

Health Journey Mapping to Identify Strength and Resilience as
experienced by an Aboriginal Woman with Kidney Disease

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Abstract

The narrative told about Aboriginal and Torres Strait Islander peoples' health often focuses on ill health, with large gaps in measured health outcomes between First Nations and non-Indigenous Australians. For chronic kidney disease, it is estimated that the burden of disease for First Nations peoples is seven times greater than that of non-Indigenous Australians. However, First Nations definitions of health are not purely biomedical focusing on illness and disease. They are instead inclusive of all aspects of an individual's lived experience, including their connection to body, mind, spirit, community, family, culture, and land. Using a Western scientific lens to examine the health of First Nations peoples further colonises their experiences and fails to portray their lived reality. Research can employ a narrow approach when identifying the lived experiences of First Nations, however decolonised research methods offer new approaches to hearing their untold stories. This project was conducted collaboratively with a female member of the *Aboriginal Kidney care together: improving outcomes now* (AKction) Reference Group, to map and identify how she thrived in her journey despite having kidney disease. Research yarning, a culturally appropriate research method, and thematic analysis were conducted with her collaboration to answer how she demonstrated strength and resilience throughout her journey. Findings highlighted that her kidney health journey was complex, with kidney health forming only one aspect of her journey. The participant demonstrated resilience while facing complex challenges, using her connections, actions, and mindset to thrive and not just survive her journey.

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Signed Alyssa Cormick

Date 27 September 2021

Acknowledgment

I would like to acknowledge that this piece of work has been collaboratively produced with Kelli Owen, a member of the *Aboriginal Kidney care together: improving outcomes now* (AKAction) Research project and a Kaurna, Narungga, and Ngarrindjeri woman with lived experience of kidney disease. Kelli was positioned as a participant and coresearcher. Her knowledge and life experiences contributed to the development, implementation, analysis, and evaluation of this project. She has requested to be identified with her name and photograph attached. This decision was made to acknowledge her involvement in the project and ownership of her story and knowledge. It is uncommon for participants to be identified in psychology research, as participants' identities are typically kept anonymous for their safety and privacy. The decision for the participant's name to be included shows the merging of cultural ways of research, and the importance of identifying ownership of knowledge. Input and knowledge from other AKAction Reference Group members also helped guide this research.

This thesis was written on Kaurna Yerta in Tarndannyangga Adelaide, and data were collected on Peramangk land in Mount Pleasant, Adelaide Hills. I acknowledge the attachment and relationship Kaurna and Peramangk peoples have with these beautiful lands, and pay respects to Elders past, present and emerging.

This psychology Honours thesis has been written according to American Psychological Association (APA) conventions with some minor adaptations and extra appendices to ensure the work aligns with decolonised psychology research principles and First Nations data sovereignty conventions (APA, 2021).

Contribution Statement

The research project and design were collaboratively developed by the researcher, AKtion Reference Group and the participant. Data were collaboratively collected by Alyssa Cormick the researcher and Kelli Owen the participant and coresearcher. Results were analysed by the researcher, but reviewed by the participant and supervisors.

Terminology

At the request of the participant the term ‘First Nations’ will be used when referring to both Aboriginal and Torres Strait Islander peoples. While Aboriginal and Torres Strait Islander peoples are distinct cultural groups, they have shared experiences which are commonly discussed together. Literature for this research explores the experiences of both groups, and consequently uses the term First Nations. The participant and other members of the AKction Reference Group (ARG) identify as Aboriginal people with lived experience of kidney disease. The researcher wishes to acknowledge the differences between these two cultural groups, without generalising or minimising the experiences of either one.

Abbreviations

AKction: *Aboriginal Kidney care together: improving outcomes now*

APA: American Psychology Association

ARG: AKction Reference Group

ART: AKction Research Team

CDs: Chronic Diseases

CKD: Chronic Kidney Disease

ESKD: End Stage Kidney Disease

HD: Haemodialysis

HJM: Health Journey Mapping

PAR: Participatory Action Research

PD: Peritoneal Dialysis

TA: Thematic Analysis

Chapter 1: Introduction

1.1 Acknowledging the History of the Aboriginal and Torres Strait Islander Peoples

The First Peoples of Australia are the Aboriginal and Torres Strait Islander peoples, comprising over two hundred distinct groups with their own unique cultures, languages, beliefs, and practices (The Australian Institute of Aboriginal and Torres Strait Islander Studies [AIATSIS], 2021). It is acknowledged that there is great diversity amongst First Nations peoples, they are not homogenous, their long and rich cultures, and strong ties to their ancestral lands. First Nations peoples have overcome extreme adversities because of colonisation; experiencing displacement, genocidal practices and policies, removal of children from families, and systematic racism. These experiences have profound and ongoing effects, resulting in intergenerational trauma and significant disparities in life outcomes between First Nations and non-Indigenous Australians (Dudgeon, Milroy & Walker, 2014). However, First Nations peoples are resilient, they have resisted against these experiences and survived to be the oldest living cultures in the world. Acknowledgment and reclamation of First Nations' cultures are essential for ongoing healing and growth from these experiences (Bulloch, Fogarty, & Bellchambers, 2019).

1.2 Chronic Kidney Disease in First Nations

There are significant disparities in reported health status between First Nations and non-Indigenous Australians. It is reported that the burden of disease amongst First Nations is 2.3 times greater than the burden of disease for non-Indigenous Australians. Sixty four percent of this burden is due to chronic diseases (CDs) like chronic kidney disease (CKD) (Australian Institute of Health and Welfare [AIHW], 2021a). CKD is the presence of impaired or reduced kidney functioning for a period of three or more months (White, 2021). Kidneys are crucial for overall health, as they are responsible for maintaining healthy levels of substances in blood and blood pressure. Kidneys filter blood, removing waste and excess fluid through urine. When kidney function is impaired, this balance is disrupted (AIHW, 2021b). CKD has five stages of increasing severity. Individuals are commonly asymptomatic in early stages resulting in these stages being under-diagnosed. End stage kidney disease (ESKD) is

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the most severe form of CKD, where kidneys cease to function, and waste products and water rapidly build up in the body. Individuals with ESKD require regular dialysis to filter their blood or receive a kidney transplant for survival (AIHW, 2021b; Stumpers, & Thomson, 2013).

Incidence and burden of CKD are especially high amongst First Nations populations. Twenty percent of First Nations adults have reported biomedical indicators for CKD, compared with ten percent of non-Indigenous Australians (AIHW, 2020). First Nations peoples are at higher risk of developing CKD due to several biomedical, social, and behavioural risk factors influenced by their historical, social, and cultural experiences (Stumpers, & Thomson 2013). Biomedical risk factors include increased incidence of: premature births, low birthweights, underdeveloped kidneys at birth, genetic predisposition to kidney damage, being overweight, and having comorbidities with other health conditions such as heart disease and diabetes. Social and behavioural risk factors include having poorer access to healthy foods, clean water, housing, and education; and engagement in high-risk behaviours including poor diet, low activity, and alcohol and tobacco use (AIHW, 2020; Schwartzkopff, Kelly, & Porter, 2020). First Nations peoples with CKD are 6.9 times more likely to start ESKD treatment, are on average ten years younger when starting ESKD treatment, and are fifteen times less likely to receive an organ transplant (AIHW, 2021b; Chaturvedi, et al., 2021). They are also more likely have comorbidities and therefore must simultaneously manage health conditions such as diabetes and heart disease. These disparities attribute to the CKD burden of disease being 7.3 times greater for First Nations than non-Indigenous Australians (AIHW, 2020).

First Nations peoples report complex health journeys impacting their social, emotional, cultural, and family connections. Many are diagnosed late into their CKD progression requiring them to immediately start dialysis, which is emotionally stressful and significantly disrupts the lives of them and their families (Rix, et al., 2014). Those living in rural and remote regions are typically required to relocate to access treatment, again causing stress. This relocation is often a negative experience, as people move away from Country, family, and community, and are unable to engage in cultural activities (Conway, Lawn, Crail, & McDonald, 2018). There is a higher incidence of First Nations peoples with ESKD being younger and female, with dependents under their care who are also

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impacted by their diagnosis (Anderson et al., 2012). Many First Nations peoples with CKD rely on other family members to care for and support them with their diagnosis and treatment. This further disrupts individual's and their family's lives and their abilities to meet other responsibilities (Rix et al., 2014). First Nation peoples with CKD often report experiencing significant gaps in CKD knowledge, unfamiliarity with health settings, and poor communication with health staff due to overuse of medical jargon and cultural differences (Anderson et al., 2008; Hughes et al., 2019). The complexity of CKD journeys has significant impacts on health and wellbeing, affecting all areas of people's lives, and the lives of those around them.

1.3 First Nations Health and Wellbeing

Many First Nations peoples have holistic and strengths-based definitions of health. These definitions differ from narrow Western bio-medical models which focus on the presence or absence of illness (Farre, & Rapley, 2017). First Nations definitions are broader identifying the holistic and interconnected parts of an individual's life that have an impact on their health and wellbeing (Fogarty, et al., 2018). These definitions are inclusive of one's language, culture, and spirituality; connection to Country; belonging and identity; strength of community and family; living conditions and lifestyle; economy and finances; mental health including intergenerational trauma; and empowerment and control (Bulloch, Fogarty, & Bellchambers, 2019). This promotes recognition of the strengths of First Nations and complex experiences they have overcome, looking beyond disparities and biomedical deficit models (Bryant et al., 2021). Currently kidney health outcomes focus on biomedical health. While essential for diagnosing and treating disease, biomedical models fail to present the full lived experiences of First Nations peoples with CKD (Schwartzkopf et al., 2020).

Health journey mapping (HJM) is a process that records stages and interactions of an individual's health journey. Journey mapping is increasingly being used in research and healthcare settings to record what is happening in patient's lives and in healthcare settings (Madathil, Lopez, & Myrtede, 2020). This method has been used in CKD research to gain insight into the experiences of First Nations peoples, and the impact of social, cultural, and emotional factors (Kelly et al., 2012; Kelly,

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Oliva, & Jesudason, 2019). By mapping journeys from a patient's perspective, a comprehensive perspective of health and wellbeing can be achieved.

1.4 Indigenous Psychology

Indigenous psychology aims to decolonise the science of psychology by incorporating First Nations' knowledge and perceptions of health. The science of psychology has been directly impacted by colonisation, as it has privileged the Western lens (Dudgeon & Walker, 2015). Psychology's understanding of the human experience often overlooks and silences the knowledges and experiences of peoples and groups who do not belong to the dominant knowledge system (Dudgeon, Darlaston-Jones, & Alexi, 2021). In comparison First Nations perceptions of psychology are holistic and strengths-based. Many First Nations peoples prefer the term social and emotional wellbeing (SEWB) over mental health or mental illness, as it is a holistic strengths-based concept, viewing an individual in their entirety, including connections to community, culture, and family (Australian Indigenous Health Info Net, 2020). The SEWB model identifies seven interrelated determinants of SEWB which have social, political, and personal components. As seen in figure 1, these determinants are connection to body, connection to mind and emotions, connection to family and kinship, connection to community, connection to culture, connection to Country, and connection to spirit, spirituality, and ancestors (Dudgeon et al., 2020). It has been proposed that connection to the seven interrelated determinants is protective for the SEWB of individuals, their families, and communities, and a disconnect is a barrier (Dudgeon et al., 2020; Dudgeon, Bray, D'Costa, & Walker, 2017).



Figure 1. *Determinants of Social and Emotional Wellbeing* (Dudgeon et al., 2020).

It has been argued that mainstream psychology fails to acknowledge the significance of these interconnected factors on the wellbeing of First Nations peoples. This failure is largely due to colonised research methods and practices. While psychological frameworks such as the biopsychosocial model consider different domains, they fail to acknowledge the cultural, spiritual, and historical determinants that are included in Indigenous psychology (Dudgeon & Walker, 2015). Strengths and values-based approaches to understanding health and wellbeing such as positive psychology focus on how individuals thrive, however these too fail to incorporate First Nations' knowledge (Kilcullen, Swinbourne, & Cadet-James, 2016). It is therefore important for First Nations' holistic and strength-based perceptions of SEWB to be included in psychology, so that the psychological experiences of First Nations can be acknowledged and addressed.

1.5 Strength and Resilience in Indigenous Psychology

Indigenous psychology focuses significantly on resilience. First Nations' concepts of resilience go beyond Western definitions of merely coping with adversities (APA, 2014), considering how individuals and their communities maintain positive wellbeing (Kilcullen, Swinbourne, & Cadet-James, 2016). As First Nations experience a higher proportion of adversities than non-Indigenous Australians, research in this area is important as it not only identifies protective

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factors that help them cope, but factors that strengthen and enable them to thrive despite disadvantage (Gregory, 2019).

In a scoping review on First Nations resilience, Usher and colleagues identified that most literature follows a socioecological model, emphasising the importance of connectedness, relationships, and supportive environments in developing resilience in individuals. (Usher et al., 2021). Socioecological models are commonly found in mainstream psychology and propose that resilience is a process rather than a trait. Protective factors which promote resilience can be broadly categorised at the individual, family, and community level, and ongoing exposure to adversity can act as a barrier to an individual's ability to be resilient (Kaiwai, 2017). First Nations resilience literature modifies this model to include community and culture together, emphasising the importance of cultural resources for First Nations peoples (Fleming, & Ledogar, 2008; Usher et al., 2021). Usher identified that factors that promote resilience for First Nations at the individual level include self-concept, internal coping, personal empowerment, and interpersonal qualities. Factors at the family level include having a secure family environment, community safeguards, role modelling and leadership. Factors at the community and cultural level included having strong community connections, cultural identity, family and community connectedness, affection and sharing, and social connectedness (Usher et al., 2021). These resilience models reflect the interconnected and holistic nature of Indigenous SEWB and are important to consider when identifying the strengths of First Nations peoples.

1.6 Strength and Resilience of First Nations Women

As a part of decolonising psychology, it is important to acknowledge the unique experiences and knowledges of First Nations women. There is diversity in the experiences of women from different racial groups and social classes, which mainstream psychology fails to describe (Macleod, Bhatia, & Liu, 2020). First Nations women are one of the most disadvantaged groups in Australia. They face worse outcomes on multiple measures including domestic violence and abuse, maternal and sexual health, chronic diseases, socioeconomic status, employment, and education (Gregory, 2019). Most research involving First Nations women focuses on the risk factors and adversities they face, rather

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than the strengths they possess to overcome and thrive despite them (Gregory, 2019). Studies which explore the strengths of First Nations women identify that their resilience is based upon a rich range of family, social, psychological, spiritual, and cultural factors (Goin & Mill, 2013).

Restoring balance between family, social, psychological, spiritual, and cultural factors, promotes resilience for First Nations women. Family factors are one of the largest reported strengths for First Nations women. Having supportive family relationships provides companionship, physical and emotional support (Gregory, 2019). Family members can act as a resource to help First Nations women overcome stressors, enabling them to be stronger, more confident, and able to cope well (Carlin et al., 2021). Family responsibilities, such as caring for children and dependents can be protective, as individuals are provided distractions and can engage in positive activities (Carlin et al., 2021). Social networks can provide physical and emotional support, act as a resource to help individuals cope with adversities, and be a source of knowledge, providing insight into how others have overcome similar experiences (Kilcullen, et al., 2013). Psychological factors can help promote resilience on the individual level. These factors include acceptance, self-reliance, problem solving and flexibility, having a positive mindset to not give up, having a sense of humour, engaging in self-care, and learning from experiences (Goin & Mill, 2013; Gregory 2019; Kilcullen, et al., 2013). Spiritual and cultural factors strengthen Inner Spirit, connect to cultural healing, and traditional practices (Goin & Mill, 2013; Gregory, 2019). Promoting harmony and balance between each of these interconnected factors is a strength promoting resilience for First Nations women, families, and communities.

1.7 Strength and Resilience of First Nations women with CKD

There are significant gaps in literature addressing how First Nations women with CDs like CKD are strong and resilient. First Nations women with CDs are disadvantaged by their gender, social position, and health status (Eades, 2017). It is important to support the health and wellbeing of this group, as they are at greater risk of experiencing life stressors due to their social situation. Studies exploring the experiences and perceptions of First Nations women with CDs identify that they have complex health journeys, with stressors impacting them and those around them (Eades et al., 2020).

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The few studies which explore the protective factors that enable women with CDs to be resilient through these stressful events report that family, culture, Country, identity, and education are strengthening for them (Eades, 2017). These findings support other research into the resilience of First Nations women, showing that connecting and having positive relationships with different domains of their SEWB is a strength.

In 2017, Eades explored the psychosocial health of First Nations women with CDs in Australia. In-depth interviews of women with a range of CDs explored the protective factors and barriers to their resilience. Four themes emerged: family, extended social networks, education, and identity and Country. Family assisted individuals obtaining help when navigating challenges and provided support. Social networks provided support, a sense of togetherness, identification, and ability to engage in cultural practices. Education enabled individuals' greater opportunities and was perceived as a positive aspect in their life. Identity and Country connected them to their community, providing them a wealth of knowledge and experiences, and providing them with inner strength when feeling vulnerable or unwell (Eades, 2017). Risk factors that First Nations women reported experiencing fit into three overarching themes: roles and responsibilities, family history, and intergenerational circumstances (Eades, 2017). Roles and responsibilities included caring for family and working, which acted as a stress as it was often prioritised over their own health. Family history included grief and loss, separation, trauma from the stolen generation, and unsafe environments. Intergenerational circumstances included incarceration, domestic violence, negative childhood events, and cycles of abuse. These acted as life stressors as they acted as another burden which women had to cope with, in some instances being a stressor that carried across multiple generations (Eades, 2017). First Nations women with CDs are strengthened and resilient through having harmony between the interconnected dimensions of their SEWB (Eades, et al., 2020).

1.8 This Research Project

There are significant disparities in health outcomes between First Nations and non-Indigenous Australians, with First Nations peoples having greater burden of disease for many conditions

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including CKD. Decolonised methods are essential for addressing this health disparity, as they enable greater insight into the lived experiences of First Nations peoples. Decolonised methods are strengths-based and utilise holistic definitions of health. There is increasing research into the strength and resilience of First Nations peoples, identifying interconnected factors that support positive SEWB. There are however significant gaps in literature exploring strengths of First Nations women with CKD. This project aims to use decolonised research methods to map the health journey of an Aboriginal women with CKD, identifying how she was strong and resilient.

Chapter 2: Methods

2.1 Researcher's position

I identify as a non-Indigenous white Australian female, who grew up in Canberra on Ngunngawal land. I have extensive experience using strengths-based and person centred approaches, having worked as a disability support worker for six years. Prior to engaging in this research I had minimal exposure to Australia's rich First Nations cultures but some knowledge of decolonised research methods. My previous university education had been based upon Western knowledge systems, from a predominantly scientific background.

Throughout my Honours project I had the privilege to work alongside many of the amazing members of the AKtion project. Many of these members were Aboriginal women who held multiple roles within the project, acting as both Reference Group members, and researchers. I was assigned two Aboriginal mentors, who supported me throughout the project. I would like to thank all of these women who I worked alongside for teaching and supporting me to navigate through this space to ensure I reflected the true experiences of Aboriginal women.

I would especially like to thank Kelli, who acted as a participant and coresearcher for this project. I appreciate both the time and honesty you provided working together. I feel privileged to have had the opportunity to map your journey, and this project would not have succeeded without your trust and collaboration. Thank you for working with me at all stages of this journey, and helping me complete this project.

I acknowledge that there is great need for First Nations peoples to be conducting research themselves. As a non-Indigenous woman I have aimed to collaborate with Aboriginal women and the AKtion Reference Group so that my research actively involves them and reflects their lived experiences. I hope that through collaborating with communities and conducting research in these vital areas we can increase awareness and the number of First Nations researchers, enabling them to share their lived experiences and cultural knowledge themselves.

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2.2 Participant's position

My name is Kelli Owen, and I am a Kurna, Narungga, and Ngarrindjeri woman. I was born and raised in Adelaide on Kuarna Yerta. I have lived experience of kidney disease, and have publically shared my journey before. I act as a Chief Investigator and Reference Group member for the AKtion project. I work for the National Indigenous Kidney Transplantation Taskforce (NIKTT), spent two decades working as a teacher, and have my Masters in Indigenous Languages and Education. Having shared my journey publically and prior experience in research, I understand the implications of being identified and have chosen for both my name and photo to be included in this Honours project. I wanted to participate because I don't want kidney disease to be a silent disease, but want to put it into the light. When kidney disease is not talked about, it's like it's not happening. This was a healing process that started within me at another level, giving me the opportunity to reflect. I had never spoken for seven hours before, but by getting it out, and reflecting, everything came together for me.



Figure 2. Participant and coresearcher Kelli Own (left) and researcher Alyssa Cormick (right)

2.3 Methodology

This research project followed a decolonised methodology, prioritising the knowledge of First Nations peoples. The term postcolonial research is commonly used but highly contested as it suggests

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that the impacts of colonisation have passed. Many First Nations researchers prefer the term decolonised research, as it describes the continuous process of conducting research in a way that gives space to those who have been oppressed by colonisation (Chilisa, 2012). Decolonised methods acknowledge the historical oppression that colonised groups have faced and allow for research to be conducted from their frame of reference (Walker et al., 2013). These methods are of particular importance when conducting research with First Nations women with CDs, as their experiences have often been minimised due to their gender, social position, and health status (Eades, 2017; Marshall et al., 2009). Decolonised research methods aim to capture the experiences of colonised groups by prioritising their voices and knowledge, moving away from traditional research methods to create new shared ones (Sharmil et al., 2021).

Yarning, Dadirri, and Ganma are First Nations methods and ways of knowing that can be used in decolonised research to prioritise First Nations knowledge (Sharmil et al., 2021). Yarning is a form of communication allowing open and honest exchange of information (Fredricks et al., 2011). Research Yarning enables individuals to have an informal conversation with a deliberate purpose to share knowledge. Unlike mainstream interviewing processes where participants answer a series of questions, Yarning allows participants to respond in a free-flowing manner. Participants have an active voice, are positioned alongside researchers, have control over information they share, and can communicate in a culturally familiar manner (Walker et al., 2013). Research Yarning centres Indigenous knowledge and ways of doing, identifying First Nations participants as experts of their own experiences (Fredricks et al., 2011). Dadirri is the Ngangikurungkurr word for deep listening, and Ganma is the Yolgnu word for sharing of knowledge. These two concepts are important when conducting decolonised research with First Nations peoples and support culturally safe research methods like Yarning. These concepts acknowledge the importance of establishing trust, mutually respectful relationships, collaboration, and creating new ways of doing research using both First Nations and Western knowledges (Sharmil, et al., 2021).

Participatory action research (PAR) is an approach which emphasises the knowledge and expertise of participants, and importance of collaboration. PAR is commonly used in decolonised research, as it

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enables First Nations peoples to be involved and drive research (Dudgeon et al., 2017). PAR enables research to achieve practical solutions, as it uses the expertise of participants to guide planning and implementation (Fredricks et al., 2011). Each stage of PAR follows the processes: look, think, and act. Researchers and participants share their perceptions and knowledge of situations, information is collaboratively analysed, and then action is taken together (Stringer, & Ortiz Aragon, 2021). This aligns with decolonised research as it acknowledges that First Nations peoples are experts, knowing what research needs to be conducted, and how it can best be implemented for real results (Dudgeon, et al., 2017).

As the researcher was non-Indigenous it was of particular importance to follow appropriate methods when conducting research with Aboriginal women to prevent the perpetuation of their experiences being colonised and silenced. To ensure that this research prioritised the knowledge and experiences of the participant, a PAR process was followed. Deep collaboration occurred at each stage. Yarning was used as a data collection method, Dadirri deep listening as a respectful communication method, and Ganma knowledge sharing as an approach to incorporating both First Nations and Western knowledges and methods. The South Australian Aboriginal Health Research Accord, states nine required principles for research with First Nation's Peoples: priorities, involvement, partnership, respect, communication, reciprocity, ownership, control, and knowledge translation (Appendices 1) (SAHMRI, 2014). This research methodology aligns with these principles and the National Health and Medical Research council (NHMRC) ethical guidelines, which emphasise agreed priorities identified by First Nations peoples and communities within South Australia (NHMRC, 2018).

2.4 Ethics Approval

This Honours project received ethics approval under the broader Improving Aboriginal Kidney Care Together: AKAction Project. Ethics approval came from the Aboriginal Health Research Ethics Committee (AHREC): 04-18-79, the University of Adelaide: 33394, and the Central Adelaide Local Health Network (CALHN): R20190124.

2.5 Collaborating with the Akction Reference Group and Akction Research Team

Aboriginal Kidney Care Together: Improving Outcomes Now (AKction), is a research project based at the University of Adelaide. The AKction project is centred around the AKction Reference Group (ARG), an Aboriginal community reference group comprised of ten Aboriginal participants with lived experience of kidney disease from Adelaide and surrounding regions. The focus of the project is to conduct PAR collaboratively with the ARG to improve experiences and outcomes of kidney care.

The ARG identified that they wanted to map their health journeys, with a focus on strength and resilience, to identify how Aboriginal people living with kidney disease flourish in different aspects of their lives, despite having kidney disease. Due to the importance of cultural gender considerations, it was decided that being female, the researcher would focus on the journeys of female members of the ARG. Multiple women offered to be involved, giving the project built in flexibility. This ensured responsibility for involvement was not reliant on one person, and that the research could be conducted around unpredictable life events and the health of ARG members.

Following a decolonising framework promoted by AKction, it was agreed that the participant would be positioned as a coresearcher, repositioning power and control to be shared between the researcher and participant. This enabled the ARG member to be active and drive research. As seen in figure 3, the project followed the PAR process look, think, and act. Consultation occurred at each stage of the project, resulting in the research project being collaboratively designed and conducted. This process enabled the participant to be active in the research project, identifying her expertise, ownership of her knowledge, and control of how this was shared. The project was therefore fluid and iterative, with the researcher and participant negotiating the process at each stage.

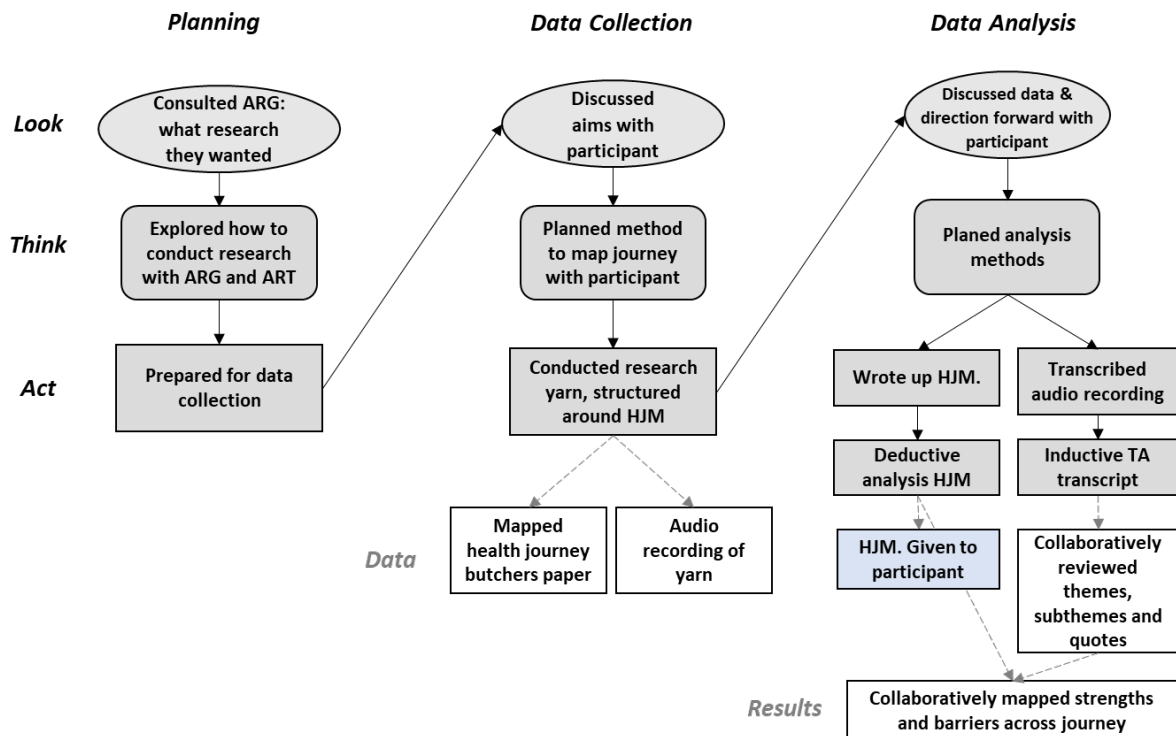


Figure 3. Steps for planning, data collection, and data analysis. Each stage was collaboratively planned and conducted with the participant or members of the ARG, following the participatory action process: look, think, and act. ARG: Akction Research Group, ART: Akction Research Team, HJM: Health Journey Mapping, TA: Thematic Analysis. (Appendices 2)

2.6 Data Collection

Materials: Health Journey Mapping Tools

The AKction research team (ART) codesigned three health journey mapping (HJM) tools with Aboriginal and Torres Strait Islander patients, family members, health professionals and managers. The HJM tools were undergoing field testing at the time of use. The strategic HJM tool was collaboratively chosen and adapted for use by the participant and researcher. This tool focuses on different stages of an individual's journey, identifying at each stage what was happening in their health journey, family, and life priorities outside healthcare interactions (Appendices 1).

Planning

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Preliminary consultations were conducted with female ARG members to agree on and plan the data collection process. A weekend camp for female ARG and ART members was collaboratively planned to provide a culturally safe space and memorable experience for the journey mapping.

Prior to the weekend away the researcher became familiar with the HJM tools, and practiced Yarning with friends and family to prepare for the journey mapping process. General planning for the trip including finances, transport, and permissions were organised. Attendees had no out of pocket expenses. Transportation and disability access was offered to those who required it. Food and accommodation were provided by the AKtion project.

Data collection: Journey Mapping and Yarning

Four women attended the trip away from the fourteenth to sixteenth of May 2021 at a property in Mount Pleasant, one ARG member, two ART members, and the researcher. During the planning phase, three Aboriginal women who were ARG members and potential participants planned to attend. Due to a series of events, only one potential participant was able to attend for the weekend. A pragmatic decision was made by the participant, ART, and Aboriginal mentors that the mapping would continue and involve the one participant.

Before commencing journey mapping the researcher provided the participant with a copy of the information and consent form (Appendices 3). The researcher explained the project to the participant, discussed the purpose of journey mapping, what participation would involve, and where information would go. The participant and researcher shared their aims for working together and discussed how they could be collaboratively achieved. The participant provided consent to be involved in the project, and to be audio recorded. It was agreed that there would be an ongoing conversation about how information collected in the yarn would be shared and included in the thesis which would be publicly accessible once complete.

The researcher and participant planned together how they would conduct the yarn and map the participant's journey. The participant was provided a printed copy of the HJM tools, and it was

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decided that the strategic tool would best fit her journey and the research purposes. It was decided that using the tool, the yarn would be structured around stages of her kidney health journey, and what was happening in her family and life outside of this. The journey would be mapped out on sheets of butchers paper, and the yarn would be audio recorded. The butchers paper was divided into three columns, matching three columns of the HJM tool; health journey, family, other life/work/study commitments. The health journey and dates of each stage were centred in the middle of the page (Figure 4).

No set interview questions were asked, as is normal with Yarning. The researcher instead invited the participant to talk about each stage of her health journey and what else was happening in her life at each stage. The participant started Yarning about when she was first diagnosed with CKD, and chronologically followed each stage of her journey until present. Prompt questions were asked about what was happening next in her journey, or for further elaboration of stages.



Figure 4. Participant Kelli Owen (left) and researcher Alyssa Cormick (right) Yarning as they mapped Kelli's health journey on butchers paper

The journey mapping was conducted over seven hours, with breaks as needed. The participant was able to debrief after Yarning, with one of the ART members who was also a close friend to help unpack content that had arisen during the mapping process. The researcher and participant discussed what would happen next, how contents would be analysed, and the participant requested she receive a

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copy of the written up butchers paper which she would keep and add photographs to. ART members followed up with the participant the next day, and over the following weeks, providing ongoing support as many memories had arisen.

2.7 Data analysis

Health Journey Mapping

After data collection, the participant and researcher reviewed the mapped journey and discussed the SEWB model (Figure 1). The participant identified how the seven determinants in this model were present in her journey, and it was agreed that deductive analysis would be conducted on the health journey to map themes (Dudgeon et al., 2020).

Contents of the butchers paper were typed into a Word Document table, using the same three columns that had been used to structure the yarn: health journey, family, and other life/work/study commitments. Sections of the journey were colour coded to the seven determinants of SEWB (Dudgeon et al., 2020). This written piece of work was kept private and only given to the participant due to the personal nature of its contents. This document was an agreed upon gift for the participant as thanks for her generosity in participation and sharing of her journey. A visual map showing the seven determinants of SEWB across her journey was created from this process (Appendices 4).

Yarning: Thematic Analysis

Audio from the yarn was uploaded to the transcription program Otter. The audio was listened to alongside the transcription to correct for errors and ensure coherence. The transcription was shared with the participant.

Inductive thematic analysis using methods from Braun and Clark was conducted on the transcript to answer the question of how an Aboriginal woman with CKD remained strong and resilient during her health journey (Braun & Clarke, 2013). The researcher immersed herself in the data, relistening to the audio and reading the transcript to becoming familiar with the contents. Initial codes were generated in NVivo 12. Subthemes and themes were then formed by collating like codes together.

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Themes were reviewed by the researcher, checking that each of the codes aligned with the overarching theme (Braun & Clarke, 2006).

The participant and researcher then collaboratively reviewed the themes, ensuring they were true to the participant's experience. The participant and researcher discussed how each of the themes and subthemes related to each other, and the participant approved selected quotes for each subtheme. Due to the personal nature of the yarn, it was decided that only the researcher and participant would have access to the full transcript, and only agreed upon quotes would be shared with others. The themes and quotes which the participant consented to being shared were then reviewed by the researcher and supervisors. The participant provided Ngarrindjeri words which related to each of the identified themes.

Strengths and barriers across health journey

As the participant's HJM was private and contained personal information about her life, it was agreed that in-depth details would not be included as data. Specific deidentified quotes would be jointly chosen. This decision was made for the safety of the participant and those in her life. A condensed and deidentified version mapping the strengths and barriers throughout her journey was collaboratively developed and included (Table 6).

Continued collaboration

Collaboration and consultation with the participant continued throughout the thesis writing phases. The participant was consulted regarding theories, language, and diagrams used, and received a final copy of the thesis to approve. This was to ensure that the research reflected her experiences and that it was not biased by the researchers non-Indigenous lens.

Chapter 3: Results

3.1 Strengths: Connections, Actions, and Mindset

The major themes identified through thematic analysis answering the question of how an Aboriginal woman with kidney disease was strong and resilient during her health journey were connections, actions, and mindset. Each of these overarching themes were interrelated and had subthemes which can be seen in figure 5.

The participant was quoted saying “*what was important to me to keep me strong...were the things I was doing, you know, and who was around me at those times*”, highlighting that connections and the actions she was doing were strengthening and giving her a strong mindset during her journey.

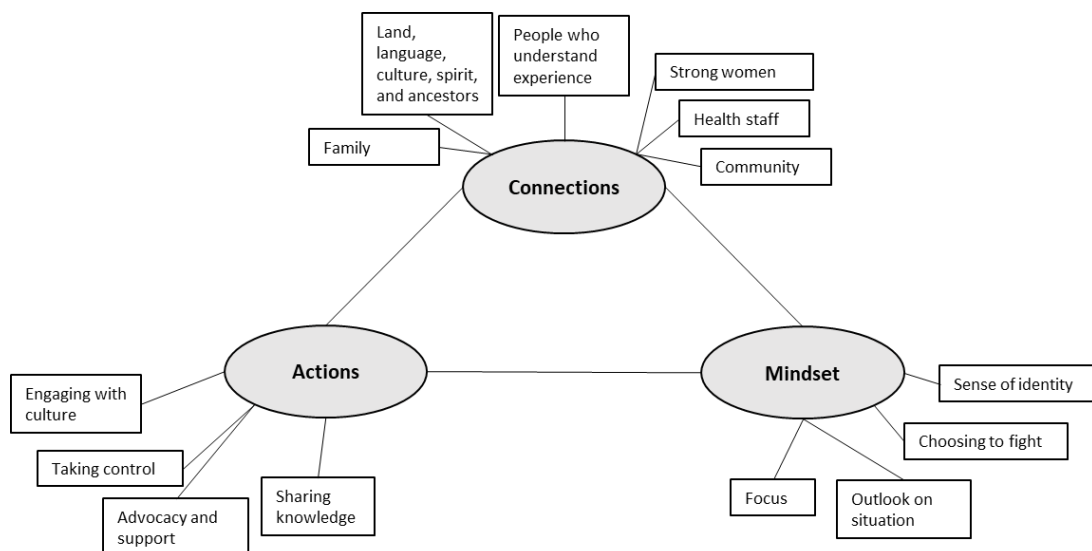


Figure 5. *Thematic analysis map of how participant was women strong and resilient during her CKD journeys*

Ngolun/ Connections

Ngolun is the Ngarrindjeri word for protecting. Throughout her journey the participant was strengthened by connecting to land, language, culture, spirit, and ancestors; family; people who understood her experiences; strong women; health staff; and her community. These factors are identified as subthemes which can be seen in table 1. Not only did connecting to these people and

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things strengthen her and enable her to be resilient, but they also enabled her to undertake protective actions and have a strong mindset.

Table 1. *Subthemes and quotes for the theme connections*

Subtheme	Example Quotes
Connecting to land, language, culture, spirit, and ancestors	<p><i>A real strengthening to being home and being on Country</i></p> <p><i>Being welcomed home, by my Aunties to being on Country</i></p> <p><i>And my spirit. I was really, that sense of belonging, had. It just connected me to them, you know. Not only being on Country, but being able to talk the language</i></p> <p><i>And that was always that pull home too with ancestors, the spiritual connection of coming home you know, even though there was a kidney purpose. It was being off Country for so long</i></p> <p><i>So that was kind of that whole strengthening in my own identity because I knew I was Ngarrindjeri but I didn't have that close connection. So reclaiming my language and being able to speak in Ngarrindjeri</i></p>
Connecting to strong women	<p><i>The strength of women</i></p> <p><i>It's beautiful from these other women in my life that want to connect</i></p> <p><i>Being around these amazing ladies that really, has helped me be centred, and know my place and community</i></p>

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Connecting to people who understood experience *It was just that outlet that someone understood how I was feeling what I was going through*

Connecting with family *It was a new family, you know, so it was a real strengthening and um. You know we talk about your sense of identity*

Connecting with community *And so that was really strengthening between the kids and the families that knew they had that trust in those families.*

And was having that, that network, new network and connection of people with the same interests

Connecting with awesome health staff *This other woman of colour coming in, and then was a nephrologist, was like awesome*

And it was just that I'm lucky I had that relationship with the nurses there. ... that support was really coming from the nurses there

Talking like we're old mates ... I've got [the nephrologist] who rang me, I've got [the doctor who] diagnosed me at nineteen in Darwin, he sitting over there. And then on the other side is ... the surgeon who put the new kidney in me. And I'm sitting in this table, like wow

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Peranbun/ Actions

Peranbun is the Ngarrindjeri word for sharing. The actions of both the participant and those around her were protective factors for her during her journey. Specific actions that were strengthening included engaging with; culture, sharing knowledge, advocacy, support, and taking control. These subthemes can be seen in table 2. Many of these actions were enabled by the people she connected with and promoted a strong mindset.

Table 2. *Subthemes and quotes for the theme Actions*

Subtheme	Example Quotes
Engaging with culture	<p><i>It's just different activities connecting us with those elements. And being able to sit with somebody to be able to, for them to tell their stories about that deep listening and unpacking where, where they're at in life and what they want to do</i></p> <p><i>It was about the healing side of things. Like bringing the four elements together, the wind, water, fire, and earth</i></p>
Sharing knowledge	<p><i>So by this stage I'm actually asking questions. Really looking at the different types of dialysis. But knowing I had five years</i></p> <p><i>It's being able to give back in our own community that that pathway or that journey that the next person is going to take is not going to be a rougher one, it's going to be a much smoother one, because we know so much more</i></p>

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Being able to actually voice my journey, because you hold it in and you experience it. But you don't really tell it as a story that you can wind it up in half an hour

That first sharing, that changed my life

I was teaching their family members,

Advocacy

I felt very lucky to have her helping me because she was a great advocate as well. [She] inspired me to keep going
Other teachers ... were really advocating and giving me different ways to deal with it.

I'm trying to advocate for families and kids at this school.

Mum's message of being able to be. You were your own advocate.

[My friend] was there advocating on behalf of my family.

My daughter advocating for me as well.

Support

"How did you do that mum?" No, how did we do that? Because I wasn't doing it by myself (quoting conversation with daughter)

Being there to help oversee and support what they were doing or advocate for them

It was that support and encouragement from all these people to apply for the job because I self-doubted.

Taking control

And sitting there, my head went into action mode

Get me a chair closer because I can't keep doing this travel.

Kungulun/ Mindset

Kungulun is the Ngarrindjeri word for mindset, referring to thinking, reflecting, and naming. The participant's mindset was a strength during her journey, as it shaped the way she perceived stressful events and enabled her to overcome them. The participant's mindset was strengthened by having a sense of identity, choosing to fight, her focus, and her outlook on situations. These subthemes can be seen in table 3.

Table 3. *Subthemes and quotes for theme mindset*

Subtheme	Example Quotes
Sense of identity	<p><i>So that was kind of that whole strengthening in my own identity because I knew I was Ngarrindjeri but I didn't have that close connection</i></p>
Choosing to fight	<p><i>Some people just give up, and just, I'm not like that.</i></p> <p><i>Realizing that the future is going to be a lot brighter, the future, you know, there's always another tomorrow. We hope.</i></p> <p><i>And so I didn't have time I felt throughout my journey to crumble. I couldn't crumble. You know, it wasn't anybody else's responsibility,</i></p>

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but mine and I had to be. I want to see my grandchildren, I want to see my daughter's married. And I want to, you know, like there were those kinds of things that I really held here.

Focus

We got a lot of dark thoughts on our down days...I could push them aside because that was my focus and come back and see them myself.

And there's times where you have to push the kidney to the back. That couldn't be the focus.

Focus is still work. I just really loved what I was doing.

It was just a really peaceful time to heal. And to focus in on me.

Outlook on situation

I just thought how lucky I was compared to others. You know, when you start looking at people that are real fighters and fighting to live I can't complain because I look around in this room and think that I'm one of the, one of the lucky ones who still has a job.

3.2 Barriers to accessing strengths: Life Stressors and not having strengths

Barriers to the participant being resilient during her journey included stressful life events and being unable to engage with the protective factors: connections, actions, and mindset. These barriers are displayed in figure 6.

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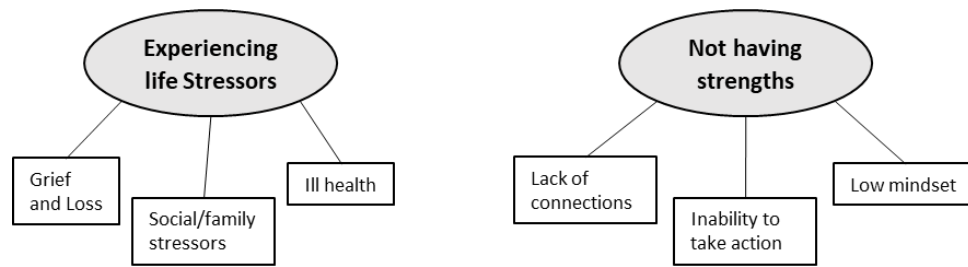


Figure 6. *Thematic analysis map of barriers to Aboriginal women with kidney disease being strong and resilient during their health journeys*

Experiencing life stressors

Stressful life events which acted as barriers to resilience for the participant were grief and loss, illness, and stressful social and family events. These themes can be seen in table 4.

Table 4. *Themes and quotes for experiencing life stressors*

Theme	Example Quotes
Grief and loss	<p><i>To be so overwhelmed and thinking about death</i></p> <p><i>It's sad to think that we're on these machines, and you may not live to see another day, or whether the next person is going to walk through that door</i></p> <p><i>Having to think about your own funeral</i></p> <p><i>So back home I'm trying to get a funeral organized and arranged. It was terrible</i></p>
Illness	<p><i>It was really kidney focused. On going as well. That year was really bad.</i></p>

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Because I was getting sick, and I was having days off and I was down

I would numb up my arm after lunch. And then I'd be at the unit by two o'clock. And then getting home you know nine ten o'clock before I even hit the bed.

Yeah five, six hours. This is all up. This is from the moment you get in you weight yourself, you wash down, you get needled up before treatment even starts and then when treatment stops. You get needled out, weighted in, wash down. So that whole thing would be about six hours.

And that's the shit shift. Wrecks your whole weekend.

Social and family stresses

I had taken stress leave. Because there was a major incident at the school

Just the implications of caring for me and the younger brother and studying and, and her trying to understand kidney disease

[My son] was with me and he stayed with me. For that whole term of school, he, I pulled him out of school, and he was my carer.

He was caring for me because the big sister had moved [and] the other siblings were gone

Not having strengths

A barrier to the participant being resilient was when she did experience the identified themes: connections, actions, and mindset, but was able to utilise them to overcome the stressors. This can be seen in table 5.

Table 5. Themes and quotes for not having connections, actions and mindset

Theme	Example Quotes
Lack of connections	<p><i>But I didn't have any connection and they were all new to me these people up, back up here.</i></p> <p><i>So you're disconnected or I felt disconnected and not supported,</i></p> <p><i>I was feeling very culturally unsafe.</i></p> <p><i>Yeah and totally disconnected from the strength that we did have.</i></p>
Inability to take action	<p><i>Really confused and not understanding why</i></p> <p><i>My problem was being on Country and having access. Some of these could have been done up there. But it was nurses knowing what was available</i></p> <p><i>At one point, I would, just wanted to give up. I couldn't take any more medications. It was just so harsh. And I didn't feel like I had any control.</i></p>

Low mindset

And you know, these are the cards I dealt with. And I was playing poor bugger me too, really letting myself be sucked into that mind game...and knowing that I didn't have control, I had no control over that.

I don't want to do this anymore

3.3 Health Journey: Strengths and barriers throughout health journey

The participant's health journey was complex, and she had both stressful and strengthening experiences in different domains of her life. Figure 7 represents the major strengths and barriers she faced across her health journey from being diagnosed, to starting dialysis and getting a kidney transplant.

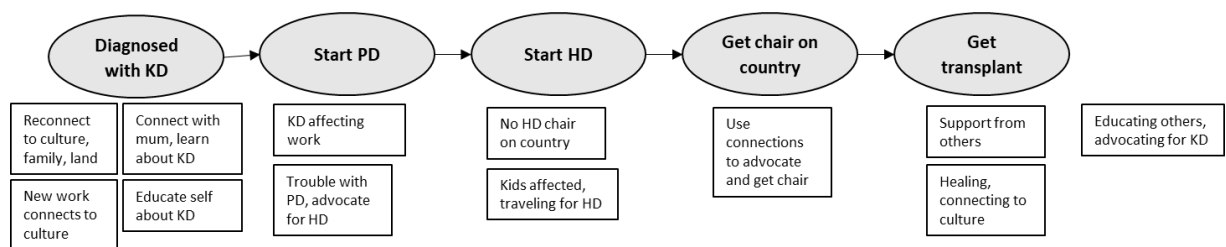



Figure 7. Health Journey from diagnosis to transplant with major strengths and barriers that were experienced. (KD: Kidney Disease, PD: Peritoneal Dialysis, HD: Haemodialysis)

Table 6 describes what was specifically happening in each domain of the participant's life, and the strengths and barriers she experienced.

Table 6. The participant's health journey, mapping what happened in her health; family and relationships; and work, education, and other things at each stage.

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Work, Education, & other things happening in life	Healthcare Journey	Family and Relationships
Working full time as teacher	 <p>Diagnosed with KD</p>	Mum of 4 kids
	Trying to control weight	Focus kids and their health
	Educating self about KD	No close connections to family where living
Stressful event at work		
Impacts on position in community and friendships		
Transferred job closer to country	Feeling tired	Behavioural issues with son become focus
Transferred job on Country, closer to family, community, and better medical access	Surgery to control weight	
Connected to language, culture, spirit, ancestors, and family with new job and being on Country		

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Health starts impacting work,
have to make adjustments

Reconnect with high school
sweetheart

Meet mum/aunties with KD on
dialysis.

Learn about KD experience
from them

Start PD

Have many complications with
PD, limited education

Advocate for self to start
haemodialysis

Start HD

Work impacted, leaving shifts
early to travel and attend
dialysis

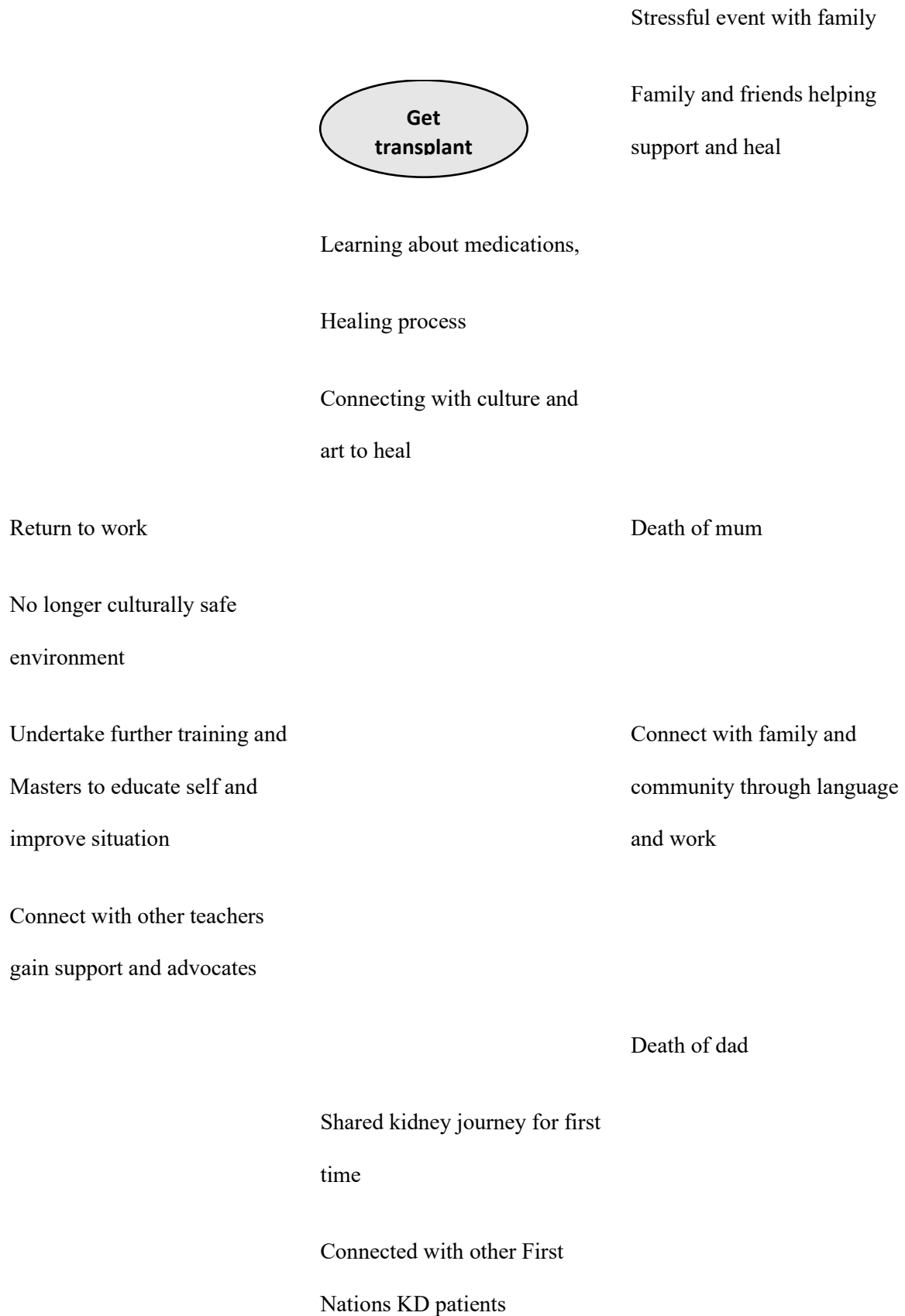
Kids impacted, taken out of
school to attend dialysis

No chairs on country so travel
to city 3 times week

Advocate for self to get chair
on Country

**Get chair
on Country**

Use connections and friends



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Networks and friends enable
job in KD health, teaching and
advocating for others

Have support from strong
women in life

Son starts his KD journey

Using knowledge, experience
and connections to make easier

Chapter 4: Discussion

4.1 Strengths and Barriers to Resilience Across Health Journey

Decolonised research methods were used to map the participant's health journey and identify how she was strong and resilient. It was identified that her health journey was complex, with CKD only encompassing one aspect of her experiences. Utilisation of multiple protective factors enabled her to be resilient and maintain positive wellbeing despite facing life stressors alongside a CKD diagnosis. These protective factors supporting her resilience fit into three interconnected themes: connections, actions, and mindset (Figure 5). Not having these protective factors and experiencing life stressors contrastingly acted as a barrier to her resilience (Figure 6). These identified themes are supported by literature and demonstrate that her resilience was promoted by various interconnected factors across different domains of her life (Eades, 2017). Understanding how the participant utilised protective factors during her health journey can be used to inform and support Indigenous psychological understandings of resilience and future journeys of First Nations peoples with CKD.

CKD Diagnosis

Many First Nations peoples with CKD are diagnosed late into their CKD progression, requiring them to immediately start ESKD treatment. This is reportedly a shocking experience, as they are underprepared and lack appropriate education (Rix et al., 2014). The participant however reported that there were five years between her diagnosis to starting dialysis. This gave her time to engage in strengthening connections and actions and to develop a strengthened mindset to support her journey. She was strengthened by having the ability to educate herself regarding CKD and different types of dialysis, connect with other women who had CKD, to learn from them and their experiences, and come to terms psychologically with her diagnosis and its implications (Table 6). Kilcullen and colleagues similarly identified in interviews with First Nations women the importance of sharing experiences and knowledge to help others with like experiences be resilient (Kilcullen et al., 2013). These findings are important as they highlight the significance of early diagnosis, testing, education, and sharing CKD journeys for First Nations peoples. Health services can learn from these results as

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they demonstrate the importance of educating First Nations peoples about CKD with culturally appropriate resources, implementing testing and prevention programs, and developing support networks to meet other people with like experiences to share knowledge. Findings have implications for First Nations resilience psychology to better understand the importance of sharing knowledge, connecting with people who have like experiences, and developing a pragmatic mindset towards challenging situations.

Moving Off Country

To receive ESKD treatment, many First Nations peoples with CKD relocate off Country, disconnecting them from their land, culture, ancestors, and language (Conway et al., 2018). In the participant's journey, she distinctively returned to Country (Figure 7). She stated that this return to being on Country itself was a strength to her spirit and identity, and that she felt her ancestors had called her back (Table 1). This return led to her reconnecting with family members she had been disconnected from, enabling her to learn Ngarrindjeri language, engage in cultural activities, and have a strengthened identity which supported her resilience (Table 3). These protective factors provided her a strong grounding to overcome and maintain a positive wellbeing throughout her subsequent health journey (Table 6). Through interviews with Aboriginal women, Gregory similarly found that connecting with culture, community, and Country provided a strengthened spirit and source of identity (Gregory, 2019). The SEWB and socioecological models also identify the importance of First Nations peoples connecting to strengthening factors such as family, community, culture, Country, and spirit to promote resilience (Dudgeon et al., 2020; Usher et al., 2021). These findings are important as non-Indigenous healthcare workers often overlook the significance of First Nations peoples connecting to these factors (Anderson et al., 2012). These findings can help healthcare workers understand the holistic nature of health and wellbeing for First Nations peoples and assist in identifying the necessity for CKD treatments to be on Country for individuals to maintain these connections. Further research could be conducted investigating how health services can better support connection to these protective factors and provide responsive service planning for First Nations with CKD.

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Healthcare Interactions

While not all healthcare interactions were positive in her journey, connecting with supportive health staff was a strength. The participant reported that supportive renal nurses, provided her a sense of community and support. She described connecting with a nephrologist who was also a woman of colour as “awesome”, providing her a sense of being understood (Table 1). These connections with health staff were a strength because of the accepting and non-hierarchical attitudes these clinicians applied. By viewing her as more than an ill patient but as a complete and equal person these interactions were supportive and promoted resilience. This approach is important for healthcare staff to recognise, as their interactions can have a significant impact on the wellbeing of patients they support. Healthcare staff play a significant role in the journeys of people with CKD, especially renal nurses who have substantial contact with patients receiving haemodialysis treatment (Anderson et al., 2012). Literature has shown that when relationships are poor due to cultural differences and communication barriers, they can be detrimental to First Nations peoples and impact treatment adherence (Hughes et al., 2019). It is consequently important to learn from positive interactions to determine how healthcare staff can be strengthening factors in people’s lives. These findings can inform both current and future healthcare workers the importance of treating patients in a responsive and holistic manner. Research can be conducted to further identify what makes interactions with healthcare staff positive for First Nations peoples, and how healthcare staff can be better trained to act in a strengthening manner.

Dialysis Experiences

Dialysis is a significant burden on the lives of those requiring it and their families. First Nations peoples with CKD are more likely to require dialysis than non-Indigenous Australians. This impacts their ability to work, their family and life responsibilities, dependents in their care, and often requires a family members to assist in providing care (Anderson et al., 2012). Dialysis was a large burden on the participant’s life, affecting her family, work, responsibilities, and wellbeing. The participant initially used peritoneal dialysis however experienced many complications, she felt underprepared and

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lacked education. She also experienced complications with haemodialysis, not having access to a chair where she lived. She was required to leave work, remove her children from school and travel multiple times a week to receive treatment (Tables 4 & 6). The participant however utilised multiple protective factors in her life to overcome these challenging situations. She used her focus and strong mindset to continue fighting and improve her situation, advocating for herself to change from peritoneal dialysis to haemodialysis, and then using her social networks to advocate and get a chair on Country (Table 6). Goin and Mill similarly identified through in-depth interviews with First Nations women that self-reliance, problem solving, having a positive mindset to not give up, and social networks promoted resilience (Goin & Mill, 2013).

Many First Nations peoples report that they lack confidence in health settings, being unfamiliar with medical jargon and lacking health literacy (Hughes et al., 2019). This limits their ability to engage in protective factors such as control and self-advocacy. Further studies can explore how First Nations peoples can be strengthened to take control of their health and how health systems can be adapted to allow them to better advocate for themselves. One proposed method to support these protective factors is implementation of peer navigators and Aboriginal Liaison Officers who advocate for individuals during their health journeys, helping them become educated and take control of their own health (Mackean et al., 2020). Further research can enhance current understandings of how advocacy and control act as protective factors for other First Nations women, and the relationship between these factors and development of a strong mindset.

Kidney Transplant and Healing Process

First Nations peoples are less likely to receive kidney transplants than non-Indigenous Australians (AIHW, 2021b). The participant reported that she did not meet another First Nations transplant recipients until after her transplantation. She consequently did not know what to expect and reported facing difficulties understanding new medications while her body was healing (Table 4). During this period, she used support from family and friends, and engaged in cultural activities to help with healing (Table 6). Resilience literature involving First Nations women identifies supportive networks,

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family, and engaging with cultural activities to be protective factors (Carlin et al., 2021; Gregory 2019). As few First Nations peoples receive transplants the participant's experiences can be used to inform future recipients and health providers of what to expect. These findings can inform healthcare workers of specific challenges First Nations face, the need to provide better information and education about medications before transplantation, and the potential strengths of using peer education. Results can also help inform Indigenous psychology about cultural healing for First Nations peoples. Impacts of families and support networks providing care for CKD patients can also be further explored, identifying how it affects their wellbeing.

Post-Transplant Experiences

The participant's health journey continued after she received a kidney transplant. After transplantation she had the ability to travel, educate herself, and share knowledge with others, using her CKD experiences to advocate for better outcomes for others (Table 6). These results identify the holistic and strengths-based nature of First Nations wellbeing, inclusive of one's family and community, defining not just their ability to cope with adversity but flourish. These findings are important as limited literature discusses First Nation experiences post-transplant. Health journeys do not finish with transplantation but continue throughout individual's lives. This is important for health workers to identify, as there is often minimal support for individuals post-transplant (Garrard & McDonald, 2019). These findings can promote future psychology research into how other First Nations peoples have flourished despite having CKDs, and potential strengths they have obtained from their health experiences.

Journey Outside of CKD

The participant's CKD was only one aspect of her health journey. Outside of her CKD she experienced significant family events, grief and loss, work and study commitments, family and community responsibilities, and her son's own CKD journey (Table 6). She utilised a range of protective factors to be resilient and strong during these events. Recording these events alongside her CKD identifies the complex interaction between different areas of her life, and how CKD was often

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not a priority or focus. In interviews with First Nations women with CDs, Eades similarly identified that life stressors often monopolised their focus and could act as a barrier to coping with CDs (Eades, 2017). These findings are important for informing and educating healthcare workers who may fail to recognise the complexities of patient's lives as their predominant focus is on patient's healthcare interactions. Further research could be conducted to explore the types of life stressor First Nations with CKD experience, their pre-existing protective factors, and how they can be best supported to maintain resilience and wellbeing despite them.

4.2 Research Methods and Considerations

Ganma/Sharing knowledge

Merging First Nations and Western knowledges involves respect, removal of hierarchies, and acknowledgment of colonisation (Sharmil et al., 2021). A consideration throughout the project was to follow decolonised methods, conduct strengths-based research that suited the AKction Reference Group (ARG), and achieve the requirements for a psychology Honours thesis. Indigenous psychology is an emerging field, which aims to create new knowledge and ways of doing research that incorporate both mainstream and First Nations methods. This has been an important factor to consider throughout this project, as there was limited research with similar processes to follow. The process was therefore fluid and iterative, directed by negotiation with the participant.

This research prioritised First Nations knowledge and research methods. First Nations definitions of resilience, health, and wellbeing were used to prioritise knowledge. Yarning and Dadirri were used to prioritise First Nations methods for data collection and collaboration. These methods enabled the participant to have control and ownership of her knowledge, with only consented information being shared. The researcher and participant actively collaborated, with the participant positioned as a coresearcher. HJM was chosen at request of the ARG as it was a method that appropriately acknowledge holistic definitions of health. A PAR approach was used to prioritise the knowledge and expertise of the participant and enable her to collaborate on developing the research question, planning, implementation, and analysis (figure 3). Thematic analysis was chosen as it is a qualitative

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method which fits within the requirements of psychology Honours and a decolonised framework, allowing the subjective experiences of the participants to be explored (Braun & Clarke, 2013). The researcher chose to incorporate diagrams, visual elements, and multiple quotes for each theme or subtheme to clearly demonstrate the results. This enabled ease of reflection and reviewing of themes with the participant, and made them understandable for a broad audience

Relationships and collaboration: The Participant and Researcher

This research would not have been able to occur without the preestablished relationships built on respect and trust between the ARG and ART. These relationships fostered an environment where complex conversations negotiating the impacts of colonisation, positions in research, and ownership of knowledge, could safely happen. The participant and researcher could therefore work collaboratively to design and implement the research project using these preestablished foundations. The participant and researcher established a relationship before data collection, which continued past the research project. This relationship was important for trust and respect, to allow open conversations, and to share information. Continuing this relationship past data collection ensured the participant was supported emotionally regarding contents which arose from the mapping process and emphasised that she was valued beyond her involvement in the project.

Both the participant and researcher's past experiences and skills were important to the research and enabled the collaborative process to occur. The participant's understanding and previous involvement in research enabled her to work with the researcher, drive research, and make informed decisions regarding the information she shared. Her lived experiences with CKD and previous sharing of her journey enabled her to openly discuss her journey and provide a rich amount of data. She reported that the process itself was therapeutic and healing, occurring at an important transitional period in her life, and that by unpacking what she had been through she was able to appropriately move on and support her son through his CKD journey. This was important, as it meant that her involvement not only supported the research project but provided her with personal benefits and potential healing.

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Therapeutic, reflective. It was an eye opener for me to share how much was happening in my life.

Thank you for taking the time to write that out. And to do it like that

The timing and location of data being collected while on a women's trip away was important in strengthening this relationship, providing space for the participant to talk, and be listened to without outside distractions and time limitations. The researcher's past work experiences provided her skills to apply a person-centred and strengths-based approach. This enabled flexibility, patience, the ability to listen for seven hours without directing research, and core details such as who the participant would be, adaptable until the day of data collection. Both the participant and researcher's attributes enabled research to be collaboratively designed and negotiated, enabling rich data to be gathered in a respectful manner.

Integrating Health Journey Mapping and Thematic Analysis

A challenge of this research was integrating the two processes of health journey mapping and thematic analysis. Due to the flexible and iterative nature of this research, which was directed by negotiation with the participant, the type of data that would be gathered and appropriate methods to analyse it were not known before research commenced. Consequently, analysis methods to use, and how these two approaches would be integrated were ongoing decisions made throughout the iterative research process.

Only after data were gathered could the researcher familiarise themselves with its content and discuss potential approaches for analysis. The participant and researcher decided that deductive analysis using the seven determinants of SEWB would be conducted on the HJM to map the determinants across her journey. The researcher and supervisors agreed that inductive thematic analysis would be conducted on the audio transcript.

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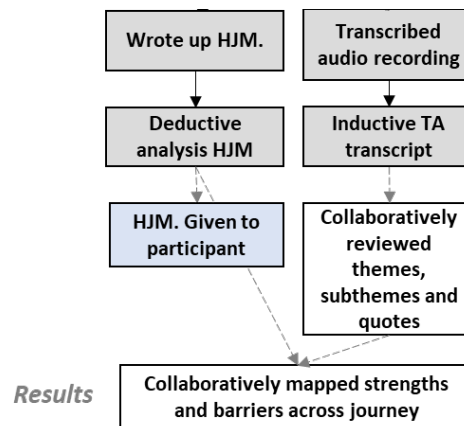


Figure 8. *Integrating Health Journey Mapping (HJM) and Thematic Analysis (TA) Results*

HJM mapping and thematic analysis consequently resulted in two sets of results based on similar pieces of data (Figure 8). As the HJM contained sensitive details it was not included in the thesis. Results from deductive analysis of the HJM are presented as a visual map included in Appendices 4. It was identified that the participant's health journey contained important information that should be shared alongside the thematic analysis results. It was therefore decided that the themes and mapping would be integrated to map strengths across her journey. This demonstrates a high-level of integration between the two different approaches and centred the themes around the participant and her lived experiences.

Ideally in decolonised research the participant herself would analyse how she was resilient herself to prevent the researcher misinterpreting her experiences. However, it is a requirement of psychology Honours for the researcher to perform the main analysis. Future research could enable participants to articulate themselves the strengths they possessed at each stage of their journeys. The three protective factors identified in this research, as well as the socioecological and SEWB models could be used in future mapping to assist participants in identifying potential strengths at each stage of their journeys, and they could map and analyse how they were resilient. This processes itself could be strengthening and empowering, enabling individuals to introspect and examine the protective factors they possess and how they utilise them to be resilient.

Evaluation of Methods

This research had strong rigour and trustworthiness. Rigour refers to strength and appropriateness of the research design and method, and trustworthiness refers to authenticity and whether results are an accurate reflection (Cypress, 2017). The research design and methods were strong, as they were developed to incorporate First Nations knowledge and ways of doing, with each step being codesigned and implemented with the participant. The research had strong authenticity as results were collaboratively reviewed with the participant to ensure they reflected her lived experience. There was transparency in the research methods and result, with the participant being informed of all processes, and an audit trail kept recording steps and decisions. The results only represent the protective factors that the participant reported during her yarn with the researcher. However, due to the extensive amount of data collected and strongly literature support, there is reason to suggest transferability in these findings to other First Nations peoples with CDs.

4.3 Considerations for Future

Future researchers and First Nations peoples involved in decolonised research and journey mapping can learn from the methods and experiences of this project. From a researcher's perspective it is important to be flexible, considerate, critically reflective, and respectful. Participants take time out of their lives to be involved in research, but their lives take priority, meaning you may be required to reschedule and work around them. It is a privilege to collaborate with First Nations peoples and have them share their knowledge and experiences. Their choice to be involved should be acknowledged and respected. It is important to constantly question why you do things, accept you will make mistakes, be honest, and be open to change. It is also important for researchers to listen to participants and let them identify how research should be conducted. By conducting research in an informal setting, using Yarning, and recording information together on butchers paper the participant was able to be transparent and for conversation to flow. She reported that this was unlike other research she had been involved in where she had no relationship, did not feel listened to, and the conversation was stunted. She also reported that by maintaining involvement in research beyond data collection, she felt that she had control and trust in the research. The participant shared that First

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Nations peoples often fear involvement in research, but it is necessary to be a part of the process to have voices lifted, to take control, and make positive changes. First Nations peoples are their biggest advocates, when feeling something they need to voice so others can stop and see you as a whole person, not just as a patient.

4.4 Conclusion

The research comprehensively mapped the health journey of an Aboriginal woman with CKD, to identify strength and resilience throughout her journey. Decolonised methods were employed to incorporate both First Nations and Western knowledges and ways of doing, to appropriately analyse her experiences whilst minimising bias by the researcher's non-Indigenous worldview. These findings are important as they highlight the interconnected nature of protective factors for First Nations resilience, and how strengthening these areas not only allows individuals to survive adversities but enables them to thrive despite them.

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Appendices

Appendices 1: How this research project aligned with the nine principles outlined in the Australian Aboriginal Health Research Accord

Table 7: *Nine Principles Outlined in the Australian Aboriginal Health Accord and how they were upheld in this research*

Principle	Upheld in this Research
<p>PRIORITIES: Research should be conducted on priorities arising from and endorsed by the Aboriginal community to enhance acceptability, relevance, and accountability.</p>	<p>The AKtion Reference group (ARG) and Aboriginal Reference group, and the participant chose the research question and design. They collaborated with the researcher at all stages of research to ensure it followed their priorities and that it was relevant to them.</p>
<p>INVOLVEMENT: The involvement of Aboriginal people and organisations is essential in developing, implementing, and translating research.</p>	<p>ARG members, the participant, and Aboriginal mentors were involved in all stages of research. They had input into development, implementation, analysis, and write up. They also provided constant feedback regarding research and the direction it was taking to.</p>
<p>PARTNERSHIP: Research should be based on the establishment of mutual trust, and equivalent partnerships, and the ability to work competently across cultures.</p>	<p>The participant was positioned as a coresearcher, to reposition her to be working alongside the researcher. The participant and researcher had an ongoing relationship throughout the research project. This relationship was built on preestablished trust</p>

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and respect from the AKtion project, enabling open communication, and collaboration to occur.

RESPECT: Researchers must demonstrate respect for Aboriginal knowledge, Aboriginal knowledge systems and custodianship of that knowledge.

The researcher demonstrated respect for Aboriginal knowledge and customs, prioritising Aboriginal knowledge and ways of doing research. The participant and ARG's preferences were respected and upheld throughout the research project, with their voices recognised as important and directing research.

COMMUNICATION: Communication must be culturally and community relevant and involve a willingness to listen and learn.

Open two-way communication occurred between participants, ARG members, and the researcher using culturally appropriate Yarning and Dadirri (deep listening). The participant and ARG were listened to, and their input shaped the project.

RECIPROCITY: Research should deliver tangible benefits to Aboriginal communities. These benefits should be determined by Aboriginal people themselves and consider outcomes and processes during, and as a result of, the research.

It was agreed that the participant would receive a written-up version of her journey as reciprocity for her involvement. The research also directly related to issues that were of importance to her, as she and other ARG members determined the research question. The participant was identified as a coresearcher, with ownership of information included in this

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	<p>thesis. She also reported that involvement itself was beneficial, as it was therapeutic and provided her the ability to be heard.</p>
<p>OWNERSHIP: Researchers should acknowledge, respect, and protect Aboriginal intellectual property rights and transparent negotiation of intellectual property use and benefit sharing should be ensured.</p>	<p>It is acknowledged that the participant has ownership of the knowledge and intellectual property which she has shared for this research project. There has been negotiation with her regarding what information will be shared publicly. She has also chosen to be identified, to further acknowledge her ownership of the information included in this research, and how it is tied to her journey and experiences.</p>
<p>CONTROL: Researchers must ensure the respectful and culturally appropriate management of all biological and non-biological research materials.</p>	<p>The participant had control over information she shared during the Yarning (data collection) process, and what happened to it. She had control over what information would be made public and what would remain private. The participant provided feedback throughout the research process to ensure direction of research was respectful and culturally appropriate.</p>
<p>KNOWLEDGE TRANSLATION: Sharing and translation of knowledge generated through research must be integrated into all elements of the research process to maximise impact on policy and practice.</p>	<p>First Nations knowledge and ways of doing were prioritised throughout research. Aboriginal mentors, the ARG members, and the participant were consulted throughout the research process</p>

to ensure knowledge was shared and integrated
in a respectful manner.

(SAHMRI, 2014)

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Appendices 2: Coloured figure showing steps for planning, data collection, and data analysis process. Following look, think, act process.



Figure 9. Coloured version of figure included in appendices as per participant's request. Red: stopping to look, orange: thinking and preparing what you will do, green: go is taking action, blue: data collected, purple: results.

Appendices 4: Participant Information and Consent Forms***Strength and Resilience in Aboriginal Kidney Journeys***

Ethics approval (AHREC #04-18-796) (19/CALHN/45)

Information form for Aboriginal Kidney Patient**The purpose of the project**

This research project aims to invite Aboriginal kidney patients to share information about their renal health care journey, focusing on their strength and resilience. This project is a part of a student's Honours thesis at the University of Adelaide. This project starts April 2021 and ends in September 2021.

Patient Journey mapping

Aboriginal people with lived experience of kidney disease will talk with an Honours student to map their kidney journey and experiences. This discussion will occur over a series of meetings at times and places of your choice. You will be actively involved in co-designing and planning the mapping approach, to find one which best fits you and your story.

The patient journey story will be written up by the student and you will get a copy of your kidney journey story to keep. This story will remain private for your use and will not be included in the student's honours thesis.

Your journey map can then be kept identified, or de-identified (your name and specific details taken out). Your journey map will be included in the student's Honours thesis, a copy of which will be available in the University of Adelaide Library. Personal healthcare results will remain confidential and will not be included in the thesis.

If you agree, your journey map could also be written into a case study that could be used by teachers and educators to train new health care staff and students, so they can better understand the experience of Aboriginal kidney patients in South Australia. The research team would get back in contact with you about this, and you would approve the final version. This activity is optional.

Can I withdraw from the project?

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You are free to withdraw from the study at any time, and your decision whether you choose to be involved or not will not affect your healthcare or relationship with the research team.

Who is undertaking the AKtion project?

The AKtion project is based at the University of Adelaide Nursing School and CNARTS- the Central and Northern Renal and Transplantation Service. The research team is made up of researchers, clinicians, managers, and educators with both Aboriginal and non-Aboriginal professionals. An Aboriginal researcher will be employed as part of the project to conduct the patient journey mapping with Aboriginal patients and family members. The project is led by Dr Janet Kelly and Dr Kim O'Donnell, with Prof Stephen McDonald, Dr Shilpa Jesudason, Dr Odette Pearson, Ms Tiffany Whittington, Ms Melissa Arnold-Chamney (Chief investigators) and Dr Andrea McKivett, Dr Gloria Mejia, Dr Samantha Bateman, Dr Richard Le Leu, Ms Tahlee Stevenson, Dr Su Crail, Ms Kylie Herman, Ms Laurel Dodd, Ms Serena Frasca, Mr Andrew Lane, Ms Christine Russell, Dr Lisa Jamieson, Ms Heather Buchanan, Mr Brian Farmer, Ms Kate Schwartzkopff, Ms Clare Dekuyer, Ms Matilda D'Antoine, Ms Tahlee Stevenson Ms Amy Graham and Ms Cassandra Glen (Associate investigators).

Who is undertaking this project?

This project is being undertaken by Alyssa Cormick, an honours student at the University of Adelaide. The project will be a part of her Psychological Science Honours thesis. The project will be co-supervised by Dr Janet Kelly (Aboriginal Health Care Research Lead & Course Coordinator) and Deborah Turnbull (Professor and Chair in Psychology).

Who is guiding the project?

The Akktion Reference Group is guiding the entire research, from planning to completion.

Who funded this project?

The Akktion project has received funding through a MRFF Rapid Applied Research Translation for Health Impact Grant and is based at the University of Adelaide and Central and Northern Adelaide Renal and Transplantation Service (CNARTS) sites (mainly Adelaide and Port Augusta).

Are there any risks associated with participating in this research?

Some participants may feel distressed talking about their experiences. If this occurs, the researcher will stop, and you can decide whether to continue or not. The researcher will offer to get in contact with a support person

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or family member for you and refer you to counselling or healthcare services as preferred. Research team members are also available to support you.

If you choose to have your identify known in relation to your journey mapping and to share your study as a case study, once it has been published on the internet it cannot be removed. You have the choice whether to be identified or not.

What are the potential benefits of the research project?

You may not immediately personally benefit from participation in this study. However, we hope that by telling your story other patients, family members, and staff will be able to better understand the experience of being an Aboriginal kidney patient.

This study aims to focus on your journey and how you have flourished and not just survived having kidney disease. We hope that focusing on your strengths and resilience will be self-empowering, and that others hearing your story can better understand the uniqueness, strengths and experiences of those facing kidney disease in Aboriginal communities.

Information will be stored securely within the University of Adelaide for 7 years, and then destroyed. Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

What if I have a complaint or any concerns?

The study has been approved by the Aboriginal Health Research Ethics Committee (#04-18-796), the CALHN Human Research Ethics Committee (HREC/19/CALHN/45) and the Human Research Ethics Committee at the University of Adelaide (ID: 33394). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Research Lead/Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

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Address: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000.

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome. **What to do if you wish to participate**

If you would like more information or wish to be involved in this project, please contact the research team. CNARTS or Aboriginal Health Staff can help you with contact if you need assistance. The researchers will get in contact with you to discuss the project and process of consent.

For further information or to become involved, please contact Dr Janet Kelly, Adelaide Nursing School,

Email: janet.kelly@adelaide.edu.au

Phone:

Strength and Resilience in Aboriginal Kidney Journeys***Ethics approval number (AHREC #04-18-796) (19/CALHN/45)*****Consent form for Aboriginal Kidney Patient*****Patient Journey Mapping*****Researcher's names: Alyssa Cormick (Psychology Honours Student),****Supported by supervisors: Janet Kelly (Aboriginal Healthcare Research Lead and Supervisor), and****Deborah Turnbull (Professor and Chair of Psychology, Supervisor).**

- I have received information about this research project.
- I have been actively involved in co-designing and planning the mapping process for this project.
- The research project has been explained to me and I fully understand the purpose and my involvement in it.
- I understand that I may withdraw from the research project at any stage.
- I understand that I may not directly benefit from taking part in the project.
- I understand that I may be audiotaped during the interviews for this project, and that the tapes will be destroyed once they are summarised and at completion of the project.
- I agree to be audio recorded Yes/ No
- I understand that the research team may be in contact with me later to gain consent about further use of my story, for education, for which I can approve or not approve.
- I understand that information gained during the patient journey mapping will be published in an Honours thesis which is publicly available in a library, I can choose to be identified in this, but my personal healthcare results will remain confidential.

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- I understand that with my consent information gained during the patient journey mapping may be published in a journal article, conference presentation, website, or report I can choose to be identified, but my personal healthcare results will remain confidential.
- I understand that I can choose to be identified and withdraw this consent at any stage of the research. I choose to be identified in the patient journey mapping Yes/ No
- I know it is okay to say no and my consent is given voluntarily for each stage of the mapping.
- I know that my decision whether to be involved or not in this study will not impact my healthcare or relationship with research team.
- I know my information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.
- I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet

Name of participant: -----

Signed: ----- **Date:** -----

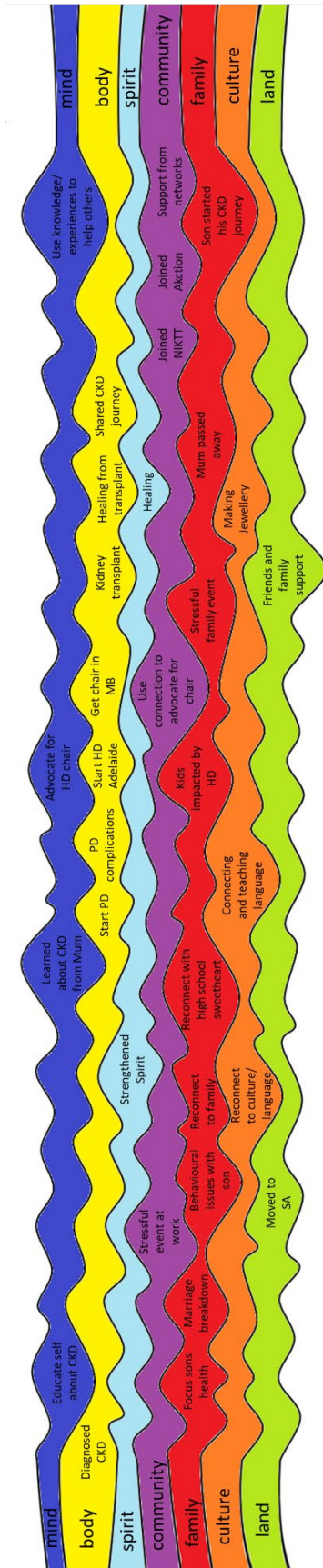
Interpreter: ----- **Date:** -----

I have explained the research project to the participant and believe that he/she understands what is involved.

Researchers/s signature and date: -----

RESILIENCE OF ABORIGINAL WOMEN

Appendices 5: Flow of life Visual Map of the Participant’s Journey, showing how major events occurred across different domains in her life



Theme and colour	Example/ my thoughts
Body = dark blue	Elements of health journey, including physical health and facts or information discussed about kidney disease
Mind/emotions = light green	Feelings, emotions, identity, opinions, educating self and learning. Learning and educating self are not just related to mind. Can have cultural, spiritual, and different types of knowledge.
Spirit/spirituality/ancestors = light blue	Spirit often an underlying theme connected to other themes and events. Related it to healing
Community = purple	Relationships and things which happen relating to people. Community, work, and life
Family/kin = red	Kids, partner, sister, Mum/Pat, Aunties, cousins etc.
Culture = orange	Language was a major connection to culture
Country = dark green	Being on Country, connection to Country and SA, Played an important role, especially for healing on returned to SA

Flow of Life Visual Map:
 Created in collaboration with the participant from data collected in her HJM and deductive analysis using the seven determinants of First Nations SEWB (Dudgeon, et. al., 2020).
 Diagram depicts each of the seven determinants as different streams in the participant’s life. As events happen in one stream, flow to that area increased causing ripple effects in the other streams.
 This shows how the participant’s focus often moved across different streams of her life, rarely focusing purely on her body and kidney disease journey.
 This portrays the holistic nature of health and wellbeing for First Nations peoples, inclusive of all interconnected areas of their lives.

Appendices 6: Diagram of Strengths and Barriers to Resilience.

Coloured version of themes and their interactions with one another included at request of participant.

Diagram in text follows APA convention.

