

Development and psychometric evaluation of a measure of perceived need for adolescents and young adults with cancer

Tara Clinton McHarg
BArts(Hons) in Psychology

Thesis submitted for fulfilment of the award of:
Doctor of Philosophy (Behavioural Science in Relation to
Medicine)

The University of Newcastle
Submitted October 2010

Statement of Originality

I hereby certify that this thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge, 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.

Signed:

Date:

Acknowledgement of Collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included (as part of the acknowledgements in this thesis), a statement clearly outlining the extent of collaboration, with whom and under what auspices.

Signed:

Date:

Acknowledgement of Authorship

I hereby certify that the work embodied in this thesis contains published papers of which I am a joint author. My supervisor declares that these papers represent my original work and leadership. Copies of these publications are included as appendices.

Signed:

Date:

Supervisor:

Date:

Acknowledgements

My sincerest and deepest thanks go to my supervisors Laureate Professor Rob Sanson-Fisher, Dr Mariko Carey, and Professor Catherine D'Este. You have all been exceedingly generous with your time, kind in your feedback, and supportive throughout the entire process. Rob, your vision and passion for research is awe inspiring, and I feel tremendously privileged to have had the benefit of your wisdom and expertise. Mariko, your attention to detail and phenomenal way with words have been instrumental in pulling this thesis together. You are a shining example of someone I hope to emulate in my own professional career. Cate, your input and statistical know-how have been invaluable, and I am extremely appreciative of the knowledge and guidance you have provided.

A number of people deserve special mention for their involvement in the initial study proposal, and the process of recruitment and data collection. My thanks go to: Dr Anthony Shakeshaft, Prof Afaf Girgis, Ms Elizabeth Tracey, Ms Christine Rowell, Prof David Hill and Dr Vicki White for their efforts in the development of the research grant; Ms Venessa Wells, Ms Nicole Bartley and Ms Laura Bailey for their assistance with preliminary data collection; Dr Frank Alvaro and members of the Paediatric Oncology Unit at John Hunter Hospital who formed the panel of health care providers; Dr Paul Jelfs, Ms Serina Faraji and Ms Julia Messer who oversaw recruitment at the New South Wales Central Cancer Registry; Dr Andrew Wei, A/Prof Ian Kerridge, Dr Julian Cooney, Ms Kate Thompson, Dr Michael Osborn, A/Prof Paula Marlton, Dr William Stevenson; Ms Angela Bayley, Mr Gavin Dyson, Ms Gillian Myles, Ms Megan Margaria, and Ms Molly Forbes who assisted with treatment centre recruitment; and Dr Anna Williamson and members of the Leukaemia Foundation Australia advisory group.

The considered feedback and approval provided by the Human Research Ethics Committees of the University of Newcastle, Cancer Institute New South Wales, Sydney West Area Health Service, The Alfred Hospital, Peter MacCallum Cancer Centre, Princess Alexandra Hospital, Royal Adelaide Hospital and Royal Perth Hospital is also greatly appreciated.

A very special thank you is extended to all the adolescents and young adults with cancer who participated in this research.

To my fellow PhD students who kept me smiling along the way I am especially grateful. Ryan, Lisa and Alix your continual encouragement was incredible. To my family and friends, your ongoing love and support has been unfailing. Mum, Dad, Mark, Kirst, Pat, Cath, Rocky, Sal and Bren, you have always been there for me to help ease the load. To Claude and Coco, who are always just happy to see me and who kept me company late at night.

This thesis is dedicated to Greg
A more amazing husband there never was.

Table of Contents

Acknowledgements.....	iii
Table of Contents.....	v
List of Tables.....	ix
List of Figures.....	xi
List of Appendices.....	xii
List of Abbreviations.....	xv
Synopsis.....	xvii
<i>Chapter 1 – The psychosocial health of adolescent and young adult (AYA)</i>	
<i>cancer survivors.....</i>	<i>1</i>
Introduction.....	2
Defining who is an adolescent and young adult (AYA).....	2
Developmental stages of AYAs.....	3
The global burden of AYA cancer.....	7
Common treatments for AYA cancer.....	11
Paediatric versus adult treatment centres and treatment regimes.....	14
Treatment adherence in AYAs.....	15
The impact of cancer on AYA development.....	16
The psychosocial impact of cancer on AYAs and their family.....	20
Palliative care and end of life issues for AYAs.....	21
Need to reduce the psychosocial burden of cancer for AYAs.....	23
Conclusion.....	23
<i>Chapter 2 – Measuring the psychosocial health of adolescent and young adult</i>	
<i>(AYA) cancer survivors: a critical review.....</i>	<i>25</i>
Introduction.....	26
Considerations when selecting health assessment measures.....	26
Generic versus disease-specific measures.....	27
Uni-dimensional versus multi-dimensional measures.....	28
Proxy versus self-report measures.....	29
Types of health measurement scales.....	30
Previous reviews of measures of psychosocial health for AYA cancer survivors.....	34
Aims.....	35
Methods.....	36

Results.....	44
Discussion.....	54
Limitations.....	56
Conclusion.....	57
 <i>Chapter 3 – Development of the Cancer Needs Questionnaire – Young People (CNQ–YP): identifying domains and items, and establishing face and content validity.....</i>	
Introduction.....	59
Ensuring a needs measure for AYA cancer survivors assesses a broad range of experiences relevant to this group.....	59
Establishing face and content validity of the unmet needs measure.....	60
Aims.....	60
Methods.....	61
Results.....	69
Discussion.....	73
Final revision of the unmet needs measure.....	73
Comparison of methodologies for establishing face and content validity.....	74
Limitations.....	75
Conclusion.....	75
 <i>Chapter 4 – Development of the Cancer Needs Questionnaire – Young People (CNQ–YP): pilot test to determine acceptability.....</i>	
Introduction.....	77
Importance of pilot testing measures.....	77
Use of cancer registries for accessing representative groups of survivors.....	78
Process for recruitment of research participants through cancer registries.....	78
Aims.....	79
Methods.....	80
Statistical analysis.....	85
Results.....	85
Discussion.....	92

Possible reasons for low recruitment rates and non-representative samples.....	94
Implication of low recruitment rates and non-representative samples..	97
Resource-efficient alternatives for achieving representative research samples.....	101
Limitations.....	104
Conclusion.....	104
 <i>Chapter 5 – Psychometric properties of the Cancer Needs Questionnaire – Young People (CNQ–YP): reliability and validity.....</i>	
Introduction.....	106
Methods of item reduction and selection.....	107
Factor analysis.....	108
Internal consistency.....	109
Test-retest reliability.....	110
Methods of determining discriminative validity.....	112
Methods of determining responsiveness and sensitivity to change.....	112
Aims.....	113
Methods.....	113
Statistical analysis.....	119
Results.....	126
Discussion.....	142
Limitations.....	143
Possible reasons for the small sample size and low response rate.....	144
Psychometric strengths of the CNQ-YP.....	146
Recommended improvements for the CNQ-YP.....	147
Conclusion.....	149
 <i>Chapter 6 – Prevalence of and factors associated with high unmet needs reported by adolescent and young adult (AYA) cancer survivors.....</i>	
Introduction.....	150
Assessing the prevalence of unmet needs at the population level.....	151
Assessing the prevalence of unmet needs at the individual level.....	152
Examining predictors of unmet need in AYA cancer survivors.....	152
Aims.....	158
Hypotheses.....	158

Methods.....	158
Statistical analysis.....	160
Results.....	162
Discussion.....	174
Prevalence of unmet need in AYAs compared with other cancer populations.....	174
Associations between high unmet needs and characteristics of AYAs.	178
Potential for routine screening of unmet needs.....	180
Potential for an online version of the CNQ-YP.....	181
Limitations.....	182
Conclusion.....	184
 <i>Chapter 7 – Addressing the unmet needs of adolescent and young adult (AYA) cancer survivors: the way forward.....</i>	
Why is this research needed?.....	186
Adolescent and young adult (AYA) cancer survivors are a vulnerable population who may experience unique psychosocial needs.....	186
Existing measures of psychosocial health for AYAs may be limited.....	187
What has this research contributed?.....	188
Development of a new measure of unmet need specifically designed for AYA cancer patients and survivors.....	188
Psychometric evaluation of the reliability and validity of the CNQ-YP..	189
Description of the prevalence of unmet needs and associations between high unmet needs and characteristics of AYAs.....	191
The way forward.....	192
Refine and redevelop the measure with a larger sample.....	192
Develop interventions to address the unmet needs of AYA cancer survivors.....	194
Conclusion.....	194
References.....	196

List of Tables

Table 2.1:	Summary of criteria used to review measures.....	39
Table 2.2:	Items and domains of measures included in the review.....	46
Table 2.3:	Reported sample characteristics for each measure.....	48
Table 2.4:	Summary of psychometric properties reported for each measure..	49
Table 2.5:	Coding of reliability criteria for each measure.....	50
Table 2.6:	Coding of validity criteria for each measure.....	52
Table 2.7:	Responsiveness, acceptability and feasibility of each measure.....	53
Table 3.1:	List of 7 domains and 108 items identified from the literature.....	64
Table 3.2:	Feedback on items from the panel of health care providers.....	71
Table 3.3:	Additional needs suggested by panel of health professionals.....	73
Table 4.1:	Description of the eight domains in the CNQ–YP and examples of items.....	84
Table 4.2:	Reasons provided by treating clinicians for not providing consent to the registry to contact survivors.....	88
Table 4.3:	Demographic characteristics of participants (n=32).....	89
Table 4.4:	Acceptability of the CNQ–YP.....	90
Table 4.5:	Comparison of final participant group with eligible non-participants (did not consent or unable to contact).....	92
Table 5.1:	Demographic characteristics of consenters and non-consenters for the baseline study.....	127
Table 5.2:	Demographic characteristics of young people who completed the baseline and retest survey, and those who completed the baseline survey only.....	127
Table 5.3:	Factor structure of the CNQ–YP from the initial factor analysis (n=111).....	131
Table 5.4:	Factor structure of the items retained following factor analysis with the additional domains and sub-domains.....	133
Table 5.5:	Cronbach's alpha for each factor of the CNQ–YP.....	134
Table 5.6:	Weighted kappa values for items retained in the measure.....	135
Table 5.7:	Factor structure of the CNQ–YP from the revised factor analysis (n=116).....	138
Table 5.8:	Revised Cronbach's alpha for each Factor of the CNQ–YP.....	139
Table 5.9:	Summary of item reduction for the measure.....	140
Table 5.10:	Comparison of factor scores between AYAs receiving treatment and AYAs who had finished treatment.....	141

Table 5.11:	Floor and ceiling effects per factor.....	142
Table 6.1:	Participant demographic characteristics (n=139).....	163
Table 6.2:	Ten most prevalent items endorsed for any level of need.....	164
Table 6.3:	Ten most prevalent items endorsed at the High to Very High level of need.....	165
Table 6.4:	Median factor scores for each domain.....	166
Table 6.5:	Chi-square tests for the item “Being able to have good food at the cancer treatment centre”.....	168
Table 6.6:	Final logistic regression model for the item “Being able to have good food at the cancer treatment centre”.....	168
Table 6.7:	Chi-square tests for the item “Finding information that was specifically designed for me”.....	169
Table 6.8:	Final logistic regression model for the item “Finding information that was specifically designed for me”.....	169
Table 6.9:	Chi-square tests for the item “Worrying about my cancer returning”.....	171
Table 6.10:	Final regression model for the item “Worrying about my cancer returning”.....	171
Table 6.11:	Chi-square tests for the item “Coping with changes in my appearance”.....	172
Table 6.12:	Final logistic regression model for the item “Coping with changes in my appearance”.....	172

List of Figures

Figure 2.1:	Number of publications related to the assessment of psychosocial well-being in AYA cancer survivors by year (1988-2008).....	37
Figure 2.2:	Flowchart of the publication and measure inclusion and exclusion process.....	45
Figure 4.1 :	Flowchart of proportion of cancer survivors filtered at each stage, and proportion of overall sample.....	87
Figure 5.1:	Scree plot of Eigenvalues for the 112 factors from the initial analysis.....	129
Figure 5.2:	Scree plot of Eigenvalues for the 74 factors from the revised analysis.....	137
Figure 6.1:	Overall level of need in the last month compared to other months.	165

List of Appendices

Appendix 2.1:	Published data.....	A–1
Appendix 3.1:	Draft questionnaire.....	A–14
Appendix 3.2:	Approval certificate from the University of Newcastle Human Research Ethics Committee.....	A–20
Appendix 3.3:	Focus group letter of invitation.....	A–22
Appendix 3.4:	Focus group project information sheet.....	A–24
Appendix 3.5:	Focus group “top five needs” sheet.....	A–26
Appendix 3.6:	Focus group thank you letter.....	A–27
Appendix 3.7:	Summary of focus group outcomes – WA Group.....	A–28
Appendix 3.8:	Summary of focus group outcomes – NSW Group.....	A–31
Appendix 3.9:	Feedback sheet regarding the response scale.....	A–34
Appendix 3.10:	Revised response scale.....	A–37
Appendix 4.1:	Approval certificate from the Cancer Institute NSW Human Research Ethics Committee.....	A–38
Appendix 4.2:	NSW Cancer Registry Patient Recruitment Protocol.....	A–41
Appendix 4.3:	Registry letter to clinicians.....	A–61
Appendix 4.4:	Registry letter to patients.....	A–63
Appendix 4.5:	Researcher’s letter to patients.....	A–65
Appendix 4.6:	Pilot version of the CNQ–YP.....	A–68
Appendix 5.1:	Approval Certificate from the Sydney West Area Health Service Human Research Ethics Committee.....	A–82
Appendix 5.2:	Approval Certificate from The Alfred Hospital Human Research Ethics Committee.....	A–84
Appendix 5.3:	Approval Certificate from the Peter MacCallum Cancer Centre Human Research Ethics Committee.....	A–85
Appendix 5.4:	Approval Certificate from the Princess Alexandra Hospital Human Research Ethics Committee.....	A–86
Appendix 5.5:	Approval Certificate from the Royal Adelaide Hospital Human Research Ethics Committee.....	A–88
Appendix 5.6:	Approval Certificate from the Royal Perth Hospital Human Research Ethics Committee.....	A–89
Appendix 5.7:	Approval Certificate from the University of Newcastle Human Research Ethics Committee.....	A–91
Appendix 5.8:	Invitation letter, project information sheet, consent form and reminder letter from Westmead Hospital.....	A–95

Appendix 5.9:	Invitation letter, project information sheet, consent form and reminder letter from Royal North Shore Hospital.....	A-102
Appendix 5.10:	Invitation letter, project information sheet, consent form and reminder letter from Princess Alexandra Hospital.....	A-109
Appendix 5.11:	Invitation letter, project information sheet, consent form and reminder letter from Royal Adelaide Hospital.....	A-116
Appendix 5.12:	Invitation letter, project information sheet, consent form and reminder letter from Royal Perth Hospital.....	A-123
Appendix 5.13:	Invitation letter, project information sheet and “do not contact” form from The Alfred Hospital.....	A-129
Appendix 5.14:	Invitation letter, project information sheet and “do not contact” form from Peter MacCallum Cancer Centre.....	A-135
Appendix 5.15:	First invitation letter from the researchers at the University of Newcastle.....	A-141
Appendix 5.16:	Information sheet from the researchers at the University of Newcastle.....	A-142
Appendix 5.17:	The Cancer Needs Questionnaire – Young People (CNQ-YP)	A-144
Appendix 5.18:	Reminder letter from the researchers at the University of Newcastle.....	A-162
Appendix 5.19:	Re-test letter from the researchers at the University of Newcastle.....	A-163
Appendix 5.20:	Proportion of responses at each level of need, and proportion of missing values, for each item.....	A-164
Appendix 5.21:	Orthogonally rotated 18-factor solution with Eigenvalues > 1...	A-167
Appendix 5.22:	Orthogonally rotated forced factor structure for 3 factors.....	A-168
Appendix 5.23:	List of 17 items removed following the initial factor analysis with 3 factors (n=111).....	A-169
Appendix 5.24:	Number of factors following factor analysis with additional items from the Education and Work domains.....	A-170
Appendix 5.25:	Number of factors following factor analysis with additional items from the Partner and Siblings sub-domains.....	A-171
Appendix 5.26:	List of 12 items removed following factor analysis with the additional domains and sub-domains.....	A-172
Appendix 5.27:	List of the 24 items removed following the calculation of test-retest reliability.....	A-173

Appendix 5.28:	List of 14 items removed following the revised factor analysis (n=116).....	A-174
Appendix 5.29:	Criteria used to review the psychometric properties of existing measures of psychosocial well-being developed for AYA cancer survivors.....	A-175
Appendix 7.1:	Final version of the CNQ-YP.....	A-176

List of Abbreviations

ALL	Acute Lymphoblastic Leukaemia
AQoL	Adolescent Quality of Life Instrument
AYA	Adolescent and Young Adult
CaSUN	Cancer Survivors' Unmet Needs measure
CI	Confidence Interval
CML	Chronic Myeloid Leukaemia
CNQ	Cancer Needs Questionnaire
CNQ–YP	Cancer Needs Questionnaire – Young People
CNS	Central Nervous System
CPNQ	Cancer Patient Need Questionnaire
CPNS	Cancer Patient Need Survey
CSF	Cerebrospinal Fluid
GP	General Practitioner
HPV	Human Papillomavirus
HRQOL	Health Related Quality of Life
ICC	Intraclass Correlation Coefficient
MMQL	Minneapolis-Manchester Quality of Life Instrument
NCI	National Cancer Institute
NCRI	National Cancer Research Institute
NEQ	Needs Evaluation Questionnaire
NHMRC	National Health and Medical Research Council
NIH	National Institutes of Health
NMSC	Non-Melanoma Skin Cancer
NSW	New South Wales
PCA	Principal Components Analysis
PCQL	Pediatric Cancer Quality of Life Inventory
PCQL–32	Pediatric Cancer Quality of Life Inventory - 32 Short Form
PedsQL	Pediatric Quality of Life Inventory
PFA	Principal Factor Analysis
PIE	Perceived Illness Experience Scale
PNAT	Patient Needs Assessment Tool
PNI	Psychosocial Needs Inventory
POQOLS	Pediatric Oncology Quality of Life Scale
QLD	Queensland
QOL	Quality of Life

QOL–CS	Quality of Life - Cancer Survivors
RCT	Randomised Controlled Trials
SA	South Australia
SCNS	Supportive Care Needs Survey
SEER	Surveillance, Epidemiology and End Results
SES	Standardised Effect Size
TCU	Teenage Cancer Unit
TYA	Teenage and Young Adult
UK	United Kingdom
US	United States
VIC	Victoria
WA	Western Australia
WHO	World Health Organization

Synopsis

An overview of the unique challenges that adolescent and young adult (AYA) cancer survivors may face due to their cancer diagnosis occurring at a critical phase of physical, psychological and social development is presented in Chapter 1. A review of the literature revealed that no psychometrically rigorous measures of unmet need for AYA cancer survivors currently exist, discussed in Chapter 2. The initial steps (face and content validity) in the development of a measure specifically designed to capture the needs of this population are described in Chapter 3. The measure was pilot tested with 32 AYAs recruited through a state-based cancer registry, discussed in Chapter 4. The construct validity and internal consistency of the measure were established with a sample of 139 AYAs recruited through seven treatment centres, presented in Chapter 5. Test-retest reliability was examined with a sub-sample of 34 AYAs. The final measure consists of 70 items and six factors. All factors achieved Cronbach's alpha values >0.80 . Item-to-item test-retest reliability was also high, with most items reaching weighted kappa values >0.60 . The prevalence of high levels of unmet need related to the availability of good food and leisure spaces at the treatment centre, body image, fertility, peer interaction, physical functioning, and tailored information were experienced by a large proportion of AYAs, described in Chapter 6. Participants who were female, diagnosed with haematological cancer, experienced a recurrence, received more than two types of treatment, or who were less than two years post-diagnosis had significantly greater odds of experiencing high levels of unmet need for a number of issues. Recommendations for further psychometric evaluation of the measure (including longitudinal studies to establish responsiveness and predictive validity) with a larger sample are discussed in Chapter 7.