whether that is mindfulness, humour training, or in this case, stories). Social interaction alone did not produce the same positive results in these other studies.

Jean Houston, author, researcher and philosopher, famously wrote "human connections are deeply nurtured in the field of shared story" (Houston, 1987, p. 91). She described life as a "treasure hunt for story" (Houston, 1987, p. 91), suggesting we connect with great stories, and she always starts her seminars by telling a story. While she may not have been referring to sharing short fictional stories, there is no reason why such stories would not fit her purpose of using stories to set the scene for what was to follow (Houston, 1987). Likewise, the researcher always reads an extract from a short story when presenting to groups – whether they are cancer support groups or psycho-oncology conference audiences. The story extract really does set the scene and engage or connect with the audience. One definition of connection is "the energy that is created between people when they feel seen, heard, and valued; when they can give and receive without judgment" (Brown, 2022, p. 29). Over the course of the 6-week intervention, connections were truly formed. Given the material read together was almost always of an uplifting nature, when some participants felt prompted to share stories about themselves, they were mostly from happy times in their lives – reminiscences – which may have developed connections more quickly. As R8 said, "I think what has been lovely, is the connection we've fostered". While we know connection is important for giving meaning to our lives, improving our QoL, improving our mental health and helping us live longer (Alcaraz et al., 2019; Hawkley & Capitanio, 2015; Yang et al.,

2016) and a shared connection between the participant and the reader was considered important by the participants, that connection was not forged over social chit-chat, but rather by the shared experience of enjoying a story together and sometimes sharing a real-life story prompted by the fictional one.

That stories were the focus of intervention sessions is a concept supported by The Reader Organisation's research, showing the crux of their program's effectiveness exists in the intrinsic value of story "liveness", that is, stories and poems read aloud in the group, making the reading "a centre for the group ... a vocally embodied presence" (Davis et al., n.d., p. 9). Accordingly, a reading aloud model has been described as a practice that both "motivates and constrains social interactions" (Steenberg, 2016, p. 183) and the focus on the text could lead to meaningful conversations that might be difficult in other circumstances (Roemhild & Turner, 2023, p. 4). Although such conversations were not sought during intervention sessions, when participants wanted to talk about stories, sometimes these conversations did come about.

It is widely accepted that it is impossible to separate emotional and physical health. When considering integrative cancer care, or holistic cancer care programs, health care professionals could typically ask questions like: What does the patient need? Which complementary therapies? Which creative modalities: art, music, literature, movement? In this study, parallels were drawn with art and music therapies and the understanding that they can transform pain and despair into hope and beauty by harnessing the imagination (Ettun et al., 2014). Imagination is an essential ingredient in a bibliotherapy program such as this one. It is the ability of the imagination to distract from the current situation that holds the power to produce the effects reported by this study's participants: reduced stress, anxiety and depression, a state of relaxation, mood lift, decreased pain and nausea, and increased self-efficacy for everyday activities.

Throughout the delivery of the intervention and during interviews with participants, the focus and value placed on stories rather than simply the social contact associated with a weekly get-together, provided confidence that the effect of the intervention was through the medium of stories. As previously detailed, the literature shows bibliotherapy can be helpful for many mild to moderate mental health conditions, loneliness and chronic pain (Billington, Humphreys, et al., 2016; Gusmao & de Souza, 2020; Hilhorst et al., 2018; Macdonald et al., 2013; Rane-Szostak & Herth, 1995; Reeves & Stace, 2005; Taleban et al., 2016; Veillette et al., 2019). Analysis of both the qualitative and quantitative data collected in this study show

positive outcomes to emotional wellbeing resulted from participation in the program. Findings showed a personalised read-aloud program for people affected by cancer can be beneficial to their emotional wellbeing and this is important because a cancer diagnosis is associated with high levels of distress (Aldaz et al., 2017) and many treatments invoke unpleasant side effects from which distraction can provide some respite.

6.8 What Part do Libraries Play?

Since this research project contributes unique findings to the field of library and information science (LIS), it is pertinent to ask, 'What part do libraries play?' Libraries are well-placed to provide both reading material and volunteer readers to assist with the implementation of a read-aloud program. This could occur via partnerships between cancer centres, hospices and libraries, or it could occur via hospital staff seeking support from their local library to resource reading material while hospital volunteers are trained to be readers. These strategies have not been researched as part of this project, but given the pragmatic paradigm used, it is reasonable to consider implementation approaches. Additionally, it is reasonable to consider how readers' advisory services could cater for the needs of those with CRCI. Ideas about how libraries might support both an intervention such as the one studied here, and also support people in their communities who are impacted by CRCI are discussed in Appendix O.

6.9 The Golden Stories

The stories of M2, M5 and R8 are of the participants known to have died during or since participating in the program. These compelling stories represent some of the participants with Stage 4 cancer, most of whom were already palliative at the commencement of the program while one became palliative mid-way through. These stories are not anecdotes – they have been created by combining mid-point survey data with systematic weekly observations and interview data. They unequivocally show the value of the reading program and the enormous impact it had on some participants (and their families) during and after the intervention. These accounts are the golden stories, and they are detailed in Appendix P.

These stories are included to illustrate the power of the intervention in palliative and end-of-life settings, which provides an indication of the transferability of the program to other settings, including hospices and as part of community palliative care programs. Transferability is considered another factor for trustworthiness of research or qualitative validity (Lincoln & Guba, 1985), and it is hoped the detail described in these stories is rich enough to allow transfer to these and other situations.

6.10 Relationship to Cancer Plans

The European Beating Cancer Plan does not just focus on the physical aspects of cancer and its treatment – it includes fair access to help with mental health and financial issues (European Commission, 2022). It acknowledges the connection between mental health and cancer is vital, and proposes that the current focus of cancer care needs to shift from being solely on the tumour (or haematological site), and to focus on oncology, surgery, radiology, patients' QoL and wellbeing (including psychosocial and mental health support) (European Commission, 2022, p. 16). Improving QoL is one of the four action areas of the plan, alongside prevention, early detection and diagnosis, and treatment (European Commission, 2022).

The recently released Australian Cancer Plan highlights supportive care as part of its 2-year action plan and specifies consideration of holistic, person-centred approaches to satisfy health needs, including physical, psychological, emotional and financial needs to improve the QoL of patients, carers and families (Cancer Australia, 2024). A draft South Australian Cancer Plan (2024-2028) has been produced, and the second of its three objectives is to "improve the cancer experience for those diagnosed with cancer, and their families" (SA Health, 2023, para. 7). Similarly, the Victorian Cancer Plan (2020-2024) comprises five action areas, with wellbeing and support as one of them (Victorian Department of Health and Human Services, 2020). These plans show the importance of QoL and emotional wellbeing have been recognised both nationally and internationally. A tailored bibliotherapy program is a low-cost psychosocial intervention, which as shown in this study, improved the emotional wellbeing of the participant group and therefore has the potential to improve emotional wellbeing more broadly, leading to improved QoL and an improved cancer experience – addressing key areas of all these cancer plans.

6.11 Discussion Chapter Summary

Anxiety, nervousness, fear, depression and distress frequently accompany cancer diagnoses and treatment (Aldaz et al., 2017; Lunevičiūtė & Masteikienė, 2014; Rankin et al., 2015; Schuurhuizen et al., 2015) and evidence points to bibliotherapy as a useful therapy when physical and mental health conditions coexist (Czernianin et al., 2019). Scores in the overall participant group decreased for stress, anxiety and depression, and increased for wellbeing, showing the successful impact of this bibliotherapeutic intervention on the participants, in terms of supporting the study hypothesis of improved emotional health of cancer patients

undergoing treatment (as indicated by increased self-reported wellbeing and decreased symptoms of anxiety and depression as a result of participating in this read-aloud program).

Cancer centres, hospices and community palliative care programs face challenges implementing innovative complementary treatments to improve the emotional wellbeing of people affected by cancer and provide comfort and respite to their families. These challenges include the existence of research supporting the efficacy of given therapies, co-ordinating patient care, patient education and funding (Greenlee & Shi, 2019). However, a number of complementary therapies, including music therapy, meditation, yoga and massage, are routinely recommended for reducing stress and anxiety, decreasing depression, and improving mood and QoL (Greenlee et al., 2017). Bibliotherapy is a low-cost option shown to help with a range of mental health conditions, thus fitting within the mind-body domain of integrative cancer care (Latte-Naor & Mao, 2019). This study has further shown that the use of imaginative literature may provide additional benefits to physical symptoms such as pain and nausea, making it eminently suited for inclusion in integrative cancer programs.

Looking at RQ1, regarding the impact on emotional wellbeing that resulted from regular participation in the reading program, the findings indicate that regular participation (or even interrupted participation that occurred due to COVID-19 isolations and infections, holidays and hospitalisations) positively impacted participants' relaxation (including improved sleep in some cases), self-efficacy for everyday activities, mood and sense of feeling valued. The program design and personal qualities of the reader were important for these to occur. Additionally, the reading program provided something for participants to look forward to each week and they reflected on the stories afterwards, which prolonged the distraction and escapism effects of the stories read during sessions. Participants spoke of the respite from pain and nausea they experienced while we were reading together, and also that they would not have enjoyed these benefits to the same extent (or at all) if the stories had not been to their liking and had not captured their imagination.

In relation to RQ2, regarding the psychosocial effects of participating in this study, the data collected showed a read-aloud program has the potential for positive psychosocial effects on people affected by cancer - poignantly illustrated by the participants who progressed from distress to laughter pre/post sessions. Family perceptions of the psychosocial effects of the program were only positive, and family members were not only happy their loved ones with cancer were experiencing some happiness, some respite from their symptoms, some care and nurturing, but also that they themselves had the opportunity for some quality time out, knowing their loved one was safe and enjoying the program.

The statistical significance of the wellbeing instruments supports the first part of the hypothesis: ‘The read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment’; while the substantial qualitative findings tell the story of the participants’ and their family members’ experiences and support the second part of the hypothesis: ‘provide a positive experience for those involved’. Noting ‘those involved’ could include nurses in an in-patient setting (which was not the case in this study as there were no in-patients enrolled in the program), and ‘those involved’ certainly includes the reader. In this instance, the researcher was the reader, who experienced joy at each participant’s laugh or exclamation of surprise. It was akin to winning a prize. So, the joy and escapism the program brought participants, the comfort and respite it offered family members and the joy it brought the reader, contribute to ‘a positive experience for those involved’ in accordance with the hypothesis.

Statistically significant change occurred pre- to post-intervention on the quantitative measures of emotional wellbeing and participants gave positive feedback via the qualitative measures. These effects were found in the overall group, even though no statistical significance was found on the quantitative measures in the rural/regional group. However, when methods and data were triangulated, the combined results indicated that the intervention made a positive difference to participants’ mood, through relaxation, increased self-efficacy for everyday activities and pain-relief. Reviewing the literature demonstrates that reading and bibliotherapy can help with a range of mild to moderate mental health conditions and chronic pain. It can be concluded the intervention impacted participants’ lives in a positive and meaningful way, and this is important because, similar to art and music therapies, this also shows an ability to bring comfort and respite, helping to improve the mental health and pain experienced by participants.

Chapter 7. Recommendations and Conclusions

"A book is not going to fix your life, but it can (alongside other medicines or therapy) make life more enjoyable."

-Rachael Johns (Johns, 2024b, para. 11)

This study explored the effects of a personalised read-aloud program on the wellbeing of cancer patients undergoing, or within a year of, treatment. This exploration, conducted on a phenomenological group using a participatory lens within a pragmatic paradigm, involved collecting and analysing both quantitative and qualitative data. Quantitative analysis was necessarily positivist, with inferential statistical testing on pre- and post-intervention scores on validated wellbeing instruments. Qualitative analysis was conducted using an essentialist epistemology with an experiential orientation to the data and coded semantically using an inductive analysis approach. The qualitative and quantitative data were compared then synthesised, which produced support for personalised read-aloud programs in integrative oncology.

Chapter 1 summarised information about reading and cancer, and the difficulty many people affected by cancer experience with reading, setting the scene for the study. The aim of the research and questions to be addressed by the study were raised. No published studies of read-aloud bibliotherapy programs for people affected by cancer were found at the time of this research, so Chapter 2 reviewed the literature on associated topics and reinforced the gap that this research addresses. Chapter 2 included a background and history of bibliotherapy, relevant studies of bibliotherapy, storytelling, and studies using didactic or creative materials as bibliotherapeutic interventions in cancer settings. Bibliotherapy has been seen as an effective tool for mild to moderate mental health conditions (Gusmao & de Souza, 2020; Macdonald et al., 2013; Reeves & Stace, 2005; Taleban et al., 2016), and although it comes in many guises, it is generally implemented either via cognitive based therapeutic self-help books or fiction and poetry. With societal values driving our thirst for information and lifelong learning, the concept of reading for simple pleasure, even escapism, is often seen as an inferior reason to read (refer sections 6.3 and 6.5.2). Yet reading fiction has more proven benefits to our health and personal development than reading non-fiction or newspapers (Bavishi et al., 2016).

Chapter 3 described the theoretical underpinnings of the design decisions and methods employed in the study. A discussion about the inclusion and exclusion criteria for recruitment followed, along with recruitment strategies. Details of the analytical methods that were conducted following data collection at the various junctures in the study were described: qualitative at intervention enrolment to inform intervention delivery, quantitative at the first session to set a wellbeing baseline, qualitative throughout the intervention with the recording of systematic observations and the mid-point survey, quantitative at the last session to enable a measurement of potential wellbeing change, and qualitative at the end via interviews.

Findings from the quantitative analysis of wellbeing instruments were presented in Chapter 4 and the results from the thematic analysis of interviews with participants and family members were presented in Chapter 5. Statistically significant reductions in stress, anxiety and depression, and increased wellbeing were demonstrated from pre- to post-intervention, and themes of program enjoyment and improved wellbeing, including relaxation, mood lift, increased self-efficacy for everyday activities, pain relief and relief from nausea were described.

In Chapter 6, the qualitative and quantitative findings were triangulated and presented as key topics relevant to foundational and current understandings in both bibliotherapy and psycho-oncology: the importance of individual tailoring and delivery of the intervention to each participant; some gender and metropolitan/RR/Zoom differences; strengths and limitations of the study, including participant reading attitudes and the difficulties associated with implementing a standard reading attitudes and habits survey to people affected by CRCI; and the presentation and implication of CRCI in the participant group with potential wider implications to future studies of people affected by cancer. Important questions about the design and implementation were considered and explained: why the researcher utilised an in-person real-time delivery, and also how we know the program's success was not just a result of the social contact that came as a consequence of this delivery method. The role of libraries was considered, as public libraries could form partnerships with palliative care services and cancer centres to help facilitate the implementation of reading programs like the one explored here, and this was discussed in light of some Australian public library frameworks. Finally, the most poignant stories, those of some of the palliative participants, were presented to highlight how the reading program made a huge impact on these participants and their families, accentuating how meaningful it was to them and correspondingly, how suitable it would be as part of routine palliative care programs, before a brief look at how this program is related to current cancer plans.

This research highlighted that reinstating the therapeutic benefits of reading to people affected by cancer is not a complicated process, but it does rely on a mechanism other than visual processing (that is, listening) combined with customisation of reading material and the warmth of one-to-one personal contact. The qualitative data identified these intricately linked elements, woven together through the intervention design and delivery, contributed to the positive outcomes experienced by participants. The reading program offered people affected by cancer the time to enjoy the therapeutic benefits of reading, including reduced stress, anxiety and depression, and improved wellbeing, in an environment that supported relaxation, provided warmth and nurturing, and distraction from pain, nausea and worries. The emotional wellbeing of people affected by cancer can be fragile and is complicated by the presence of CRCI (Lange et al., 2019). The findings of this study support and refine the role and relevance of bibliotherapy, and the way in which the individual elements of CRCI, bibliotherapy and the warmth of human presence fit together in practice to foster improved emotional wellbeing has been described.

The primary goal of medical care is to alleviate suffering, which is verily considered the assessment and treatment of total pain - the sum of physical, psychological, spiritual and social pain (Rome et al., 2011). Especially at end of life, treating total pain is important because physical pain, psychological distress and lack of social support are associated (Zaza & Baine, 2002). Across the continuum of the cancer journey, integrative cancer care, comprising a multidisciplinary team approach, has been shown to help with relieving some distress, distract from pain and provide additional social support. This research has shown that this reading program did all those things (relieved some distress, distracted from pain and provided additional social support) and therefore it could be a part of a multidisciplinary team approach. The findings reinforce the value of creative therapies (ANZACATA, 2021) for the often-untreated distress that frequently accompanies cancer diagnosis and treatment (Cardy et al., 2006; Galway et al., 2012; Lally et al., 2020) and further illustrate the value of bibliotherapy. Based on these findings, a read-aloud bibliotherapy program would be a fitting addition to the integrative and palliative cancer suites.

Throughout chapters two, five and six, the interconnectedness of themes was demonstrated: the benefits of bibliotherapy (especially using fiction), the role of storytelling (or listening rather than reading visually), CRCI, the value of creative therapies and social support. Ingredients of the intervention may be described as the use of short stories to achieve a sense of success and mitigate the need for remembering from session to session, customisation of reading material, one-on-one delivery in-person whenever possible, and low participant

burden by removing the need to travel to participate. This is important to note for the design of future programs, as the blending of these program characteristics during design and delivery phases was important for achieving meaningful results that demonstrate the value of this read-aloud program to people undergoing cancer treatment and their families. It has been argued that the statistically significant results and participant feedback support the hypothesis, as summarised below.

7.1 Key Findings of this Study

Research question 1: What impact does regular participation in a read-aloud program have on the emotional wellbeing of cancer patients currently undergoing treatment?

This research examined the emotional wellbeing of cancer patients currently undergoing (or within a year of) treatment, with both quantitative and qualitative results revealing improved emotional wellbeing after participating in this reading program. Quantitative results indicated this improvement was statistically significant. Qualitative results showed evidence of improved mood and distraction from pain, illness, treatment, side effects and worries in general. Participants reported an increase in self-efficacy for everyday activities, which was another indication of improved emotional wellbeing. Qualitative results via observation then interview attested to the fact that participants looked forward to sessions and speculated about the choice of stories, which also points to mood lift and increased emotional wellbeing. Based on the results of this study, this read-aloud program resulted in improved emotional wellbeing in cancer patients currently undergoing treatment.

Research question 2: What are the psychosocial effects of read-aloud programs from the perspectives of patients and families?

This research question was addressed through quantitative analysis of pre- and post-intervention self-report measures and through interviews with patients and family members. The psychosocial effects of the read-aloud program were numerous: decreased symptoms of stress, anxiety and depression, and increased wellbeing (all measured quantitatively), improved mood and relaxation (observed and self-reported) and also positive effects on family members (self-reported during interviews) such as experiencing pleasure or comfort knowing their loved one was enjoying the program and was more relaxed, as well as the relief of sharing their caring load (however briefly) and some time of respite from undertaking this role themselves which enabled them to undertake an activity of their own choosing during intervention sessions. The program design and qualities of the reader were

important for producing these positive outcomes. Based on the results of this study, cancer patients undergoing treatment and participating in a read-aloud program experienced a reduction in stress, anxiety and depression (all emotional/psychological issues) and participants described improvements correlating to the other psychosocial domains, such as reading and distraction (behavioural domain) and social interaction (social domain). Family members perceived their loved ones as more relaxed and happier after reading sessions, with many enjoying the stories shared as a topic of family conversation, providing welcome deviation from cancer-related topics.

Hypothesis: The read-aloud program will be associated with improvements in the emotional health of cancer patients undergoing treatment, as indicated by increased self-reported wellbeing and decreased symptoms of stress, anxiety and depression, and will provide a positive experience for those involved.

This study has shown the potential effectiveness of a personalised read-aloud bibliotherapy program for improving emotional health: demonstrated by statistically significant reductions in stress, anxiety and depression symptoms (as measured by DASS-21) and increased mental wellbeing (as measured by WEMWBS). The qualitative analysis supported these findings with participants reporting the program provided a positive and relaxing experience that served to effectively distract them from cancer treatment, distress and pain, and bring comfort to family members, thus according it a positive experience to all. Given the known link between mood and pain (Bjurstrom & Irwin, 2016; Fishbain et al., 2003; Gatchel et al., 2007; Snekkevik et al., 2014), the pain benefits may also have resulted from participants' improved mood which resulted from participation and enjoyment of the program. This supports all aspects of the study hypothesis.

7.2 Contribution of this Study

This research project contributes unique findings to the fields of library and information science, integrative oncology and psycho-oncology. Whilst the individual issues of CRCI, self-administered and group bibliotherapy and the (unmet) emotional needs of patients during cancer treatment are documented (refer Chapter 2), there have been no studies exploring the interaction of readers and cancer patients, and the possible effects of bibliotherapy through regular read-aloud sessions on patient wellbeing. The ability of this study to support its hypothesis and demonstrate the value of the read-aloud program, particularly to people affected by cancer, but also to their loved ones, is a significant contribution. Real-world

application of this contribution is not a complex task – reading to people is not difficult – and so these findings matter because they have the potential to improve the emotional wellbeing of people affected by cancer and therefore are relevant to cancer centres (and hopefully libraries with whom partnerships can be formed) and families of people with cancer.

This study makes a modest contribution to current understandings of the impact of CRCI, particularly with respect to its impact on reading and listening. Although the self-reported CRCI incidence in this study was higher than is generally reported, this study lacked the statistical power to draw conclusions about it, and it simply may have been that people affected by CRCI were attracted to participate in this study and thus a recruitment bias towards people with CRCI may have occurred, although this does not detract from the methodological rigour of the study. Reading can play a vital role in managing mental health issues, including distress, yet reading can be impossible for people experiencing CRCI.

This study also contributes to knowledge about the use of creative therapies in integrative oncology. With the evidence base already established for movement, mindfulness, art and music therapies, and with growing awareness of the comfort and respite that can result from emerging therapies such as pet therapy and humour/laughter therapy, this study provides evidence for the potential role of bibliotherapy in integrative oncology programs, as well as palliative care programs and in hospices. This is timely with the ever-increasing numbers of people being diagnosed with cancer but also the increasing rates of living longer with cancer (refer Chapter 1), the challenge this creates for the provision of psychosocial support when needed, and the emergence of more integrative cancer centres and cancer wellness centres.

These findings contribute to the evidence base for the usefulness of bibliotherapy, and they provide support for the implementation of programs that may improve the experience of living through cancer treatment, even if only by providing a respite from the distress of cancer. The original contribution is showing how bibliotherapy through a read-aloud program can sit alongside other complementary therapies aimed at improving the emotional wellbeing of people affected by cancer. These findings provide evidence that may be used for advocating to make psychosocial interventions more commonplace for cancer patients, in particular under the guise of bibliotherapy and reading aloud to cancer patients suffering cognitive impairment.

7.3 Suggestions for Future Read-Aloud Research

The implications of this research are applicable to a variety of contexts. The findings provide justification for reading innovations for people affected by cancer - initiating an evidence base to support it and also to advocate for further research both in this area and within a general palliative context. This study offers a new way to understand the link between listening during CRCI, the therapeutic benefits of reading, the warmth of human connection and the benefits of low program burden. The intervention developed in this study was not delivered during cancer treatment sessions, although it is suitable to be conducted during treatment (some participant feedback supports this). Rural and regional people who need companionship while in the city receiving treatment may find this particularly helpful as it has the potential to not only distract from discomfort but also from feelings of aloneness.

Based on overwhelming qualitative participant feedback, it is important that any future programs maintain personalised delivery, as this made participants feel important and cared for. Small group programs do have a place in bibliotherapy programs, for instance the SR and RAYS programs described in Chapter 2, but such programs have not been set in a cancer context, and for people affected by cancer, this research strongly supports individual delivery because it set participants at ease (with only themselves and a reader present), reduced their participation burden by eliminating their need to travel and (most importantly) allowed for personalisation of the reading material and the delivery. Additionally, a larger project could have the resources to source volunteer readers in other states, to visit people in their homes or local libraries.

Based on reader experiences during this study, any future studies should ensure all readers are at least trained in psychological first aid, as well as general first aid, and more detailed current health information should be sought. Additionally, given the positive effect most participants experienced from humorous stories, and the known benefits of humour on health, a future study could focus specifically on humorous stories. Furthermore, as recruitment appears to be difficult for most interventions with people with cancer, future research could explore reasons for recruitment difficulties and possible barriers to participation.

Some participants expressed sadness at the program ending, did not have a substitute for this weekly time slot and were anticipating feeling a loss. This was similar to feelings expressed by users of RA services who were surveyed at the height of the pandemic: “my only problem is that I want to be friends with my recommending librarian so we can talk about the books” (Lockley et al., 2021, p. 192). Lockley and colleagues (2021) also found “human exchange”

(p. 192) about books and reading was important for their users. Therefore, it is recommended that any future studies have a connection in place with another service, such as Red Cross Aged Care Volunteer Visitors Scheme for over 70s living in metropolitan areas (where perhaps the friend/visitor could be asked to read aloud), and search for other schemes for younger people so that sense of loss, the breaking of a connection, is not felt so keenly. Specific strategies for support are needed at the conclusion of bibliotherapy programs.

Given so many participants said the program was relaxing, and one participant even said she could feel her heart rate and blood pressure go down while listening, a future study of read-aloud programs for adults undergoing cancer treatment could involve attaching blood pressure and heart rate monitors to participants, or other non-invasive methods of measuring physical effects. This suggestion is supported by the stress-reducing effects of reading found in studies by Rizzolo and colleagues (2009) and Lewis (Chiles, 2009; Galaxy, 2009). Likewise, with bibliotherapy's link to chronic pain relief (Billington, Humphreys, et al., 2016; National Association of Primary Care (NAPC), 2016; Veillette et al., 2019), and the comments about pain relief expressed by participants in this study, further investigations into read-aloud programs for cancer patients experiencing chronic pain are warranted.

With the link between CRCI and reduced brain connectivity, a reading program could form the basis of cognitive retraining for people suffering CRCI after the conclusion of their treatment, especially considering the evidence around reading building neural pathways. Additionally, research exploring the role listening to stories can play in potentially improving confidence with understanding (leading to more confident conversation) with those suffering aphasia would be worthwhile.

Given the complexities with randomised controlled trials (RCTs) in a population affected by cancer (refer section 3.1), future studies could include a control group receiving a weekly social visit of similar duration, or a group that is read material that is not catered to their individual interests, as well as a group charged with listening to selected audiobooks in order to compare results with this study (where participants valued the reading aloud in preference to a recording). A future study could also administer pre- and post-intervention wellbeing instruments then administer them again at a future point in time, perhaps three or six months later to evaluate whether outcomes are maintained over time. It is not recommended the ASRA be used in future studies as there is little confidence in the ASRA results in this group, as discussed in section 6.5.2 (and Appendix M). If a similar tool is developed and validated for use with people experiencing cognitive impairment, then that tool could be used,

otherwise it would be better to not attempt to measure reading attitudes and habits quantitatively.

Based on this research, a grant application to implement a read-aloud program aimed at improving the emotional wellbeing of children undergoing cancer treatment was recently applied for and was successful (Channel 7 Children's Research Foundation, 2023). The same personalised approach to choosing reading material and one-to-one delivery was core to the application, which has a strong co-design emphasis, and will use standard wellbeing measures appropriate to this younger cohort. It is hoped similar improvements in wellbeing will be seen, which will hopefully aid the participants' transition back to school at the completion of their treatment, or provide some comfort for palliative participants and their families.

7.4 Implications and Future Directions

When the germ of this research idea began in a small country library in the Victorian central highlands, after noticing a pattern among avid readers undergoing cancer treatment abandoning their reading for pleasure and all the therapeutic benefits that accompany reading, it was hoped a way forward could be found to reinstate those benefits. At the time, those readers were directed to large print books, magazines and audiobooks. However, this exploratory study has shown that the intervention of another person to read aloud may hold a key to relieving some distress and pain, provide relaxation and distraction and a statistically significant improvement in mental wellbeing. Therefore, this program is recommended for implementation at cancer centres. It is eminently suitable to be situated alongside other complementary evidence-based therapies, such as art, music, movement and touch. It is the researcher's hope (and dream) that a personalised, read-aloud, bibliotherapy program will become a recognised therapy in integrative oncology.

Considering the links between distress, depression and treatment non-compliance (Adler & Page, 2008; DiMatteo et al., 2000), and conversely increased QoL and treatment compliance (DiMatteo et al., 2000; Greer et al., 2008), complementary therapies have an important role to play. The framework for including new complementary therapies into integrative oncology is that they must "optimise outcomes; enhance the experience of people with cancer and their families; support treatment goals and adherence; manage side effects; provide emotional support" (McDonald et al., 2022, p. 7). In light of the findings presented in the preceding chapters, it can be concluded that this read-aloud bibliotherapy program meets the criteria of the framework to be included in the integrative oncology toolkit.

The value most participants placed on not needing to travel (or to travel only as far as their local library) is vital for the formation of future reading programs, so their uptake can be as widespread as possible. This means the program is likely to be best suited to in-patient wards, including hospice, chemotherapy infusion suites and via community delivery (in homes and libraries or local health centres). Trained hospital or library volunteers could be involved in reading, with the support of an experienced librarian or bibliotherapist.

Australian Cancer Councils produce excellent pamphlets to help those newly diagnosed, undergoing treatment, or just finished treatment (and their families) but there are no references to either bibliotherapy or read-aloud programs and their potential benefits. With this research showing benefits to emotional wellbeing, the inclusion of bibliotherapy in the list of complementary therapies in such pamphlets and in the toolkits of health care providers may be a prudent direction.

Approximately half the participant group were palliative, and thus the transferability of the read-aloud program to hospices and community palliative care units is apparent. Equally, with the experiences and effects of reading to participants near end of life, transferability to this setting is also plausible. When considering the suitability of the program for palliative settings, it is likely to be useful in general palliative care - not just for people affected by cancer. Of the drugs typically used in palliative settings, the three often prescribed for nerve pain (gabapentin, pregabalin and amitriptyline) have cognitive side effects similar to chemotherapy (Knegtering et al., 1994; Oh et al., 2022; Zaccara et al., 2011) making reading aloud a more accessible way of ingesting a story than attempting to read to oneself, just as we saw in many of the participants of this study. Bringing laughter to the palliative participants in this study was joyful for the participant, their loved ones and the reader. Further along the palliative trajectory, to be able to bring distraction and comfort near end of life is a privilege, and although that only happened twice during this study, it shows promise for a future additional application.

7.5 A New Bibliotherapy Model

A suitable name for the program developed and studied here could be ‘Read-Aloud for Wellbeing’ (RAW). It is a person-centred, individually tailored approach and combines the warmth of real-time in-person reading aloud with the powerful effect of distraction from well-chosen stories. With empathy and compassion at its heart, this model or approach seeks to restore the therapeutic benefits of reading to individuals undergoing cancer treatment or those who have recently completed cancer treatment, especially for those impacted by CRCI.

This model is steeped in reader response theory and the long-acknowledged role of escapism/distraction for providing solace and respite. Reading for the relief of physical symptoms (such as pain) and emotional distress via escapism/distraction has a long history and is still recognised today as an important outcome of reading. In order to keep participant burden low, comments about the stories themselves or memories the stories invoke would always be welcome from participants but are not essential. Comprehension will never be tested and there will be no pauses in reading to test for predictions about what might happen next within this model as both these tasks would likely be too difficult (and thus stressful) for some people suffering CRCI. The essential component, however, is that the reader is fully present with the participant and the story, as this speaks directly to the need for caring human interaction and reinstatement of stories with all their therapeutic benefits. This study has demonstrated the effectiveness of this approach in the cancer community.

7.6 Concluding Comments

The burden of cancer can be immense, for both the person diagnosed and their families. Consider some of the many hurdles that may be part of the experience of people affected by cancer: emotional impacts, including distress; physical impacts, including recovering from surgery, treatment side effects and pain; relationship impacts, including familial and workplace; financial impacts; and cognitive impacts resulting from cancer itself or from treatment-induced CRCI. Building upon the researcher's first-hand experience of cancer through her own diagnosis and treatment, and through her support of her mother, friends, colleagues and regular library patrons on their cancer journeys, this study has provided an in-depth objective assessment of the effect reading, particularly fiction (as well as narrative non-fiction and poetry), can have on the emotional wellbeing of people experiencing cancer. The warmth of a caring reader, the lack of expectation around contributing to the reading experience, the ease of understanding a story read aloud rather than trying to make sense of reading to oneself when plagued by CRCI, the anticipation of the next reading session and the reflection on the last one, and of course the value of the carefully chosen story for each person at each session, all contributed to making a difference in the lives of the participants in this study.

Determining whether or not the effects of the program continued for weeks or months beyond the end of the intervention, was beyond the scope of this study. It is known that CRCI can last a considerable length of time after treatment concludes and it is also known that some cancer types and treatment combinations result in worse or more prevalent CRCI than others (refer

section 2.4.2). Amongst the participants who had finished treatment, or were less affected by CRCI, many felt inspired to try reading for themselves again at the conclusion of the intervention in order to keep their improved moods and distraction from worries and pain continuing, which also points to the difference this reading program made in their lives.

Sharing stories may be a way to remind people with a terrible diagnosis that life is not over yet and there are still some things that can be enjoyed. Even the study's two participants with brain cancer, both with disabilities resulting from their treatment, were able to listen and enjoy stories. Proponents of poetry therapy remind us of the importance of experiencing some pleasure: "such a programme could help individuals to derive more enjoyment from life and living, after all, without enjoyment as T.S. Eliot noted in his poem, 'Chorus from the Rock', 'Where is the life we have lost in living?'" (Philipp, 2010, p. 58).

Reading has so many benefits: decreased anxiety, depression and loneliness, increased empathy, protection from some ailments and from some physical harm (refer section 2.1). It has the potential to provide a place of respite from pain and some treatment side effects. Reading is free entertainment (after all, libraries are free), and other than literacy, special skills are not needed to operate a book. It stimulates the imagination and frees us from the confines of our bodies. However, CRCI can impact the ability to read effectively and consequently all the wonderful attributes of reading can be lost on people undergoing cancer treatment unless some intervention exists to reinstate these benefits. As this research has shown, read-aloud programs may be the answer. This study, using methodological rigour, has demonstrated that a tailored read-aloud program has the potential to increase wellbeing and decrease symptoms of anxiety and depression, and provide a positive experience for all involved.

Storytelling has been part of cultures for eons and the natural warmth of connection with an empathetic person can be a tonic. Combining these ideas into a personalised, face-to-face read-aloud program provided respite, transformed mood, improved participants' days (and also their sleep) and was simply an enjoyable experience. It is rare to find someone unaffected by cancer, whether it is their own cancer journey, or that of a loved one or friend. This research shows statistically significant positive impacts on the emotional wellbeing of people undergoing cancer treatment and their families. Decreased stress, anxiety and depression scores, increased wellbeing scores, and interview themes all demonstrate the positive impact of this intervention, supporting the study hypothesis: improved emotional health of cancer patients undergoing treatment, associated with participating in this read-

aloud program. Reading together is such a simple but powerful idea and may be the missing psychosocial modality in the integrative oncology toolkit. The researcher is honoured to share these results and hopes to help cancer centres, community palliative care teams and hospices implement reading programs.

"Cancer is messy and scary. You throw everything at it, but don't forget to throw love at it. It turns out that might be the best weapon of all." (Brett, 2013, para. 15)

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Appendices

Appendix A – The Transformed PhD

As part of this research project, the following research translations were undertaken –

- Interviews with librarians overseas regarding their adult storytimes
- Attendance at an adult storytime in Adelaide
- Writing for cancer support organisation newsletters and magazines such as:
    - 'Therapeutic effects of reading in cancer recovery', YWCA's Encore newsletter November 2023.
    - 'Volunteers needed for University of South Australia research study on listening to fiction to improve emotional wellbeing during cancer treatment', *Myeloma Muster*, Myeloma Foundation of Australia Inc., September 2022.
    - 'Read aloud for wellbeing during cancer treatment', *MyeNews,* September 2022.
    - 'Read aloud programs for cancer patients research', Australian Council for Adult Literacy (ACAL) newsletter, May 2021.

- A social media presence became necessary to disseminate recruitment flyers and consequently appropriate skills were learned. Refer FB and Instagram handles Reading for Wellbeing: https://www.facebook.com/profile.php?id=100083124141168 and https://www.instagram.com/reading.for.wellbeing/ . Additionally, social media posts were written for Cancer Council SA and SA RSL. A LinkedIn presence was created, and used to forge new professional connections, within both the libraries and health sectors (predominantly in Australia), as well as with The Reading Agency and The Reader in the UK.
- Attempted to negotiate a UK visit to help translate this research into a program that would have been of benefit to people affected by cancer (and their families) in Australia and overseas. After all, contributing to society is the end-goal. Unfortunately, funding became a problem, and this did not proceed.
- Volunteered to help two other studies as a participant: PhD project collecting cancer stories in Adelaide and St Vincent Hospital Melbourne study about CRCI.

Conference presentations

'Bibliotherapy program to improve emotional wellbeing during cancer treatment', ALIA National Conference, May 2024 in Adelaide.
https://alianational2024.alia.org.au/program/bibliotherapy/

‘Bibliotherapy program for emotional wellbeing during cancer treatment’, Australian Library and Information Association (ALIA) Library Technicians' Symposium, March 2024 online. file:///Users/user/Downloads/2024%20LibTech%20Program%207.3.24.pdf

‘Reading aloud to cancer patients for improved emotional wellbeing’, CP3 UniSA - Health & Humanities Symposium, November 2023 in Adelaide.

‘Bibliotherapy program to improve emotional wellbeing during cancer treatment’, Psycho-oncology Co-operative Research Group (PoCoG) Annual Scientific Meeting, September 2023 in Melbourne (poster presentation).

‘Bibliotherapy program to improve emotional wellbeing during cancer treatment’, International Psycho-oncology Society conference 2023 (IPOS 2023), September 2023 in Milan. https://journals.lww.com/jporp/toc/2023/09001

‘Reading aloud to cancer patients for improved emotional wellbeing’, University of South Australia STEM Research Day, June 2023 in Adelaide.

‘Reading aloud to cancer patients for improved emotional wellbeing’, Research Applications, Information and Library Studies (RAILS) Conference, November 2022 online.

Survivorship panel discussion, Otorhinolaryngology Head & Neck Nurses Group Inc Annual Conference, June 2022 in Adelaide

‘Cancer-related Cognitive Impairment’, Myeloma Month webinar, Myeloma Foundation of Australia, May 2022 online.

Other presentations

Radio interview - ‘Read-aloud program for people during cancer’, ABC Victoria & ABC Melbourne, December 2023.

Radio interview - ‘Bibliotherapy’, Mind Ya Head on MainFM, October 2022.

Podcast interview - ‘The Healing Power of Bibliotherapy’, Tsundoku, October 2022.

Radio interview - ‘The power of reading escapist fiction to cancer patients’, ABC Radio Adelaide, April 2022.

Television interview - ‘Reading therapy study for cancer patients’, Channel 9 News Adelaide, April 2022.

Cancer support group and hospital staff presentations - ‘Reading aloud for wellbeing during cancer treatment’, presented at:

- Compass Cancer Support Group in Mitchell Park (March 2022)
- Head and Neck Cancer Support Group in Kurralta Park (March 2022)
- Myeloma Support Group in Marion (March 2022)
- Neuroendocrine Tumours Support Group in Adelaide (April 2022)
- Pink Sisters Walking Group in Gawler (May 2022)
- YWCA Encore Group in Angle Park (August and November 2022)
- YWCA Encore Group in Victor Harbour (September 2022)
- YWCA Encore Group in Noarlunga (September 2022)
- YWCA Encore Group in Brighton (September and November 2022)
- St Andrew’s Chemotherapy Suite staff (September 2022)
- Flinders Medical Centre Chemotherapy Suite staff (September 2022)
- Southern Adelaide Palliative Service staff (via Flinders Medical Centre) (September 2022)
- Copper Coast Prostate Cancer Support Group in Kadina (October 2022)
- Limestone Coast Prostate Cancer Support Group in Mount Gambier (October 2022) - cancelled

Other publications

Media release, including video, created by UniSA’s media department: https://www.unisa.edu.au/media-centre/Releases/2022/in-reality-escapist-fiction-could-be-what-the-doctor-orders/

‘In reality, escapist fiction could be what doctor orders’, *The National Tribune,* 2022 April 27 – based on the UniSA media release.

‘Responding to cancer fog’, *Northern Living,* 2020 May – based on an interview with the editor.

Appendix B – Program Practicalities

All projects have practical considerations. The key factors with this project centred on the logistics of visiting participants, determination of accurate reading times for stories and COVID-19.

For the safety of the reader/researcher, a participant contact details spreadsheet was maintained on the RDS, which was a shared access document with supervisors, and the researcher shared her calendar with the principal supervisor. The onsite safety protocol was the sending of a text message on arrival and when leaving participants' homes. This was not done when meeting in a public place or on the university campus. The protocol was for the supervisor to attempt to contact the researcher using her mobile phone number after the passing of about an hour since the first text message, if no subsequent message had been received. If the supervisor received no answer, she would contact the participant whose session it was, and if there was no answer or they refused to put the reader on the phone, the police would be called. Fortunately, this protocol was never activated.

Travel logistics existed around feasible travelling distances, the combining of trips to lessen travel times and the number of participants that could be reasonably seen in one day. Some RR participants were within reasonable driving distance of Adelaide and face-to-face visits were feasible when combined with visits to other participants on the same day. One RR participant was happy to meet half-way between her home and Adelaide and she also indicated her enjoyment of the program, despite the travel involved. Additionally, researcher fatigue resulted in the need to become stricter about combining trips. Sometimes four participants could be seen in one day, which was in itself tiring. Some potential RR participants approached the research team some considerable time after seeing a presentation at a local cancer support group and only wanted in-person visits (not Zoom) but they were not accommodated because the bulk of the interested people in their area had already (or almost) completed the intervention, as the travel area and time had to be delimited. Travel of around an hour to see a participant (along the route to see multiple participants) was feasible but the delimiting process meant individuals beyond that distance could not enrol for face-to-face visits. Into the mix of these travel logistics was the often almost-full diaries of some participants - working around their existing commitments and maintaining a reasonable balance of driving, visits, time to write reflections and observations, and time to prepare for the following day all had to be considered.

Differences in participant conduct resulted in another program practicality. A few participants liked to close their eyes while listening, apparently to help their concentration. I could generally tell if someone was awake or asleep, with one exception: M22 who appeared asleep during our first session, and even when I stopped reading, paused then asked if he was asleep and had no answer, before he jerked upright, claiming he was not asleep. He mentioned this in his interview, giving a long explanation of his ability to conserve energy and appear to be asleep, while actually absorbing what is being said. That felt like excuses and perhaps embarrassment at being seen sleeping. R2 fell asleep on one occasion mid-way through the program and was most embarrassed by it. Remembering that as a regional participant, he was far from home, undergoing active treatment, with severe anxiety and difficulties sleeping at night, it was perhaps a great indication of the ability of the shared story to relax him sufficiently to sleep. When it happened, I waited a little while, then woke him, we recapped the part of the story he had missed, and we moved on. There was one other occasion when a participant appeared to be struggling to stay awake – R7, another regional participant, having his reading sessions via Zoom. He was anxious about his upcoming scans. On one occasion I could see him battling with his eyelids, and so the dialogue became much louder (almost shouting) which fitted the storyline at the time and his sleepy state vanished. M8, who never actually fell asleep in a session, but had perhaps worried he would, especially at the 'wrong' juncture of his chemotherapy cycle, realised that the personalised sessions would allow for this. In his interview, he indicated having a real person reading to him in real time was superior to anything pre-recorded and said: "If I would be too tired, asleep, yes, so maybe raise your voice a little bit or ask me a question or something like that yeah. So what it means is that's all the difference".

Requests for evening and weekend program delivery were received by potential and enrolling participants. Evenings were considered in cases of potential participants with full-time working or caring commitments, although the personal safety of the reader/researcher had to be paramount and so evening sessions were only ever held in public spaces such as a library. When a retired potential participant asked about sessions on Saturdays, the opportunity to enrol them was declined on the basis of the reader/researcher needing a work/life balance and already having a weekly Saturday commitment. There was a sense that some potential participants made excuses to not participate, perhaps due to reading attitudes, but this cannot be confirmed. Given participation was completely voluntary, there were no attempts to persuade or insist.

Holding a psychological first aid qualification was an additional practical measure. Although one participant presented as distressed at the start of half the sessions and one spouse became distressed during the interview, the researcher was able to de-escalate the distress and the Distress Protocol (refer Appendix Q) that was created was not used.

Another practical consideration was that of COVID-19 exposure and the use of Rapid Antigen Tests (RAT) and masks. Although the COVID-19 protocol for this study contained specifics about social distancing, handwashing and the disinfection of book covers and pens, a mask-wearing exemption was applicable: "Where the nature of the work or education means that clear enunciation (ie speech) or visibility of their mouth is essential. This includes teachers, lecturers, broadcasters or call centre staff" (Refer https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/infectious+diseases/covid-19/about+covid-19/protecting+yourself+and+others+from+covid-19/face+masks/face+masks). On one occasion, a mask was worn while reading to a participant because of her anxiety around potential COVID-19 exposure and she wore a mask at all sessions. When the researcher felt at potential COVID-19 risk, a RAT was performed prior to being near participants, all of whom were considered immunocompromised by the research team.

Chemotherapy cycles were another practical consideration. Some people can feel fine the following day or two after an infusion, then they may become sick, but others can be at their worst the next day. There was a need to be aware of nausea and fatigue. However, participants reported that the intervention sessions distracted them from feeling sick (refer Chapter 6).

Attracting sufficient participants is vital to studies like this. As part of the evolving recruitment strategy, PhD student skills needed to expand to include marketing and public speaking. This was challenging but necessary.

Aside from the challenges recruiting participants for this study (refer sections 3.4 and 6.5), the recruitment process attracted people who misread or misunderstood the recruitment posters and flyers, which is mentioned here for the consideration of future studies or implementation of this (or similar) reading interventions. Some people saw the participant recruitment poster or flyer and thought volunteers were being sought to read to people undergoing cancer treatment, even though the eligibility criteria were clearly laid out in dot points, and one of those criteria was to be currently undergoing or within 12 months of cancer treatment. Additionally, some people long past cancer treatment wanted to help, and people

who heard/saw the radio/tv interviews also contacted the research office wanting to help with reading. At one stage, there were more potential volunteer readers noted down than participants, but through a combination of the requirement for COVID-19 vaccination, the need for a reasonably small geographic distance between potential volunteer and participant, and the difficulty with getting reading material to volunteers (especially if they were not library members), volunteers were ultimately not used in this study. Implementation of this reading program would likely involve volunteer training and ready access to reading material (either through a small collection in a cancer centre or via a partnership with a local library).

The reading-aloud skill of the reader is a consideration of paramount importance. During interviews, M6 expressed the opinion that I had a lisp, which was confusing both at the time and later in discussions with the research team. Questioning him further about this at the time, he decided that perhaps it was my interstate accent that made some vowel sounds different to those of a South Australian. Without further information, we are obliged to take his comment on board as an issue of accent, something which is very difficult to adjust, but something to consider in future implementations of read-aloud programs and the choice of suitable readers.

Appendix C – Book Selection Minutiae

While working in public libraries, the researcher regularly encountered occasions where people assumed library staff had read all the classics and could speak at length about them. In Australia, 35% of regular readers deliberately try to include more classics in their reading (Australia Reads 2021, 2023), and the question begs: why? Aside from the idea that many library patrons seem to think that librarians have read every book on the shelves, there is still the notion in the community that somehow people who read from the literary canon are smarter (perhaps because the classics are often considered difficult to read and understand), and this is supported by university-level English major students (Adams, 2021). Some English literature academics have attempted to explain this common viewpoint as "to master the classics is to remake ourselves in their image, to subordinate ourselves to their powerful efficacy" (Radway, 1994, p. 278), suggesting readers think they will improve themselves by reading them, yet the perpetuation of the idea that people should read classics because it is 'good for us' is unfounded. People quit smoking, reduce their alcohol and red meat consumption, exercise and try to remember to drink eight glasses of water a day because it is 'good for us'. However, studies show that reading and language invoke 17 areas of the brain (Shaywitz et al., 1998, p. 2637) and in section 2.1 other benefits of reading were described. These benefits are not dependent on the type of books read (although, as described earlier, reading fiction makes people more empathetic). Reading should be enjoyed and so it is time to reconsider the materials traditionally used for bibliotherapy, to also include material for distraction and escapism, that is, to read about someone or something that does not necessarily remind people about themselves and thus be given the opportunity to temporarily forget their life situation (Pettersson, 2014, p. 63). Also supporting this encompassing of stories beyond literary fiction is librarian and storyteller David Wright, with his utilisation of gripping short stories in his Thrilling Tales (adult storytime) program, including "gaslighting, murder, pursuit, aliens, ghosts, and even a touch of cannibalism", noting "the genres, styles, and tones vary, but each story generates intense interest in *what happens next*" (D. Wright, 2017, para. 4). Furthermore, the long-running Kirklees bibliotherapy program also encompasses flexible reading choices, free from value judgements about what is considered worthy or quality literature (Brewster & McNicol, 2021). In the words of an English literature student:

> Reading the classics can be an amazing experience, and they are important pieces of literature. But YA novels and any other genre of literature can also be a great reading experience. Don't force yourself to read a book just because you think it'll make you sound smart. (Adams, 2021, para. 8)

In this study, story selection resulted from an exploration of many forms and styles. For instance, novellas, particularly The Reading Agency's excellent 'Quick Reads' collection (The Reading Agency, 2021d), generally consisting of a fairly low language level (estimated by the researcher to be at mid high school level) with basic storylines, which could be helpful for people with impairments in memory and/or attention, were considered but they were too long to read in a single intervention session and thus too long for the purposes here. Adult 'readers' (short stories and abridged novels produced predominantly for migrants learning English, with publishers including Penguin, Cambridge and Pearson) were also evaluated for suitability. They are produced at a variety of reading levels. The upper-level readers include abridged titles from renowned authors, including Agatha Christie and Leo Tolstoy, which one would expect to be eminently suitable as quality short novels for existing readers whose concentration prohibits reading full length novels, however, the writing style was found to be so altered from the original authors' that an experienced reader would consider it poorly written, and so they were also excluded. Although these books might have been good choices for some new readers, or ESL participants with developing English skills, they were not needed during this study.

Young adult fiction was considered as it is generally character-driven, with storylines appearing quickly in preference to preamble, and it is usually shorter in length than adult fiction. Authors who write for both adult and young adult audiences were particularly worthy of inclusion (such as Jackie French and James Patterson) as they seem to encapsulate stories well without making them overly simplistic in either style or expression for their younger readers. In a discussion about reading material between the researcher and a person with long-term metastatic cancer experience, the viewpoint was offered that in the midst of treatment sometimes the patient is simply tired and unwell, and does not really know what he/she wants, so something a little different can capture the imagination. In her case, it was both quality children's fiction and a narrative non-fiction audiobook about the re-creation of a lost garden (*The Lost Gardens of Heligan* by Tim Smit (1997)). During wartimes, as described in Chapter 2, doctors requested any reading material at all for their bedridden patients simply to give them something else to think about; and more recent findings indicate any literature can function well in a bibliotherapeutic role since the act of reading can be regarded as more important than the choice of reading material (Brewster, 2011). These are relevant concepts under the premise of distraction. However, with the participants in this study generally not confined to bed, and in light of the dropout rate in the Hammer et al. (2017) study, it was decided that it was important that reading material be enjoyable for each

participant, and thus it was imperative that material be tailored to each person to provide the best chance of keeping them engaged and enjoying the stories. Other studies confirm that a variety of literature and the act of reading are more important than literary quality (Pettersson, 2018).

The Reading Agency's booklists of items chosen by cancer patients for their mood enhancing effects (The Reading Agency, 2021a, 2021b) was initially considered for inclusion, alongside lists published by reputable bibliotherapists (such as Susan McLaine, Ella Berthoud and Susan Elderkin). Many of these books were available through the South Australian public libraries network, but as the intervention design developed, short stories became the material of choice. These other sources, however, were recommended to people outside of the intervention enquiring about appropriate reading material.

Previous and existing readers supplied details of favourite genres and/or authors, and short stories based on those preferences were sourced via the South Australian public libraries network and the books used most often were purchased to ensure their availability throughout the data collection period. Material for non-readers was chosen according to indicated childhood reading preferences, viewing (television and film) preferences, personal interests, sometimes gender (with efforts made to avoid stereotyping) and any other information they cared to contribute (for instance, that they loved comedies). The material for the participant who specified two books she already owned as her reading preference for the program, was attempted with caution due to the memory impairment associated with CRCI, which she reported suffering. However, one book was in fact short stories, and the other was an autobiography which skipped around in a lovely narrative style so chapters could easily stand alone.

Short stories remained the preferred option. A search of the South Australian public libraries network catalogue using the search term 'short stories', and limiting the output location to adult fiction, returned 2343 books, including mystery, fantasy, science fiction and general short stories. A variety of both genre and literary canon short stories were kept on hand, as well as some high-quality picture books such as *Yellow Jacket Jock* which is distracting and engaging, and can be enjoyed by all ages. Whilst being cautious about the use of material written for children, for fear of turning the sessions into children's storytimes and insulting the intelligence of the participants, which this researcher suspected was the cause of the failure of the adult storytime program at Winona Public Library, based on a discussion with a library staff member (S. TerBeest Berhow, personal communication, May 21, 2021),

nevertheless some quality children's literature was appropriate, and enjoyed by some participants. Studies at the University of Cambridge found that children's literary classics remain cherished by adults (Joy, 2011). Some easily accessible poetry such as classic Australian (for instance Banjo Patterson, Dorothea Mackellar and Henry Lawson) was also enjoyed.

Verbal feedback about the choice of reading material was a regular component of intervention sessions, which was recorded in the observational notes. The mid-point survey, administered half-way through the program, served as an indicator of how successfully reading material was being matched to each participant. Reading short stories and stand-alone book chapters afforded the opportunity for a sense of achievement by finishing stories, which would have been difficult with novels. The researcher's experience in public libraries was an important component of selecting appropriate reading material. Choosing books for the intervention was akin to choosing material for library patrons using home library services such as those offered by many Australian public libraries – matching books to individuals' tastes. Reading stories that captured the interest of participants was intended to take the focus away from illness, offer participants an opportunity to regain some normality, and provide a topic for their conversations with family and friends that was not about cancer treatment or symptoms.

Every story was pre-read by the researcher to evaluate for appropriateness, which was a time-consuming task. Given the mandate to not cause or add to participant distress, there were some clearly off-limits topics, for instance chronic illness, death, funerals and will readings. Surprisingly, it was hard to find stories without any death in them. Even romance collections and 'Dr Who' fairy tales had many stories involving death, so when forced to choose from a particular collection (for instance, the 'Dr Who' stories specially requested) the stories where only supporting characters died (rather than main characters) were read. The importance of pre-reading was two-fold: to "avoid unpleasant surprises" and "increase the practitioner's comfort level" (McMillen & Pehrsson, 2004, p. 78). Advice about the importance of pre-reading potential selections is also an echo of the findings of L. J. Cohen (1992b). Recording observations to assist in the planning of reading material for future sessions was a necessary ingredient of this study, and this is supported by McMillen and Pehrsson (2004) who found recording observations essential for "the development of resources for the patient" (p. 79).

Choosing reading material was a complex process, considering genre, preferences within genre (for instance dark science fiction versus general science fiction), timing (length of

story), language (old-fashioned versus contemporary) and humour. It was anticipated that participant education level would be a consideration when choosing stories, in relation to determining approximate reading level, but it quickly became obvious during the first sessions as to which participants understood a plot twist in a story, and which ones did not. This appeared to be independent of education level and CRCI may have been a contributing factor. When a participant did not understand an ending, it was apparent in their facial expression and/or comments, and so the ending was gently, and conversationally, discussed with them, so they could experience their own "aha" moment.

Some older short stories proved a conundrum. For instance, many stories by Agatha Christie and P.G. Wodehouse are excellent, and some are very funny, but both authors sometimes refer to historical figures, which in general did not detract from the stories but one participant found it a big roadblock to enjoyment. When considering use of these stories for others, changing the names of people from yesteryear, or people who are famous (or infamous) overseas, was considered but it was decided not to change authors' words based solely on one participant's feedback (given other participants had enjoyed them). However, this may be something to reconsider in a future study or program implementation. Similarly, some things are known to particular cultures (for instance, a Tara brooch – Irish; Ellis – man's name of Welsh origin, sounds like "Alice" but was a leading male character in an entertaining story where gender was relevant) and where it was warranted, these terms were briefly explained to participants prior to reading.

The researcher met with UniSA's visiting research fellow, author Mark Carthew, who offered interesting suggestions for reading material. He encouraged word play and fun stories, as well as easily accessible stories and factual articles from in-flight magazines (which unfortunately were unavailable due to COVID-19).

Quirky stories, stories with twists in their plotlines and stories with an element of humour were most popular. An individual's sense of humour is a complex thing to gauge, however most humorous stories chosen for them were well-received by their intended listener(s). For instance, the older style of language and the almost slap-stick style of humour of some P.G. Wodehouse stories was enjoyed by the researcher but deemed not suitable for all participants because of variations in senses of humour. However, his stories were appreciated by a number of participants of various ages, including one younger participant who likened them to radio plays and she enjoyed them immensely. Interestingly, stories of yesteryear, including those by P.G. Wodehouse, were mentioned in a study by Brewster (2016), where her

participants also liked the escapist nature of these stories, which she suggested was because they offered a glimpse into life at a time far removed from today which can easily then allow a distraction and disconnection from the current time. Different senses of humour are part of being individual – people do not all laugh at the same things. It was particularly satisfying when participants told of being preoccupied by a story during the week that followed a reading session, and sometimes beyond. In these cases, the stories were always funny ones, although not always overtly so, and they always involved animals: 'Far North' by Alexander McCall Smith (1995), 'Where's the Barra?' by Bill 'Swampy' Marsh (2021b) which was read to a participant in week one of the program and he was still thinking about it at our interview six weeks later, and 'The Loaded Dog' by Henry Lawson (1995/1901). Weeks after reading 'The Loaded Dog', three participants were still recalling it and laughing. During her interview, R10 laughingly told me her favourite part of the reading program was "the exploding dog!", referring to the Henry Lawson story.

Only one participant (M18) had initial specific story requests: she had two books given to her by her children as gifts, *Dr Who: Time Lord Fairy Tales* ('Dr Who' themed short stories by Richards (2015)) and *What's it all About?* (Michael Caine's (1993) autobiography), but CRCI had prevented her from reading them. Additional reading material was taken to her first few sessions in case it was required, but she clearly enjoyed the books she had nominated, and so stand-by material became unnecessary. Reading the participant's own books posed a difficulty with pre-reading for appropriateness as well as pre-reading for the comfort of the reader (regarding offensive language and sexual content). Fortunately, one of the books was available via the SA library system, and the other was loaned to the reader by a colleague. Obviously with the Dr Who book there was nothing for the participant to recall from one week to the next. However, I would recap the end of the previous chapter, before moving on with Michael Caine's book, although this was not strictly necessary as he had a moving (rather than linear) timeline when telling the story of his life. Interestingly, M18 preferred the ongoing story over the short stories, mostly due to the familiar world in which Michael Caine's story was set, as well as his writing style: "the Michael Caine book really engaged me, and it was funny and it's things that I understand about, from my own background" (M18).

At the mid-point survey, three participants asked about including some specific short story titles or stories by a specific author, and these were accommodated. In one of those cases, the story had been written by a participant's friend and it was emailed to the researcher so it could be pre-read. In the second case, some particularly dark science fiction stories that the

participant enjoyed many years ago and wanted to revisit, were requested. The stories were found online and pre-read by the researcher before being read together. During and after reading these stories, the participant's facial expression indicated absolute enjoyment (this was the participant with no larynx). During the family member interview at the conclusion of the program, his spouse emphatically told of how being able to choose stories was valuable for her husband. The other participant who made story requests was introduced to 'Jack Reacher' books near the start of the program, and he enjoyed them so much that he requested more at the mid-point survey. In each of these cases, I did not unilaterally choose the reading material, which could be argued gave more power to these participants – emphasising the participatory worldview through which the study was conducted – although participants who preferred that I chose the stories were not in any lesser position. Most participants enjoyed the anticipation of not knowing exactly what was going to be read, however, the experience of these participants illustrates that either reader-chosen or participant-chosen material can work well, provided the participant enjoys it; and chapters of a book are a possibility if the style is one that allows dipping in and out of the storyline. The chapters of the Michael Caine book (1993) were written in such a way that they could easily stand alone as vignettes, and I did in fact read the first chapter to a couple of other participants, who also thoroughly enjoyed it.

Hundreds of stories were evaluated for appropriateness prior to including (or excluding) them in the reading guide (refer Appendix D), yet participants were observed during sessions to gauge responses to stories, especially to ensure that none caused obvious distress or boredom. Observation notes were made after each session with each participant to help inform the choice of reading material for the next session and also to reflect on best practice with this and other participants. Depending on story length, two stories were generally read at each intervention session. Often, the researcher took a story or two more than was required at each session, in order to facilitate a change if necessary, based on mood, fatigue or time constraints. Especially with lapsed readers, participants might have been asked which genre (from a choice of two) they felt more in the mood for that day. For some participants, treatment side effects (especially in relation to their treatment cycle and the number of days since treatment that the reading session was held) left them unable to make decisions and so the reader would choose for them.

One palliative participant requested that humorous material continue, and with her wide-ranging interests and keen sense of humour, that was easy to accommodate. A couple of participants preferred the problem-solving associated with action or crime stories, while some

others discovered new authors and requested more written by them. The most popular genres were action/adventure, biographies/autobiographies, detective/mystery, romance and science fiction. Very few participants indicated women's fiction as a preference on their enrolment paperwork, yet it was read to those whose favourite authors included people who write in this genre and those who displayed an enjoyment of stories featuring the interweaving of relationships between characters and centred around family or community.

Some participants were pleasantly surprised by the incorporation of books that were similar to, but not exactly, the ones they indicated in the favourite authors section of the reading habits questionnaire they completed during enrolment. For instance, R12 commented on the way her preferences were used as a starting point: "And I also like the fact that, you did use the genre of what I liked, and took me to different authors, instead of just staying with *the author* that I wanted". The overwhelming success of the story choices indicates the need for an experienced library professional to choose the material (discussed in section 6.8). This is important and is reflected in R13's comment: "you looked beyond sort of my genre, I think a bit and yeah, and picked things, yeah, that I probably wouldn't have read, and I really enjoyed". The idea of hearing stories they most likely would not have chosen for themselves was mentioned quite often in interviews. For existing or lapsed readers, preconceived ideas about some authors were challenged by the inclusion of stories that they would never have selected for themselves, for instance, M13 said:

> And things I had been unaware of. I would *never* have, *never* have picked up a Jeffrey Archer book, short story or long, because I sort of always thought they're a little bit violent, and a bit criminal and when you read that first one, I was just hooked.

The idea of enjoying stories they most likely would not have chosen for themselves was mentioned by several participants, including M21: "I liked the short stories and all the differences, and hearing authors that I wouldn't necessarily find" and R11, "I think there are a couple of stories there which, had I read the blurb on the back, I probably wouldn't have chosen … they are stories that like, I probably would have missed out on". Observation notes were made after each and every reading session (refer section 5.1), and those notes included participants' reactions to the stories selected for them. A handful of participants maintained very closed expressions, classic 'poker faces', and it was hard to understand whether or not they were enjoying the material being read. However, the mid-point survey provided another vehicle for understanding and developing the intervention for each participant.

A number of participants thought novels would be read at sessions and wondered how that would work:

> I think they were chosen well, because there's a bit of a laugh and the relationships within them, particularly that last story, last week. Those relationships were really drawn upon. Was it Maeve Binchy? So yeah, I really didn't know what you were going to choose. I kind of was thinking, actually, that was something I thought maybe, we would be reading a novel where you read a bit each week, but it was short stories, and I'm glad for that because I think that was good because it would have been very tempting if I got into the novel to go and find the novel and read it (chuckling). (R3)

Despite very few participants nominating short stories as a favourite read, they were universally enjoyed when chosen in participants' favourite genres: "I've never read short stories, as such, and I really liked that, yeah, having yeah different stories each week and there was great variety and yeah, and things that I normally wouldn't have read, probably" (R13).

A love of Australian fiction was expressed or observed in many participants. For instance, R10's favourite story from the intervention was Colin Thiele's (1969) children's book, *Yellow Jacket Jock*, with its beautiful descriptive language. I did not describe it as a work of children's literature to anyone, even though I did read it to several participants, because I was always wary of not wanting them to feel as though the material was 'dumbed down' for them in any way because of their CRCI. M1 and her spouse, however, in a brief chat about classic children's literature, mentioned *Wind in the Willows* (Grahame, 2005/1908): "Oh, I like the *Wind in the Willows*! … those classics are not dumb" (M1) and her spouse added: "brilliant kids' book – kids' books are not dumb, and you learn beautiful English in them. I'm sure the Arthur Ransome books must have had beautiful English".

Although humour was successfully read to most participants, caveats exist around its use and it must be chosen with sensitivity. What could be considered as appropriate and funny for one participant, can be entirely unsuitable for another. It was vital to be able to 'read' (that is, have an awareness or perception of) the participants to gauge this. For instance, M2's wife had told me about his sense of humour, including that he had recently been to a comedy show, and had laughed at the cancer-themed jokes. He also told me about enjoying Roald Dahl's (2023/1982) *Revolting Rhymes*. Based on this input, one of the stories I read him, which he laughed uproariously at, was 'Pauper's Funeral' from *Great Australian Outback Yarns* by Bill 'Swampy' Marsh (2021a). This particular story may seem like an odd choice for anyone with cancer, and it was read only a few times during the program because I had to be absolutely confident that it would be enjoyed by the listener and not serve as a reminder about death. It is a very funny story for the right audience. It would have been unsuitable for R17, for instance, however she enjoyed the humour in James Herriot's and Maeve Binchy's stories, and as someone unused to fiction, humour was a point she raised in an extremely

positive way in our interview, when asked what she enjoyed most about the reading program: "you, the humour you gave me; the humour you exposed me to" (R17).

As an illustration of the importance and skill involved with tailoring the material to each person, I refer to an entirely harmless collection of vignettes by Morris Gleitzman from the book *Kids' Night In!* (Earls, 2003). The first time I read this to a participant, it was to R4, and we both had tears of laughter. I really thought she would appreciate that style of humour from her background in children's literature, and she did. However, I read one of the vignettes to another participant, to gauge their reaction before reading more, and they remained straight faced, so I learned more about that person's humour and reading interests, and was able to move onto another story. I quickly learned to have an extra story or two on standby because of the value I placed, and now I see for good reason, on participants enjoying what was being read.

While reading stories with twists and/or humour, it was rewarding to see the participants almost 'on the edge of their seats' in anticipation of hearing the story unfold and hearing their laughter. R4 expressed the sentiment of the fun aspect of the program beautifully:

> It was obvious what was going to happen, but it didn't matter because he wrote quite well and it was, ah it was just a bit of nonsense. Not everything has to be deep and meaningful. You know, it was just rather fun.

R4's comment not only speaks of the fun of being read to, but it also points favourably to the story selections chosen for her and the value of distraction and escapism. Participants quickly developed an expectation around relaxing and fun. When asked in interviews if the program met those expectations, a common sentiment was "Absolutely, and beyond" (M13). M21 spoke of her fun as "laughs and curiosities" that kept her listening and entertained, and both she and R17 compared the reading aloud to watching television and found the reading aloud superior: "And it is more enjoyable than, you know, actually watching something on television" (M21) and "better than what's on television" (R17) – so for these readers, successful story choices ensured high entertainment value.

Intervention personalisation was highly valued by participants (refer section 6.1). All the time and effort devoted to story selection was worthwhile, as reflected by M9's feedback:

> The stories that were chosen were really quite quirky and interesting. … I loved the choice of books. … Diverse ... all had a surprise ending … the stories that we had were really funny and plus they had a twist, and that's the type of stories that I like, it wasn't just mundane. It was like the, you know, choosing the material was done really well, in a variety of different authors with different styles and twists.

Appendix D – Reading Guide

The following were read during intervention sessions, listed in alphabetical order by author:

Ahern, Cecilia
'The Woman Who Slowly Disappeared', from *Roar* (2018, HarperCollinsPublishers)

Aldiss, Brian
'But who can Replace a Man?' from *A Century of Science Fiction* (edited by Damon Knight, 1976, 2nd edition, Amereon Ltd.) and found here
https://img.4plebs.org/boards/tg/image/1494/26/1494260422851.pdf
Chapters 1-3 from *Supertoys Last All Summer Long* (2001 edition, St. Martin's Griffin)

Archer, Jeffrey – note that these stories often appear in multiple Jeffry Archer collections
'Broken Routine', from *The Collected Short Stories* (1999 edition, HarperCollinsPublishers)
'Cheap at Half the Price', from *The Collected Short Stories*
'The First Miracle', suitable for Christian participants, from *The Collected Short Stories*
'Just Good Friends', from *The Collected Short Stories*
'Never Stop on the Motorway', from *The Collected Short Stories*
'The Queen's Birthday Telegram', from *The Short, the Long and the Tall* (2020, Macmillan)
'Stuck on You', from *The Short, the Long and the Tall*
'Who Killed the Mayor?' from *The Short, the Long and the Tall*

Barr, Emily
'Revenge', from *Girls Night In 2* (2001, Penguin Books)

Baumann, Kayla
'An Unexpected Resolution', 2023, from Christian short fiction blog
https://blog.reedsy.com/short-stories/christian/ (or go directly to this story here https://blog.reedsy.com/short-story/ijjueu/ or scroll through the Christian New Year's Eve stories here https://blog.reedsy.com/creative-writing-prompts/contests/179/)

Binchy, Maeve
'The Apprenticeship'
'The Business Trip'
'Cross Lines'
'Miss Martin's Wish'
'The Ten Snaps of Christmas'
All these stories are from *Maeve Binchy's Treasury* (2020, 4th edition, Allen & Unwin)

Birch, Tony
'Sissy', from *Common People* (2017, University of Queensland Press)
'The Blood Bank: A Love Story', from *Dark as Last Night* (2021, University of Queensland Press)

Buckell, Tobias S.
'Zen and the Art of Starship Maintenance', from *The Best Science Fiction & Fantasy of the Year (Vol.12)* (edited by Jonathan Strahan, 2018, Solaris)

Caine, Michael
Chapter 1 and others (use with caution for language and mild-moderate sexual content) from his autobiography *What's it All About?* (1993, Ballantine Books)

Child, Lee
'Everyone Talks'
'Guy Walks Into a Bar'
'Maybe they have a Tradition'
'No Room at the Motel'
All these stories are from *No Middle Name* (2017, Penguin Books)

Christie, Agatha
'The Actress', from *Miss Marple and Mystery: The Complete Short Stories (*2008, HarperCollinsPublishers)

Cornell, Philip
'The Adventure of the Purloined Bunyip', from *Sherlock Holmes: The Australian Casebook* (edited by Christopher Sequeira, 2017, Bonnier Publishing Australia)

Dahl, Roald
'The Landlady'
'Mrs Bixby and the Colonel's Coat'
Both stories are from *Complete Tales of the Unexpected* (2001, The Folio Society)

Dalton, Trent
'Two Believers', from *Love Stories* (2021, HarperCollinsPublishers)

Ellison, Harlan
'I Have No Mouth, and I Must Scream' (use with caution – very graphic science fiction – this was a special reading request) - online from https://openlab.citytech.cuny.edu/?get_group_doc=22694/1540157347-HarlanEllison-IHaveNoMouthandIMustScream.pdf

Fforde, Katie
'Christmas Shopping', from *A Christmas Feast and other stories* (2014, Penguin Books)

Flanagan, Kitty
'Food' section, from *488 Rules for Life* (2019, HarperCollinsPublishers)

Gaiman, Neil
'We can Get Them for you Wholesale', from *The Neil Gaiman Reader: Selected Fiction* (2021, William Morrow)

Garner, James Finn
'The Tortoise and the Hare', from *Once Upon a More Enchanted Time: More Politically Correct Bedtime Stories* (1995, Macmillan Publishing Company)

Gilchrist, Ellen
'1944', from *The Story: 100 Great Short Stories Written by Women* (edited by Victoria Hislop, 2021, 2nd edition, Head of Zeus)

Gleitzman, Morris
Excerpts from 'Bits of an Autobiography I May Not Write', from *Kids' Night In!* (edited by Nick Earls, 2003, Penguin Books)

Hannes, Jo
'The Adventure of the Demonic Abduction', from *Sherlock Holmes: The Australian Casebook* (edited by Christopher Sequeira, 2017, Bonnier Publishing Australia)

Hazeley, James & Morris, Joel
Excerpts from *The Ladybird Book of the Meeting* (show illustrations to participant) (2016, Penguin Books)

Herriot, James
Chapters 10, 13 and 33 of *All Creatures Great and Small* (2013 edition, Pan)

Horowitz, Anthony
'Tea with Smithers', from *Secret Weapon* (2019, Candlewick Press)

Jacobs, Anna
'The Cotton Lass', from *The Cotton Lass and other Stories* (2018, Allison & Busby)
'Dance with Me', from *Short and Sweet* (2011, Severn House Publishers)
'Moving Day', from *The Cotton Lass and other Stories*
'Possibilities', from *Short and Sweet*

Lawrence, D.H.
'The Spinner and the Monks', from *Bedtime Stories for Stressed Out Adults* (edited by Lucy Mangan, 2018, Hodder & Stoughton)

Lawson, Henry
'The Drover's Wife'
'The Loaded Dog'
These stories are widely available but these were from *Favourite Australian Stories* (complied by Colin Thiele, 1995, Lansdowne Publishing)

Marsh, Bill 'Swampy'
'Pauper's Funeral' (use with caution – it's very funny BUT only use this story if sure it will suit participant's humour)
'Where's the Barra?'
Both stories from *Great Australian Outback Yarns (Vol.1)* (2021, HarperCollinsPublishers)

McCall Smith, Alexander
'Far North', from *Heavenly Date and Other Flirtations* (2004 edition, Canongate Books)
'Sphinx', from *Pianos and Flowers* (2019, Pantheon Books)
'The Unfortunate Fate of Kitty Da Silva', from *One City* (along with Ian Rankin and Irvine Welsh; with an introduction by J.K. Rowling, 2005, Polygon)

McDermott, Pat
Excerpts from *Family Matters* (2014, Allen & Unwin)

McInerney, Monica
‘Hippy Hippy Shake’, from *All Together Now* (2018 edition, Penguin Books)
‘Just Desserts’, from *Girls' Night In 2* (2001, Penguin Books)
‘Spellbound’, from *All Together Now*

McKellar, Dorothy
A Sunburnt Country (book of the poem) illustrated by Bill Beavan (show illustrations) (1978, Rigby Publishers)

MacLean, Alistair
‘The Gold Watch’
‘The Good Samaritan’
Both stories are from *The Lonely Sea: Collected Short Stories* (1985, Doubleday)

Moyes, JoJo
‘Crocodile Shoes’
‘Holdups’
‘Last Year’s Coat’
All stories from *Paris for One and other Stories* (2017, Penguin Books)

O'Brien, Edna
‘Number Ten’, from *The Love Object* (2015 edition, Little, Brown and Company)

O'Flanagan, Shiela
‘A Good Sense of Humour’
‘Rebel’
Both stories are from *Destinations* (2006 edition, Headline Review)

Potter, Alexandra
‘No Strings Attached’, from *Girls Night In 2* (censor offensive language and blasphemy) (2001, Penguin Books)

Reynolds, Louise
‘Alfred's Gift’, from *Little Gems: Pearl* – Romance Writers of Australia’s annual short story anthology (2008) (use this book with caution – many stories contain death and grief)

Richards, Justin
‘Frozen Beauty’
‘The Twins in the Woods’
‘Cinderella and the Magic Box’
‘Snow White and the Seven Keys to Doomsday’
‘Jak and the Wormhole’
‘The Gingerbread Trap’
All stories from *Doctor Who: Time Lord Fairy Tales* (2015, Penguin Books)

Richards, Laura E
‘The Golden Windows’, from *Bedtime Stories for Stressed Out Adults* (edited by Lucy Mangan, 2018, Hodder & Stoughton)

Saki (Hector Hugo Munro)
'The Mouse', from *Bedtime Stories for Stressed Out Adults* (edited by Lucy Mangan, 2018, Hodder & Stoughton)

Thiele, Colin
Yellow Jacket Jock (1969, F. W. Cheshire Publishing)

Tolstoy, Leo
'Three Questions', from *Bedtime Stories for Stress Out Adults* (edited by Lucy Mangan, 2018, Hodder & Stoughton)

Weir, Alison
'Arthur Prince of the Roses'
'The Blackened Heart'
Chapters from *In the Shadows of Queens* (2021, Headline Review)

Winn, Rhylle
Poem – 'Just When Your Boots Begin to Fit', from *I Kid You Not...At All* (illustrated by Joanne Applegate, 1999, Boolarong Press)

Wodehouse, P.G.
'Mulliner's Buck-U-Uppo'
'Strychnine in the Soup'
Both stories are from *Mulliner's Buck-U-Uppo* (2017 edition, Arrow Books)

This reading guide is presented with books in title case since that is commonly used by both library staff and the general public, for whom this reading guide is intended.

Appendix E – Participant Forms – Participant Information Sheet (PIS)

University of South Australia

Participant Information Sheet

Short Title	**Boost wellbeing with read-aloud programs during cancer fog**
Title	*An exploration of the potential benefits of read aloud programs to the wellbeing of cancer patients undergoing treatment: A mixed methods study.*
Project Number	*204027*
Principal Investigator	*Elizabeth Wells*
Supervisor	*Dr Diane Velasquez*

Introduction – What does my participation involve?

You are invited to take part in this research project, which is called **Boost wellbeing with read-aloud programs during cancer fog**. You have been invited because you are about to commence, are currently undergoing, or recently completed your cancer treatment.

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker/your doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent for your family to be contacted for an interview if you provide their details
- Consent to the use of your information as described.
- You will be given a copy of this Participant Information Sheet to keep.

What is the purpose of this research?

This research came about from observations that people affected by cancer who had previously read for pleasure were denied that activity (and all the benefits that go with it) because of cancer fog affecting their concentration. This research aims to restore that love of reading to regular readers and introduce the joy of reading to those who don't read regularly, with all the known therapeutic benefits that reading provides. In particular we aim to explore the potential improvement in the emotional wellbeing of participants as a result of taking part in the reading program. There has been no research to date in this area, and it is hoped this research will lead to reading programs in cancer centres. This research is being conducted as a PhD research project.

Do I need to be an avid reader to take part?

No! We are hoping to recruit both people who don't currently read for pleasure, as well as those with a regular reading habit who may be struggling to keep reading because of cancer fog.

What does participation in this research involve?

Interested potential participants will be screened for eligibility according to the following criteria:

- Over 18 years of age
- Confidently able to read, write and speak English
- About to receive, currently receiving, or have recently completed cancer treatment

A consent form will need to be signed prior to any assessments being performed.
After completing an initial demographic questionnaire (asking about general demographic information and briefly about your cancer and treatment) and reading habits and attitudes questionnaires, the researcher will source suitable reading material based on your responses, and organise a weekly day, time and place for you to come along and relax, listening to stories being read aloud. You will be able to choose your preferred venue for the reading program: your home, your usual cancer centre (if available), a UniSA campus, your local library or via Zoom when required. Each reading session will run for about 30-40 minutes, weekly for 6 weeks. At the start of the first session, you will need to complete two short questionnaires designed to measure your emotional wellbeing (which will take less than 10 minutes to complete). Reading material will be fiction, narrative non-fiction or poetry, based on your reading preferences. This is a one-to-one program. You will not be required to do any preparatory reading, read aloud during sessions, nor participate in any discussions about the meaning of the stories, although you will be welcome to comment if you wish. This is to be an immersive experience, where you can simply lose yourself in the story and enjoy the pleasure of being read to. Mid-way through the program, a very short survey will be conducted to gauge your enjoyment of the material being read. At the conclusion of the program, you will need to complete the wellbeing and reading attitude questionnaires again and we will schedule a short (half-hour) interview about your experiences with the research program. Relatives of participants (where nominated by you) will also be asked to participate in a short (half-hour) interview about the program, as will nursing staff if you are an inpatient during the reading program and you consent for us to speak to them. All interviews will be audio-recorded then transcribed.

The researcher will take every care to remove any identifying material from the responses you provide as early as possible. Likewise, individuals' responses will be kept confidential by the researcher and will (or participants will) not be identified in the reporting of the research. However, the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include relaxing and enjoying stories being read to you, without any pressure to maintain concentration, while enjoying the face-to-face contact with an experienced reader. You might discover new authors you enjoy. New readers may discover a love of stories. You might experience a boost in your emotional wellbeing.

What are the possible risks and disadvantages of taking part?

It is not anticipated that there are any risks to participation in this study beyond those encountered in everyday life.

Do I have to take part in this research project?

Participation in this research is voluntary. If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will ask you to provide us with feedback.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about/from you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Information collected or used will be stored electronically as re-identifiable via an identification number.

All information that may be used to identify you will be removed from all written documents and survey data and replaced with an identification number. Information about you (i.e. your name and contact details) will be stored separately from the survey data, in a locked cabinet in D-building at University of South Australia's Mawson Lakes campus. We will only use your information to contact you about the study.

All audio files and transcriptions will be stored and backed up according to University of South Australia's policies.

Access to data will only be available to the researcher and her supervisors.

Data will be kept for a minimum of 5 years on a password-protected computer connected to a secure network and will be securely destroyed thereafter. At this point, all consent forms will be shredded and electronic data permanently deleted.

All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law.

What if something goes wrong?

Whilst all reading material will be chosen based on your existing reading interests, or perceived interests for new readers, and reading material of a distressing nature will be actively avoided, we understand that a cancer diagnosis is distressing, and unforeseen issues may arise. If you need support at any time please call the Cancer Council on 13 11 20 (Mon-Fri 9am-5pm) or Lifeline on 13 11 14 (24-hour / 7 days/week).

What happens when the research project ends?

A summary of project results will be available January 2023 from the researcher.

Who is organising and funding the research?

This research project is being conducted by Elizabeth Wells.
It is being funded by the University of South Australia.

Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on (08) 8302 3737 or any of the following people:

Research contacts

Name	Elizabeth Wells
Position	PhD Candidate
Telephone	+618 8302 3737
Email	elizabeth.wells@mymail.unisa.edu.au

Research supervisor

Name	Dr Diane Velasquez
Position	Program Director – Information Management
Telephone	+618 8302 3074
Email	diane.velasquez@unisa.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	University of South Australia Human Research Ethics Committee
HREC Executive Officer	Human Ethics Officer
Telephone	+618 8302 6330
Email	humanethics@unisa.edu.au

University of South Australia

Participant Information Sheet – Family Member

Short Title	**Boost wellbeing with read-aloud programs during cancer fog**
Title	*An exploration of the potential benefits of read aloud programs to the wellbeing of cancer patients undergoing treatment: A mixed methods study.*
Project Number	*204027*
Principal Investigator	*Elizabeth Wells*
Supervisor	*Dr Diane Velasquez*

Introduction – What does my participation involve?

Your family member has been invited to take part in this research project, which is called **Boost wellbeing with read-aloud programs during cancer fog**. You have also been invited because we are keen to talk to family members of the participants of the reading program.

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker/your doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the use of your information as described.
- You will be given a copy of this Participant Information Sheet to keep.

What is the purpose of this research?

This research came about from observations that people affected by cancer who had previously read for pleasure were denied that activity (and all the benefits that go with it) because of cancer fog affecting their concentration. This research aims to restore that love of reading to regular readers and introduce the joy of reading to those who don't read regularly, with all the known therapeutic benefits that reading provides. In particular we aim to explore the potential improvement in the emotional wellbeing of participants as a result of taking part in the reading program. There has been no research to date in this area, and it is hoped this research will lead to reading programs in cancer centres. This research is being conducted as a PhD research project.

As a family member, what does my participation involve?

We are hoping to recruit family members of the reading program participants to participate in a short (approximately 30 minute) interview, at a location that suits you, after the conclusion of the reading program. During the interview you will be asked to comment on your perception of your family member's wellbeing and any cancer fog. The interviews with family members are designed to help us get a complete picture of the impact of the program.

Is this program only for avid readers?

No! We are hoping to recruit both people who don't currently read for pleasure, as well as those with a regular reading habit who may be struggling to keep reading because of cancer fog.

What does participation in the reading program involve?

Interested potential participants will be screened for eligibility according to the following criteria:

- Over 18 years of age
- Confidently able to read, write and speak English
- About to receive, currently receiving, or have recently completed cancer treatment
- No currently diagnosed mental health issue

A consent form will need to be signed prior to any assessments being performed.
After completing an initial demographic questionnaire (asking about general demographic information and briefly about your cancer and treatment) and reading habits and attitudes questionnaires, the researcher will source suitable reading material based on your responses, and organise a weekly day, time and place for you to come along and relax, listening to stories being read aloud. You will be able to choose your preferred venue for the reading program: your home, your usual cancer centre (if available), a UniSA campus or your local library. Each reading session will run for about 30-40 minutes, weekly for 6 weeks. At the start of the first session, you will need to complete two short questionnaires designed to measure your emotional wellbeing (which will take less than 10 minutes to complete). Reading material will be fiction, narrative non-fiction or poetry, based on your reading preferences. This is a one-to-one program. You will not be required to do any preparatory reading, read aloud during sessions, nor participate in any discussions about the meaning of the stories, although you will be welcome to comment if you wish. This is to be an immersive experience, where you can simply lose yourself in the story and enjoy the pleasure of being read to. Mid-way through the program, a very short survey will be conducted to gauge your enjoyment of the material being read. At the conclusion of the program, you will need to complete the wellbeing and reading attitude questionnaires again and we will schedule a short (half-hour) interview about your experiences with the research program. Relatives of participants (where available) will also be asked to participate in a short (half-hour) interview about the program. All interviews will be audio-recorded then transcribed.

The researcher will take every care to remove any identifying material from the responses you provide as early as possible. Likewise, individuals' responses will be kept confidential by the researcher and will (or participants will) not be identified in the reporting of the research. However, the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

What are the possible benefits of taking part in the reading program?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include relaxing and enjoying stories being read to you, without any pressure to maintain concentration, while enjoying the face-to-face contact with an experienced

reader. You might discover new authors you enjoy. New readers may discover a love of stories. You might experience a boost in your emotional wellbeing.

What are the possible risks and disadvantages of taking part?

It is not anticipated that there are any risks to participation in this study beyond those encountered in everyday life.

Do I have to take part in this research project?

Participation in this research is voluntary. If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will ask you to provide us with feedback.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about/from you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Information collected or used will be stored electronically as re-identifiable via an identification number.

All information that may be used to identify you will be removed from all written documents and survey data and replaced with an identification number. Information about you (i.e. your name and contact details) will be stored separately from the survey data, in a locked cabinet in D-building at University of South Australia's Mawson Lakes campus. We will only use your information to contact you about the study.

All audio files and transcriptions will be stored and backed up according to University of South Australia's policies.

Access to data will only be available to the researcher and her supervisors.

Data will be kept for a minimum of 5 years on a password-protected computer connected to a secure network and will be securely destroyed thereafter. At this point, all consent forms will be shredded and electronic data permanently deleted.

All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law.

What if something goes wrong?

Whilst all reading material will be chosen based on existing reading interests, or perceived interests for new readers, and reading material of a distressing nature will be actively avoided, we understand that a cancer diagnosis is distressing, and unforeseen issues may arise. If you or your family member need support at any time please call the Cancer Council on 13 11 20 (Mon-Fri 9am-5pm) or Lifeline on 13 11 14 (24-hour / 7 days/week).

What happens when the research project ends?

A summary of project results will be available January 2023 from the researcher.

Who is organising and funding the research?

This research project is being conducted by Elizabeth Wells.
It is being funded by the University of South Australia.

Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on (08) 8302 3737 or any of the following people:

Research contacts

Name	Elizabeth Wells
Position	PhD Candidate
Telephone	+618 8302 3737
Email	elizabeth.wells@mymail.unisa.edu.au

Research supervisor

Name	Dr Diane Velasquez
Position	Program Director – Information Management
Telephone	+618 8302 3074
Email	diane.velasquez@unisa.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	University of South Australia Human Research Ethics Committee
HREC Executive Officer	Human Ethics Officer
Telephone	+618 8302 6330
Email	humanethics@unisa.edu.au

Appendix F – Participant Forms – Consent Form

University of South Australia | Research and Innovation Services

Human Research Ethics Committee
Consent Form

This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer of this Committee, Tel: +618 8302 6330; Email: humanethics@unisa.edu.au.

SECTION 1: CONTACT AND PROJECT DETAILS	
Researcher's Full Name	Elizabeth Wells
Contact Details	Elizabeth.Wells@mymail.unisa.edu.au Ph. (08) 8302 3737
Supervisor's Name	Dr Diane Velasquez
Contact Details	Diane.Velasquez@unisa.edu.au Ph. (08) 8302 3074
Project Number	204027
Project Title	An exploration of the potential benefits of read aloud programs to the wellbeing of cancer patients undergoing treatment: A mixed methods study.

SECTION 2: PARTICIPANT CERTIFICATION

In signing this form, I confirm that:

- I have read the Participant Information Sheet, and the nature and the purpose of the research project has been explained to me. I understand and agree to take part.
- I understand I will be asked about demographic information, cancer and emotional wellbeing.
- Where details of a family member have been supplied, I understand they will be contacted for an interview about their perception of the reading program and its impact on me.
- For inpatients, I understand my nursing staff may be contacted for an interview about their perception of the reading program and its impact on me unless I indicate otherwise.
- I understand the nature of my involvement in the project.
- I understand that I may not directly benefit from taking part in the project.
- I understand that I can withdraw from the project at any stage and that this will not affect my status now or in the future.
- I confirm that I am over 18 years of age.
- I understand that while information gained during the project may be published, I will not be identified and my personal results will remain confidential, unless required by law.
- I understand that de-identified data collected during this project may be shared.
- I understand that I may be audio-recorded during the project.
- I understand that the recording will be stored digitally on a password-protected computer at UniSA connected to a secure network.

Participant's Signature	*Printed Name*	*Date*

OPTIONAL: PARTICIPANT CERTIFICATION

In signing this section, I confirm that: *(please indicate with a ✓)*

☐ I grant the researchers permission to contact me again to share a report on the findings from this study.

☐ I grant the researchers permission to contact me again for future research purposes.

Email: _____ Phone number: _____

Postal address: _____ Postcode: _____

Participant's Signature	*Printed Name*	*Date*

University of South Australia | Research and Innovation Services

Human Research Ethics Committee
Consent Form

SECTION 3: RESEARCHER CERTIFICATION

I have explained the study to the participant and consider that he/she understand what is involved.

Researcher Signature	*Printed Name*	*Date*

Consent form for family

University of South Australia | Research and Innovation Services

Human Research Ethics Committee
Consent Form – Family member

This project has been approved by the University of South Australia's Human Research Ethics Committee. If you have any ethical concerns about the project or questions about your rights as a participant please contact the Executive Officer of this Committee, Tel: +618 8302 6330; Email: humanethics@unisa.edu.au.

SECTION 1: CONTACT AND PROJECT DETAILS	
Researcher's Full Name	Elizabeth Wells
Contact Details	Elizabeth.Wells@mymail.unisa.edu.au Ph. (08) 8302 3737
Supervisor's Name *(students only)*	Dr Diane Velasquez
Contact Details	Diane.Velasquez@unisa.edu.au Ph. (08) 8302 3074
Project Number	204027
Project Title	An exploration of the potential benefits of read aloud programs to the wellbeing of cancer patients undergoing treatment: A mixed methods study.

SECTION 2: PARTICIPANT CERTIFICATION

In signing this form, I confirm that:

- I am a family member of a participant in the aforementioned reading program.
- I have read the Participant Information Sheet, and the nature and the purpose of the research project has been explained to me. I understand and agree to take part.
- I understand I will be asked about my perception of my family member's wellbeing and impact of any cancer fog.
- I understand the nature of my involvement in the project.
- I understand that I may not directly benefit from taking part in the project.
- I understand that I can withdraw from the project at any stage and that this will not affect my status now or in the future.
- I confirm that I am over 18 years of age.
- I understand that while information gained during the project may be published, I will not be identified and my personal results will remain confidential, unless required by law.
- I understand that de-identified data collected during this project may be shared.
- I understand that I may be audio-recorded during the project.
- I understand that the recording will be stored digitally on a password-protected computer at UniSA connected to a secure network.

Participant's Signature	*Printed Name*	*Date*

SECTION 3: RESEARCHER CERTIFICATION

I have explained the study to the participant and consider that he/she understand what is involved.

Researcher Signature	*Printed Name*	*Date*

Appendix G – Participant Forms – Demographic Questionnaire



Read-aloud program participant demographic questionnaire

1. What gender do you identify as?

☐ Male ☐ Transgender

☐ Female ☐ Other (please specify) _____

2. How old are you?

☐ 18 – 34 ☐ 55 – 64

☐ 35 – 44 ☐ 65 – 74

☐ 45 – 54 ☐ 75+

3. Is English your second language?

☐ Yes

☐ No

4. Which of the following best describes your racial or ethnic background?

☐ Australian

☐ Indigenous Australian or Torres Strait Islander

☐ New Zealand peoples

☐ British ☐ Middle Eastern

☐ European ☐ African

☐ Asian ☐ North American

☐ Indian ☐ South American

☐ Other (please specify) _____

5. What is your marital status?

☐ Married or in a domestic partnership

☐ Widowed

☐ Divorced

☐ Separated

☐ Never married

6. What is your current living arrangement?

☐ I live alone

☐ I live with family

☐ I live in supported accommodation (e.g. nursing home),

7. What is the highest degree or level of education you have completed?

☐ Some High School

☐ High School

☐ Bachelor's Degree

☐ Master's Degree

☐ Ph.D. or higher

☐ Trade School

8. Which of the following categories best describes your employment status?

☐ Employed, working 1-36 hours per week

☐ Employed, working 37 or more hours per week

☐ Not employed, looking for work

☐ Not employed, NOT looking for work

☐ Retired

☐ Student

☐ Homemaker

☐ Disabled, not able to work

9. If employed, how would you best describe your occupation?

☐ Managers

☐ Professionals

☐ Technicians and Trades Workers

☐ Community and Personal Service Workers

☐ Clerical and Administrative Workers

☐ Sales Workers

☐ Machinery Operators and Drivers

☐ Labourers

10. Cancer history

Type of cancer _____

Stage _____

Treatment type _____Stage _____

Time since diagnosis _____

Anticipated duration of treatment _____

11. a. Has your cognition (memory, concentration, decision-making, ability to think clearly, etc.) changed since your cancer **diagnosis**?

☐ Yes

☐ No

b. Has it changed since commencing **treatment**?

☐ Yes

☐ No

c. How is that impacting your day-to-day life (trouble remembering words, trouble reading, trouble navigating, trouble following a conversation, forgetful, other …) ?

_____

_____

_____

12. Are you currently undergoing any other treatments?

☐ Psychologist

☐ Counsellor

☐ Exercise program

☐ Oncology massage

☐ Other treatments – please describe: _____

13. What is your preference of venue for the reading program?

☐ Your home (we visit you) - address:

_____

☐ Cancer centre (subject to approval) – nominate which one:

_____

☐ UniSA campus – circle choice: City East / City West / Mawson Lakes

☐ Your local library

☐ Rural participants – Zoom; or in-person at your home (subject to volunteer availability)

☐ Rural participants – Greenhill or Flinders Lodge – nominate which one:

_____

14. a. Are you willing to participate in a half-hour interview about this read-aloud program at the end of the study?

☐ Yes

☐ No

b. We would love to chat to a relative about their perception of the reading program. Do you have a relative who is willing to participate in a short interview about their perceptions of your emotional wellbeing before and after the read-aloud program?

☐ Yes - Please supply relative's name and phone number

_____

☐ No

Appendix H – Participant Forms – Reading Habits Questionnaire



Reading Habits questionnaire

1. Do you read for pleasure?

☐ Yes ☐ No

2. Do you listen to audiobooks or podcasts for pleasure?

☐ Yes ☐ No

If you answered Yes to either of the questions above, please answer the following questions. (If you answered No, skip down to question 9)

3. What are your favourite genres? (tick all that apply)

☐ Action and adventure

☐ Biographies and autobiographies

☐ Chick lit.

☐ Classics

☐ Detective and mystery

☐ Fantasy

☐ Historical Fiction

☐ Horror

☐ Magazines

☐ Non-fiction – please specify what type _____

☐ Poetry

☐ Romance

☐ Science fiction

☐ Short stories

☐ Suspense and thrillers

☐ Women's fiction

☐ Other (please specify) _____

4. Who are some of your favourite authors?

_____

_____

_____

5. About how often do you read each week?

☐ More than once every day

☐ Daily

☐ A few times each week

☐ Weekly

☐ Fortnightly

☐ Other (please specify) _____

6. Approximate duration of each reading session?

☐ Less than half an hour ☐ Between half an hour and an hour

☐ An hour ☐ Between one and two hours

☐ More than two hours

7. Why do you like to read? (tick all answers that apply)

☐ Entertainment

☐ Pleasure

☐ Escapism

☐ To learn something new

☐ To give me something to talk to others about

☐ Other (please specify) _____

8. Has cancer fog limited your ability to read for pleasure?

☐ Yes ☐ No

-- If you answered Yes to questions 1 or 2 and have completed this section, you're finished, thank-you --

If you answered No to questions 1 & 2 -

9. Why do you think you don't read for pleasure?

☐ Time limitations - I am a young Mum, work long hours, lots of sports or other hobbies that consume my time

☐ I can't find books I enjoy

☐ My reading ability limits what I can read

☐ I've never even considered it as a pastime

☐ Other (please specify) _____

10. Did you enjoy reading as a child?

☐ Yes ☐ No

11. When you read books as a child, what genres did you enjoy? (tick all that apply)

☐ Action and adventure

☐ Classic fairy tales and folk tales

☐ Detective and mystery

☐ Fantasy

☐ Non-fiction – please specify what type _____

☐ Poetry

☐ Romance

☐ Science fiction

☐ Short stories

☐ Other (please specify) _____

12. Are you open to a bit of storytelling / being read to for pleasure – entertainment, escapism…?

☐ Yes ☐ No

13. Are there any genres listed in Question 3 (above) that you'd like to try?

Please specify _____

Appendix I – Participant Forms – Mid-point Survey



Short mid-point program satisfaction check

Are you enjoying what we're reading?

Any suggestions for other items to read?

Is there anything we could improve?

Appendix J – Interview Questions

Read-aloud program – Participant interview questions

Greeting and introduction.

Ice-breaker question: What's a favourite childhood book of yours?

Just a reminder that I'll be audio-recording us, so I can concentrate on you rather than try to scribble down a summary of what you're saying, while you're still talking.

Question 1 - Why did you decide to take part in this reading program?

Follow-up 1 – How did the program meet those expectations?

Follow-up 2 – Were there any consequences of the program that you didn't expect? (please describe)

Question 2 – Did you enjoy the reading program? … What did you enjoy about it?

Follow-up 2 - How did you *feel* being read to?
(some prompts: relaxed, cared for, happy, sad, it was great to get back into some reading, bored …)

Probing 2 – Did the books serve as a good distraction? (from the cancer treatment)
Can you tell me more about that?

Question 3 – Did you enjoy the choice of books? … If not, what do you think went wrong here?

Follow-up 3 - How did you find the volunteer who read to you? … was his/her voice easy to listen to?

Probing 3 - How do you think human voice and presence contributed to your enjoyment of the program?

Question 4 – How do you think the read-aloud program helped you?

Follow-up 4 - What was something about the read-aloud program that made you feel more positive?

Probing 4a - Can you tell me what exactly was it about the program that had a positive impact on you?

Probing 4b – Did this sense of something positive continue/last outside of the reading time?

Probing 4c – Was there anything about the program that had a negative effect on you?

Probing 4d – Did you find yourself looking forward to the sessions?

Concluding Question a) - What kinds of things do you most enjoy reading? … was that catered for in the program?

Concluding Question b) During the program, did you discover any good books that you might not have chosen for yourself?

Concluding Question c) What did you enjoy most about the program?

Concluding Question d) - Is there anything you didn't enjoy?

Concluding Question e) For New Readers - Do you think you'll continue reading for pleasure now that the program has ended?

Thank-you - acknowledge time given for interview and to the program.

Read-aloud program – Family or Nurse interview questions

Greeting and introduction.

Ice-breaker question: What's a favourite childhood book of yours?

Just a reminder that I'll be audio-recording us, so I can concentrate on you rather than try to scribble down a summary of what you're saying, while you're still talking.

Question 1 - Why did you think <participant's name> decided to take part in this reading program?

Follow-up 1a – Do you think the program met those expectations? … How?

Follow-up 1b – Did you encourage <participant's name> to take part? Why / why not?

Follow-up 1c – Did <participant's name> complain of cancer fog, or have you noticed they've been experiencing some cancer fog?

Question 2 – Do you think <participant's name> enjoyed the reading program?

Follow-up 2 - Knowing how they felt, how did that make *you* feel?
(some prompts: happy knowing someone was spending some quality time with <participant's name> ; it gave me some time to myself, to relax or go out …)

Question 3 – What do you think <participant's name> enjoyed *the most* about the program?

Follow-up 3 – Do you think any of these apply to <participant's name> experience of the reading program?

- being able to enjoy stories again because cancer fog was interfering with reading?
- discovering new stories?
- having another person there reading i.e. the warmth of this type of contact?
- it was a good distraction from the cancer treatment?
- it gave another topic of conversation for <participant's name> ?
- or something else?

Question 4 – Do you think the read-aloud program helped <participant's name> in any way?

Follow-up 4 - Do you think the program helped <participant's name> feel a bit more positive?

Probing 4a - Why do you think that was?

Probing 4b – Did this sense of something positive continue/last outside of the reading time?

Probing 4c – Do you think <participant's name> looked forward to the sessions? Did you look forward to the sessions?

Concluding Question a) - Do you think <participant's name> 's reading interests were catered for in the program?

Concluding Question b) What do you think <participant's name> enjoyed most about the program?

Concluding Question c) - Do you think there was anything <participant's name> didn't enjoy?

Concluding Question d) For New Readers - Do you think <participant's name> will continue reading for pleasure now that the program has ended?

Thank-you - acknowledge time given for interview and to supporting the program.

Appendix K – Spontaneous Mid-point Survey Comments

While some participants simply wrote ‘yes’, ‘no’, ‘no’ on their surveys, in answer to questions 1, 2 and 3 respectively (Are you enjoying what we’re reading? / Any suggestions for other items to read? / Is there anything we could improve?), others chose to provide additional feedback. Comments are presented below:

“Short stories are perfect for this” (M1)
“Enjoying what is chosen” (M4)
“Good choice and fun” (M8)
“Happy for you to choose … quite enjoyable as it is” (M12)
“Loving it … Happy as we’re going” (M15)
“I like the surprise! … I enjoy it very much, have even read at home, feeling not stressed” (M17)
“The two books are perfect” (M18, who requested her own two books)
“It’s your choice … All good” (M19)
“Would prefer to have no choice as enjoying new authors” (M23)
“All the stories are enjoyable and within my taste” (M24)
“Enjoying your choice” (R2)
“I can’t choose at the moment – happy for you to choose. I really enjoyed that Colin Thiele this morning too” (R3)
“I like the variety. (I) like the surprise / not knowing” (R4)
“One of the great things is for you to choose – surprise me” (R5)
“I like surprises” (R6)
“Quite happy with the selection – especially the one about Jack Reacher” (R7)
“I enjoy listening to different authors that I wouldn’t normally choose” (R9)
“I’ve enjoyed being made aware of authors I’ve not heard of before but also being made aware of different readings of authors that I’ve not read before” (R10)
“I like the variety” (R11)
“No suggestions. I’ve been enjoying what you’ve been reading – where it’s been taking me” (R13)
“No suggestions – I’m loving the choices. There’s always a nice mix … it’s terrific” (R14)
“Happy with what is being read” (R15)
“I will leave it to you” (R17)

Appendix L – The Reader Experience

This section describes both the most relevant and surprising experiences encountered as the reader. They are shared to help with the planning of future reading research or read-aloud program implementation.

Establishing a rapport with participants was considered an important ingredient in the program delivery, and this was confirmed by participants during interviews (refer to section 5.3.4). However, managing very talkative people who could happily chat for some considerable time, as well as enjoy their stories, required some delicate social skills to ensure time for reading as well as talking.

Staying aware of participant posture and expression was important during reading sessions, as potential indicators of fatigue, anxiety, depression and story enjoyment. The preference of some participants to listen with their eyes closed led to the two instances of participants falling asleep (both anxious and not sleeping well; both male; both relaxed enough in the session to fall asleep and described in Appendix B). As part of trying to stay empathetic to participants, reading facial expressions and body language was considered important but was difficult in some instances. Additionally, all except one participant were easy to deal with.

Interacting with people diagnosed as palliative and dealing with the death of participants was part of the reader's experience. Seeing participants becoming increasingly frail was difficult. Having psychological first aid training was imperative for knowing how to respond to some of the confidences shared about their cancer experiences and also for how to cope with arriving for a session and finding a participant in a distressed state. This is similar to one of the recommendations from Walwyn and Rowley (2011), where they suggest having a healthcare professional discreetly on-hand.

One participant died during the course of the intervention and two died shortly afterwards. Considering the high proportion of palliative or stage 4 participants (about half), there is no doubt others will have followed by the time of writing this thesis. The research team had not anticipated the need to cope with death, given the intervention was only six weeks duration. However, it is important to document this as an awareness for future studies and implementations of a read-aloud program in these settings. This should not deter readers in future programs, as time spent sharing stories with these people in particular was precious and highlights the transferability of this program to palliative settings. This is discussed further in section 6.9 and Appendix P.

Personal reflections

There is a need for people working in this space to look after themselves emotionally / psychologically. Future studies need to be aware of researcher fatigue. The demanding task of recruiting participants, which included speaking at cancer support groups and staff meetings at hospitals, and the need to rapidly improve public speaking skills, as well as travelling, evaluating reading material, planning for each participant, writing a reflection of each session with each participant (with sometimes four participants in one day) was tiring. Writing reflections and observations became an evening job, as did planning reading material for the next day. At one point in the data collection phase, 11 participants were taking part in the program concurrently, which meant researcher down-time was hard to find, particularly when the research was occurring within the time and resource constraints of a PhD.

When a strong connection had been forged with participants (which did happen over some stories that prompted them to share about themselves), it was difficult to simply cut ties with them, but research ethics dictated that once the intervention had concluded, contact should stop until completion of the study. It was obvious some participants found this severing of connection upsetting, and for some of them, the researcher did too. Knowing that some participants did not have a lot of time left to live increased the difficulty.

The reader experience was an overwhelmingly positive one. It felt like the sun came out when participants exclaimed, chuckled or laughed aloud at stories. It was wonderful to bring some lightness into participants' days.

Appendix M – Reading Attitude Details

The improvement in attitudes to reading, based on the pre- and post-intervention ASRA scores, was statistically significant, as reported in Chapter 4, however, there were some problems with taking this measurement. The main problem was intrinsically linked to participants' perceptions of their reading. Whether their current reading habits were in mind when they completed the ASRA, or their pre-diagnosis, pre-treatment or pre-COVID-19 reading habits were uppermost in their minds was unclear. These issues came to light as the researcher formed connections with the participants and learned more about them, then scored their ASRA questionnaires and found that the scores contradicted what they described during the intervention or during interviews. Although it is not usual to drill down in instrument results at a level of detail smaller than a subscale, it has been done previously with the ASRA (for instance, by Asif and Gouqing (2023)) and it is done here to illustrate that (in hindsight) the ASRA was not an ideal choice to administer to a cohort undergoing cancer treatment, with many suffering CRCI. In previous studies, the ASRA appears to have only been used in healthy populations. The problems that were found are discussed below.

Regarding ASRA Q1, "I can read but I don't understand what I've read" and Q7, "I have trouble understanding what I read", these questions caused some difficulty, in either or both of two ways. Participants found it confusing to distinguish between *understanding* and *remembering* and indeed, this seems a logical confusion as forgetting part of a story soon after reading it would result in a subsequent part of the story being difficult to understand. Additionally, their answers indicated that a number of participants directly contradicted themselves when answering these two questions. CRCI could hinder their understanding of the questions themselves, which may be argued for any of the instruments used, however the DASS-21 and WEMWBS have been validated in a cancer context, while the ASRA has not. For this cohort, the main difficulty with these two questions lies in the wording of the question and participant interpretation, that is, the difference between *understanding* and *remembering.* For a number of participants, it was their inability to remember what they had just read, or what they'd read earlier that day (or the previous day) that was a huge problem affecting their reading pleasure. Being unable to remember affects understanding. One participant (M5) had developed a strategy to help with this – he used an iPad to keep track of characters because he regularly forgot who they were and how they related to each other, which is an innovative idea. This concern about memory difficulties leading to difficulty understanding when reading visually was consistent with observations during the intervention and information shared in interviews.

Regarding ASRA Q8, “When I read I usually get tired or sleepy”, 82% of the participants were actively receiving treatment at the time of the intervention. Fatigue is an extremely common side-effect of treatment (National Cancer Institute, 2021), which also affects motivation (Lacourt et al., 2018). Additionally, 79% of the cohort reported suffering CRCI at enrolment, which typically affects motivation as well as thinking (Cancer Council, 2023b). This is reflected in the low scores for this question: pre-intervention, only 7% of RR participants and 30% of metropolitan participants reported they did not get tired or sleepy reading. Post-intervention, these figures had increased to 33% RR and 35% metropolitan, which is consistent with the renewed enthusiasm for reading that came out during the interviews.

The responses to several ASRA questions contradicted what participants themselves had previously disclosed verbally. For instance, R9 had a low pre-intervention score despite her describing the joy of reading books on her phone because it enabled her to read anywhere, and how pleased she was to be almost all the way through reading every book ever written by popular author Monica McInerney. These comments appear inconsistent with a low ASRA score, yet that is what she had. Likewise, M17 who had happily started reading short books in her native language as well as other Jeffrey Archer short stories (she was introduced to his writing during the intervention) and even described some of the stories in detail during sessions (signifying she was clearly enjoying them), yet her ASRA score dropped 11 points pre- to post-intervention, indicating a significant decline in reading attitude. Although this could have stemmed from the fact that English was her second language, it seems unlikely as she appeared competent at reading and speaking, and was employed in an occupation that relies on reading ability. This adds additional weight to the argument that the ASRA measure is cognitively too demanding for people affected by CRCI.

Regarding ASRA Q14, “I would rather watch TV than read a book”, anticipating the almost all-pervasive nature of television in our society, the responses to this question were not as biased towards television as expected. However, this could be because most people who enrol in a reading program already have an interest in reading, even if they are not currently doing it. Pre-intervention, only 29.7% of participants indicated they would rather watch TV than read a book, 29.7% were unsure and 40.6% indicated they would rather read a book. Post-intervention, there was a big increase in the uncertainty of the responses: only 8.6% indicated they preferred to watch TV than read a book, while 48.5% became unsure, and 42.9% preferred to read a book. Although the preference to read only increased marginally (2.4%), the shift from definitely preferring TV to being unsure about whether to choose a book or TV

rose significantly (18.8%). This could mean participating in the program and experiencing improved wellbeing as a result, made them question their television-watching habits, and consider if reading a book might be at least as good an option, if not better.

The administration of the ASRA in this digital age also posed a question for the researcher: does reading posts on support group forums and/or social media count as reading for the purposes of the ASRA? As a lover of books, the researcher feels that it does not count, however, it *is* still reading, and neither the ASRA guidelines nor prior studies that used it, made a distinction. The UK's National Literacy Trust defines "reading for pleasure" as "reading that we to do of our own free will anticipating the satisfaction that we will get from the act of reading" (Clark & Rumbold, 2006). Furthermore, considering reading from a socio-psycholinguistic viewpoint, "What is universal among people is the need and ability to create language. The form it takes depends on its functions and the characteristics of the people who use it" (Goodman & Goodman, 2014, p. 45). Using these definitions, the accounts participants gave of reading social media, reading real estate websites, reading company annual reports (for enjoyment, as a retiree), and spending hours reading the newspaper each day all count as reading for pleasure. However, the Australian Bureau of Statistics (ABS) defined reading when they looked at how Australians spend their leisure-time, and they defined reading as "reading newspapers, books, magazines, e-books", but they excluded "checking news, emails or social media; reading news online; reading messages or texts; reading paperwork, mail, household administration; reading for study; participating in book club" (Australian Bureau of Statistics, 2024, para. 1). This makes a definition of what constitutes reading, and reading for pleasure, extremely difficult, and until a firm definition is found, measures like the ASRA may be without meaning.

The ABS mapped the steady decrease of reading in Australia by generation: Interwar, Baby Boomers, Generation X, Millennials and Generation Z (Australian Bureau of Statistics, 2024). Young people today, 'Gen Z', are technology focussed and more than 74% engage in online activities during their free time, 66% use two or more internet-connected devices at a time, and in the UK it is reported that they spend an average of 10.6 hours online each day (Gresswell, 2023, para. 3). Across society, and despite the digital divide, the ease with which a person can access information and entertainment makes it almost all-pervading; technology is such a part of our lives that 'google' is now a verb in our English language! There is no denying the online world offers a convenient and flexible way to access content and it can be cheaper than printed materials, however, it does require some skills to access it, a level of discernment and access to technology; and enormous issues around copyright accompany

digitisation of existing material (Darnton, 2009). Studies show increasing exposure to digital reading is changing reading habits, such as shallow, fast reading which is changing brain reading circuitry (Wolf & Gottwald, 2016); and scanning rather than reading in-depth, leads to a reduced ability to concentrate (Greenfield, 2014; Liu, 2012). However, these studies also concluded that print media is "unlikely to disappear in the digital age" (Liu, 2012, p. 92) because many people still prefer paper-based reading to avoid the distractions that are inherent with on-screen reading and when in-depth reading is required or desired (Liu, 2022). Baron et al. (2017) also found that most students report concentrating better on texts in print form, and they prefer hardcopy over electronic books (e-books) for both pleasure and academic reading. Although studies exist comparing learning outcomes from printed and e-books (Lim et al., 2021; Suyatna et al., 2018), their results are mixed. While some studies show advantages of e-books, such as using well-designed, properly selected e-books for the purpose of improving children's literacy (López-Escribano et al., 2021; Picton & Clark, 2015), a study by Scholastic books found students qualified the situations in which they preferred e-books or printed books, and although the number of young people (especially boys) reading e-books has increased dramatically, the students nevertheless stated printed books are better for tracking progress through a book, sharing with others and reading in bed (Scholastic, 2012). Especially relevant to this research, is Scholastic (2019) also found that more parents are reading aloud to their children. Although this is not academic research, it is heartening in light of all the research supporting reading aloud to babies and children, and hopefully future research will evaluate this rigorously,

With all the convenience and accessibility advantages of digital media, it is no wonder debates exist around online reading overtaking reading physical items, yet studies still turn up some surprises, such as Berens and Noorda (2023) showing Millennials' and Gen Z's return to physically visiting libraries even though more than half borrow from digital collections; but most surprising is their finding that Gen Z's buy and read more than Millennials and despite their "blurring of the digital and physical worlds", print is their preferred book format (Berens & Noorda, 2023, p. 3). This interesting finding goes hand-in-hand with the Gen Z "reading revolution" on TikTok, with the BookTok hashtag reaching billions of people worldwide and impacting booksellers' bestselling lists (Novak, 2023). The debate about digital versus print reading is beyond the scope of this study, but current trends that see a melding of traditional and online reading, point to the need to reconsider the notion of reading as sitting with a book in-hand, and any future attempts at creating measures of reading attitudes and habits should consider this range of reading options.

In a similar vein to the digital debate, during administration of the ASRA, some participants were unsure as to whether the instrument referred only to reading to oneself, or if it included listening to audiobooks. The researcher indicated it included both, so some participants distinguished their experience of the differences they found between the two methods by indicating two answers for some questions, and indicating which applied to visual reading and which applied to audio reading. Although this points to the need for the ASRA to be updated to accommodate this modern age of reading various formats and the ease of some formats over others for many reasons (examples include cognitive, physical or vision impairment, dyslexia, and convenience), this is of great interest, as the answers participants gave indicated more difficulty and less motivation with reading (visually) to themselves than listening. Of note is the fact that 71% of participants reported difficulties reading for pleasure due to CRCI; one participant reported she did not know if she had difficulties (she listened to audiobooks and was not sure about the impact of reading to herself) and another participant felt the question was not applicable to him (so he did not answer it) because he had no interest in reading and therefore was unaware of any effect. M9 told us: “I'm interested in reading, in getting involved in reading again because I, you know, I haven't read for a while, I mean I did read a little bit while I was in chemo treatment, but couldn't really concentrate.” Consistent with section 6.3, 67% of the participants who reported no difficulties with reading for pleasure (due to CRCI) were male.

Towards or at the end of the program, the researcher did encourage reading via listening to audiobooks, when prompted for reading suggestions, but this idea was met with mixed responses, and in general, not favourable ones. Most preferred to try reading to themselves again, so less demanding books (like the ‘Quick Reads’ series) were suggested. Some reported wanting to try short stories, however, some wanted to dive straight back into reading (not listening to) novels, and so they were gently cautioned about the difficulty they were likely to experience in the midst of CRCI. Likewise, when appropriate, some participants were gently cautioned against some of the reading and listening choices they were attempting when they described them in the exit interview. *The Grapes of Wrath* by John Steinbeck (2014/1939) for instance, is not a short book, not generally considered an easy read, and although considered a classic, it is not something likely to be recommended as an uplifting read, and so the researcher feared choices like this would lead to disappointment given their CRCI. This highlights an area where education of library staff and library outreach services could help, and guide people affected by cancer in their reading choices when they are still suffering CRCI or starting their recovery from CRCI. When librarians were interviewed

about why Australian libraries matter, Karys McEwen from Prahran High School library said “there isn’t a single librarian who isn’t passionate about making sure their shelves are filled with accessible, inclusive material for all” (Stella, 2022, para. 18) which is undoubtedly a sentiment of librarians and experienced public library staff everywhere. Unfortunately many public libraries in Australia are staffed by inexperienced, non-qualified staff, who do their best, but do not always have the breadth of knowledge to perform adequate reader advisory services. The researcher has even worked with staff in public libraries who watch DVDs but do not read books! These are the same libraries where managers with no library training or experience are employed. Perhaps our professional association can help with promoting awareness and resources about the need for accessible material for all reading audiences.

It had been intended to match wellbeing and ASRA results according to existing and lapsed/new readers, however, the problems described here with acquiring accurate reading habit and ASRA data meant that was not possible. Future studies could try to obtain a more accurate picture of reading habits and attitudes via personal interviews prior to intervention delivery, with an emphasis on distinguishing between habits and attitudes prior to diagnosis and treatment, and current habits and attitudes. However, this could potentially exclude non- or long-lapsed- readers from participating as they would be likely to view this as irrelevant to them.

Appendix N – Retention Specifics and Comparisons

The estimand framework released by the International Council for Harmonization of Technical Requirements for Pharmaceuticals for Human Use (ICH) is described as relevant in palliative situations for behavioural as well as drug trials, and contains recommended strategies for handling intercurrent events (Grobler et al., 2022). The intercurrent events for the two participants who did not complete the reading intervention were "disease progression so that participants are too unwell to complete trial procedures" and death, where the recommended strategy in each instance is "hypothetical strategy", that is, "estimation of the treatment effect" (Grobler et al., 2022, pp. e435-e436). Although it was impossible to estimate the effect of the intervention using quantitative measures, researcher observations could be included, as could the unsolicited feedback provided by the spouse of the participant who died part-way through the intervention.

Using the framework outlined above with the recommendation to estimate results as if these events (death and health deterioration) had not occurred (Grobler et al., 2022), it can therefore be concluded that the metropolitan drop-out rate was 0% and the RR drop-out rate was also 0%. In reverse, the retention rate was 100% (based on N=38 enrolments and the hypothetical strategy described above). When comparing these rates to other studies in groups of people affected by cancer, two studies were described previously with low retention rates: Krebber et al. (2016, p. 1756) had 40% retention and Hammer et al. (2017, pp. 474-475) had a retention rate of 57%, the main reasons being the program was potentially too demanding or stressful, and lack of enjoyment with the book choices (respectively – refer section 2.4.4), and given the high retention rate for this program, clearly something appealed to participants and potentially supported them. Other bibliotherapy studies in a cancer context had retention rates of 98% (Angell et al., 2003, p. 499) which is very high, likely due to the use of a participant-focused recruitment model and multiple in-person contacts prior to program enrolment; 91% (Semple et al., 2009, p. 380) which is also very high, possibly due to the intervention also being delivered in participants' homes; 85% (Körner et al., 2019, p. 736); 98% (Schulman-Green & Jeon, 2017, p. 176); 95% (Roberts et al., 2016, p. 590); 93% (Beatty, Oxlad, et al., 2010, p. 1598); 92% (Beatty, Koczwara, et al., 2010, p. S69; Tegnér et al., 2009, p. 125) and Carpenter et al. (2014, p. 460) had an 80% retention rate in their intervention group although their waitlist control group had 97%. Studies of psychosocial interventions for cancer patients and their families have been seen to have an average retention rate of 69% (Song et al., 2021, p. e279). Other than the studies by Hammer et al. (2017) and Krebber et al. (2016) with low retention rates, retention rates for bibliotherapy

studies are very high in comparison to the average rate for psychosocial interventions in this population, which begs the question: Do bibliotherapy studies have higher than average retention rates because they are so enjoyable, or easy to comply with, or people feel benefits from them? The qualitative data indicate that the universal enjoyment of this read-aloud program is likely the reason for participants wanting to complete it. Additionally, rapport and compassionate communication will be influencing factors (Chaudhari et al., 2020). The response from R7 when asked if there was anything about the program that had a negative effect on her, "No, I loved it" (R7) encapsulates the reasonable reason for high participant retention.

Appendix O – Libraries

Today, libraries are so much more than books, and their collections extend far beyond a physical building. The concept of 'third place', as a place to gather informally in the community, for leisure or learning, was developed by sociologist Ray Oldenburg (Oldenburg, 2009). Libraries fit that description and are regularly described as the 'third place' (Accart, 2022). They have also been described as the communities' living rooms in a multitude of places, including at the reopening ceremony of Toronto Public Library's Malvern branch, when the local mayor described the "enormous value" of libraries and linked them with improved QoL (Sobchak, 2005, para. 16). People go to their libraries to get help applying for jobs, to learn new skills, use maker spaces, participate in community groups, workshops and after-school clubs, to help their little ones develop pre-literacy skills and so much more. All these things are wonderful, and important to communities, but reading is still a necessary skill and even if people fail to realise, it underpins so many (but not all) of the program offerings at public libraries and everyday life. It is hard to get a job without being able to read, or to get a driving licence, do the shopping, or follow directions. Our lives would be quite different if we could not read. Additionally, reading for pleasure has associated health benefits (discussed in Chapter 2). Although libraries are not just a place to find a book, connecting people with reading, and the difference that can make in their lives, should be part of libraries' core business. The Victorian Book Well pilot program noted that a "fundamental principle of public libraries" has always been "access for everyone to reading and literature" (McLaine, 2011, p. 84).

A concept beyond the scope of this project is an analysis of the role of readers' advisory (refer later section in this appendix for more about readers' advisory) and the lamenting of the introduction of self-serve borrowing stations in libraries that serve to reduce staff numbers (and therefore library running costs) and serve to distance library staff from their readers and their reading choices. Librarians have been called "part wizard, part genius, part explorer" (Stephens, 2016, p. 85) but there is a huge challenge in getting to know the needs of library patrons, quite separate from coming up with ideas to meet those needs. However, with library staff regularly extending and reinventing themselves according to the latest trends (be it maker spaces or otherwise), it needs more than wizardry in the face of squeezed public library budgets to grow user-focussed services and community engagement, which may already be impeded by a lack of public awareness, a lack of forward-looking administrators, emphasis on collections rather than library patrons and confusion about how best to progress (Stephens, 2016). How many librarians in today's libraries notice when any regular readers

gradually stop coming to the library? Would staff recognise, or have the time to recognise, when someone starts struggling with their reading? This struggle could be for a variety of reasons, but it could also be the direct result of a common side effect of cancer treatment, and that is the part of concern to this project.

Not only were most SA public libraries unable or unwilling to advertise this reading program, but (as previously discussed) they also would not allow the researcher, an LIS student delivering a reading program, to use a meeting room free of charge. This is not supportive behaviour towards a peer trying to make a difference via a cross-over between the LIS and psycho-oncology fields. However, over the course of meeting a participant regularly at one regional public library, the staff were always friendly and happy to draw attention to the many quiet reading corners; they showed off their impressive collection of short stories, they put a recruitment poster up in the library space itself and while exploring the library space, the researcher found almost a dozen different trifold brochures about literary genres. Perhaps a new brochure could be created with a title similar to 'Cancer Treatment – reading tips and help'.

Practical implications

If libraries could allocate funds in their budgets to allow staff the time to chat to patrons about what they're borrowing, they would gain more than by simply looking at borrowing statistics because it would lead to understanding why these items are being borrowed by these particular people. Additionally, libraries could have clearly visible promotional material onsite and online to help guide reading choices for those needing some extra help. Also catering for those who need some extra help, library staff could receive extra training about how to perform a readers' advisory (RA) service for those with reading difficulties arising from a mental or physical health problem. Furthermore, staff in-service days could allocate time for some simple training about empathy for regular readers undergoing cancer treatment and the potential implications on their reading habits. This could include some time role-playing so that they can confidently recommend books or audiobooks to satisfy the needs of this part of our community. Given cancer is estimated to affect one in two Australians before the age of 85 (Cancer Council, 2023a), this is a huge sector of our community. Granted, not all will experience CRCI, but as discussed in Chapter 2, up to 75% will (C. G. Brown, 2015, p. 204), and although this study is small in size, it had an even larger proportion of people reporting CRCI symptoms: a staggering 95%. Library professionals, already experienced in RA, could use the recommended story list associated with this research project as a starting

point when assisting their patrons undergoing cancer treatment. The story list is in Appendix D and it may also be useful for people with mild cognitive impairment.

Public Libraries Victoria (PLV) recently produced a report, *Libraries for Health and Wellbeing: A Strategic Framework for Victorian Public Libraries towards 2024*, which provides a blueprint for the priorities, roles and practicalities of public libraries in Victoria supporting community health and wellbeing (SLV & PLV, 2021). The report cites caring, committed staff, and a willingness to form and work in partnerships. Research has revealed a need for cooperative partnerships between libraries and healthcare providers (Brewster, 2008b). By affirming Victorian public libraries' commitment to advocating for their communities' health and wellbeing needs, with a focus on local health and wellbeing services (including specific mentions of yoga, music therapy and programs encouraging reading for pleasure) within a statewide health and wellbeing program, PLV may be ready to embrace opportunities to help people affected by cancer in their communities. Targeting mental wellbeing, social connection and physical health, PLV's focus on the areas of equity of access (and accessing reading is often difficult or impossible when impacted by CRCI) and collaborating with partners, suggests they are well-placed for discussions around possible partnerships for helping to implement a reading program such as the one studied here. Contrastingly, Public Libraries SA have a network structure that would prohibit the rollout of any equivalent plan if it was to be developed in South Australia (D. Garcia, personal communication, October 3, 2023). Also in Victoria, last year the SLV and PLV produced the research paper, *The Health and Wellbeing Benefits of Public Libraries Across Victoria*, which reported Victorian library users had an 8% higher health and wellbeing score than non-library-users (SLV & PLV, 2023, p. 4). Additionally, 44% of their study respondents self-reported library use helps with their mental wellbeing, and given 48% of Victorians engaged with a library in the preceding year (either in-person or online) (SLV & PLV, 2023, p. 5), these are encouraging results.

Looking overseas, in the UK, the Reading Well program was formed through a partnership between The Reading Agency and a variety of expert health organisations, including The British Psychological Society, Royal College of General Practitioners, Anxiety UK and Public Health England (The Reading Agency, 2023a). As part of the Welsh government's commitment to the program, they have provided funding for bilingual Welsh and English copies of the books in every library in Wales (The Reading Agency, 2023c). The Reading Agency has collected evidence about the effectiveness of their reading programs for wellness, including their Books on Prescription model, creative reading (novels and poetry), reading

groups and the role of public libraries in the health and wellbeing of local communities (The Reading Agency, 2013). They found that 2.6 million books have been borrowed under wellness initiatives and 91% of those surveyed found them helpful (The Reading Agency, 2023c, para. 7). Much of the material in those programs is available as physical items, audiobooks and eBooks. In Scotland, tailored health and wellbeing initiatives, coupled with core library services (including reading) and welcoming staff/space have led to mental and physical health benefits, improved wellbeing and an estimated saving to the Scottish National Health Service of £3.2million (approximately AU$6.3million) each year (Tyler, 2020, p. 12). These initiatives are so broad, and some so innovative, they are reproduced in Figure 6.1.

Figure 0.1

A to Z of Health and Wellbeing Services in Scottish Libraries



Note. The Scottish Library and Information Council commissioned the report 'Health on the shelf: Health and wellbeing in public libraries in Scotland' in 2019 (Tyler, 2020). This figure appears in the report and is made available separately for libraries to display (Scottish Library and Information Council, 2020). Reprinted with permission.

In the USA, although the American Library Association's (ALA) division Public Library Association does not specifically make mention of any health-related links in their latest

strategic plan, they do describe an advocacy goal to champion “public libraries as a public good” (Public Library Association, 2022, p. 2). A direct correlation to wellbeing could be a good next step.

With their social conscience, library staff are tasked with reaching all library users, and outreach programs and resources of all descriptions try to do this. Could libraries partner with cancer centres, palliative care providers and hospices to provide reading programs? As described in Chapter 2, reading can improve many aspects of wellbeing, and as the results of this study have shown, there is great potential for read-aloud programs to have positive psychosocial effects on people undergoing cancer treatment and their families. “Libraries encourage the heart, which means we should lead from the heart, learn from the heart and play from the heart” (Stephens, 2016, p. xiv) and now CRCI is recognised but there is no known specific cause or cure, there is a place for libraries to help. Libraries are well-equipped to provide staff, volunteers, structures and physical resources – they could make a difference in the lives of people affected by cancer.

Bibliotherapy in a cancer context has been explored very little. This study has shown some promising results for the difference a read-aloud program can make in the lives of people and their families affected by cancer. Librarians are known facilitators of knowledge, co-creators of novel programs and resources, and also with sufficient patience to be able to answer countless directional queries throughout the day. Alongside censorship, librarians take accessibility seriously, under the guise of enabling all library patrons access to all material, and they could provide access to the benefits of reading to those undergoing cancer treatment if they are aware of the problem and know how to help. It is acknowledged repeatedly that librarians struggle to implement bibliotherapy because of the lack of consensus about what bibliotherapy is, and how to deliver it (Brewster, 2008a), yet the incarnation of bibliotherapy used to positive effect in this study is simple to deliver and the ‘how to’ is detailed herein.

From an oncology team’s perspective, or from the viewpoint of the manager of integrative cancer services at any hospital, if they could rely on their local public library to help run a read-aloud program, that could remove an obstacle to implementing it. Acknowledged barriers of project implementation include lack of resources (including financial, human resources and clear guidelines), lack of motivation and lack of coordination and collaboration (Health Policy Project, 2014). Libraries have the physical resources to assist a cancer centre or hospice with the implementation of a reading program, while readers could potentially be sourced and trained via either facility. The creation of a joint-use library according to current

models (McNicol, 2008) would not be feasible, but rather the local public library could maintain a collection of appropriate short stories through either a special collection (similar to a collection of book club sets) or as part of their general collection. Additionally, if reading volunteers are used, librarians should also be involved, especially those with experience choosing books for recipients of a home library service, for instance, and with a willingness to always have another suggestion on hand 'just in case'. These are good starting points before drilling down to more specific details, such as those presented in section 3.5.3 and Appendix C.

As previously discussed, reading material personalisation is very important in a program like this, and so is access to an experienced reader. Reports by Australian state library organisations and UK reading organisations show an increased awareness of the benefits of partnerships between libraries and health care providers. Some public library staff are trained and experienced in RA roles and libraries often have access to (literate, reading advocate) volunteers. Therefore, partnerships between libraries and cancer centres, community palliative care programs and hospices could work well because resources are always limited at each of these institutions and thus partnerships would ultimately benefit people affected by cancer and their families, as well as the institutions. Equally, integrative cancer centres could employ bibliotherapists, just as they employ art and music therapists, and there would be real value in doing so, or otherwise they could employ experienced librarians with the recommended characteristics of empathy, perception, maturity, respectfulness, adaptability and integrity, and an ability to read-aloud well (refer section 5.3.4). These are two possible ways for a program like the one studied here to be implemented.

Benefits to LIS profession

Highlighting adult storytimes and the value of being read to and listening, especially when reading to oneself is difficult, is of benefit to the LIS profession. LIS education would be well placed to incorporate some aspects of this in their courses. Additionally, libraries could become involved in providing resources (reading material and perhaps volunteers) to cancer centres, showcasing their expertise in these areas, and their willingness to help others. Additionally, a reading guide will be an output of this project, which will be of use to others in the LIS profession. Highlighting bibliotherapy as an evidence-based integrative cancer therapy, just as valid as music and art therapy, mindfulness and yoga in the integrative oncology toolkit also highlights the LIS profession and the role library staff play in communities.

Readers' advisory (RA)

Readers' advisory (RA) can be described in different ways: "the process of matching readers with books and books to readers" (Library Training and Learning Hub, 2022, para. 1); or to "provide the right book in the hands of the user at the right time" (Spiteri et al., 2016, p. 91). Reading can be broadly assigned to two purposes: education or entertainment. RA services are generally considered to assist with leisure reading via fiction or non-fiction, and the service should offer suggestions rather than recommendations, based on a reader's particular interests, likes and dislikes. RA is taught in most tertiary library courses and is central to the role of public library staff and bookshop staff alike. A RA librarian may have a list of pre-determined questions to probe a patron about reading preferences (much like the participants were probed for information to inform the choice of intervention reading material) so that some meaningful suggestions can be made. Reading preferences are quite personal and some people will not approach a librarian for help, for fear that their reading interests will be dismissed or judged (Hollands, 2006). The incorporation of user-generated content in library catalogues may help bridge this perceived gap by assisting RA staff when formulating suggestions and facilitating more interaction between readers and librarians (Spiteri et al., 2016). More interaction between readers and librarians would also occur if self-service borrowing kiosks are removed. Library staff can be fearful of the RA role because of the ever-expanding list of genres and books, and the need for cross-over between adult, young adult and children's literature (Lumpkin, 2021). Yet, staff training and RA tools are invaluable allies for librarians.

COVID-19 caused changes in the way libraries operate, with increased uptake of e-books and increased participation in virtual book groups and online library programs; and with physical browsing no longer possible, RA enjoyed a renaissance with staff and patrons communicating via social media, library websites, email, newsletters and phone calls (Lockley et al., 2021). RA services were increasingly called upon "as readers isolated themselves, they found solace in their connection with a librarian ready to listen and chat about books ... patron after patron commented on how grateful they were for the service" (Lockley et al., 2021, para. 6). To be able to deliver a meaningful, personalised reading experience for the participants in this study, RA skills were employed by the researcher in order to match stories to participants.

Appendix P – The Golden Stories

Although it seems disrespectful to use numerical assignations for them, there is no other way to tell these stories and still protect their privacy. As with Chapter 5, which used first-person narrative because the researcher was a tool in the analysis process, this section will also be told in that voice, because it was the profound interactions between these participants and the researcher that led to these stories and thus it is fitting, and respectful of their memory, to relate their stories in this way.

M2. Although not previously a regular reader, and in fact unable to read following a bleed in the brain during his surgery, M2 had already shown his appreciation of funny stories from our first session together. I vividly remember the day I arrived to read and M2's wife told me he was not feeling well and was in bed: she thought I would not mind reading by his bedside rather than cancelling the session. Although I sat on a chair next to his side of the bed, he faced away from me, because it was the easier side of his head to rest on his pillow following his surgery. He did speak to me a little but was not very communicative that day. I thought it would be good to start with something light-hearted (Australian yarns – a barramundi story). There were no comments or chuckles from him until the end, which I suppose was to be expected given the way the story unfolded. I read a Neil Gaiman story next, and worried about the length of it, but he enjoyed it - laughing each time there was a new opportunity for the main character to strike a bargain. That story had a darkly funny, but somewhat shocking ending. It was about 30 minutes into the session at that point, but I thought it would be good to finish on something lighter since he was feeling so unwell. I told him I had brought a Kitty Flanagan book (which excited him) and Michael Rosen (since the Roald Dahl's *Revolting Rhymes* he had requested had not come into the library yet). Given his enthusiastic reaction to Kitty Flanagan, I read the 'Food' section (Flanagan, 2019). I was going to stop after 10 minutes (because that would be 40 minutes in total then) but he kept laughing, so I kept going until the end of the section. On the way out, I made next week's appointment with his wife and apologised for taking an hour when I had told her 40 minutes. I explained M2 had kept laughing, so I kept reading, and she said she had heard, and was really glad of it. M2 was about my age, with terminal brain cancer. He was unwell on that occasion. I knew it was something that was only going to progress, however, I felt like I had made a difference to his day - brought some lightness and laughter, and that is a really special thing to do. That was the last time I saw M2.

Unexpectedly, the next week, his wife contacted me to let me know that he was near end of life. She commented on the intervention: “I wanted to let you know how much he enjoyed your reading. It was a joy for me too” (permission gained to include this feedback). After his death, she contacted me again, and again commented on our reading together: “Thank you again for the time you spent reading to him. It was really special” (permission gained to include this feedback). Her messages conveyed the delight they both gained from M2’s participation in the program. What an honour to be able to make a difference during someone’s last days, and to know that it was a comfort to family too.

M5. Some months after the 6-week intervention, at the request of M5’s spouse, my nurse-practitioner liaison at one of the hospitals contacted me with a request that I go to the hospice to read to him. After clearing it with the university in case of contraindications with my HREC approval, I sat by his bedside and read from his favourite genre. Although he was unable to interact much, he was clearly excited to see me. M5 was my (sometimes gory) science fiction fan. A couple of family friends and his wife were present, so I introduced the story as one of M5’s favourite genre, making no apology for the choice of story. His wife, who I had only ever spoken to over the phone, greeted me with a big hug, and asked for a copy of what I read afterwards. M5 relaxed into a peaceful sleep towards the end of the story. It was a privilege to be able to provide enjoyment and distraction during his last days and be a comfort to his family.

This was the closest situation to an in-patient / nurse situation but M5’s participation in the program had concluded and an interview with the nurse-practitioner was not appropriate. However, her feedback was “Thank you so much … (M5’s spouse) was so pleased you came” (deidentified nurse-practitioner, personal communication, May 16, 2023). Although this comment does not show her perception of the effect of reading on M5, it clearly shows her perception of the effect it had on M5’s spouse. I was able to read M5’s favourite genre to him on one of his final days. Additionally, being able to bring comfort to family members at such a difficult time is also hugely important. Palliative care at end of life is tasked with assessing and treating patients’ physical, spiritual and psychosocial symptoms and relieving the suffering of both the patient and their family: “as comfort measures intensify, so does the support provided to a dying patient's family” (Rome et al., 2011, p. 351).

Reading together is such a simple but powerful idea. These two experiences in end-of-life settings are potent illustrations that the reading program is eminently translatable to palliative settings.

Would I ever have been called to read via Zoom at the bedside of a participant near end of life? It is difficult to imagine, which in itself is an indication of the preferred delivery method, but it is not inconceivable.

M4 & M13. Although all the participants greeted me warmly each week and asked keenly about what was to be read that day, M4 and M13, despite both being beyond physical cure, had an almost childlike exuberance about them when greeting me and after settling into their chairs. They obviously looked forward to each session. They both had their favourite chairs; they would put their feet up and pull a blanket up to their chins. M4 had her little dog come onto her lap, who would invariably start snoring shortly afterwards, and the importance of her dog being there was mentioned in both M4 and her husband's interviews. Over the weeks, she felt increasingly unwell and her experience with contracting COVID-19 was a shock because it made her think that being so unwell was something to expect as her cancer progressed, yet she loved the funny stories. M4 linked her enjoyment of the stories to relaxing and escapism:

> Well, it was, it was lovely just to umm lie back in my recliner with my little dog and just have someone read to me and just feel … just really engaged in the story which was often quite funny with unexpected twists.... Yeah, just to be in that lovely little sanctuary and just escape.

M13 also had a pet in her life and enjoyed the freedom for her cat to wander in and out of the room during our sessions. She loved everything I read to her and exclaimed at the parts of stories that she found surprising or funny. Having exhausted conventional treatment options, M13 was participating in a drug trial. Her treatments were weekly, on Wednesdays, and we always met late on Tuesday afternoons. Not only did the sessions help her relax the evenings before treatment, when she was "getting a bit stewed up" or "twitchy", but she would also, during the infusion the next day, use the time to look up other books by the authors she discovered during our sessions:

> I look up the favourite books, the Jeffrey Archer. And I was looking at, while I was having the chemo so I could, relive, sort of relive the stories, especially that one about the 100-year-old man, I love that story ... So, uh, yeah, so I did relive it and it did help me to relax. (M13)

She summed up her experience and why it had such an impact on her:

> I felt like someone cared. You know, you feel like you mean something to somebody. … I think that's probably part of the joy of being read to, that you also makes you feel loved and, and cherished in a way. (M13)

The way both M4 and M13 looked at me so expectantly, with anticipation and enthusiasm - they were clearly looking forward to whatever I had brought with me to read that day. They both loved the surprise element of not knowing ahead of time what was to be read. As discussed in section 6.7, regarding the question of whether or not simple social contact could have resulted in the same positive qualitative and quantitative results that have been found in this study, M4 and M13's reactions were extremely strong illustrations of the value placed on "Story", redolent of librarian David Wright's description of the importance of "Story": "It is almost impossible to overstate how important Story is to people, and to libraries. Story is what makes us human. We think in terms of narrative … our dreaming minds spin tales even in our sleep" (Wright, 2010, pp. 131-132); and Neil Gaiman's (2013) imploration about the importance of fiction: "escapist fiction is just that: fiction that opens a door, shows the sunlight outside, gives you a place to go where you are in control" (2013, para. 21-22). These terminally ill participants were entitled to some 'sunlight'. The delight they exhibited around the stories being read, and the anticipation of which stories we would read next, shows the overwhelmingly positive psychosocial effect of the read-aloud program, in accordance with RQ2. In answer to RQ1, it was clear to see the impact of improved emotional wellbeing resulting from distraction and warmth for both M4 and M13. To see such joy around anticipation of a story was a treasure, and exactly what I had hoped to achieve.

R15. A case of distress to laughter.

For R15, our first session included a Jeffrey Archer short story. At her interview, she said: "Jeffrey Archer. I couldn't believe that, when you brought that out. It was like psyche … you know, there's no way on God's earth I would have thought of reading his. I gave all the books away." R15's late husband had been a Jeffrey Archer enthusiast and R15 had always thought his stories would not be to her liking. However, Archer's short stories are quite different to his novels, and were enjoyed by many participants. For R15, her delight stemmed from enjoying something her beloved late husband had enjoyed (once she recovered from the shock of seeing the author's name). The uplifting nature of the stories we read together acted as prompts for her to tell me about similarly happy times in her life – they were a catalyst for generating happy memories, which she generously shared with me. Telling these tales seemed to act like a tonic to R15 and only served to further lift her mood. This most likely helped with the dramatic mood lifts she experienced during sessions and is not unlike the therapeutic changes described in creative bibliotherapy literature, where mental health improvement results from identification, catharsis and insight (Shrodes, 1955). During our interview, R15 referred to the time she spent recounting some anecdotes from her life and

also compared reading aloud in-person to listening to audiobooks: “I like this because this is more personal … You know, it’s personal, even though I talk too much. You need to say stop, you know – timeout! (laughing)” (R15).

R15 was quite distressed when I arrived at about half the intervention sessions. She was not the only member of her family with a terminal cancer diagnosis, and the other member was very young and very dear to her, and she was struggling to cope. The most dramatic embodiment of the effect of reading humorous fiction together was seen in the mood lift of R15 on these occasions. Although she made comments about the soothing nature of the reader’s voice, her ability to immerse herself in stories was apparent, and in her own words:

> When you were here the other week, I was having a real downer because of the family situation. And by the time you left, I was laughing. So it really built up … a different vibe in my body. Sort of, my attitude changed, which was fantastic. (R15)

R15’s comments are unmistakably linked to mood enhancement and the humour of the stories clearly played a huge role, as did the personal qualities of the reader (especially regarding personality and smiling, as discussed in section 5.3.4). Whilst she recognised that the stories lifted her mood, she also acknowledged that she would not have made the effort to read for herself (even if her CRCI allowed it): “I wouldn't have sat and read myself. Because I was engrossed in … all this misery you know. I feel so light-hearted now, I feel so much, so much better with it”. She valued the program very much for the way it lifted her mood: “all the negatives that's been happening around my life, and while you're reading I’ve forgotten them … It changed my whole attitude for the day”.

R8. R8 decided to discontinue active treatment about mid-way through our six weeks together. She told me she felt it was a good decision and would now only have treatment linked to pain relief. Part of the role of the reader is to listen and empathise.

My visits with R8 were rather like a ritual, with her excited puppy greeting me and adoring being picked up and hugged, the preparation of tea in nice cups, the heater on, and lap rugs nearby if needed. Again, this participant was around my age, yet loved writing styles of yesteryear, like P.G. Wodehouse - she found his stories hilarious, and she likened them to radio plays. There was something in her manner that made me feel like a member of her family and strangely, she said as much during the interview: “It’s been a pleasure to have you – you're part of the family”. This comment clearly shows the value of personal connection. Her cancer treatment had hindered her concentration and motivation to read, as well as her energy levels, but when she stopped treatment, her concentration improved and she

developed an enthusiasm for trying to create the escapism and pain relief she experienced when I was there reading with her, so she started getting books for a new ritual of tucking herself into a warm bed early in the winter evenings to enjoy some time reading.

Chronic pain is exhausting and affects emotions negatively (Bjurstrom & Irwin, 2016; Fishbain et al., 2003; Snekkevik et al., 2014). Additionally, it is known that cognitive and emotional factors are fundamental to how pain is perceived, and heightened negative emotions intensify pain, "thus perpetuating a vicious circle of nociception, pain, distress, and disability" (Gatchel et al., 2007, p. 582). Mechanisms to reduce negative emotions, or replace them with positive emotions, as was the experience of the intervention participants, may be the reason for the pain reduction reported by participants, rather than simply the distraction and escapism of the stories. Pain itself is typically associated with cognitive impairment (Moriarty et al., 2011) and so for a person affected by cancer, this may represent a two-pronged attack on their cognition: CRCI and pain. For R8, pain relief was the most impactful consequence of the reading program. For her, the stories were "a lovely, pointed distraction, to take me away from pain" and she really valued being read to: "It's a very nurturing feeling … it feels like a gift". She found being read to helped her relax into the story and be able to engage in "picturing all these things" in the stories. Although R8 regained some focus as a result of ceasing her treatment, and tried to read for herself again, she loved the program, and she loved being read to. This adds more weight to the recommendation of the suitability of tailored read-aloud programs as part of community palliative care programs. Just as a nurse visits regularly, a volunteer reader could also visit regularly. Having seen what a difference the reading sessions made to these people, it felt awful to cease them at the conclusion of the program. The reading sessions brought them some joy and relief from symptoms and worries. Knowing they had little time left and something that brought them pleasure and pain relief was stopping, was hard on both the participants and me. However, it does serve to highlight the absolute suitability of the program in an ongoing way, in palliative care settings

Sadly, I attended M8's funeral some months after her completion of the intervention.

Appendix Q – Distress Protocol

University of South Australia

Distress protocol for intervention sessions and interviews

Reading aloud to cancer patients for improved emotional wellbeing

Distress

- Participant indicates they are experiencing high levels of stress or emotional distress

OR

- The reader or interviewer feels the participant is indicating feelings of stress or emotional distress, such as shaky voice, long pauses or crying.

Stage one response

- Ask the participant if they would like to take a break or stop the session or interview
- Assess the participant for levels of stress through the following questions
  - How are you feeling?
  - Would you like to stop the session/interview and reschedule?

Review

- If participant feels they are able to continue
  - continue with session or interview
  - check how they are feeling/coping periodically
- If participant feels unable to continue, proceed to stage two

Stage two response

- Discontinue session or interview
- Encourage participant to contact GP, or to ring one of the helplines: Lifeline (24/7) ph. 13 11 14, Beyond Blue (24/7) ph. 1300 22 4636, Cancer Council (Mon-Fri, 9-5) ph. 13 11 20
- Offer (with participant consent) for either Associate Professor Amanda Hutchinson or Dr Kate Gunn to contact participant for further support or guidance

If you have imminent concerns about the participant a) physically - phone an ambulance if no family member is present; b) mentally – phone AH on xxxx xxxx or KG on xxxx xxxx for advice.

Follow up

- If participant consents, follow up with a phone call to check on wellbeing
- Encourage participant to contact GP or support lines for added advice and support.

Modified from:

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing Distress Protocols for Research on Sensitive Topics. *Archives of Psychiatric Nursing*, *23*(5), 343–350. https://doi.org/10.1016/j.apnu.2008.10.008

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Elizabeth

Good morning. Many thanks for your enquiry. You can indeed use the Health on the Shelf report in your theses. It sounds like a really interesting project. Please do let us see it when it is finished. SLIC is pushing ahead with A Collective Force for Health and Wellbeing as a delivery mechanism for health related initiatives in public libraries in Scotland https://scottishlibraries.org/advice-guidance/frameworks/a-collective-force-for-health-wellbeing/

Please do credit the report and yes it was published in 2020.

Good luck with your project.

Best wishes,

Pamela

From: Wells, Elizabeth Ann - welea001 <elizabeth.wells@mymail.unisa.edu.au>
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Good morning,

I am a PhD student in Australia, researching a bibliotherapy program for improving emotional wellbeing during cancer treatment.

I have just been reading your 'Health on the Shelf' full report and executive summary, and am very impressed by the initiatives in libraries in Scotland. I am writing today seeking permission to reproduce your figure on page 12 of your executive summary (https://scottishlibraries.org/media/3899/health-on-the-shelf-executive-summary.pdf) in my thesis and also your A-Z of wellbeing services and include both of these as examples of how public libraries can assist in the delivery of health programs and initiatives. I was very pleased to see Macmillan Cancer Support in your A-Z listing. Congratulations on such a comprehensive list! Of course I will attribute the figures to Scottish Library and Information Council (2020? – please confirm), it's just that, unlike quotes (which can be included in

theses providing they are referenced appropriately), permission is needed to included to include a figure from someone else's work.

I have a section in my thesis entitled 'What part do libraries play?' where I outline ways our public libraries could assist people undergoing cancer treatment better, whether by considered reading recommendations or partnering with cancer centres to deliver bibliotherapy programs, and I'd love to include these two figures from your report as examples of what libraries can do, and the benefits (including monetary benefit as per your p.12 figure).

Thank you for your consideration,

Kind regards,

Elizabeth.

Elizabeth Wells
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