THE PSYCHOSOCIAL NEEDS OF RURAL CANCER PATIENTS

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ABSTRACT

Psychosocial interventions are increasingly recommended as a standard part of care for cancer patients due to their proven utility and this patient groups’ elevated risk of psychological distress. However, providing the third of Australian cancer patients who live in rural areas with psychosocial care is challenging.

Little is known about rural cancer patients’ level of psychosocial service use or how suitable existing rurally-based services are to deal with cancer. Therefore, Study 1 identified key issues with the provision of psychosocial care from the perspective of rural South Australian cancer patients and explored ways these issues could be addressed. A thematic analysis of data from 17 semi-structured interviews revealed that, contrary to previous research, rural South Australian cancer patients do not consider lay support as an adequate substitute for professional services. However, a lack of relevant information, beliefs that such services are unnecessary and concerns about stigma and dual relationships hindered access to professional help. The study concluded that providing rurally relevant information on psychosocial services may improve knowledge about their availability and help to address rural cancer patients’ attitudinal barriers to service use.

In light of the barriers identified in Study 1, the objectives of Study 2 were to develop a website that provided rural-specific information on psychosocial care for those affected by cancer in rural South Australia, (by engaging people with relevant life experience and reviewing the psychological literature), and to document the lessons learnt during this process. A Participatory Action Research (PAR) framework guided the website’s development. To motivate users to access psychosocial care, behaviour change techniques were also incorporated. The resulting 84-page interactive website, entitled Country Cancer Support, garnered widespread interest and use. It includes practical written information, low-intensity Cognitive Behaviour Therapy (CBT) self-help material, videos and a distress screening tool that provides tailored feedback and is linked to a support services directory. This
method resulted in collaboration between several stakeholders, increased awareness of the value of rural-specific information and participants also reported a sense of empowerment associated with being involved. This study demonstrates the utility of PAR in addressing the psychosocial information needs of rural cancer patients and may inform the development other online, consumer-driven health-promotion interventions.

In Study 3, how acceptable this website is to its users was evaluated using an online survey and Google Analytics. There were 3957 visits to the website in the first 5 months. It was evaluated as easy to use, helpful and relevant, written by people who understood what they were going through and self-report measures suggested it was associated with increased motivation to access professional psychosocial support services and/or travel for medical treatment (if relevant). Of relevant patients and supporters, 73% said using the website made them less isolated and 54% felt less distressed.

The results reiterate the importance of interventions being targeted, creative and flexible, attitudinal barriers being addressed and the value of consumer involvement, particularly when developing interventions for populations whose unique needs are often overlooked and/or can easily be misunderstood. These findings have implications for isolated rural cancer patients in many parts of the world.
DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Kate Gunn and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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The first paper contained in this thesis has been accepted for publication in Supportive Care in Cancer. The other two papers are currently under consideration for publication by the Australian Journal of Rural Health (Study 2) and the Journal of Medical Internet Research (Study 3).

Signed: Miss Kate Gunn
Date: 3 April 2013
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this research. I would like to make special mention of John Casey who played a key role in the
development of the *Country Cancer Support* website. He was a great help, a real character and his
wisdom and friendship are greatly missed.

Although in working with rural cancer patients to design the *Country Cancer Support* website I set
out primarily to make a difference to the lives of others, there is no doubt that it has made a difference
to my own. The interest shown in the research by a variety of organisations, together with the inspiring
people it has allowed me to meet, has made conducting this research a most fulfilling experience.
DEDICATIONS

For Mum and Anny (from whom I have inherited a love of learning and helping others) and the rural South Australian cancer patients who inspired me to take on this task.
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACT</td>
<td>Acceptance and Commitment Therapy</td>
</tr>
<tr>
<td>ARIA</td>
<td>Accessibility and Remoteness Index of Australia</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behaviour Therapy</td>
</tr>
<tr>
<td>CHERRIES</td>
<td>Checklist for Reporting Results of Internet E-Surveys</td>
</tr>
<tr>
<td>DT</td>
<td>Distress Thermometer</td>
</tr>
<tr>
<td>MBCT</td>
<td>Mindfulness-Based Cognitive Therapy</td>
</tr>
<tr>
<td>MBSR</td>
<td>Mindfulness-Based Stress Reduction</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
</tr>
<tr>
<td>PAR</td>
<td>Participatory Action Research</td>
</tr>
<tr>
<td>PDF</td>
<td>Portable Document Format</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
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OVERVIEW

Outline of candidature

This dissertation was undertaken to fulfil the requirements of a combined Master of Psychology (Clinical) with Doctor of Philosophy at The University of Adelaide, South Australia. This program combines the coursework and 1000 hours of clinical placement from the Master of Psychology (Clinical), with a full research program for a Doctor of Philosophy. All placement and coursework requirements of the Master of Psychology have been completed successfully. This thesis is submitted to fulfil the remaining requirements of a Doctor of Philosophy.

Outline of thesis

This dissertation investigates the psychosocial needs of rural cancer patients and how they could be better addressed. Based on the current literature, Chapter I begins by explaining how rural cancer patients are different to their urban counterparts and why their psychosocial needs require special consideration. Chapter II provides background information on the aims of the research and the methodological and theoretical methods and assumptions employed throughout. Chapter III outlines the context of the research, in keeping with the epistemology outlined in Chapter II. Chapters IV-VI contain prefaces, the three studies in manuscript format and an accompanying statement about each author’s contribution. Finally, Chapter VII summarises the findings from across the three studies and discusses their application to other settings as well as strengths, limitations and directions for future research.