

THE PSYCHOSOCIAL NEEDS OF RURAL CANCER PATIENTS

Kate M. Gunn

Bachelor of Psychology (Hons)

A thesis submitted in fulfilment of the requirements for the degree of
Masters of Psychology (Clinical) with Doctor of Philosophy

School of Psychology

Faculty of Health Sciences

The University of Adelaide

April, 2013

TABLE OF CONTENTS

List of Tables	viii
List of Figures.....	x
Abstract.....	xii
Declaration	xiv
Acknowledgements	xv
Dedications	xviii
List of Abbreviations	xix
Overview	xx
<i>Outline of candidature.....</i>	<i>xx</i>
<i>Outline of thesis.....</i>	<i>xx</i>
Chapter I: Literature Review	21
<i>Unique stressors rural cancer patients face.....</i>	<i>23</i>
<i>Travel for specialist treatment</i>	<i>23</i>
<i>Lack of local medical services</i>	<i>24</i>
<i>Poor access to psychosocial services.....</i>	<i>25</i>
<i>Cultural and social issues</i>	<i>27</i>
<i>Comparing cancer patient outcomes in rural and urban areas</i>	<i>28</i>
<i>Quality of life.....</i>	<i>28</i>
<i>Treatment outcomes</i>	<i>28</i>
<i>Levels of psychological distress</i>	<i>29</i>
<i>Barriers to the provision of psychosocial services in rural areas.....</i>	<i>31</i>
<i>Lack of trained staff.....</i>	<i>31</i>
<i>Geographic isolation and small patient numbers</i>	<i>31</i>
<i>Lack of integration between psychosocial services and primary health care.....</i>	<i>32</i>
<i>Stigma.....</i>	<i>32</i>
<i>Other cultural issues</i>	<i>33</i>
<i>Facilitators of support-giving in rural communities</i>	<i>34</i>
<i>Summary and rationale for this work.....</i>	<i>35</i>

Chapter II: Aims, Research Method and Theoretical Framework	38
<i>Study 1</i>	38
<i>Semi-structured interviews</i>	38
<i>Thematic analysis</i>	39
<i>Study 2</i>	40
<i>Participatory Action Research</i>	41
<i>Reflexivity</i>	44
<i>Study 3</i>	45
<i>Online surveys</i>	46
<i>Google Analytics</i>	46
<i>Conventional qualitative content analysis</i>	46
<i>Multi-methods</i>	47
<i>Defining ‘rurality’</i>	48
<i>Sampling/ data collection</i>	49
Chapter III: Research Context.....	51
<i>Introduction</i>	51
<i>Cancer in context</i>	51
<i>The state of health in rural Australia</i>	52
<i>The South Australian context</i>	53
<i>South Australia’s population density</i>	53
<i>The provision of cancer care in South Australia</i>	55
<i>Catalysts for the present research</i>	59
<i>Academic supervisors’ backgrounds</i>	59
<i>Personal perspective</i>	62
<i>How the project unfolded - Beyond the data and literature</i>	65
<i>Study 1</i>	65

<i>Study 2</i>	67
<i>Study 3</i>	67
Chapter IV: Study One	69
<i>Preface</i>	69
<i>Statement of contributors</i>	70
<i>Psychosocial service use: a qualitative exploration from the perspective of rural Australian cancer patients</i>	71
<i>Abstract</i>	73
<i>Introduction</i>	75
<i>Method</i>	76
<i>Results</i>	78
<i>Discussion</i>	83
<i>Acknowledgements</i>	88
Chapter V: Study Two.....	93
<i>Preface</i>	93
<i>Internet use in Australia</i>	94
<i>Online interventions</i>	95
<i>Why provide information to people affected by cancer?</i>	98
<i>Development of the Country Cancer Support website</i>	100
<i>Self-help/ empowerment</i>	117
<i>Promotion of the County Cancer Support website</i>	117
<i>Rationale for Study 2</i>	119
<i>Statement of contributors</i>	121
<i>Connecting rural cancer patients and their families and carers with psychosocial support; the development of a website using a Participatory Action Research Framework and Behavioural Change Theory</i>	122
<i>Abstract</i>	124
<i>Introduction</i>	126

<i>Method</i>	128
<i>Results</i>	131
<i>Discussion</i>	135
<i>Acknowledgments</i>	135
Chapter VI: Study Three	144
<i>Preface</i>	144
<i>Statement of contributors</i>	146
<i>Connecting rural cancer patients and their families and carers with psychosocial support; an evaluation of the Country Cancer Support website</i>	148
<i>Abstract</i>	151
<i>Introduction</i>	153
<i>Methods</i>	154
<i>Results</i>	162
<i>Discussion</i>	169
<i>Acknowledgments</i>	173
Chapter VII: Discussion.....	174
<i>Summary and synthesis of findings</i>	174
<i>Problems encountered and potential limitations</i>	175
<i>New findings from this research/ contribution to knowledge</i>	177
<i>Study 1</i>	177
<i>Study 2</i>	178
<i>Study 3</i>	179
<i>Strengths</i>	180
<i>Significance of this research</i>	181
<i>Conclusion</i>	185
References.....	187
Appendix 1.....	199
Appendix 2.....	201

Appendix 3	213
Appendix 4	252
Appendix 5	267
Appendix 6	269
Appendix 7	274
Appendix 8	284

LIST OF TABLES

Chapter IV

Table 1	89
<i>Demographic Characteristics of Participants</i>	89
Table 2	90
<i>Medical Characteristics of Participants</i>	90
Table 3	91
<i>Participants' Self-reported Psychosocial Service Use</i>	91
Table 4	92
<i>Interview Topic Guide</i>	92

Chapter V

Table I	107
<i>What Types of Psychological Interventions are Used With Cancer Patients, What Do They Involve and How Strong is the Evidence They 'Work'?</i>	107
Table 1	141
<i>Examples of Behaviour Change Techniques Incorporated into Website Design and Their Theoretical Basis (adapted from Abraham & Michie, 2008)</i>	141
Table 2	142
<i>Demographic Characteristics of Participants</i>	142
Table 3	143
<i>Medical Characteristics of Participants Diagnosed with Cancer</i>	143

Chapter VI

Table 1. <i>Demographic Characteristics of Participants</i>	160
Table 2	168

Online Survey Response Frequencies for Acceptability Items168

Table 3169

Patients and Supporters' Online Survey Response Frequencies for Impact Items169

LIST OF FIGURES

Chapter III

<i>Figure I.</i> Population density of South Australia and Australia (ABS, 2011).....	54
<i>Figure II.</i> Location of cancer services in South Australia (Deloitte Access Economics, 2011).....	55
<i>Figure III.</i> Locations of proposed cancer treatment centres	58

Chapter V

<i>Figure I.</i> Internet use in Australia by age group and year (Ewing & Thomas, 2012).....	95
<i>Figure II.</i> <i>Country Cancer Support</i> website plan.....	103
<i>Figure III.</i> The tiered model of psychosocial care (Hutchinson et al., 2006)	114
<i>Figure IV.</i> Screen shot of the ‘Find help near you’ page for patients and supporters on <i>Country Cancer Support</i> website	116
<i>Figure V.</i> Screen shot of example ‘Results’ page on <i>Country Cancer Support</i> website	116
<i>Figure VI.</i> <i>Country Cancer Support</i> promotional tour route	118
<i>Figure 1.</i> Recruitment method	136
<i>Figure 2.</i> The Participatory Action Research cycle	137
<i>Figure 3.</i> Method	138
<i>Figure 4.</i> Examples of how behaviour change elements have been incorporated into <i>Country Cancer Support</i> website	139
<i>Figure 5.</i> Resulting <i>Country Cancer Support</i> website content and structure	140

Chapter VI

<i>Figure 1.</i> Screen shot of <i>Country Cancer Support</i> home page	156
<i>Figure 2.</i> Screen shot of the ‘I’m a person with cancer’ page on <i>Country Cancer Support</i> website	162

Figure 3. Screen shot of the ‘I’m a health professional’ page on Country Cancer Support website
.....163

Figure 4. Screen shot of the ‘I’m a family member, carer or supporter’ page on Country Cancer Support website.....163

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.

I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

I acknowledge that copyright of published work contained within this thesis (as listed below) resides with the copyright holder(s) of that work.

I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue, and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

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

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the wisdom and support of my panel of excellent supervisors to whom I am greatly indebted. To Professor Deborah Turnbull, thank you for your invaluable encouragement, guidance, wisdom and friendship throughout this journey. Thank you also for helping me through difficult political terrain, keeping me focused on the ‘big picture’ and supporting me in all of my academic pursuits.

To Professor Ian Olver AM, thank you very much for sharing your wisdom and knowledge on a broad range of issues, your attention to detail, caring ‘can do’ attitude, generous support and making me feel totally inspired and excited about our work, upon leaving each meeting. It has been a great privilege to work with you.

Lindsay McWha, thank you for your unwavering support and guidance, attention to detail and friendship. Your emails, phone calls and text messages to ‘check in’ on how things are going, both personally and professionally, have helped immensely. I could not have completed this project without you.

Dr Matthew Davies, thank you for encouragement, wise advice and helping me through ups and downs.

Thank you also to everyone at Cancer Council SA where I have been based for the past two years. I have really appreciated your help, the interest you have taken in my work and the friendly, fun work environment you have provided. Steph Potter, thank you very much for your friendship and the hours of voluntary work you did to compile information on services included in the ‘Find help near you’ section of the website.

I am also greatly indebted to Associate Professor Niranjan Bidargaddi for believing in me and this project, facilitating the collaboration with Country Health SA and providing wise advice and encouragement throughout the website development and evaluation process.

Josh Pugh, thank you for your patience, for being such a pleasure to work with and doing a great job with the technical side of the *Country Cancer Support* website.

I am also indebted to the wonderful supervisors I had whilst on clinical placements, Maggie Hentschke (nee Nicolson), Dr Matthew Smout, Dr Rowena Conroy and Dr John Ashfield, as well as to Jill Exton, who so generously accommodated me during my placement in Melbourne.

Thank you also to Professor Ted Nettelbeck, Professor Christopher Sweeny, Alan Morris, Assistant Professor Vikki Knott, Lee Martinez, Timothy Paull, Rochelle Hay, Dr Lisa Kettler, Andrew Livingstone, the Spencer Gulf Rural Health School staff (especially Mark, Sarah, Chelsea, Amanda and Tanita) and the Psychology office staff (particularly Wanda, Deidre, Jess, Carola and Angela).

To Mum, Dad and Angus, thank you so much for all of the love, support and encouragement you have given me throughout my life and for providing me with the opportunities that have enabled me to study at this level. It is a real privilege. In particular to Mum, who has always taken a great interest in my education, spent hundreds of hours editing and heard so much about this work she could have written this thesis herself - thank you. I could not have done it without you.

Thank you also to the friends who have kept me sane, taken an interest in my work and encouraged me to do this PhD- especially Prue, Adele, Bec, Soph, Gemma, Sonja, Erin, Tiff, Courtney, Louise and Rachel.

Thanks to the Lords for being my second family, whisking me away when I needed a break and to Briony for her valuable help with data entry. Thank you also to Anny, Mama and Will for your encouragement and being as proud as I am of this achievement.

Lastly, but by no means least, I am greatly indebted to the rural people whom I have interviewed, whose lives have been touched by cancer. Thank you for courageously letting me into your lives at a difficult time and generously sharing your wisdom. Your passion and commitment to helping other people affected by this dreadful condition is what inspired me to take on the second and third parts of

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

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

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.