Development of a measure of health literacy for caregivers of people with cancer

By

Eva Yee-Nga Yuen
MSc, Postgrad Dip (Psych), BA

Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Deakin University
March 2015

This thesis may be made available for consultation, loan and limited copying in accordance with the Copyright Act 1968.

'I certify that I am the student named below and that the information provided in the form is correct'

**Full Name:** Eva Yee Nga Yuen

**Signed:** [Signature Redacted by Library]

**Date:** 23rd March 2015

Access to Thesis A Form
DEAKIN UNIVERSITY

CANDIDATE DECLARATION


a. I am the creator of all or part of the whole work(s) (including content and layout) and that where reference is made to the work of others, due acknowledgment is given.

b. The work(s) are not in any way a violation or infringement of any copyright, trademark, patent, or other rights whatsoever of any person.

c. That if the work(s) have been commissioned, sponsored or supported by any organisation, I have fulfilled all of the obligations required by such contract or agreement.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any university or institution is identified in the text.

'I certify that I am the student named below and that the information provided in the form is correct'

Full Name: Eva Yee Nga Yuen

Signed: [Signature Redacted by Library]

Date: 23rd March 2015

Candidate Declaration
# GENERAL DECLARATION

The table below outlines the current publication status and details of my contributions to the manuscripts arising from this thesis:

<table>
<thead>
<tr>
<th>Thesis chapter</th>
<th>Publication title</th>
<th>Publication status</th>
<th>Nature and extent of candidate’s contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Health literacy of caregivers of adult care recipients: A systematic review</td>
<td>Under review in Social Science and Medicine</td>
<td>Developed key ideas, hypothesis and study design. Collected and analysed data. Wrote the manuscript as first and corresponding author.</td>
</tr>
<tr>
<td>6</td>
<td>Development of a conceptual model of cancer caregiver health literacy</td>
<td>Published in European Journal of Cancer Care</td>
<td>Developed key ideas, hypothesis and study design. Collected and analysed data. Collaborated with external stakeholders. Wrote the manuscript as first and corresponding author.</td>
</tr>
<tr>
<td>7</td>
<td>Development of the Health Literacy of Caregivers Scale - Cancer (HLCS-C): Item generation and content validity testing</td>
<td>Published in BMC Family Practice</td>
<td>Developed key ideas, hypothesis and study design. Collected and analysed data. Collaborated with external stakeholders. Wrote the manuscript as first and corresponding author.</td>
</tr>
<tr>
<td>8</td>
<td>Measuring cancer caregiver health literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C)</td>
<td>Under review in PLoS One</td>
<td>Developed key ideas, hypothesis and study design. Collected and analysed data. Collaborated with external stakeholders. Wrote the manuscript as first and corresponding author.</td>
</tr>
</tbody>
</table>

The manuscripts currently under review are presented in Chapters 3 & 8 in the format in which they were submitted to their respective journals, thus Tables and Figures are numbered as per their submitted format. The manuscripts in Chapters 6 & 7 are presented in their published format, with sections numbered as per publication.

Name: Eva Yuen

Signed: **Signature Redacted by Library**

Date: 23rd March 2015

General Declaration
Abstract

A diagnosis of cancer has significant impacts on the individual diagnosed, as well as their family members and friends. These support persons are often required to assume an active caregiving role, participate in decision-making, and engage in self-management of people with cancer. There is the assumption that these individuals providing informal care, also known as caregivers, possess adequate knowledge and skills, or levels of health literacy, to effectively manage the tasks.

Health literacy can be understood as the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions. Inadequate health literacy has been associated with poorer health outcomes, poorer self-management behaviours, and increased healthcare costs. Understanding and responding to health literacy issues is considered a key health promotion priority given the implications for individuals’ self-management of health, and for equity related to access to, and use of, healthcare services.

A considerable gap exists in public health research related to validated and suitable measurement approaches of caregiver health literacy. Given the important role of caregivers in aspects of care for people with cancer, it is important that more is understood about the way in which health literacy impacts caregivers’ capacity to perform their role. This thesis sought to address this gap.

The overarching aim of the thesis was to advance the conceptualisation and measurement of caregiver health literacy within a cancer population. The objectives were to: 1) critically
appraise the current state of peer-reviewed literature on health literacy of caregivers of adult care recipients; 2) develop a conceptual model of caregiver health literacy from the perspective of key stakeholders, and; 3) use the conceptual model to guide the development of a comprehensive, multidimensional measure to assess health literacy of caregivers of people with cancer.

The thesis is comprised of four studies that used a multi-method qualitative and quantitative approach to address the overarching research aim and objectives. Study A is comprised of a systematic review that appraised peer-reviewed literature related to studies that assessed levels of health literacy in caregivers of adult care recipients. Associations between caregiver health literacy and care recipient, and caregiver health outcomes were also examined. Findings revealed that low health literacy in caregivers differed depending on the measures and scoring criteria used. Limited evidence was available to determine the relationship between caregiver health literacy and care recipient, or caregiver health outcomes.

In Study B, in-depth consultations with cancer patients, caregivers of cancer patients, healthcare providers, and a policymaker were conducted to inform the development of a conceptual model of caregiver health literacy. Six major themes and 17 subthemes were identified following consultations with key stakeholders. Findings from the development of the conceptual model demonstrated that caregiver health literacy is: multidimensional, includes a broad range of individual and interpersonal elements, and influenced by the broader healthcare system and community factors.

In Study C, initial processes in the development of the Health Literacy of Caregivers Scale - Cancer (HLCS-C), were presented. Domain selection for the scale was guided by the conceptual model of cancer caregiver health literacy. Item generation for the scale was guided by
consultation data generated by key stakeholders in the study. Expert review, and cognitive interviews with caregivers were conducted to assess the content validity of the draft items. Overall, the HLCS-C was designed to measure individual, interpersonal, and healthcare provider factors related to caregiver health literacy.

In Study D, the psychometric properties of the HLCS-C were investigated. Draft items were analysed to identify poorly performing items for removal. Following validation, the HLCS-C consisted of 46 items across 10 domains. Rigorous psychometric testing demonstrated that the HLCS-C has strong construct validity and high reliability (composite reliability indices between 0.78-0.92 across the 10 domains).

The research has provided unique contributions to the conceptualization and measurement of health literacy of caregivers of people with cancer. Substantial gaps in research related to assessment of caregiver health literacy in adult care recipient populations has been highlighted through a systematic process. Lack of evidence related to the relationship between caregiver health literacy and care recipient, and caregiver health outcomes was also identified in the systematic review.

A conceptual model grounded in the perspectives of key stakeholders identifies a range of subthemes that provides new insight into domains that should be included in measures of caregiver health literacy, and target areas for improving caregiver health literacy. Together, the conceptual model, and the HLCS-C are likely useful resources to guide the development of initiatives for improving health service delivery. The findings also have the potential to inform the development and evaluation of interventions to enhance caregiver health literacy capacities in the management of care recipient health outcomes.

Abstract
Acknowledgements

Looking back on the PhD experience, I am immensely grateful for the many wonderful people who have supported, encouraged, and provided their expertise to help get me over the finish line. I extend my deepest appreciation to the following people, without whom this thesis would not have been possible.

Firstly, I would like to sincerely thank my primary supervisor, Associate Professor Tess Knight; a bold, thoughtful, and courageous leader. You built me up when it was needed the most with your unwavering belief, encouragement, patience, and good humour; and here we are at completion. I am so grateful for your expert input and perspectives on my research, the light-speed turnaround on writing, and for teaching me how to focus on the important things in life. In the time that I have known you, you have taught me not only how to finish a PhD, but also how to enjoy the research and learning process, and to not sweat the small stuff. I have immensely enjoyed our discussions, on research, on life, and on topics that matter. I truly hope we continue the discussions long into the future, both as colleagues and friends.

To my associate supervisors, Professor Lina Ricciardelli and Dr. Sue Burney, thank you for your continued encouragement, enthusiasm, good humour, and positive words that were instrumental to helping me finish the PhD. Lina, thank you for making me feel so welcome in the School of Psychology and taken care of as a budding researcher; Sue, thank you for your phenomenal editing skills on drafts, and introducing me to your world at conferences. I sincerely hope we continue the research collaborations long into the future.

Thank you to Professor Richard Osborne, Professor Trish Livingston, and Dr. Sarity Dodson, for their help in the early phases of my PhD. Thank you to Roy Batterham teaching me how to conduct concept mapping workshops, and to analyse concept mapping data.

A big thank you to Professor Gerry Elsworth for teaching me the theory behind Structural Equation Modelling, your guidance on using Mplus, and incredible patience when discussing various aspects of psychometric analyses. A sincere thank you to Dr. Lucy Busija for your sound advice on statistics (shared before and after yoga, and during and after business hours), for your Acknowledgements
joyful help with celebrating each milestone, and for your insightful, and delightfully humorous views on life. I hope we continue as colleagues and friends well into the future.

A big thank you to Associate Professor Jacquie Chirgwin for opening proverbial doors to building effective collaborations with healthcare providers at Eastern Health, and enabling participant recruitment at Eastern Health Box Hill and Maroondah hospitals. I am so grateful for your encouragement over the years, and your insights into cancer experiences. I hope we continue the research collaboration long into the future.

A big thank you also to: Anne Muldowney, for providing your expertise on caregivers, as well as help with recruitment, I am so grateful for your input, I hope we can continue our collaborations well into the future; Dr. Phillip Parente for your help with recruitment, and great enthusiasm for the study, I would be delighted to continue our research collaboration in the future; Rosemary Petrie for your warmth, your good humour, and wonderful help with recruitment; and the staff at the Day Oncology departments at Box Hill and Maroondah hospitals who were so helpful with identifying eligible patients and caregivers for the workshops in their clinics. A special thank you to Dr. Anna Williamson and Stephanie Hechenberger who warmly welcomed the study into Leukaemia Foundation to assist with recruiting caregivers; it was a pleasure working with you both, and I hope we can continue the research collaborations in the future.

My sincere thank you to all of the people with cancer and caregivers who participated in the concept mapping workshops for good naturedly volunteering their time to speak candidly and wholeheartedly about their experiences with cancer. Thank you also to the caregivers who participated in the cognitive interviews and the validation study. In particular, thank you to the cancer support group members who welcomed me into their groups, who distributed the questionnaire packs, and who shared the study with their networks; your efforts were vital to the completion of the validation study. A big thank you also to all the experts who took time out of their busy schedules to participate in the concept mapping workshops and/or review of the draft questionnaire items.

Acknowledgements
Thank you to Dr. Helen Mavoa for your supportive words, and shoulder to cry on when it was needed. Thank you to Professor John Toumbourou for always seeing the best in people.

Thank you also to my delightful friends from the Schools of Health and Social Development, and Psychology at Deakin University who supported me when the going got tough, and the tougher got going.

To my family members, my wonderful Mother Sara and Aunt Laiping; thank you for your continued support, encouragement, and prayers along the way. A special thank you to Aunt Bridgid, you built me up with your words of encouragement when it was needed the most, and reminded me that the sky is the limit, thank you for always seeing the best in people.

Finally, to my inspiration, my rock, the love of my life, My Husband, Diarmuid Walsh. I have worked long hours, but you have always managed to work even longer, whilst exercising more, and making time to take good care of our little black shar-pei Charlie, and little Bruno. All whilst staying immeasurably positive and good humoured. You have always believed in me. I will always believe in you. This thesis is dedicated to you.

*******************

Professional editor, Dr Terri Grote, provided copyediting and proofreading services, according to the guidelines laid out in the university-endorsed national ‘Guidelines for editing research theses’.

In undertaking this research, I was supported financially by the following scholarships and grants:

- Deakin University Postgraduate Research Scholarship
- Deakin Population Health Strategic Research Centre Small Project Grant
- Clinical Oncological Society of Australia (COSA) Trainee Travel Grant

Acknowledgements
Publications and Conference Abstracts Arising From This Thesis

Journal Articles


Conference Abstracts


2. **Yuen, E.Y.N.**, Knight, T., Dodson, S., Ricciardelli, L., Burney, S., & Livingston, P.M. *Item generation and content validity testing of the Health Literacy of Caregivers Scale-Cancer (HeLiCaS-C).* Clinical Oncological Society of Australia (COSA)’s 41st Annual Scientific Meeting. Melbourne, Australia. 2nd – 4th December 2014

Publications and conference abstracts arising from this thesis
3. **Yuen, E.Y.N.** Knight, T., Dodson, S., Batterham, R., Chirgwin, J., Ricciardelli, L.,
Burney, S., Livingston, P.M. *Development of a conceptual model of cancer caregiver health literacy: Results from concept mapping.* Australian Psychological Society (APS) Health Psychology Conference. Sydney, Australia. 10\textsuperscript{th} – 11\textsuperscript{th} April 2015

Table of Contents

ACCESS TO THESIS - A ............................................................................................................. II
CANDIDATE DECLARATION ..................................................................................................... III
GENERAL DECLARATION ....................................................................................................... IV
ABSTRACT ....................................................................................................................................... V
ACKNOWLEDGEMENTS ............................................................................................................... VIII
PUBLICATIONS AND CONFERENCE ABSTRACTS ARISING FROM THIS THESIS............................. XI
  JOURNAL ARTICLES .................................................................................................................... XI
  CONFERENCE ABSTRACTS ......................................................................................................... XI
TABLE OF CONTENTS ................................................................................................................. XIII
LIST OF TABLES ......................................................................................................................... XXII
LIST OF FIGURES ...................................................................................................................... XXIV
LIST OF APPENDICES ................................................................................................................. XXV
LIST OF ABBREVIATIONS ......................................................................................................... XXVII
CHAPTER 1. INTRODUCTION .......................................................................................................... 1
  AIMS AND OBJECTIVES ........................................................................................................... 3
CHAPTER 2. LITERATURE REVIEW ................................................................................................ 7
  CANCER: A PUBLIC HEALTH ISSUE ........................................................................................... 7
  SELF-MANAGEMENT IN CANCER CARE ..................................................................................... 8
  ROLE OF CAREGIVERS’ IN CANCER CARE ............................................................................. 10
  CAREGIVER INFORMATION NEEDS ....................................................................................... 13
UNDERSTANDING HEALTH LITERACY ...................................................................................... 16
  What is health literacy? ........................................................................................................... 16
  Conceptualisations of health literacy ...................................................................................... 19
    Health literacy as an individual capacity ........................................................................... 20
    Health literacy as an interaction between individual, and broader societal and systemic factors .......................................................... 22
    Health literacy from the perspective of key stakeholders .................................................. 24
  Importance and relevance of health literacy ......................................................................... 26
Table of contents

Measurement of health literacy ........................................................................................................ 27
Social determinants of health literacy ............................................................................................... 30
Health outcomes and behaviours associated with inadequate health literacy ....................................... 32
  Health literacy and health-related knowledge ..................................................................................... 32
  Health literacy and use of healthcare services .................................................................................... 33
  Health literacy and self-reported health status ................................................................................... 35
  Health literacy and participation in screening programs ...................................................................... 36
  Health literacy and adherence to treatment medication ....................................................................... 38
  Health literacy and patient-healthcare provider communication ..................................................... 39
  Health literacy and self-management of chronic conditions ................................................................ 41
  Health literacy and increased risk of mortality .................................................................................. 44
The role of caregivers in self-management support for individuals with low health literacy .................. 45
The need for measures of caregiver health literacy .............................................................................. 47
SIGNIFICANCE OF THE THESIS ........................................................................................................ 48
RATIONALE AND PURPOSE OF THE STUDY .................................................................................... 49
CHAPTER 3. SYSTEMATIC REVIEW .................................................................................................... 51
CHAPTER OVERVIEW .......................................................................................................................... 51
MANUSCRIPT A ..................................................................................................................................... 54
Abstract ................................................................................................................................................ 55
Methods ............................................................................................................................................... 58
  Search strategy .................................................................................................................................... 58
  Inclusion criteria ................................................................................................................................. 59
  Review process ................................................................................................................................. 59
Results ................................................................................................................................................ 60
  Origins of studies and populations .................................................................................................... 61
  Caregiver Characteristics .................................................................................................................... 61
  Conceptualization ............................................................................................................................... 61
  Research design and methods ............................................................................................................. 62
  Measures of health literacy ................................................................................................................. 62
  Caregiver health literacy .................................................................................................................... 63
  Caregiver versus care recipient health literacy ................................................................................. 64
Table of contents

Caregiver health literacy and health outcomes of the care recipient and caregiver...... 65
Caregiver health literacy following intervention.............................................................. 66
Caregiver health literacy and readability of written health materials ......................... 66
Caregiver health literacy and demographic characteristics ............................................ 67
Discussion ................................................................................................................. 67
Caregiver health literacy: need for adequate measures ................................................... 67
Caregiver and care recipient health literacy................................................................. 69
Caregiver health literacy and care recipient health outcomes ....................................... 70
Caregiver health literacy and caregiver health outcomes ............................................... 71
Caregiver health literacy and intervention outcomes .................................................... 71
Limitations and future directions .................................................................................. 72
Conclusions ....................................................................................................................... 74
References ....................................................................................................................... 75

CHAPTER SUMMARY ........................................................................................................ 83

CHAPTER 4. PROCESS OF SCALE DEVELOPMENT............................................................. 84

FUNDAMENTAL PROPERTIES IN SCALE DEVELOPMENT: RELIABILITY AND VALIDITY........ 84

Processes in Scale Development ................................................................................ 86

Conceptualisation of the phenomenon to be measured ............................................... 87
Item generation ............................................................................................................. 89

Item generation: Item difficulty ................................................................................... 92
Generation of the response format .............................................................................. 93
Review of initial item pool by experts .......................................................................... 96
Cognitive interviewing ................................................................................................. 96
Initial field testing ......................................................................................................... 98

Structural analysis ....................................................................................................... 99

Overview of factor analysis ......................................................................................... 100
Item analysis ................................................................................................................ 106

CTT and IRT in item analysis......................................................................................... 107
Establish convergent and discriminant validity............................................................ 111
Establish internal consistency...................................................................................... 112
Sample size considerations for field testing............................................................... 112
CHAPTER SUMMARY ................................................................................................................ 113

CHAPTER 5. METHOD ................................................................................................................. 115

CHAPTER OVERVIEW ............................................................................................................... 115

Manuscript B. Development of the conceptual model of cancer caregiver health literacy ................................................................. 116

Study objective .................................................................................................................................................. 116

Research design .................................................................................................................................................. 117

Overview of concept mapping processes ........................................................................................................ 119

Preparation ......................................................................................................................................................... 120

Generation of statements .................................................................................................................................. 121

Sorting of statements ......................................................................................................................................... 122

Generation of the concept map .......................................................................................................................... 122

Interpretation of concept map ............................................................................................................................... 123

Post-workshop analyses and integration of workshop results .................................................................................. 124

Three-dimensional analysis of workshop data ..................................................................................................... 125

Constant comparative approach: Qualitative version of Ward’s analysis ......................................................... 126

Integration of the synthesised concepts: A hypothesised conceptual model of caregiver health literacy ......................................................................................................................................................... 127

Participants and recruitment ................................................................................................................................ 128

Summary of methods for Manuscript B ............................................................................................................. 128

Manuscript C. Development of the health literacy of caregivers scale - cancer (HLCS): Item generation and content validity testing .................................................................................................................. 129

Study objective ....................................................................................................................................................... 129

Study design and summary of methods for Manuscript C ...................................................................................... 129

Manuscript D. Validation of the Health Literacy of Caregivers Scale - Cancer (HLCS-C) .................................................. 130

Study objective ....................................................................................................................................................... 130

Study design ......................................................................................................................................................... 130

Participants and recruitment .................................................................................................................................. 131

Data preparation .................................................................................................................................................... 132

Data analysis .......................................................................................................................................................... 133

Summary of methods for Manuscript D .............................................................................................................. 133

Table of contents
CHAPTER SUMMARY .......................................................................................................................... 134

CHAPTER 6. DEVELOPMENT OF THE CONCEPTUAL MODEL OF CANCER CAREGIVER HEALTH
LITERACY ........................................................................................................................................ 135

CHAPTER OVERVIEW .................................................................................................................. 135

MANUSCRIPT B. ............................................................................................................................. 136

Abstract ........................................................................................................................................ 139

Methods .......................................................................................................................................... 141

Participants and recruitment ........................................................................................................... 141

Concept mapping workshops .......................................................................................................... 142

Development of the conceptual model: synthesis of concept maps ............................................ 142

Results ........................................................................................................................................... 143

Concept mapping workshop statements and clusters ................................................................. 143

The cancer caregiver health literacy conceptual model ............................................................. 143

Discussion ..................................................................................................................................... 144

References ..................................................................................................................................... 149

EXTENDED RESULTS RELATED TO THE DEVELOPMENT OF THE CONCEPTUAL MODEL OF
CAREGIVER HEALTH LITERACY .................................................................................................... 152

Interpretation of concept maps: Clusters ...................................................................................... 152

Results from workshop #1 with caregivers .................................................................................. 152

Results from workshop #2 with caregivers .................................................................................. 155

Results from workshop #3 with people with cancer ..................................................................... 155

Results from workshop #4 with people with cancer ..................................................................... 157

Results from workshop #5 with healthcare providers/policymakers ......................................... 157

Results from workshop #6 with healthcare providers/policymakers ......................................... 158

Development of the conceptual model: Synthesis of concept maps ............................................ 159

Key components of caregiver health literacy ............................................................................... 168

Information presented in quality formats ..................................................................................... 168

Supported by healthcare providers to understand information .................................................. 168

Proactivity and determination to seek health information .............................................................. 169

Active engagement with healthcare providers ............................................................................. 169

Understanding information about the cancer, treatment, and potential outcomes ............... 169

Table of contents
Understanding the healthcare system ................................................................. 170
Understanding information for day-to-day care provision ............................... 170
Processing health information ............................................................................. 171
Self-care ................................................................................................................ 171
Attitudes, approaches and emotional challenges ................................................ 171
Role recognition and understanding caregiver rights ........................................... 171
Communication with the care recipient ............................................................... 172
Understanding the care recipient ........................................................................ 172
Social support ...................................................................................................... 172
Psychosocial support .......................................................................................... 173
Practical support .................................................................................................. 173
Financial and legal support .................................................................................. 174

CHAPTER SUMMARY .................................................................................................. 174

CHAPTER 7. DEVELOPMENT OF THE HEALTH LITERACY OF CAREGIVERS SCALE: ITEM
GENERATION AND CONTENT VALIDITY TESTING .................................................. 175

CHAPTER OVERVIEW ................................................................................................. 175
MANUSCRIPT C ........................................................................................................ 176

ABSTRACT .................................................................................................................... 179

Background ............................................................................................................. 179
Methods ................................................................................................................... 181
   Content area specification .................................................................................. 181
   Generation of items and response scale ............................................................ 181
   Expert review ..................................................................................................... 183
   Cognitive interviews .......................................................................................... 184
Results .................................................................................................................... 184
   Selection of content areas .................................................................................. 184
   Item generation and response options ............................................................ 184
   Expert review ..................................................................................................... 185
   Cognitive interviews .......................................................................................... 185
Discussion ............................................................................................................... 185
Conclusion .............................................................................................................. 188

Table of contents
**Table of contents**

*Practice implications* .......................................................... 188

**EXTENDED RESULTS** .......................................................... 191

**CHAPTER SUMMARY** .......................................................... 193

**CHAPTER 8. MEASURING CANCER CAREGIVER HEALTH LITERACY: VALIDATION OF THE HEALTH LITERACY OF CAREGIVERS SCALE-CANCER (HLCS-C)** .......................................................... 194

**CHAPTER OVERVIEW** .......................................................... 194

**MANUSCRIPT D** .......................................................................................................................... 198

- **Abstract** ................................................................................................................................. 199
- **Introduction** ............................................................................................................................... 201
  - The informational needs of caregivers ................................................................................. 201
  - The role of caregiver health literacy .................................................................................... 202
  - The need for caregiver health literacy measurement ......................................................... 203
- **Method** ..................................................................................................................................... 204
  - Recruitment processes ........................................................................................................... 204
  - Participants ............................................................................................................................... 205
  - Materials .................................................................................................................................. 205
  - Ethics ....................................................................................................................................... 206
- **Statistical Analyses** ................................................................................................................ 206
  - Descriptive statistics ............................................................................................................. 206
  - Confirmatory factor analyses ............................................................................................... 207
  - Item assessment and removal criteria .................................................................................. 208
  - Discriminant validity of HLCS-C domains ........................................................................... 210
  - Internal consistency ............................................................................................................... 210
- **Results** ..................................................................................................................................... 210
  - Item analysis ............................................................................................................................ 210
  - One-factor Confirmatory Factor Analysis models ............................................................... 211
  - Pairwise Confirmatory Factor Analysis models .................................................................... 212
  - Ten-factor Confirmatory Factor Analysis model ................................................................. 212
  - Internal consistency reliability .............................................................................................. 213
  - Post-analysis modification of the scale ................................................................................. 213
- **Discussion** ................................................................................................................................ 214
Table of contents

Construct validity of the HLCS-C (revised) ................................................................. 214
Reliability of the HLCS-C (revised) ............................................................................... 215
Utility of the HLCS-C (revised) .................................................................................... 216
Limitations of the HLCS-C (revised) .......................................................................... 217
Study limitations ......................................................................................................... 217
Future directions ......................................................................................................... 218
Conclusions ................................................................................................................ 218
References .................................................................................................................. 220
Extended Results ....................................................................................................... 243
Missing data and outliers check .................................................................................. 243
Descriptive statistics ................................................................................................. 243

CHAPTER SUMMARY ......................................................................................................... 247

CHAPTER 9. DISCUSSION ................................................................................................. 249

CHAPTER OVERVIEW .................................................................................................... 249

SUMMARY OF MAIN FINDINGS .................................................................................. 249

State of the field: Caregiver health literacy ............................................................... 250
A conceptual model of caregiver health literacy derived from stakeholder perspectives ......................................................................................................................... 252
A comprehensive new measure of caregiver health literacy: The Health Literacy of Caregivers Scale – Cancer (HLCS-C) .......................................................... 254

IMPLICATIONS OF THESIS FINDINGS ....................................................................... 258

STRENGTHS AND LIMITATIONS OF THE STUDIES .................................................. 261
Key strengths ............................................................................................................... 261
Key limitations ............................................................................................................. 263

FUTURE DIRECTIONS .................................................................................................... 264
Suggestions for future validation and refinement of the HLCS-C ............................... 264
Exploring the prevalence and impacts of caregiver health literacy ......................... 265

CONCLUSION ............................................................................................................... 267

REFERENCES ............................................................................................................... 269

APPENDIX A .................................................................................................................. 290
# List of Tables

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Table #</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.1</td>
<td>Summary of prominently used, and more recent, definitions of health literacy</td>
<td>19</td>
</tr>
<tr>
<td>1</td>
<td>1.2</td>
<td>Summary of capacities included in the shortlisted definitions of health literacy</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>Details of studies that differentiated between health literacy levels when assessing health literacy in caregivers (and care recipients)</td>
<td>80</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>Details of studies that reported a mean health literacy score when assessing health literacy in caregivers (and care recipients)</td>
<td>82</td>
</tr>
<tr>
<td>3</td>
<td>3.1</td>
<td>Key recommendations for generating quality items (Clark &amp; Watson, 1995; DeVellis, 2011; FDA, 2009; Hinkin, 2005) and example criteria for evaluating new items (Patrick et al., 2011)</td>
<td>91</td>
</tr>
<tr>
<td>3</td>
<td>3.2</td>
<td>Examples of response formats in scale development (adapted from Clark &amp; Watson, 1995; DeVellis, 2011)</td>
<td>94</td>
</tr>
<tr>
<td>5</td>
<td>5.1</td>
<td>Research objectives and corresponding research methods used</td>
<td>116</td>
</tr>
<tr>
<td>5</td>
<td>5.2</td>
<td>Seeding statements for the concept mapping workshops with caregivers, people with cancer, and healthcare providers/policymakers</td>
<td>121</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>Demographic and clinical characteristics of people with cancer and caregivers who participated in workshops</td>
<td>141</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>Summary of clusters and statements derived from the six concept mapping workshops</td>
<td>145</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>Six categories, 17 concepts and their definitions, and example statements derived from concept mapping workshops with relevant stakeholders</td>
<td>146</td>
</tr>
<tr>
<td>6</td>
<td>6.1</td>
<td>Statements and clusters from workshop #1 with caregivers</td>
<td>152</td>
</tr>
<tr>
<td>6</td>
<td>6.2</td>
<td>Major categories and concepts of caregiver health literacy identified from the synthesis of concept mapping data</td>
<td>165</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>Specification of the ten scales hypothesized to define cancer caregiver health literacy, reasons for exclusion of content areas, and example items for</td>
<td>182</td>
</tr>
<tr>
<td>Table Number</td>
<td>Description</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>7.2</td>
<td>Structured item development criteria used to assess quality of items</td>
<td>183</td>
<td></td>
</tr>
<tr>
<td>7.3</td>
<td>Demographic characteristics of caregivers who participated in cognitive interviews</td>
<td>184</td>
<td></td>
</tr>
<tr>
<td>7.4</td>
<td>Range of CVI scores for relevance and clarity for ten hypothesized scales of cancer caregiver health literacy</td>
<td>185</td>
<td></td>
</tr>
<tr>
<td>7.5</td>
<td>Seven revised items in response to content validity index scores for relevance and clarity, and comments from experts</td>
<td>186</td>
<td></td>
</tr>
<tr>
<td>7.6</td>
<td>Revised items following expert suggestions for revision</td>
<td>187</td>
<td></td>
</tr>
<tr>
<td>7.7</td>
<td>New items following expert review and reasons for inclusion</td>
<td>187</td>
<td></td>
</tr>
<tr>
<td>7.7.1</td>
<td>Vignettes to describe an individual with high capacity, and low capacity for the ten domains included in the HLCS-C</td>
<td>191</td>
<td></td>
</tr>
<tr>
<td>8.1</td>
<td>Demographic characteristics of 297 participants who completed the HLCS-C</td>
<td>224</td>
<td></td>
</tr>
<tr>
<td>8.2</td>
<td>Descriptive statistics for HLCS-C draft 88 items in Australian caregivers of cancer patients, identification of the point at which poorly performing items were deleted, and remaining items for inclusion in final scale</td>
<td>226</td>
<td></td>
</tr>
<tr>
<td>8.3</td>
<td>Psychometric properties of the revised domains and items from the HLCS-C</td>
<td>236</td>
<td></td>
</tr>
<tr>
<td>8.4</td>
<td>Inter-factor correlations for ten domains in HLCS-C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.8.1</td>
<td>Descriptive statistics for the 88 draft items of the HLCS-C</td>
<td>244</td>
<td></td>
</tr>
</tbody>
</table>
## List of Figures

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Figure #</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>1</td>
<td>PRISMA Flow diagram</td>
<td>79</td>
</tr>
<tr>
<td>4</td>
<td>4.1</td>
<td>Processes of scale development used in the current study</td>
<td>87</td>
</tr>
<tr>
<td>4</td>
<td>4.2</td>
<td>Example of factorially simple items, a key objective in questionnaire development. The relationship between an item and an underlying construct is referred to as the factor loading (De Vet et al., 2011)</td>
<td>100</td>
</tr>
<tr>
<td>5</td>
<td>5.1</td>
<td>Example of a point map generated using the Concept System Software Version 1 (Trochim, 1989) during concept mapping workshops</td>
<td>119</td>
</tr>
<tr>
<td>5</td>
<td>5.2</td>
<td>Example of a point map with ten clusters generated using the Concept System Software Version 1 (Trochim, 1989) during concept mapping workshops</td>
<td>120</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>Concept map produced during a concept mapping workshop with caregivers of people with cancer (workshop #1)</td>
<td>144</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>Conceptual model of cancer caregiver health literacy derived from the perspective of relevant stakeholders</td>
<td>148</td>
</tr>
<tr>
<td>6</td>
<td>6.1</td>
<td>Concept map generated from workshop #2 with caregivers. Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved</td>
<td>156</td>
</tr>
<tr>
<td>6</td>
<td>6.2</td>
<td>Major categories and concepts hypothesised to represent caregiver health literacy</td>
<td>162</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>Conceptual model of cancer caregiver health literacy (Yuen et al., in press)</td>
<td>180</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
<td>Steps undertaken to develop items for the new measure of cancer caregiver health literacy</td>
<td>181</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>Decisions and modifications made to the item pool and domains in response to IRT and CFA analyses</td>
<td>242</td>
</tr>
</tbody>
</table>
List of Appendices

Appendix A  Recruitment letters to people with cancer related to Study D .........................290
  Appendix A1  Recruitment letter to people with cancer identified from cancer support
groups .........................................................................................................................290
  Appendix A2  Recruitment letter to people with cancer identified from a public health
service ..........................................................................................................................292
Appendix B  Recruitment letters to caregivers related to Study D .................................294
  Appendix B1  Recruitment letter to caregivers of cancer support group members ......294
  Appendix B2  Recruitment letter to caregivers of patients from a public health
service ..........................................................................................................................296
Appendix C  Participant Information Forms for caregivers ........................................298
  Appendix C1  Participant information form – Cancer Support Groups .................298
  Appendix C2  Participant Information Form - Caregivers of people from the public
health service ..............................................................................................................303
Appendix D  Health Literacy of Caregivers Scale – Cancer (HLCS-C) completed by caregivers
for Study D ..................................................................................................................308
Appendix E  Follow-up letters related to recruitment for Study D ...............................316
  Appendix E1  Follow-up letters to patients from the public health service ..........316
  Appendix E2  Follow-up letter to caregivers of patients from the public health service
........................................................................................................................................318
  Appendix E3  Follow-up recruitment letter to cancer support group members identified
through Leukaemia Foundation ....................................................................................320
  Appendix E4  Follow-up recruitment letter to caregivers of Leukaemia Foundation
cancer support group members ..................................................................................322
Appendix F  Tables of results from concept mapping workshops with key stakeholders……324
  Appendix F1  Statements and clusters from workshop #2 with caregivers ............324
  Appendix F2  Statements and clusters from workshop #3 with people with cancer ....327
  Appendix F3  Concept map generated from workshop #3 with people with cancer*....329
  Appendix F4  Statements and clusters from workshop #4 with people with cancer ....330
  Appendix F5  Concept map generated from workshop #4 with people with cancer*...332

List of Appendices
Appendix F6  Statements and clusters from workshop #5 with healthcare providers/policymakers…………………………………………………………..333
Appendix F7  Concept map generated from workshop #5 with healthcare providers/policymakers* ………………………………………………………………..335
Appendix F8  Statements and clusters from workshop #6 with healthcare providers/policymakers ……………………………………………………………..336
Appendix F9  Concept map generated from workshop #6 with healthcare providers/policymakers…………………………………………………………..338
List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AACR</td>
<td>Australasian Association of Cancer Registries</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>AMA</td>
<td>American Medical Association</td>
</tr>
<tr>
<td>CaTCoN</td>
<td>Cancer Caregiving Tasks, Consequences, and Needs Questionnaire</td>
</tr>
<tr>
<td>CFA</td>
<td>Confirmatory Factor Analysis</td>
</tr>
<tr>
<td>CFI</td>
<td>Comparative Fit Index</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>CTT</td>
<td>Classical Test Theory</td>
</tr>
<tr>
<td>DF</td>
<td>Degrees of freedom</td>
</tr>
<tr>
<td>EFA</td>
<td>Exploratory Factor Analysis</td>
</tr>
<tr>
<td>eHEALS</td>
<td>eHealth literacy scale</td>
</tr>
<tr>
<td>FCCHL</td>
<td>Functional, communicative and critical health literacy scales</td>
</tr>
<tr>
<td>GFI</td>
<td>Goodness of Fit</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HLCS-C</td>
<td>Health Literacy of Caregivers Scale - Cancer</td>
</tr>
<tr>
<td>HLQ</td>
<td>Health Literacy Questionnaire</td>
</tr>
<tr>
<td>ICC</td>
<td>Item Characteristic Curve</td>
</tr>
<tr>
<td>IOM</td>
<td>Institute of Medicine</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>IRR</td>
<td>Internal Rate of Return</td>
</tr>
<tr>
<td>IRT</td>
<td>Item Response Theory</td>
</tr>
<tr>
<td>MDS</td>
<td>Multidimensional Scaling</td>
</tr>
<tr>
<td>NVS</td>
<td>Newest Vital Sign</td>
</tr>
<tr>
<td>OR</td>
<td>Odds Ratio</td>
</tr>
<tr>
<td>PHLAT</td>
<td>Parent Health Literacy Activities Test</td>
</tr>
<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>REALM-S</td>
<td>Rapid Estimate of Adult Literacy in Medicine - Shortened</td>
</tr>
<tr>
<td>REALM-teen</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>RMSEA</td>
<td>Root Mean Square Error of Approximation</td>
</tr>
<tr>
<td>TOFHLA</td>
<td>Test of Functional Health Literacy in Adults</td>
</tr>
<tr>
<td>SEM</td>
<td>Structural Equation Modelling</td>
</tr>
<tr>
<td>SAHLSA</td>
<td>Short Assessment of Health Literacy for Spanish-speaking Adults</td>
</tr>
<tr>
<td>S-TOFHLA</td>
<td>Short Test of Functional Health Literacy in Adults</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>WLSMV</td>
<td>Weighted Least Squares Mean and Variance Adjusted</td>
</tr>
<tr>
<td>WRMR</td>
<td>Weighted Root Mean Square Residual</td>
</tr>
</tbody>
</table>
Chapter 1. Introduction

Caregivers play a vital role in the self-management of people living with cancer. In the current study, caregivers are defined as any relative, partner, friend, or neighbour who provide a broad range of physical, medical, personal, and emotional support to an older person, or an adult with a chronic or disabling condition (Reinhard, Given, Petlick, & Bemis, 2008). These individuals often assume responsibility for providing care in an informal, non-professional, and predominantly unpaid capacity (Given, Given, & Sherwood, 2012).

Research has shown that caregivers also play an instrumental role in providing informational support, through sourcing health information, participating in health decision-making, assisting care recipients to navigate the healthcare system, and facilitating information exchange between the care recipient and healthcare providers (Eggly et al., 2006; Laidsaar-Powell et al., 2013). However, despite national health strategies recognising the integral role that caregivers play in the decision-making, health promotion, and self-management of people with chronic conditions, caregivers have reported significant unmet information needs related to medical, practical and psychosocial issues (Longacre, 2013; Washington, Meadows, Elliott, & Koopman, 2011). As caregivers are not the primary recipients of health care, they have reported a number of issues unique to the caregiving role when seeking health information and engaging with the healthcare system. Barriers to accessing information have included a lack of time and direct communication with healthcare providers, and a lack of recognition of their caregiving role (Dolce, 2011; Guo, Phillips, & Reed, 2010; A. L. Williams & Bakitas, 2012), which have resulted in caregiver disenchantment with the healthcare system (Dolce, 2011). There is also the assumption that caregivers possess the knowledge and skills required to seek, understand, appraise and use health information to participate in health-related decision-making and be an
active partner in care (Bevan & Pecchioni, 2008).

Health literacy is defined as the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health; it includes the capacity to communicate, assert and enact these decisions (Dodson, Beauchamp, Batterham, & Osborne, 2014; Sorensen et al., 2012). Health literacy is considered a key determinant of health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Inadequate health literacy has been associated with a number of poor health outcomes and behaviours including poorer medication adherence (Zhang, Terry, & McHorney, 2014), poorer physical functioning and poorer quality of life (Apter et al., 2013; Kamimura, Christensen, Tabler, Ashby, & Olson, 2013), later stage disease detection (Berkman et al., 2011), increased rates of hospitalisation and emergency room presentations (Berkman et al., 2011; Mitchell, Sadikova, Jack, & Paasche-Orlow, 2012), and in older persons, increased mortality (Bostock & Steptoe, 2012; Peterson et al., 2011).

Recent research suggests that for people with inadequate health literacy, caregivers may play an important role in promoting positive health outcomes (Levin, Peterson, Dolansky, & Boxer, 2014; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Rosland, Piette, Choi, & Heisler, 2011). In a study of people with heart failure or diabetes, Rosland and colleagues found that for those with low health literacy, caregivers actively participated in disease management by providing support with self-management tasks (e.g., healthy eating, exercise, information seeking and decision-making, medications, and testing; Rosland et al., 2010), as well as assisting with understanding information and facilitating information exchange during clinical encounters (Rosland et al., 2011). However, few studies have examined health literacy of caregivers of adults with a chronic condition.

Chapter 1. Introduction
Given the vital role of caregivers in providing care for people with cancer, it is important that more is understood about the way in which caregiver health literacy impacts their capacity to perform their role. While evidence has linked inadequate health literacy to an individual’s own health outcomes, to date, it is unclear the extent to which health literacy of caregivers impacts care recipient health outcomes. One key barrier to further research in this area is the lack of appropriate and validated measurement approaches (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014). A measure that comprehensively assesses caregiver health literacy has the potential to guide the development and evaluation of interventions and health system improvement, and to further our understanding of the mediating effect of caregiver health literacy on care recipient behaviours and outcomes.

Aims and objectives

The overarching aim of this thesis was to advance both the conceptualisation and measurement of health literacy of caregivers of people with cancer. The objectives of the study were to:

1. Appraise the current state of peer-reviewed literature on health literacy of caregivers of adult care recipients;
2. Develop a conceptual model of caregiver health literacy from the perspective of key stakeholders, and;
3. Use the conceptual model to guide the development of a comprehensive, multidimensional measure to assess health literacy of caregivers of people with cancer.

In this thesis, the research objectives are addressed in four manuscripts (A to D). While each manuscript has individual merit, when taken together, the manuscripts serve to address the overarching aim of the thesis identified above, by addressing the following research questions:
1. How is health literacy assessed in caregivers of adult care recipients? What are the levels of health literacy among caregivers of adult care recipients? Are caregiver health literacy skills independently associated with care recipient health outcomes? Are caregiver health literacy skills associated with caregiver health outcomes?

2. What are the constituent elements for caregivers in accessing, understanding and using health information and health services?

3. Using a grounded approach, what elements are required in a comprehensive model of health literacy to guide the development of a robust psychometric measure of caregiver health literacy?

4. What are the psychometric properties of a new measure of caregiver health literacy that has been developed from the conceptual model?

**Thesis structure**

In Chapter 2, an overview of the thesis is provided and relevant literature is reviewed to give context for the research. The chapter begins with an overview of cancer as a public health issue in Australia, and the role of caregivers in cancer care and their needs for information are discussed. An overview of health literacy is provided, including the various definitions and conceptualisations, and how they have evolved. The importance and relevance of health literacy are discussed through presenting the range of associations between inadequate health literacy and health behaviours and outcomes. Gaps in the literature pertaining to the understanding and assessment of caregiver health literacy are also highlighted to provide justification for the current research.

In Chapter 3, the first objective of the thesis is addressed. Results from a systematic review of the literature that examined health literacy in caregivers of adult care recipients are
presented in the form of a manuscript (Manuscript A). Each study included in the review was evaluated using an eight-item quality criterion.

In Chapter 4, an overview of the processes of scale development is presented. The fundamental properties of scale development, reliability and validity are introduced. Steps in scale development aimed to improve accuracy and minimise measurement error of the resultant measure are described.

In Chapter 5, the research methods used to develop a conceptual model and measurement tool are outlined. The discussion of the methods in Chapter 5 vary in content and length as the author sought to provide details not included in the ‘Methods’ sections of manuscripts B, C, and D.

In Chapter 6, the second objective of this thesis is addressed. Findings from the development of conceptual model of cancer caregiver health literacy are presented in the form of a manuscript (Manuscript B). Using a grounded theory approach, findings from consultations with a broad range of people with cancer, caregivers of people with cancer, and healthcare providers and a policy maker were synthesised to generate the conceptual model. Key themes and sub-themes identified in the conceptual model present a new way of understanding health literacy specifically for caregivers of people with cancer.

The third objective of the thesis is addressed in Chapters 7 and 8. In Chapter 7, findings from the development and content validity testing of the Health Literacy of Caregivers Scale-Cancer (HLCS-C) are presented in the form of a manuscript (Manuscript C). Identification of domains for inclusion in the HLCS-C was informed by results from the conceptual model of cancer caregiver health literacy. Generation of items for the scale was informed by results from consultations with key stakeholders (detailed in Chapter 5).

Chapter 1. Introduction
In Chapter 8, results from the validation of the HLCS-C are presented in the form of a manuscript (Manuscript D). As part of the evaluation process, poorly performing and redundant items were identified and removed, and the scale’s construct and discriminant validity, and internal consistency were investigated.

In Chapter 9, the main findings and implications of the thesis are discussed. Key strengths and limitations of the research are identified, and directions for future research are highlighted. A summary of the scholarly contributions of the research to the field of cancer care and health literacy is also detailed.
Chapter 2. Literature Review

In this chapter, an overview of the relevant literature on cancer as a public health issue in Australia, and the role of caregivers in self-management for people with cancer are presented. Health literacy, and the evolution of its definitions and conceptualisations are also described. The importance and relevance of health literacy in health promotion and public health research are detailed through presenting the range of associations between inadequate health literacy and health behaviours and outcomes. For individuals with low health literacy, the integral role of caregivers in self-management support is discussed. The need for measures of caregiver health literacy is identified. The chapter concludes with the rationale and purpose of the studies undertaken as part of the thesis.

Cancer: A Public Health Issue

In Australia, cancer is one of the leading causes of death and a major contributor to the burden of disease and injury (Australian Institute of Health and Welfare [AIHW] & Australasian Association of Cancer Registries [AACR], 2012). In 2011, cancer was the underlying cause of over 43,200 deaths, which accounted for approximately 30% of all registered deaths in Australia (AIHW & AACR, 2012). In 2014, an estimated 128,000 new cases of cancer were diagnosed, with cancer incidences expected to increase to 150,000 by 2020 (AIHW, 2012). The financial and human costs of cancer are substantial, and have significant economic impacts. Costs are associated with treatment, care, rehabilitation, as well as reduced economic output from lost work productivity, and premature death (American Cancer Society [ACS], 2011). Direct health expenditure on cancer costs the Australian community over $4.5 million annually, with cancer comprising almost 80% of expenditure for hospital admitted patient services ($3,566 million; AIHW, 2013).
Medical advances in the early detection, diagnosis, and treatment of cancer have facilitated increases in cancer survival, with five-year survival rates increasing from 46% in 1982–1986 to 67% in 2007–2011 (AIHW, 2014). Further, with shifts in treatment patterns over the past twenty years, people diagnosed with cancer now spend less time in hospital and more time in outpatient care, as demonstrated by increases in day surgery, outpatient-based chemotherapy and radiotherapy, and home care (McCorkle et al., 2011). These advances in healthcare provision have resulted in a shift in responsibility from healthcare providers to patients who are required to self-manage significant aspects of the disease and treatment outside of the healthcare setting (Stenberg, Ruland, & Miaskowski, 2010). Management of care is now seen to overlap between individuals, healthcare providers and healthcare systems (McCorkle et al., 2011).

**Self-Management in Cancer Care**

The role of self-management in chronic disease care has gained increased attention as a vital component of health care (McCorkle et al., 2011; Paterson, Jones, Rattray, & Lauder, 2014). Self-management has been defined as an individual’s capacity to “*manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. To monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life*” (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p.178). Self-management is considered a dynamic, interactive and daily process in which individuals actively participate in actions and decisions to manage their health and illness (Wagner & McCorkle, 2010). Within the cancer context, self-management tasks can include: adhering to medication schedules, managing symptoms, problem-solving, making lifestyle changes or undertaking preventive action, making day-to-day...
decisions about what actions are to be taken, and navigating an increasingly complex healthcare system (Hammer et al., 2015; Risendal et al., 2014). Self-management models have also emphasised the role of the individual in collaboration with family members, communities and healthcare providers to effectively manage the disease, along with the psychosocial and lifestyle outcomes of chronic conditions (Holman & Lorig, 2000; Lorig & Holman, 2003; Richard & Shea, 2011).

In contrast to traditional, paternalistic approaches where healthcare providers were seen as the experts and patients were viewed as passive participants in their healthcare, self-management models highlight a patient-centred approach. Individuals are viewed as experts in their own life, and healthcare providers are viewed as coaches, collaborators, or partners who bring knowledge about the disease—to support the individual to make decisions about, and to manage their health (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Key concepts in self-management models include patient empowerment, self-efficacy and self-mastery, in which the individual’s values, needs and priorities are placed at the centre of health care (Bodenheimer et al., 2002; Lorig, Mazonson, & Holman, 1993).

For a person with cancer, their capacity to self-manage their health and potentially complex demands can be significantly impacted by the effects of cancer and treatment, which can include fatigue, depression, cognitive impairment, and pain (Lawn et al., 2014). For these individuals, family members and friends can play a vital role by providing informal care and support with self-management tasks (Richard & Shea, 2011). Recognition of the important role of caregivers has led to the identification that to advance primary health care reform in Australia (Commonwealth of Australia, 2009), there is the need for healthcare systems to better engage caregivers as partners in care, and as individuals who require support in their caring role.

Chapter 2. Literature review
Promoting individual and caregiver capacities to participate in health care has been recognised as an essential component of effective self-management, as well as secondary prevention, and a strategy to reduce the burden on chronic conditions on individuals, families, and the broader community (Grey, Schulman-Green, Knafl, & Reynolds, 2014). The critical role of caregivers in cancer care is detailed in the following section.

**Role of Caregivers’ in Cancer Care**

A cancer diagnosis is a traumatic event often accompanied by ongoing, complex, and diverse challenges which can affect both the person diagnosed, and their family members and friends. Depending on the diagnosis and illness severity, family members and friends are often called upon to provide informal care and assistance with disease management tasks in the home care setting (Kim & Schulz, 2008). The Australian Carer Recognition Act 2010 defined a caregiver as “an individual who provides personal care, support and assistance to another individual who needs it because that other individual, has a disability, has a medical condition (including a terminal or chronic illness), has a mental illness; or is frail and aged” (Phillips & Magarey, 2010; p.3). In the current study, a caregiver is defined, as any relative, partner, friend, or neighbour who provides a broad range of physical, medical, personal, and emotional support to an older person, or an adult with a chronic or disabling condition (Reinhard et al., 2008). The definition is considered to adequately cover the broad social, informational, instrumental, and emotional dimensions of care and support provided by caregivers.

Caregiving responsibilities can include: monitoring the disease and symptoms, managing unpleasant side effects, ensuring treatment compliance, conducting home-based medical procedures, maintaining continuity of care, liaising with healthcare providers, navigating the healthcare system, as well as ensuring the patient’s ability to respond to, and cope with the stress...
of living with the disease (DuBenske, Chih, Gustafson, Dinauer, & Cleary, 2010). Caregivers may also be required to provide practical support for day-to-day living, such as shopping, cleaning, providing transportation, and personal care (Given et al., 2004; Glajchen, 2004; Northouse, Williams, Given, & McCorkle, 2012). They may also be required to take on the care recipient’s responsibilities, whilst managing pre-existing roles and their own emotional responses to the person’s cancer diagnosis (Bevan & Pecchioni, 2008). The caregiving role is often assumed under unexpected circumstances, with little preparation, and minimal guidance and support from healthcare providers (Glajchen, 2004).

The Australian Bureau of Statistics (ABS) reported that in 2012 almost 2.7 million Australians provided informal care, with close to 40% of those spending 40 hours or more in that role. It was also shown that caregivers were more likely to have lower rates of labour work force participation, poorer health, and lower annual income compared to non-caregivers (ABS, 2012). In 2010, Carers Australia commissioned Access Economics Pty Ltd (now part of the Deloitte group) to quantify the economic contribution of caregivers. They reported that the cost of informal care provided by unpaid caregivers for people with a disability, mental illness, chronic condition, terminal illness and the aged exceeded $40 billion, which was 33% higher than in 2005. This was attributed to an ageing population and increase in the costs of caring. While an estimated 1.32 billion hours of care per annum is provided, informal caregiving is still one of the lowest subsidised forms of care and remains under-resourced in terms of education and information compared to paid care workers (Access Economics, 2010).

Although the economic burden of caregiving has been identified, individuals who assume the caregiving role often report positive experiences, including satisfaction and meaning (Wolff, Dy, Frick, & Kasper, 2007), personal growth (Thombre, Sherman, & Simonton, 2010), and
strengthened relationships with the care recipient (Wong, Ussher, & Perz, 2009). However
caregiving can also place significant strain and result in serious psychological, physical, social
and financial consequences for caregivers (Hodgkinson et al., 2007; Stenberg et al., 2010). A
recent review reported that depression and anxiety amongst caregivers have ranged from 10 to
53%, and 16 to 56% respectively, and in some studies, have exceeded care recipient levels
(Girgis, Lambert, Johnson, Waller, & Currow, 2013). A recent longitudinal study found that
caregivers who reported high levels of anxiety and depression at baseline, maintained these
levels at six and 12 months after care recipient diagnosis (Lambert, Jones, Girgis, &
Lecathelinais, 2012). The challenges in the caregiving role reflect both care recipient factors,
such as personality and illness severity, as well as caregiver physiological and psychological
factors, (e.g., a caregiver’s capacity to provide physical assistance; Given, Sherwood, & Given,
2008). While some caregiving tasks such as medication administration and accompanying the
care recipient to appointments are merely time-consuming, other caregiving tasks such as
decision-making, solving problems, providing emotional support and comfort and coordinating
care can be challenging for some individuals (Given et al., 2008). Some caregivers have a range
of personal, social and financial resources to draw upon to cope with the stress of caregiving,
however, others have limited resources to cope with the competing demands whilst managing
their own responsibilities and their own health (van Ryn et al., 2011). When caregiving
responsibilities exceed an individual’s knowledge and skills, they can feel overwhelmed by the
increasingly complex and demanding requirements, and burdened by the caregiving role (Girgis
& Lambert, 2009; Park et al., 2010; Pinquart & Sörensen, 2003; Sharpe, Butow, Smith,
McConnell, & Clarke, 2005).

Caregiver burden has been associated with poor health outcomes, for both the caregiver

Chapter 2. Literature review
and the care recipient. Although reports of caregiver burden have been greatest in caregivers of people with dementia (Christakis & Allison, 2009), caregivers of people with cancer have reported substantial negative psychosocial outcomes including: depression, anxiety and distress, poorer health behaviours, reduced quality of life, and increased mortality (Grunfeld et al., 2004; Janda et al., 2007). Further, caregiver burden has been shown to negatively affect the health outcomes of the care recipient. For example, Kuzuya and colleagues (2011) explored the effects of caregiver burden on care recipient mortality and hospitalisation in a longitudinal community-based study with 1,067 pairs of care recipients aged 65 years and over and their caregivers. Care recipients included those with heart disease, cerebrovascular disease, respiratory disease, dementia, as well as cancer (8% of sample). At the three-year follow-up, care recipients whose caregivers reported the highest burden were 1.5 times more likely to show increased risk of mortality and hospitalisation compared to individuals whose caregivers reported low burden (Kuzuya et al., 2011).

**Caregiver Information Needs**

To effectively participate in caregiving responsibilities, caregivers have reported a need for information related to the disease, treatment options, prognosis, how to navigate the healthcare system, and how to manage psychosocial care (Adams, Boulton, & Watson, 2009; Given et al., 2012; Lambert et al., 2012). At various points along the cancer continuum, caregivers have reported requiring different types of information, for example, at diagnosis, following hospital discharge, at recurrence, during symptom crisis, and/or during the end stages of care (Adams et al., 2009; Gansler et al., 2010).

Information that is adequate, appropriate, and presented in a timely manner has the potential to influence how caregivers manage their caregiving experience, enables active
participation in health-related decision-making, can establish meaningfulness, and can assist
caregivers adapt and cope with the caregiving role (Given et al., 2012). However in current
practice, caregivers frequently report they are left on their own to find information about cancer
care (Given et al., 2012; Kidd, Forbat, Kochen, & Kearney, 2011; Koenig, Steiner, & Pierce,
2011; Lambert et al., 2012; Marcusen, 2010; McCarthy, 2011).

For example, in a qualitative study of 25 caregivers of people with brain tumours,
Schubart, Kinzie and Farace (2008) reported that caregivers’ greatest need for information
occurred following diagnosis. However, caregivers in the study reported not receiving
information they needed from healthcare providers, and thus, were left to obtain information by
trial and error or via social networks. These caregivers also reported having to solve problems,
make decisions, and undertake tasks they were not trained to do as care needs changed. Schubart
and colleagues’ study highlighted that caregivers had substantial information needs related to
care provision, particularly at diagnosis that were not adequately met by healthcare providers.

Extensive unmet information needs of caregivers were reported in a systematic review
that examined the information needs of caregivers of older people with chronic conditions
(Washington et al., 2011). Sixty-two studies were included in the review that explored health
information needs of caregivers of people with cancer, stroke, dementia, traumatic brain injury,
and Alzheimer’s disease. Caregivers reported substantial unmet needs related to information on:
the disease, treatment and prognosis, available resources, financial guidance and support, and
specific information about how to provide the care required.

While some caregivers have reported that healthcare providers are their preferred sources
of information and that their experiences with them have been positive (Tunin, Uziely, &
Woloski-Wruble, 2010; Waldrop et al., 2012), others have reported dissatisfaction with
information received from healthcare providers (Fridriksdóttir et al., 2011; Lund, Ross, Petersen, & Groenvold, 2014b). Caregivers have reported barriers to seeking information from healthcare providers as they are not the primary recipients of healthcare. Their concerns relate to a lack of recognition in their role, and few opportunities to discuss information during consultations with healthcare providers (Boehmer et al., 2014; Dolce, 2011; Guo et al., 2010; Waldrop et al., 2012).

In a cross-sectional study with 590 participants, Lund et al. (2014b) examined caregivers’ needs related to their interactions with healthcare providers. Caregiver needs were identified using the Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN; Lund, Ross, & Groenvold, 2012; Lund, Ross, Petersen, & Groenvold, 2014a), a measure developed to assess caregiving tasks and consequences and the caregivers’ needs related to the caregiver-healthcare provider interaction. Thirty-nine per cent of caregivers in the study reported inadequate information provision from healthcare providers. Nearly one third of caregivers also reported that healthcare providers rarely or never included them in the patient’s disease treatment or care, and over half the caregivers reported that healthcare providers had rarely or never shown interest in their wellbeing. Caregivers also reported substantial unmet information needs related to: disease and prognosis (36%), symptoms and side effects (43%), optimal ways to support the cancer patient (51%), potential psychological reactions in the cancer patient (55%), nutrition (33%), who to turn to as a caregiver after patient discharge (37%), rights and possibilities of assistance on discharge and in general (39%), and where to seek help as a caregiver (31%). Over one third of caregivers reported needing to ask healthcare providers questions to obtain information they needed (Lund et al., 2014b).

Caregivers’ perceived lack of support from healthcare providers has been associated with caregiver disenchantment with the healthcare system (Dolce, 2011). In a qualitative descriptive
study with 488 online cancer survivors and caregivers Dolce found that respondents’ information needs were not adequately met through clinical encounters with healthcare providers. Disenchantment with the information provided by healthcare providers propelled respondents to seek information from other sources, including the internet, to influence and actively participate in making healthcare decisions. The study was limited by the self-selection of participants, and to individuals with skills to access and navigate online surveys. Education has also been shown to be a significant factor where caregivers with higher levels of education (attended university compared to not having attended university) have been shown to be more than twice as likely to report high internet use and likelihood of having information needs met through the internet (Paul, Clinton-McHarg, Lynagh, Sanson-Fisher, & Tzelepis, 2012).

While some caregivers have the skills to actively ask questions of healthcare providers, or seek information from other sources outside of clinical encounters, other caregivers may lack the knowledge, capacity, self-efficacy, motivation and resources to effectively obtain information they need to make health-related decisions to assist individuals manage their treatment and impact of the illness on their day-to-day lives (Bevan & Pecchioni, 2008). Health literacy, its definition and conceptualisation, its importance in healthcare, and relevance to caregivers and care recipient health outcomes will be discussed in the following sections.

Understanding Health Literacy

What is health literacy?

Definitions of the term ‘health literacy’ have evolved substantially since its first appearance in the education field in 1974 (Simonds, 1974). Initial conceptualisations focussed on an individual’s ability to read and comprehend words and numbers in medical contexts and health-related materials (Tones, 2002). From the mid-1990s, public health proponents,
predominantly from the United States, broadened conceptualisations of health literacy to include psychological, social and environmental factors that influence an individual’s capacity to manage their health (World Health Organisation, 1998). The construct has further expanded to include complex and interconnected capacities, including decision making, problem solving, critical thinking, communication and interaction, in addition to having a range of social, personal and cognitive skills considered essential for navigating the healthcare system (Buchbinder, Batterham, Ciciriello, et al., 2011; Dodson et al., 2014; Mancuso, 2009; Peerson & Saunders, 2009; Sorensen et al., 2012). Culture, context and language have also been identified to play a role in health literacy (Nielsen-Bohlman, Panzer, & Kindig, 2004; Zarcadoolas, Pleasant, & Greer, 2005).

Although studies have shown associations between general literacy and health outcomes and behaviours (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Weiss, Hart, McGee, & D'estelle, 1992), health literacy is considered to encompass broader capacities such as social, communicative and critical skills, and is viewed as the interaction between individual capacities, and health, social and broader environmental contexts (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005). General literacy has been defined as the ability to “use printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). An individual may have adequate general literacy; however, still have difficulty understanding information and concepts within a health setting. Although general literacy and health literacy measure different attributes, they also share links to one another: people with low general literacy typically also have low health literacy (Weiss et al., 2005).

The most frequently cited definitions of health literacy include those developed by the
World Health Organisation (WHO; 1998), American Medical Association (AMA; 1999), and the Institute of Medicine (IOM; Nielsen-Bohlman et al., 2004), as outlined in Table 1.1. Sorensen and colleagues (2012) in a comprehensive systematic review identified 17 explicit definitions of health literacy. Content analysis identified six broad areas captured across health literacy definitions: 1) competence, skills, abilities; 2) actions; 3) information and resources; 4) objective, 5) context; and 6) time. Sorensen and colleagues (2012) combined existing definitions to create an ‘all inclusive’ definition of health literacy (see Table 1.1). More recently, Dodson and colleagues (2014) sought to capture health literacy as a constellation of attributes needed by individuals and communities to make effective health-related decisions for themselves, their families and their community (see Table 1.1).

Notably, a common theme across definitions of health literacy is the focus on an individual’s set of skills to find, understand and use health information and services necessary to make appropriate health decisions (Sorensen et al., 2012). However, it is evident that definitions have evolved over the years, from a narrow focus on individual literacy skills (e.g., AMA), to broader definitions that capture health literacy as a complex interaction between individual capacities, health system demands, and societal and community factors (see Table 1.1). A summary of the range of capacities identified in the aforementioned health literacy definitions is provided in Table 1.2. The health literacy capacities used to assess the included definitions are based on the expanded version of Sorensen’s taxonomy of skills (Haun et al., 2014; Sorensen et al., 2012). In this thesis, the researcher draws on the definition of health literacy developed by Dodson et al. (2014), as it captures health literacy as the interaction between individual skills and social resources to engage with information and broader services to make health-related decisions.

Chapter 2. Literature review
Table 1.1

<table>
<thead>
<tr>
<th>Author</th>
<th>Definition of health literacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>World Health Organisation (1998)</td>
<td>“Health literacy is the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health” (p.357).</td>
</tr>
<tr>
<td>American Medical Association (1999)</td>
<td>“Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment. Patients with adequate health literacy can read, understand and act on healthcare information” (p. 553).</td>
</tr>
<tr>
<td>Healthy People 2010 (2000)¹</td>
<td>“Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (p.11-20).</td>
</tr>
<tr>
<td>Sorensen et al. (2012)</td>
<td>“Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (p.3).</td>
</tr>
<tr>
<td>Dodson et al. (2014)</td>
<td>“Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health, or that have implications for health. Health literacy includes the capacity to communicate, assert and enact these decisions” (p.1).</td>
</tr>
</tbody>
</table>

¹ Adopted in the Institute of Medicine’s 2004 report on health literacy (Nielsen-Bohlman et al., 2004)

**Conceptualisations of health literacy**

A number of conceptual models have been developed to operationalise and identify constituent elements related to health literacy (McCormack, Haun, Sørensen, & Valerio, 2013). In a comprehensive systematic review, Sorensen and colleagues (2012) identified 12 existing
conceptual models of health literacy, the majority of which identified individual, and broader systemic factors that influenced the levels of an individual’s health literacy. Dimensions of health literacy have varied considerably depending on whether the model was focused on: individual capacities, or, an interaction between individual and broader societal and systemic factors. In the following sections, examples of different models within the two categories are discussed.

Table 1.2
*Summary of capacities included in the shortlisted definitions of health literacy*¹

<table>
<thead>
<tr>
<th></th>
<th>AMA</th>
<th>WHO</th>
<th>IOM</th>
<th>Sorensen</th>
<th>Dodson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Interaction</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Comprehension</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Numeracy</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information seeking</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Application/Function</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Decision-making/critical thinking</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Evaluation</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Responsibility</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Confidence</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Navigation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

¹ A more comprehensive list of existing health literacy definitions is available in Sorensen and colleagues’ (2012) publication.

**Health literacy as an individual capacity**

Some researchers have developed models that conceptualise health literacy by identifying

Chapter 2. Literature review
dimensions related to an individual’s capacity to function in the role of a patient within the healthcare system (Sorensen et al., 2012). For example, in Nutbeam’s (2000) model, three typologies of health literacy are described: 1) Functional health literacy which refers to the basic skills in reading and writing to be able to function effectively in everyday situations; 2) Interactive health literacy which refers to advanced cognitive and literacy skills which, when combined with social skills, can be used to actively participate in everyday situations to extract information and derive meaning from different forms of communication; and 3) Critical health literacy which refers to advanced cognitive skills, which together with social skills can be applied to critically analyse information and use the information to exert greater control over life events and situations. The three typologies in Nutbeam’s model represent increasing levels of knowledge and skills that progressively support increased autonomy and personal empowerment in health-related decision making that benefits individuals, communities and broader populations.

Zarcadoolas and colleagues (2005) also focused on individual capacities, and described four different types of literacy in their model: fundamental literacy (skills and strategies used in reading, speaking, writing and numeracy), science literacy (levels of competence with science and technology), civic literacy (abilities that enable citizens to become aware of public issues and become involved in the decision-making process), and cultural literacy (ability to recognise and use collective beliefs, customs, world-view and social identity to interpret and act on information).

Mancuso’s (2009) model also focused on individual capacities and described three key attributes related to health literacy that evolve over a person’s lifetime: Capacity (related to seeking and critically appraising health information, communication skills, social skills,
developing a sense of self, creating and pursuing a vision and goals, and keeping pace with change); *Comprehension* (described as a complex process based on the effective interaction of logic, language, and experience and is crucial to the accurate interpretation of a myriad of health information), and *Communication* (how thoughts, messages or information are exchanged and includes speech, signals, writing or behaviour).

*Health literacy as an interaction between individual, and broader societal and systemic factors*

In contrast to models that viewed health literacy as an individual capacity, other conceptualisations of health literacy have included dimensions that extend beyond individual capacities to include broader social and systemic factors that interact to influence health literacy. For example, in the conceptual model developed by the Institute of Medicine (IOM; Nielsen-Bohlman et al., 2004), health literacy was identified as a shared function of cultural, social and individual factors. In the IOM’s conceptual model, health literacy was mediated by a range of factors, including individual factors (such as education, culture and language), the communication and assessment skills of healthcare providers, and the capacity of the media, marketplace and government agencies to provide health information in effective ways for the audience. The IOM model also identified three major areas that may serve as potential intervention points for health literacy: culture and society, the health system, and the education system (Nielsen-Bohlman et al., 2004). In the IOM model, health literacy was viewed as the product of an individual’s interaction within educational systems, health systems, and cultural and social factors, with these factors ultimately contributing to health outcomes and costs. Four domains of individual health literacy skills were also identified: 1) cultural and conceptual knowledge; 2) oral literacy; 3) print literacy; and 4) numeracy.

Chapter 2. Literature review
Baker’s (2006) conceptual model sought to supplement the IOM model to assist with identifying more specific and precise dimensions for inclusion in measures of health literacy, and to identify potential relationships between health literacy and health outcomes. In Baker’s model, health literacy was comprised of two dimensions: health-related print literacy (the ability to understand written information) and health-related oral literacy (the ability to orally communicate about health). It was hypothesised that these health literacy capacities were influenced by individual capacities such as reading fluency and prior knowledge as well as broader systemic factors (such as the complexity and difficulty of spoken and printed messages). In the model, health literacy capacities were considered to contribute to new knowledge, positive attitudes, greater self-efficacy, positive behaviours, and improved health outcomes.

Sorensen and colleagues (2012) developed an integrated model of health literacy based on their review of the literature that sought to capture the progression from the individual to population factors that influenced health literacy. Four individual competencies were identified: 1) access (ability to seek, find, and obtain health information); 2) understand (ability to comprehend health information that is accessed); 3) appraise (ability to interpret, filter, judge and evaluate health information); and 4) apply (ability to communicate and use the information to make a decision to maintain and improve health). Three broader population health domains were also identified that interacted with individual capacities to influence health literacy: healthcare, disease prevention, and health promotion. A range of societal and environmental determinants, personal determinants, and situational determinants were also identified as distal and proximal factors that influenced health literacy. In Sorensen’s model, methods to address low health literacy included educating individuals to become more resourceful (e.g. individual health literacy), and to make the task or situation less demanding (e.g., improving “readability of the
More recently, Harrington and Valerio (2013) developed a conceptual model of ‘verbal exchange health literacy’ that sought to extend existing models of health literacy by capturing factors that influence information exchange during patient-provider interactions. A multi-method approach was used to generate the model. This comprised of a systematic review of the relevant literature followed by the collection of data from consultations with patients and healthcare providers. Verbal exchange health literacy included two key skills: the capacity to speak (oral) and the capacity to listen (aural). These skills were hypothesized to facilitate understanding, interpreting and exchanging of health information to adequately make health decisions, engaging in self-management, and navigating the healthcare system (Harrington & Valerio, 2013). In their model, individual and healthcare provider characteristics, patient-provider relationship characteristics, as well as healthcare system characteristics were identified as factors that influence verbal exchange. In addition, verbal exchange health literacy was considered fluid, and influenced by each exchange with healthcare providers and the healthcare system.

In brief, conceptualisations of health literacy have evolved to capture both individual and broader factors that interact to influence an individual’s health literacy. Core individual competencies included: the capacity to seek, understand, appraise and apply health information. Additional individual capacities identified across models include communication, decision-making, problem-solving, critical thinking, and social skills that are necessary to promote optimal health outcomes. Broader capacities related to health literacy have included educational, cultural, environmental, and healthcare provider and healthcare system factors.

**Health literacy from the perspective of key stakeholders**

Although conceptualisations of health literacy have evolved significantly to capture

Chapter 2. Literature review
broader dimensions that influence an individual’s capacity to find, understand and appraise health information, they are limited by their development through review of existing health and literacy related literature, with minimal involvement from key stakeholders. Recently, researchers have sought to conceptualise health literacy through qualitative research with relevant population groups. For example, Jordan, Buchbinder and Osborne (2010) combined results from one-on-one interviews and structured focus groups with individuals from three groups: those with a chronic condition, the general community, and individuals who presented to a metropolitan hospital emergency department in Australia. Seven key capacities were captured in the conceptual model of health literacy: 1) knowing when to seek health information; 2) knowing where to seek health information, 3) verbal communication skills; 4) assertiveness; 5) literacy skills; 6) capacity to process and retain information, and 7) application skills. The individual capacities were considered in the context of broader healthcare system factors.

Edwards, Wood, Davies and Edwards (2012) also used qualitative approaches to develop the ‘health literacy pathway model’ that sought to capture the development of health literacy over time for individuals with a range of health literacy capacities. A longitudinal qualitative approach was used, with 18 participants interviewed at three time points over nine months to explore development of health literacy and changes in attitudes, knowledge and experiences over time. Health literacy in the Pathway Model was described as a fluid process that develops along a trajectory that includes five increasingly complex capacities: 1) development of knowledge; 2) health literacy skills and practices; 3) health literacy actions; 4) abilities in seeking options, and; 5) informed and shared decision making opportunities. These capacities facilitated an individual’s increased knowledge and understanding of how to manage conditions. Higher order capacities (health literacy actions, abilities in seeking options, and information and shared
decision making) were proposed to enable an individual’s active participation in health consultations. Edwards, Wood, Davies, and Edwards (2012) proposed that health literacy is both a process and an outcome that develops over time, through content and context specific health-related experiences.

Edwards, Wood, Davies, and Edwards (2013) in a follow-up study examined the role of social networks in the process of becoming health literate. They described the ‘distributed’ nature of health literacy in which individuals drew on the health literacy skills of their family members and those in their social networks to find, understand, appraise and use health information. Edwards and colleagues hypothesised that social networks mediate the development and practice of health literacy by supporting individuals to become more health literate by sharing knowledge, facilitating learning how to self-manage, and supporting health-related decision-making.

Although these recent conceptualizations of health literacy from the patient perspective (Edwards et al., 2012; Jordan, Buchbinder, et al., 2010) have provided useful insights into the concept of health literacy, these models are focused on the perspective of the individual as the primary recipient of health care. Current models provide limited insights into the health literacy needs of caregivers. There exists a gap in the literature pertaining to understanding and conceptualising the health literacy needs of caregivers of adult care recipients.

**Importance and relevance of health literacy**

Health literacy is considered to be one of the pertinent causes of health inequalities and sources of extensive patient disempowerment, particularly with respect to equity and access to the health care system (Nielsen-Bohlman, et al., 2004). Although evidence on the economic impacts of health literacy is scarce, at the health system level, costs associated with inadequate
literacy have been estimated at an additional 3% to 5% per year (Eichler, Wieser, & Brügger, 2009). At the patient level, additional expenditure (on outpatient care, medication and so forth) per year for those with limited health literacy compared to those with adequate health literacy has been estimated at $143 to $7,798 per year.

Inadequate health literacy has been associated with a range of poor health behaviours and outcomes. In the following sections, widely used measures of health literacy are presented, social determinants of health literacy are outlined, and key associations between inadequate health literacy and various health behaviours and outcomes are described.

Measurement of health literacy

A central issue in widely used measures of health literacy is their focus on literacy capacities such as reading, comprehension and numeracy skills within a health context, rather than an individual’s broader capacity to ‘find’, ‘understand’, ‘use’ and ‘appraise’ health information (Jordan et al., 2013; Jordan, Osborne, & Buchbinder, 2010; Mancuso, 2009). An individual’s capacity to read, or pronounce medical words is not necessarily reflective of their capacity to understand health information in order to problem solve, communicate, or make decisions about their health. Commonly used measures are further limited by their exclusion of broader factors associated with health literacy, such as communication, problem-solving, critical thinking and acting on health information.

The current state of knowledge on health literacy is predominantly based on scores from two measures: the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1991) and the Test of Functional Health Literacy in Adults (TOFHLA; Parker, Baker, Williams, & Nurss, 1995). The REALM was developed in the USA as a screening tool to assist healthcare providers identify patients with limited reading skills in the healthcare setting (Davis et al., 1991; Chapter 2. Literature review
Davis et al., 1993). The tool is comprised of a list of medical words that are ordered by difficulty and number of syllables, beginning with the least difficult one-syllable words. The TOFHLA was developed to measure ‘functional health literacy’, defined as reading comprehension of health-related materials and numeracy skills (Parker et al., 1995). A literacy expert from the USA derived items for the TOFHLA by reviewing commonly used hospital texts. Derivatives of both the REALM and TOFHLA have been developed and widely used.

In a critical appraisal of the development and content of generic (i.e., not discipline or population specific) health literacy measures, Jordan and colleagues (2010) identified 12 original instruments and seven modified instruments. These authors identified three main approaches used in health literacy measurement: 1) direct testing of individual abilities; 2) self-report of abilities; and; 3) proxy measures of health literacy in the population. Numerous limitations to available health literacy measures were highlighted in the review including: being focussed primarily on literacy indicators such as reading, comprehension, and numeracy skills; substantial variation in the underlying constructs across all measures; few measures derived from a conceptual framework; and poorly defined scoring categories. Notably, only five of the 19 measures had been tested for reliability (Rapid Estimate of Adult Literacy in Medicine [REALM], Rapid Estimate of Adult Literacy in Medicine – Shortened [REALM-S], Rapid Estimate of Adult Literacy in Medicine- Teenagers [REALM-Teen], The Short Assessment of Health Literacy for Spanish Adults [SAHLSA], and eHealth Literacy Scale [eHEALS]; Jordan et al.).

Haun and colleagues (2014) found similar limitations in their recent review that sought to provide an inventory and descriptive summary of published health literacy measures. By contrast to Jordan and colleagues’ (2010) study, both generic and population-specific measures were
include in the review. Specific skills and competencies assessed by the tools were examined using Sorensen and colleagues (2012) taxonomy of health literacy skills, which included 11 dimensions: literacy, interaction, comprehension, numeracy, information seeking, application/function, decision-making/critical thinking, evaluation, responsibility, confidence, and navigation (Sorensen et al., 2012). Fifty-one original measures of health literacy were included in the inventory, of which 26 measured generic health literacy, 15 were disease or content-specific, and 10 were designed for specific populations. Haun and colleagues found that health literacy measures were limited by substantial variations in: dimensions of health literacy measured (between 0 - 9 out of 11 skills identified in the taxonomy), their design (screening items to performance-based assessments), operationalisation of health literacy as a measurable construct, mode of administration (e.g. self-report, timed performance tests, and electronic data collection), and psychometric rigour to determine validity.

It has been argued that using measures of health literacy that assess different underlying constructs and limited subsets of health literacy dimensions hinders the capacity for researchers to accurately interpret and compare health literacy at individual and population levels across studies (Jordan, Osborne, et al., 2010). Limitations in health literacy assessment have been attributed to a general problem in questionnaire development, whereby existing measures are often based on theory, or historically convenient indicators and measures (Buchbinder, Batterham, Elsworth, et al., 2011). Buchbinder and colleagues have argued that measures developed using this process may lead to an under- or over-representation of the construct to be measured and pose a substantial threat to the validity of a measure. Measures that inadequately cover the breadth of the construct have the potential to result in oversights in identifying and addressing key components that may affect individual outcomes, and this can result in gaps in
program design or policy development. Thus, to adequately address health disparities associated with inadequate health literacy, researchers have called for the development of comprehensive validated measures for broad populations that capture the full range of dimensions highlighted in conceptualisations of health literacy (Haun et al., 2014; Jordan, Osborne, et al., 2010).

**Social determinants of health literacy**

While studies have found predominantly positive associations between health literacy and educational attainment and race, mixed results have been reported for associations between health literacy and age. Individuals with lower educational attainment have been shown to be at greatest risk of low health literacy across general populations (Adams et al., 2009; Carthery-Goulart et al., 2009; Kutner, Greenberg, Jin, & Paulsen, 2006) and amongst chronic disease populations (Bauer et al., 2013; Chen et al., 2014; Morrow et al., 2006). However, educational attainment is not considered a reliable indicator of health literacy status given its potential to misclassify a substantial proportion of individuals on adequacy of health literacy (Cho, Lee, Arozullah, & Crittenden, 2008; Lindau et al., 2002; Williams, Baker, Honig, Lee, & Nowlan, 1998). For example, in a study of 483 individuals who presented at an emergency department or asthma clinic for asthma-related healthcare, only 27% had adequate health literacy as assessed using the REALM (≥ 9th grade reading level) despite two-thirds of the sample reporting at least a high school education (Williams, Baker, Honig, et al., 1998). More recently, in a large cross-sectional, random population survey (n = 2824), Adams, Appleton and colleagues (2009) also found that educational levels could not reliably identify health literacy status as up to 20% of individuals with a university degree were identified as at risk of low health literacy, as assessed using the NVS.

Individuals from a minority race are also at risk of low health literacy (Morrow et al., 2006).
in particular those with limited English proficiency (Sentell & Braun, 2012). In a large population-based study of individuals with and without limited English proficiency \((n = 48,427)\) in California, Sentell and Braun found that 44.9% of those with limited English proficiency had low health literacy compared to 13.8% of those with adequate English proficiency. Among those with adequate English proficiency, Latinos had the highest rates of low health literacy (17.9%), followed by Chinese (17.8%), Korean, and other race/ethnicity (both 15.1%), Caucasians (12.0%), and Vietnamese (8.1%) (Sentell & Braun, 2012). Although Sentell and Braun’s study provides useful insights into racial disparities, health literacy was assessed using two questions that assessed reading comprehension rather than broader concepts of health literacy (“When you get written information at a doctor’s office, would you say that it is very easy, somewhat easy, somewhat difficult, or very difficult to understand?”, and “When you read the instructions on a prescription bottle, would you say that it is very easy, somewhat easy, somewhat difficult, or very difficult to understand?”). Thus, the prevalence of low health literacy across racial groups, and amongst those with limited English proficiency must be interpreted with caution.

Mixed findings have been found regarding the association between older age and inadequate health literacy. Although the prevalence of inadequate health literacy was found to increase with advancing age (Gazmararian et al., 1999; Lee, Kang, Kim, & Son, 2013; Morrow et al., 2006; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Shieh, Mays, McDaniel, & Yu, 2009; Wolf et al., 2012; Zamora & Clingerman, 2011), attempts to understand the mechanisms underlying the relationship between age and health literacy have found that this association was explained by cognitive functioning. For example, a recent study by Kaphingst, Goodman, MacMillan, Carpenter, and Griffey (2014) who excluded older adults...
with cognitive dysfunction when examining the relationship between age and health literacy, found that health literacy did not differ between older adults without cognitive dysfunction (60 years and older) and younger participants. They interpreted the findings as evidence that the relationship between age and health literacy was attributed in part to cognitive dysfunction in a subset of adults, rather than age-related changes in cognitive capacities; and recommended the need for health information delivered in ways appropriate for the cognitive capacity and health literacy levels for older adults.

**Health outcomes and behaviours associated with inadequate health literacy**

Studies predominantly from the United States have demonstrated associations between inadequate health literacy and a range of health behaviours and outcomes (Berkman et al., 2011; Herndon, Chaney, & Carden, 2011; Paasche-Orlow et al., 2005). The following section provides an overview of key findings that detail the consequences of low health literacy and why health literacy has emerged as an important area for improving individual and population health. Health literacy and its associations with the following health behaviours and outcomes will be discussed: 1) health-related knowledge; 2) use of health care services; 3) self-reported health status; 4) participation in screening programs; 5) adherence to treatment medication; 6) patient-healthcare provider communication; 7) self-management of chronic conditions; and 8) increased risk of mortality.

**Health literacy and health-related knowledge**

Positive associations have been found between health literacy and health-related knowledge on chronic conditions, preventative cancer screening, and tobacco use (Arnold et al., 2001; Stewart et al., 2013). In an early study, Williams, Baker, Parker and Nurss (1998) reported positive associations between health literacy and knowledge of hypertension and diabetes. They found...
that individuals with hypertension and adequate health literacy (as measured by the TOFHLA) were significantly more likely to identify a high blood pressure reading compared to individuals with inadequate health literacy (92% vs. 55%; P < .001). Participant knowledge of hypertension or diabetes was measured by items developed by the authors. Knowledge of hypertension was assessed using 21 items that sought information on normal and high blood pressure readings, duration of disease, lifestyle modifications, symptoms, and complications. Knowledge of diabetes was assessed using 10 items that sought information on normal blood glucose levels, symptoms, medications, lifestyle modifications, and complications. In the same study, individuals with diabetes and adequate health literacy were more likely to identify symptoms of hypoglycaemia (high blood glucose levels) compared to individuals with inadequate health literacy (94% vs. 50%; P <.001). Similar associations between health literacy and an individual’s knowledge about their own chronic condition have been reported in older adults (Gazmararian, Williams, Peel, & Baker, 2003), and patients with asthma (Williams, Baker, Honig, et al., 1998), diabetes (McCleary-Jones, 2011), and HIV/AIDS (Kalichman & Rompa, 2000; Wolf et al., 2004).

**Health literacy and use of healthcare services**

The association between health literacy and use of healthcare services has been explored via emergency department presentations, hospital admissions, or use of outpatient services. However, findings have been mixed. For example, in an early study, Baker and colleagues (Baker, Parker, Williams, & Clark, 1998; Baker, Parker, Williams, Clark, & Nurss, 1997) examined associations between health literacy and hospitalisation and emergency department admissions in Atlanta, and Los Angeles. Individuals with inadequate health literacy were more likely to be hospitalised or admitted to an emergency department in the past year compared to
individuals with adequate health literacy. Similar associations have been found between low health literacy and increased hospitalisation and emergency department visits in elderly patients (hospitalisation \( \beta = -0.24 \); emergency department visits \( \beta = -0.35 \); Cho et al., 2008), chronic obstructive pulmonary disease patients (hospitalisations \( \text{OR} = 6.6; 95\% \text{ CI} 1.3–33 \), emergency department visits \( \text{OR} = 4.7; 95\% \text{ CI} 1.5–15 \); Omachi, Sarkar, Yelin, Blanc, & Katz, 2013), and among maintenance haemodialysis patients (emergency department visits \( \text{adjusted IRR}, 1.37; 95\% \text{ CI}, 1.01-1.86 \), disease-related hospitalisations \( \text{adjusted IRR}, 1.55; 95\% \text{ CI}, 1.03-2.34 \); Green et al., 2013).

Low health literacy has also been significantly associated with hospital or emergency department readmissions. Mitchell et al. (2012) examined associations between health literacy and 30-day post-discharge hospital use (i.e., readmission or emergency department presentation) among people admitted to a general medical unit in an urban hospital in the United States. Individuals with low health literacy (defined as \( \leq 6\text{th grade reading level, or REALM score of 0–18} \) were 1.46 times (95% CI 1.04, 2.05) more likely than those with adequate health literacy to be readmitted to hospital or the emergency department within 30 days. These results were found even after controlling for potentially confounding variables, such as education, gender, race, and income. Similar results were found in a study by Griffey, Kennedy, McGownan, Goodman, and Kaphingst (2014), who examined associations between health literacy and emergency department use in an urban, academic hospital in the USA. Individuals with inadequate health literacy (defined as \(< 45\% \text{ correct responses as measured by the S-TOFHLA} \) were 1.64 times more likely to visit the emergency department than those with adequate health literacy.

By contrast, other studies have found no associations between health literacy and healthcare use in elderly (Cho et al., 2008), inpatient (Arozullah et al., 2006), asthma patient
Chapter 2. Literature review

(Apter et al., 2006), and general (Lee, Tsai, Tsai, & Kuo, 2010) populations. In a national study of 1,493 adults in Taiwan, Lee and colleagues (2010) found no associations between low health literacy (assessed using the Mandarin Health Literacy Scale; Tsai, Lee, Tsai, & Kuo, 2010) and increased health service use in the general population. It has been hypothesised that sociodemographic factors such as age, educational attainment, and household income could explain associations between health literacy and health service use, which were inadequately considered in existing literature (Lee et al., 2010).

Health literacy and self-reported health status

Studies predominantly from the USA have shown a link between health literacy and self-reported health status. These studies have largely explored associations between health literacy and health status among older individuals in the USA, although studies of individuals with HIV and chronic obstructive pulmonary disease (COPD) have been explored. Gazmararian and colleagues (1999) in a large study ($n = 3260$) of individuals aged 65 years and older from a managed care organisation found that those with inadequate health literacy (as measured by the S-TOFHLA) compared to those with adequate health literacy were twice as likely to rate their health poorly. Consistent with these findings, positive associations between health literacy and self-reported health status have also been found in other studies of older adults (Cho et al., 2008; Serper et al., 2014; Wolf, Gazmararian, & Baker, 2005).

Positive associations among individuals with chronic diseases have also been shown (Caplan, Wolfe, Michaud, Quinzanos, & Hirsh, 2014; Kalichman & Rompa, 2000; Omachi et al., 2013). Kalichman and Rompa in a community-based study of individuals living with HIV/AIDS in the USA examined perceptions of health using a single item with five-response options (excellent-very poor). Individuals with lower health literacy (defined as < 80% correct responses...
as measured by the TOFHLA) were almost twice as likely to perceive their health as ‘poor’ compared to those with adequate health literacy. In a national cross-sectional study of individuals with chronic obstructive pulmonary disease (COPD) in the USA, Omachi and colleagues found that health literacy was significantly associated with self-reports of greater COPD severity. In this study, health literacy was assessed using three screening items with scores divided into tertiles for analysis. Self-reported COPD severity was measured using the COPD Severity Score (Eisner et al., 2005). Adjusted multivariate analysis showed that having low health literacy was associated with greater COPD severity scores compared to having adequate health literacy (Omachi et al., 2013). Caplan and colleagues in a study of 6,052 people with rheumatoid arthritis in the USA, also found that health literacy was associated with functional health status, as assessed using the Health Assessment Questionnaire (Fries, Spitz, Kraines, & Holman, 1980). Health literacy in Caplan and colleagues’ study was measured using two single-item screening questions.

**Health literacy and participation in screening programs**

Participation, knowledge, and attitudes towards public health screening programs have been used as factors to assist understanding of associations between health literacy and disease prevention behaviours in cancer screening programs (Kobayashi, Wardle, & von Wagner, 2014; Oldach & Katz, 2014) and screening programs for HIV (Barragan et al., 2005) with mixed results.

A recent systematic review examined associations between health literacy and cancer screening (Oldach & Katz, 2014). Of the ten publications included in the review, which addressed screening for four cancer types: colorectal, breast, cervical, and prostate, seven studies reported a significant positive relationship, one reported a significant negative relationship, and Chapter 2. Literature review
six found no significant associations between health literacy and cancer screening rates. Oldach and Katz noted that evaluation of the studies was limited by methodological issues, such as variation in measures used to assess health literacy, use of self-report to determine screening rates, and variation in cancer screening test intervals and age recommendations for different screening tests. Notably, included studies in the review were limited to those that adhered to health guidelines specific to the USA, thus, limiting the generalisability of the findings to other countries. The mixed findings may be attributed to sociocultural factors, such as influence of social support, and for migrant individuals, acculturation to their adoptive culture, and influence and trust of healthcare providers (Shelton, Jandorf, Ellison, Villagra, & DuHamel, 2011). For example, Guerra, Dominguez and Shea (2005) examined the relationship between health literacy and colorectal cancer screening rates in 136 patients aged 50 years and over recruited from community clinics or primary care practices in the USA. In their study, 90% of patients reported they would likely undergo screening if their healthcare provider recommended it (amongst those who had not undergone screening), or responded that their healthcare provider had encouraged the screening process (among those who had been screened). Mechanisms by which sociocultural factors influence or mediate the associations between health literacy and screening behaviours need further investigation.

By contrast to studies that assessed cancer screening behaviours, Barragan and colleagues (2005) found that among 372 individuals who attended a public urgent care centre in the USA, those with low health literacy were twice as likely to accept a test for HIV, compared to those with adequate health literacy. These results were found after adjusting for confounding factors, such as age and education (Adjusted Odds Ratio [AOR] 2.0, 95%, 1.2-3.4). The results suggested that low health literacy was not a barrier for individuals in accepting HIV testing when

Chapter 2. Literature review
recommended by a healthcare provider. However, Barragan and colleagues noted that HIV tests are relatively non-invasive compared to screening tests for cancer, and thus, cannot be generalised to screening for other chronic health conditions. Notably, the majority of quantitative studies that examined associations between health literacy and screening behaviours were conducted in the USA, which limits the generalisability of findings to countries with different healthcare systems.

**Health literacy and adherence to treatment medication**

The majority of studies exploring associations between health literacy and adherence to treatment medications have focussed on cardio-vascular conditions or HIV (Gazmararian et al., 2006; Kalichman, Pellowski, & Chen, 2013; Kalichman, Ramachandran, & Catz, 1999; Murray et al., 2009; Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Paasche-Orlow et al., 2006; Wolf et al., 2007). Recently, some studies have emerged that examine medication adherence within cancer populations (Rust, Davis, & Moore, 2015). However, mixed results have been found.

Studies among individuals with HIV/AIDS have reported a positive association between health literacy and medication adherence (Graham, Bennett, Holmes, & Gross, 2007; Kalichman et al., 2008; Kalichman et al., 1999; Osborn et al., 2007; Wolf et al., 2007). Among African-American cancer survivors, positive associations between health literacy and medication adherence were also found (Rust et al., 2015). However, studies using other population samples, such as individuals with cardiovascular conditions (Gazmararian et al., 2006) and those receiving anticoagulation medication (Fang, Machtinger, Wang, & Schillinger, 2006) have found no associations between health literacy and medication adherence.

Zhang and colleagues (2014) recently conducted a meta-analysis on studies that examined the direct relationship between health literacy and medication adherence. The thirty-
five studies included in the review covered six disease categories: HIV/AIDS \((n = 10)\), cardiovascular diseases \((n = 8)\), diabetes \((n = 5)\), glaucoma \((n = 3)\), mental illness \((n = 1)\), and asthma/respiratory illness \((n = 1)\). Two included studies covered two disease categories (cardiovascular and diabetes). Individuals with no specified conditions were included in eight general studies. All except one study were conducted in the USA. Zhang and colleagues reported a small statistically significant, but weak, positive association between health literacy and medication adherence (conservative estimates of unweighted and weighted correlation coefficients were 0.081 and 0.056, respectively, with \(P\) values <0.001).

The studies that examine associations between health literacy and medications are limited by their assessment of health literacy using the TOFHLA, REALM or their derivatives that assess an individual’s capacity to read and write in a health context. Other health literacy capacities that may influence medication adherence, such as critical thinking and communication skills were not assessed. As such, it can only be inferred from these studies that medication adherence may not depend on an individual’s reading, comprehension and/or numeracy skills.

**Health literacy and patient-healthcare provider communication**

Studies have demonstrated positive associations between health literacy and patient-healthcare provider communication (Jensen, King, Guntzviller, & Davis, 2010; Katz, Jacobson, Veledar, & Kripalani, 2007; Nouri & Rudd, 2015; Schillinger et al., 2003). In an early cross-sectional study, Schillinger and colleagues examined the relationship between functional health literacy and quality of patient-provider communication among 408 English and Spanish-speaking individuals with diabetes in San Francisco, USA. People with inadequate health literacy (as measured by the S-TOFHLA), compared to those with adequate health literacy, were 6 times more likely to report worse communication with healthcare providers in the domains of general

Chapter 2. Literature review
clarity (AOR 6.29, p <.01, 95% 1.71-23.07), however the confidence intervals were large. In addition, individuals with inadequate health literacy were twice as likely to report worse communication regarding explanation of processes of care (AOR 2.70, 95% CI, 1.1-6.66), and close to 5 times as likely to report worse communication regarding an explanation of a condition (AOR 4.85, 95% CI 1.2-19.58) compared to those with adequate health literacy.

In further support of these findings, studies have shown positive associations between inadequate health literacy and reduced question-asking during healthcare appointments. Katz and colleagues (2007) examined the relationship between health literacy and the number of questions asked during health appointments among 57 predominantly African-American individuals attending a primary care clinic in Atlanta, USA. Over one-third (38.6%) of participants had literacy skills below sixth grade level as assessed using the REALM. Individuals’ with low health literacy compared to those with high health literacy asked fewer questions about medical care issues (median number of questions: 4 vs. 6, p = .01). As the odds ratios were not reported in this study, it is difficult to determine the strength of the association. Individuals with inadequate health literacy also tended to ask fewer questions overall compared to participants with adequate health literacy (7 vs. 10; p = .07) although these findings were not significant. The small sample size limits the generalisability of these findings.

Roter, Erby, Larson, and Ellington (2009) examined the relationship between demands of communication with healthcare providers and patient outcomes related to learning genetics information. In their study, 96 simulated genetic counselling sessions were presented to 312 individuals recruited from community settings within two cities in the USA. Health literacy was assessed using a derivative of the REALM, the Rapid Estimate of Adult Literacy in Genetics. An interesting finding was that the impact of communication demands was dependent on an
individual’s level of health literacy. For individuals with low health literacy, even after controlling for ethnicity, increased interactivity ($\beta = 0.1, p < 0.05$) and fewer dense ($\beta = -0.35, p < 0.001$) and shorter counsellor speaking turns ($\beta = -0.34, p < 0.01$) were associated with increased learning. Information personalised to the individual was also positively associated with learning for those with low health literacy ($\beta = 0.17, p < 0.05$). However, for those low in health literacy, no significant associations were found between learning and use of medical jargon or language complexity. By contrast, individuals with adequate health literacy learned more with longer sentences ($\beta = 0.14, p < 0.05$), higher language complexity ($\beta = 0.15, p < 0.05$), and less interactivity ($\beta = 0.11, p < 0.05$). These findings suggested that individuals with low health literacy have difficulty understanding information when communication requires high cognitive demands, characterised by long, dense information sessions. Rather they benefit from communication that is interactive, and provides information that is personalised to their needs. However, these results must be interpreted with caution as the counselling sessions were simulated, and participants were role-playing as clients.

Together, results from studies regarding patient-healthcare provider communication suggest that inadequate health literacy is associated with reports of poor patient-provider communication, poor engagement with healthcare providers, and inadequate understanding of health information when communication has high cognitive demands.

Health literacy and self-management of chronic conditions

Improved self-management of chronic conditions has been suggested as a key outcome of optimal health literacy (Commonwealth of Australia, 2009). However, studies that have explored associations between health literacy and self-management skills have yielded mixed results. These studies have predominantly examined chronic disease self-management behaviours among
individuals with diabetes, with some attention given to chronic conditions such as asthma, HIV, and heart failure.

In a review of ten asthma-related studies conducted within the USA, Thai and George (2010) found positive associations between health literacy and asthma-self-management behaviours, such as accurate metered-dose inhaler technique, and less use of peak flow meters and asthma action plans. Similar results were found in Macabasco-O’Connell and colleagues (2011) cross-sectional study with 605 heart failure patients. They found those with adequate health literacy (as measured by the TOFHLA) had higher prevalence of self-care behaviours (such as monitoring weight, knowing the appropriate response to dealing with a weight increase, exercising, and reducing salt intake) compared to those with inadequate health literacy (mean 63.9 vs. 55.4, adjusted difference 7.20, p < .01).

By contrast, Fransen, von Wagner and Essink-Bot (2012) in a recent literature review found that the majority of included studies (8 of 11) found no significant associations between health literacy and self-management in diabetes patients. The studies included in Fransen and colleagues’ review were limited by their use of measures that assessed an individual’s reading and writing skills within a health context (i.e., functional health literacy), such as the REALM, TOFHLA, and their derivatives. Broader capacities related to health literacy (such as communication, critical appraisal, and making health decisions) and their association with self-management behaviours were not measured. However, recent studies have shown that broader health literacy capacities – such as the capacity to extract, compare, communicate and critically analyse information – rather than functional health literacy, are positively associated with self-management behaviours (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013).
Lai and colleagues (2013) in their study of 63 people with diabetes and end-stage renal disease in Japan found that communicative and critical - but not functional (i.e., reading and writing capacities) - health literacy skills were associated with an individual’s capacity to effectively engage in diabetes self-management behaviours. Communicative health literacy was defined as capacities related to extracting information and deriving meaning from various forms of communication, while critical health literacy was defined as the capacity to evaluate health information to make health decisions (Lai et al.). Health literacy in their study was measured using the Functional, Communicative and Critical Health Literacy (FCCHL) Scale (Ishikawa, Takeuchi, & Yano, 2008). No significant correlations were found between functional health literacy and diabetes self-management. However, significant, but weak positive correlations were found between communicative and critical health literacy and diabetes self-management ($r = 0.40, p = .001; r = 0.32, p = .01$). Similar results were found in a large cross-sectional study with 1341 people with a chronic disease in the Netherlands (Heijmans et al., 2015). Positive associations between communicative and critical health literacy and self-management behaviours were found. Communicative health literacy had positive relationships with all aspects of self-management, including coping with consequences ($\beta = .16 < .001$), playing an active role in treatment ($\beta = .18 < .001$), knowledge ($\beta = .26 < .001$), recognition and management of symptoms ($\beta = .22 < .001$), and confidence to act in medical consultations ($\beta = .18 < .001$). Critical health literacy had positive relationships with playing an active role in treatment ($\beta = .12 < .001$), knowledge ($\beta = .16 < .001$), and confidence to act in medical consultations ($\beta = .09 < .05$); however, no associations were found for coping with consequences or symptom monitoring.

The results from the above studies suggest that higher order health literacy skills such as
capacities to communicate and critically appraise health information - rather than reading, comprehension and numeracy - have stronger influences on self-management. Further examination of the impact of broader elements of health literacy on self-management behaviours or variables that mediate the relationship may provide useful insights into initiatives to address potential health disparities.

**Health literacy and increased risk of mortality**

Associations have been found between low health literacy and increased risk of mortality among elderly people (Baker, Wolf, Feinglass, & Thompson, 2008; Baker et al., 2007; Bostock & Steptoe, 2012), patients with end stage renal disease (Cavanaugh et al., 2010), and people with heart failure (McNaughton, Kripalani, Cawthon, & Roumie, 2014; Peterson et al., 2009). In a large prospective study of 2512 community dwelling elderly people from two states in the USA, Sudore and colleagues (2006) found that low health literacy (defined as < ninth grade reading level as assessed using the REALM) was independently associated with a 1.75-fold (95% CI: 1.27 - 2.41) increased risk of mortality. Similar findings were reported in Baker and colleagues’ (2007) study of 3260 Medicare managed-care enrollees from four metropolitan areas in the USA. In their study, low health literacy (score of ≤ 55 out of 100 on the S-TOFHLA) was associated with a 1.52-fold (95% confidence interval, 1.26-1.83) increase in mortality, compared to those with adequate health literacy, after adjusting for confounding variables, such as demographic, SES, and baseline health. Marginal health literacy (scores between 56-66 on the S-TOFHLA) was associated with a 1.13 increase in mortality. In a follow-up study, Baker and colleagues (2008) reported a hazard ratio of 1.27 (CI: 1.03 - 1.57) among Medicare enrollees with low health literacy (assessed using the S-TOFHLA) after adjusting for cognitive dysfunction. More recently Bostock and Steptoe (2012) examined associations between health literacy and mortality in a
large sample of 7857 adults aged 57 years or older in England. Health literacy was assessed using a 4-item test of functional health literacy. Low health literacy was associated with a 1.26 (1.02 - 1.55) increase in mortality compared to those with adequate health literacy, after adjusting for cognitive dysfunction.

The role of caregivers in self-management support for individuals with low health literacy

Emerging evidence suggests that for people with low health literacy, caregivers may play an important role in promoting positive health outcomes by supporting care recipients to access health information, communicate with health providers, process information, make care decisions and undertake self-management activities. Rosland and colleagues (2010) conducted a cross-sectional study of 439 patients with diabetes and heart failure to examine patient characteristics (including health literacy) and the role of caregiver support or interference in disease self-management. Low health literacy in patients was determined by a single screening item (“I have problems learning about medical conditions because of difficulty understanding written information”; Chew, Bradley, & Boyko, 2004), which has limited focus on an individual’s reading and comprehension skills, rather than broader concepts of health literacy (Jordan, Osborne, et al., 2010). Individuals with low health literacy were more likely to receive support from a caregiver to undertake self-management tasks including healthy eating, exercise, self-testing, medication, general information, and decision-making (Rosland et al., 2010). In a follow-up study that examined caregiver participation in clinical encounters, Rosland and colleagues (2011) reported that patients with lower health literacy were more likely to have a caregiver participate in clinical encounters. Further, the presence of caregivers in these encounters resulted in enhanced patient understanding of medical advice and capacity to discuss...
Individuals with low health literacy are also more likely to participate in self-management support programs with a caregiver. In an observational program implementation study, Aikens, Zivin, Trivedi, and Piette (2014) examined individual characteristics of 303 Veteran Affairs patients diagnosed with Type II diabetes as predictors of engagement in a diabetes self-management mobile health (mHealth) program. Patients who participated in the program with a caregiver, compared to those who participated without a caregiver, were more likely to have low health literacy and lower income (both p values = .007). Health literacy in patients was assessed using a single screening item (Chew et al., 2004).

However, health literacy of caregivers was not measured in the aforementioned studies (Aikens et al., 2014; Rosland et al., 2010; Rosland et al., 2011). Thus, it remains uncertain the extent to which caregiver health literacy mitigates the association between health outcomes and patient health literacy (Bevan & Pecchioni, 2008; Sparks & Nussbaum, 2008).

Recently, Levin, Peterson, Dolansky, and Boxer (2014) did report an association between low health literacy of caregivers and poorer care recipient self-management behaviours. In a small, cross-sectional study with 17 dyads comprised of older adults with heart failure and their caregivers, caregivers were more likely to have higher health literacy than patients. Health literacy was assessed using a 3-question measure, and the NVS. Low health literacy in caregivers was associated with poorer behaviours to maintain clinical stability in care recipients. Levin and colleagues argued that both individuals with a chronic disease and caregivers should be targeted in efforts to improve patient self-management. However, given the small sample size of their study, further studies to examine associations between caregiver health literacy and patient health outcomes are warranted. Further, caregiver health literacy in Levin and colleagues’ study Chapter 2. Literature review
was assessed using measures known for their limited capacity to capture broader elements related to health literacy.

**The need for measures of caregiver health literacy**

Given the critical role of caregivers in all aspects of patient care, it is important that more is understood about the way in which caregiver health literacy impacts their capacity to perform their role. Some caregivers may lack the knowledge, skills, self-efficacy, motivation and resources to effectively assist individuals to manage their treatment and the impact of the illness on their day-to-day lives (Bevan & Pecchioni, 2008). In current practice, caregivers report they are often left on their own to find information about how to optimise health outcomes for people with cancer (Given et al., 2012; Kidd et al., 2011; Koenig et al., 2011; Lambert et al., 2012; Marcusen, 2010; McCarthy, 2011; Washington et al., 2011). The extent of a caregiver’s capacity to find, understand, appraise and use health information and make decisions related to care provision has the potential to directly negatively affect care recipient health outcomes.

One key barrier to further research in the area of caregiver health literacy is the lack of validated and suitable measurement approaches (Haun et al., 2014). Caregiver health literacy has been examined within paediatric (Pizur-Barneckow, Darragh, & Johnston, 2011; Wittich, Mangan, Grad, Wang, & Gerald, 2007), Alzheimer’s/dementia (Bliss et al., 2013), elderly (Greenberg, Dave, Cagan, & Ehrlich, 2009; Lindquist, Jain, Tam, Martin, & Baker, 2010), and heart disease populations (Yehle, Chen, Plake, & Albert, 2011). However, these studies used general health literacy measures designed to assess reading, comprehension, and numeracy skills, rather than broader underlying concepts related to health literacy. Although measurement tools have recently emerged that capture the multidimensional nature of health literacy (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013; Sorensen et al., 2013), these tools are...
grounded in the perspectives of the potential care recipient, and thus have limited use in assessing caregiver health literacy needs.

To the author’s knowledge, there currently exists only one measure to assess the health literacy of caregivers. The Parent Health Literacy Activities Test (PHLAT; Kumar et al., 2010) is a 20-item self-administered questionnaire designed to assess health literacy and numeracy skills of parents of infants under one year of age. Given the paediatric context of the PHLAT and its Spanish derivative (PHLAT-Spanish; Yin et al., 2011) the domains covered are of little relevance to the role of caregiving for an adult recipient, and thus have limited utility in such populations.

Further, although measures of cancer literacy are emerging, these instruments are designed specifically to assess health literacy of individuals diagnosed with cancer (Williams, Templin, & Hines, 2013), or breast cancer related knowledge (Dumenci et al., 2014). The unique challenges faced by caregivers when assisting with complex decision-making and provision of care may not be captured in such measures.

**Significance of the Thesis**

A comprehensive understanding and measurement of how caregiver health literacy impacts care recipient and caregiver health outcomes has been a neglected area in public health and health promotion. Thus, to reliably assess the uptake and impact of effective health interventions on caregiver skills and care recipient health outcomes, it is first necessary to develop a measure of caregiver health literacy. Similar to health literacy measures for people with chronic conditions, the new measure may have potential application to serve a range of purposes including needs identification, service planning, evaluation, research, and in the long term, for individual clinical assessment, planning and monitoring (Buchbinder, Batterham, Chapter 2. Literature review
Ciciriello, et al., 2011).

**Rationale and Purpose of the Study**

The research presented in this chapter has identified cancer as a significant public health issue, and one of the leading causes of death and a major contributor to the burden of disease and injury in Australia. Medical advances and shifts in treatment patterns over the past twenty years from inpatient to outpatient settings have resulted in individuals being required to manage increasingly complex disease and treatment tasks in the home care setting. Caregivers play an integral role in the self-management and information support for people with cancer. However, caregivers have reported significant information needs related to the disease, treatment options, prognosis, how to navigate the healthcare system, and how to manage psychosocial care.

Despite identification of health literacy as a key health promotion priority given its associations with individual health behaviours and health outcomes, few studies have examined health literacy of caregivers of adult care recipients. It is unclear the extent to which caregiver health literacy impacts upon care recipient health outcomes. One potential reason for the dearth of research on caregiver health literacy is the lack of empirically-based health literacy measurement tools that researchers can use to enhance our understanding of health literacy levels of caregivers.

To address the gap in the literature, the aim of this thesis was to develop, and assess the psychometric properties of a new measure of health literacy of caregivers of people with cancer. To advance understanding of cancer caregiver health literacy, a well-grounded conceptual model was first developed to understand key elements that comprise health literacy for caregivers of people with cancer. Results from the conceptual model informed the development of the Health
Literacy of Caregivers Scale - Cancer (HLCS-C). The convergent and discriminant validity of the HLCS-C was then assessed in a large sample of caregivers of people with cancer.
Chapter 3. Systematic Review

Chapter Overview

In Chapter 3, the objective of the study was to systematically review literature related to health literacy of caregivers of adult care recipients, and its relationship with care recipient, and caregiver, health outcomes. The study is presented as a manuscript (A) which was submitted to, and is under review in Social Science and Medicine.
### AUTHORSHIP STATEMENT

1. **Details of publication and executive author**

<table>
<thead>
<tr>
<th>Title of Publication</th>
<th>Publication details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Literacy of Caregivers of Adult Care Recipients: A Systematic Review</td>
<td>Under review</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eva YN Yuen</td>
<td>School of Psychology</td>
<td>0410 571 698</td>
</tr>
</tbody>
</table>

2. **Inclusion of publication in a thesis**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it intended to include this publication in a higher degree by research (HDR) thesis?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

If Yes, please complete Section 3. If No, go straight to Section 4.

3. **HDR thesis author’s declaration**

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
</tr>
</thead>
<tbody>
<tr>
<td>As above</td>
<td>School of Psychology</td>
<td>Development of a measure of health literacy for caregivers of people with cancer</td>
</tr>
</tbody>
</table>

Conceived and designed the study; collected data; undertook data analyses; drafted, refined and finalised the manuscript as the first and corresponding author.

**Extent of contribution: 95%**

*I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.*

<table>
<thead>
<tr>
<th>Signature and date</th>
<th>22nd March 2015</th>
</tr>
</thead>
</table>

4. **Description of all author contributions**

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s) (for example, conception of the project, design of methodology or experimental protocol, data collection, analysis, drafting the manuscript, revising it critically for important intellectual content, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tess Knight</td>
<td>Contributed to coordination of the study; contributed to data analysis; provided comments on drafts of the manuscript; and approved the final manuscript.</td>
</tr>
<tr>
<td>Lina Ricciardelli</td>
<td>Contributed to coordination of the study; provided comments on drafts of the manuscript; and approved the final manuscript.</td>
</tr>
</tbody>
</table>

Chapter 3. Systematic review
Chapter 3. Systematic review

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tess Knight</td>
<td></td>
<td>22/3/15</td>
</tr>
<tr>
<td>Lina Ricciardelli</td>
<td></td>
<td>23/3/15</td>
</tr>
<tr>
<td>Susan Burney</td>
<td></td>
<td>25/3/15</td>
</tr>
</tbody>
</table>

6. Data storage

The original data for this project are stored in the following locations. (The locations must be within an appropriate institutional setting. If the executive author is a Deakin staff member and data are stored outside Deakin University, permission for this must be given by the Head of Academic Unit within which the executive author is based.)

<table>
<thead>
<tr>
<th>Data format</th>
<th>Storage Location</th>
<th>Date lodged</th>
<th>Name of custodian if other than the executive author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic</td>
<td>Password protected computer file</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

This form must be retained by the executive author, within the school or institute in which they are based. If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
Manuscript A

Manuscript title: Health literacy of caregivers of adult care recipients: A systematic review

Authors: Eva YN Yuen\textsuperscript{a}, Tess Knight\textsuperscript{b}, Lina A Ricciardelli\textsuperscript{c}, Susan Burney\textsuperscript{d,e}

\textsuperscript{a}School of Psychology, Deakin University, 221 Burwood Highway, Burwood VIC, 3125, Australia, eva.yuen@deakin.edu.au.

\textsuperscript{b} School of Psychology, Deakin University, 221 Burwood Highway, Burwood VIC, 3125, Australia, tess.knight@deakin.edu.au

\textsuperscript{c} School of Psychology, Deakin University, 221 Burwood Highway, Burwood VIC, 3125, Australia, lina.ricciardelli@deakin.edu.au

\textsuperscript{d} School of Psychological Sciences, Monash University, Wellington Road, Clayton VIC 3800, Australia; sue.burney@monash.edu

\textsuperscript{e} Cabrini Monash Psycho-oncology, Cabrini Health, 154 Wattletree Road, Malvern 3144, Vic

Corresponding author
Eva Yuen, Deakin University, School of Psychology, 221 Burwood Highway, Burwood VIC 3125, Australia. Contact details: (email) eva.yuen@deakin.edu.au; (Phone) +61 410 571 698

Acknowledgements
The authors would like to sincerely thank Michael Barham for his help with reviewing the references.

Chapter 3. Systematic review
Abstract

Caregivers play a vital role in providing support to adults with a chronic condition, or cognitive or physical impairment. Low health literacy in caregivers has the potential to impact adequate care provision, and consequently, care recipient health outcomes. The study aimed to systematically review literature related to health literacy of caregivers of adult care recipients, and examine its relationship with care recipient, and caregiver, health outcomes.

Electronic databases were searched for relevant English-language publications that assessed health literacy in caregivers, and reported original data. One reviewer assessed each abstracted study for inclusion, while a second reviewer independently assessed a random 10% sample. Included studies were abstracted into evidence tables and assessed using an eight-item quality scale.

The search identified 2715 new titles and abstracts, with 65 shortlisted for full review. Eleven papers from 2003 to 2015 met the inclusion criteria. Seven caregiver cohorts were represented, whose care recipients were: people aged ≥ 65 years, stroke survivors, adults with developmental disabilities, or patients with heart failure, diabetes, from an ICU unit, or who were receiving hip surgery. The prevalence of limited health literacy in caregivers ranged from 0 – 52.5% depending on the measure and cut-off criteria used. Associations were found between low caregiver health literacy and: poorer care recipient self-management behaviors, increased care recipient use of health services, and increased caregiver burden. The quality of the studies ranged from fair to good.

Low health literacy in caregivers differed depending on the measures and scoring criteria used. Evidence to support the relationship between caregiver health literacy and care recipient, and caregiver was limited to individual studies. Recommendations for further research include: the development of caregiver health literacy measures across different populations; investigating associations between caregiver health literacy and care recipient...
outcomes; and the development of interventions designed to improve caregiver health literacy.

**Keywords:**

Caregivers, health literacy, adult care recipients, care recipient health outcomes
Health literacy of caregivers of adult care recipients: A systematic review

Health literacy is broadly defined as the personal characteristics and social resources needed for individuals to access, understand, appraise, and use information and services to participate in decisions related to their health (1-3). Low health literacy has been associated with poorer disease self-management (4, 5), poorer health outcomes (6, 7), reduced psychological wellbeing (8), increased health service use (9, 10), and among the elderly, increased mortality (11). Recent studies have shown that those with low health literacy are more likely to receive greater self-management support from family members (12, 13).

Family and friends often play an important role in providing practical, emotional, physical, and social support to people with a chronic condition, cognitive or physical impairment (14). These support persons, or caregivers, may participate in self-management activities such as: accessing and understanding of health information, symptom and medication management, psychosocial consequences management, communication with healthcare providers, coordinating support services, participating in medical decision-making, and problem-solving (15). Health literacy of caregivers may be particularly important if the care recipient is heavily dependent on the caregiver to oversee and manage healthcare tasks.

The role of caregivers in self-management support has been recognised in conceptualizations of health literacy (16, 17). Although comprehensive reviews have linked parental health literacy with child health outcomes (18, 19), little is known about the relationship between caregiver health literacy and adult care recipient health outcomes (20, 21).

Emerging evidence suggests that for people with low health literacy, caregivers can either facilitate or impede optimal health outcomes. Rosland and colleagues have shown that for diabetes and heart failure patients with low health literacy, caregivers facilitated positive health outcomes by providing support with self-management tasks (13), and assisting with
understanding information and facilitating information exchange during clinical encounters (22). However, Mayberry and Osborne (23) found evidence to suggest that people with limited health literacy may be particularly vulnerable to harmful aspects of social influence. For people with diabetes, family member disease-specific obstructive behaviors (such as nagging/arguing, or lack of support with self-care behaviors), and fewer supportive behaviors (e.g. exercising and / or eating together) had the strongest association with poor glycemic control in those with low health literacy (23). However, as health literacy of caregivers was not assessed in these studies, it is unclear whether caregiver health literacy was a mediating factor.

The purpose of this systematic review was to appraise the current state of peer-reviewed literature on health literacy of caregivers of adult care recipients, and its relationship with caregiver and care recipient health outcomes. The key questions for the literature review included:

- How is health literacy assessed in caregivers of adult care recipients?
- What are the levels of health literacy among caregivers of adult care recipients?
- Are caregiver health literacy skills independently associated with care recipient health outcomes?
- Are caregiver health literacy skills associated with caregiver health outcomes?

**Methods**

**Search strategy**

The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (24, 25). A systematic search of MEDLINE, CINAHL, EMBASE, PsycInfo, Cochrane database library, Global Health, Scopus, PubMed, ERIC, and Dissertations Abstracts International was conducted using Boolean search terms, from the inception of the databases until June 2014. The full-text
collections, Science Direct, Ingenta Select, Ovid Full Text and Wiley Online Library were also searched.

For the search, no limitations were placed on language or publication type. A secondary search was conducted in February 2015 to ensure that recent publications were included. Reference lists of the retrieved articles were also screened for relevant studies.

The search terms were: carer* or caregiver* or family* or “family member*” or families or partner* or spous* or relative* or couple* or “significant other*” or “next of kin” or wife* or husband* AND “health literacy” or literac* NOT infant* or child* or pediatric or paediatric* or minor* or adolescent* or adolescenc* or kindergarten* or preschool*. The same search terms were used for all databases; however if a database had relevant MeSH term/s, then these were included.

**Inclusion Criteria**

Publications were selected for inclusion in the review if they met the following criteria: i) included caregivers of an adult care recipient, ii) the caregiver’s care recipient was aged 18 years or over, iii) the publication examined health literacy of caregivers, iv) a validated health literacy measure was used to assess health literacy; v) the publication was in English, and vi) the publication reported original research data. Studies of paid caregivers, and grey literature, such as dissertations were included in the review. Studies were excluded if: they were published in languages other than English due to language barriers; they had a focus on care recipients’ aged under 18 years as these individuals had a dependent relationship to the caregiver; or if they were presented as a conference proceeding due to a lack of information.

**Review Process**

One reviewer ran the search terms, and screened and assessed the titles and abstracts of all the identified publications against the eligibility criteria. Full texts of publications
considered for inclusion were obtained to determine eligibility. A second reviewer independently screened and assessed a random 10% sample of identified publications, then examined full texts of potential publications for inclusion in the review (the agreement level was 100%).

One reviewer extracted and entered data from included articles into an evidence table. A second reviewer examined the articles and checked the tabled data for accuracy. Extracted data from each article included author, title, year published, study design, caregiver sample size, care recipient’s chronic condition, caregiver-care recipient relationship, outcomes assessed, health literacy measurement tool, levels of health literacy in caregivers, results, and limitations.

The quality of included studies was appraised using an eight-item assessment criteria adapted from West and colleagues (26) system to assess study quality: 1) adequacy of study question; 2) adequacy of study population; 3) comparability of participants; 4) validity and reliability of outcome measurement; 5) exposure variable or intervention clearly defined; 6) use of appropriate statistical analyses; 7) clarity of results; and 8) presentation of discussion (e.g., non-biased, limitations addressed). The approach is consistent with previous systematic reviews that focused on health literacy studies (18, 27, 28). Each study was rated (0 = poor, 1 = fair, 2 = good) for each of the quality assessment items. A composite score was used to determine its quality using the following grading system: Good (a score of 12 to 16); fair (6 to 11); poor (0 to 5). Two reviewers independently rated the studies, then averaged the results for each study.

**Results**

An online search of databases identified 3816 articles, with an additional 16 identified through secondary sources. Of these, 1117 were duplicates and thus excluded. The remaining 2715 were screened according to title and abstract, with 2650 excluded (see Figure 1). Sixty-
five articles underwent full text screening. Eleven articles met the inclusion criteria which were published between 2003 and 2015. As the study design, participants, and outcome measures varied widely across studies, outcomes were not pooled.

**Origins of Studies and Populations**

Seven of the 11 studies were from the United States (20, 21, 29-32), three from Australia (33-35), and one from Egypt (36; see Tables 1 & 2). Across the 11 studies, seven caregiver cohorts were identified. Three studies focused on caregivers of older persons (21, 31, 36), three on stroke survivors (33-35), and one each on people who received hip surgery (32) people with Type II diabetes (29), people with heart failure (20), Intensive care unit (ICU) patients (37), or adults with developmental disabilities (30). Caregiver sample sizes ranged from 8 (34) to 200 (SD ± 69.7; 36).

**Caregiver Characteristics**

Across the 11 studies, 1160 caregivers were included in the analyses, with a mean age of 54.5 years (SD ± 7.5), and comprised of 73.8% (n = 812) female participants (see Tables 1 & 2). Two studies (33, 36) did not include information on the relationship of the caregiver to the care recipient. Across the nine studies that specified caregiver relationships to the care recipient (n = 939), these included: 29.8% spouses, 23.1% children, 21.7% other family member (e.g., parents, sibling, other not specified), 15.1% paid caregivers, and 9.6% other.

**Conceptualization**

The majority of studies (n = 8) examined health literacy, while two focused on literacy status or reading ability (33, 38), and one study focused on eHealth literacy (32). Six of the 11 studies provided a definition of health literacy (21, 29-31, 36). Although two studies (33, 34) provided a definition of readability rather than health literacy, to assess participant reading ability, these studies used a measure typically employed to assess health literacy - the Rapid Estimate of Adult Literacy in Medicine (REALM; 39).
Although the six studies that included a definition of health literacy presented different sources, their definitions broadly captured an individuals’ capacity to find, understand and use health information and services to make health decisions. Four studies (21, 29, 30, 36) drew on the definition originally published in the National Library of Medicine bibliography (40), which defined health literacy as: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (P.vi; 41). One study (31) defined health literacy as “an individual’s ability to read, understand, and use health care information to make effective health care decisions and follow instructions for treatment” (p474) which they attributed to Kirsch and colleagues (42). Another study (32) drew on Norman and Skinner’s (43) definition of eHealth literacy: “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem”.

**Research Design and Methods**

Of the 11 studies reviewed, eight were cross-sectional (20, 21, 29-31, 33, 36), one was quasi-experimental (32), one was longitudinal (38), and one was a randomized controlled trial (35). Five of the 11 studies examined both caregiver and care recipient health literacy. All 11 studies provided descriptive information on caregivers’ sex, age, ethnicity and other demographic factors. Only one study (29) included these covariates in their multivariate analyses. Ten studies were rated as good quality according to the eight item quality assessment criteria. The quality of the studies varied in relation to: care recipient’s reasons for needing a caregiver, objectives, location, and sampling strategy (see Table 1).

**Measures of Health Literacy**

Of the 11 studies, three used more than one measure to assess health literacy levels of caregivers (20, 31, 36). Across the included studies, to assess health literacy, five used Parker
and colleagues’ (44) Test of Functional Health Literacy in Adults (TOFHLA; 31) or its short form (21, 29, 30, 37), four used the REALM (33, 35, 36, 38), and two used the Newest Vital Sign (NVS; 20, 36) which was developed by Weiss and colleagues (45). One study each used Chew and colleagues’ (46) three screening questions (20) or Norman and Skinner’s (43) eHealth Literacy Scale (eHEALS; 32). One study used a measure designed for the study in conjunction the TOFHLA (31).

Studies differed on how caregiver health literacy was reported. Six studies distinguished between health literacy levels (see Table 1), whilst the remaining five reported an average health literacy score (see Table 2; 30, 32, 34, 35, 36). Differences were also found amongst the six studies that distinguished between health literacy levels. Two studies differentiated between two levels of health literacy (adequate, inadequate; 21, 31), whilst one study differentiated between three levels (inadequate, marginal, adequate; 37), one study differentiated between four levels (reading levels at 3rd grade and below, 4th – 6th grade, 7th – 8th grade, or 9th grade and above; 33) and one study differentiated between five levels (low, marginal, moderate, average, or above average health literacy; 29). The remaining study (20) used two measures to assess health literacy, and reported different levels of health literacy depending on the measure.

**Caregiver Health Literacy**

As the studies varied in their use of measurement tools, the number of tools used to assess health literacy, and cut-off criteria, results for caregiver health literacy are presented as follows: 1) studies that differentiated between levels of health literacy (e.g., inadequate, marginal, adequate); 2) studies that used two measures to assess caregiver health literacy, and; 3) studies that reported an average caregiver health literacy score.

Of the five studies that differentiated between levels of health literacy as assessed using a single measure (21, 29, 31, 33, 37), the prevalence of limited health literacy among
caregivers varied between 0 to 42.9% depending on the measure and cut-off criteria used. As the caregiving population differed across studies, a pooled effect size was not calculated.

In the one study (20) that used two measures to assess health literacy of caregivers, mixed results were reported. Levin, Peterson and colleagues (20) assessed health literacy in caregivers of heart failure patients using Chew and colleagues’ (46) three screening questions and the NVS. Adequate caregiver health literacy was found when using the three screening questions. However, when using the NVS, up to 52.5% caregivers reported limited health literacy (23.5% limited health literacy possible, and 29% limited health literacy likely).

Of the five studies that reported an averaged health literacy score, four studies showed adequate health literacy in their caregiver sample (see Table 2; 30, 32, 35, 38). By contrast, Nahm and colleagues (36) reported inadequate health literacy in up to 75% of their caregiver sample as determined by aggregating the percentage of individuals who scored in the inadequate health literacy range from both the REALM \((m = 36.6, \text{SD 29.6})\) and NVS \((m = 2.7, \text{SD 2.5})\).

**Caregiver versus Care Recipient Health Literacy**

Mixed results were found across the five studies that explored both caregiver and care recipient health literacy due to the disparate objectives of each study. Four studies reported higher health literacy scores in caregivers compared to care recipients (20, 21, 33-35). However, only one of these four studies (20) examined whether differences were significant. Levin, Peterson and colleagues (20) found that caregivers of heart failure patients were more likely to have higher levels of health literacy than care recipients, as assessed using both the three screening questions and the NVS.

By contrast, Garcia and colleagues (21) sought to assess health literacy, and to determine patterns of association among dyads comprised of Hispanic care recipients aged \(\geq 65\) years and their caregivers. To assess health literacy, both English and Spanish versions of
the S-TOFHLA were made available to participants. Garcia and colleagues (21) found that 41% of dyads were comprised of caregivers’ with adequate health literacy and care recipients with low health literacy. Close to one-quarter of dyads had caregivers and care recipients with low health literacy (24%), whilst 28% dyads had adequate health literacy. Another 7% of dyads were comprised of a caregiver with low health literacy, and a care recipient with adequate health literacy. Further, care recipients with low health literacy were more likely than those with adequate health literacy to have a caregiver with low health literacy; however, these findings were significant only among Spanish-interview care recipients. No associations were found between English-interview care recipients with low health literacy, and low caregiver health literacy.

**Caregiver Health Literacy and Health Outcomes of the Care Recipient and Caregiver**

Two studies examined the relationship between caregiver health literacy, and care recipient health outcomes. Levin, Peterson and colleagues (20) examined associations between caregiver health literacy and their matched care recipient’s scores on three self-care heart failure management scales: maintenance, management and confidence. Caregivers with low health literacy as measured by the NVS were more likely to have care recipients who reported poorer self-care maintenance, or behaviors to maintain clinical stability. No associations were found between caregiver health literacy and care recipient self-care management or confidence to manage symptoms. Rahman (36) found significant associations between caregivers’ low health literacy and frequency of elderly care recipient hospital admission, duration of care recipient hospital stay, and care recipient health-related quality of life.

Only one study (29) was found which examined associations between caregiver health literacy and caregivers’ levels of stress in a sample of caregivers of people with diabetes. Gibson (29) reported a significant negative relationship between caregiver health literacy and
caregiver burden.

**Caregiver Health Literacy Following Intervention**

Two studies (29, 32) examined caregiver health literacy outcomes following intervention. Gibson (29) examined health literacy associations between caregivers who had previously attended a diabetes educational class (any type) and those who had not. No differences in levels of health literacy were found between caregivers who had, or had not attended educational class. Nahm and colleagues (32) examined levels of health literacy in caregivers before and after participation in an online hip fracture resource center intervention using a single group pre-post design (baseline and 8 weeks). The online intervention was comprised of learning modules, online access to healthcare providers, a social networking component, and a library of relevant information. Following intervention, caregivers reported significant improvements in knowledge about caring for people with hip fractures and eHealth literacy. No significant changes were reported for computer mediated social support and caregiver stress and coping. Caregiver knowledge and computer mediated social support were significantly associated with care recipient’s self-efficacy for osteoporosis medication adherence at follow up.

**Caregiver Health Literacy and Readability of Written Health Materials**

Two studies examined relationship between caregiver health literacy and readability of written information. Eames and colleagues (33) found that while 57.1% of their caregiver sample (n = 14) read at ninth grade level or above, the readability of the majority (67.9%) of the 53 stroke materials assessed as part of the study were at ninth grade level or above. Further, as material readability increased in complexity, participant satisfaction decreased.

Similarly, Hoffmann and colleagues (34) analyzed 18 of 22 materials received by stroke survivors and their caregivers. Using the SMOG readability formula (47), the majority of written materials (89%) had a readability level at ninth grade or above, with over one-fifth
at university level. Using the Suitability Assessment of Materials (48), suitability of written materials averaged 56% for patients and caregivers.

**Caregiver Health Literacy and Demographic Characteristics**

One study (29) examined the influence of demographic characteristics on caregiver health literacy. Age, race, (Asian, Black, Hispanic, White, or other) and education, but not gender or income, were significantly and negatively associated with caregiver health literacy.

**Discussion**

To the authors’ knowledge, this is the first published systematic review examining peer-reviewed literature related to health literacy of caregivers of adult care recipients. Results from the review suggested that for some caregiver groups, over half of caregivers may have inadequate levels of health literacy depending on the measure used. Moreover, the majority of caregivers had higher health literacy levels than care recipients. Studies have also suggested that available health information was too complex for many caregivers. Emerging studies suggest positive associations between low caregiver health literacy and poorer care recipient health outcomes, such as poorer self-management behaviors and increased care recipient use of health services. Studies have also suggested negative impacts of low caregiver health literacy on caregiver health outcomes, such as increased caregiver burden. However, these findings related to the impacts of low caregiver health literacy on caregiver and care recipient health outcomes are limited to individual studies; strong evidence to support these relationships are lacking.

**Caregiver Health Literacy: Need for Adequate Measures**

Similar to findings from existing health literacy reviews (49), this review showed substantial variation in measurement tools used to assess health literacy and cut-off criteria to differentiate health literacy levels across studies. In a study by Levin and colleagues (20) that assessed health literacy using the NVS in combination with three screening questions,
prominent ceiling effects were found when using the latter measure; results from the three screening questions suggested that the majority of caregivers had adequate health literacy. By contrast, the NVS appeared to be a more sensitive discriminator of health literacy levels in caregivers of adult care recipients, and identified over 50% caregivers at risk of low health literacy. The finding that widely-used health literacy measurement tools function and predict outcomes differently supports results from studies that assessed parental health literacy (50, 51). For example, Morrison and colleagues recently compared the performance of the S-TOFHLA and NVS amongst caregivers of children under 12 years. In their study, the S-TOFHLA demonstrated a ceiling effect, whilst the NVS appeared to show predictive validity and the capacity to discriminate caregivers of children across a range of scores with a broader distribution. The combined findings suggest that health literacy measures should not be considered equal across populations (Morrison et al.).

Limitations of widely-used health literacy measures have been acknowledged, in that they assess reading, comprehension and numeracy skills (52, 53), rather than capturing broader elements identified in conceptualizations of health literacy, such as communication, critical appraisal, and interaction (1). Although comprehensive measurement tools, such as the Health Literacy Questionnaire (HLQ; 54) and the European Health Literacy Questionnaire (HLS-EU-Q; 55) have recently been developed to address the shortcomings of existing measures, they were designed to assess health literacy among the general populations, rather than specific groups. Thus, critical aspects related to caregiver health literacy are not included in these measures. Further, although measures such as the Parental Health Literacy Activities Test (PHLAT; 51, 56) have been developed to assess parental health literacy, few measures are available that examine health literacy needs of caregivers of adult care recipients (57).
Recently the Health Literacy of Caregivers Scale – Cancer (HLCS-C; 58) was developed to assess health literacy of caregivers of cancer patients, and is comprised of 10 domains relevant within the cancer care setting. However these domains may not be applicable to caregivers of other patient groups. In the absence of comprehensive measures of caregiver health literacy that capture the full spectrum of constructs included in health literacy definitions, the NVS may serve as more sensitive discriminator for caregivers of adult care recipients. Future research is needed to identify elements pertaining to caregiver health literacy across different care recipient populations to inform the development of measurement tools that comprehensively assess caregiver health literacy.

Notably, Lindquist and colleagues (31) found that caregivers with inadequate health literacy (35% as assessed using the TOFHLA) were more likely to make medication errors on three out of five medication dispensing tasks, compared to those with adequate health literacy. However, for complex prescription directions, caregivers were likely to make errors regardless of health literacy levels. These results highlight that effective strategies for optimizing health outcomes will involve a combined effort of improving individual health literacy, as well as improving delivery of health information.

**Caregiver and Care Recipient Health Literacy**

Mixed results were also found across studies that examined health literacy of both caregivers and care recipients. The majority of studies that assessed both caregiver and care recipient health literacy reported higher health literacy levels in caregivers. However, the focus was predominately on care recipients who had experienced cognitive changes (e.g. following stroke), which may have impacted their capacity to understand and act upon health information (33-35). Notably, one study that examined health literacy of dyads found up to one-quarter of their sample was comprised of dyads with low health literacy (Garcia et al., 2013).
Together, the findings suggest that up to 52.5% caregivers, and up to one-quarter of caregiver-care recipient dyads had inadequate health literacy is concerning. As noted by Garcia and colleagues, regardless of care recipient health literacy levels, caregiver low health literacy has the potential to influence the health outcomes of the care recipient if the caregiver plays a major role in self-management support, such as medication dispensing or monitoring symptoms. Given the important role that caregivers play in self-management support, it is recommended that researchers and healthcare providers be mindful of including caregivers in education programs and interventions that seek to optimise health literacy.

**Caregiver Health Literacy and Care Recipient Health Outcomes**

There was some evidence to suggest that lower health literacy among caregivers was independently associated with poorer care recipient health outcomes; however, the overall understanding is weak. Only two studies explored the association between caregiver health literacy and care recipient health outcomes or health service use. Low health literacy in caregivers was associated with poorer self-management behaviors in care recipients (20); however, it was unclear whether care recipients also had low health literacy.

Low health literacy in caregivers was also associated with increased frequency and duration of hospital admission and health-related quality of life for caregivers (36). However, the limited available evidence precludes firm conclusions being drawn. Recently, Mayberry and colleagues (12) identified potential mediating pathways between caregiver supportive/obstructive behaviors and self-care for patients with low health literacy; however, the relationship between caregiver health literacy and supportive behaviors, and how caregiver health literacy influences care recipient self-management are unknown. Future research should consider examining how caregiver health literacy influences caregiver self-management support, care recipient self-management behaviors and care recipient health outcomes.
Caregiver Health Literacy and Caregiver Health Outcomes

Only one study examined the relationship between caregiver health literacy and caregiver health outcomes, with results suggesting that low health literacy in caregivers was associated with increased caregiver burden (29). Thus, the limited evidence precludes firm conclusions being drawn. While unmet needs, including needs for information, in caregivers across various care recipient populations has been associated with increased burden (59), stress (60) and depression (61, 62), to date, few studies have examined the relationship between health literacy, unmet information needs and caregiver health outcomes. As caregivers are not the primary recipients of healthcare, they may already experience a number of challenges when seeking health information and engaging with health services (58), including fewer opportunities to communicate with, and lack of recognition from, healthcare providers (Dolce, 2011, Guo et al., 2010, Williams and Bakitas, 2012). It is unclear the extent to which caregiver low health literacy contributes to their unmet information needs, and further, how, and whether it relates to caregiver burden, stress and depression. Further research should examine relationships between caregiver health literacy, information needs, and caregiver health outcomes.

Caregiver Health Literacy and Intervention Outcomes

Only one study examined feasibility of an intervention to improve caregiver health literacy (32), while another study (29) examined whether prior attendance to an educational class impacted self-reported health literacy in caregivers, with mixed results found. No differences in caregiver health literacy levels were found between those who had, or had not, participated in a diabetes educational class (29). However, it was unclear how many educational classes caregivers had attended, or the outcomes of those classes (29). By contrast, one study (32) showed improvements in knowledge and eHealth literacy following an online hip fracture resource intervention. However, it was unclear the proportion of
caregivers who had low eHealth literacy at baseline, and thus, whether engagement with the intervention was able to reduce the gap between caregivers with low and high health literacy.

Recently, Sheridan and colleagues (63) conducted a review of interventions aimed at mitigating the effects of low health literacy across populations, and found that not all interventions improve health literacy; some interventions provided no benefit to individuals with low health literacy, whilst others (e.g., replacing the words more/fewer with plus or minus symbols; [64]) appeared to have detrimental effects. Their review highlighted the possibility that interventions may have different effects for those with low and high health literacy. In addition, a range of approaches may be needed to improve health outcomes for people with low health literacy.

Across various populations, preliminary evidence has shown that interventions that reduced the effects of low health literacy appeared to work by increasing knowledge, self-efficacy, or by modifying behavior (6). Further research could examine whether existing caregiver interventions improve caregiver health literacy, and whether these interventions reduce the gap between caregivers with low and high health literacy. Future studies could also identify what features make these interventions successful in improving caregiver health literacy, particularly for those with low health literacy. Future research could also examine whether there are factors not yet targeted in current intervention literature that could potentially improve low caregiver health literacy.

Limitations and Future Directions

Several limitations of the reviewed studies need to be noted. Studies were predominantly cross-sectional in their design. Substantial heterogeneity was found across the included studies, which varied by care recipient populations, aims, and methods of recruitment. As previously outlined, studies differed in measurement tools used to assess health literacy, and cut-off criteria for determining health literacy levels. The majority of
included studies had small sample sizes, which limited their sample distribution, and the generalizability of the results. Further, studies assessed caregivers’ reading, comprehension and numeracy skills and their association with care recipient and caregiver health outcomes, rather than the full spectrum of constructs captured in definitions of health literacy.

A number of gaps and opportunities to inform caregiver research have been identified. From a research perspective, there is a need for validated measures that assess the full spectrum of caregiver health literacy needs across various caregiving populations. Identification of content areas relevant to caregiver health literacy has the potential to inform the development of interventions that comprehensively address caregiver health literacy difficulties. In addition, the search strategy identified a number of studies of caregiver health literacy that were excluded due to use of unvalidated or proxy measures of health literacy, particularly for caregivers of people with mental health issues (65-67). These findings highlight the need for validated measures of mental health literacy for patients as well as caregivers.

From a broader healthcare system perspective, healthcare providers should be mindful that caregivers who provide support to individuals with a chronic condition, cognitive or physical impairment, might also have low health literacy. In particular, for caregivers who engage in clinical healthcare activities (such as administering medication, monitoring symptoms), healthcare providers may consider adopting various processes and communication strategies to ensure that these caregivers have adequate access to, and understanding of, information pertinent to engaging in the healthcare tasks. For caregivers whose role entails high clinical demand, care recipient and caregiver health outcomes could benefit from tailored interventions to support their health literacy needs. Such interventions have the potential to reduce health disparities by enabling caregivers with health literacy difficulties to provide adequate self-management support to promote health outcomes of the
care recipient.

Conclusions

The current systematic review highlights that examination of health literacy of caregivers of adult care recipients is in its infancy, despite the important role that caregivers play in self-management support. Whilst conceptualizations of health literacy have acknowledged the role of social networks in promoting an individual’s health literacy (Edwards et al., 2013; Lee et al., 2004), the impact of caregivers’ health literacy on care recipient and caregiver health outcomes is largely unknown. Insights into caregiver health literacy are vital, particularly if the caregiving role has high clinical demands, or the care recipient has low health literacy. Further research is needed to identify elements that comprise caregiver health literacy to assist in the development of interventions that adequately address caregiver health literacy needs. In addition, development of comprehensive health literacy measurement tools is needed to assist in the assessment and evaluation of such interventions.

The current literature review identifies existing gaps in knowledge, related to caregiver health literacy and its relationship with care recipient health outcomes and caregiver health outcomes. There also exist gaps related to effective interventions targeted at caregivers with low health literacy. Further research is needed to better understand the impacts of caregiver health literacy on care recipient and caregiver health outcomes. Better understanding of elements that comprise caregiver health literacy will enable the development of interventions that adequately address caregiver health literacy needs.
References


29. Gibson JT. Correlation of health literacy to the stress level of informal caregivers for people with Type 2 diabetes. US: ProQuest Information & Learning; 2013.


Chapter 3. Systematic review

57. Yuen EYN, Dodson S, Batterham RW, Knight T, Chirgwin J, Livingston PM. Development of a conceptual model to understand cancer caregiver health literacy. European Journal of Cancer Care [Internet]. 2015:[1-13 pp.].


Chapter 3. Systematic review

Figure 1. PRISMA Flow diagram

Records identified through database search
\((n = 3816)\)

Additional records identified through other sources
\((n = 16)\)

Records after duplicates removed
\((n = 2715)\)

Records screened
\((n = 2715)\)

Records excluded for not meeting inclusion criteria
\((n = 2650)\)

Full-text articles assessed for eligibility
\((n = 65)\)

Full-text articles excluded:
- Not original research \((n = 11)\)
- Doesn’t assess caregiver health literacy using validated measure \((n = 29)\)
- Poor quality \((n = 2)\)
- Did not focus on caregivers of adult care recipients \((n = 7)\)
- Duplicate study \((n = 3)\)
- Conference proceeding \((n = 2)\)

Studies included in the systematic review
\((n = 11)\)
Table 1.
Details of studies that differentiated between health literacy levels when assessing health literacy in caregivers (and care recipients)

| Study, Location | Sample size of caregivers | Type of care recipients | Sample | Measure of health literacy | Levels of health literacy identified in study | Caregivers with low health literacy | Care recipient health literacy | Significant differences between caregiver and care recipient HL | Study quality |
|-----------------|---------------------------|--------------------------|--------|-----------------------------|---------------------------------------------|-----------------------------------|-------------------------------|-----------------------------------|----------------|----------------|
| Chiarchiaro et al. (2015), USA | 464 | ICU patients | Academic medical centers | S-TOFHLA | Three levels: Inadequate, marginal, adequate | 3.3% Inadequate health literacy; 1.1% Marginal health literacy | n/a | n/a | Good |
| Eames et al. (2003), Australia | 14 | 20 Stroke survivors | Community and university based support groups | REALM | Four reading levels: ≤ 3rd Grade and below, Grades 4 – 6; 7th – 8th Grade; ≥ 9th Grade | 42.9% reading level grade 7 – 8 | n/r | Good |
| Gibson (2013), USA | 90 | n/a Adults with diabetes | Diabetes Centre | S-TOFHLA | Five levels: low, marginal, moderate, average, above average. | 6.7% moderate health literacy; 1.1% low health literacy | n/a | n/a | Good |
| Lindquist et al. (2010), USA | 98 | n/a people ≥ 65 years | Physician and nurse referrals; caregiver word of mouth and flyers across metropolitan and suburban areas Heart failure management program | TOFHLA; Medication dispensing knowledge using mock up pill bottles | Two levels: inadequate, adequate | 35.7% inadequate health literacy | n/a | n/a | Good |
| Levin et al. (2014), USA | 17 | 17 ≥ 65 years with heart failure | Three health literacy | Three screening questions - two levels: adequate (scores < 10 of possible 15); | Three screening questions: 0% scored in inadequate range in 3 | 47% scored in inadequate range in 3 | 3 screening questions: r = 4.6 (df = |

Chapter 3. Systematic review
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Description</th>
<th>Screening Instrument</th>
<th>Adequate Health Literacy</th>
<th>Inadequate Health Literacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Garcia (2013), USA</td>
<td>174 Hispanic adults ≥ 65 years, Outpatient clinics and community senior centres</td>
<td>S-TOFHLA Two levels: Low, adequate</td>
<td>27.8% low health literacy (From: clinic: 11.4%; senior center: 44.2%)</td>
<td>64.9% low health literacy (From: clinic 64.3%; senior center 65.4%)</td>
</tr>
</tbody>
</table>

*P* < .05 Good

n/n = not reported
### Table 2.
Details of studies that reported a mean health literacy score when assessing health literacy in caregivers (and care recipients)

<table>
<thead>
<tr>
<th>Study Location</th>
<th>Caregivers</th>
<th>Care recipients</th>
<th>Sample</th>
<th>Measure of health literacy</th>
<th>Mean caregiver health literacy &amp; interpretation</th>
<th>Care recipients with low health literacy</th>
<th>Significant differences between caregiver and care recipient HL</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erickson &amp; LeRoy (2015), USA</td>
<td>47</td>
<td>n/a</td>
<td>Adults with developmental disabilities</td>
<td>S-TOFHLA</td>
<td>M = 34.5 (22-36, SD 2.5); Adequate health literacy</td>
<td>n/a</td>
<td>n/a</td>
<td>Good</td>
</tr>
<tr>
<td>Hoffmann et al. (2004), Australia</td>
<td>12</td>
<td>57</td>
<td>Stroke survivors</td>
<td>REALM</td>
<td>M = 65.4 (63-66, SD 1.1); Adequate health literacy (≥ 9th grade reading level)</td>
<td>n/a</td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Hoffmann et al. (2010), Australia</td>
<td>8</td>
<td>26</td>
<td>Stroke survivors</td>
<td>REALM</td>
<td>M = 62 (59-65, SD n/a); Adequate health literacy (≥ 9th grade reading level)</td>
<td>n/a</td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Nahm et al. (2012), USA</td>
<td>36</td>
<td>36</td>
<td>Individuals who received hip surgery due to hip fracture</td>
<td>eHealth Literacy Scale</td>
<td>Baseline: M = 38.89 (SD6.49) Scores range from 8 – 40 with higher scores indicating higher self-perceived eHealth literacy</td>
<td>n/a</td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Rahman (2014), Egypt</td>
<td>200</td>
<td>200</td>
<td>Geriatrics</td>
<td>REALM</td>
<td>M = 36.6 (SD 29.6); 4th-6th grade reading level; NVS: M = 2.7 (SD2.5); Limited health literacy possible</td>
<td>n/a</td>
<td></td>
<td>Fair</td>
</tr>
</tbody>
</table>

n/a = not applicable; n/r = not reported

---

Chapter 3. Systematic review
Chapter Summary

In this chapter, Manuscript A was presented, which comprised a systematic review of literature related to health literacy of caregivers of adult care recipients. Amongst the 11 papers included in the review, the prevalence of limited health literacy in caregivers varied substantially depending on the measure and scoring criteria used. In addition, although associations were found between low caregiver health literacy and poorer care recipient self-management behaviours, increased care recipient use of health services, and increased caregiver burden, these findings were limited to individual studies. The review highlighted that investigation of health literacy of caregivers of adult care recipients has largely been neglected, despite the important role that caregivers play in self-management. There currently exists a gap in the literature related to availability of multidimensional measures of caregiver health literacy. Understanding and accurate assessment of the elements that comprise caregiver health literacy has the potential to guide the development and evaluation of interventions that adequately address caregiver health literacy needs. Thus, in the absence of a measurement tool that could effectively capture the breadth and depth of caregiver health literacy, the purpose of this thesis was to develop a psychometrically sound measure that could be used to assess health literacy of caregivers of people with cancer. In the next chapter, the processes of scale development used to generate the Health Literacy of Caregivers Scale – Cancer (HLCS-C) are presented.
Chapter 4. Process of scale development

To address the gap in the literature related to available measures to assess health literacy for caregivers of people with a chronic condition, the overarching purpose of the thesis was to develop a measure of health literacy for caregivers of people with cancer, the Health Literacy of Caregivers Scale – Cancer (HLCS-C). To develop a new measure, the literature of scale development was reviewed. In this chapter, the fundamental properties in scale development, reliability, and validity are presented. The steps in scale development designed to enhance a scale’s accuracy are then described: conceptualisation of the phenomenon to be measured, item generation, response formats, expert review of draft items, cognitive interviewing, and initial field testing. Steps related to structural analysis using factor analytic approaches are detailed. The processes of item analysis, derived from two measurement theories, Classical Test Theory and Item Response Theory, are then outlined. The chapter concludes with a summary of the processes of scale development.

Fundamental Properties in Scale Development: Reliability and Validity

The overarching purpose in scale development is to develop an accurate measure of a phenomenon of interest (Clark & Watson, 1995). Broadly, the phenomenon of interest is often considered a latent trait, that is, an attribute of an individual that cannot be directly observed or quantified (DeVellis, 2011). In developing a scale using classical test theory approaches, a set of items within a scale which are considered proxies of the underlying phenomenon are identified. Depending on the complexity of the phenomenon, the scale may be comprised of single or multiple ‘domains’ that represent the latent trait. For health-related scales to provide useful information on the phenomenon of interest in clinical practice, policy development, and research,
it is critical that the scales demonstrate sound psychometric properties, such as reliability and validity (Clark & Watson, 1995; Hinkin, 2005).

Reliability refers to the extent to which a measure is consistent and free from error (Mokkink et al., 2010). Error in measurement leads to variation in scores, thus, reliability is an indicator of consistency, or how well a measure produces the same results over repeated trials (Hair, Black, Babin, & Anderson, 2010). Measures with high reliability will produce consistent values across multiple measurements, given the phenomenon of interest does not change (De Vet, Terwee, Mokkink, & Knol, 2011; DeVellis, 2011; Mokkink et al., 2010). Notably, although scale reliability is associated with its validity in that reliability is a prerequisite of validity, a measure can be valid without demonstrating reliability (Nunnally & Bernstein, 1994).

Validity, on the other hand, refers to the extent to which a scale measures what it purports to measure (Hair et al., 2010; Nunnally & Bernstein, 1994). If a scale is valid, then it has demonstrated that the observed scores are a reflection of a specific variable, or the phenomenon of interest (De Vet et al., 2011; DeVellis, 2011). DeVellis argued that conventionally, validity is “inferred from the manner in which a scale was constructed, its ability to predict specific events, or its relationship to measures of other constructs” (p.59).

Several types of validity have been proposed (De Vet et al., 2011; DeVellis, 2011; Mokkink et al., 2010; Mosier, 1947): face validity, content validity, criterion validity, and construct validity. Face validity refers to whether items within a scale appear to adequately represent the phenomenon of interest (Mosier, 1947). Content validity refers to the extent to which a specific set of items reflects the construct under investigation (De Vet et al., 2011); and criterion-related validity refers to the degree of association between the measure and a specific
criterion, or ‘gold standard’. Specifically, criterion-related validity is associated with a measure’s capacity to predict a process, and thus, is also known as predictive validity (DeVellis, 2011).

However, construct validity\(^1\), is useful when no gold standard exists, and refers to whether the instrument ‘behaves’, or provides the “expected scores based on existing knowledge about the construct” (De Vet et al., 2011, p. 150). To demonstrate construct validity, items within a scale should adequately reflect the dimensionality, or factor structure, of the phenomenon of interest (i.e., structural validity). Construct validity is also demonstrated by examining whether scale items within a specific construct are homogenous and share a high proportion of variance (i.e., internal convergent validity; Hair et al., 2010). Another process to determine construct validity is to assess whether items are unique, and not highly correlated with items from other constructs (i.e., discriminant validity; Campbell & Fiske, 1959). These different types of validity presented above will be referred to throughout the relevant sections within this thesis.

**Processes in Scale Development**

The planning and processes in scale development are considered critical to establishing validity of a new measure (De Vet et al., 2011; DeVellis, 2011; Nunnally & Bernstein, 1994). Various steps to improve the accuracy and minimise measurement error in scale development have been proposed (Clark & Watson, 1995; DeVellis, 2011; Lasch et al., 2010; Food and Drug Administration [FDA], 2009) and have been applied successfully to develop questionnaires with

---

\(^1\) Notably, a scale’s construct validity is often incorrectly described as being ‘demonstrated’ (Cronbach & Meehl, 1955). However, it is argued that scale validation is a process, rather than an outcome (Strauss & Smith, 2009). Thus, construct validity provides evidence to support specific interpretations of a score from a measure as well as actions based on such interpretations within specific populations (Strauss & Smith, 2009).

Chapter 4. Processes of scale development
sound psychometric properties (Buchbinder, Batterham, Elsworth, et al., 2011; Busija, Buchbinder, & Osborne, 2013; Osborne et al., 2013). The processes of scale development adopted in the current thesis are outlined in Figure 4.1 and are described in more detail in subsequent sections.

Figure 4.1. Processes of scale development used in the current study

Conceptualisation of the phenomenon to be measured

Item generation

Generation of the response format

Review of initial item pool by experts

Cognitive interviewing of draft items

Initial field testing

Conceptualisation of the phenomenon to be measured

One of the key aspects in the development of a questionnaire is a clear and precise conceptualisation of the phenomenon of interest and its theoretical context (Clark & Watson, 1995; DeVellis, 2011). A conceptual model that adequately describes concepts that comprise the

Chapter 4. Processes of scale development
phenomenon of interest, enables the researcher to understand what the phenomenon is, and what it is not (Clark & Watson, 1995). Thus, a conceptual model assists with making decisions about relevant concepts to include and exclude from the measure (DeVellis, 2011).

A conceptual model enables the researcher to: identify the dimensions that comprise the phenomenon of interest (in terms of this thesis, the phenomenon of interest is caregiver health literacy), identify the relationships between the dimensions of caregiver health literacy, and describe the content of these dimensions (Clark & Watson, 1995; DeVellis, 2011; FDA, 2009). When developing a new questionnaire, one consideration is the adequacy of the generated items to support the final conceptual model of the questionnaire (FDA, 2009). When developing questionnaire items in response to specific dimensions, and when identifying relationships between the dimensions, the conceptual model can assist with the identification of a measurement model that can be used for the construct validation of the scale within the structural equation modelling framework (Rothman, Beltran, Cappelleri, Lipscomb, & Teschendorf, 2007). Thus, a conceptual model has the potential to assist in both the analysis, and the interpretation of scores because it specifies a priori what the scores from a questionnaire represent (Busija, 2010).

When the conceptualisation of the phenomenon of interest is unknown, the FDA (2009) argued that an initial hypothesised conceptual model could be developed to support the drafting of items and domains to be included in the measure. The conceptual model is then confirmed and amended over the course of the instrument development process as empirical evidence is gathered to support groups of items that represent concepts (FDA, 2009).

Traditionally, the development of conceptual models and questionnaire items has been guided by published literature, existing questionnaires, and consultations with experts, with minimal input from individuals from the target population (Streiner & Norman, 2008).
Conceptual models and questionnaires developed using this process have the potential to exclude elements that comprise the phenomenon of interest and can severely impact the validity of a questionnaire (Buchbinder, Batterham, Elsworth, et al., 2011). Measures developed from conceptual models that inadequately address the phenomenon of interest have the potential to inadequately identify problem areas, which in turn can negatively affect services provided. Thus, scale developers have increasingly focussed on the inclusion of stakeholder perspectives (e.g. interviews and focus groups) as a critical foundation in conceptualising the phenomenon of interest to ensure elements relevant to the target population are captured (Lasch et al., 2010; FDA, 2009). When the conceptual model is used to guide the development of a measure, inclusion of stakeholder perspectives in conceptualising the phenomenon of interest has been considered fundamental to assuring content validity (Lasch et al., 2010; FDA, 2009).

**Item generation**

The generation of items is the process of constructing an item pool. The first step is to determine how items will be generated, for example, whether item writing is guided by reviews of the literature, theoretical definition of the construct, previous theoretical or empirical research on the phenomenon of interest, input from experts, and/or interviews with individuals from the target population (MacKenzie, Podsakoff, & Podsakoff, 2011). To ensure that questionnaire items reflect the phenomenon of interest, input from representative individuals from the target population is essential to improve the content validity of a measure (Lasch et al., 2010; FDA, 2009). In addition, relevant stakeholder input allows the use of language that is culturally relevant and appropriate for the intended population (Dawis, 1987).

In generating items, the initial pool of items should be as broad and comprehensive as possible, with potential redundant items in order to cover a range of content potentially relevant.
to the target construct (Barry, Chaney, Stellefson, & Chaney, 2011; Clark & Watson, 1995; Dillman, 2011). The logic underlying this process is that psychometric analyses can identify and exclude weak and unrelated items without losing predictive/explanatory power. However, psychometric analyses are unable to detect content that should be included but is not (Clark & Watson, 1995).

Key recommendations for generating quality items have been identified from the literature (Clark & Watson, 1995; DeVellis, 2011; Dillman, 2011; Hinkin, 2005; FDA, 2009), and are outlined in Table 3.1. In addition, the use of a structured item development criteria has also been advocated to guide and evaluate the item development process (Patrick et al., 2011). The criteria is considered useful to assess the quality of items and to ensure systematic decisions are made regarding the attributes of item content (Patrick et al., 2011). Example criteria for evaluating items proposed by Patrick and colleagues are presented in Table 3.1; however, these were suggestive, and it was recommended that criteria should be tailored for the purpose of the scale.

It has also been recommended that both positively and negatively worded items be represented in scales in order to minimise ‘agreement’ or ‘acquiescence bias’ (DeVellis, 2011). Negatively worded items are phrased to indicate low levels, or absence of the trait. These items have been included in scales to ensure that participants pay greater attention to the content of the
Table 3.1

Key recommendations for generating quality items (Clark & Watson, 1995; DeVellis, 2011; FDA, 2009; Hinkin, 2005) and example criteria for evaluating new items (Patrick et al., 2011)

<table>
<thead>
<tr>
<th>Key recommendations for generating quality items</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Language should be simple, straightforward, and appropriate for the reading level of the measure’s target population</td>
<td></td>
</tr>
<tr>
<td>Trendy or colloquial expressions that may become out dated, and/or language for which familiarity will vary widely with age, ethnicity, region, gender and so on should be avoided</td>
<td></td>
</tr>
<tr>
<td>Items are written to ensure variability in responses</td>
<td></td>
</tr>
<tr>
<td>Complex or double barrelled items that assess more than one characteristic should be avoided</td>
<td></td>
</tr>
<tr>
<td>Items should be worded carefully as the exact phrasing of the items can exert a profound influence on the construct that is actually measured</td>
<td></td>
</tr>
<tr>
<td>Exceptionally lengthy items should be avoided to reduce complexity and improve clarity</td>
<td></td>
</tr>
<tr>
<td>Items should be worded so that content is relevant to all potential respondents from the target population (e.g., appropriate for caregiving across many cancer types and all cancer stages)</td>
<td></td>
</tr>
<tr>
<td>Items should be worded so that respondents with varying levels of caregiving experiences can find a response option that is reasonably appropriate</td>
<td></td>
</tr>
<tr>
<td>Items should be phrased to maximise willingness to answer truthfully</td>
<td></td>
</tr>
</tbody>
</table>

Criteria for evaluating new items proposed by Patrick and colleagues (2011)

| The item captures the intended concept |  |
| The item is relevant to all members of the target population |  |
| The item is worded in a manner consistent with language used by the target population |  |
| The item reflects different levels of magnitude (e.g., severity, frequency) |  |
| The item represents a single concept, rather than multiple concepts |  |
| The item is not likely to be vulnerable to ceiling or floor effects within the target population |  |
| The content of the item is appropriate for the recall period |  |
| The content of the item is appropriate for the mode of administration |  |
| The response scale corresponds with the stem |  |

items and provide responses that more accurately reflect the phenomenon of interest (Barnette, 2000). However, negatively worded items could also confuse many individuals, leading to errors, or item non-response (Kline, 2005). Moreover, it has been shown that combining positively and negatively worded items can adversely impact the internal consistency of a measure, as negative items are not considered a direct opposite of positive items (Barnette, 2000). As the measure was intended for people with a range of education levels, only positively worded items were included in the development of the new measure.

Chapter 4. Processes of scale development
**Item generation: Item difficulty**

An additional consideration when generating items is to ensure that items within each scale collectively represent the full range of the construct, in order to identify individuals with low, moderate and high capacities. Scales that distinguish individual levels of capacity are useful in tailoring services to meet the needs of the individual. One method of achieving this is to ensure items within scales have a range of ‘difficulty’ levels. The difficulty (or threshold parameter) of an item refers to the extent to which an item is difficult for individuals to respond correctly (DeVellis, 2011), or the difficulty for an individual to endorse the extreme response (e.g., choosing 1 or 5 on a 5-point scale (Raykov, 2012). In theory, if an individual responds positively for a difficult item, they will be more likely to respond positively on all easier items; conversely, individuals who respond negatively to an easy item, will also respond negatively to items with greater difficulty (De Vet et al., 2011). Thus, the higher an individuals’ level of trait in relation to the difficulty of an item, the higher the probability of a positive response to that item.

Recent studies have used the revised version of Bloom’s taxonomy (Krathwohl, 2002) to guide the development of items for health literacy measures (Leung, Lou, Cheung, Chan, & Chi, 2012; Osborne et al., 2013). The taxonomy was originally developed to classify levels of learning and changes in cognitive processes during learning (Bloom, Engelhart, Furst, Hill, & Krathwohl, 1956). The revised taxonomy includes six categories of cognitive processes with increasing complexity: remembering, understanding, applying, analysing, evaluating, and creating. In general, higher order processes (such as analysing, evaluating, and creating) are considered more difficult as they require some mastery of the lower order processes (such as remembering, understanding and applying).
Generation of the response format

As part of item generation, the scale developer must also consider the response format to use. Considerations when deciding on a response format include: the number of response options, how responses are presented, and whether options are weighted or unweighted (Dawis, 1987). Likert-type and dichotomous scales are the most frequently used response formats, although others are available (Clark & Watson, 1995). The range of response formats and their advantages and disadvantages are outlined in Table 3.2.

An important consideration when determining a response format is the number of response options (DeVellis, 2011). A response format with many options may generate greater variability in responses. However, the range of options may limit the respondent’s capacity to discriminate meaningfully, and introduce random responding which increases the error attributable to the observed scores (Clark & Watson, 1995). By contrast, a dichotomous response format with limited options allows completion of many items in a short amount of time. However, the limited response options provide little variability, and have the potential to affect the quality or breadth of information obtained (Clark & Watson, 1995).

For Likert-type scales, 5-point and 7-point scales have been widely adopted (Lozano, García-Cueto, & Muñiz, 2008), although the optimal number of response options reported in
Table 3.2

Examples of response formats in scale development (adapted from Clark & Watson, 1995; DeVellis, 2011)

<table>
<thead>
<tr>
<th>Response format</th>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dichotomous responses</td>
<td>Two response options (e.g., yes / no, true / false)</td>
<td>Simple to complete, and non-time consuming</td>
<td>Has minimal variability, and as such, has the potential to provide unbalanced response distributions which can lead to distorted correlational results (Clark &amp; Watson, 1995; DeVellis, 2011).</td>
</tr>
<tr>
<td>Checklists</td>
<td>Scales that permit respondents to scan a list and check only the options that apply</td>
<td>Easy to administer and score</td>
<td>Susceptible to response bias compared to formats that require a response for every item (DeVellis, 2011)</td>
</tr>
<tr>
<td>Visual analogue scales</td>
<td>Visual analogue scales provide a free range of response options</td>
<td>Most useful when a single (or few) measurement is desired and the target construct is either very simple or represents a summary judgment.</td>
<td>Rarely used for multi item scales because they are extremely laborious to score</td>
</tr>
<tr>
<td>Forced choice formats</td>
<td>A number of alternatives that represent different constructs are listed. Participants are asked to choose a response they support most strongly.</td>
<td>Do not allow for neutral or undecided responses</td>
<td>Resulting score reflect “only the relative intra-individual strength of the assessed constructs and do not provide normative, Inter-individual information” (Clark &amp; Watson, 1995, p. 316).</td>
</tr>
<tr>
<td>Likert type scales (Likert, 1932)</td>
<td>A number of response options presented on a continuum that indicate varying degrees of agreement or endorsement of an item (for example, strongly agree to strongly disagree)</td>
<td>Have the potential to provide reliable and stable results when scales are well constructed. Easy to administer and score.</td>
<td>Susceptible to response bias (e.g. social desirability bias). In addition, the assumption of equal intervals between points on the scale is not always justified.</td>
</tr>
</tbody>
</table>
studies have been inconsistent (Weng, 2004). Early researchers asserted that the number of response options has no effect on reliability scores (Jacoby & Matell, 1971; Schutz & Rucker, 1975). By contrast, others have suggested that reliability is maximised with specific response options, although the options range from 3-point (Matell & Jacoby, 1972), 5-point (Contractor & Fox, 2011; Cox III, 1980), 7-point (Preston & Colman, 2000), and up to 17-point scales (Matell & Jacoby, 1971). Despite decades of research, the optimal number of response options for Likert-type scales is undetermined, with agreement only in that the minimum number of response options to ensure adequate reliability is four categories (Lozano et al., 2008; Weng, 2004). Current methodological studies in the area have advocated response options with between four and seven categories to optimise the psychometric properties of the scales (Lozano et al., 2008; Preston & Colman, 2000), while allowing the respondents to make a meaningful choice among the response alternatives (Viswanathan, Sudman, & Johnson, 2004).

When using Likert-type scales, an additional consideration is the inclusion of a mid-point (i.e., odd or even number of response options). Proponents of including a midpoint state that some respondents may have a neutral stance, and thus require a middle option (Nunnally, 1967; Schuman & Presser, 1981). Moreover, the inclusion of a middle point has the added benefit of making respondents feel more comfortable when selecting a response option. However, opponents of the midpoint argue that the midpoint provides an easy option for respondents when their interpretation of an item is unclear, and has the potential to encourage social desirability bias (i.e., respondent’s desire to please the respondent, appear helpful, or not give what they perceive to be a socially unacceptable answer; Clark & Watson, 1995). By contrast, an even number of response options (e.g., four or six) forces respondents to make at least a weak commitment in the direction of one or the other extreme, for example, to either agree or disagree.
(Clark & Watson, 1995; DeVellis, 2011). Although exclusion of a midpoint has the potential to increase data quality, studies on optimal response options have not identified a preference for an odd or even number of categories (Preston & Colman, 2000).

**Review of initial item pool by experts**

Prior to testing the questionnaire with individuals from the target population, expert review of the draft item pool has the potential to assist with maximising the content validity (DeVellis, 2011). Specifically, review of the items by individuals with extensive experience related to the phenomenon of interest has the potential to improve content validity by: 1) confirming or validating the definition of the phenomenon by identifying how relevant each item is to the measure; 2) assessing the clarity or conciseness of items; and 3) identifying items or content that taps into the phenomenon not already included in the measure (Worthington & Whittaker, 2006). However, DeVellis (2011) cautioned the scale developers to carefully consider the suggestions provided by experts, as content experts may not understand the principles of scale construction, which can lead to erroneous advice. Thus, the scale developer must pay careful attention to the suggestions received from experts, prior to accepting or rejecting their advice.

**Cognitive interviewing**

Cognitive interviewing is frequently used in questionnaire development to assess whether respondents interpret and respond to questionnaire items in the way the researchers intended (Willis, 2005). The process evaluates questionnaire items by asking respondents to explain their cognitive processes when responding to items (Willis, 2004). Specifically, semi-structured, in-depth interviews are conducted with people from the target population to determine whether 1) respondents interpret the items in the way the scale developers intended; and 2) response options...
allow respondents to reply in the way that best reflects their opinions and circumstances (Conrad & Blair, 1996). The key objective in cognitive interviewing is to identify potential sources of error associated with questionnaire items, and to modify these items when necessary (Conrad & Blair, 1996; Willis, 2005).

A consideration when conducting cognitive interviews is to determine the method in which to elicit responses from respondents. Two primary paradigms of cognitive interviewing have been proposed: 1) the ‘think-aloud’ procedure, in which interviewers facilitate respondent verbalisation of thought processes with minimal intervening; and 2) intensive interviewing with verbal probing, in which the interviewer guides the interaction more proactively, and asks additional, direct questions or probes about cognitive processes for responses (Beatty & Willis, 2007). Both cognitive interviewing paradigms have similar purposes (i.e., to evaluate whether items are understood as intended). However, the ‘think aloud’ approach employs an unobtrusive interviewing style that relies on standardised protocols and scripted probes. By contrast, the probing method employs an active interviewing style, with greater flexibility to explore topics during interviews (Beatty & Willis, 2007).

The two cognitive interviewing approaches each have their advantages and disadvantages. While the think aloud approach is relatively standardised and thus minimises the introduction of bias from the interviewer and creates less artificiality (e.g. change of content and flow) compared to the probing method, it can be more burdensome for participants, particularly if they are unable to articulate their thoughts (Conrad, Blair, & Tracy, 1999; Willis, 2005). By contrast, the probing method can provide focus on a respondent’s behaviour, and keep respondents on topic by directing attention to relevant issues with minimal interference in the process of responding (Beatty & Willis, 2007). However, probing has the potential to lead
respondents to particular types of responses, and thus introduce bias into responses (Willis). Despite the differences in approaches, given the similar objectives of the two paradigms, Willis concluded that researchers could, in practice, adopt both methods according to the needs of the research.

Another consideration prior to conducting cognitive interviews is whether to ask questions concurrently with administering the items, or retrospectively after the questionnaire has been completed (Willis, 2005). Although asking questions concurrently with administering items can be helpful in assessing a respondent’s thoughts as they occur, it has been suggested the think aloud process may interfere with the response process due to verbal information being collected during the creation of a response (Redline, Smiley, Lee, & DeMaio, 1998; Russo, Johnson, & Stephens, 1989). By contrast, the retrospective approach is better suited for the administration of self-report questionnaires, by replicating the real life situation in which respondents complete the items individually.

**Initial field testing**

To determine the clinical and research utility of the scale, the next step in the scale development process is to administer the draft items to individuals from the target population (Clark & Watson, 1995; DeVellis, 2011). Field testing is an important step to: evaluate the factor structure (structural analysis) of the scale; assess relationships between the observed items and the latent construct (i.e., item fit); and identify poorly performing or redundant items for removal or revision from the scale (i.e., item analysis; Dillman, 2011). Evaluating convergent and discriminant validity, and internal consistency of the measure are also key components of field testing. The processes related to structural analysis, item analysis, convergent and discriminant
validity, internal consistency, and sample size considerations in field testing are presented in the following sections.

**Structural analysis**

A vital criterion in establishing the construct validity of a scale is to establish that the structure, or factors within the measure are comprised of items that represent a single, underlying construct, also referred to as being factorially simple or homogeneity (see Figure 4.2; De Vet et al., 2011; DeVellis, 2011; Hair et al., 2010). It has been argued that factorial simplicity within scales is particularly important when measures are to be used for needs assessment or program evaluation where unambiguous measurement of constructs is crucial (Osborne et al., 2013). Scales that contain items that are factorially simple are considered unidimensional. Items that load on more than one factor, are referred to as ‘factorially complex’ (Nunnally & Bernstein, 1994). Factorially complex items are undesirable in a measure for a number of reasons. A scale comprised of factorially complex items is non-unidimensional, and creates ambiguity in the interpretation of change in an observed variable because it is uncertain which underlying factor caused the observed change. In addition, a significant relationship between two items of different factors may suggest problems with the internal convergent and discriminant validity of a measure (Hair et al., 2010). Structural analysis allows the identification of items that best represent their specified factor, and enables identification of poorly performing or redundant items for revision or removal (DeVellis, 2011). Factor analysis is a statistical method frequently used to conduct structural analysis and to determine validity of a measure. Factor analysis and its family of procedures are described in the following section.
Overview of factor analysis

Factor analysis is a multivariate statistical technique designed to analyse patterns of complex, multidimensional relationships among variables at a group level (Hair et al., 2010). The purpose of factor analysis is to examine the structure of relationships (also known as correlations) among a large number of observable variables (e.g., questionnaire items) by identifying or confirming one or more underlying latent construct(s) that account(s) for the correlations (Child, 1990; Hair et al., 2010). Variables with high inter-correlations are assumed to measure a single underlying construct, also known as a ‘factor’, whilst variables with low inter-correlations are assumed to measure a different underlying construct (Brown, 2006).

There are two main categories of factor analysis: exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). The major difference between the two categories of factor analysis is that EFA is an inductive approach that does not specify a preconceived structure and aims to explore the underlying factor structure of a set of observed variables (Child, 1990). By contrast, CFA is a deductive approach that aims to confirm or reject a preconceived structure that
hypothesises relationships between observed variables and underlying latent constructs (Child, 1990). A brief overview of EFA and CFA and related analyses is provided below.

*Approaches to factor analysis: Exploratory and confirmatory*

Factor analysis is commonly divided into two approaches, exploratory factor analysis (EFA), and confirmatory factor analysis (CFA). In EFA, when identifying the properties of a set of items, relationships between items are explored without *a priori* knowledge or structure about the composition of the measurement model (Child, 1990; Floyd & Widaman, 1995). Rather, EFA aims to group variables with high correlations together in order to determine the underlying factor structure (Hair et al., 2010). To identify the number of factors, a correlation matrix is used to identify general factors (latent constructs) that explain the covariance among the items (Fayers & Hand, 1997). For solutions with more than one factor, the extracted factors are rotated in order to improve the psychometric properties and interpretability of the measurement model (Tabachnick & Fidell, 2012). Factor rotation manipulates the reference axes that represent the underlying factors until a factor solution is uncovered. To uncover the simple structure, various rotation methods are available, including orthogonal (uncorrelated relationships between factors) and oblique factors (factors are allowed to correlate; Child, 1990).

By contrast, the purpose of CFA is to confirm the factor structure of a predefined measurement model (Child, 1990). In CFA, hypotheses about the number of factors and a separate set of items for each factor are predefined *a priori* and tested for their fit with the observed correlation matrix (Jöreskog, 1969). By contrast to EFA, which has the potential for multiple solutions, CFA is ‘restricted’ to the predefined measurement model. The hypothesised factors within the model, and thus its internal convergent validity, is ‘confirmed’ when the model
demonstrates good fit with the data (Brown, 2006). Although the aim of CFA is to assess the overall fit of a hypothesised model, CFA is not always strictly confirmatory, that is predefined models can be modified until acceptable solutions have been demonstrated (Jöreskog, 1969; Jöreskog & Sörbom, 1993). Alternatively, when an initial model fit is not satisfactory, CFA can be used in an exploratory manner in order to find an optimal factor solution by specifying several competing models (Jöreskog, 1969; Jöreskog & Sörbom, 1993).

**Confirmatory factor analysis processes**

As the hypothesised constructs for the caregiver health literacy measure were specified *a priori*, CFA was used in this thesis. Three processes have been proposed to evaluate the fit of a measurement model. A one-factor CFA model is firstly conducted for each hypothesised domain and their respective items. One-factor CFA analysis assists with determining how well an item fits within their hypothesised domain, and enables identification of poorly performing and redundant items, through examination of factor loadings, explained variance, and correlated errors. Fit of the one-factor CFA model with the data and magnitude of item loadings on the factor also provides evidence for internal convergent validity (extent to which indicators [i.e., items] of a specific construct share a high proportion of variance; Hair et al., 2010) of a hypothesised factor.

Pairwise CFA models are then conducted on all possible pairwise combinations of factors to determine whether items are uniquely associated with their hypothesised factor (Anderson & Gerbing, 1988). Pairwise CFA analyses enable identification of items that demonstrate loading onto a factor other than their originally specified factor (i.e., factorially complex) or items with inter-factor correlated errors (i.e., correlated errors between items from different hypothesised
factors) for revision or removal. Pairwise CFA analyses also enable examination of whether factors are distinct, and not highly correlated with other factors (i.e., no factor cross loadings), which provides support for discriminant validity of the scale.

A full factor CFA model is evaluated in the final step to determine model fit. Results from the full factor model also provide evidence to determine discriminant validity of the domains, or presence of higher order factor(s), by examining inter-factor correlated errors or factor cross-loadings.

**Evaluating model fit**

To assess whether the hypothesised model fits the data, acceptable levels of ‘goodness of fit’ must be established (Yuan, 2005). Model fit compares the hypothesised model to the observed data by assessing the similarity of the estimated covariance matrix (i.e., hypothesised model) to the observed covariance matrix (observed scores; Hair et al., 2010). The closer the values of the observed and estimated covariance matrices, the better the model is said to fit, with a perfect model fit established if the two matrices were the same (Hair et al., 2010).

To establish measurement model validity, a number of goodness of fit indices have been developed. Three types of fit indices have been proposed when evaluating the fit of a model: absolute, incremental, and parsimonious (Gerbing & Anderson, 1988). These three types of fit indices are presented in the following sections.

Absolute fit indices assess how well the *a priori* model reflects the observed scores, and are a direct measure of differences between the estimated and observed covariance matrices (Hair et al., 2010; Hu & Bentler, 1999). A basic assessment of model fit is provided, rather than an explicit comparison of the goodness of fit with an alternative model as a base for comparison.
Examples of absolute fit indices include the: chi square $\chi^2$, and Weighted Root Mean Square Residual (WRMR).

The chi square $\chi^2$ test is the most commonly used to assess absolute fit, and examines whether a null hypothesis is plausible in the population (Hooper, Coughlan, & Mullen, 2008; Hu & Bentler, 1999). A significant chi square indicates the rejection of a null hypothesis, which suggests that the model is not a good fit in the population (Bollen & Long, 1993). The chi square test represents indexes that range from zero to one, with zero indicating a perfect fit, and one indicating a complete lack of fit. However, the chi square test (similar to other goodness of fit tests) is sensitive to sample size, with chi square ratios increasing as the sample size increases (Bollen & Long, 1993). Thus, although a model may fit the data reasonably well, the probability of rejecting a model increases as the sample size increases (Lei & Wu, 2007). Similarly, a model with poor fit may be accepted due to a non-significant chi-square attributed to a small sample size (Yu, 2002). Chi square values are also affected by model size and the distribution of variables. Specifically, models with greater variables tend to result in larger chi square ratios. In addition, highly skewed and kurtotic variables also increase chi square ratios. As such, chi square is often used in addition to other goodness of fit tests to assess model fit.

Due to the sensitivity of the chi square statistic to sample size, examination of additional indices of model fit have been recommended (Brown, 2006; Kline, 2011; Worthington & Whittaker, 2006). The Weighted Root Mean Square Residual (WRMR) developed by Muthen and Muthen (1998-2012) was an additional index of model fit developed in response to the chi square statistic’s sensitivity to sample size. WRMR reflects the average amount of variance and covariance not accounted for by the model (Yu, 2002). WRMR is considered suited for models whose variables have unequal variances, whose variables are assessed using different scales, and
for models with non-normally distributed data (Muthen & Muthen, 1998-2012; Yu, 2002). Values range from zero to one with smaller WRMR values indicating less unexplained variance, with values less than 0.05 indicating better fit (Muthen & Muthen, 1998-2012).

Incremental fit indices, also known as comparative (Bentler, 1990) or relative fit indices (McDonald & Ho, 2002) differ from absolute fit indices because they establish the proportionate improvement in fit by assessing the estimated model with a more restricted baseline model, nested baseline model where all covariances equal zero (Bentler, 1990). The most typically used baseline model (i.e., null hypothesis) is that all observed variables are uncorrelated (McDonald & Ho, 2002). A commonly used incremental fit index is the Comparative Fit Index (CFI; Bentler, 1990) that has demonstrated good performance with categorical data (Yu, 2002). An advantage of CFI is its resilience to small sample size (Tabachnick & Fidell, 2012). The values for CFI range from zero to one with values closer to one indicating good fit (Hooper et al., 2008). To ensure misspecified models are not accepted, the recommended threshold is 0.95 (Hu & Bentler, 1999). Another incremental fit index is the Tucker Lewis Index (Bollen, 1989; Tucker & Lewis, 1973), which assesses improvement in fit of the estimated model based on degrees of freedom. However, the TLI is sensitive to sample size, and can indicate poor fit, when other indices suggest a good fit (Kline, 2011; Tabachnick & Fidell, 2012). The recommended threshold for TLI is $\geq 0.95$ (Hu & Bentler, 1999).

Parsimonious fit indices are designed to identify the best model, among a range of competing models, by considering its fit relative to its complexity (Hair et al., 2010). Models with many estimated paths, reduces the model’s parsimony, thus, a parsimony fit measure is improved either by a better fit, or by a simpler model (i.e., fewer estimated parameter paths; Hair et al., 2010). The Root Mean Square Error of Approximation (RMSEA; Steiger & Lind, 1980) is
a commonly used parsimony corrected measure of fit (Browne & Cudeck, 1993). RMSEA focuses on the discrepancy between the model and observed covariance matrices per degree of freedom, with the results favouring the model that provides a good fit for the observed scores using fewer parameters. RMSEA values of 0.05 or less is considered a good fit, values between 0.06 and 0.08 reasonable fit, and values 0.08 to 0.1 mediocre fit, and values greater than 0.1 considered poor fit (Diamantopoulos & Siguaw, 2000; Yu, 2002). For this thesis, CFA models were considered to demonstrate good fit with the observed scores using the following cut-off values of fit indices:

- Chi-square goodness of fit: \[ p < 0.05 \]
- WRMR: \[ \leq 1.00 \]
- CFI: \[ > 0.95 \]
- TLI: \[ > 0.95 \]
- RMSEA: \[ < 0.08 \]

**Item analysis**

To ensure inclusion of items in the scale that best represent their specified factor, item analysis is also conducted. Traditionally, scale developers use only one measurement theory to guide item analysis, although the complementary nature of using both CTT and IRT at various stages of analysis has been acknowledged (De Champlain, 2010; Ellis & Mead, 2002). Specifically, De Champlain has proposed that CTT is a useful approach in the early stages of scale development to identify potential errors, with IRT useful as a subsequent approach to estimate final item difficulties and individual capacities. Thus, combining both measurement theories has the potential to provide a more thorough assessment of item characteristics than using either theory in isolation, and result in a more psychometrically robust measure (Ellis & Mead, 2002).
Item analysis in this thesis was performed using a range of approaches derived from Classical Test Theory and Item Response Theory. Although comprehensive descriptions of CTT and IRT are beyond the scope of the study, an overview of CTT and IRT, and their family of approaches are provided in the following sections.

*CTT and IRT in item analysis*

CTT and IRT are similar in that they both assume that individual responses to scale items represent observed manifestations of a latent construct (e.g., anxiety, or depressive symptoms; Streiner & Norman, 2008). In addition, both theories assume that observed scores are imperfect indicators of individual levels of the underlying variable, which are affected by varying degrees of error. However, the theories differ in their representation of the relationship between the latent and observed variables, and their interpretation of measurement error (Hambleton & Jones, 1993; van der Linden & Hambleton, 1997). A limitation of CTT is that analyses provide information at domain levels, rather than at individual item level, and although item analyses can be generated, the results are not generalisable outside of the targeted sample (Tabachnick & Fidell, 2012). On the other hand, IRT was developed to address the limitations of CTT, with the purpose of assessing the relationship of each item to the latent variable, independent of the targeted sample (DeVellis, 2011). By contrast to CTT that has relatively weak assumptions which enable application across many testing situations (Fan, 1998), IRT analysis is complex, and stronger assumptions must be met in order to yield robust results (De Champlain, 2010).

*Classical test theory*

In brief, classical test theory is the traditional and widely used approach to scale development, and assumes that the observed score is comprised of a true score and an error score.
(Tabachnick & Fidell, 2012). The observed score is an individual’s score on the scale whilst the true score represents the amount of latent trait possessed by an individual. The true score is defined as an individual’s hypothesised mean score over an infinite number of testing sessions (Kline, 2005). The error score on the other hand, represents random variation, in response to scale items (De Vet et al., 2011). The less random error in the measure means the greater likelihood the observed score reflects the true score.

The foundations of CTT rest on several assumptions about random error. These assumptions include: 1) that random error is normally distributed, and thus, over repeated testings, the expected value of error is zero; 2) random error is uncorrelated among items; and 3) random error is uncorrelated to the true scores (De Vet et al., 2011; Kline, 2005; Nunnally & Bernstein, 1994). These assumptions guide the basis of factor analytic approaches to item analysis (i.e., exploratory and confirmatory factor analysis, detailed in following sections), where the true score component of each item is represented by the amount of variation (also known as variance) it shares with other items in the set (Nunnally & Bernstein, 1994; Streiner & Norman, 2008). Items with larger amounts of shared variance are said to have less random error, and thus, represent their underlying construct with greater accuracy, and have strong relationships with their construct (Clark & Watson, 1995).

In this thesis, using CTT approaches, results from one-factor and pairwise CFA models related to factor loadings, amount of variance explained by the specified factor in a given item ($R^2$), and factor cross-loadings were used to determine the item fit and dimensionality of a scale. Items with factor loadings less than 0.55 (Comrey & Lee, 1992), explained variance less than 0.50, or cross-loadings $\geq 0.32$ (Tabachnick & Fidell, 2012) were considered problematic and
were flagged for revision or deletion. The following section outlines IRT and its usefulness in evaluating item fit.

*Item response theory*

As outlined in earlier sections, the statistical technique IRT was developed to address limitations of CTT. By contrast to CTT, which focuses on the amount of error for specific scales, IRT models assess the probability that an individual will endorse items in a particular direction (e.g., agree/disagree) according to their overall ability in relation to the latent trait (Reeve & Fayers, 2005). In addition, whilst CTT assumes that the relationship between each item to the specified construct is equal and is strengthened by their aggregation as a scale, IRT assesses the relationship of each item to the latent trait (DeVellis, 2011).

Rather than one specific theory, IRT is comprised of several probabilistic models, differentiated by the number of item parameters assessed. A commonly used model in scale construction is the three-parameter model, which assesses three parameters of an item’s performance, including ‘difficulty’, ‘discrimination’, and ‘susceptibility to false positives’. However, given the current study aims to develop a measure with no right or wrong response options, only models that assessed an item’s difficulty will be used. These models are also known as a one parameter model, which is outlined below.

*One-parameter model (i.e., Rasch model)*

The one-parameter model, or also referred to as the Rasch model is the simplest IRT model and establishes the relationship between an individual’s trait level and a given item, based on the probability of endorsing an item of particular *difficulty* by an individual with a certain trait level (Streiner, 1994). The *difficulty* (or threshold parameter) of an item refers to the extent to
which an item is difficult to respond to positively (DeVellis, 2011). Specifically, the one-parameter model estimates the construct level required in order to have a 50% chance of endorsing an item (Hays, Morales, & Reise, 2000). As presented earlier, the principle is that if an individual responds positively for a difficult item, then the probability is they will respond positively for all items that are easier, and conversely, individuals who respond negatively to an easy item, will respond negatively to more difficult items (De Vet et al., 2011). Thus, if an individual possesses a greater amount of the phenomenon of interest in relation to the difficulty of an item, then the probability of a positive response to that item will increase. To estimate item difficulty, for each item, all participant responses are summed, with higher values indicating items that are more difficult (Fan, 1998). The observed raw scores and item difficulty are computed using a nonlinear transformation into log of the odds (also known as logits), which places items and individuals on one scale of measurement (Hays et al., 2000).

The relationship between the predicted responses to an item and the latent trait is represented by an s-shaped curve, known as the item-characteristic curve (ICC; Hays et al., 2000). The ICC graphically presents the expected probability of endorsing a particular response option (y-axis) as a function of an individual’s trait level (x-axis). The point of inflection of the curve is known as the item threshold, and refers to the point at which an individual has fifty percent likelihood of endorsing a particular item (Hambleton, Swaminathan, & Rogers, 1991). The item threshold represents an item’s difficulty parameter, and is calculated as an expected value of an item based on: how individuals have responded to all items, and how all individuals in the sample have responded to each item. The ICC for easier items will be located further to the left on the trait scale, and more difficult items will be located further to the right (Hays et al., 2000).
Items are accepted or rejected based on an assessment of the model fit between the Rasch model and the data (Hair et al., 2010). Good fit between the Rasch model and data is achieved when individuals with high levels of the latent trait consistently endorse items of greater difficulty (Edelen & Reeve, 2007). However, model misfit occurs when individual responses deviate from those predicted by the Rasch model (Hair et al., 2010).

Good model fit is demonstrated by item thresholds that are hierarchically ordered from lowest to highest. However, a model misfit indicates a lack of expected probabilistic relationship between an item and other items within a scale, or a lack of ordered responses, also known as ‘disordered thresholds’ (Lamoureux, Pallant, Pesudovs, Hassell, & Keeffe, 2006). Disordered thresholds occur when item responses do not accurately reflect increasing levels of a latent trait. Disordered thresholds tend to occur when there are too many response options, or when the response options are ambiguous, or similarly labelled (Lamoureux et al., 2006).

Since the interpretation of item scores for the caregiver health literacy measure implicitly assumes that a higher score represents higher levels of caregiver health literacy, the assessment of threshold ordering provides valuable information on the measurement properties of scale items. In this thesis, items with disordered thresholds will be considered for revision or removal.

Establish convergent and discriminant validity

As outlined in previous sections, to provide support for construct validity, a scale should also demonstrate evidence of internal convergent validity, and discriminant validity. Internal convergent validity for each domain can be assessed by inspecting fit of a one-factor CFA model with the data, and magnitude of factor loadings. Good overall fit of a CFA model, and high factor loadings is interpreted as supporting internal convergent validity of a given domain.
Discriminant validity can be determined by inspecting results from pairwise and full factor CFA models. High inter-factor correlations from the pairwise models or from the 10-factor model suggest poor discriminant validity of the domains or the presence of a higher order factor(s) (Kline, 2011).

**Establish internal consistency**

Internal consistency is an index related to factorial simplicity and homogeneity of a scale, and refers to the extent to which items measure the same construct (Nunnally & Bernstein, 1994). Thus, internal consistency is concerned with the interrelatedness, or inter-correlations within of a set of items (Tavakol & Dennick, 2011). However, internal consistency is a necessary, but not sufficient condition to demonstrate the factorial simplicity of a scale (Hattie, 1985). Internal consistency is also a widely used method to demonstrate the reliability of a scale. Although Cronbach’s alpha coefficient is a widely referenced index of internal consistency, it assumes that items within a factor have equal factor loadings, and thus, is known to under- or over-estimate population reliability (Raykov, 1998). By contrast, Raykov (1997) has argued that the composite reliability coefficient, which is based on the polychoric correlation matrix, provides unbiased estimates of reliability. Cut-off scores for composite reliability are similar to those for Cronbach’s alpha, with values between 0.70–0.95 considered acceptable (Terwee et al., 2007).

**Sample size considerations for field testing**

Adequate sample size is an important consideration during initial field testing; however, the sample size recommendations vary between researchers (Hogarty, Hines, Kromrey, Ferron, & Mumford, 2005). Two types of approaches have been proposed for sample size calculation. The first approach recommends a sample size based on the overall number of respondents.
included in the sample, however the optimal sample size proposed is inconsistent. For example, some authors have suggested an overall sample size of 100 or greater (Hair et al., 2010), whilst other authors have recommended a minimum of 300 respondents based on evidence regarding the stability and replicability of statistical analyses (Clark & Watson, 1995; Tabachnick & Fidell, 2012). Hair et al. (2010) proposed the following guidelines regarding overall sample sizes for initial field testing: 100 = poor, 200 = fair, 300 = good, 500 = very good, and 1000 or more = excellent.

The second approach for determining sample size is based on the minimum ratio of the number of respondents to the number of items in the scale. For example, respondent-to-item ratios have ranged from 3:1 to 20:1 (Everitt, 1975; Floyd & Widaman, 1995; Gorsuch, 1983; Hair et al., 2010; Tabachnick & Fidell, 2012; Thompson, 2004). Studies have suggested that when communalities (proportion of the variance in a variable that can be accounted for by all extracted factors; Cattell, 1966) are high, then good recovery of population parameters is possible with small sample sizes (MacCallum, Widaman, Zhang, & Hong, 1999). However, when communalities are low, and factors are weakly determined, larger sample sizes (e.g. 300 to 500) are recommended (MacCallum et al., 1999; Worthington & Whittaker, 2006).

**Chapter Summary**

In this chapter, an overview of the important concepts and processes associated with the development of a new measure to enhance content and construct validity was presented. The purpose of initial field testing, and an overview of factor analytic approaches including exploratory factor analysis and confirmatory factor analysis to examine structure of scales were introduced, and explanations of model fit indices were provided. Approaches to item analyses derived from the two measurement theories, CTT and IRT, were detailed, and a justification of Chapter 4. Processes of scale development
combining approaches from the two theories was provided. The processes to guide scale
development were carefully chosen to ensure the resultant cancer caregiver health literacy scale
has sound psychometric properties to provide useful information in clinical practice, policy
development, and research. The concepts and processes detailed in this chapter will be referred
to extensively throughout the remainder of the thesis in describing the development of a new
measure of caregiver health literacy. The following chapter details the methods used in this
thesis to address two of the study’s objectives: to develop a conceptual model of cancer caregiver
health literacy, and to develop a comprehensive measure of health literacy of cancer caregiver
health literacy.
Chapter 5. Method

Chapter Overview

In chapter 5, an overview of the research methods used in the three cross-sectional studies detailed in chapters 6, 7, and 8 are presented. Chapters 6-8 are each comprised of a manuscript, B, C and D. Both qualitative and quantitative research methods were employed, with methods for each study chosen to maximise reliability and rigor of the results. The different methods used to address each of the research objectives are summarised in Table 5.1.

There are three main sections to this chapter. In the first section, the study objective, research design and research method for Manuscript B, “Development of the conceptual model of cancer caregiver health literacy” are presented. Described are the processes for conducting grounded theory and structured group conceptualisation (also known as concept mapping) with key stakeholders. The methods to synthesise and integrate concept mapping workshop data are also detailed. The section concludes with an overview of inclusion criteria for participants and recruitment for the study.

In the second section, a brief overview of the study objective and research design for Manuscript C, “Development of the Health Literacy of Caregivers Scale-Cancer (HLCS-C): Item generation and content validity testing”, is provided. In the final section of the chapter, the study objective and research design for Manuscript D “Measuring cancer caregiver health literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C)”, are described.

As some details were already covered in the ‘Methods’ sections of manuscripts B, C, and D, in the current chapter, the author sought to provide details that were not already addressed. Thus, discussion of the methods for each manuscript differs in content and length.
## Table 5.1

<table>
<thead>
<tr>
<th>Research objective</th>
<th>Manuscript</th>
<th>Research methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop a conceptual model that describes the constituent elements of health literacy of caregivers of people with cancer</td>
<td>B</td>
<td>Concept mapping workshops</td>
</tr>
<tr>
<td>Develop and assess the content validity of a conceptually-driven scale to measure caregiver health literacy in cancer populations</td>
<td>C</td>
<td>Validity driven approach to questionnaire development</td>
</tr>
<tr>
<td>Build upon the content validity testing of the HLCS-C and: 1) identify and remove poorly performing and redundant items; and 2) determine the scale’s construct and discriminant validity, and internal consistency</td>
<td>D</td>
<td>Psychometric evaluation using confirmatory factor analysis and item response theory</td>
</tr>
</tbody>
</table>

### Manuscript B. Development of the conceptual model of cancer caregiver health literacy

**Study objective.**

The objective of Manuscript B was to develop a conceptual model that describes the constituent elements of health literacy of caregivers of people with cancer. In scale development, a conceptual model serves three major purposes: identification of dimensions that comprise the target construct; identifying relationships between the dimensions; and assisting with the identification of a measurement model that can be used for the construct validation of the scale within the structural equation modelling framework. The study sought to address the following research question: “What are the constituent elements required in a comprehensive model of caregiver health literacy?”
Chapter 5. Method

Research design.

Given the lack of theory available on health literacy for caregivers of people with a chronic condition (see Chapters 2 & 3), qualitative research methods were considered the best approach to identify elements that comprise caregiver health literacy from the perspective of key stakeholders. The overarching purpose of qualitative research methods is to understand social behaviour, complex processes of interaction, and aspects of a phenomenon of interest from the perspectives and experiences of individuals in their social setting (Patton, 2005). Thus, qualitative approaches are particularly useful for gaining insight into situations and phenomena of which there is limited knowledge (Berg, 2004; Mays & Pope, 2000; Pope, Ziebland, & Mays, 2000; Silverman, 2013). One particular qualitative approach, grounded theory was considered the best approach for the study since its purpose is to generate theory about social phenomena that is ‘grounded in’ or derived from, the data (Lingard, Albert, & Levinson, 2008). It has been argued that a strength of this approach is its capacity to generate theory empirically derived from real-world situations via an inductive, or ground up approach (Oktay, 2012). Grounded theory approaches have been used successfully to: build theory that reflects the realities of the research area (Corbin & Strauss, 1990; Glaser & Strauss, 1967); provide explanations for how social circumstances could explain the interactions, behaviours and experiences of the target population (Benoliel, 1996); provide higher level understanding of concepts by explaining the relationships between different concepts (Corbin & Strauss, 2008; Strauss & Corbin, 1998) and inform the development of interventions (Boychuk Duchscher & Morgan, 2004).

Grounded theory was considered the best approach for the current study for several reasons. Firstly, the purpose of the study was to identify the key elements pertinent and relevant for caregivers when finding, understanding, and seeking health information to guide the
development of a conceptual model of caregiver health literacy. This is consistent with the purpose of grounded theory, which is to develop an explanatory theory or conceptual model of human action, interaction, and social processes within their social setting (Annells, 1997; Benoliel, 1996; Charmaz, 2006; Glaser & Strauss, 1967; Oktay, 2012).

In addition, the study described in Manuscript B had a strong focus on in-depth engagement with stakeholders to understand their perspectives to guide identification of elements that comprise caregiver health literacy. The grounded theory approach was designed to avoid imposing a priori categories and concepts from the literature within the field, or from the researcher’s own views or experiences (Charmaz, 2006; Glaser & Strauss, 1967).

Further, the thesis sought to understand relationships and connections between concepts identified by caregivers as important when finding, understanding and using health information. Grounded theory processes assist the researcher to move from identifying concepts, to identifying inter-relationships between these concepts to generate theory (Bryant & Charmaz, 2007; Charmaz, 2006; Corbin & Strauss, 2008; Strauss & Corbin, 1998).

A ‘structured group conceptualisation’ process (Kane, Trochim, & Trochim, 2007) was the grounded theory approach used in the current study to understand elements that comprise health literacy for caregivers. This approach, also known as concept mapping, refers to a process which has a sequence of concrete, operationally-defined steps to produce a picture, map of ideas, or concepts of an individual or group (Trochim & Linton, 1986). Kane and colleagues have argued that concept mapping offers an additional advantage over other approaches of grounded theory data collection by combining nominal group techniques with group processes such as brainstorming and structured sorting, and multivariate statistical methods to create a shared conceptual model. Further, Creswell (2009) argued that a key advantage of this mixed methods
Overview of concept mapping processes

In brief, concept mapping was developed by American sociologist William Trochim (1989) who proposed the structured process to generate a purposeful concept map (as shown in Figure 5.1). In a concept map, a range of ideas are presented in the form of a visual picture or map (see Figure 5.2). These ideas are clustered into groups to form a complex set of ‘concepts’ to better understand the topic of interest (Trochim & Kane, 2005).

Figure 5.1. Example of a point map generated using the Concept System Software Version 1 (Trochim, 1989) during concept mapping workshops
Figure 5.2. Example of a point map with ten clusters generated using the Concept System Software Version 1 (Trochim, 1989) during concept mapping workshops

The five main steps to undertaking concept mapping workshops include: preparation, generation of statements, sorting of statements, generation of the concept map, and interpretation of the concept map. Each workshop is between 3 to 3.5 hours in duration. Participants in the study were given two refreshment breaks, one lasting 15 minutes following the brainstorming exercise, and one lasting 25 minutes following the sorting and rating tasks. The processes used in the current thesis are a modification of Trochim’s (1989) concept mapping methods for use in questionnaire development. In the following sections, the five steps undertaken for the concept mapping workshops are presented.

Preparation.

In preparation to conduct the concept mapping workshops, a seeding statement was generated for the workshop brainstorming exercise to enable generation of ideas or statements on
the topic of interest (see Table 5.2; Kane et al., 2007). The seeding statement was carefully crafted to ensure participant responses would be relevant to the phenomenon of interest (i.e., caregiver health literacy). Minor modifications were made to accommodate the different stakeholder groups. The seeding statements were developed by the researcher in consultation with a concept mapping consultant and an expert in questionnaire development.

Table 5.2

Seeding statements for the concept mapping workshops with caregivers, people with cancer, and healthcare providers/policymakers

<table>
<thead>
<tr>
<th>Participant group</th>
<th>Seeding statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers</td>
<td>Thinking broadly about your experiences in trying to look after your health and the health of your family member/friend receiving treatment… What does a person need to have in order to get and to use all of the information they need?</td>
</tr>
<tr>
<td>People with cancer</td>
<td>Thinking broadly about the experiences of people who provide support for you, when trying to look after your health and their own health… What do the people who help you need to have in order to get, and to use, all of the information they need?</td>
</tr>
<tr>
<td>Healthcare providers/policymakers</td>
<td>Thinking broadly about caregivers’ experiences in trying to look after their own health and the health of their family member/friend with cancer… What does a person need to have in order to get and to use all of the information they need?</td>
</tr>
</tbody>
</table>

Generation of statements

The concept mapping workshops comprised four main tasks. The first task invited participants to individually brainstorm ideas or statements in response to the seeding statement. Participants were asked to work individually writing down as many ideas as possible in statement form, and to capture one idea per statement to keep domains and constructs separate. No limit was imposed on the number of ideas generated. Participants were given five to 10 minutes to brainstorm ideas.
Using the nominal group process, participants were then invited by the workshop facilitator to share their statements in an egalitarian manner. Each participant in turn presented one idea on their list until all items were presented. Prior to sharing, participants were asked to participate according to two rules: the first was to share one idea per round; the second to refrain from arguing or disagreeing about a certain statement. Participants had the opportunity to state whether they thought the idea was important or whether their needs had been met (rating statements task). The facilitator clarified any unclear concepts with the group to ensure consensus with the meaning of concepts identified. All statements were entered into Microsoft Word.

**Sorting of statements**

Once all concepts had been identified, a structured task for participants to identify potential relationships between statements was conducted. All statements generated were printed onto cards for participants to sort into piles that made sense to them. Instructions for the sorting task included: there had to be more than one pile of cards, each statement could only be placed into one pile, and statements could not all be placed into one pile. However if a statement did not ‘fit’ with other statements, it could be placed in a pile on its own. The sorted piles of data were then entered into the Concept System Software Version 1 (Trochim, 1989).

**Generation of the concept map**

The concept mapping program was designed specifically to perform the analyses required for structured concept mapping, and to analyse the sorted piles of data (i.e. sorted data) generated by participants to produce the concept map. The program analyses the sorted data by performing the following processes: 1) developing a similarity matrix; 2) multidimensional scaling of the similarity matrix; and 3) hierarchical cluster analysis (Kane et al., 2007). These processes are
briefly described below.

In the first step, a square similarity matrix is produced from the sorted data that identifies the number of participants who grouped each pair of statements (Kane et al., 2007). Then, the statements are grouped according to their degree of similarity through multidimensional scaling of the similarity matrix which places the statements in a two-dimensional configuration on a ‘point map’ (Buchbinder, Batterham, Elsworth, et al., 2011). Statements, or representative points, which are sorted together frequently by participants, are placed closer on the map, and statements sorted together less frequently are placed further apart (Trochim, Cook, & Setze, 1994). Hierarchical cluster analysis using Ward’s algorithm (Everitt, 1980) is then performed on the multidimensional scaling results, or the point map, to partition the points (i.e., statements) into clusters (Kane et al., 2007). Hierarchical cluster analysis enables non-overlapping cluster groups to be configured over the “point map” into a “cluster map” for participants to view (see Figure 5.1 and 5.2).

*Interpretation of concept map*

A limitation of the concept mapping program is that it does not provide a simple mathematical solution by which a final number of clusters is included (Elsworth, Anthony-Harvey-Beavis, & Rhodes, 2006). As such, and as part of the data analysis process, workshop participants review and interpret each cluster on the concept map produced. Group consensus is used to ensure that statements are placed in the appropriate cluster and that these groupings are given a label that reflect their meaning. Group consensus is also used to confirm the contents of the map to ensure that cluster labels and statement clusters reflect group opinion.

In the final stage of the concept mapping workshop, participants are asked to review the statements and clusters within the concept map to ensure it reflected the group’s opinion.
Participants are given a list of statements grouped into clusters to review to ensure that the groupings adequately represented the meaning behind the statements. If a statement is not considered representative of the grouping, participants have the option to move the statement into another cluster. A representative name for each grouping is determined via group discussion and consensus. Once all groupings have been named, participants are given the opportunity to review all the items and clusters, and identify any items or concepts that are missing on the map. These statements or concepts are recorded on the concept map. Once group consensus has been reached regarding the clusters, the concept map is complete.

**Post-workshop analyses and integration of workshop results**

To establish the conceptual model of caregiver health literacy, following completion of the six concept mapping workshops, the concepts identified in all six workshops were refined and synthesised using a three-step mixed methods analysis. Firstly, data from individual concept mapping workshops were re-analysed using a quantitative, three-dimensional multidimensional scaling (MDS) analysis to refine the clusters. Secondly, clusters identified from individual workshops following the three-dimensional analysis were synthesised using a constant comparisons approach, known as ‘Qualitative version of Ward’s analysis’ (Elsworth et al., 2006). This was to ensure the clusters were only represented once in the conceptual model. To ensure homogeneity within the integrated clusters, a focused coding process (Charmaz, 2006) was conducted via an iterative examination of statements both within and across clusters. In the final step, a constant comparative approach was used to categorise the clusters into major categories to produce a visual hierarchical representation of the developing theory (i.e., the conceptual model). The three steps to analyse and synthesise workshop data are detailed below.
Three-dimensional analysis of workshop data.

Although similarities with two-dimensional solutions produced during the workshops are often identified (Buchbinder, Batterham, Elsworth, et al., 2011; Elsworth et al., 2006; Elsworth, Anthony-Harvey-Beavis, & Rhodes, 2008), it has been argued that three-dimensional MDS analysis of concept mapping data has the potential to identify subtle relationships and nuances between the sorted data (i.e., statements sorted into piles by participants; Elsworth et al., 2006). As such, three-dimensional MDS analysis has the potential to identify more homogenous clusters and provide a more precise statistical representation of workshop results. Thus, prior to synthesis of workshop results, data from individual concept mapping workshops were re-analysed using three-dimensional MDS analysis to ensure accurate relationships between statements and clusters were identified.

A specialised cluster analysis and MDS program, Clustan Graphics (Wishart, 2006), was used on the outputs of the data across all six workshops. A conceptual meta-matrix was produced in the form of a tree diagram that formed a systematic representation of the information for examination. Buchbinder, Batterham, Elsworth and colleagues (2011) have asserted that tree diagrams allow “examination of the division of items each time a cluster is split into smaller clusters to examine whether this split has substantive meaning” (p.4). This process has been considered useful to determine: the smallest number of clusters (most general categories) that make sense, the largest number of clusters (most refined clusters) that make sense, and to identify items that best represent each of the refined cluster (Buchbinder, Batterham, Elsworth, et al., 2011). Further, it has been proposed that within the three-dimensional analysis, results from different concept mapping workshops tend to produce similar major categories (i.e., the smallest number of clusters that make sense). Thus, results across workshops could be combined at this
level, with refined concepts identified from individual concept mapping workshops included to provide the meaningful concepts or sub-categories (Buchbinder, Batterham, Elsworth, et al., 2011).

*Constant comparative approach: Qualitative version of Ward’s analysis.*

In the next step to synthesise workshop data, constant comparative analysis was conducted for two purposes: to ensure that concepts from all workshops were captured, and to ensure that refined clusters were only represented once in the conceptual model. As such, two reviewers analysed and synthesised the refined clusters using a constant comparative process, described by Elsworth and colleagues (2006) as a ‘qualitative version of Ward’s analyses’.

To begin the constant comparative analysis, the statements generated from each workshop were printed out onto a set of cards that were colour-coded according to workshop allocation. These statements were sorted into clusters derived from the three-dimensional MDS analysis. In identifying and labelling general categories and refined concepts, cluster names assigned by the original workshop participants were used as a guide. Two reviewers were used to minimise bias and ensure reliable results (Hruschka et al., 2004). The two reviewers independently reviewed each of the clusters by cluster label and statements for all six workshops. The reviewers independently paired the clusters that were most similar in meaning as identified by cluster labels and statements. Additional clusters were added to paired clusters in a hierarchical manner if the cluster labels and statements were deemed similar in meaning. This process continued until all clusters across the six workshops had been integrated into new clusters.

Following the individual analysis of the data by the two reviewers, the individual results of the integrated clusters were compared in a confirmatory analysis process. Clusters that were
grouped in a similar manner by the two reviewers remained together. Clusters that were grouped differently by the two reviewers underwent a secondary analysis process whereby reasons for the grouping were discussed and a consensus was reached on the best approach to integrate the cluster. In the event consensus was not reached, it was agreed prior to the analysis that an external panel comprised of an expert in questionnaire development, and an expert in cancer caregiving issues, would adjudicate the integration of the clusters.

To ensure homogeneity within the integrated clusters, the statements within each synthesised cluster were then analysed via a focussed coding process (Charmaz, 2006) to assess whether consistent patterns and meaning existed. A three-step examination process was performed for each statement. Using content analysis, each statement was analysed for meaning and then compared with other statements within its own integrated cluster. Each statement was lastly compared to statements in other integrated clusters. The purpose of the examination was to identify statements that could not be grouped within the synthesised clusters, and to move these statements to other groupings with closer conceptual meaning. This process also enabled the identification of integrated clusters with multiple concepts that may have needed to be split (Buchbinder, Batterham, Elsworth, et al., 2011). Each refined cluster was assigned a label that matched the statement content. The labels generated during concept mapping workshops were used as a guide to preserve participant meaning. Extensive analysis using structured and constant comparison of results across the six workshops ensured theoretical saturation.

Integration of the synthesised concepts: A hypothesised conceptual model of caregiver health literacy

To produce a visual hierarchical representation of the developing theory (i.e. the conceptual model), in the final step, a constant comparative approach was used to categorise the
clusters into major categories. Labels for the major categories that were identified in the tree diagrams were printed onto large cards and used to guide categorisation. Through an iterative constant comparative process, the integrated clusters were designated into major categories by examining cluster groups identified in the tree diagrams. As major categories across the six workshops tended to be similar, it was possible to group integrated clusters into major categories that best represented their conceptual meaning. Within clusters, statement content was examined to ensure best fit.

**Participants and recruitment**

To comprehensively understand elements relevant to caregiver health literacy in the cancer population, three stakeholder groups were included in the study: caregivers, people with cancer, and healthcare providers/policymakers. Pitceathly and Maguire (2003) in a review of the impact of cancer on caregivers found that caregivers can neglect, or avoid disclosing their own needs. Thus, to ensure broad elements of caregiver health literacy were identified, people with cancer were deliberately included in the study. Further, Greenhalgh, Robert, Macfarlane, Bate, and Kyriakidou (2004) found that an important pre-requisite for the successful uptake and implementation of research findings in service organisations was the relevance of the results to stakeholders. As such, to ensure clinical and policy relevance and breadth of issues covered, healthcare providers with experience working with cancer caregivers and policy makers were invited to take part in the study. Further details related to participants and recruitment for the study are presented in Chapter 6.

**Summary of methods for Manuscript B**

In summary, for Manuscript B, a grounded theory approach was used to gain an in-depth understanding of constituent elements that comprise caregiver health literacy. Results from Chapter 5. Method
concept mapping workshops were refined, synthesised, and integrated using a mixed methods approach to develop a comprehensive conceptual model of caregiver health literacy. Further details of the methods used in Manuscript B are presented in Chapter 6.

**Manuscript C. Development of the health literacy of caregivers scale - cancer**

*(HLCS): Item generation and content validity testing*

**Study objective**

The objective of Manuscript C was to develop a conceptually-driven scale to measure caregiver health literacy in cancer populations. The study aimed to generate items for the scale and to assess the content validity of these items.

**Study design and summary of methods for Manuscript C**

To develop the conceptually-driven scale of caregiver health literacy, the study adopted a structured, ‘validity driven’ approach to questionnaire development (Buchbinder, Batterham, Elsworth, et al., 2011). To ensure content validity of the scale, content areas and items for inclusion were guided by results of the stakeholder-driven conceptual model generated in Manuscript C. Content areas for inclusion were carefully considered to ensure the resultant scale was applicable to caregivers across the cancer caregiving continuum, caregivers with different caregiving experiences, and caregivers who were providing different levels of support.

Item generation was guided by statements produced by participants during concept mapping workshops to maximise content validity. Items were developed to represent the individual content areas. Draft items were also examined against a structured item development criteria to ensure quality items. Item readability was assessed using Flesch Reading Ease (Flesch, 1948) and Flesch-Kincaid Grade Level (Kincaid, Fishburne Jr, Rogers, & Chissom, 1975) formulas available through Microsoft Word. To ensure the final items formed a scale that could
distinguish between low, moderate, and high levels of health literacy (i.e., scale sensitivity), items were developed to ensure they captured a range of difficulty. To assess item difficulty, the revised Bloom’s taxonomy, which includes two dimensions (knowledge and cognitive process; Anderson & Krathwohl, 2011; Krathwohl, 2002) was used.

To assess content validity of the draft items and scale domains, the scale underwent content validity testing through an expert review and through cognitive interviews with caregivers of cancer patients. Further details of the methods used in this study are presented in Chapter 7.

**Manuscript D. Validation of the Health Literacy of Caregivers Scale - Cancer (HLCS-C)**

**Study objective**

The objective of the study was to build upon the content validity testing of the HLCS-C and: 1) identify and remove poorly performing and redundant items; and 2) determine the scale’s construct and discriminant validity, and internal consistency.

**Study design**

The aim of the study described in Manuscript D was to assess the Health Literacy of Caregivers Scale – Cancer (HLCS-C) on a large sample of caregivers of people with cancer. Although literature on optimal sample sizes for scale development studies varies, there is some consensus that a sample size of 300 is sufficient for measures in which each domain within the scale contains a minimum of four items (Marsh, Hau, Balla, & Grayson, 1998). Given that the refined draft version of the caregiver health literacy measure contained 88 items within 10 hypothesised domains, a sample of 300 was considered sufficient for the initial field testing of the measure.
Participants and recruitment

Given the large sample size requirement, both current and former caregivers of people with cancer were sought for the initial testing phase of the study. In this study, a current caregiver referred to a family member or friend who was currently providing care and support to someone diagnosed with cancer. Former caregivers included people who had previously provided care and support to someone with cancer. Eligibility criteria for caregivers included identifying themselves as providing physical, emotional or social support to someone diagnosed with cancer, and being aged 18 years or over. Cancer caregivers from Victoria, Australia were referred to the study through people with cancer. People with cancer were identified through one public health service (Eastern Health), cancer support groups, and the researcher’s formal and informal networks.

Cancer patients were given an introductory recruitment letter (see Appendix A), and a questionnaire pack, comprised of a generic introductory recruitment letter to their caregiver (see Appendix B), a Participant Information Form (see Appendix C), the questionnaire (see Appendix D), and a reply paid envelope. In the introductory letter to cancer patients, the purpose and processes of the study were explained, and a request was made for the person with cancer to pass on the questionnaire pack to a family member or friend who was providing physical, social, and/or emotional support. In the introductory letter to caregivers, they were invited to complete the questionnaire anonymously, and return it to the researcher in the reply paid envelope. Caregivers were also given the option to complete the questionnaire online. Participants were informed that return of a completed questionnaire implied their consent to participate.

To recruit through the public health service, outpatient databases for three cancer types, breast, lung and genitourinary, were generated. The three cancer types were chosen based on
collaborating oncologists’ areas of expertise. Two Eastern Health oncologists screened the patient databases to identify people to contact about the study. Outpatients were eligible if they had received treatment for cancer within the last 13 months, had not been admitted to palliative care, had no identifiable mental health or intellectual difficulties, and were aged 18 years or over. One follow-up occurred four weeks after the initial mail out. People with cancer received one follow-up letter asking them to remind their family member or friend to complete the questionnaire (see Appendix E1). A follow-up letter for the caregiver was included in the mail out to people with cancer (see Appendix E2).

To recruit through metropolitan cancer support groups, and following discussions with the group facilitator, the researcher attended a support meeting to briefly present the study, and distribute the questionnaire packs. For regional cancer support groups, the group facilitator distributed the questionnaire packs to their group members. Facilitators were asked to follow-up the study at the next group meeting by asking their support group members to remind their caregivers to complete and return the survey.

One cancer foundation (Leukaemia Foundation) facilitated recruiting caregivers through their cancer support groups. Introductory letters and the questionnaire pack were mailed on behalf of the researcher to individuals listed on the Leukaemia Foundation cancer support group database. One follow-up comprised of a generic letter to the cancer support group member (see Appendix E3) and a generic letter to their caregiver (see Appendix E4) was conducted four weeks after the initial mail out. In addition, individuals from the researchers’ formal and informal networks were invited to participate in the study.

Data preparation

For returned questionnaires, the data were entered into a Microsoft Excel database. This
Chapter 5. Method

provided a mechanism for easy transfer of data to relevant statistical packages, such as SPSS version 21 (IBM SPSS Inc, 2012) and Mplus version 7 (Muthen & Muthen, 1998-2012). All surveys were stored in a locked filing cabinet in a secure building at Deakin University. The Excel database was checked for missing data and where relevant, the hardcopy questionnaire was referred to and checked for response. The Excel database was also checked for possible entry errors, with every fifth hard copy questionnaire used to compare inputted data. Demographic information was exported to SPSS (IBM SPSS Inc, 2012) for analysis.

Data analysis

To assess item fit, internal convergent validity, discriminant validity, and to confirm the hypothesised 10-dimensional structure of the item set, confirmatory factor analysis (CFA) was used (Armstrong, 1967). Initially, a one-factor model was fitted for each scale. Then, all possible pairwise CFA models, and a final ten-factor model were fitted to the data. Following one-factor and pairwise modelling analyses, poorly performing and redundant items were removed. Item response theory analysis was also conducted to assess ordering of item thresholds. Both CFA and IRT were conducted with Mplus Version 7 with Weighted Least Squares Mean and Variance (WLSMV; Muthen, 1984) adjusted estimator as this is considered the optimal approach for categorical data (Beauducel & Herzberg, 2006). Missing data were handled with pairwise exclusion of cases with missing values.

Summary of methods for Manuscript D

Confirmatory factor analysis and item response theory approaches were used to assess fit of items within their hypothesised domains. CFA was also conducted to assess internal convergent and discriminant validity of the hypothesised 10-factor structure of the HLCS-C. Further details of the methods used in this study are presented in Chapter 8.

Chapter 5. Method
Chapter summary

In this chapter, the overall approach to the research was described, and the three studies that comprise this thesis were presented. For Manuscript B, a grounded theory approach was used to gain an in-depth understanding of elements that comprise caregiver health literacy from the stakeholder perspective. The mixed methods approach to the synthesis and integration of the concept mapping data to develop the conceptual model of caregiver health literacy was also described. For Manuscript C, the conceptual model was used to guide the development of a new measure of caregiver health literacy. The methods associated with the development of scale to enhance face, content and construct validity were outlined. Methods to assess content validity of the scale were described. For Study D, the components and steps of confirmatory factor analysis, item response theory and assessment of reliability and item difficulty were presented. The following chapters (6-8) present Manuscripts B, C, and D.
Chapter 6. Development of the Conceptual Model of Cancer Caregiver Health Literacy

Chapter Overview

In Chapter 6, the objective of the study was to develop a conceptual model that describes the constituent elements of health literacy of caregivers of people with cancer. The study is presented as a manuscript (B) which was submitted to, and subsequently published in *European Journal of Cancer Care*. Given the word limits and scope of peer-reviewed journals, extended results of the study are also presented in the later section of the chapter.
Manuscript B.


Chapter 6. Development of a conceptual model
AUTHORSHIP STATEMENT

1. Details of publication and executive author

<table>
<thead>
<tr>
<th>Title of Publication</th>
<th>Publication details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of a conceptual model to understand cancer caregiver health literacy</td>
<td>European Journal of Cancer Care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eva YN Yuen</td>
<td>School of Psychology</td>
<td>0410 571 698</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:eva.yuen@deakin.edu.au">eva.yuen@deakin.edu.au</a></td>
<td></td>
</tr>
</tbody>
</table>

2. Inclusion of publication in a thesis

<table>
<thead>
<tr>
<th>Is it intended to include this publication in a higher degree by research (HDR) thesis?</th>
<th>Yes</th>
<th>If Yes, please complete Section 3. If No, go straight to Section 4.</th>
</tr>
</thead>
</table>

3. HDR thesis author’s declaration

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
</tr>
</thead>
<tbody>
<tr>
<td>As above</td>
<td>School of Psychology</td>
<td>Development of a measure of health literacy for caregivers of people with cancer</td>
</tr>
</tbody>
</table>

If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication

Conceived and designed the study, recruited participants, collected data, undertook data analyses, drafted, refined and finalised the manuscript as the first and corresponding author.

Extent of contribution: 75%

I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below. 

Signature and date

3rd March 2015

4. Description of all author contributions

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarity Dodson</td>
<td>Contributed to the conception and design of the study, assisted with data analysis, provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
<tr>
<td>Roy W Batterham</td>
<td>Assisted with data collection and analysis, provided comments on the manuscript, and approved the final manuscript.</td>
</tr>
<tr>
<td>Tess Knight</td>
<td>Assisted with data analysis, provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
<tr>
<td>Jacqueline Chirgwin</td>
<td>Assisted with participant recruitment, provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
<tr>
<td>Patricia M Livingston</td>
<td>Contributed to the conception and design of the study, assisted with data collection and analysis, provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
</tbody>
</table>

Chapter 6. Development of a conceptual model
Chapter 6. Development of a conceptual model

5. Author Declarations
I agree to be named as one of the authors of this work, and confirm:
that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,
that there are no other authors according to these criteria,
that the description in Section 4 of my contribution(s) to this publication is accurate,
that the data on which these findings are based are stored as set out in Section 7 below.
If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further
consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin
University and, if the higher degree is awarded, the subsequent publication of the thesis by the university
(subject to relevant Copyright provisions).

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarity Dodson</td>
<td></td>
<td>4/3/15</td>
</tr>
<tr>
<td>Roy W Batterham</td>
<td></td>
<td>24/3/15</td>
</tr>
<tr>
<td>Tess Knight</td>
<td></td>
<td>22/3/15</td>
</tr>
<tr>
<td>Jacqueline Chirgwin</td>
<td></td>
<td>3/3/15</td>
</tr>
<tr>
<td>Patricia M Livingston</td>
<td></td>
<td>4/3/15</td>
</tr>
</tbody>
</table>

6. Data storage
The original data for this project are stored in the following locations. (The locations must be within an
appropriate institutional setting. If the executive author is a Deakin staff member and data are stored
outside Deakin University, permission for this must be given by the Head of Academic Unit within which
the executive author is based.)

<table>
<thead>
<tr>
<th>Data format</th>
<th>Storage Location</th>
<th>Date lodged</th>
<th>Name of custodian if other than the executive author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic</td>
<td>Password protected computer file</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Paper</td>
<td>Locked filing cabinets within a secure office at Deakin University, Burwood campus</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

This form must be retained by the executive author, within the school or institute in which they are
based. If the publication is to be included as part of an HDR thesis, a copy of this form must be
included in the thesis with the publication.
Development of a conceptual model of cancer caregiver health literacy

E.Y.N. YUEN, MSC, PHD CANDIDATE, Public Health Innovation, Population Health Strategic Research Centre, Deakin University, Melbourne, Victoria, S. DODSON, DPSYCH, RESEARCH FELLOW, Public Health Innovation, Population Health Strategic Research Centre, Deakin University, Melbourne, Victoria, R.W. BATTERHAM, MED, SENIOR RESEARCH FELLOW, Public Health Innovation, Population Health Strategic Research Centre, Deakin University, Melbourne, Victoria, T. KNIGHT, PHD, ASSOCIATE PROFESSOR, School of Psychology, Faculty of Health, Deakin University, Melbourne, Victoria, J. CHIRGWIN, MBBS, MEDICAL ONCOLOGIST, Department of Medical Oncology, Eastern Health, Melbourne, Victoria, & P.M. LIVINGSTON, PHD, PROFESSOR, Faculty of Health, Deakin University, Melbourne, Victoria, Australia


Development of a conceptual model of cancer caregiver health literacy

Caregivers play a vital role in caring for people diagnosed with cancer. However, little is understood about caregivers’ capacity to find, understand, appraise and use information to improve health outcomes. The study aimed to develop a conceptual model that describes the elements of cancer caregiver health literacy.

Six concept mapping workshops were conducted with 13 caregivers, 13 people with cancer and 11 healthcare providers/policymakers. An iterative, mixed methods approach was used to analyse and synthesise workshop data and to generate the conceptual model.

Six major themes and 17 subthemes were identified from 279 statements generated by participants during concept mapping workshops. Major themes included: access to information, understanding of information, relationship with healthcare providers, relationship with the care recipient, managing challenges of caregiving and support systems.

The study extends conceptualisations of health literacy by identifying factors specific to caregiving within the cancer context. The findings demonstrate that caregiver health literacy is multidimensional, includes a broad range of individual and interpersonal elements, and is influenced by broader healthcare system and community factors. These results provide guidance for the development of: caregiver health literacy measurement tools, strategies for improving health service delivery, and, interventions to improve caregiver health literacy.

Keywords: health literacy, cancer, caregivers, conceptual model, concept mapping.

DEVELOPMENT OF A CONCEPTUAL MODEL OF CANCER CAREGIVER HEALTH LITERACY

Caregivers play a vital role in the self-management of people living with cancer. Depending on an individual’s diagnosis and illness severity, caregivers may participate in a range of care tasks such as wound care, medication and symptom management, transportation and provision of emotional support (Glajchen 2004; Dubenske et al.)
Caregivers often also play an important role in making health-related decisions, communicating and sharing health information with healthcare providers, finding and interpreting health information, and facilitating complex medical procedures (Buchbinder et al. 2008; Hubbard et al. 2010; Wolff & Roter 2011; Laidtsaar-Powell et al. 2013). The varied and complex responsibilities adopted by caregivers are often assumed unexpectedly, and with little prior experience or support (van Ryn et al. 2011). As caregivers are not the primary recipients of health care, they may face a number of challenges unique to the caregiver role when engaging with health information and the healthcare system. A number of caregiver health literacy issues have been identified. For example, when attending healthcare appointments with their care recipient, caregivers have reported a lack of time and direct communication with healthcare providers, and a lack of recognition of their caregiving role (Guo et al. 2010; Dolce 2011; Williams & Bakitas 2012). In addition, caregivers have reported significant unmet information needs related to medical, practical and psychosocial issues (Washington et al. 2011; Longacre 2013). Issues such as these have been associated with caregiver ‘disenchantment’ with the health system (Dolce 2011), increased distress (Fried et al. 2005) and caregiver burden (Venetis et al. 2013).

Understanding and responding to health literacy issues is a key health promotion priority given the implications for individuals’ self-management of their health, and for equity related to access to, and use of, healthcare services (Commonwealth of Australia 2009, Nielsen-Bohman et al. 2004, Kickbusch et al. 2013, World Health Organization 2009). Inadequate health literacy has been associated with poorer health outcomes including increased rates of hospitalisation and emergency room presentations (Berkman et al. 2011, Mitchell et al. 2012), poorer medication adherence (Zhang et al. 2014), poorer physical functioning and poorer quality of life (Apter et al. 2013, Kamimura et al. 2013), later stage disease detection (Berkman et al. 2011) and, among older populations, increased mortality (Peterson et al. 2011, Bostock & Steptoe 2012). Notably, these studies predominately assessed health literacy using measures that have been criticised for their focus on an individual’s reading, comprehension and numeracy abilities, rather than the full breadth of concepts covered in modern definitions of health literacy (Mancuso 2009; Jordan et al. 2010b; Buchbinder et al. 2011a). Health literacy can be understood as a range of ‘personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health, or that have implications for health. Health literacy includes the capacity to communicate, assert and enact these decisions’ (Dodson et al. 2014). Incomplete coverage of health literacy domains in widely used measures, such as the Rapid Estimate of Adult Literacy in Medicine (Davis et al. 1991), Test of Functional Health Literacy in Adults (Parker et al. 1995) and Newest Vital Sign (Weiss et al. 2005), limits exploration and understanding of people’s capacity to effectively engage with health information and services.

Although there is evidence to link an individual’s health literacy to their own health outcomes, the impact of inadequate health literacy of caregivers upon adult care recipient outcomes is largely unknown (Bevan & Pecchioni 2008; Sparks & Nussbaum 2008). There is however, emerging evidence detailing the implication of parent health literacy on children’s health outcomes (Morrison et al. 2013; Pulgarón et al. 2014).

Existing studies of caregiver health literacy focus predominantly upon describing levels of inadequate health literacy among caregivers of older adults (Greenberg et al. 2008; Garcia et al. 2013; Lindquist et al. 2011; Levin et al. 2014), caregivers of stroke patients (Hoffmann et al. 2004) and caregivers of people with heart failure (Yehle et al. 2011). These studies suggest the need to address caregiver health literacy, but provide insufficient details pertaining to the health literacy needs of caregivers to guide the development of effective responses. One potential reason for limited availability of adult caregiver health literacy studies is the absence of measures that adequately assess caregiver-specific health literacy needs (Bevan & Pecchioni 2008).

While the need to understand and assess cancer caregiver health literacy has been identified (Bevan & Pecchioni 2008), a conceptual model that comprehensively and clearly articulates elements of caregiver health literacy is lacking. Best practice guidelines increasingly recognise that outcome measures are more robust when based on a conceptual model (U.S. Department of Health and Human Services Food Drug Administration 2009, Streiner & Norman 2008) that describes the constructs to be measured (Reeve et al. 2013).

A range of health literacy models have been developed that describe health literacy as a multidimensional construct and provide useful insights into the concept of health literacy (Nutbeam 2000; Baker 2006; Paasche-Orlows & Wolf 2007; Manganello 2008; Mancuso 2009; Jordan et al. 2010a; Edwards et al. 2012, 2013; Sorensen et al. 2012; Harrington & Valerio 2013; Smith et al. 2013). These include qualitatively derived models such as ‘the distributed health literacy model’ (Edwards...
et al. 2013), the ‘health literacy pathway model’ (Edwards et al. 2012), and Jordan et al.’s (2010a) and Osborne et al.’s (2013) patient perspective models that provide useful insights into the concept of health literacy. However, current models of health literacy remain focused on the perspectives of the individual, and provide limited insights into the health literacy needs of caregivers.

The aim of the current study was to develop a conceptual model that describes the constituent elements of health literacy of caregivers of people with cancer. The resultant model of cancer caregiver health literacy has the potential to guide measurement development, and assist in the development and evaluation of programmes that target the health literacy needs of caregivers.

**METHODS**

Concept mapping was used to identify and organise ideas related to caregiver health literacy from the perspective of caregivers, people with cancer and healthcare providers/policymakers. A three-step mixed methods approach to the analysis and synthesis of concept mapping workshop data was used to ensure ideas from all workshops were captured in the resultant conceptual model. Approval for the current study was provided by the Human Research Ethics Committees of Eastern Health (approval number E41-1011), Epworth HealthCare (approval number 51311) and Deakin University (approval number 2011-115).

**Participants and recruitment**

Caregivers and people with cancer were recruited from two chemotherapy clinics from one public health service in Melbourne, Australia. Recruitment included participants with a range of demographic and clinical backgrounds.

Eligibility criteria for caregivers included being: (1) identified as a caregiver for someone with cancer; (2) aged 18 years and over; and (3) able to provide informed consent. Eligibility criteria for people with cancer were that they: (1) had a confirmed diagnosis of cancer [any type/stage and treatment] of at least 1 month; (2) were able to identify someone who is a caregiver for him/her; (3) were aged 18 years and over; and (4) were able to provide informed consent. As the study did not seek to explore dyadic perspectives, caregivers were eligible to participate regardless of whether their care recipient took part, and vice versa for people with cancer.

Overall, 13 people with cancer participated in the two workshops, ranging in age from 26 to 69 years (Mdn = 58) nearly 40% were female, and over two thirds were aged over 50 years [Table 1]. Six people living with cancer

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Caregivers (n = 13)</th>
<th>People with cancer (n = 13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender – Female (%)</td>
<td>n = 10, % = 77</td>
<td>n = 5, % = 38</td>
</tr>
<tr>
<td>Age [years]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤49</td>
<td>n = 3, % = 23</td>
<td>n = 4, % = 31</td>
</tr>
<tr>
<td>≥50</td>
<td>n = 10, % = 77</td>
<td>n = 9, % = 69</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>n = 6, % = 46</td>
<td>n = 6, % = 46</td>
</tr>
<tr>
<td>Solid</td>
<td>n = 7, % = 54</td>
<td>n = 7, % = 54</td>
</tr>
<tr>
<td>Length of diagnosis [years]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>n/a, n/a</td>
<td>n = 6, % = 46</td>
</tr>
<tr>
<td>1 to 2 years</td>
<td>n/a, n/a</td>
<td>n = 0, % = 0</td>
</tr>
<tr>
<td>More than 2 years</td>
<td>n/a, n/a</td>
<td>n = 7, % = 54</td>
</tr>
<tr>
<td>Education [%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed some or all high school</td>
<td>n = 7, % = 54</td>
<td>n = 7, % = 54</td>
</tr>
<tr>
<td>Completed some or all of University</td>
<td>n = 6, % = 46</td>
<td>n = 6, % = 46</td>
</tr>
<tr>
<td>Speaks a language other than English at home</td>
<td>n = 0, n/a</td>
<td>n = 2, % = 15</td>
</tr>
<tr>
<td>Length of time as a caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>n = 3, % = 23</td>
<td>n/a, n/a</td>
</tr>
<tr>
<td>6 months to 1 year</td>
<td>n = 3, % = 23</td>
<td>n/a, n/a</td>
</tr>
<tr>
<td>More than 1 year</td>
<td>n = 7, % = 54</td>
<td>n/a, n/a</td>
</tr>
<tr>
<td>Caregiver relationship to care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>n/a, n/a</td>
<td>n/a, n/a</td>
</tr>
<tr>
<td>Child</td>
<td>n = 3, % = 23</td>
<td>n/a, n/a</td>
</tr>
<tr>
<td>Parent, sibling or friend</td>
<td>n = 3, % = 23</td>
<td>n/a, n/a</td>
</tr>
</tbody>
</table>

n/a, not applicable.

© 2015 John Wiley & Sons Ltd

Chapter 6. Development of a conceptual model
reported being diagnosed with a haematological cancer, and seven reported being diagnosed with a solid tumour. Thirteen caregivers who participated in the two workshops ranged in age between 31 and 69 years ($Mdn = 56$) with over three-quarters female ($77\%$; Table 1). Over half ($54\%$) of the caregivers were caring for their spouse and had been providing care for over 1 year ($54\%$).

Healthcare providers/policymakers were identified from the research team’s existing professional networks, and were selected to ensure a diverse range of professional backgrounds. Healthcare providers/policymakers were approached if they had: (1) experience in the care of people with cancer; (2) direct contact with caregivers; (3) expertise in caregiving issues; and/or (4) experience in planning, funding or evaluation of cancer or caregiver-related health services and programmes at a state or national level. Of the 11 healthcare providers/policymakers who participated in the study, the majority were oncology nurses ($n = 4$) or worked in cancer services ($n = 4$), one was a cancer researcher, and one was a policy advisor for caregivers. Of the 163 individuals ($68$ people with cancer, $55$ caregivers, $40$ healthcare providers/policymakers) invited to participate in the study, $37$ took part [response rates: people living with cancer ($20\%$), caregivers ($24\%$) and healthcare providers/policymakers ($28\%$)]. The main reasons for non-participation included: time conflicts ($56\%$), lack of interest in study ($15\%$) and being unable to contact the prospective participant ($20\%$).

**Concept mapping workshops**

Concept mapping is defined as a structured group process that uses a mixed methods approach to identify and organise ideas on a topic of interest [Trochim 1989a]. Concept mapping has been used previously to guide conceptual model development [Buchbinder et al. 2011b; Busija et al. 2013]. The approach to concept mapping developed by Trochim [1989a] was used as it is considered to have particular utility in ensuring equality of input from all participants.

Within the current study, two workshops per stakeholder group were held to yield a comprehensive understanding of caregiver health literacy. There are four key tasks to concept mapping workshops: brainstorming statements, sorting statements, generation of the concept map and interpretation of the concept map.

In brief, for the brainstorming phase, participants were asked to brainstorm ideas in the form of statements in response to a seeding statement: *Thinking broadly about a caregiver’s experiences in trying to look after their health and the health of their family member/friend receiving treatment, what does a person need to have in order to get and to use all of the information they need.* The seeding statement was varied slightly to ensure relevance to each target audience. For the sorting task, statements generated during the brainstorming task were printed onto cards, and participants were asked to sort the cards into piles in a way that made sense to them [Buchbinder et al. 2011b; Jordan et al. 2013]. Participants were also asked to meaningfully label each pile.

To generate the concept map, the statement groupings were entered into Concept System software [version 1; Trochim; Concept Systems, Inc., Ithaca, NY, 1989] [Trochim 1989b], which performed two types of analyses: two-dimensional multidimensional scaling [MDS] analysis and hierarchical cluster analysis using Ward’s algorithm [Everitt 1980]. The generated concept map presents in a visual form, a two-dimensional representation of the combined statement groupings.

In the final phase of concept mapping workshops, participants discussed the clusters represented in the concept map, identified statements they felt were inappropriately represented on the map and collectively labelled each of the clusters. For further detail on the activities undertaken during the concept mapping workshops, please refer to Buchbinder et al. (2011b).

**Development of the conceptual model: synthesis of concept maps**

The concept mapping workshops generated six concept maps, two from each stakeholder group. To establish the cancer caregiver health literacy conceptual model, the six maps were synthesised and refined using a three-step, iterative, mixed methods approach.

In the first step, the statements and participant groupings from individual maps were re-analysed using three-dimensional MDS to identify statement clusters. Although two-dimensional MDS was deemed suitable for use during the workshops, to synthesise the results of multiple workshops, three-dimensional MDS analysis was considered more appropriate given its capacity to produce more accurate representations of the relationships between statements and clusters [Elsworth et al. 2006, 2008; Buchbinder et al. 2011b]. To perform three-dimensional MDS analysis, Clustan Graphics (Wishart 2005) was used on the outputs of the data for each workshop. For further detail relating to the approach used to conduct three-dimensional MDS analysis please refer to Buchbinder et al. (2011b).

The second step in the synthesis process involved the production of a tree diagram that represented a conceptual
meta-matrix of workshop statements and potential cluster solutions. The tree diagrams enabled researchers to identify: the smallest number of clusters (‘major categories’) that made sense; the largest number of clusters (‘refined clusters’) that made sense; and the statements that best represented each refined cluster (Buchbinder et al. 2011b).

At the level of the major categories, it has been argued that results from the different workshops have similarities, thus enabling the synthesis of results across workshops (Buchbinder et al. 2011b). The major categories guided higher order conceptual analysis in the later stages of analysis.

The next step was to synthesise data across the six workshops using a constant comparisons approach, known as ‘Qualitative version of Ward’s analysis’ (Elsworth et al. 2006). This process ensured that in the conceptual model, refined concepts from each individual workshop were represented, and that these concepts were not included more than once. To begin the process, statements generated from each workshop were colour coded according to workshop, printed onto cards and sorted into clusters derived from the three-dimensional MDS analysis (Busija et al. 2013). Two reviewers then independently grouped clusters that were perceived to be similar in meaning, and then compared results. Two reviewers were used to minimise researcher bias and ensure reliable results (Hruschka et al. 2004). Clusters that were grouped in a similar manner by the two reviewers remained grouped. Clusters that were grouped differently were discussed to determine if a consensus could be reached. In the event consensus was not reached, it was agreed prior to the analysis that an external panel, comprised of an expert in questionnaire development, and an expert in cancer caregiving issues, would adjudicate the integration of the clusters. Consensus was reached in all cases.

To ensure homogeneity within the integrated clusters, a focused coding process (Charmaz 2006) was conducted via an iterative examination of statements both within and across clusters. The purpose of the examination was to: (1) identify statements that did not belong within its integrated cluster, and where relevant, re-assign the statement into a different cluster that better represented its conceptual meaning; and to (2) identify clusters with multiple concepts that may need to be split (Buchbinder et al. 2011b). A meaningful label was assigned to each integrated cluster. The labels were guided by cluster labels from concept mapping workshops to preserve participant meaning.

In the final step, to provide a hierarchical representation of the integrated clusters, a constant comparative approach was used to categories the clusters into major categories. Labels for the major categories that were identified in the tree diagrams were printed onto large cards and used to guide categorisation. Through an iterative process, the integrated clusters were designated into major categories by examining cluster groups identified in the tree diagrams. As major categories across the six workshops tended to be similar, it was possible to group integrated clusters into major categories that best represented their conceptual meaning. Examination of statement content within clusters ensured best fit.

RESULTS

Concept mapping workshop statements and clusters

Across the six workshops, 279 statements were generated by participants in response to the seeding statement, with each workshop generating between 30 and 56 statements ($Mdn = 49$). An example of the concept map produced during workshops is shown in Figure 1. This concept map was produced by caregivers in workshop #1 and contained nine clusters based on 50 statements generated by participants. The statements were represented in the map by the smaller numbers, and the clusters were represented by the larger numbers. Statements grouped together frequently by participants during the sorting phase were located closer together on the map.

The cluster names and number of statements associated with each cluster are presented in Table 2. A broad range of concepts was identified across the six workshops. While there was some overlap in concepts across workshops, there were also some differences in the conceptualisation of caregiver health literacy between caregivers, people with cancer and healthcare providers/policymakers. Statements related to understanding the healthcare system, and caregiver recognition of their role and rights, occurred more frequently in healthcare provider/policymaker groups, rather than caregiver or people with cancer groups. Statements related to the relationship between the caregiver and care recipient were identified exclusively by participants with cancer.

The cancer caregiver health literacy conceptual model

The six major themes identified within the synthesised data related to cancer caregiver health literacy are shown in Table 3: (1) access to information; (2) understanding of information; (3) relationship with the care recipient; (4) relationship with healthcare providers; (5) managing challenges of caregiving; and (6) support systems. Within these
major themes, 17 subthemes also emerged, as shown in Figure 2. Each theme contained between two and four subthemes. For example, the theme ‘access to information’ contained two subthemes: proactivity and determination to seek information, and information presented in quality formats. Statements used to generate each subtheme were used to articulate the theme labels. For example, statements in the proactivity and determination to seek information concept represented the caregiver’s individual motivation (‘Caregiver needs to take initiative to search for information’) and persistence (‘Persistence in seeking information until you get what you want [patience]’) to find health information. Examples of statements generated in workshops for each of the 17 subthemes are outlined in Table 3.

DISCUSSION

This paper describes the development of a conceptual model that reflects the elements of cancer caregiver health literacy. Caregivers, people with cancer, and healthcare providers/policy makers informed the development of this model, which represents individual, and interpersonal health literacy needs from the perspective of key stakeholders. Caregivers’ needs for support from the healthcare system and community services were also identified. The model highlights concepts associated with caregiver’s capacity to access, understand, appraise and use health information, and importantly, the caregivers’ relationships with the care recipient and healthcare providers.

Consistent with existing health literacy models (Sorensen et al. 2012; Squiers et al. 2012), the conceptual model presented here reveals the multidimensional nature of caregiver health literacy. Further, it includes functional, interactive and critical health literacy abilities, consistent with Nutbeam’s (2000) hierarchical model. Edwards et al. (2013) ‘distributed health literacy’ framework proposed that health literacy is distributed through an individual’s broader social networks. The results of the current study support the idea that individuals draw upon the health literacy of others to become health literate (Edwards et al. 2013).

The findings from this study extend conceptualisations of health literacy by identifying factors specific to the caregiving context, in particular, caregiver’s relationships with others. Not surprisingly, concepts related to the relationship between the caregiver and care recipient, namely caregiver communication with the care recipient [i.e.
Table 2. Summary of clusters and statements derived from the six concept mapping workshops

<table>
<thead>
<tr>
<th>Cluster #</th>
<th>Workshop (# of clusters)/Cluster name</th>
<th># Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshop #1 with caregivers [9]</td>
<td>1.1. Support services</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>1.2. Wellbeing, coping with demands of carer role in a way that is sustainable</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>1.3. Social support (sharing with people with similar experiences)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>1.4. Information access and clarification</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>1.5. Group support</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>1.6.* Information seeking and maximising information from appointments (tools)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.8. Understanding and assessing information</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>1.9. Processes related to treatment</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>1.10. Health systems organised to help [little things that make a difference]</td>
<td>5</td>
</tr>
<tr>
<td>Workshop #2 with caregivers [11]</td>
<td>2.1. Information gathering and access to accurate information</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>2.2. Understanding and deciphering and clarifying information</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2.3. Integrated information on complementary and alternative therapies (with traditional)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>2.4. Effective processes and systems support</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>2.5. Personal support for caregivers from people who understand</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>2.6. Practical and financial support</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>2.7. Mutual respect and honest communication from Health Care Providers with caregivers and patients</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2.8 Caregiver life skills [e.g. time management, caregiver self-care]</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>2.9 Balance, relationship, intimacy [togetherness and closeness] along the journey</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>2.10. Attitudes, intellectual and emotional challenges of the caregiver</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2.11. Uncertainty and making sense of the future</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>3.2. Gathering information and understanding /processing information/diagnosis</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>3.3. Caregiver support</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>3.4. Patient information and available services/where to seek help</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>3.5. Self-help/self-management</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>3.6. Hospital access and parking</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>3.7. Support services/strategies: non-medical/government</td>
<td>5</td>
</tr>
<tr>
<td>Workshop #4 with people with cancer [8]</td>
<td>4.1. Specific and clear guides to illness, treatment and services available [cancer/chronic disease]</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>4.2. Information and support programs for family members to cope with diagnosis</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>4.3. Information to meet the needs of all community members [e.g. all ages and all cultures]</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>4.4. Financial government support services</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4.5. Caregiver practical services/support and community responsibilities</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4.6. Sourcing relevant nutritional information [e.g. caregiver food support to help the patient]</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4.7. Merged into other clusters (21, 28)</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>4.8. Caregiver attitudes and skills to understand the [changes] patient</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>4.9. Carer empathy/insight – caring for the carers</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>5.2. Communication capacity [emotional intelligence] – helped by higher level of education (17)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>5.3. Seeking and interpreting information</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>5.4. Access to practical social support</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>5.5. Opportunity</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>5.6. Diversity of info needs – form and presentation</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>5.7. Understanding and navigating the system</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>5.8. Identity and valuing of the carer role</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>5.9. Diversity of info needs – content</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>5.10. Community/societal recognition and understanding</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>5.11. Patient and family centred practice of health services [formal and informal recognition]</td>
<td>6</td>
</tr>
<tr>
<td>Workshop #6 with healthcare providers [5]</td>
<td>6.1.† Caregiver capability and core skills and CG understanding of the impact of illness on the patient</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>6.2.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6.3. Understanding and navigating the health care system</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>6.4. Direct support for caregivers/caring for the caregiver</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>6.5. Healthcare provider education, skills and support</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>6.6. Understanding of, and referral to, palliative care</td>
<td>2</td>
</tr>
</tbody>
</table>

*Combined with cluster 1.7.
†Combined with cluster 6.2.
Table 3. Six categories, 17 concepts and their definitions, and example statements derived from concept mapping workshops with relevant stakeholders

<table>
<thead>
<tr>
<th>Category/concept</th>
<th>Concept definition</th>
<th>Example statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Access to information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proactiveness and determination to seek information</td>
<td>Caregiver’s motivation and capacity to actively seek information from various sources in order to assist with managing the health of the care recipient</td>
<td>Caregiver needs to take initiative to search for information. Persistence in seeking information until you get what you want (patience).</td>
</tr>
<tr>
<td>Information presented in quality formats</td>
<td>Information presented in simple, clear language and in a variety of formats to enable greater access to, and understanding of, health information.</td>
<td>Information in plain language or pictures. Receive information in a variety of formats.</td>
</tr>
<tr>
<td>2. Understanding information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding the healthcare system</td>
<td>Caregiver’s capacity to understand the right healthcare and healthcare services to provide optimal care for the care recipient.</td>
<td>Understanding roles and hierarchies among hospital or health services staff. Caregivers need to make sure they have all the contact details of the treating team (e.g. nurse coordinator).</td>
</tr>
<tr>
<td>Understanding the disease, treatment, and potential outcomes</td>
<td>Caregiver’s capacity to understand information related, but not limited, to: the short and long-term effects of the cancer; prognosis with and without treatment; potential side effects of treatment; and, advanced care planning for managing the cancer.</td>
<td>Understanding short term and long term effects of illness and potential outcomes. A clear understanding of the treatment and the side-effects of treatment.</td>
</tr>
<tr>
<td>Understanding information for day-to-day care</td>
<td>Caregiver’s capacity to understand information that assists with the day-to-day caregiving tasks.</td>
<td>Understanding and information on food and nutrition for patients. Caregivers need to understand what drugs the patients need to take and when.</td>
</tr>
<tr>
<td>Processing health information</td>
<td>Caregiver’s capacity to attend to information, such as: recognise information that is meaningful; make sense of information, relate the information to what is already known, organise the information, decide what is important, remember the information, compare and contrast information, and critically appraise information related to the cancer.</td>
<td>Able to contextualise information to their personal circumstances. Need capacity (clear head) to take in the information and decipher what’s important and what the most relevant questions are.</td>
</tr>
<tr>
<td>3. Relationship with healthcare providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active engagement with healthcare providers</td>
<td>Caregiver’s cognitive and social capacity to interact with, and ask questions of, healthcare providers to get information.</td>
<td>Being confident enough to ask questions. Knowing what and how to ask questions.</td>
</tr>
<tr>
<td>Supported by healthcare providers to understand information</td>
<td>Caregiver has at least one healthcare provider who engages in various strategies to assist him/her to understand, compare and contrast, and make decisions about health information.</td>
<td>[not] Feeling rushed from health professionals. Need to be able to ask any questions without being made to feel foolish (even basic questions).</td>
</tr>
<tr>
<td>4. Relationship with the care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication with the care recipient</td>
<td>Quality of the communication between the caregiver and care recipient about the cancer.</td>
<td>Ability to communicate openly with the person with cancer. Good honest communication with patient in order for patient to share with caregiver the information about the health condition.</td>
</tr>
<tr>
<td>Understanding the care recipient</td>
<td>Caregiver’s understanding of the care recipient’s health condition, and how to best support the care recipient.</td>
<td>Carer sensitivity to information needs of patient. Carers need to know ‘when to let go’ and ‘when to push to motivate patient’.</td>
</tr>
<tr>
<td>5. Managing challenges of caregiving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care</td>
<td>Caregiver’s active engagement with managing his or her own health and wellbeing, whilst providing care.</td>
<td>Carers need to look after their own health. Carers need to take time out for themselves (e.g. taking holidays for themselves).</td>
</tr>
</tbody>
</table>
dyadic communication) and understanding of the care recipient have been identified in the conceptual model. Previous studies have shown that open dyadic communication about cancer-related issues has been associated with less distress [Fried et al. 2005], decreased caregiver burden [Venetis et al. 2013] and, among couples, increased relationship functioning [Li & Loke 2014; Traa et al. 2014]. Fewer studies, however, have examined the impact of dyadic communication on caregiver knowledge and skills related to care provision, although the relationship has been implied [Griffin et al. 2013; Li & Loke 2014]. It is unclear to what extent dyadic communication impacts upon a caregiver’s capacity to assist the care recipient to manage cancer symptoms, make decisions about treatment, identify relevant health information or identify relevant healthcare services. Further examination of the impact of dyadic communication on a caregiver’s health literacy levels, and in turn, its impact on a caregiver’s capacity to provide optimal care is warranted.

The findings also highlighted the caregiver’s relationship with healthcare providers as potentially influencing caregiver health literacy. Relationships with healthcare providers were identified as requiring personal attributes on the part of the caregiver (active engagement with healthcare providers), and healthcare provider factors: (supported by healthcare providers to understand information). The capacity of the caregiver to actively seek information from, and ask questions of, healthcare providers was highlighted. Importantly, the capacity of healthcare providers to ensure adequate time to explain information, provide a supportive environment to discuss information and facilitate caregiver understanding of information were also identified as key factors that contribute towards a caregiver’s capacity to find, understand and use health information when providing care. These concepts are notable as caregivers have reported unsatisfactory interactions with providers, citing lack of time, inadequate communication or their attendance at consultations being viewed as unfavourable [Waldrop et al. 2012; Williams & Bakitas 2012; Laidsaar-Powell et al. 2013]. Insufficient information exchange during consultations may hinder a caregiver’s capacity to understand the disease and provide adequate support to the care recipient, and may contribute to poorer health outcomes [Waldrop et al. 2012].

A potential limitation of the study was that themes and subthemes identified largely focused on caregivers’ capacity to find, and understand information; a caregiver’s

<table>
<thead>
<tr>
<th>Table 3. Continued</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category/concept</td>
</tr>
<tr>
<td>Role recognition and understanding caregiver rights</td>
</tr>
<tr>
<td>Attitudes, approaches, and emotional challenges</td>
</tr>
<tr>
<td>6. Support systems</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
capacity to use health information was underrepresented in the statements generated during the concept mapping workshops. Existing definitions of health literacy refer to an individual’s capacity to find, understand and use health information [Sorensen et al. 2012]. Although participant statements generated in concept mapping workshops implied a caregivers’ capacity to use health information, they did not explicitly describe how the health information was used to assist in their caregiving role. This limitation may be attributed to the seeding statements that generated participant responses. The seeding statements asked participants about what caregivers needed ‘to get’ and ‘to use’ information. Participants may have focused on elements that enabled them to access and use health information, rather than explicitly identifying the actions taken as a result of having all health information they need.

In addition, caregivers and people with cancer were recruited from one metropolitan healthcare service. This limits the generalizability of the results to caregivers’ from other settings such as rural and regional areas who may have additional or differing health information and healthcare needs [Butow et al. 2012; Brazil et al. 2014]. Further, participation rates across the three stakeholder groups were low, which also limits generalizability of the results.

Strengths of the study include the use of grounded approaches to identify key themes related cancer caregiver health literacy. During concept mapping workshops, all participants contributed to data generation, initial coding of data and analysis of preliminary results which allowed for greater accuracy, credibility and transferability of the results [Barbour 2001]. Further, the perspectives of key stakeholders were triangulated to ensure the breadth and depth of elements that comprised cancer caregiver health literacy was captured in the model. An additional strength of the study was the use of a mixed methods approach to analyse and synthesise the concept mapping workshop data to generate the conceptual model. Mixed methods research contributes to the strengths of a study by allowing greater insight and understanding of a phenomenon, as well as providing greater depth in data analysis [Johnson & Onwuegbuzie 2004; Johnson et al. 2007].
In conclusion, the study presents the first conceptual model of cancer caregiver health literacy derived from the perspective of relevant stakeholders. The model proposes that cancer caregiver health literacy is a multidimensional construct comprised of individual and interpersonal elements and influenced by healthcare system and community factors. Understanding the elements that comprise caregiver health literacy will assist healthcare providers and policymakers appropriately tailor information, communication and education strategies to caregiver needs.

The detailed concepts within the conceptual model provide the first insights into targeted areas for the development of new measures of cancer caregiver health literacy. A measure that accurately assesses caregiver health literacy has the potential to identify key intervention areas to assist caregivers’ find, understand, appraise and use health information to facilitate optimal health for the caregiver and the care recipient.

REFERENCES


AUTHOR CONTRIBUTIONS

Conception and design: EYNY, PML, SD
Collection/assembly of data: EYNY, RWB, PML, JC
Data analysis and interpretation: EYNY, PML, TK, SD, RWB
Manuscript writing: All authors
Final approval of manuscript: All authors

ACKNOWLEDGEMENTS

The authors would like to sincerely thank the caregivers, people with cancer and healthcare providers/policymakers who participated in the concept mapping workshops; Professor Richard Osborne for his contributions to the study; and Professor Gerald Elsworth for his insights on multi-dimensional scaling analysis.

© 2015 John Wiley & Sons Ltd
Chapter 6. Development of a conceptual model


Chapter 6. Development of a conceptual model


Extended Results Related to the Development of the Conceptual Model of Caregiver Health Literacy

As the results presented in manuscript B were limited by the word count and scope of the peer-reviewed journal, results from the interpretation of the concept maps are presented in this section. Synthesis of concept mapping data to develop the concept model is also presented in greater detail and the 17 key components identified in the conceptual model of caregiver health literacy are described.

Interpretation of concept maps: Clusters

In the final stage of the concept mapping process, participants were invited to interpret and review the cluster map to ensure the clusters generated reflected the group’s opinion. As outlined in Chapter 3, participants were asked to consider 1) whether statements within clusters related to each other; 2) whether each cluster only contained one idea; 3) to determine a name for each cluster that represented the statements within their respective cluster; and 4) to identify any concepts or ideas that were not covered during the brainstorming session, and should be included in the concept map. Following participant reviews, a number of changes were made to clusters within the concept maps across the six workshops, and several new concepts and ideas were identified. These changes and additions are outlined below.

Results from workshop #1 with caregivers

From workshop #1 with caregivers, six statements were moved to different clusters considered more appropriate (see Table 6.1). For example, the statement “Carer needs to look after their own health” (Caregiver workshop #1, item 18) was moved from cluster 1 (Support...
### Table 6.1

**Statements and clusters from workshop #1 with caregivers**

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cluster 1: Support services</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Support with a range of practical issues (financial, time, transport)</td>
</tr>
<tr>
<td>2</td>
<td>Support for the person with cancer</td>
</tr>
<tr>
<td>3</td>
<td>Support with emotional issues</td>
</tr>
<tr>
<td>16</td>
<td>Able to provide support in a large range of daily tasks (e.g. around the home)</td>
</tr>
<tr>
<td>24</td>
<td>Supporting families and friends around you</td>
</tr>
<tr>
<td>40</td>
<td>People to help monitor how you are going (e.g. Royal District Nursing Service)</td>
</tr>
<tr>
<td><strong>Cluster 2: Wellbeing, coping with demands of carer role in a way that is sustainable</strong></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Persistence in seeking information until you get what you want (patience)</td>
</tr>
<tr>
<td>9</td>
<td>Given exercises and offered techniques that you can keep using at home</td>
</tr>
<tr>
<td>13</td>
<td>Explaining resources (what help is available) to the family</td>
</tr>
<tr>
<td>17</td>
<td>Dealing with the time demands of the range of tasks involved</td>
</tr>
<tr>
<td>34</td>
<td>Support to other family members (who are not the primary carers)</td>
</tr>
<tr>
<td>32*</td>
<td>Not being subject to endless phone calls from other people asking questions about how the person is going</td>
</tr>
<tr>
<td>18*</td>
<td>Carer needs to look after their own health</td>
</tr>
<tr>
<td><strong>Cluster 3: Social support (sharing with people with similar experiences)</strong></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Ongoing opportunity to share with people in similar circumstances</td>
</tr>
<tr>
<td>28</td>
<td>Share ideas with other carers</td>
</tr>
<tr>
<td>27**</td>
<td>Having the opportunity to debrief and share experiences with other carers</td>
</tr>
<tr>
<td><strong>Cluster 4: Information access and clarification</strong></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Receiving written information</td>
</tr>
<tr>
<td>30</td>
<td>A feedback mechanism to ensure that the carer is caught up with information that is discussed when they are not there</td>
</tr>
<tr>
<td>38</td>
<td>Time to absorb information</td>
</tr>
<tr>
<td>43</td>
<td>Help to be able to evaluate information about side-effects reliably</td>
</tr>
<tr>
<td>49</td>
<td>Have information about where you can go for more information</td>
</tr>
<tr>
<td><strong>Cluster 5: Group support</strong></td>
<td></td>
</tr>
<tr>
<td>5**</td>
<td>Maintain hope that you will be able to find the answers that you need</td>
</tr>
<tr>
<td>27**</td>
<td>Having the opportunity to debrief and share experiences with other carers</td>
</tr>
<tr>
<td>33</td>
<td>Access to suitable courses and information sessions</td>
</tr>
<tr>
<td>39</td>
<td>Opportunities to discuss information with someone else soon after receiving it</td>
</tr>
<tr>
<td><strong>Cluster 6 &amp; 7 merged: Information seeking and maximising info from appointments (tools)</strong></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Ask question when you have the opportunity</td>
</tr>
<tr>
<td>7</td>
<td>Write down questions in advance of appointments</td>
</tr>
<tr>
<td>19</td>
<td>Assistance in knowing what questions to ask (e.g. a list)</td>
</tr>
<tr>
<td>20</td>
<td>Writing down questions at the time you think of them</td>
</tr>
<tr>
<td>21</td>
<td>Tools or assistance to help you remember questions and answers</td>
</tr>
<tr>
<td>35</td>
<td>Confidence in your healthcare provider that you can ask any questions</td>
</tr>
<tr>
<td>50</td>
<td>A brief written summary of key information at the end of appointments</td>
</tr>
<tr>
<td>22</td>
<td>Having someone to go to appointments with you</td>
</tr>
<tr>
<td>23</td>
<td>Tools to help you remember everything about medications and appointments</td>
</tr>
<tr>
<td>36</td>
<td>Being confident enough to ask questions</td>
</tr>
</tbody>
</table>

Chapter 6. Development of a conceptual model
Cluster 7 (Merged with cluster 6)

Cluster 8: Understanding and assessing information

11 A clear understanding of the disease
12 A clear understanding of the treatment and the side-effects of treatment
26 Practical information about how to respond to problems that may arise (e.g. side-effects)
41 Help to be able to evaluate information about side-effects reliably
42 Being diligent with information about medications
45 Having information that is specific and relevant to the patient (e.g. highlight the relevant bits)
46 Having information at the right level for your understanding
47 Healthcare providers who can gauge what level of information that people need
48 Healthcare providers should ask about what you already understand and work from there

29*** Hospital staff need to recognize that it is a lot for the patient and carer to take in

Cluster 9: Processes related to treatment

8 Support with dealing with the process of treatment
14 Practical issues of accessing services (parking, transport, waiting rooms)

Cluster 10: Health systems organised to help (little things that make a difference)

15 Good information in waiting rooms
31 Opportunity to talk to a healthcare provider without the person you are caring for the being there
37 Some people prefer having other people in your room that they can talk to (encouragement, information)

44**** Having 24 hour access to specialists

* Statement moved from cluster 1 to cluster 2 due to group consensus that these statements related more to statements in cluster
** This statement had the potential to be moved to many clusters as indicated by many arrows in Figure 1 in manuscript B.
*** Statement moved from cluster 10 to cluster 8

services) to cluster 2 (Wellbeing, coping with demands of carer role in a way that is sustainable) following group discussion that this statement related more closely to items in cluster 2. Two clusters (cluster 6 & 7) were merged into one cluster after a consensus in the group that all statements were related to the one key concept (e.g., “Write down questions in advance of appointments” [cluster 6, item 7] and “Confidence in your healthcare provider that you can ask any questions” [cluster 7, item 35]). This resulted in nine clusters as shown in Table 6.1. One statement was identified as being omitted during the brainstorming session when the concept

Chapter 6. Development of a conceptual model
map was reviewed by participants (“Want your healthcare provider to be honest”). The statement was recorded on the map in the bottom right corner (see Figure 1 in manuscript B).

**Results from workshop #2 with caregivers**

From workshop #2 with caregivers, six statements were moved into different clusters considered more appropriate (see Appendix F1). For example, the statement “Asking questions of the health care professional” (Caregiver workshop #2, item 10) was moved from cluster 3 (Integrated information on complementary and alternative therapies [with traditional]) to cluster 1 (Information gathering and access to accurate information) following group discussion that this statement related more closely to items in cluster 2. The 11 clusters generated and their respective statements are presented in Appendix F1. Upon reviewing the concept map, several ideas were identified as being omitted during the brainstorming sessions; thus these ideas were included as statements in a separate section on the concept map (see Figure 6.1). Examples of additional statements identified following review of the concept include: “Availability of religious systems, beliefs and/or spirituality”, "Openness to new experiences”, and "Sufficient time from health professionals”.

**Results from workshop #3 with people with cancer**

From workshop #3 with people with cancer, eight statements were moved into different clusters considered more appropriate (See Appendix F2). For example, the statement “Need to be able to ask any questions without being made to feel foolish (even basic questions)” (Workshop with people with cancer #1, Item #17) was moved from cluster 2 to cluster 1. As all statements from
Figure 6.1. Concept map generated from workshop #2 with caregivers. Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved.

Chapter 6. Development of a conceptual model
one cluster (cluster 8) were moved into different clusters, this resulted in seven clusters
generated (see Appendix F2). Upon reviewing the concept map, several ideas were identified as
being omitted during the brainstorming sessions, thus these ideas were included as statements in
a separate section on the concept map (see Appendix F3). Examples of additional statements
included in the concept map include: “What to do in an emergency”, “Patient doctor
confidentiality”, and “Communication is essential between departments”.

Results from workshop #4 with people with cancer

From workshop #4 with people with cancer, seven statements were moved into different
clusters considered more appropriate. For example, the statement “Information on appropriate
foods to manage symptoms and pain” (Workshop with people with cancer #2; statement 20) was
moved from cluster 5 (Caregiver practical services/support and community responsibilities) to
cluster 6 (Sourcing relevant nutritional information – caregiver food support to help the patient)
following group discussion that this statement related more closely to items in cluster 2. As all
statements (n = 2) from one cluster (cluster 7) were moved into different clusters, this resulted in
eight clusters generated (see Appendix F4). One statement was identified as being omitted during
the brainstorming sessions (“Being aware about generic probabilities of illness”), thus the
statement was included on the map in a separate section (see Appendix F5).

Results from workshop #5 with healthcare providers/policymakers

From workshop #5 with healthcare providers, five statements were moved into different clusters
considered more appropriate (see Appendix F6). For example, “Capacity to cope with the
unknowable [especially about the future]; statement #53) was moved from cluster 1 (Carer health
and self-care [balancing the care]) to cluster 2 (Communication capacity [emotional intelligence]
–helped by higher level of education) following group discussion that this statement related more

Chapter 6. Development of a conceptual model
closely to items in cluster 2. One statement (“Carers understand what their rights are”; cluster 8, statement #20) was identified as being related to clusters 3 and 11 (Seeking and interpreting information, and Patient and family centred practice of health services [formal and informal recognition], respectively), however participants opted to leave the statement in its respective cluster (cluster #8: Identity and valuing of the carer role). One statement was identified as being omitted during the brainstorming sessions (“Guidelines for carer roles”), thus the statement was included on the map in a separate section (see Appendix F7).

**Results from workshop #6 with healthcare providers/policymakers**

From workshop #6 with healthcare providers/policymakers, two clusters (1 & 2) were merged into one after a consensus in the group that the meaning behind all statements was related. Two statements were moved into different clusters considered more appropriate. For example, statement #2 (“Willingness of the caregivers to accept information and support provided by health professionals”) was moved from cluster 3 (Understanding and navigating the health care system) to cluster 1 (Caregiver capability and core skills and caregiver understanding of the impact of illness on the patient) following group discussion that this statement related more closely to items in cluster 1. The five clusters generated and respective statements are outlined in Appendix F8. Upon reviewing the concept map, a number of ideas were identified as being omitted during the brainstorming sessions, thus these ideas were included as statements in a separate section on the concept map (see Appendix F9). Examples of omitted statements included: “Physical capabilities of caregivers (e.g. technical skills they might need i.e. dressing, but also physical ability of caregiver e.g. showering”, “Willingness to take on physical caring role”, and “Consistency of information delivery to ALL family members”).

Chapter 6. Development of a conceptual model


**Development of the conceptual model: Synthesis of concept maps**

To develop the conceptual model, following individual concept mapping workshops, data across the six workshops were synthesised to ensure that clusters from all workshops were captured, and that clusters were represented only once in the model. As detailed in Chapter 3, a three-step iterative process was used to synthesise clusters across workshops and to develop the model. The processes were: to firstly re-analyse workshop data using three-dimensional multidimensional scaling (MDS) analysis; to conduct a qualitative version of Ward’s analysis and a focussed coding process to synthesise concepts across the six workshops, and finally, to conduct a constant comparative analysis to integrate and categorise synthesised concepts into major categories. The extended results from the synthesis of workshop data and development of the model are presented below.

As outlined in Chapter 4, to ensure precise statistical representation of workshop results, concept mapping data were reanalysed using the three-dimensional MDS method. This presented somewhat different clusters from the cluster solutions that emerged from the two-dimensional solutions during the workshops. For example in Workshop #1, participants identified a nine-cluster solution:

1. Support services
2. Wellbeing, coping with demands of being a caregiver in a way that is sustainable
3. Social support (sharing with people with similar circumstances)
4. Information access and clarification
5. Group support
6. Information seeking and maximizing information from appointments (tools)
7. Understanding and accessing information
8. Process related to treatment
9. Health systems organised to help (little things that make a difference)
Three-dimensional re-analysis of the results from Workshop #1 resulted in the identification of eight clusters. The two statements that comprised the cluster Process related to treatment, “Support with dealing with the process of treatment” (item #8) and “Practical issues of accessing services [parking, transport, waiting rooms]”; item #14) which were re-grouped into the following clusters: 1) caregiver support, and 2) organised healthcare systems respectively. Content analysis of the two statements confirmed that the two statements were better represented in their new groupings.

Overall, three-dimensional analysis and synthesis of workshop data identified 17 synthesised clusters related to a caregiver’s capacity to find, understand, and use health information. To produce a visual hierarchical representation of the developing theory (i.e. the conceptual model), major categories were hypothesised to represent the synthesised clusters by identifying the minimum number of meaningful clusters in the three-dimensional analysis. Although the following sections describe the results in a somewhat linear fashion, classification of the synthesised clusters and major categories was an iterative process that consisted of constant comparative analysis of statements both within, and across clusters, and with results from the three-dimensional analysis.

Constant comparative analysis of the synthesised clusters and results from the three-dimensional MDS analysis identified six overarching major categories: (i) access to information; (ii) understanding information; (iii) relationships with healthcare providers; (iv) relationship with the care recipient; (v) support systems; and (vi) caregiving-specific attributes. Two major categories were common across all six workshops: Access to information and Support systems. Two categories Understanding information and Caregiving-specific attributes were common to four of six workshops. The major category Relationships with healthcare providers was common
to three of the six workshops. The major category *access to information* was common to two of the six workshops. Following refinement of the synthesised clusters, an additional major category, *relationship with the care recipient* was identified.

Constant comparison of synthesised clusters with results from the three-dimensional MDS output identified distinguishable concepts within the categories; *Access to information; Understanding information; Relationships with healthcare providers; Caregiving-specific attributes;* and *Support systems* (see Figure 6.2). For example, the *Access to information* general category included statements related to two clusters: *Information presented in quality formats* and *Proactivity and determination to seek information* (see Figure 6.2). The Relationships with healthcare providers included statements related to two clusters: *Active engagement with healthcare providers*, and *Supported by healthcare providers to understand information*.

Initially three clusters were identified in the general category *Understanding information*; these were: *Understanding the disease, treatment and potential outcomes; Understanding information for day-to-day care provision;* and *Understanding the healthcare system*. Microanalysis of statements that comprised the three clusters related to *Understanding information* identified an additional cluster: *Processing health information*. Statements related to the emergent cluster had homogenous content, however did not form groupings of their own during concept mapping workshops or in three-dimensional MDS analysis. These statements were limited within individual concept mapping workshops, which may have explained their groupings with other clusters. Re-analysis of individual concept maps showed that statements representing the cluster *processing health information* frequently formed clusters of their own within broader concepts. This suggested these statements were sorted more often with each other than with other statements. In order to capture all the nuances of the data, statements that
represented *processing health information* were classified as a distinct concept that required further exploration (Pope et al., 2000).

![Diagram of Caregiver health literacy]

**Figure 6.2**
*Major categories and concepts hypothesised to represent caregiver health literacy*

Constant comparative analysis initially identified three synthesised clusters related to the general category *Caregiving-specific attributes*. These clusters were: *self-care*, *attitudes*, *approaches and emotional challenges*, and; *role recognition and understanding caregiver rights*. Microanalysis of statements within the three clusters identified an additional concept: *relationship with the care recipient*. Within the emergent concept, two distinct ‘sub-concepts’ were identified: *understanding the care recipient*, and *communication with the care recipient*.
The sub-concept *understanding the care recipient* contained statements related to a caregiver’s capacity to understand the informational, psychosocial, and physical needs of the care recipient. These statements included: “Carers need to understand some patients’ needs to ‘get on with life; and current affairs/normal life’” (Workshop #4, statement #39), “Carer sensitivity to information needs of patient” (Workshop #4, statement #41), and “Caregivers need to understand how to be a good help and support” (workshop #6, item 19). Inspection of statements that related to the sub-concept *understanding the care recipient* found that in individual concept maps, the statements were embedded with broader concepts such as carer empathy/insight, and caregiver capacity and core skills.

Similarly, the sub-concept *communication with the care recipient* contained distinct statements related to the caregiver’s interaction with the care recipient in relation to health information. These statements included “Caregiver needs the patient to be willing to talk to them and pass information on”, (Workshop #3, statement #28), and “Good honest communication with patient in order for patient to share with caregiver the information about the health condition” (Workshop #2, statement #14). Inspection of items that related to *communication with the care recipient* showed that items were embedded within broader concepts such as general communication, and caregiver support.

Statements related to the emergent clusters related to *Relationship with the care recipient* had homogenous content, however did not form groupings of their own during concept mapping workshops or in three-dimensional analysis. Statements related to the three additional clusters were limited within individual concept mapping workshops, which may have explained their groupings with other clusters. Re-analysis of individual concept maps showed that statements representing the two clusters *understanding the care recipient*, and *communication with the care recipient*...
recipient, frequently formed clusters of their own within broader concepts. This suggested these statements were sorted more often with each other than with other clusters.

Constant comparative analysis suggested that unlike other clusters within the general category Caregiving-specific attributes, statements within the clusters related to Relationships with the care recipient comprised a unique concept that involved interpersonal interactions with the care recipient. As such, the cluster Relationships with care recipient was re-classified as a general category comprising two clusters (understanding the care recipient and communication with the care recipient) in order to capture the nuances of the data. Table 6.2 provides a brief summary of the general categories and 17 synthesised clusters related to caregiver health literacy with example statements.

In sum, the qualitative version of Ward’s technique identified 17 synthesised clusters hypothesised to represent elements that comprise a caregivers’ capacity to find, understand, and use health information. Three-dimensional MDS analysis and constant comparative analysis identified six general categories that broadly represented caregiver health literacy. Specifically, the general category Access to information included two concepts: 1) Information presented in quality formats, and 2) proactivity and determination to seek information. The general category Understanding information included four concepts: 1) understanding the disease, treatment, and potential outcomes, 2) understanding the healthcare system, 3) understanding information for day-to-day care provision, and 4) processing health information. The general category Relationships with healthcare providers was comprised of two concepts: 1) active engagement with healthcare providers, and 2) supported by healthcare providers to understand information. The general category Support systems also contained four concepts: 1) social support, 2) psychosocial support, 3) practical support, and 4) financial and legal support. As outlined above,

Chapter 6. Development of a conceptual model
Table 6.2

**Major categories and concepts of caregiver health literacy identified from the synthesis of concept mapping data**

<table>
<thead>
<tr>
<th>Major categories and clusters</th>
<th>1. Access to information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.1. Information presented in quality formats: Refers to information presented to caregivers in a format or language that they can clearly understand. Example statements:</td>
</tr>
<tr>
<td></td>
<td>• Information in plain language or pictures</td>
</tr>
<tr>
<td></td>
<td>• People need information in a language they can understand (other languages or plain English)</td>
</tr>
<tr>
<td></td>
<td>• Information that is written in a language that they understand</td>
</tr>
<tr>
<td></td>
<td>1.2. Proactivity and determination to seek information: A caregiver’s capacity to proactively seek information from various sources in order assist with managing the health of the care recipient. A caregiver’s capacity to persevere and persist with searching for information until they have all that they need, despite any challenges or difficulties they may face was also identified. Example statements include:</td>
</tr>
<tr>
<td></td>
<td>• Caregiver needs to take initiative to search for information</td>
</tr>
<tr>
<td></td>
<td>• Motivation to seek out information</td>
</tr>
<tr>
<td></td>
<td>• Persistence in seeking information until you get what you want (patience)</td>
</tr>
<tr>
<td>2. Understanding information</td>
<td>2.1. Understanding information for day to day care provision: Caregiver’s skills to understand information on how to assist with managing the disease, treatment and side-effects, in addition to self-management tasks and healthcare services and options available for the care recipient. Example statements include:</td>
</tr>
<tr>
<td></td>
<td>• Imperative to understand medications and ‘frequency’ of when to take medications</td>
</tr>
<tr>
<td></td>
<td>• Understanding and information on food and nutrition for patients</td>
</tr>
<tr>
<td></td>
<td>• Caregivers need to understand what drugs the patients need to take and when</td>
</tr>
<tr>
<td>2.2. Understanding the healthcare system: caregiver’s skills to understand the right healthcare and healthcare services to assist with caring for the health of the care recipient. Example statements include:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Understanding the healthcare system</td>
</tr>
<tr>
<td></td>
<td>• Understanding referral processes</td>
</tr>
<tr>
<td></td>
<td>• Knowing who is responsible for the management of the patient at any point in time</td>
</tr>
<tr>
<td>2.3. Understanding the disease, treatment, and potential outcomes: Understanding information about the cancer, the treatment and potential side effects, and the potential outcomes. Includes, but is not limited to understanding of: 1) the short and long-term effects of the cancer, 2) prognosis with and without treatment, 3) potential side effects of treatment, and, 4) advanced care planning for managing the cancer. Example statements include:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• A clear understanding of the disease</td>
</tr>
<tr>
<td></td>
<td>• Understanding short term and long term effects of illness and potential outcomes</td>
</tr>
<tr>
<td></td>
<td>• A clear understanding of the treatment and the side-effects of treatment</td>
</tr>
</tbody>
</table>
2.4. Processing health information: cognitive skills associated with higher order tasks of attending to information, such as: recognising information that is meaningful, making sense of information, relating the information to what is already known, organising the information, deciding what is important, remembering the information, comparing and contrasting information, and critically appraising information related to the cancer. Example statements include:

- Need capacity (clear head) to take in the information and decipher what’s important and what the most relevant questions are
- Being able to remember all of the information you are given
- Ability to assess the reliability and validity of information

3. Relationship with healthcare providers
3.1. Active engagement with healthcare providers: cognitive and social skills that influence the caregiver’s interaction with healthcare providers in order to get the information they need. Example statements include:

- Feel safe and comfortable to ask questions (including on sensitive issues)
- Ask question when you have the opportunity
- Getting “straight answers” from healthcare providers

3.2. Supported by healthcare providers to understand information: Refers to a caregiver identifying at least one healthcare provider who engages in various strategies to assist the caregiver to understand, compare and contrast, and make decisions about information. Strategies used by healthcare providers to assist the caregiver to understand information include: 1) providing adequate time to discuss information, and 2) including the caregiver in discussions during appointments to understand information about the cancer. Example statements include:

- Time to rehash information with healthcare providers
- Allowed to repeat questions on different occasions
- Help to be able to evaluate information about side-effects reliably

4. Support systems
4.1. Practical support: Refers to government and/or community services that are available to assist the caregiver in their caregiving role such as: 1) respite care, 2) day care, 3) housekeeping, and 4) transport facilities. Example statements include:

- Practical help and support (like day care)
- Coping and managing with transport when carer does not drive
- Help with housework and practical tasks around the house for both the carer and patients and kids

4.2. Financial and legal support: Relates to financial and legal support available for caregivers from the government and/or community to assist in their caregiving role. Example statements include:

- Government financial support for carers and families
- Assisted to set up their life financially and otherwise, in a way that allows them to fulfil a carer role
- Access to good financial and legal advice

4.3. Social support: Refers to family, friends, and/or broader community groups who provide informal emotional, social, and/or informational support to the caregiver. Example statements include:

- Ongoing opportunity to share with people in similar circumstances
- Caregivers need someone to talk to about the situation (friends and others)

Chapter 6. Development of a conceptual model
• Talking to others (e.g. family, friends) who are in similar situation to get a bit of perspective

4.4. Psychosocial support: Support from healthcare providers who are professionally trained to assist the caregiver to cope and manage with the stress and emotions that can arise because of the cancer diagnosis and/or the caregiving role. Example statements include:
  • Relief-valve - carers having someone to vent to (e.g. psychologist)
  • Ongoing checks to make sure CAREGIVERS is coping (from GP, HP, cancer coordinator)
  • Availability of counselor or support person to discuss issues with carers and family

5. Caregiving-specific attributes
5.1. Self-care: Refers to a caregiver’s active engagement with managing their own physical and psychosocial health and wellbeing, whilst caring for someone with cancer. Example statements include:
  • Carers need to take care of themselves as well as care for patient
  • Time to perform the role of the caregiver while still considering their own health and the health of the person they are caring for
  • Carers have an understanding of the importance of looking after their own health to enable them to continue in their role

5.2. Attitudes and approaches, and emotional challenges: Refers to attitudes and approaches to caregiving and the caregivers ‘willingness’ to take on the caregiving role. Example statements include:
  • Objectivity at a sensitive time
  • Acceptance is the hardest thing BUT life is uncertain and need to keep positive
  • Fear of the loved one dying

5.3. Role recognition and understanding caregiver rights: Refers to the cognitive skills of the caregiver to understand: 1) that the ‘caregiver’ label refers to them, and 2) their rights as a caregiver, 3) their government/healthcare/health benefit/informational entitlements as a caregiver. Example statements include:
  • Carers understand what their rights are
  • Clear authority for the carer to be provided with information
  • Understanding that the term ‘carer’ may refer to THEM

6. Relationship with the care recipient
6.1. Understanding the care recipient: Relates to the caregiver’s skills to understand how to best support the care recipient. Example statements include:
  • Working out the fine line between caregiving and stepping back
  • Carer sensitivity to information needs of patient
  • Carers and family being aware of vulnerabilities of the patient

6.2. Communication with the care recipient: Relates to the quality of the communication between the carer and care recipient about the cancer. Example statements include:
  • Good honest communication with patient in order for patient to share with caregiver the information about the health condition
  • Ability to communicate openly with the person with cancer
  • Caregiver needs the patient to be willing to talk to them and pass information on

Chapter 6. Development of a conceptual model
the general category *Relationships with the care recipient* contained two concepts: 1) understanding the care recipient, 2) communication with the care recipient. The category *Caregiving-specific attributes* contained three concepts: 1) attitudes, approaches, and emotional challenges, 2) role recognition, and understanding caregiver rights, and 3) self-care.

**Key components of caregiver health literacy**

The descriptions of the 17 concepts hypothesised to represent caregiver health literacy are outlined below. As the concepts were refined from results presented in the previous section, participant statements are not reproduced.

**Information presented in quality formats**

The concept *information presented in quality formats* refers to availability of information from a range of sources, in both verbal and written formats. Participants across groups discussed the need for information that is presented in simple, clear, and easy to understand language to enable individuals with or without prior knowledge of health and healthcare to interpret the information. The concept also relates to information that is age appropriate, culturally-sensitive, and available in languages other than English. Availability of information in written, and pictorial formats was also discussed.

**Supported by healthcare providers to understand information**

As might be expected when managing a chronic condition such as cancer, being supported by healthcare providers to understand information was identified as playing a key role in a caregiver’s capacity to understand information. Support from healthcare providers to identify relevant support systems was also discussed. Healthcare providers’ support was discussed in a number of forms including: 1) providing sufficient time to discuss information, 2) tailoring information to meet the needs of the individual, as well as; 3) assisting the caregiver to
process health information. Examination of statements suggested that support from healthcare
providers also contributed to a caregivers’ capacity to ask questions.

**Proactivity and determination to seek health information**

The concept *proactivity and determination to seek information* was identified by
participants as necessary for caregivers to obtain information about the disease, treatment, or
aspects of the caregiving role in order to provide optimal care for the care recipient. The concept
relates to a caregiver’s capacity to proactively seek information from various sources in order to
assist with managing the health of the care recipient. This concept also refers to a caregiver’s
capacity to persevere and persist with searching for information until they have all that they
need, despite any challenges or difficulties they may face.

**Active engagement with healthcare providers**

The concept *active engagement with healthcare providers* relates to the cognitive and
social skills that influence the caregiver’s interaction with healthcare providers to access and
understand information. Participants discussed knowing *what* questions to ask, as well as
knowing *how*, and having the confidence to ask the questions. Although engagement with
healthcare providers to some extent involves the skills of the healthcare provider, the concept
sought to address the interpersonal skills of the caregiver when accessing information to promote
the health of the care recipient.

**Understanding information about the cancer, treatment, and potential outcomes**

The concept *understanding information about the cancer, treatment and potential outcomes*
relates to the caregiver understanding information about the cancer, the treatment and
potential side effects, and the potential outcomes. Participants discussed needs to understand: 1)
the short and long-term effects of the cancer; 2) prognosis with and without treatment; 3)

Chapter 6. Development of a conceptual model
Chapter 6. Development of a conceptual model

Understanding information can be influenced by individual, interpersonal, and broader factors such as the caregiver’s capacity to seek information, their engagement with healthcare providers, their capacity to process health information, availability of information, as well as being supported by healthcare providers to understand information.

**Understanding the healthcare system**

The concept *understanding the healthcare system* refers to the caregiver’s cognitive skills to understand the right healthcare providers and healthcare services who facilitate optimal health outcomes of the care recipient. The caregiver’s capacity to understand the healthcare system is influenced by healthcare provider factors as well as broader community factors, for example, the availability of information and/or support to assist caregivers to understand and navigate the healthcare system. Understanding the healthcare system was influenced by a number of individual, interpersonal, and broader factors such as: 1) proactivity and determination to seek information; 2) active engagement with healthcare providers; 3) capacity to process health information; 4) relationship with the care recipient; 5) support from healthcare providers; and 6) information presented in quality formats.

**Understanding information for day-to-day care provision**

The construct *understanding information for day-to-day care provision* relates to the caregiver’s cognitive skills to comprehend information that assists with the day-to-day caring tasks. Participants discussed the need to understand information related to managing the disease, treatment and side-effects, as well as self-management tasks and healthcare services and options available for the care recipient outside of the hospital setting.
**Processing health information**

The concept *processing health information* relates to a caregiver’s capacity to attend to information. Themes that emerged from participant statements included: the capacity to recognise information that is meaningful; making sense of information; relating information to what is already known; organising health-related information; deciding what is important; remembering information; and critically appraising health information. An individual’s capacity to process health information contributed to their capacity to understand information, as well as their capacity to actively engage with healthcare providers.

**Self-care**

The concept *self-care* relates to a caregiver’s active engagement with managing his or her own health and wellbeing, whilst caring for someone with cancer. Self-care was identified as an important factor to optimise caregiver health outcomes and caregiver capacity to provide adequate care.

**Attitudes, approaches and emotional challenges**

The concept *attitudes, approaches, and emotional challenges* refers to the caregiver’s attitudes and approaches to caregiving and ‘willingness’ to take on the caregiving role. Participants discussed the need to maintain a rational attitude or use optimal coping strategies to cope with the demands of the caregiving role. The process of engaging with the caregiving role and the tasks required was also discussed.

**Role recognition and understanding caregiver rights**

The concept *role recognition and understanding of caregiver rights* relates to the cognitive skills of the caregiver to understand that the ‘caregiver’ label refers to them, their rights as a caregiver, and their government/healthcare/health benefit/informational entitlements as a
Chapter 6. Development of a conceptual model

caregiver. To some extent, this construct is affected by external factors, such as healthcare provider support and acknowledgement of the role, and information presented in quality formats about the caregiving role. However, this concept addresses the caregiver’s awareness of their role and caregiving rights.

**Communication with the care recipient**

The concept *communication with the care recipient* relates to the quality of the communication between the carer and care recipient about the care recipient’s health. Open and honest communication with the care recipient about the cancer (including the day to day health of the care recipient, needs of the care recipient, potential outcomes of the cancer, the impact of the cancer on the future of both the care recipient and the caregiver, and/or information provided by healthcare providers) was a factor identified as enabling the caregiver to provide optimal care. Open communication with the care recipient also has the potential to assist the caregiver to cope with the cancer, its prognosis, and potential impacts on the future.

**Understanding the care recipient**

The concept *understanding the care recipient* relates to the concept *communication with the care recipient* and explores the caregiver’s skills to understand how to best support the care recipient. Understanding the care recipient’s physical, informational, and psychosocial needs was identified as a factor that assisted the caregiver to find and apply information that facilitates the quality, type, and amount of care provided.

**Social support**

The concept *social support* refers to family, friends, and/or broader community groups who provide informal emotional and social support to the caregiver. Social support was identified as a factor that assisted caregivers: 1) to discuss and debrief about the caregiving
situation and/or role; 2) with an opportunity to share their experiences with others in a similar situation; and 3) to discuss and share information and resources available for caregivers, and/or the care recipient. Informal social support was a strategy for caregivers to cope with the caregiving role by de-briefing and/or sharing experiences with others. Social support networks also assisted the caregiver to find and understand information about the cancer to facilitate the caregiving role.

**Psychosocial support**

The construct *psychosocial support* refers to support from healthcare providers who are professionally trained to assist the caregiver to cope and manage with the stress and emotions that can arise because of the cancer diagnosis and/or the caregiving role. Access to professional psychosocial support was identified as a factor that assisted caregivers with: developing strategies to monitor and take care of their own health and wellbeing, monitoring the wellbeing of the caregiver, developing strategies to manage family members and friends’ needs for information, and, provision of psychological support to cope with the impact of cancer in their life.

**Practical support**

The construct *practical support* refers to government and/or community services that are available to assist the caregiver in their caregiving role. Access to practical support was identified as a factor that assisted the caregiver to cope with the physical and psychosocial demands of providing care, and assisted with practical tasks in the home, as well as giving caregivers time away from caregiving. Examples of government and community services include but are not limited to: respite care, day care, housekeeping, transport facilities, and translation services.
Financial and legal support

The concept financial and legal support relates to financial and legal support available for caregivers from the government and/or community to assist in their caregiving role. Access to good financial and legal support was discussed as a factor that enables caregivers to be assisted financially and/or legally in order to fulfil tasks associated with the caregiving role.

Chapter Summary

In this Chapter, the development of a conceptual model of caregiver health literacy grounded in the perspectives of key stakeholders was presented in manuscript B. Grounded consultations were conducted with caregivers, people with cancer, and healthcare providers/policymakers to identify elements that influence a caregiver’s capacity to find, understand, and use health information to promote and maintain the health of their care recipient. Consultation data was synthesised and integrated using a mixed methods approach in order to develop a conceptual model hypothesised to represent caregiver health literacy. Synthesis of results from workshops allowed for theoretical saturation and identified 17 concepts related to caregiver health literacy. The 17 components were described in the extended results. The emergent model captures distinct individual, interpersonal, and broader elements that influence a caregiver’s capacity to find, understand, and use health information. Although some components are generic and potentially modifiable which would meet the criteria for inclusion in a new measure of caregiver health literacy, other components are not. However the purpose of capturing all elements in the conceptual model was to comprehensively identify the range of possible components that may influence caregiver health literacy capacities. In the next chapter, results from the conceptual model were used to guide the development of a new measure of caregiver health literacy.

Chapter Overview

In Chapter 7, the objective of the study was to develop a conceptually-driven scale to assess caregiver health literacy in the cancer setting. The study aimed to generate items for the scale, and to assess the content validity of these items. The study is presented as a manuscript (Manuscript C) which was submitted to, and subsequently published in *BMC Family Practice*. 
Manuscript C

Yuen E.Y.N., Knight, T., Dodson, S., Ricciardelli, L., Burney, S., Livingston, P.M. (2014). Development of the Health Literacy of Caregivers Scale-Cancer (HLCS-C): Item generation and content validity testing. *BMC Family Practice*
# AUTHORSHIP STATEMENT

## 1. Details of publication and executive author

<table>
<thead>
<tr>
<th>Title of Publication</th>
<th>Publication details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of the Health Literacy of Caregivers Scale-Cancer (HLCS-C): Item generation and content validity testing</td>
<td>BMC Family Practice</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of executive author</th>
<th>School/Institute/Division if based at Deakin; Organisation and address if non-Deakin</th>
<th>Email or phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eva Y N Yuen</td>
<td>School of Psychology</td>
<td>0410 571 698</td>
</tr>
</tbody>
</table>

## 2. Inclusion of publication in a thesis

<table>
<thead>
<tr>
<th>Is it intended to include this publication in a higher degree by research (HDR) thesis?</th>
<th>Yes</th>
<th>If Yes, please complete Section 3. If No, go straight to Section 4.</th>
</tr>
</thead>
</table>

## 3. HDR thesis author’s declaration

<table>
<thead>
<tr>
<th>Name of HDR thesis author if different from above. (If the same, write “as above”)</th>
<th>School/Institute/Division if based at Deakin</th>
<th>Thesis title</th>
</tr>
</thead>
<tbody>
<tr>
<td>As above</td>
<td>School of Psychology</td>
<td>Development of a measure of health literacy for caregivers of people with cancer</td>
</tr>
</tbody>
</table>

If there are multiple authors, give a full description of HDR thesis author’s contribution to the publication

Conceived and designed the study, recruited participants, collected data, analysed the data, drafted, refined, and finalised the manuscript as the first and corresponding author.

Extent of contribution: 80%

I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.

Signature and date: 3rd March 2015

## 4. Description of all author contributions

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tess Knight</td>
<td>Participated in coordination of the study, data analysis, provided comments on drafts of the study, and approved the final manuscript.</td>
</tr>
<tr>
<td>Sarity Dodson</td>
<td>Participated in the conception and design of the study, contributed to data interpretation; provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
<tr>
<td>Lina Ricciardelli</td>
<td>Participated in coordination of the study, data analysis, provided comments on drafts of the study, and approved the final manuscript.</td>
</tr>
<tr>
<td>Susan Burney</td>
<td>Participated in coordination of the study, data analysis, provided comments on drafts of the study, and approved the final manuscript.</td>
</tr>
<tr>
<td>Patricia M Livingston</td>
<td>Participated in the conception and design of the study, contributed to the data interpretation, provided comments on drafts of the manuscript, and approved the final manuscript.</td>
</tr>
</tbody>
</table>
5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:
that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,
that there are no other authors according to these criteria,
that the description in Section 4 of my contribution(s) to this publication is accurate,
that the data on which these findings are based are stored as set out in Section 7 below.
If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further
consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin
University and, if the higher degree is awarded, the subsequent publication of the thesis by the university
(subject to relevant Copyright provisions).

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tess Knight</td>
<td></td>
<td>22/3/15</td>
</tr>
<tr>
<td>Sarity Dodson</td>
<td></td>
<td>4/3/15</td>
</tr>
<tr>
<td>Lina Ricciardelli</td>
<td></td>
<td>23/3/15</td>
</tr>
<tr>
<td>Susan Burney</td>
<td></td>
<td>25/3/15</td>
</tr>
<tr>
<td>Patricia M Livingston</td>
<td></td>
<td>4/3/15</td>
</tr>
</tbody>
</table>

6. Data storage

The original data for this project are stored in the following locations. (The locations must be within an
appropriate institutional setting. If the executive author is a Deakin staff member and data are stored
outside Deakin University, permission for this must be given by the Head of Academic Unit within which
the executive author is based.)

<table>
<thead>
<tr>
<th>Data format</th>
<th>Storage Location</th>
<th>Date lodged</th>
<th>Name of custodian if other than the executive author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic</td>
<td>Password protected computer file</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Paper</td>
<td>Locked filing cabinets within a secure office at Deakin University, Burwood campus</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

This form must be retained by the executive author, within the school or institute in which they are
based. If the publication is to be included as part of an HDR thesis, a copy of this form must be
included in the thesis with the publication.

Chapter 7. Development of the HLCS-C
Development of the Health Literacy of Caregivers Scale - Cancer (HLCS-C): item generation and content validity testing

Eva YN Yuen1*, Tess Knight1, Sarity Dodson2, Lina Ricciardelli1, Susan Burney3 and Patricia M Livingston4

Abstract

Background: Health literacy refers to an individual’s ability to engage with health information and services. Cancer caregivers play a vital role in the care of people with cancer, and their capacity to find, understand, appraise and use health information and services influences how effectively they are able to undertake this role. The aim of this study was to develop an instrument to measure health literacy of cancer caregivers.

Method: Content areas for the new instrument were identified from a conceptual model of cancer caregiver health literacy. Item content was guided by statements provided by key stakeholders during consultation activities and selected to be representative across the range of cancer caregiver experiences. Content validity of items was assessed through expert review (n = 7) and cognitive interviews with caregivers (n = 16).

Results: An initial pool of 82 items was generated across 10 domains. Two categories of response options were developed for these items: agreement with statements, and difficulty undertaking presented tasks. Expert review revealed that the majority of items were relevant and clear (Content Validity Index > 0.78). Cognitive interviews with caregivers suggested that all except three items were well understood.

Conclusion: A resultant 88 item questionnaire was developed to assess cancer caregiver health literacy. Further work is required to assess the construct validity and reliability of the new measure, and to remove poorly performing and redundant items, which will result in a shorter, final measure. The new measure has the potential to inform the development and evaluation of interventions and the improvement of health service delivery to cancer caregivers.

Keywords: Cancer, Caregivers, Health literacy, Information needs, Questionnaire development

Background

A diagnosis of cancer impacts not only the person diagnosed, but also their family members and friends. These social supports are often called upon to provide informal care and assistance managing the disease [1] and to provide practical, emotional and physical support [2]. Individuals who provide informal care and support, often referred as caregivers [3], also play a significant role in health-related decision-making [4], are involved in communications with healthcare providers [5], and assist with sourcing and interpreting health information [6]. These caregiving responsibilities are often undertaken unexpectedly, and caregivers are often provided limited information and support [1]. Recognition of the challenges of the caregiving role has led to development of interventions designed to meet the informational, practical, and psychosocial needs of caregivers [7-9]. Although information provision is included in the majority of these interventions [10], few studies have examined improvements in the level of caregivers’ knowledge and skills [7,10]. This may, in part, be due to the lack of measurement tools that assess caregiver knowledge and skills [2].

Consistent with broad definitions of health literacy [11-13], caregiver health literacy is defined here as the personal characteristics and social resources needed for caregivers to access, understand, appraise and use information and services to participate in decisions relating
to the health and care of the care recipient. This includes the capacity to communicate, assert and enact these decisions. Whilst evidence suggests an association between poor health literacy and poorer health outcomes [14], worse physical functioning and reduced quality of life [14-18], little is understood about the relationship between caregiver health literacy and the health outcomes of care recipients.

To accurately identify the health literacy needs of cancer caregivers, and understand the impact of caregiver health literacy on care recipient health outcomes, it is essential to measure the construct effectively. Previous studies of caregiver health literacy [19-22] have used measures that assess a subset of health literacy constructs. Measures such as the Test of Functional Health Literacy in Adults (TOFHLA [23]) or its short form [24], the Rapid Estimate of Adult Literacy in Medicine [25], and the Newest Vital Sign [26] assess an individual’s reading, numeracy, and comprehension skills in relation to healthcare. Reviews of health literacy measurement instruments increasingly call for the development of tools that capture the full range of health literacy constructs [27-29], such as critical thinking, interaction and communication, and confidence [11].

In response to this gap in the literature, health literacy measurement tools are now emerging that capture the multidimensional nature of health literacy [30,31]. However, these tools are grounded in the perspectives of the potential care recipient, and have limited utility for the identification of the needs of caregivers. Similarly, caregiver health literacy measures designed to assess health literacy of parents of infants [32,33] cover domains not relevant to the role of caregiving for an adult recipient.

The aim of the current study was to develop a measure of health literacy specifically for caregivers of people with cancer. Best practice guidelines for questionnaire development require a detailed conceptual basis to guide development [34,35]. The conceptual model of caregiver health literacy developed by the authors (Yuen, Dodson, Batterham, Knight, Chirgwin, & Livingston, in press) was used as the basis for the development of the Health Literacy of Caregivers Scale - Cancer (HLCS-C). The model, as shown in Figure 1, proposes six major

![Figure 1 Conceptual model of cancer caregiver health literacy (Yuen et al., in press).](image)
themes and 17 sub-themes associated with caregiver health literacy.

**Methods**

A validity-driven approach [36] was employed in the development of the HLCS-C. The steps undertaken are outlined in Figure 2. The study was approved by the Eastern Health Human Research Ethics Committee (E41-1011) and Deakin University Human Research and Ethics Committee (2011–115), in Melbourne, Australia.

**Content area specification**

The content areas for inclusion in the questionnaire were drawn directly from 17 sub-themes in the conceptual model of cancer caregiver health literacy (see Figure 1). The following considerations were used to determine whether (and how) themes should be represented in the questionnaire: 1) the questionnaire should capture the experiences of caregivers caring for recipients with a wide range of cancer types, stages, treatments, and potential outcomes; 2) the questionnaire should capture the experience of caregivers providing differing forms and levels of support; 3) the questionnaire should be consistent with the broad definition of caregiver health literacy, and encompass factors associated with accessing, understanding, appraising and using health information to promote and maintain the health of the care recipient; 4) the questionnaire should be presented as a list of items/statements accompanied by an appropriate set of response options; and 5) the questionnaire should contain the fewest number of domains as possible to reduce length and administration burden.

Another consideration when identifying content areas for inclusion was whether representative statements generated by participants during consultation activities captured caregiver experiences or whether they captured broader contextual factors that influenced caregiver health literacy. In addition, content areas were examined to determine whether statements representative of a sub-theme could be combined to form a scale; previous scale development studies that used similar processes to derive a conceptual model, have found that although statements within some sub-themes were conceptually related, could not be summed to form a scale score, and required deletion on psychometric grounds [30]. Further, to assist cross-referencing of the new measure against other measurement tools that assess related constructs, the included content areas were also aligned with a recently developed taxonomy that identified 12 dimensions of health literacy [11]: literacy; interaction; comprehension; numeracy; information seeking; application/function; decision making/critical thinking; evaluation; responsibility; confidence; navigation; and maintaining and promoting health (Table 1).

**Generation of items and response scale**

Statements and words provided by participants during consultation activities associated with the development of the cancer caregiver health literacy conceptual model (see Table 1) were used as the starting point for questionnaire items [37] to maximize content validity. For each content area, item selection and refinement was guided by two vignettes developed to describe an individual with a high degree of capacity in that area, and the other with low levels [30]. Where the proposed content areas for the new measure were similar to domains included in the Health Literacy Questionnaire (HLQ; [30]), a validated measure of health literacy derived using similar approaches, the HLQ items were used as the basis and revised to accommodate the caregiver audience. Response scales for each content area were developed to match the nature of the associated items and vignettes. Refinements to how content areas and vignettes were framed were undertaken to ensure consistency in response scales across the content areas of the proposed questionnaire. Items were also examined against a structured item
<table>
<thead>
<tr>
<th>Content area identified in conceptual model</th>
<th>Draft scale included in pre-testing/Reason for exclusion</th>
<th>Example item</th>
<th>Health literacy dimension*</th>
<th>Number of items included in each scale</th>
<th>Response options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Proactivity and determination to seek information</td>
<td>1. Proactivity and determination to seek information</td>
<td>I keep looking until I get all the information that I need</td>
<td>Information seeking</td>
<td>9</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>2. Information presented in quality formats</td>
<td>Subsumed into &quot;Adequate information about cancer and cancer management&quot; to minimize questionnaire length</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3. Understanding the healthcare system</td>
<td>2. Understanding the healthcare system</td>
<td>I understand what healthcare services the person I care for is entitled to</td>
<td>Comprehension</td>
<td>9</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>4. Understanding the disease, treatment, and potential outcomes</td>
<td>3. Adequate information about cancer and cancer management</td>
<td>I have all the information I need to help look after the health of the person I care for</td>
<td>Comprehension</td>
<td>8</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>5. Information for day-to-day care</td>
<td>Subsumed into &quot;Adequate information about cancer and cancer management&quot; to ensure relevance of items to all caregivers</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6. Processing health information</td>
<td>4. Processing health information</td>
<td>[Please indicate how easy or difficult the following tasks are for you to do now] Compare information about cancer from different sources</td>
<td>Critical thinking/evaluation</td>
<td>9</td>
<td>Difficulty</td>
</tr>
<tr>
<td>7. Active engagement with healthcare providers</td>
<td>5. Active engagement with healthcare providers</td>
<td>[Please indicate how easy or difficult the following tasks are for you to do now] Ask a healthcare provider to explain things to me</td>
<td>Interaction</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>8. Supported by healthcare providers to understand information</td>
<td>6. Supported by healthcare providers to understand information</td>
<td>At least one healthcare provider has helped me understand information about cancer</td>
<td>Support networks**</td>
<td>8</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>9. Communication with the care recipient</td>
<td>7. Communication with the care recipient</td>
<td>I have honest talks with the person I care for about how the cancer may impact on the future</td>
<td>Interaction</td>
<td>8</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>10. Understanding the care recipient</td>
<td>8. Understanding the care recipient</td>
<td>I know how much help to give the person I care for</td>
<td>Comprehension</td>
<td>9</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>11. Financial and legal support</td>
<td>Considered a broader contextual factor related to availability of support from Government services</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>12. Practical support</td>
<td>Considered a broader contextual factor related to availability of support from community services</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>13. Psychosocial support</td>
<td>Subsumed into &quot;Understanding the healthcare system&quot; to ensure relevance of items to all caregivers</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>14. Social support</td>
<td>9. Social support</td>
<td>I have at least one person who understands and supports me</td>
<td>Support networks**</td>
<td>9</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>15. Self-care</td>
<td>10. Self-care</td>
<td>I regularly take time away from caring</td>
<td>Responsibility</td>
<td>11</td>
<td>Agree/disagree</td>
</tr>
<tr>
<td>16. Role recognition and understanding caregiver rights</td>
<td>Statements within the sub-theme although conceptually related were considered unable to be additively combined, thus were excluded from the scale</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>17. Attitudes, approaches, and emotional challenges</td>
<td>Statements within the sub-theme although conceptually related were considered unable to be additively combined, thus were excluded from the scale</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Total items in scale: 84

*Adapted from health literacy dimensions identified by Sorensen et al. [11].
**Additional dimension included by authors, not identified in taxonomy.

Chapter 7. Development of the HLCS-C
development criteria [38] (see Table 2). Readability of items was assessed using Flesch Reading Ease [39] and Flesch-Kincaid Grade Level [40] formulas available through Microsoft Word.

Item difficulty was included in the item development criteria to ensure that the final items formed a scale that could distinguish between low, moderate, and high levels of health literacy (i.e., scale sensitivity). The revised Bloom’s taxonomy, which includes two dimensions (knowledge and cognitive process; [41,42]) was used to guide the selection of set of items for each content area to ensure they captured a range of difficulty. The first Bloom dimension describes levels of knowledge acquired (factual, conceptual, procedural, or metacognitive) whilst the second dimension describes cognitive processes that occur during learning (remembering, understanding, applying, analyzing, evaluating, and creating; [41,42]). It is posited that items that address higher level cognitive tasks (e.g., decision-making) would elicit fewer maximum ratings compared to items that addressed lower level cognitive tasks (e.g., access to information). The taxonomy has been previously used to guide the development of health literacy measures [30,43,44].

**Expert review**

Expert review of items was undertaken to establish the content validity of the proposed items [45]. In a judgment-quantification process [46], items within each proposed scale were assessed by seven experts for relevance and clarity. Participants included two oncologists, a general practitioner, an oncology social worker, a general medical nurse, a health researcher, a policy advisor for a state-wide caregiver organization, and a retired executive member of a cancer information and support service. The content validity of the tool as a representation of its intended purpose was also qualitatively assessed. Experts were identified and recruited from the research team’s existing professional networks. Between 5 and 10 experts have been suggested as a number sufficient for establishing content validity using expert review [46].

Experts were asked to assess each item for relevance and clarity using a 3-point scale ("low, moderate, high" and "unclear, neutral, clear" respectively). To determine content validity, expert ratings for relevance and clarity were quantified using the Content Validity Index (CVI) calculated as the percentage of experts who indicated 2 or 3 on the scale. It has been recommended that when six or more experts have evaluated the instrument, items with a CVI less than 0.78 should be considered for revision or deletion [46].

Experts were also asked to consider all items within individual scales and respond to two open-ended questions, “Do you suggest including any other ideas to represent the scale”, and “Do you suggest changing any words for any of the above items”. Experts were also asked to provide feedback on whether any major concepts or ideas were omitted in the questionnaire and to make suggestions on how to improve the instrument. To

<table>
<thead>
<tr>
<th>Table 2 Structured item development criteria used to assess quality of items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>#</strong></td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>9</td>
</tr>
<tr>
<td>10</td>
</tr>
</tbody>
</table>

Chapter 7. Development of the HLCS-C
guide the revision of items, responses to the open-ended questions were synthesized and reviewed.

Cognitive interviews
Cognitive interviews are frequently used in questionnaire development to determine whether respondents interpret and respond to items in the way the researchers intended [47]. The think-aloud approach [47,48] was the predominant method used in the current study. A convenience sample of participants was recruited from a not-for-profit government funded caregiver organization. Ninety-nine caregivers who identified themselves as providing care to a family member or friend with cancer were invited to participate. Nineteen caregivers (19%) who returned the questionnaire were then contacted via telephone about taking part in a telephone interview. Three respondents completed the questionnaire; however, they declined to participate in the cognitive interview because of personal circumstances. Of the 16 caregivers who participated, the majority were female (94%), and ranged in age between 42 and 80 years (Mdn = 61.5; see Table 3).

To minimize respondent burden, a sampling scheme was applied to allow each participant to be interviewed on items from approximately 6, rather than all 10, constructs in the questionnaire. Participants were randomly assigned an item set that included items from complete constructs. Using this method, each item in the questionnaire was reviewed by at least 8 participants (range = 8 – 11; Mdn = 9). Although participants did not complete the full set of items, the sampling scheme was sufficient as the purpose of the cognitive interviews was to test the items across a range of individuals to inform decision making [47].

Responses from the cognitive interviews were analyzed using a systematic evaluation of participant responses for each item [49]. Each item was assessed using three criteria: whether the participant interpreted the question as the researchers had intended; whether the item was applicable to the participant; and whether the participant found it difficult to respond to the item. In cases where responses had problems with an item, common themes and issues were noted.

Results
Selection of content areas
Inspection of the 17 sub-themes outlined in the cancer caregiver health literacy model against the considerations for inclusion of content areas led to the identification of 10 constructs for the new questionnaire (see Table 1). Several sub-themes were subsumed under the encompassing scale titles: Adequate information about cancer and cancer management, and Understanding the healthcare system. Two sub-themes were considered broader contextual factors that influenced caregiver health literacy, and thus were excluded from the questionnaire. For example, statements in the Financial and Legal Support sub-theme related to availability of support from Government services, which was considered a broader contextual factor that influenced a caregiver’s capacity to effectively engage with the caregiving role. Two additional sub-themes were excluded because their representative statements, although conceptually related, were considered unable to be summed to form a scale.

Item generation and response options
Eighty-two items were developed for expert review, with 7 to 12 items for each construct (see Table 1). An item pool 50% larger than that intended for the final scale was drafted to enable identification of items with adequate internal consistency as determined through psychometric analyses (Phase 3; see Figure 2) [45]. For eight content areas, an ‘agree/disagree’ Likert scale was suitable. For the remaining two content areas (Processing health information, and Active engagement with healthcare providers) a ‘cannot do/very easy’ Likert scale was more suitable. Readability analysis of the items showed a Flesch-Kincaid reading level of grade 6.7, with a Flesch reading ease of 80.6 (out of a possible 100, with higher scores indicating greater ease).
Expert review

The range of content validity indices for relevance and clarity for the ten scales as assessed by 7 experts are provided in Table 4. Although 8 experts responded, one participant provided general comments about including additional content areas rather than assessing all individual items, thus, was excluded from the content validity analysis. The participant's comments were considered when determining the inclusion of additional content areas. Items were considered relevant by experts (CVI > 0.78) for all but one item related to processing health information (#70, “Find out if the health information that I have received is suitable for the person I am caring for”). Item #70 was considered invalid both for relevance and clarity (CVI < 0.78), and thus was revised (see Table 5) after considering expert comments, and reviewing participant statements generated during concept mapping workshops.

Using the content validity equation, five items although deemed relevant by experts, were considered to lack clarity (CVI < 0.78; see Table 4). These five items were revised (see Table 5). An additional item (#81, “I know which healthcare providers look after the health of the person I care for”), although deemed relevant and clear, was deleted in response to expert comments about its similarity to another item in the scale.

Twelve items, although demonstrated adequate relevance and clarity (CVI > 0.78), underwent minor revisions in response to suggested improvements from experts (See Table 6). Item #12 (“I have strong support from at least one friend” was combined with item #66 (“I have strong support from at least one family member”) following feedback about the similarity of items, and suggestions from experts to merge the two items.

Nine new items were included in the questionnaire in response to comments from experts (see Table 7). Revision of the item pool resulted in 89 items for testing through cognitive interviews. Experts identified three main areas that were missing from the questionnaire: understanding of healthcare services, palliative care, and sexuality issues. However, only the concept of understanding of healthcare services was captured in newly generated items.

Cognitive interviews

Overall, participants interpreted and responded to the majority of the questionnaire items in ways intended. However, three items (#18, #74 and #1) emerged as having common issues. For item #18 (“I have all the information I need to help make decisions about treatments”) two participants reported that they did not help make decisions about treatments, thus the item was not personally relevant to them (e.g. “I’m not a doctor and I wouldn’t know of other treatments, so I trusted what doctors told me” [Participant 1]). For item #74 (“Find out if health information from various resources is suitable for the person I am caring for”) participants interpreted the word ‘resource’ as being internet-specific (e.g. “Yeah I think it is, you just borrow the kids internet and have a look” [Participant #11]). Further, for item #1 (“I spend a lot of time looking for information about the cancer”) two caregivers reported that although they spent time looking for information when their care recipient was first diagnosed with cancer, it was no longer relevant after many years of providing care (e.g. “My husband has had cancer now for years. At the beginning I spent a lot of time researching but now only when you feel up to it” [Participant #10]).

Discussion

The current study describes item generation and content validity testing of a new questionnaire to assess the self-reported health literacy of caregivers of people with cancer, the Health Literacy of Caregivers Scale—Cancer (HLCS-C). As a result of the expert review and cognitive interviews, the HLCS-C now contains 88 items across 10 scales: proactivity and determination to seek information, self-care, social support, communication with the care recipient, understanding the care recipient, active engagement with healthcare providers, supported by healthcare providers to understand information, adequate information about cancer and cancer management, understanding the healthcare system, and proactivity and determination to seek information.

Table 4 Range of CVI scores for relevance and clarity for ten hypothesized scales of cancer caregiver health literacy

<table>
<thead>
<tr>
<th>#</th>
<th>Construct</th>
<th>Relevance</th>
<th>Clarity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>CVI range</td>
<td>Items with CVI &lt;0.78</td>
</tr>
<tr>
<td>1</td>
<td>Proactivity and determination to seek information</td>
<td>0.86 – 1.00</td>
<td>-</td>
</tr>
<tr>
<td>2</td>
<td>Understanding the healthcare system</td>
<td>1.00</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>Adequate information about cancer and cancer management</td>
<td>1.00</td>
<td>-</td>
</tr>
<tr>
<td>4</td>
<td>Processing health information</td>
<td>0.71 – 1.00</td>
<td>#70</td>
</tr>
<tr>
<td>5</td>
<td>Supported by healthcare providers to understand information</td>
<td>0.86 – 1.00</td>
<td>-</td>
</tr>
<tr>
<td>6</td>
<td>Active engagement with healthcare providers</td>
<td>1.00</td>
<td>-</td>
</tr>
<tr>
<td>7</td>
<td>Communication with the care recipient</td>
<td>0.86 – 1.00</td>
<td>-</td>
</tr>
<tr>
<td>8</td>
<td>Understanding the care recipient</td>
<td>0.86 – 1.00</td>
<td>-</td>
</tr>
<tr>
<td>9</td>
<td>Social support</td>
<td>1.00</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>Self-care</td>
<td>0.86 – 1.00</td>
<td>-</td>
</tr>
</tbody>
</table>
Table 5 Seven revised items in response to content validity index scores for relevance and clarity, and comments from experts

<table>
<thead>
<tr>
<th>Construct</th>
<th>Item #</th>
<th>Initial item</th>
<th>Relevance</th>
<th>Clarity</th>
<th>Comments from experts</th>
<th>Action</th>
<th>Revised item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding the healthcare system</td>
<td>81</td>
<td>I know which healthcare providers look after the health of the person I care for</td>
<td>1.00</td>
<td>1.00</td>
<td>Almost identical to another item in the scale</td>
<td>Deleted</td>
<td>-</td>
</tr>
<tr>
<td>Adequate information about cancer and cancer management</td>
<td>42</td>
<td>I am sure I have all the information I need to help manage the health of the person I care for</td>
<td>1.00</td>
<td>0.71</td>
<td>Item #42 and #64 are similar</td>
<td>Revised</td>
<td>I have enough information to look after the health of the person I care for</td>
</tr>
<tr>
<td>Processing health information</td>
<td>70</td>
<td>Find out if the health information that I have received is suitable for the person I am caring for</td>
<td>0.71</td>
<td>0.43</td>
<td>Implies that health information e.g. by healthcare providers is not suitable</td>
<td>Revised</td>
<td>Find out if the health information that I have found from various resources, is suitable for the person I am caring for</td>
</tr>
<tr>
<td>Communication with the care recipient</td>
<td>21</td>
<td>The person I care for tells me how they are, in order for me to help</td>
<td>1.00</td>
<td>0.71</td>
<td>Items #21 and 29 are similar</td>
<td>Revised</td>
<td>The person I care for tells me about their health, in order for me to help</td>
</tr>
<tr>
<td></td>
<td>37</td>
<td>I talk honestly about the cancer with the person that I care for</td>
<td>1.00</td>
<td>0.71</td>
<td>Item seems general</td>
<td>Revised</td>
<td>I have honest talks about the cancer with the person I care for</td>
</tr>
<tr>
<td>Understanding the care recipient</td>
<td>6</td>
<td>I understand how much information about the cancer, the person I am caring for needs to know</td>
<td>0.86</td>
<td>0.71</td>
<td>There is a difference between 'needs' and 'wants'</td>
<td>Revised</td>
<td>I understand how much information about the cancer, the person I am caring for needs to know</td>
</tr>
</tbody>
</table>

adequate information about cancer and cancer management; supported by healthcare providers to understand information; social support; communication with the care recipient; understanding the care recipient; self-care; understanding the healthcare system; processing health information; and active engagement with healthcare providers.

The scales included in the HLCS-C covered a broad range of themes that assessed individual, interpersonal as well as healthcare provider and healthcare system factors that may be relevant to caregiver health literacy. Many of these themes are currently not included in widely-used measures of health literacy. For example, some scales in the HLCS-C assess an individual’s comprehension (e.g., Adequate information about cancer and cancer management, and Understanding the healthcare system), or their critical thinking skills (e.g., Processing health information), while other scales assess a caregiver’s interpersonal relationship with the care recipient (e.g., Communication with the care recipient, and Understanding the care recipient). Caregivers’ capacity to effectively engage with healthcare providers was also included (Active engagement with healthcare providers). Further extending dimensions of health literacy measures, the HLCS-C assesses external influences on an individual’s health literacy. Similar to the Health Literacy Questionnaire [30], the HLCS-C contains a scale that assesses the caregivers’ perspectives of healthcare provider provision of services and information in ways that enable them to adequately navigate the caregiving role and the healthcare system (e.g., Supported by healthcare providers to understand information). Unlike the existing unidimensional measures of health literacy, the multidimensional nature of the HLCS-C allows identification of specific strengths and difficulties and therefore the identification of opportunities to improve caregiver health literacy and the health literacy responsiveness of the healthcare system.

As part of the expert review, experts suggested including items related to sexuality issues. However, the authors made the decision to not include items related to sexuality issues as this topic was not identified by stakeholders during the concept mapping workshops. Concept mapping workshop participants included caregivers providing care for, and people with cancer, across a range of cancer types and stages. It is possible that issues of sexuality were not their primary concern when identifying health literacy needs. Further, it is possible that given the workshop setting, participants may have felt uncomfortable discussing the topic of sexuality. Moreover, studies have shown that caregivers of people with gender-specific cancers (e.g., breast or prostate) were more likely to report additional information needs related to sexual and physical intimacy [50]. Further revisions of the questionnaire could consider sub-sets of items relevant to specific cancer types.

Similarly, experts commented on the inclusion of items related to palliative care. However, the questionnaire was

Chapter 7. Development of the HLCS-C
Table 6 Revised items following expert suggestions for revision

<table>
<thead>
<tr>
<th>Construct</th>
<th>Item #</th>
<th>Initial item</th>
<th>Revised item</th>
<th>Comments from experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supported by healthcare providers to understand information</td>
<td>50</td>
<td>Healthcare providers have helped us compare information about treatments</td>
<td>Healthcare providers have helped me compare information about treatments</td>
<td>Consider using ‘me’ rather than ‘us’ to avoid confusion</td>
</tr>
<tr>
<td>Communication with the care recipient</td>
<td>57</td>
<td>Healthcare providers have helped me understand the potential side effects of treatments</td>
<td>Healthcare providers have helped us understand the potential side effects of treatments</td>
<td>Consider using ‘me’ rather than ‘us’ to avoid confusion</td>
</tr>
<tr>
<td>Understanding the care recipient</td>
<td>58</td>
<td>After appointments, I discuss the information given by doctors with the person I care for</td>
<td>After appointments, I discuss the information given by healthcare providers with the person I care for</td>
<td>Referring to doctors or all healthcare providers</td>
</tr>
<tr>
<td>Social support</td>
<td>14</td>
<td>I understand when to let the person I am caring for do things by themselves in their own time</td>
<td>I understand when to let the person I am caring for do things for themselves in their own time</td>
<td>Perhaps “for themselves” better captures the concept</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>I know which everyday activities the person I care for would like to be involved in</td>
<td>I know which everyday activities the person I care for would like to do</td>
<td>Changing “involved in” might improve clarity</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>There is at least one person who understands and supports me</td>
<td>I have at least one person who understands and supports me</td>
<td>Consider changing the stem to follow other items</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>I have strong support from at least one family member</td>
<td>I have strong support from at least one family member or friend</td>
<td>Is it necessary to differentiate between family member and friend</td>
</tr>
<tr>
<td></td>
<td>66</td>
<td>I have strong support from at least one friend</td>
<td>Not applicable: Subsumed into above item</td>
<td>As above</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>I get plenty of chances to talk to other people who are caring for someone with cancer</td>
<td>I get enough chances to talk to other people who are caring for someone with cancer</td>
<td>Might not need ‘plenty’</td>
</tr>
<tr>
<td></td>
<td>44</td>
<td>I have family or friends who can attend medical appointments with us</td>
<td>I have at least one family member or friend who can attend medical appointments with us</td>
<td>Identifying one person would be adequate</td>
</tr>
</tbody>
</table>

Table 7 New items following expert review and reasons for inclusion

<table>
<thead>
<tr>
<th>Construct</th>
<th>Comments from experts</th>
<th>New item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding the healthcare system</td>
<td>(General comment) It is important for caregivers to understand what services and supports are available for the caregiver and care recipient</td>
<td>I know what healthcare services are available to help the person I care for</td>
</tr>
<tr>
<td>Adequate information about cancer and cancer management</td>
<td>Suggest including additional items about managing side effects, and caregivers’ having enough information to support the care recipient</td>
<td>I know which side-effects require immediate medical attention</td>
</tr>
<tr>
<td>Processing health information</td>
<td>Suggest including additional questions that explore caregiver’s capacity to identify relevant information</td>
<td>[How easy or difficult is it for you to…?] Work out which sources have information that is relevant for the person I care for</td>
</tr>
<tr>
<td>Supported by healthcare providers to understand information</td>
<td>(General comment) It is important for caregivers to understand what services and supports are available for the caregiver and care recipient</td>
<td>Healthcare providers have helped me understand services available for the person I care for</td>
</tr>
<tr>
<td>Active engagement with healthcare providers</td>
<td>(General comment) It is important for caregivers to understand what services and supports are available for the caregiver and care recipient</td>
<td>Ask a healthcare provider to explain what healthcare services are available to help me provide care</td>
</tr>
<tr>
<td>Self-care</td>
<td>Suggest including a question about physical activity or exercise</td>
<td>Despite other things in my life, I make sure I regularly exercise</td>
</tr>
</tbody>
</table>
designed for use with caregivers across the cancer trajectory. Thus, the authors considered that items related to palliative care would not be relevant to all cancer caregivers. Future revisions of the questionnaire could consider items that are specific to caregivers providing care to people with advanced stage cancer.

To address the three items identified as having common issues following cognitive interviews, the decision was made to revise two items and delete one item. To ensure included items were relevant to all cancer caregivers, item #18 was revised to "I have enough information to understand the potential side effects of cancer treatment", which still captured the concept of adequate cancer information. To improve clarity for item #74, the word ‘resources’ was replaced with ‘places’, as participants frequently used this word during cognitive interviews to describe sources of information. Further, as item #1 was not relevant for all caregivers across the caregiving trajectory, the item was deleted. Cognitive testing of the revised items is suggested to ensure items are understood as intended.

Two of the 16 participants responded with ‘disagree/very difficult’ on five items, which suggested that they had difficulty, or were unable to complete that task. However, during the cognitive interviews, it was revealed that these participants had provided care to someone who had deliberately avoided conventional cancer treatments for exclusive use of complementary and alternative therapies to manage the cancer. Thus, in responding to specific items, these participants were not conveying difficulty or inability to complete the task; rather their intention was to convey that the item was ‘not applicable’ to their circumstance. Item writing was guided by statements generated by participants during concept mapping workshops who were recipients of, or caregivers of people who received, conventional cancer treatments. It is therefore recommended that future studies be conducted with caregivers of people who solely receive complementary and alternative therapies to manage their cancer to ensure a sub-set of items that address the health literacy needs of this caregiver population.

Limitations of the study included the low response rate for expert reviews (29%). Although low response rates may potentially affect generalizability of the results, the sample size for the expert review analysis was in line with recommendations [51]. Participation rate was also low for the cognitive interviews (19%); however, between 8 to 11 interviews were conducted for each item, which met the recommended sample size of 5 to 15 participants to identify problems with items [47]. Further, participants for cognitive interviews were predominantly female (94%), which limits generalizability of the findings. Further, reporting error may occur due to the self-report nature of the questionnaire, in which respondents may report differently depending on their social experiences [52].

Conclusion
Using systematic grounded approaches, a new measure of cancer caregiver health literacy is being developed that contains 10 key constructs hypothesized to represent a caregiver’s capacity to find, understand, appraise, and use health information to provide optimal care. The next step in the development of this measure is to assess the reliability and validate the questionnaire in a large sample of Australian cancer caregivers, and reduce the number of items it contains.

Practice implications
The current study represents the first attempt to establish an instrument to measure the health literacy of caregivers of people with cancer. Assessment and understanding of the health literacy needs of caregivers has the potential to enable the evaluation and development of interventions designed to improve caregiver knowledge and skills.

Consent
Written informed consent was obtained from caregivers for the publication of this report.

Abbreviations
CMI: Content Validity Index; HLCS-C: Health Literacy of Caregivers Scale-Cancer; HLQ: Health Literacy Questionnaire; TOFHLA: Test of Functional Health Literacy in Adults.

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
EYNY conceived and designed the study, coordinated participant recruitment, conducted the cognitive interviews, analyzed the data, and drafted the manuscript. PML and SD participated in the conception and design of the study, and helped to draft the manuscript. TK, LR and SB participated in the coordination of the study, data analysis, and helped to draft the manuscript. All authors read and approved the final manuscript.

Acknowledgements
The authors would like to sincerely thank the experts who participated in the expert review, the caregivers who participated in the cognitive interviews, Anne Muldowney from Carers Victoria for her help with recruiting caregivers, and Professor Richard Osborne for his contributions to the study.

Eva YN Yuen was supported by a Deakin University Postgraduate Research Scholarship.

The research was, in part, supported by a Deakin University Population Health Strategic Research Centre small project funding grant.

Author details
1School of Psychology, Deakin University, 221 Burwood Highway, Burwood, VIC 3125, Australia. 2Public Health Innovation, Deakin University, Melbourne, Australia. 3School of Psychological Sciences, Monash University, Melbourne, Australia. 4Faculty of Health, Deakin University, Melbourne, Australia.

Received: 21 September 2014 Accepted: 24 November 2014
Published online: 10 December 2014

doi:10.1186/s12875-014-0202-9
Cite this article as: Yuen et al.: Development of the Health Literacy of Caregivers Scale - Cancer (HLCS-C): item generation and content validity testing. BMC Family Practice 2014 15:202.

Chapter 7. Development of the HLCS-C
**Extended Results**

To enhance understanding of the processes that guided item selection and refinement described in manuscript C, the two vignettes developed for each domain that described high and low capacity in that area are presented in Table 7.1.

![Table 7.1](image)

**Table 7.1**

*Vignettes to describe an individual with high capacity, and low capacity for the ten domains included in the HLCS-C*

<table>
<thead>
<tr>
<th>Low level of the construct</th>
<th>High level of the construct</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Proactivity and determination to seek information</strong>&lt;br&gt;Caregiver is passive in their approach to seeking information. They do not seek information for themselves, and are not motivated to seek information outside of what is offered to them.</td>
<td>Caregiver actively seeks information related to the cancer. They search many places for information in order to provide optimal care for the care recipient, and persist with finding information until they find what they want. The caregiver ensures they have all the information they need to provide optimal care. Caregiver actively seeks new sources of information. Feels empowered.</td>
</tr>
<tr>
<td><strong>2. Adequate information about cancer and cancer management</strong>&lt;br&gt;Caregiver feels there are many gaps in their knowledge about cancer. They feel they do not have the information they need to assist the care recipient manage the cancer and their concerns</td>
<td>Caregiver feels confident they have all the information they need to assist the care recipient manage the cancer and to make health-related decisions.</td>
</tr>
<tr>
<td><strong>3. Supported by healthcare providers to understand information</strong>&lt;br&gt;Caregiver does not feel supported by healthcare providers to understand health information. They do not receive, or have great difficulty receiving, information from healthcare providers in ways they can easily understand. Caregiver feels ignored by healthcare providers during the care recipient’s medical appointments.</td>
<td>Caregiver feels that healthcare providers provide ideal support to themselves and their care recipient to ensure they understand all of the information they need about the cancer. Ideal support includes: adequate time with healthcare providers to discuss all of the information they need; healthcare providers provide information in ways that are easy for them to understand. Caregiver feels included during discussions with healthcare providers in order understand information related to the cancer.</td>
</tr>
<tr>
<td><strong>4. Social support</strong>&lt;br&gt;Caregiver feels isolated and alone. They have difficulty identifying at least one family member or friend who can provide psychosocial and/or support in their caregiving role.</td>
<td>Caregiver feels strongly supported by at least one family member or friend who provides psychosocial and/or informational support in relation to the caregiving role.</td>
</tr>
<tr>
<td><strong>5. Communication with the care recipient</strong>&lt;br&gt;Caregiver does not, or is unable to, engage in discussions with the care recipient about their health or the potential outcomes and impacts of the cancer</td>
<td>Caregiver has open and honest discussions with the care recipient about: 1) the cancer, 2) the potential outcomes and impacts on the future, 3) information</td>
</tr>
</tbody>
</table>
on their future. Caregiver is unable to get information from the care recipient that assists them to provide optimal care.

6. **Understanding the care recipient**
Caregiver lacks understanding of the care recipient’s needs and is unable to determine, or is unaware of, the care recipient’s needs for information about the cancer. Caregiver is uncertain of the care recipient's potential physical limitations during treatment and is unaware of, or is uncertain of, self-management behaviours that the care recipient must adopt to promote their own health.

7. **Self-care**
Caregiver is unable, does not engage in strategies, or make time, to take care of their own health and wellbeing. Caregiver is unable to, or does not find healthy strategies to cope with the caregiving role, and/or cancer diagnosis in their life. Caregiver does not take time to participate in activities outside of providing care.

8. **Understanding the healthcare system**
Caregiver has difficulty understanding, or limited knowledge of, health services available to themselves and/or the care recipient.

9. **Processing health information**
Caregiver is unable to understand health information they have been given to assist in their role, or information to help the care recipient. Caregiver has great difficulty, or is unable to evaluate information provided from different sources. Is unable to differentiate as to which information would be of most benefit to their role. Unable to remember pertinent information provided by healthcare providers.

10. **Active engagement with healthcare providers**
Caregiver is passive in their approach to healthcare and during interactions with healthcare providers. Caregiver does not proactively seek or clarify information and advice from healthcare providers. They accept information without question. Unable to share concerns or get a second opinion. Feels powerless in relationships with healthcare providers.

provided by healthcare providers’, 4) how the caregiver can assist with managing the cancer, and/or 5) the care recipient’s health and wellbeing.

Caregiver clearly understands the support needs of the care recipient. They are sensitive to the care recipient’s capacity for information about the cancer. Caregiver has a clear understanding of the care recipient's physical capacities during treatment and has a clear understanding of self-management tasks the care recipient must engage in to promote their own health.

Caregiver actively engages in managing their own health and makes time and engages in behaviours and activities to care of their own health and wellbeing, for example, eats regular meals, exercises regularly, and gets regular check-ups from healthcare providers. They find healthy strategies to cope with the caregiving role and cancer diagnosis in their life, and they participate in activities outside of providing care.

Caregiver understands all the health services available for themselves and the care recipient.

Caregiver understands all information, is able to identify the important information, and compare and contrast information from different sources. Caregiver is able to critically appraise information, and remembers pertinent information provided by healthcare providers.

Caregiver is active in their approach to healthcare and actively asks health providers questions to understand health information. Feels in control in relationships with healthcare providers. They are able to seek advice from additional health care providers when necessary.
Chapter Summary

In this chapter, the manuscript related to the development of the health literacy of caregivers scale (HLCS-C) was presented. In this manuscript, item generation for the HLCS-C and content validity testing of the draft items were described. Item generation and identification of content areas for inclusion in the scale was guided by results from consultations with key stakeholders, previously presented in Chapter 5. Minor revisions were made to the item pool following content validity assessment through expert review and cognitive interviews with caregivers of people with cancer. The next step in the development of the HLCS-C was to identify and remove poorly performing and redundant items, and assess the scale’s construct and discriminant validity, and internal consistency reliability. Such an investigation was the topic of the fourth manuscript related to the thesis, which is presented in the next chapter.
Chapter 8. Measuring Cancer Caregiver Health Literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C)

Chapter overview

In Chapter 8, the objective of the study was to build upon the content validity testing of the HLCS-C and: 1) identify and remove poorly performing and redundant items; and 2) determine the scale’s construct and discriminant validity, and internal consistency. The study is presented as a manuscript (D) which has been submitted for publication in *PLoS One*. 
### Title of Publication

**Measuring cancer caregiver health literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C)**

**Publication details**

Under review

### Name of executive author

**Eva YN Yuen**

School of Psychology

0410 571 698

### Inclusion of publication in a thesis

**Yes**

If Yes, please complete Section 3. If No, go straight to Section 4.

### HDR thesis author’s declaration

**Name of HDR thesis author if different from above. (If the same, write “as above”)**

**As above**

School of Psychology

**Thesis title**

Development of a measure of health literacy for caregivers of people with cancer

**Conceived and designed the study; recruited participants; collected data; undertook data analyses; interpreted the data; drafted, refined and finalised the manuscript as the first and corresponding author. Extent of contribution: 95%**

**I declare that the above is an accurate description of my contribution to this paper, and the contributions of other authors are as described below.**

**Signature and date**

3rd March 2015

### Description of all author contributions

<table>
<thead>
<tr>
<th>Name and affiliation of author</th>
<th>Contribution(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tess Knight</strong></td>
<td>Contributed to coordination of the study; provided comments on drafts of the manuscript; and approved the final manuscript.</td>
</tr>
<tr>
<td><strong>Sarity Dodson</strong></td>
<td>Contributed to the conception and design of the study; contributed to the interpretation of the results, provided comments on drafts of the manuscript; and approved the final manuscript.</td>
</tr>
<tr>
<td><strong>Jacqueline Chirgwin</strong></td>
<td>Contributed to participant recruitment and data collection, provided comments on the manuscript; and approved the final manuscript.</td>
</tr>
<tr>
<td><strong>Lucy Busija</strong></td>
<td>Contributed to data analysis; contributed to the interpretation of the results, provided comments on drafts of the manuscript; and approved the final manuscript.</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
Lina Ricciardelli: Contributed to coordination of the study; provided comments on drafts of the manuscript; and approved the final manuscript.

Susan Burney: Contributed to coordination of the study; provided comments on drafts of the manuscript; and approved the final manuscript.

Phillip Parente: Contributed to participant recruitment and data collection, provided comments on the manuscript; and approved the final manuscript.

Patricia M Livingston: Contributed to the conception and design of the study; contributed to the interpretation of the results, provided comments on drafts of the manuscript; and approved the final manuscript.

5. Author Declarations

I agree to be named as one of the authors of this work, and confirm:
that I have met the authorship criteria set out in the Deakin University Research Conduct Policy,
that there are no other authors according to these criteria,
that the description in Section 4 of my contribution(s) to this publication is accurate,
that the data on which these findings are based are stored as set out in Section 7 below.
If this work is to form part of an HDR thesis as described in Sections 2 and 3, I further consent to the incorporation of the publication into the candidate’s HDR thesis submitted to Deakin University and, if the higher degree is awarded, the subsequent publication of the thesis by the university (subject to relevant Copyright provisions).

<table>
<thead>
<tr>
<th>Name of author</th>
<th>Signature*</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tess Knight</td>
<td></td>
<td>22/03/15</td>
</tr>
<tr>
<td>Sarity Dodson</td>
<td></td>
<td>4/03/15</td>
</tr>
<tr>
<td>Jacqueline Chirgwin</td>
<td></td>
<td>3/03/15</td>
</tr>
<tr>
<td>Lucy Busija</td>
<td></td>
<td>03/03/2015</td>
</tr>
<tr>
<td>Lina Ricciardelli</td>
<td></td>
<td>23/03/15</td>
</tr>
<tr>
<td>Susan Burney</td>
<td></td>
<td>25/3/15</td>
</tr>
<tr>
<td>Phillip Parente</td>
<td></td>
<td>3/03/15</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
6. **Data storage**

The original data for this project are stored in the following locations. (The locations must be within an appropriate institutional setting. If the executive author is a Deakin staff member and data are stored outside Deakin University, permission for this must be given by the Head of Academic Unit within which the executive author is based.)

<table>
<thead>
<tr>
<th>Data format</th>
<th>Storage Location</th>
<th>Date lodged</th>
<th>Name of custodian if other than the executive author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic</td>
<td>Password protected computer file</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Paper</td>
<td>Locked filing cabinets within a secure office at Deakin University, Burwood campus</td>
<td>n/a</td>
<td>n/a</td>
</tr>
</tbody>
</table>

This form must be retained by the executive author, within the school or institute in which they are based. If the publication is to be included as part of an HDR thesis, a copy of this form must be included in the thesis with the publication.
Chapter 8. Validation of the HLCS-C

Manuscript D

Manuscript title: Measuring cancer caregiver health literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C)

Authors: Eva YN Yuen¹, Tess Knight¹, Sarity Dodson², Jacqueline Chirgwin³, Lucy Busija⁴, Lina A Ricciardelli¹, Susan Burney⁵, ⁶, Phillip Parente³, Patricia M Livingston⁷.

¹School of Psychology, Deakin University, Burwood VIC, 3125, Australia; ²Public Health Innovation, Deakin University, Burwood VIC, 3125, Australia; ³Department of Medical Oncology, Eastern Health, 5 Arnold Street, Box Hill VIC 3128, Australia; ⁴Deakin Biostatistics Unit, Deakin University, Burwood VIC, 3125, ⁵School of Psychological Sciences, Monash University, Clayton VIC 3800, Australia; ⁶Cabrini Monash Psycho-oncology, Cabrini Health, Malvern 3144, Vic, ⁷Faculty of Health, Deakin University, Burwood VIC, 3125, Australia

Corresponding author

Eva Yuen, Deakin University, School of Psychology, 221 Burwood Highway, Burwood VIC 3125, Australia. Contact details: (email) eva.yuen@deakin.edu.au; (Phone) +61 3 9251 7221.
Abstract

Purpose

The field of health literacy measurement has undergone significant expansion in recent years, yet the measurement of caregiver health literacy has been largely neglected. The aims of the current study were to determine the construct validity, and internal consistency of the Health Literacy of Caregivers Scale – Cancer (HLCS-C), and to present a revised, psychometrically robust measurement tool to aid research exploring the role of caregiver health literacy.

Methods

Using data from a sample of 297 Australian caregivers of people with cancer who completed the HLCS-C, confirmatory factor analysis (CFA) was used to evaluate the proposed factor structure of the HLCS-C. Each item was evaluated in terms of: item difficulty, unidimensionality, and overall item fit within their domain. Item threshold ordering was examined through one-parameter Item Response Theory models. Internal consistency was assessed using Raykov’s composite reliability coefficient.

Results

CFA results identified 42 poorly performing or redundant items. A 10-factor model was fitted to the 46 acceptable items with no correlated residuals or factor cross-loadings accepted. The results revealed an adequate fit for the factor solution ($\chi^2_{WLSMV} = 1463.807$ ($df = 944$), $p < 0.001$, RMSEA = 0.043, CFI = 0.980, TLI = 0.978, WRMR = 1.00). The 10 domains identified were: Proactivity and determination to seek information; Adequate information about cancer and cancer management; Supported by healthcare providers to understand information; Social support; Cancer-related communication with the care recipient; Understanding care recipient needs and preferences; Self-care; Understanding the healthcare system; Capacity to process
health information; and Active engagement with healthcare providers. Internal consistency was adequate across domains (0.78-0.92).

**Conclusions**

The revised HLCS-C demonstrated good structural, convergent, and discriminant validity, and high internal consistency in a sample of Australian caregivers. The scale may be useful for individual assessment, and evaluation of healthcare interventions for caregivers.

**Keywords**

Caregivers, cancer, health literacy, questionnaire development, psychometric assessment, confirmatory factor analysis
Chapter 8. Validation of the HLCS-C

Introduction

A cancer diagnosis has a significant, and often long-lasting impact on an individual, as well as on their family and friends. Depending on the diagnosis and illness severity, family members or friends may be involved in the provision of direct care, management of medications, monitoring of symptoms, and the provision of emotional and social support (Sherwood, Given, & Given, 2012; Wolff & Roter, 2011). Often referred to as caregivers, support persons also often provide informational support by sourcing health information, participating in health decision-making, assisting care recipients to navigate the healthcare system, and facilitating information exchange between care recipients and healthcare providers (Eggly et al., 2006; Laidsaar-Powell et al., 2013).

The informational needs of caregivers

To effectively engage in caregiving responsibilities, caregivers have reported a need for information about the cancer, treatment and management, services and supports, and approaches to coping with the emotional and social impacts of the disease (Adams, Boulton, & Watson, 2009; Lambert et al., 2012). Adequate access to information can support the development of caregiver skills, reduce distress, and promote self-care, participation, and quality of life (Northouse, Katapodi, Song, Zhang, & Mood, 2010; Northouse, Williams, Given, & McCorkle, 2012). However, as caregivers are not the primary recipients of healthcare, their role is often unrecognized by healthcare providers (Dolce, 2011; Guo, Phillips, & Reed, 2010). Caregivers report limited opportunities to discuss information during consultations with healthcare providers (Boehmer et al., 2014), a lack of support to understand information (Bee, Barnes, & Luker, 2009), and a lack of information to support them in their caregiving role (Washington, Meadows, Elliott, & Koopman, 2011).
The role of caregiver health literacy

Health literacy refers to the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health; it includes the capacity to communicate, assert and enact these decisions (Dodson, Beauchamp, Batterham, & Osborne, 2014; Sorensen et al., 2012). Health literacy has been identified as a critical determinant of health outcomes (Berkman et al., 2011). Suboptimal health literacy has been associated with poor disease-management (Federman et al., 2013; Zhang, Terry, & McHorney, 2014), later stage disease detection (Berkman et al., 2011), and increased mortality among the elderly (Baker et al., 2007; Bostock & Steptoe, 2012).

Emerging evidence suggests that for people with low health literacy, caregivers may play an important role in promoting positive health outcomes by supporting care recipients to access health information, communicate with health providers, process information, make care decisions and undertake self-management activities. A recent study conducted by Rosland and colleagues (2010) examined the role of caregivers in supporting diabetes and heart failure patients in self-management. Their findings suggested that patients with suboptimal health literacy were more likely to receive support from a caregiver to undertake self-management tasks. In a follow up study they reported that for patients with lower health literacy, caregivers more often participated in clinical encounters and that the presence of caregivers in these visits resulted in enhanced patient understanding of medical advice and capacity to discuss difficult topics (Rosland, Piette, Choi, & Heisler, 2011). Health literacy of caregivers was, however, not assessed in these studies. It remains unclear the extent to which health literacy of the caregiver mitigates the association between health outcomes and patient health literacy. Recently, Levin and colleagues (2014) reported an association between low health literacy of caregivers and...
poorer self-management behaviours among older heart failure patients, however, given the small sample size of the study \( (n = 17) \), and unavailability of additional studies to support the findings, further evidence relating to this link is needed.

**The need for caregiver health literacy measurement**

Given the critical role of caregivers in all aspects of patient care, it is important that more is understood about the way in which caregiver health literacy may impact on their capacity to perform their role. One key barrier to previous research in this area is the lack of validated and suitable measurement approaches (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014). A measure that assesses caregiver health literacy has the potential to guide the development and evaluation of interventions and health system improvement, and to deepen our understanding about the possible mitigating effect of caregiver health literacy on care recipient behaviours and outcomes.

The Health Literacy of Caregivers Scale – Cancer (HLCS-C; Yuen et al., 2014) is a multi-dimensional, self-report measure that examines the health literacy of caregivers of people with cancer. It contains 88 items across 10 domains. The scale was developed using a validity-driven approach that seeks to maximise the content validity of a measure by explicitly deriving scale domains and measurement items from the perspectives of key stakeholders (Buchbinder et al., 2011). To ensure the included domains and their representative items capture the lived experience of caregivers of people with cancer, the HLCS-C was based upon a conceptual model of cancer caregiver health literacy (Yuen et al., 2015). The current study was designed to assess the HLCS-C’s convergent and discriminant validity (both indicators of construct validity), and internal consistency. The study also sought to identify poorly performing and redundant items for removal. We present a revised, psychometrically robust, shorter
measurement tool that can be applied within clinical settings and research studies examining
caregiver health literacy and its role in cancer patient health outcomes.

Method

Recruitment processes

Caregivers were approached to participate in the study by their care recipient. Care
recipients were either patients of a cancer outpatient clinic at one of Melbourne’s public health
services, or members of a Victorian cancer support group. Patients under the age of 18, receiving
palliative care, or with a cognitive impairment were excluded from the study. Patients who had
not received treatment in the past 13 months were also excluded. Caregivers were eligible to
participate if they were over 18 years of age, and identified as a person who provides informal
physical care, or emotional or social support to someone diagnosed with cancer.

People with cancer identified through their public health service received a questionnaire
pack by mail. People with cancer recruited through cancer support groups received their
questionnaire packs during a group meeting (either by an investigator or group facilitator) or via
mail if they were registered on the Leukaemia Foundation’s Victorian cancer support group
database.

Recipients of the questionnaire pack were asked to distribute the pack to a partner, family
member or friend whom they identified as providers of informal physical, social and/or
emotional support. Return of the completed questionnaire implied consent. Prospective
participants were given the option to complete the questionnaire online. To facilitate
questionnaire returns, people with cancer who received their pack via mail were sent a follow up
letter one month after the initial mail out. People from support groups who received a pack
during a group meeting were given a verbal reminder by the support group facilitator at the next
group meeting. Data were collected from January to June 2014. The number of caregiver packs distributed through the public health service and cancer support groups were 525 and 1894, respectively.

**Participants**

Of the 2419 questionnaires distributed, 301 caregivers completed the questionnaire (12.4% response rate). Four participants did not report their care recipient’s cancer type and treatment, and were therefore excluded from the analysis. Caregivers were aged between 18 and 89 years \( M = 59.71, SD = 13.02 \), and were mostly female (64.6%). The majority of participants reported living with their care recipient (81.1%; see Table 1), with over two-thirds reporting providing care to their spouse (71.7%). Over one-third began providing care at least 5 years prior to completing the questionnaire, while one-fifth began providing care in the past 12 months \( M = 4 \text{ years}, 9 \text{ months} \). A quarter of the caregivers had not completed high school (24.6%), while over half the sample had attended tertiary education (53.9%).

**Materials**

The “caregiver questionnaire pack” contained the HLCS-C, and questions on demographic characteristics (i.e., gender, age, educational level, employment status, postcode, birthplace, language spoken at home, and health status), caregiver characteristics (i.e., length of time as caregiver, relationship to care recipient, living arrangements with care recipient), and care recipient characteristics (i.e., cancer diagnosis, date of diagnosis, treatment type).

The HLCS-C contains a total of 88 items, distributed across 10 domains: 1) proactivity and determination to seek information (8 items); 2) adequate information about cancer and cancer management (8 items); 3) supported by healthcare providers to understand information (10 items); 4) social support (7 items); 5) communication with the care recipient (8 items); 6)
understanding the care recipient (9 items); 7) self-care (12 items); 8) understanding the healthcare system (9 items); 9) processing health information (9 items); and 10) active engagement with healthcare providers (8 items). A 4-point Likert response format was used for domains one to eight: strongly agree, agree, disagree, or strongly disagree. A 5-point difficulty level response format is used for domains nine and ten; cannot do, very difficult, quite difficult, quite easy, or very easy. Most items had good content validity, with most items rated by experts \( (n = 7) \) and caregivers \( (n = 16) \) as being relevant, clear, and easy to understand (Content Validity Index > 0.78; Yuen et al., 2014).

**Ethics**

The study was granted ethical approval from both Eastern Health Human Research Ethics (E41-1011) and Deakin University Human Research and Ethics (2011-115) Committees, in Melbourne, Australia.

**Statistical Analyses**

**Descriptive statistics**

The normality of the items was assessed by examining the skewness and kurtosis of the indicators. Descriptive statistics, including skewness and kurtosis, floor and ceiling effects, and extent of missing values were examined using SPSS Version 21 (IBM SPSS Inc, 2012). If 15% or more participants endorsed the lowest or highest possible response options, floor and ceiling effects respectively, were considered present and noted (Terwee et al., 2007). Using Mplus Version 7 (L. K. Muthén & Muthén, 2012), Item Response Theory (IRT) analysis (one-parameter model) was also conducted to check response category threshold ordering and identify disordered thresholds.

Estimates of domain reliability-if-item-deleted and “item difficulty” were also obtained. Reliability-if-item-deleted was calculated using Raykov’s (2012) approach, which utilises
polychoric and polyserial correlations and is therefore more suitable acceptable for use with ordinal data than the traditional Cronbach’s alpha-if-item-deleted. To determine item difficulty for domains with an agree/disagree response format, the proportion of respondents who endorsed strongly disagree or disagree compared to agree or strongly agree was examined (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). For domains with difficulty response options, item difficulty was examined as a proportion of those who responded from ‘cannot do’ and ‘very difficult’ through to ‘quite easy’, or ‘very easy’. Items with a low difficulty score (i.e. <10%) were noted and considered for revision or deletion, pending results of Confirmatory Factor Analysis (CFA).

**Confirmatory factor analyses**

To confirm the hypothesized 10-dimensional structure of the item set (i.e. structural validity), to identify items that best represented each domain, and to assess convergent and discriminant validity of the HLCS-C, CFA was used (Armstrong, 1967). CFA was conducted with Mplus Version 7 (L. K. Muthén & Muthén, 2012), with weighted least squares mean and variance adjusted (WLSMV; B. O. Muthén, 1984) estimator as it is considered the optimal approach for categorical data (Beauducel & Herzberg, 2006). For missing data (0-1.7%; Table 2), parameters were estimated using all available data for each pair of variables.

CFA processes followed a sequence of pre-specified steps. Initially, a one-factor model was fitted for each domain. Then, all possible pairwise CFA models, and a final ten-factor model were fitted to the data. At each step, the results were used to identify and remove items that had poor fit with the domain (see next section). In the final step, ten-factor model was respecified for the remaining items. Good fit of this highly restricted 10-factor CFA model was interpreted as providing support for the construct validity of the HLCS-C.
Fit of CFA models with the data was assessed on both absolute and incremental fit indices, including chi-square (Bentler & Bonett, 1980), Comparative Fit Index (CFI; Bentler, 1990), Root Mean Square Error of Approximation (RMSEA; Browne & Cudeck, 1993), Tucker Lewis Index (TLI; Tucker & Lewis, 1973), and Weighted Root Mean Square Residual (WRMR; Muthen & Muthen, 1998). Although a non-significant chi-square is indicative of a good fit (Marsh, Balla, & McDonald, 1988), this index is sensitive to large sample sizes and large correlations between items (Jöreskog & Sörbom, 1993); thus a significant chi-square index was interpreted in conjunction with other fit indices. Criteria for good fit were: RMSEA < 0.06; CFI > 0.95; TLI > 0.95; and WRMR ≤ 1.0. Additionally, RMSEA below 0.08 but above 0.06 was considered a reasonable fit (Browne & Cudeck, 1993).

**Item assessment and removal criteria**

Information on threshold ordering, item difficulty, and domain reliability—if item deleted, together with the results of CFA that examined convergent and discriminant validity of the domains was used to assess domain items according to a set of criteria as either performing adequately or poorly. Poorly performing items were removed from the scale or earmarked for revision to improve the psychometric properties of the HLSC-C. Fit of revised single-factor models were reassessed following each item removal.

Items identified through IRT as having disordered thresholds were judged as performing poorly and considered for revision or removal. Disordered thresholds suggest either respondent difficulty differentiating between response categories for an item, or item ambiguity (Pallant & Tennant, 2007). Items with low estimates of item difficulty (i.e. <10%) - which suggests that the majority of respondents would endorse the item, making it difficult to discriminate between individuals with low or high level of the capacity - were flagged for revision or deletion.

Chapter 8. Validation of the HLCS-C
following consideration of CFA results. In addition, for domains which showed that reliability would be increased following deletion of an item (reliability-if-item deleted scores), the item was flagged for revision or deletion following consideration of CFA results.

During CFA, results of one-factor models were examined to determine item fit within their specified factor (i.e., item unidimensionality). To assess item fit, factor loadings, the amount of variance explained by the specified factor in a given item ($R^2$) and modification indices (MI) were examined. In one-factor CFA, high modification indices suggest that the model fit will improve if the model is respecified by allowing error terms between items to covary. Items with loadings less than 0.55 (Comrey & Lee, 1992) on their factor, and explained variance less than 0.50 were identified as problematic, and considered reasons for item deletion. Modification indices were examined to identify possible presence of correlated error terms between pairs of items. Modifications indices greater than 10 (Thompson, 2004) suggest the possibility of item redundancy (i.e. similarly worded items, or overlap in item content), and are considered reasons for item removal. Prior to item removal, content of problematic items were examined against results from the conceptual model that guided the development of HLCS-C to ensure that item removal did not impact content validity of the emergent domain.

For pairwise CFA results, items that demonstrated substantial loading onto a factor other than their originally specified factor ($\geq 0.32$) were considered for removal (Tabachnick & Fidell, 2012). Such loadings suggested either item ambiguity, or that the item was representative of two or more factors (and thus, non-unidimensional). Item removal (i.e., modification) for both one factor and pairwise models was carefully considered to ensure they were theoretically justified, and were implemented one-by-one (Brown, 2006; Byrne, 2012).
**Convergent validity of HLCS-C domains**  
Internal convergent validity (extent to which indicators [i.e., items] of a specific construct share a high proportion of variance; Hair, Black, Babin, & Anderson, 2010) for each domain was assessed by inspecting fit of a one-factor CFA model with the data, and magnitude of factor loadings. Good overall fit of a CFA model was interpreted as supporting internal convergent validity of a given domain.

**Discriminant validity of HLCS-C domains** Discriminant validity (extent to which the measure [i.e., domain] is unique, and not highly correlated with items from other measures; D. T. Campbell & Fiske, 1959) of domains was assessed by conducting a series of pairwise CFA models with all possible pairwise combinations, followed by a 10-factor model. Inter-factor correlations from the pairwise models or from the 10-factor model ($\geq 0.85$; Kline, 2011) suggested poor discriminant validity of the domains or the presence of a higher order factor(s).

**Internal consistency**  
Internal consistency of the domains was assessed using Raykov’s (1997) composite reliability index. Although Cronbach’s alpha coefficient is a widely referenced index of internal consistency, it assumes that items within a factor have equal factor loadings, and thus, is known to under- or over-estimate population reliability (Raykov, 1998). By contrast, the composite reliability coefficient, based on the polychoric correlation matrix, provides unbiased estimates of reliability (Raykov, 1997). Cut-off scores for composite reliability are similar to those for Cronbach’s alpha, with values between 0.70–0.95 considered acceptable (Terwee et al., 2007).

**Results**

**Item analysis**  
Analysis was performed on the 297 returned questionnaires. Assessment of normality revealed that skewness and kurtosis of all items were within an acceptable range ($< 3$ and $< 8$
respectively), and the floor effects for all items were also acceptable (0 to 12.5%). Ceiling effects (≥15%) were, however, present in 67 items. The proportion of non-response to items was low, and ranged between 0-1.7%. Two items were identified as having disordered thresholds, one each from domains Processing health information and Active engagement with healthcare providers, and thus were removed (see Table 2).

Examination of item difficulty revealed that the domain Understanding the care recipient had the smallest difficulty range (difficulty range 4 - 11%). The most difficult item from this domain was “I know how much help to give the person I care for” (difficulty = 11%) for which the most difficult response option (“strongly disagree”) was endorsed by only one participant (0.3%). The domain with the largest difficulty range was Self-care (difficulty range 13 - 43%). The domain Proactivity and determination (difficulty range 27 - 49%) contained the item most difficult to endorse ‘I regularly search for up to date information about the cancer’ (difficulty = 49%). The domain with the most difficult items overall was Capacity to process health information, where all items had a difficulty index of 33% or greater. The remaining domains had item difficulty scores that ranged from 3% to 49%. Items with low estimates of item difficulty (i.e. < 10%) were flagged for review following CFA. Difficulty scores are shown in Table 2.

One-factor Confirmatory Factor Analysis models

For all domains, initially proposed one-factor measurement models did not fit the data satisfactorily. Relatively low factor loading, low explained variance, or high modification indices were observed for 33 items. Each of these items was carefully examined in turn against the item removal criteria and consideration was given to whether revision or removal was appropriate. Considerations resulted in decisions to remove all 33 items with factor loadings less than 0.55,
explained variance less than 0.5, or modification indices greater than 10. These items were removed one-by-one to improve model fit. Modifications to the domains resulted in retained items with high factor loadings (0.64-0.98) and adequate model fit for the majority of domains. For one domain (Social Support), one-factor CFA results showed that the RMSEA exceeded reasonable fit criterion (0.08). The reduced pool of items (53 items) was included in the pairwise CFA models.

**Pairwise Confirmatory Factor Analysis models**

Pairwise CFA modelling analysis identified significant cross-loadings ($\geq 0.32$) for eight items on a domain other than their specified domain. These items were carefully examined in turn and consideration was given to whether revision or removed was appropriate. Seven of the items were removed (see Table 2). One item from the domain Supported by Healthcare Providers (“Healthcare providers have helped me understand health services available for the person I care for”; estimated primary loading 0.85) was retained despite substantial cross-loading on a secondary domain Understanding the Healthcare System (estimated cross-loading 0.37) because of its high difficulty score.

**Ten-factor Confirmatory Factor Analysis model**

A 10-factor CFA model performed with the reduced item pool (46 items; see Table 2) demonstrated acceptable fit on the basis of $X^2_{WLSMV} = 1463.807$ ($df = 944$), $p < 0.001$, RMSEA = 0.043, CFI = 0.980, TLI = 0.978, WRMR = 1.00. The final psychometric properties of the retained items and 10 domains are shown in Table 3.

Inspection of the modification indices suggested potential cross-loadings for 14 items (modification index $> 10$). However, examination of the cross-loading estimates suggested that these were below the cut-off criterion for a substantial cross-loading ($<0.32$), thus providing
support for the convergent validity of the questionnaire. Inter-factor correlations showed
reasonable discrimination between most domains (range 0.13 - 0.84; see Table 4). However,
*Understanding the healthcare system*, showed high inter-factor correlations with the domain
*Adequate information about cancer and cancer management* (0.86).

Following CFA analyses, domain names were reviewed in light of the reduced item pool.
The revised domain names are those presented in Table 3. The domains *Communication with the
care recipient*, *Understanding the care recipient*, and *Processing health information* were
revised to *Cancer-related communication with the care recipient*, *Understanding care recipient
needs and preferences*, and *Capacity to process health information*, respectively.

**Internal consistency reliability**

All domains with the revised items achieved a composite reliability score between 0.78
(*Understanding care recipient needs and preferences*) and 0.92 (*Proactivity and determination
to seek information; Capacity to process health information; Active engagement with healthcare
providers*) with a median reliability of 0.86, demonstrating adequate internal consistency. Results
of internal consistency assessment are shown in Table 3.

**Post-analysis modification of the scale**

Issues relating to item difficulty identified during item analysis were revisited at the
completion of statistical analyses. The domain *Understanding care recipient needs and
preferences* contained items with lower difficulty levels (3-11%). Thus, to potentially improve
domain sensitivity, and to increase range of difficulty, the wording for two items was altered.
The item “I understand when to let the person I am caring for do things for themselves in their
own time” was altered to “I always know when to let the person I am caring for do things for
themselves in their own time”. The item “Most of the time, I understand the needs of the person I care for” was altered to “I always understand the needs of the person I care for”.

In addition, one item from the domain Supported by Healthcare Providers although showed substantial cross-loading on a secondary domain Understanding the Healthcare System was retained because of its high difficulty score to ensure the domain contained items that represented a range of the dimension. To minimise cross-loading, the item was altered from “Healthcare providers have helped me understand health services available for the person I care for” to “Healthcare providers have helped me understand supports and services available for the person I care for”. Given the alterations to the wording of the three items, although relatively minor, the item difficulty, and CFA parameters for all items within domains in question (Table 3) should be considered tentative estimates. Decisions and modifications made to the item pool and domains in response to IRT and CFA analyses are outlined in Figure 1.

Discussion

The current study provided an initial evaluation of the psychometric properties of the HLCS-C, a measure of caregiver health literacy in the cancer setting. The results from 297 cancer caregivers provided support for a 46 item, 10-domain scale with acceptable structural, convergent, and discriminant validity, and internal consistency. To the authors’ knowledge, this is the first study to validate a multidimensional measure of health literacy specifically for caregivers.

Construct validity of the HLCS-C (revised)

Overall, the majority of domains in the HLCS-C (revised) demonstrated adequate construct validity, as evidenced by adequate convergent and discriminant validity. The majority of the domains in the HLCS-C demonstrated adequate convergent validity as evidenced by high
factor loadings across domains (0.64-0.98). The majority of domains also demonstrated adequate discriminant validity as evidenced by inter-factor correlations below 0.85.

For the domain, Social support, one-factor CFA results showed that the RMSEA exceeded reasonable fit criterion (0.08). However, the small degrees of freedom ($df = 2$; Kenny, Kaniskan, & McCoach, 2014) and high standardized factor loadings (all above 0.73) may have contributed to the high RMSEA index for this domain (Saris, Satorra, & Van der Veld, 2009). As three fit indices demonstrated acceptable model fit (CFI = 0.997, TLI = 0.991, WRMR = 0.458), the authors believe that an acceptable level of construct homogeneity was reached for the Social support domain.

Although most domains of the HLCS-S (revised) showed reasonable discrimination, high inter-factor correlations (0.86) were found between two domains Understanding the healthcare System and Adequate information about cancer and cancer management. The results suggest either a lack of discriminant validity, an interdependency between these two constructs, or the presence of a higher order factor, such as adequate information about health and the healthcare system. Further evaluation of these two domains is needed.

Reliability of the HLCS-C (revised)

All domains in the HLCS-C (revised) demonstrated adequate composite reliability (> 0.78). The high composite reliability indices on three domains (> 0.90; Proactivity and Determination to Seek Information, Capacity to process health information, and Active Engagement with Healthcare Providers) suggest that these domains could be used in clinical settings to assess individual caregiver needs (Streiner & Norman, 2008). Lower scores on these domains may indicate that caregivers require additional or alternative support to ensure adequate engagement with health information and services.
Utility of the HLCS-C (revised)

The HLCS-C assessed both individual and contextual factors relating to health literacy. While some domains included in the HLCS-C measure a caregiver’s capacity to find, understand, and use health information, other domains assess caregiver’s perceptions of the adequacy of information provision and support. Importantly, the HLCS-C uniquely measures constructs specific to the caregiving role.

Difficulties in the caregiver–care recipient relationship has the potential to impact a caregiver’s capacity to provide optimal care, and in turn, impact care recipient health outcomes (Zhang, Zyzanski, & Siminoff, 2010). Further given the potential importance of caregivers in health decision making and self-management, and the dissatisfaction with healthcare interactions often reported by caregivers (Dolce, 2011; Williams & Bakitas, 2012), the HLCS-C has the potential to provide greater insight into the nature of these difficulties and whether there are particular groups of caregivers that experience particular difficulties. Interventions that optimize caregiver health literacy and/or improve the information and support provided to caregivers have the potential to improve outcomes for both caregivers and recipients.

Given that caregivers have reported dissatisfaction with healthcare provider interactions (Dolce, 2011; Williams & Bakitas, 2012), the domain Supported by healthcare providers to understand information can be used to provide insights into which caregivers seek greater support from healthcare providers, and how caregiver–healthcare provider relationships can be improved to assist caregivers adequately understand health information. Further, the two constructs that assessed the relationship between the caregiver and care recipient (Communication with the care recipient, Understanding care recipient needs and preferences) have the potential to identify dyadic difficulties that could impact a caregiver’s capacity to
provide optimal care, and in turn, impact on care recipient health outcomes (Zhang et al., 2010). In theory, caregiver health literacy could be optimised through interventions targeted at the caregiver and the care recipient, as well as efforts from healthcare providers and the healthcare system.

**Limitations of the HLCS-C (revised)**

The domain *Understanding care recipient needs and preferences* contained items with lower difficulty levels than the authors anticipated. Domains comprised of items that capture a range of difficulty levels have the potential to increase scale sensitivity to detect small changes across low, moderate and high levels of health literacy (Osborne et al., 2013). Minor modifications were made to two items in the domain, which the authors expect will improve item difficulty. Further, one item from the domain *Supported by Healthcare Providers* showed substantial cross-loading on a secondary domain. However, given the item’s high difficulty score, minor modifications were made to the wording of the item to minimise the cross-loading. The authors anticipate these minor modifications to the three items will improve their performance in future studies.

**Study limitations**

A large proportion of respondents had commenced providing care two or more years prior to completing the questionnaire. Consequently, health literacy needs and skills of experienced caregivers may differ from those of caregivers with less experience. The response rate was lower compared to other studies that recruited caregivers using a similar approach (H. S. Campbell et al., 2009; Krishnasamy, Wilkie, & Haviland, 2001) which limits the generalizability of the results. In addition, spouses, and those with more years of formal education were overrepresented in the study; thus, the potential generalizability of the scale remains a limitation.
Chapter 8. Validation of the HLCS-C

Future directions

Further research is needed to assess the HLCS-C’s test-retest reliability, and its responsiveness/sensitivity to change. In addition, future studies should consider assessing the content, and construct validity and item difficulty of the revised items in the domain Understanding care recipient needs and preferences, in addition to assessing model parameters for the domain. Comparisons of the HLCS-C with other indicators such as measures designed to assess caregiver cancer-related communication with the care recipient (Siminoff, Zyzanski, Rose, & Zhang, 2008), and existing measures of health literacy (Davis et al., 1991; Osborne et al., 2013; Parker, Baker, Williams, & Nurss, 1995; Weiss et al., 2005) to examine external convergent validity are also recommended. Moreover, studies that examine how factors such as caregiver burden, depression and anxiety are associated with caregiver health literacy will provide a more comprehensive understanding of the impacts of caregiver health literacy on the health outcomes of the caregiver and the person with cancer. Longitudinal studies that examine associations between caregiver health literacy and patient health outcomes following caregiver interventions are also recommended.

Conclusions

The HLCS-C demonstrated good construct validity and high internal consistency reliability attributed to the rigorous scale development process. The need for validated, multidimensional measures to adequately assess health literacy across diverse (Haun et al., 2014) and within caregiver (Bevan & Pecchioni, 2008) populations has been highlighted. The HLCS-C contributes to this gap by providing a measure for assessing caregiver health literacy in the
cancer setting. The tool can be used by health educators and researchers in the field of health literacy and psycho-oncology. The measure has the potential to identify caregivers who may benefit from additional supports or interventions to support health outcomes of people with cancer. In addition, the measure may assist to guide service improvements in healthcare systems, and develop and evaluate interventions for caregivers.

Acknowledgements

The authors sincerely thank all the caregivers who participated in the study; people with cancer who supported the study by taking a questionnaire home to give to their family members/friends; cancer support group facilitators who supported the study by inviting the primary author to present at their support group, distributed the questionnaire to their group members, and reminded group members about the study; Rosemary Petrie from Eastern Health Clinical School for her assistance with recruiting people with cancer from Eastern Health; Dr Anna Williamson and Stephanie Hechenberger from Leukaemia Foundation for their support with distributing the questionnaires to cancer support groups; Jackie Gleeson for her support with recruiting caregivers of people with cancer and advertising the study through networks; Professor Gerald Elsworth his advice on psychometric testing; Dr Claudia Strugnell for her comments on manuscript drafts; and Professor Richard Osborne for his contribution in the initial stages of the project.

Eva YN Yuen was supported by a Deakin University Postgraduate Research Scholarship. The research was, in part, supported by a Deakin University Population Health Strategic Research Centre small project funding grant.

Conflict of interest

The authors have no conflicts of interest to declare.

Chapter 8. Validation of the HLCS-C
References


Chapter 8. Validation of the HLCS-C
systematic review. *BMJ Supportive & Palliative Care*. doi: 10.1136/bmjspcare-2012-000226


Chapter 8. Validation of the HLCS-C
Chapter 8. Validation of the HLCS-C


<table>
<thead>
<tr>
<th>Participant characteristic</th>
<th>n</th>
<th>%</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td>Female</td>
<td>192</td>
<td>64.6%</td>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>Born in Australia</td>
<td>228</td>
<td>76.8%</td>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>English spoken at home</td>
<td>286</td>
<td>96.3%</td>
<td>3 (1.0%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school or less</td>
<td>7</td>
<td>2.4%</td>
<td></td>
</tr>
<tr>
<td>High school (not completed)</td>
<td>66</td>
<td>22.2%</td>
<td></td>
</tr>
<tr>
<td>High school (completed)</td>
<td>62</td>
<td>20.9%</td>
<td></td>
</tr>
<tr>
<td>TAFE/Trade</td>
<td>56</td>
<td>18.9%</td>
<td></td>
</tr>
<tr>
<td>University</td>
<td>104</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>Employed full time</td>
<td>68</td>
<td>22.9%</td>
<td></td>
</tr>
<tr>
<td>Employed part time</td>
<td>44</td>
<td>14.8%</td>
<td></td>
</tr>
<tr>
<td>Unemployed/looking for work</td>
<td>7</td>
<td>2.4%</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>6</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>17</td>
<td>5.7%</td>
<td></td>
</tr>
<tr>
<td>Caregiver full time</td>
<td>17</td>
<td>5.7%</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>120</td>
<td>40.4%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>5.4%</td>
<td></td>
</tr>
<tr>
<td>Illness or disability (more than one response possible)</td>
<td>189</td>
<td>63.6%</td>
<td>7 (2.4%)</td>
</tr>
<tr>
<td>Arthritis, osteoporosis or other musculoskeletal condition</td>
<td>84</td>
<td>28.3%</td>
<td></td>
</tr>
<tr>
<td>Respiratory condition e.g., asthma, emphysema</td>
<td>45</td>
<td>15.2%</td>
<td></td>
</tr>
<tr>
<td>Back pain</td>
<td>72</td>
<td>24.2%</td>
<td></td>
</tr>
<tr>
<td>Heart disease</td>
<td>22</td>
<td>7.4%</td>
<td></td>
</tr>
<tr>
<td>Depression, anxiety or other mental health condition</td>
<td>37</td>
<td>12.5%</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>19</td>
<td>6.4%</td>
<td></td>
</tr>
<tr>
<td>Neurological condition (e.g., stroke, multiple sclerosis)</td>
<td>9</td>
<td>3.0%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>(3.7)</td>
<td>n/a</td>
</tr>
<tr>
<td>Has private health insurance</td>
<td>164</td>
<td>55.2%</td>
<td>4 (1.3%)</td>
</tr>
<tr>
<td>Receives Government benefit</td>
<td>151</td>
<td>50.8%</td>
<td>5 (1.7%)</td>
</tr>
<tr>
<td>Age pension</td>
<td>89</td>
<td>30.0%</td>
<td></td>
</tr>
<tr>
<td>Carer benefit</td>
<td>30</td>
<td>10.1%</td>
<td></td>
</tr>
<tr>
<td>Unemployment benefit</td>
<td>5</td>
<td>1.7%</td>
<td></td>
</tr>
<tr>
<td>Disability benefit</td>
<td>13</td>
<td>4.4%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
<td>4.7%</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>141</td>
<td>47.5%</td>
<td></td>
</tr>
</tbody>
</table>

Table 1. Demographic characteristics of 297 participants who completed the HLCS-C
<table>
<thead>
<tr>
<th>Relationship to care recipient</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife/Husband/Partner/Spouse</td>
<td>213</td>
<td>71.7%</td>
</tr>
<tr>
<td>Daughter/Son</td>
<td>35</td>
<td>11.8%</td>
</tr>
<tr>
<td>Mother/Father</td>
<td>19</td>
<td>6.4%</td>
</tr>
<tr>
<td>Friend</td>
<td>15</td>
<td>5.1%</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>4.4%</td>
</tr>
<tr>
<td>Lives with the care recipient</td>
<td>241</td>
<td>81.1%</td>
</tr>
<tr>
<td>Lives with the care recipient</td>
<td>2</td>
<td>0.7%</td>
</tr>
<tr>
<td>Length of time providing care</td>
<td>17</td>
<td>5.7%</td>
</tr>
<tr>
<td>1 year or less</td>
<td>61</td>
<td>21%</td>
</tr>
<tr>
<td>1 – 2 years</td>
<td>44</td>
<td>15%</td>
</tr>
<tr>
<td>2 – 5 years</td>
<td>87</td>
<td>30%</td>
</tr>
<tr>
<td>More than 5 years</td>
<td>98</td>
<td>34%</td>
</tr>
<tr>
<td>Care recipient’s cancer type</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>106</td>
<td>35.7%</td>
</tr>
<tr>
<td>Prostate</td>
<td>45</td>
<td>15.2%</td>
</tr>
<tr>
<td>Bowel</td>
<td>15</td>
<td>5.1%</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>21</td>
<td>7.1%</td>
</tr>
<tr>
<td>Lung</td>
<td>26</td>
<td>8.8%</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>18</td>
<td>6.1%</td>
</tr>
<tr>
<td>Myeloma</td>
<td>26</td>
<td>8.8%</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>18</td>
<td>6.1%</td>
</tr>
<tr>
<td>Other tumour</td>
<td>40</td>
<td>15.3%</td>
</tr>
<tr>
<td>Treatment received by care recipient (more than one response possible)</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>81</td>
<td>27.3%</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>63</td>
<td>21.2%</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>121</td>
<td>40.7%</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>71</td>
<td>23.9%</td>
</tr>
<tr>
<td>Complementary and alternative medicines</td>
<td>13</td>
<td>4.4%</td>
</tr>
<tr>
<td>Other</td>
<td>93</td>
<td>31.3%</td>
</tr>
<tr>
<td>Completed treatment</td>
<td>50</td>
<td>16.8%</td>
</tr>
<tr>
<td>n/a: Care recipient deceased</td>
<td>6</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

n/a = not applicable

Chapter 8. Validation of the HLCS-C
Table 2. Descriptive statistics for HLCS-C draft 88 items in Australian caregivers of cancer patients, identification of the point at which poorly performing items were deleted, and remaining items for inclusion in final scale.

<table>
<thead>
<tr>
<th>Item #</th>
<th>Domain / Item</th>
<th>Missing n (%)</th>
<th>Floor %</th>
<th>Ceiling %*</th>
<th>Threshold ordering</th>
<th>Difficulty score (95% CI)</th>
<th>Deleted following one-factor CFA</th>
<th>Deleted following pairwise CFA</th>
<th>Included in final scale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Domain 1. Proactivity and determination to seek information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>To help provide the best care, I actively search for information</td>
<td>3 (1%)</td>
<td>9 (3%)</td>
<td>51</td>
<td>Ordered</td>
<td>0.27</td>
<td>(0.22-0.32)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>17</td>
<td>I search several different places to find information about the cancer</td>
<td>1 (0.3%)</td>
<td>12 (4%)</td>
<td>45</td>
<td>Ordered</td>
<td>0.32</td>
<td>(0.27-0.37)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>25</td>
<td>I make sure I have all of the information that I need to help the person I am caring for</td>
<td>0</td>
<td>3 (1%)</td>
<td>44</td>
<td>Ordered</td>
<td>0.21</td>
<td>(0.16-0.25)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>33</td>
<td>I keep looking until I get all the information that I need</td>
<td>0</td>
<td>6 (2%)</td>
<td>55</td>
<td>Ordered</td>
<td>0.33</td>
<td>(0.28-0.39)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>41</td>
<td>I regularly search for up to date information about the cancer</td>
<td>0</td>
<td>20 (6.7%)</td>
<td>30</td>
<td>Ordered</td>
<td>0.49</td>
<td>(0.44-0.55)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>49</td>
<td>I keep searching until I find information that I understand</td>
<td>3 (1%)</td>
<td>9 (3%)</td>
<td>41</td>
<td>Ordered</td>
<td>0.33</td>
<td>(0.28-0.38)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>56</td>
<td>I look for new opportunities to get information about the cancer</td>
<td>1 (0.3%)</td>
<td>12 (4%)</td>
<td>35</td>
<td>Ordered</td>
<td>0.40</td>
<td>(0.35-0.46)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>62</td>
<td>To help the person I care for, I actively search for information about cancer</td>
<td>2 (0.7%)</td>
<td>12 (4%)</td>
<td>35</td>
<td>Ordered</td>
<td>0.42</td>
<td>(0.37-0.48)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td><strong>Domain 2. Adequate information about cancer and cancer management</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I know enough about how to</td>
<td>1 (0.3%)</td>
<td>6 (2.0%)</td>
<td>44</td>
<td>Ordered</td>
<td>0.25</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th>Statement</th>
<th>Category</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Total (%)</th>
<th>Ordered (%)</th>
<th>Value</th>
<th>Valid?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have all the information I need to help look after the health of the person I care for</td>
<td>16</td>
<td>0 (4.0%)</td>
<td>43</td>
<td>(14.5%)</td>
<td>Ordered</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>I have enough information to understand the potential side effects of treatment</td>
<td>18</td>
<td>1 (0.3%)</td>
<td>62</td>
<td>(20.9%)</td>
<td>Ordered</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>I know how to manage the side-effects of treatment</td>
<td>26</td>
<td>1 (0.3%)</td>
<td>34</td>
<td>(11.4%)</td>
<td>Ordered</td>
<td>0.35</td>
<td></td>
</tr>
<tr>
<td>I feel I have good information about the cancer</td>
<td>34</td>
<td>1 (0.3%)</td>
<td>63</td>
<td>(21.2%)</td>
<td>Ordered</td>
<td>0.15</td>
<td></td>
</tr>
<tr>
<td>I have enough information to look after the health of the person I care for</td>
<td>42</td>
<td>0 (2.0%)</td>
<td>40</td>
<td>(13.5%)</td>
<td>Ordered</td>
<td>0.20</td>
<td></td>
</tr>
<tr>
<td>I know which side-effects require immediate medical attention</td>
<td>66</td>
<td>2 (0.7%)</td>
<td>70</td>
<td>(23.6%)</td>
<td>Ordered</td>
<td>0.23</td>
<td></td>
</tr>
<tr>
<td>I know the routine things the person I care for needs to do to look after their own health</td>
<td>69</td>
<td>1 (0.3%)</td>
<td>80</td>
<td>(26.9%)</td>
<td>Ordered</td>
<td>0.03</td>
<td></td>
</tr>
</tbody>
</table>

Domain 3. Supported by healthcare providers

<table>
<thead>
<tr>
<th>Statement</th>
<th>Category</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Total (%)</th>
<th>Ordered (%)</th>
<th>Value</th>
<th>Valid?</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one healthcare provider has helped me understand information about cancer</td>
<td>3</td>
<td>1 (0.3%)</td>
<td>84</td>
<td>(28.3%)</td>
<td>Ordered</td>
<td>0.17</td>
<td></td>
</tr>
<tr>
<td>Healthcare providers have helped us make the right choices about treatment</td>
<td>11</td>
<td>0 (4.0%)</td>
<td>93</td>
<td>(31.3%)</td>
<td>Ordered</td>
<td>0.15</td>
<td></td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th>Question</th>
<th>Median</th>
<th>Interquartile Range</th>
<th>% of Orders</th>
<th>% of Mean</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one healthcare provider explains health information in a way that is easy for me to understand</td>
<td>0.28</td>
<td>(0.23-0.33)</td>
<td>(25.9%)</td>
<td>(0.10-0.18)</td>
<td>27</td>
</tr>
<tr>
<td>At least one healthcare provider gives me enough time to discuss all the information that I need</td>
<td>0.28</td>
<td>(0.23-0.33)</td>
<td>(17.2%)</td>
<td>(0.10-0.18)</td>
<td>27</td>
</tr>
<tr>
<td>Healthcare providers include me in discussions to help me understand information about cancer</td>
<td>0.25</td>
<td>(0.20-0.30)</td>
<td>(21.5%)</td>
<td>(0.10-0.18)</td>
<td>35</td>
</tr>
<tr>
<td>At least one healthcare provider makes sure I understand enough information about the cancer</td>
<td>0.28</td>
<td>(0.23-0.34)</td>
<td>(16.2%)</td>
<td>(0.10-0.18)</td>
<td>43</td>
</tr>
<tr>
<td>Healthcare providers have helped me understand information about treatments</td>
<td>0.20</td>
<td>(0.15-0.24)</td>
<td>(17.8%)</td>
<td>(0.10-0.18)</td>
<td>50</td>
</tr>
<tr>
<td>Healthcare providers have helped me understand the potential side effects of treatments</td>
<td>0.27</td>
<td>(0.22-0.32)</td>
<td>(18.2%)</td>
<td>(0.10-0.18)</td>
<td>57</td>
</tr>
<tr>
<td>Healthcare providers have helped me understand health services available for the person I care for</td>
<td>0.32</td>
<td>(0.27-0.38)</td>
<td>(16.5%)</td>
<td>(0.10-0.18)</td>
<td>67</td>
</tr>
<tr>
<td>Healthcare providers have helped me understand services available to support me</td>
<td>0.40</td>
<td>(0.34-0.45)</td>
<td>(13.1%)</td>
<td>(0.10-0.18)</td>
<td>71</td>
</tr>
<tr>
<td>I have at least one person who</td>
<td>0.16</td>
<td>(0.10-0.18)</td>
<td>(8.4%)</td>
<td>(0.10-0.18)</td>
<td>4</td>
</tr>
</tbody>
</table>

Domain 4. Social support

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th>Domain 5. Communication with the care recipient</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I talk with the person I care for about their health condition</td>
<td>0</td>
<td>5 (1.7%)</td>
<td>110</td>
<td>Ordered</td>
</tr>
<tr>
<td>The person I care for tells me about their health, in order for me to help</td>
<td>1</td>
<td>6 (2.0%)</td>
<td>78</td>
<td>Ordered</td>
</tr>
<tr>
<td>I have honest talks with the person I care for about how the cancer may impact on the future</td>
<td>0</td>
<td>5 (1.7%)</td>
<td>93</td>
<td>Ordered</td>
</tr>
<tr>
<td>The person I care for tells me about their health, in order for me to help</td>
<td>0</td>
<td>5 (1.7%)</td>
<td>93</td>
<td>Ordered</td>
</tr>
<tr>
<td>If I need help, I have at least one person I can rely on</td>
<td>0</td>
<td>12 (4.0%)</td>
<td>83</td>
<td>Ordered</td>
</tr>
<tr>
<td>I have at least one family member or friend who can help me understand health information</td>
<td>1 (0.3%)</td>
<td>33 (11.1%)</td>
<td>52</td>
<td>Ordered</td>
</tr>
<tr>
<td>People around me really understand what I am going through as a caregiver</td>
<td>1 (0.3%)</td>
<td>37 (12.5%)</td>
<td>35</td>
<td>Ordered</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter 8. Validation of the HLCS-C</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I have strong support from at least one family member or friend</td>
<td>0</td>
<td>10 (3.4%)</td>
<td>111</td>
<td>Ordered</td>
</tr>
<tr>
<td>I get enough chances to talk to other people who are caring for someone with cancer</td>
<td>0</td>
<td>32 (10.8%)</td>
<td>27</td>
<td>Ordered</td>
</tr>
<tr>
<td>If I need help, I have at least one family member or friend who can attend medical appointments with us</td>
<td>1 (0.3%)</td>
<td>18 (6.1%)</td>
<td>67</td>
<td>Ordered</td>
</tr>
<tr>
<td>People around me really understand what I am going through as a caregiver</td>
<td>1 (0.3%)</td>
<td>37 (12.5%)</td>
<td>35</td>
<td>Ordered</td>
</tr>
<tr>
<td>Question</td>
<td>N</td>
<td>% (95% CI)</td>
<td>Ordered (95% CI)</td>
<td>Validated</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------------------</td>
<td>----</td>
<td>-----------</td>
<td>------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>About the condition of their health</td>
<td>37</td>
<td>0 (1.0%)</td>
<td>98 (33.0%)</td>
<td>0.16</td>
</tr>
<tr>
<td>I have honest talks about the cancer with the person I care for</td>
<td>37</td>
<td>0 (1.0%)</td>
<td>98 (33.0%)</td>
<td>0.16</td>
</tr>
<tr>
<td>To help make decisions, I discuss all of the healthcare options with the person I care for</td>
<td>45</td>
<td>0 (1.7%)</td>
<td>106 (35.7%)</td>
<td>0.13</td>
</tr>
<tr>
<td>Ordered</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>After appointments, I discuss the information given by healthcare providers with the person I care for</td>
<td>58</td>
<td>0 (1.0%)</td>
<td>93 (31.3%)</td>
<td>0.11</td>
</tr>
</tbody>
</table>

### Domain 6. Understanding the care recipient

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>% (95% CI)</th>
<th>Ordered (95% CI)</th>
<th>Validated</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand how much information about the cancer, the person I am caring for wants to know</td>
<td>6</td>
<td>1 (0.3%)</td>
<td>87 (29.3%)</td>
<td>0.13</td>
</tr>
<tr>
<td>I understand when to let the person I am caring for do things for themselves in their own time</td>
<td>14</td>
<td>2 (0.7%)</td>
<td>110 (37.0%)</td>
<td>0.03</td>
</tr>
<tr>
<td>I know when it is best to leave the person I am caring for alone</td>
<td>22</td>
<td>2 (0.7%)</td>
<td>86 (29.0%)</td>
<td>0.06</td>
</tr>
<tr>
<td>I know which everyday activities the person I care for</td>
<td>30</td>
<td>0 (0.7%)</td>
<td>83 (27.9%)</td>
<td>0.07</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th>Domain</th>
<th>Question</th>
<th>Score (n, %)</th>
<th>Score (95% CI)</th>
<th>Score (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I know what the person I care for can and cannot do physically during</td>
<td>2 (0.7%)</td>
<td>1 (0.3%)</td>
<td>100 (33.7%)</td>
</tr>
<tr>
<td></td>
<td>treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I know the important things the person I care for needs to do to look</td>
<td>2 (0.7%)</td>
<td>17 (5.7%)</td>
<td>77 (25.9%)</td>
</tr>
<tr>
<td></td>
<td>after their health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I know how much help to give the person I care for</td>
<td>0 (0.3%)</td>
<td>1 (0.3%)</td>
<td>77 (25.9%)</td>
</tr>
<tr>
<td></td>
<td>Most of the time, I understand the needs of the person I care for</td>
<td>0 (0.3%)</td>
<td>0 (0.3%)</td>
<td>83 (27.9%)</td>
</tr>
<tr>
<td></td>
<td>I know which everyday activities the person I care for can do</td>
<td>3 (1.0%)</td>
<td>1 (0.3%)</td>
<td>87 (29.3%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Domain 7. Self-care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I find healthy ways to cope with things in my life</td>
<td>1 (0.3%)</td>
<td>2 (0.7%)</td>
<td>46 (15.5%)</td>
</tr>
<tr>
<td></td>
<td>from caring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I do as much as I can to stay as healthy as possible</td>
<td>0 (0.3%)</td>
<td>5 (1.7%)</td>
<td>78 (26.3%)</td>
</tr>
<tr>
<td></td>
<td>Most of the time, I understand the needs of the person I care for</td>
<td>0 (0.3%)</td>
<td>8 (2.7%)</td>
<td>53 (17.8%)</td>
</tr>
<tr>
<td></td>
<td>I make sure I get enough rest</td>
<td>2 (0.7%)</td>
<td>7 (2.4%)</td>
<td>57 (19.2%)</td>
</tr>
<tr>
<td></td>
<td>There are things I do regularly to take care of my health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I spend quite a lot of time actively managing my own health</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
Chapter 8. Validation of the HLCS-C

<table>
<thead>
<tr>
<th>Domain 8. Understanding the healthcare system</th>
</tr>
</thead>
<tbody>
<tr>
<td>I get regular check ups for my own health</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>67</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.23</td>
</tr>
<tr>
<td>0.23-0.27</td>
</tr>
<tr>
<td>✓</td>
</tr>
<tr>
<td>I make plans for what I need to do to be healthy</td>
</tr>
<tr>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>6 (2.0%)</td>
</tr>
<tr>
<td>41</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.28</td>
</tr>
<tr>
<td>0.23-0.34</td>
</tr>
<tr>
<td>✓</td>
</tr>
<tr>
<td>I make sure that I regularly eat healthy meals</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>6 (2.0%)</td>
</tr>
<tr>
<td>83</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.12</td>
</tr>
<tr>
<td>✓</td>
</tr>
<tr>
<td>I make sure I see healthcare providers for my own health</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>8 (2.7%)</td>
</tr>
<tr>
<td>60</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.20</td>
</tr>
<tr>
<td>0.16-0.25</td>
</tr>
<tr>
<td>✓</td>
</tr>
<tr>
<td>Despite other things in my life, I make sure I regularly exercise</td>
</tr>
<tr>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>11</td>
</tr>
<tr>
<td>53 (17.8)</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.35</td>
</tr>
<tr>
<td>0.29-0.40</td>
</tr>
<tr>
<td>✓</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 8. Understanding the healthcare system</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know what healthcare services are available to help me</td>
</tr>
<tr>
<td>I know who can provide the right healthcare for the person I care for</td>
</tr>
<tr>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>42</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.24</td>
</tr>
<tr>
<td>0.20-0.29</td>
</tr>
<tr>
<td>✓</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 8. Understanding the healthcare system</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand what healthcare services the person I care for is entitled to</td>
</tr>
<tr>
<td>I know which healthcare providers are looking after the health of the person I care for</td>
</tr>
<tr>
<td>I know where to find the right healthcare for the person I care for</td>
</tr>
<tr>
<td>I know the right place to get the healthcare the person I care for needs</td>
</tr>
<tr>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>1 (0.3%)</td>
</tr>
<tr>
<td>98</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.08</td>
</tr>
<tr>
<td>0.05-0.10</td>
</tr>
<tr>
<td>✓</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 8. Understanding the healthcare system</th>
</tr>
</thead>
<tbody>
<tr>
<td>I make sure I regularly eat healthy meals</td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td>6 (2.0%)</td>
</tr>
<tr>
<td>83</td>
</tr>
<tr>
<td>Ordered</td>
</tr>
<tr>
<td>0.12</td>
</tr>
<tr>
<td>✓</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th>Domain</th>
<th>Activity Description</th>
<th>Percentage (Count)</th>
<th>Standard Error</th>
<th>Mean (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>85</td>
<td>Healthcare appointments for the person I care for</td>
<td>(31.6%) (77)</td>
<td>0.17</td>
<td>(0.07-0.14)</td>
</tr>
<tr>
<td></td>
<td>I know how to find healthcare providers who can help the person I care for</td>
<td>3 (1.0%) (4)</td>
<td>0.13</td>
<td>(0.10-0.16)</td>
</tr>
<tr>
<td></td>
<td>I know what healthcare services are available to help the person I care for</td>
<td>2 (0.7%) (6)</td>
<td>0.23</td>
<td>(0.18-0.27)</td>
</tr>
<tr>
<td></td>
<td>Ordered</td>
<td>17</td>
<td>0.17</td>
<td>(0.13-0.21)</td>
</tr>
<tr>
<td></td>
<td>23</td>
<td>0.23</td>
<td>(0.18-0.27)</td>
<td></td>
</tr>
<tr>
<td>70</td>
<td>I know how to find healthcare providers who can help the person I care for</td>
<td>3 (1.0%) (4)</td>
<td>0.13</td>
<td>(0.10-0.16)</td>
</tr>
<tr>
<td></td>
<td>I know what healthcare services are available to help the person I care for</td>
<td>2 (0.7%) (6)</td>
<td>0.23</td>
<td>(0.18-0.27)</td>
</tr>
<tr>
<td></td>
<td>Ordered</td>
<td>17</td>
<td>0.17</td>
<td>(0.13-0.21)</td>
</tr>
<tr>
<td></td>
<td>23</td>
<td>0.23</td>
<td>(0.18-0.27)</td>
<td></td>
</tr>
<tr>
<td>74</td>
<td>Understand information given by healthcare providers</td>
<td>1 (0.3%) (3)</td>
<td>0.18</td>
<td>(0.14-0.23)</td>
</tr>
<tr>
<td></td>
<td>Find out if health information from various resources is suitable for the person I am caring for</td>
<td>3 (1.0%) (3)</td>
<td>0.35</td>
<td>(0.30-0.41)</td>
</tr>
<tr>
<td>76</td>
<td>Remember advice given by healthcare providers</td>
<td>1 (0.3%) (3)</td>
<td>0.21</td>
<td>(0.17-0.26)</td>
</tr>
<tr>
<td></td>
<td>Find out if the information that I have received is reliable</td>
<td>5 (1.7%) (9)</td>
<td>0.40</td>
<td>(0.35-0.46)</td>
</tr>
<tr>
<td>78</td>
<td>Decide where the trustworthy places are to get information about cancer</td>
<td>0 (0.0%) (10)</td>
<td>0.38</td>
<td>(0.32-0.43)</td>
</tr>
<tr>
<td>80</td>
<td>Work out which sources have information that is relevant for the person I care for</td>
<td>2 (0.7%) (7)</td>
<td>0.37</td>
<td>(0.32-0.43)</td>
</tr>
<tr>
<td></td>
<td>Decide which health information is relevant for the person I care for</td>
<td>2 (0.7%) (6)</td>
<td>0.34</td>
<td>(0.29-0.39)</td>
</tr>
<tr>
<td>82</td>
<td>Compare information about cancer from different sources</td>
<td>3 (1.0%) (13)</td>
<td>0.45</td>
<td>(0.39-0.51)</td>
</tr>
<tr>
<td></td>
<td>Remember information given</td>
<td>1 (0.3%) (50)</td>
<td>0.25</td>
<td>(0.20-0.30)</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
by healthcare providers to help the person I care for (16.8%) (0.20-0.30)

<table>
<thead>
<tr>
<th>Domain 10. Active engagement with healthcare providers</th>
<th>Ask healthcare providers</th>
<th>Have good discussions with healthcare providers about the health of the person I care for</th>
<th>Ask a healthcare provider to explain things to me</th>
<th>Discuss things about the cancer with healthcare providers</th>
<th>Make sure that healthcare providers understand all I need to know about the health problems of the person I care for properly</th>
<th>Feel able to discuss my concerns about the health of the person I care for with a healthcare provider</th>
<th>Ask a healthcare provider to explain what healthcare services are available to help me provide care</th>
<th>Ask questions if I don’t understand the information given to me by healthcare providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>73</td>
<td>2 (0.7%)</td>
<td>4 (1.3%)</td>
<td>6 (1.7%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (0.3%)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 (0.7%)</td>
<td>7 (2.4%)</td>
<td>6 (2.0%)</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>3 (1.0%)</td>
<td>6</td>
</tr>
<tr>
<td>75</td>
<td>59 (19.9%)</td>
<td>45 (15.2%)</td>
<td>60 (20.2%)</td>
<td>11 (3.7%)</td>
<td>10 (3.5%)</td>
<td>10 (3.5%)</td>
<td>1 (0.3%)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>2 (0.7%)</td>
<td>2 (0.7%)</td>
<td>2 (0.7%)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>77</td>
<td>Disordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
</tr>
<tr>
<td></td>
<td>0.23</td>
<td>0.31</td>
<td>0.21</td>
<td>0.30</td>
<td>0.31</td>
<td>0.27</td>
<td>0.28</td>
<td>0.21</td>
</tr>
<tr>
<td>79</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>(0.18-0.28)</td>
<td>(0.26-0.37)</td>
<td>(0.16-0.26)</td>
<td>(0.25-0.36)</td>
<td>(0.26-0.36)</td>
<td>(0.22-0.32)</td>
<td>(0.23-0.33)</td>
<td>(0.16-0.26)</td>
</tr>
<tr>
<td>81</td>
<td>2 (0.7%)</td>
<td>5 (1.7%)</td>
<td>59 (19.9%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (0.3%)</td>
<td>0</td>
</tr>
<tr>
<td>83</td>
<td>6 (2.0%)</td>
<td>63 (21.2%)</td>
<td>52 (17.5%)</td>
<td>6 (2.0%)</td>
<td>5 (1.7%)</td>
<td>5 (1.7%)</td>
<td>3 (1.0%)</td>
<td>6</td>
</tr>
<tr>
<td>84</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
<td>Ordered</td>
</tr>
<tr>
<td>86</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td>(0.20-0.30)</td>
<td>(0.23-0.33)</td>
<td>(0.23-0.33)</td>
<td>(0.16-0.26)</td>
<td>(0.16-0.26)</td>
<td>(0.16-0.26)</td>
<td>(0.16-0.26)</td>
<td>(0.16-0.26)</td>
</tr>
</tbody>
</table>
* **Bolded indices indicate a ceiling effect (> 15%)**

CI = Confidence Interval
<table>
<thead>
<tr>
<th>Domain#/Item #</th>
<th>Domain/item</th>
<th>Difficult y (95% CI)</th>
<th>Factor loading (95% CI)</th>
<th>R²</th>
<th>Ceiling effect (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1. Proactivity and determination to seek information (4 items)</td>
<td>I regularly search for up to date information about the cancer</td>
<td>0.49 (0.44-0.5)</td>
<td>0.88 (0.85-0.90)</td>
<td>0.77</td>
<td>30 (10.1%)</td>
</tr>
<tr>
<td></td>
<td>(5) I keep searching until I find information that I understand</td>
<td>0.33 (0.28-0.3)</td>
<td>0.86 (0.82-0.89)</td>
<td>0.74</td>
<td>41 (13.8%)</td>
</tr>
<tr>
<td></td>
<td>(9) I look for new opportunities to get information about the cancer</td>
<td>0.40 (0.35-0.4)</td>
<td>0.90 (0.88-0.93)</td>
<td>0.82</td>
<td>35 (11.8%)</td>
</tr>
<tr>
<td></td>
<td>(6) To help the person I care for, I actively search for information about cancer</td>
<td>0.42 (0.37-0.4)</td>
<td>0.98 (0.97-0.99)</td>
<td>0.97</td>
<td>35 (11.8%)</td>
</tr>
<tr>
<td></td>
<td>CFA Model Fit - $\chi^2_{WLSMV} = 1.645$, p = 0.4393, CFI = 1.00, TLI = 1.00, RMSEA = 0.00, WRMR = 0.147. Composite reliability = 0.92 (0.90-0.94)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 2. Adequate information about cancer and cancer management (4 items)</td>
<td>I have all the information I need to help look after the health of the person I care for</td>
<td>0.25 (0.21-0.2)</td>
<td>0.77 (0.70-0.83)</td>
<td>0.59</td>
<td>43 (14.5%)</td>
</tr>
<tr>
<td></td>
<td>(6) I have enough information to understand the potential side effects of treatment</td>
<td>0.21 (0.17-0.2)</td>
<td>0.86 (0.80-0.83)</td>
<td>0.73</td>
<td>62 (20.9%)</td>
</tr>
<tr>
<td></td>
<td>(6) I know how to manage the side-effects of treatment</td>
<td>0.35 (0.30-0.4)</td>
<td>0.73 (0.66-0.73)</td>
<td>0.54</td>
<td>34 (11.4%)</td>
</tr>
<tr>
<td></td>
<td>(1) I feel I have good information about the cancer</td>
<td>0.15 (0.12-0.2)</td>
<td>0.80 (0.73-0.87)</td>
<td>0.65</td>
<td>63 (21.2%)</td>
</tr>
<tr>
<td></td>
<td>CFA Model Fit - $\chi^2_{WLSMV} = 1.296$, p = 0.5230, CFI = 1.00, TLI = 1.002, RMSEA = 0.00, WRMR = 0.188. Composite reliability = 0.81 (0.78-0.84)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 3. Supported by healthcare providers to understand information (5 items)</td>
<td>At least one healthcare provider has helped me understand information about cancer</td>
<td>0.167 (0.13-0.2)</td>
<td>0.67 (0.60-0.74)</td>
<td>0.45</td>
<td>84 (28.3%)</td>
</tr>
<tr>
<td></td>
<td>(1) Healthcare providers include me in discussions to help me understand information about cancer</td>
<td>0.25 (0.20-0.3)</td>
<td>0.87 (0.84-0.91)</td>
<td>0.76</td>
<td>64 (21.5%)</td>
</tr>
<tr>
<td></td>
<td>35 (1) Healthcare providers include me in discussions to help me understand information about cancer</td>
<td>0.25 (0.20-0.3)</td>
<td>0.87 (0.84-0.91)</td>
<td>0.76</td>
<td>64 (21.5%)</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
At least one healthcare provider makes sure I understand enough information about the cancer (0.23-0.3) (0.87-0.93) (16.2%)

Healthcare providers have helped me understand information about treatments (0.15-0.2) (0.89-0.91) (17.8%)

Healthcare providers have helped me understand supports and services available for the person I care for (0.27-0.3) (0.81-0.9) (16.5%)

CFA Model Fit - χ^2_{WLSMV} = 7.250, p = 0.203, CFI = 1.00, TLI = 1.00, RMSEA = 0.039, WRMR = 0.322. Composite reliability = 0.89 (0.86-0.91)

I have at least one person who understands and supports me (0.12-0.2) (0.74-0.84) (28.6%)

I have strong support from at least one family member or friend (0.12-0.2) (0.87-0.95) (37.4%)

If I need help, I have at least one person I can rely on (0.15-0.2) (0.85-0.92) (27.9%)

I have at least one family member or friend who can help me understand health information (0.25-0.3) (0.67-0.79) (22.6%)

CFA Model Fit - χ^2_{WLSMV} = 8.861, p = 0.0119, CFI = 0.997, TLI = 0.991, RMSEA = 0.107, WRMR = 0.458. Composite reliability = 0.86 (0.83-0.88)

I have honest talks with the person I care for about the cancer information given to us by healthcare providers (0.10-0.1) (0.88-0.9) (31.3%)

After appointments, I discuss the information given by healthcare providers with the person I care for (0.08-0.1) (0.84-0.9) (31.3%)

Domain 4. Social support (4 items)

Domain 5. Cancer-related communication with the care recipient (4 items)
Domain 6. Understanding care recipient needs and preferences (6 items)

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>I understand how much information about the cancer, the person I am caring for wants to know</td>
<td>0.13</td>
<td>0.71</td>
<td>51</td>
<td>87</td>
</tr>
<tr>
<td>14</td>
<td>I always know when to let the person I am caring for do things for themselves in their own time.</td>
<td>0.03</td>
<td>0.64</td>
<td>42</td>
<td>110</td>
</tr>
<tr>
<td>38</td>
<td>I know what the person I care for can and cannot do physically during treatment</td>
<td>0.06</td>
<td>0.88</td>
<td>77</td>
<td>100</td>
</tr>
<tr>
<td>53</td>
<td>I know how much help to give the person I care for</td>
<td>0.11</td>
<td>0.88</td>
<td>77</td>
<td>77</td>
</tr>
<tr>
<td>59</td>
<td>I always understand the needs of the person I care for</td>
<td>0.04</td>
<td>0.85</td>
<td>71</td>
<td>83</td>
</tr>
<tr>
<td>64</td>
<td>I know which everyday activities the person I care for can do</td>
<td>0.05</td>
<td>0.84</td>
<td>71</td>
<td>87</td>
</tr>
</tbody>
</table>

CFA Model Fit - $\chi^2_{WLSMV} = 5.223$, $p = 0.0734$, CFI = 0.999, TLI = 0.996, RMSEA = 0.074, WRMR = 0.321. Composite reliability = 0.85 (0.82-0.87)

Domain 7. Self-care (5 items)

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>I make sure I get enough rest</td>
<td>0.27</td>
<td>0.71</td>
<td>50</td>
<td>53</td>
</tr>
<tr>
<td>47</td>
<td>I spend quite a lot of time actively managing my own health</td>
<td>0.43</td>
<td>0.87</td>
<td>76</td>
<td>37</td>
</tr>
<tr>
<td>54</td>
<td>I make plans for what I need to do to be healthy</td>
<td>0.28</td>
<td>0.89</td>
<td>79</td>
<td>41</td>
</tr>
<tr>
<td>63</td>
<td>I make sure I see healthcare providers for my own health</td>
<td>0.20</td>
<td>0.68</td>
<td>47</td>
<td>60</td>
</tr>
<tr>
<td>68</td>
<td>Despite other things in my life, I make sure I regularly exercise</td>
<td>0.35</td>
<td>0.80</td>
<td>65</td>
<td>53</td>
</tr>
</tbody>
</table>

CFA Model Fit - $\chi^2_{WLSMV} = 10.689$, $p = 0.0579$, CFI = 0.995, TLI = 0.991, RMSEA = 0.076, WRMR = 0.62. Composite reliability = 0.78 (0.73-0.83)

Chapter 8. Validation of the HLCS-C
Domain 8. Understanding the healthcare system (6 items)

<table>
<thead>
<tr>
<th>Item</th>
<th>Statement</th>
<th>Factor Load</th>
<th>Reliability</th>
<th>Validity</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>I know who can provide the right healthcare for the person I care for</td>
<td>0.19</td>
<td>(0.15-0.2)</td>
<td>0.77</td>
<td>(0.72-0.81)</td>
</tr>
<tr>
<td>24</td>
<td>I understand what healthcare services the person I care for is entitled to</td>
<td>0.35</td>
<td>(0.29-0.4)</td>
<td>0.75</td>
<td>(0.70-0.81)</td>
</tr>
<tr>
<td>40</td>
<td>I know where to find the right healthcare for the person I care for</td>
<td>0.19</td>
<td>(0.15-0.2)</td>
<td>0.91</td>
<td>(0.88-0.94)</td>
</tr>
<tr>
<td>48</td>
<td>I know the right place to get the healthcare the person I care for needs</td>
<td>0.15</td>
<td>(0.12-0.2)</td>
<td>0.92</td>
<td>(0.89-0.94)</td>
</tr>
<tr>
<td>55</td>
<td>I know how to make healthcare appointments for the person I care for</td>
<td>0.10</td>
<td>(0.07-0.1)</td>
<td>0.76</td>
<td>(0.71-0.81)</td>
</tr>
<tr>
<td>65</td>
<td>I know how to find healthcare providers who can help the person I care for</td>
<td>0.17</td>
<td>(0.13-0.2)</td>
<td>0.92</td>
<td>(0.90-0.94)</td>
</tr>
</tbody>
</table>

CFA Model Fit - $\chi^2_{WLSMV} = 23.046$, p = 0.0061, CFI = 0.997, TLI = 0.996, RMSEA = 0.072, WRMR = 0.532. Composite reliability = 0.84 (0.82-0.87)

Domain 9. Capacity to process health information (4 items)

<table>
<thead>
<tr>
<th>Item</th>
<th>Statement</th>
<th>Factor Load</th>
<th>Reliability</th>
<th>Validity</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>78</td>
<td>Find out if the information that I have received is reliable</td>
<td>0.40</td>
<td>(0.35-0.4)</td>
<td>0.87</td>
<td>(0.83-0.90)</td>
</tr>
<tr>
<td>80</td>
<td>Decide where the trustworthy places are to get information about cancer</td>
<td>0.38</td>
<td>(0.32-0.4)</td>
<td>0.95</td>
<td>(0.93-0.96)</td>
</tr>
<tr>
<td>82</td>
<td>Work out which sources have information that is relevant for the person I care for</td>
<td>0.37</td>
<td>(0.32-0.4)</td>
<td>0.94</td>
<td>(0.92-0.96)</td>
</tr>
<tr>
<td>85</td>
<td>Decide which health information is relevant for the person I care for</td>
<td>0.34</td>
<td>(0.29-0.3)</td>
<td>0.87</td>
<td>(0.83-0.90)</td>
</tr>
</tbody>
</table>

CFA Model Fit - $\chi^2_{WLSMV} = 2.286$, p = 0.3189, CFI = 1.00, TLI = 1.00, RMSEA = 0.022, WRMR = 0.159. Composite reliability = 0.92 (0.90-0.93)

Domain 10. Active engagement with healthcare providers (4 items)

<table>
<thead>
<tr>
<th>Item</th>
<th>Statement</th>
<th>Factor Load</th>
<th>Reliability</th>
<th>Validity</th>
<th>% Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>75</td>
<td>Have good discussions with healthcare providers about the health of the person I care for</td>
<td>0.31</td>
<td>(0.26-0.3)</td>
<td>0.91</td>
<td>(0.89-0.93)</td>
</tr>
<tr>
<td>77</td>
<td>Ask a healthcare provider to</td>
<td>0.21</td>
<td>(0.20-0.2)</td>
<td>0.91</td>
<td>(0.89-0.93)</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
explain things to me (0.16-0.2 (0.88-0.94) (20.2%) 6 94)

79 Discuss things about the cancer (0.25-0.3 (0.93-0.97) (17.2%) 6 97)
with healthcare providers until I understand all I need to
0.30 0.95 0.91 51

86 Ask questions if I don't (0.16-0.2 (0.84-0.93) (21.2%) 6 88)
understand the information given to me by healthcare providers
0.21 0.86 0.74 63

CFA Model Fit - $\chi^2_{WLSMV} = 1.887$, $p = 0.3892$, CFI = 1.000, TLI = 1.000,
RMSEA = 0.000, WRMR = 0.142. Composite reliability = 0.92 (0.90-0.93)

CI = Confidence Interval
### Table 4. Inter-factor correlations for ten domains in HLCS-C

<table>
<thead>
<tr>
<th>Variable</th>
<th>Proactivity and determination</th>
<th>Adequate information about cancer and cancer management</th>
<th>Supported by HCP</th>
<th>Social support</th>
<th>Communication with the CR</th>
<th>Understanding the CR</th>
<th>Self-care</th>
<th>Understanding the HCS</th>
<th>Capacity to process health information</th>
<th>Engagement with HCP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proactivity and determination</td>
<td>-</td>
<td>-</td>
<td>0.30</td>
<td>0.73</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Adequate information about cancer and cancer management</td>
<td>0.46</td>
<td>-</td>
<td>0.23</td>
<td>0.39</td>
<td>0.55</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Supported by HCP</td>
<td>0.30</td>
<td>0.73</td>
<td>0.23</td>
<td>0.39</td>
<td>0.55</td>
<td>0.31</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Social support</td>
<td>0.46</td>
<td>0.65</td>
<td>0.39</td>
<td>0.76</td>
<td>0.52</td>
<td>0.42</td>
<td>0.21</td>
<td>0.42</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Communication with the CR</td>
<td>0.46</td>
<td>0.65</td>
<td>0.39</td>
<td>0.76</td>
<td>0.52</td>
<td>0.21</td>
<td>0.42</td>
<td>0.42</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Understanding the CR</td>
<td>0.22</td>
<td>0.28</td>
<td>0.23</td>
<td>0.39</td>
<td>0.46</td>
<td>0.27</td>
<td>0.42</td>
<td>0.32</td>
<td>0.21</td>
<td>0.67</td>
</tr>
<tr>
<td>Self-care</td>
<td>0.42</td>
<td>0.86</td>
<td>0.39</td>
<td>0.60</td>
<td>0.46</td>
<td>0.25</td>
<td>0.44</td>
<td>0.33</td>
<td>0.18</td>
<td>0.56</td>
</tr>
<tr>
<td>Understanding the HCS</td>
<td>0.22</td>
<td>0.28</td>
<td>0.23</td>
<td>0.39</td>
<td>0.46</td>
<td>0.25</td>
<td>0.44</td>
<td>0.33</td>
<td>0.18</td>
<td>0.56</td>
</tr>
<tr>
<td>Capacity to process health information</td>
<td>0.23</td>
<td>0.62</td>
<td>0.39</td>
<td>0.60</td>
<td>0.46</td>
<td>0.25</td>
<td>0.44</td>
<td>0.33</td>
<td>0.18</td>
<td>0.56</td>
</tr>
<tr>
<td>Engagement with HCP</td>
<td>0.23</td>
<td>0.62</td>
<td>0.42</td>
<td>0.42</td>
<td>0.42</td>
<td>0.21</td>
<td>0.42</td>
<td>0.42</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

CR = Care recipient; HCP = Healthcare providers; HCS = Healthcare system

Chapter 8. Validation of the HLCS-C
Chapter 8. Validation of the HLCS-C

Figure 1. Decisions and modifications made to the item pool and domains in response to IRT and CFA analyses
Extended Results

To enhance understanding of statistical processes undertaken as part of the psychometric assessment of the HLCS-C in the current section, analysis of missing data and outliers are presented. The descriptive statistics are also presented.

Missing data and outliers check

Missing data ranged between 0 – 5 for all variables (0 – 1.7%), which is less than 2%, thus, is considered acceptable. To identify potential outliers for each item, mean scores were compared to the 5% trimmed mean (Tabachnick & Fidell, 2012). As comparisons of the mean scores and 5% trimmed mean score showed negligible differences, the decision was made to retain the cases in the data file.

Descriptive statistics

Descriptive statistics, including skewness, kurtosis, and item means for the 88-items included in the analyses are presented in Table 8.1.
### Table 8.1.

**Descriptive statistics for the 88 draft items of the HLCS-C**

<table>
<thead>
<tr>
<th>Item #</th>
<th>Construct / Item</th>
<th>M</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Scale 1. Proactivity and determination to seek information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>To help provide the best care, I actively search for information</td>
<td>2.87</td>
<td>0.72</td>
<td>-0.29</td>
<td>-0.05</td>
</tr>
<tr>
<td>17</td>
<td>I search several different places to find information about the cancer</td>
<td>2.79</td>
<td>0.74</td>
<td>-0.24</td>
<td>-0.17</td>
</tr>
<tr>
<td>25</td>
<td>I make sure I have all of the information that I need to help the person I am caring for</td>
<td>2.93</td>
<td>0.17</td>
<td>-0.22</td>
<td>-0.37</td>
</tr>
<tr>
<td>33</td>
<td>I keep looking until I get all the information that I need</td>
<td>2.89</td>
<td>0.71</td>
<td>-0.18</td>
<td>-0.27</td>
</tr>
<tr>
<td>41</td>
<td>I regularly search for up to date information about the cancer</td>
<td>2.54</td>
<td>0.77</td>
<td>0.08</td>
<td>-0.38</td>
</tr>
<tr>
<td>49</td>
<td>I keep searching until I find information that I understand</td>
<td>2.78</td>
<td>0.72</td>
<td>-0.15</td>
<td>-0.21</td>
</tr>
<tr>
<td>56</td>
<td>I look for new opportunities to get information about the cancer</td>
<td>2.68</td>
<td>0.74</td>
<td>-0.03</td>
<td>-0.33</td>
</tr>
<tr>
<td>62</td>
<td>To help the person I care for, I actively search for information about cancer</td>
<td>2.66</td>
<td>0.76</td>
<td>0.01</td>
<td>-0.44</td>
</tr>
<tr>
<td></td>
<td><strong>Scale 2. Adequate information about cancer and cancer management</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I know enough about how to manage the health problems of the person I care for</td>
<td>2.88</td>
<td>0.67</td>
<td>-0.25</td>
<td>0.15</td>
</tr>
<tr>
<td>16</td>
<td>I have all the information I need to help look after the health of the person I care for</td>
<td>2.88</td>
<td>0.65</td>
<td>-0.17</td>
<td>0.04</td>
</tr>
<tr>
<td>18</td>
<td>I have enough information to understand the potential side effects of treatment</td>
<td>2.97</td>
<td>0.72</td>
<td>-0.45</td>
<td>0.27</td>
</tr>
<tr>
<td>26</td>
<td>I know how to manage the side-effects of treatment</td>
<td>2.71</td>
<td>0.73</td>
<td>-0.27</td>
<td>-0.08</td>
</tr>
<tr>
<td>34</td>
<td>I feel I have good information about the cancer</td>
<td>3.05</td>
<td>0.64</td>
<td>-0.26</td>
<td>0.15</td>
</tr>
<tr>
<td>42</td>
<td>I have enough information to look after the health of the person I care for</td>
<td>2.93</td>
<td>0.59</td>
<td>-0.17</td>
<td>0.04</td>
</tr>
<tr>
<td>66</td>
<td>I know which side-effects require immediate medical attention</td>
<td>2.98</td>
<td>0.75</td>
<td>-0.45</td>
<td>0.27</td>
</tr>
<tr>
<td>69</td>
<td>I know the routine things the person I care for needs to do to look after their own health</td>
<td>3.24</td>
<td>0.50</td>
<td>-0.27</td>
<td>-0.08</td>
</tr>
<tr>
<td></td>
<td><strong>Scale 3. Supported by healthcare providers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>At least one healthcare provider has helped me understand information about cancer</td>
<td>3.07</td>
<td>0.76</td>
<td>-0.73</td>
<td>0.60</td>
</tr>
<tr>
<td>11</td>
<td>Healthcare providers have helped us make the right choices about treatment</td>
<td>3.12</td>
<td>0.76</td>
<td>-0.82</td>
<td>0.79</td>
</tr>
<tr>
<td>19</td>
<td>At least one healthcare provider explains health information in a way that is easy for me to understand</td>
<td>3.09</td>
<td>0.69</td>
<td>-0.67</td>
<td>0.98</td>
</tr>
<tr>
<td>27</td>
<td>At least one healthcare provider gives me enough time to discuss all the information that I need</td>
<td>2.82</td>
<td>0.79</td>
<td>-0.51</td>
<td>0.05</td>
</tr>
<tr>
<td>35</td>
<td>Healthcare providers include me in discussions to help me understand information about cancer</td>
<td>2.92</td>
<td>0.78</td>
<td>-0.49</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>43</td>
<td>At least one healthcare provider makes sure I understand enough information about the cancer</td>
<td>2.84</td>
<td>0.74</td>
<td>-0.38</td>
<td>0.04</td>
</tr>
<tr>
<td>50</td>
<td>Healthcare providers have helped me understand information about treatments</td>
<td>2.95</td>
<td>0.70</td>
<td>-0.60</td>
<td>0.82</td>
</tr>
<tr>
<td>57</td>
<td>Healthcare providers have helped me understand the potential side effects of treatments</td>
<td>2.87</td>
<td>0.75</td>
<td>-0.41</td>
<td>0.04</td>
</tr>
<tr>
<td>67</td>
<td>Healthcare providers have helped me understand health services available for the person I care for</td>
<td>2.80</td>
<td>0.76</td>
<td>-0.24</td>
<td>-0.26</td>
</tr>
<tr>
<td>71</td>
<td>Healthcare providers have helped me understand services available to support me</td>
<td>2.65</td>
<td>0.81</td>
<td>-0.23</td>
<td>-0.39</td>
</tr>
<tr>
<td>4</td>
<td>I have at least one person who understands and supports me</td>
<td>3.11</td>
<td>0.71</td>
<td>-0.55</td>
<td>0.34</td>
</tr>
<tr>
<td>12</td>
<td>I have strong support from at least one family member or friend</td>
<td>3.18</td>
<td>0.78</td>
<td>-0.76</td>
<td>0.29</td>
</tr>
<tr>
<td>20</td>
<td>I get enough chances to talk to other people who are caring for someone with cancer</td>
<td>2.40</td>
<td>0.80</td>
<td>0.23</td>
<td>-0.37</td>
</tr>
<tr>
<td>28</td>
<td>If I need help, I have at least one person I can rely on</td>
<td>3.05</td>
<td>0.77</td>
<td>-0.62</td>
<td>0.24</td>
</tr>
<tr>
<td>36</td>
<td>I have at least one family member or friend who can help me understand health information</td>
<td>2.87</td>
<td>0.83</td>
<td>-0.39</td>
<td>-0.36</td>
</tr>
<tr>
<td>44</td>
<td>I have at least one family member or friend who can attend medical appointments with us</td>
<td>2.66</td>
<td>0.90</td>
<td>-0.21</td>
<td>-0.68</td>
</tr>
<tr>
<td>61</td>
<td>People around me really understand what I am going through as a caregiver</td>
<td>2.50</td>
<td>0.86</td>
<td>-0.04</td>
<td>-0.63</td>
</tr>
<tr>
<td>5</td>
<td>I talk with the person I care for about their health condition</td>
<td>3.24</td>
<td>0.69</td>
<td>-0.66</td>
<td>0.44</td>
</tr>
<tr>
<td>13</td>
<td>I have honest talks with the person I care for about how the cancer may impact on the future</td>
<td>3.08</td>
<td>0.79</td>
<td>-0.49</td>
<td>-0.36</td>
</tr>
<tr>
<td>21</td>
<td>The person I care for tells me about their health, in order for me to help</td>
<td>3.08</td>
<td>0.70</td>
<td>-0.47</td>
<td>0.30</td>
</tr>
<tr>
<td>29</td>
<td>The person I care for tells me about the condition of their health</td>
<td>3.16</td>
<td>0.70</td>
<td>0.52</td>
<td>0.23</td>
</tr>
<tr>
<td>37</td>
<td>I have honest talks about the cancer with the person I care for</td>
<td>3.16</td>
<td>0.70</td>
<td>-0.42</td>
<td>-0.26</td>
</tr>
<tr>
<td>45</td>
<td>To help make decisions, I discuss all of the healthcare options with the person I care for</td>
<td>3.21</td>
<td>0.71</td>
<td>-0.61</td>
<td>0.23</td>
</tr>
<tr>
<td>52</td>
<td>After appointments, I discuss the information given to us by healthcare providers</td>
<td>3.16</td>
<td>0.68</td>
<td>-0.47</td>
<td>0.14</td>
</tr>
<tr>
<td>58</td>
<td>I understand how much information about the cancer, the person I am caring for wants to know</td>
<td>3.16</td>
<td>0.65</td>
<td>-0.39</td>
<td>0.22</td>
</tr>
<tr>
<td>14</td>
<td>I understand when to let the person I am caring for do things for themselves in their own time.</td>
<td>3.34</td>
<td>0.54</td>
<td>0.06</td>
<td>-0.83</td>
</tr>
<tr>
<td>22</td>
<td>I know when it is best to leave the person I am caring for alone</td>
<td>3.22</td>
<td>0.58</td>
<td>-0.38</td>
<td>1.23</td>
</tr>
</tbody>
</table>

Chapter 8. Validation of the HLCS-C
Chapter 8. Validation of the HLCS-C

<table>
<thead>
<tr>
<th>Scale 7. Self-care</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>I know which everyday activities the person I care for would like to do</td>
<td>3.21</td>
<td>0.57</td>
<td>-0.24</td>
</tr>
<tr>
<td>38</td>
<td>I know what the person I care for can and cannot do physically during treatment</td>
<td>3.27</td>
<td>0.58</td>
<td>-0.23</td>
</tr>
<tr>
<td>46</td>
<td>I know the important things the person I care for needs to do to look after their health</td>
<td>3.20</td>
<td>0.53</td>
<td>0.18</td>
</tr>
<tr>
<td>53</td>
<td>I know how much help to give the person I care for</td>
<td>3.14</td>
<td>0.60</td>
<td>-0.16</td>
</tr>
<tr>
<td>59</td>
<td>Most of the time, I understand the needs of the person I care for</td>
<td>3.24</td>
<td>0.51</td>
<td>0.31</td>
</tr>
<tr>
<td>64</td>
<td>I know which everyday activities the person I care for can do</td>
<td>3.24</td>
<td>0.55</td>
<td>-0.08</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale 8. Understanding the healthcare system</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>I find healthy ways to cope with things in my life</td>
<td>3.02</td>
<td>0.55</td>
<td>-0.23</td>
</tr>
<tr>
<td>7</td>
<td>I regularly take time away from caring</td>
<td>2.60</td>
<td>0.84</td>
<td>-0.23</td>
</tr>
<tr>
<td>15</td>
<td>I do as much as I can to stay as healthy as possible</td>
<td>3.11</td>
<td>0.66</td>
<td>-0.48</td>
</tr>
<tr>
<td>23</td>
<td>I make sure I get enough rest</td>
<td>2.89</td>
<td>0.72</td>
<td>-0.27</td>
</tr>
<tr>
<td>31</td>
<td>There are things I do regularly to take care of my health</td>
<td>2.99</td>
<td>0.67</td>
<td>-0.47</td>
</tr>
<tr>
<td>39</td>
<td>Despite other things in my life, I make time just for me</td>
<td>2.81</td>
<td>0.76</td>
<td>-0.32</td>
</tr>
<tr>
<td>47</td>
<td>I spend quite a lot of time actively managing my own health</td>
<td>2.64</td>
<td>0.77</td>
<td>0.01</td>
</tr>
<tr>
<td>51</td>
<td>I get regular check ups for my own health</td>
<td>2.97</td>
<td>0.74</td>
<td>-0.44</td>
</tr>
<tr>
<td>54</td>
<td>I make plans for what I need to do to be healthy</td>
<td>2.84</td>
<td>0.68</td>
<td>-0.19</td>
</tr>
<tr>
<td>60</td>
<td>I make sure that I regularly eat healthy meals</td>
<td>3.14</td>
<td>0.66</td>
<td>-0.58</td>
</tr>
<tr>
<td>63</td>
<td>I make sure I see healthcare providers for my own health</td>
<td>2.97</td>
<td>0.70</td>
<td>-0.45</td>
</tr>
<tr>
<td>68</td>
<td>Despite other things in my life, I make sure I regularly exercise</td>
<td>2.80</td>
<td>0.77</td>
<td>-0.12</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale 9. Processing health information</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>72</td>
<td>Understand information given by healthcare providers</td>
<td>3.97</td>
<td>0.71</td>
<td>-0.94</td>
</tr>
</tbody>
</table>
Chapter 8. Validation of the HLCS-C

In this chapter, the final manuscript in the thesis was presented. The main purpose of the study described in Manuscript D was to assess the psychometric properties of the Health Literacy of Caregivers Scale – Cancer (HLCS-C), a measure designed to assess health literacy of caregivers of people with cancer. The findings detailed in this Chapter provide strong preliminary evidence to support the robustness of the resultant 46-item scale. The HLCS-C demonstrated adequate construct validity, as determined through confirmatory factor analyses. The majority of the domains demonstrated good discriminant validity, however high inter-factor correlations were found between two domains Understanding the Healthcare System and Information Adequacy. Further research is recommended to determine whether the concepts
should be represented as two distinct domains, or whether they should be integrated. The final measurement model demonstrated adequate statistical fit. Items within each domain showed high homogeneity, and captured clear and distinct constructs. Further, items with a range of difficulty levels were represented within each domain.

In addition, the high reliability of the HLCS-C suggests the 10 domains were measured with adequate precision. In particular, for three scales with reliability indices above .90, evidence suggests that information derived from the scale can be used with some certainty to identify caregivers who may require assistance with health literacy-related tasks.

Overall, the HLCS-C advances measurement of caregiver health literacy by providing a robust scale that assesses a broad range of components that represent caregiver health literacy. The included domains were identified by key stakeholders as critical for caregivers when finding, understanding, and using health information to promote and maintain the health of the care recipient. Following further validation and refinement, the scale has the potential to be used by researchers, health educators, healthcare providers and policymakers to inform the development of effective strategies to optimise caregiver health literacy. In the next and concluding Chapter, the findings from all four manuscripts are integrated in a general discussion of the research.
Chapter 9. Discussion

Chapter Overview

The main purpose of the thesis was to advance the conceptualisation and measurement of health literacy for caregivers of people with cancer. The objectives of the thesis were to:

1. Appraise the current state of peer-reviewed literature on health literacy of caregivers of adult care recipients;
2. Develop a conceptual model of caregiver health literacy from the perspective of key stakeholders, and;
3. Use the conceptual model to guide the development of a comprehensive, multidimensional measure to assess health literacy of caregivers of people with cancer.

In this final chapter, the key findings of the studies from the four individual studies presented as manuscripts (A-D) are summarised. The implications of research findings are then presented, key strengths and limitations of the research identified, and directions for future research are highlighted. Conclusions of the four individual studies that comprise the thesis were discussed in their respective manuscripts. Thus, the focus of this chapter is to provide a broad overview of the thesis as a whole, a discussion of the way in which the four studies inter-relate, and the conclusions that can be drawn from the collective results. The chapter concludes with a summary of the scholarly contributions of the research to the field of cancer care and health literacy.

Summary of Main Findings

To address the research objectives, the thesis was comprised of four manuscripts. Manuscript A presented in Chapter 3 addressed the first objective of the thesis. Specifically, the manuscript detailed the results from a systematic review which critically appraised the current state of available literature pertaining to health literacy of caregivers of adult care recipients.
Manuscript B presented in Chapter 6 addressed the second objective of the research. Specifically, the results from concept mapping workshops conducted with key stakeholders to identify elements that were important to caregivers when finding, understanding and using health information to promote and maintain the health of their care recipient were detailed. These workshop results were integrated and synthesised to derive the conceptual model of caregiver health literacy. Manuscripts C and D presented in Chapters 7 and 8 respectively, addressed the third objective of the research. In Chapter 7, item generation and content validity testing of the new measure of caregiver health literacy, the Health Literacy of Caregivers Scale-Cancer (HLCS-C), was presented. In Chapter 8, the validation of the HLCS-C was detailed. In the following sections, findings from the four manuscripts are summarised in the context of the three objectives: the state of the field of caregiver health literacy, a conceptual model of caregiver health literacy, and the development of a comprehensive new measure of cancer caregiver health literacy.

**State of the field: Caregiver health literacy**

In Chapter 3, findings from a systematic review that sought to appraise the current state of peer-reviewed literature on health literacy of caregivers of adult care recipients was presented. In the review, associations between caregiver health literacy and caregiver and care recipient health outcomes were also examined. The four key questions for the literature review included: How is health literacy assessed in caregivers of adult care recipients? What are the levels of health literacy among caregivers of adult care recipients? Are caregiver health literacy skills independently associated with care recipient health outcomes? Are caregiver health literacy skills associated with caregiver health outcomes?
Ten studies that examined caregiver health literacy in five caregiver cohorts (elderly, stroke survivors, heart failure patients, hip surgery patients, people with Type II diabetes, and adults with developmental disabilities) were identified. Across the 10 studies, the prevalence of inadequate health literacy in caregivers ranged from 0 to 75%. However, a key finding was the substantial variation across studies related to measurement tools and the cut-off criteria used to assess caregiver health literacy. Thus, the prevalence of findings for caregiver health literacy must be interpreted with caution. In addition, the inconsistencies in measurement tools and scoring criteria made it difficult to pool results and compare results across studies.

Further, two studies found discrepancies when assessing inadequate health literacy in caregiver samples using two different health literacy measures (Greenberg et al., 2009; Levin et al., 2014). For example, Greenberg and colleagues found when using the REALM, the majority of caregivers (85%) scored at ninth grade reading level or above. However, when using the NVS, up to 56% reported questionable or inadequate health literacy (25% limited health literacy possible, 31% limited literacy likely). Thus, these findings present uncertainties about the actual levels of inadequate health literacy in caregiver populations. Further, health literacy measures should not be considered equal across populations (Morrison, Schapira, Hoffmann, & Brousseau, 2014). One potential limitation to advancing caregiver health literacy research identified in the systematic review was the lack of comprehensive measures to adequately assess the health literacy needs of caregivers of adult care recipients.

In addition, there was some evidence to suggest an association between caregiver low health literacy and poorer care recipient health outcomes, however the overall understanding is weak. Although one study did find an association between low health literacy in caregivers and poorer self-management behaviours in care recipients (Levin et al., 2014), it was unclear whether
caregivers’ corresponding care recipients also had low health literacy. Another study found an association between low health literacy in caregivers and increased frequency and duration of hospital admission and health-related quality of life for caregivers (Rahman, 2014). However, the limited available evidence precludes firm conclusions being drawn about the potential mediating effect of caregiver health literacy on care recipient self-management behaviours and health outcomes.

Further, only one study was identified that examined the relationship between caregiver health literacy and caregiver health outcomes (Gibson, 2013), specifically caregiver burden in a sample of caregivers of people with diabetes. The findings suggested that low health literacy in caregivers was associated with increased caregiver burden; however, further research is needed to determine potential associations between caregiver health literacy and caregiver health outcomes.

Overall, the results from the systematic review highlighted that understanding of caregiver health literacy was in its infancy, despite the important role that caregivers play in self-management support. It was evident that further research was necessary to identify elements that comprise health literacy of adult care recipients, and for this knowledge to be used to develop a comprehensive measurement tool to assess caregiver health literacy.

A **conceptual model of caregiver health literacy derived from stakeholder perspectives**

In Chapter 5, the study presented as Manuscript B sought to develop a conceptual model using grounded approaches that described the constituent elements of caregiver health literacy in the cancer population. As detailed in Chapter 5, the conceptual model that was guided by results from consultations with key stakeholders, identified 17 clear and distinct elements that represent
caregiver health literacy from the stakeholder perspective. These 17 elements were: 1) proactivity and determination to seek health information; 2) active engagement with healthcare providers; 3) information presented in quality formats; 4) understanding information about the cancer; 4) understanding information for day-to-day care provision; 5) understanding the healthcare system; 6) processing health information; 7) communication with care recipient; 8) understanding the care recipient; 9) self-care; 10) attitudes, approaches and emotional challenges; 11) role recognition and understanding caregiver rights; 12) supported by healthcare providers to understand information; 13) psychosocial support; 14) information presented in quality formats; 15) social support; 16) practical support; and 17) financial and legal support. The model proposes that cancer caregiver health literacy is comprised of both individual and interpersonal elements, and is influenced by healthcare system and community factors.

The study presented the first known conceptual model of caregiver health literacy that has been guided by in-depth consultations with relevant stakeholders. In line with recent conceptualisations of health literacy (Sorensen et al., 2012; Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012), the model highlighted the multidimensional nature of caregiver health literacy. The model also includes functional, interactive, and critical health literacy abilities, consistent with Nutbeam’s (2000) hierarchical model. Further, the results support Edwards et al. (2013) framework that proposes that individuals draw upon the health literacy of those in their social network to become health literate.

Factors specific to the caregiving context were identified in the conceptual model, such as the caregivers’ relationships with others. Concepts related to the relationship between the caregiver and care recipient were highlighted (caregiver communication with the care recipient [i.e. dyadic communication] and understanding of the care recipient). In addition, concepts
related to caregivers’ relationship with healthcare providers were identified as potentially influencing caregiver health literacy. The caregiver-healthcare provider relationship was considered to be influenced by both the caregivers’ personal attributes as well as healthcare provider factors. For example, the capacity of the caregiver to actively seek information from, and ask questions of, healthcare providers (active engagement with healthcare providers) was identified. Importantly, the capacity of healthcare providers to ensure adequate time to explain information, provide a supportive environment to discuss information, and facilitate caregiver understanding of information, were also identified as key factors that contribute towards caregiver health literacy (supported by healthcare providers to understand information).

A comprehensive new measure of caregiver health literacy: The Health Literacy of Caregivers Scale – Cancer (HLCS-C)

In Chapter 7, the development of a new measure of caregiver health literacy - the Health Literacy of Caregivers Scale–Cancer (HLCS-C) was detailed. The purpose of the HLCS-C is to comprehensively assess a broad range of individual, interpersonal as well as broader healthcare provider and healthcare system factors that influence a caregiver’s capacity to access, understand, and use health information to promote the health of the care recipient. Ten distinct domains that influence caregiver health literacy were identified for inclusion in the measure.

The measure was developed in accordance with best practice guidelines that recommend a conceptual basis to guide scale development (Streiner & Norman, 2008; FDA, 2009). To identify content domains within the scale, the conceptual model of caregiver health literacy detailed in Chapter 5, which was developed from consultations with key stakeholders, was used. Following structured criteria, 10 domains were selected for inclusion in the scale. These domains were: 1)
proactivity and determination to seek information; 2) adequate information about cancer and cancer management; 3) supported by healthcare providers to understand information; 4) social support; 5) communication with the care recipient; 6) understanding the care recipient; 7) self-care; 8) understanding the healthcare system; 9) processing health information; and 10) active engagement with healthcare providers.

Initially, 82 items across the 10 domains were developed, with 7 to 12 items for each domain (see Chapter 6). Participant statements generated during concept mapping workshops guided item writing to enhance content validity. Eight domains suited an ‘agree/disagree’ Likert scale, while the remaining two domains (Processing health information, and Active engagement with healthcare providers) suited a ‘cannot do/very easy’ Likert scale. Readability analysis of the items showed a Flesch-Kincaid reading level of grade 6.7, with a Flesch reading ease of 80.6 (out of a possible 100, with higher scores indicating greater ease). Content validity was assessed through review by experts and cognitive interviews with caregivers of people with cancer.

Review by seven experts of the 82 items revealed the majority of items were considered relevant and clear (Content Validity Index > 0.78). In response to expert reviews, five items were revised to improve clarity (see Chapter 6), 12 items underwent minor revisions in response to suggested improvements (see Table 6 in Manuscript B), one item was considered redundant and thus deleted, and two items were merged. In addition, nine new items were included in the questionnaire in response to comments from experts (see Table 7 in Manuscript B).

Following expert review, 89 items underwent testing through cognitive interviews with caregivers. Overall, participants (n = 16) interpreted and responded to the majority of the questionnaire items in ways intended. Three items (#18, #74 and #1; see Chapter 6) emerged as
having common issues; that is, two or more participants either misinterpreted the meaning of the item, or responded to the item in a way not intended by the researcher. To address the problematic items, two items were revised, and one item was deleted. The resultant draft HLCS-C comprised of 88-items across 10 domains. The next step was to assess the convergent and discriminant validity of the scale, and to identify poorly performing and redundant items for removal.

In Chapter 8, a combined classical and modern approach to psychometric assessment of the HLCS-C was described. These approaches ensured good construct and discriminant validity and high reliability of the HLCS-C. Confirmatory factor analysis was performed to determine construct and discriminant validity, the results of which informed the removal of poorly performing and redundant items and confirmed the hypothesised 10-factor structure of the HLCS-C. The item response theory approach to item analysis assisted with identifying items with disordered thresholds for exclusion from the scale. Item difficulty indices were also examined to ensure that each scale comprised items with a range of difficulty levels. The HLCS-C was assessed among caregivers (n = 297) recruited through cancer patients identified from one public health service in Melbourne, and cancer support groups across Victoria, Australia. Assessment of the hypothesised 10-factor measurement model demonstrated adequate statistical fit. All 10 domains demonstrated acceptable construct and discriminant validity. The results provided support for a scale comprised of 10 specific and distinct domains.

All scales in the HLC-C demonstrated acceptable internal consistency reliability (> 0.78). Notably, scales showed reliability indices above 0.90 (Proactivity and Determination to Seek Information, Capacity to process information, and Active Engagement with Healthcare Providers). The high reliability indices suggest that the three scales could be used for individual
assessment (Streiner & Norman, 2008). An example outlined in Chapter 7 included using the scale Active engagement with healthcare providers as an assessment of caregivers’ participation during clinical encounters. Lower scores on the aforementioned scale could indicate that alternative strategies are required to ensure caregivers have adequate understanding of information and that their health information needs are met.

The refined HLCS-C is comprised of 46 items across 10 domains. As discussed in Chapter 7, the domains assess individual, interpersonal, and contextual factors related to caregiver health literacy. For example, some domains assess caregiver knowledge and skills (e.g. Proactivity and determination to seek information), while other domains assess caregiver perspectives on the capacity of healthcare providers to provide a supportive environment for caregivers to effectively understand available health information (e.g., Supported by healthcare providers to understand information). Further, unlike existing generic health literacy measures, the HLCS-C includes two constructs specific to the caregiving role: Communication with the care recipient, and Understanding the care recipient.

The results suggest that effective responses to optimise caregiver health literacy would involve interventions and education programs targeted at improving individual skills and caregiver-care recipient relationships. These strategies would be combined with efforts from healthcare providers and the healthcare system to improve access and support to understand information and healthcare services.

Overall, the findings suggest that the HLCS-C has adequate content, construct and discriminant validity, is reliable, and addresses individual, interpersonal, and contextual factors that influence caregiver health literacy. Following further validation of the refined scale to ensure
that the psychometric properties of the measure are upheld in different settings and a different caregiver sample, the scale has the potential to provide new insights into these identified key elements that influence caregiver health literacy. Information provided by the scale may be useful for health educators, and researchers in the field of health literacy and psycho-oncology to guide, develop and evaluate interventions for caregivers, and identify areas for improvement in healthcare systems. Further, results from the tool have the potential to assist policymakers to develop tailored and effective policies that target areas that contribute to inequalities in caregiver health literacy.

**Implications of Thesis Findings**

Results from the thesis contribute to the understanding and conceptualisation of caregiver health literacy. The systematic findings from the thesis suggest that health literacy in caregivers of adult care recipients is under-explored. Further, for studies included in the review, different measures were used to assess caregiver health literacy, which may in part, have contributed to the differences in health literacy levels reported. These findings support previous investigations of health literacy in other populations that also reported variations in health literacy scores and measurement tools used (Berkman et al., 2011). Variation in outcome measures used made the comparison across studies difficult, and highlighted the need for reliable, adequate, and rigorous measures of caregiver health literacy. The measure of health literacy presented in the current thesis, the HLCS-C, has the potential to be used by psycho-oncology researchers and health educators to assess and compare caregiver health literacy levels across the cancer setting. For research related to caregiver health literacy in the cancer setting, the HLCS-C is preferable to existing health literacy measures given its specific purpose and substantiated psychometric properties.
Consultations with key stakeholders demonstrated that caregiver health literacy is influenced by multidimensional factors. The identified elements in the conceptual model highlighted that although the individual skills of the caregiver are important, these skills interacted with broader contextual factors to influence caregiver health literacy. For example, similar to existing conceptualisations of individual health literacy (Edwards et al., 2012; Nielsen-Bohlman et al., 2004; Sorensen et al., 2012), interactions with, and feeling supported by, healthcare providers were identified as important factors. However, in the current model, which is unique to caregivers, their relationship with the care recipient was also highlighted. These results suggest that interventions to improve caregiver health literacy target not only individual and interpersonal factors but also broader organisational factors to optimise care provision.

Further, the conceptual model in this research was developed using a systematic and rigorous approach to comprehensively identify and understand the elements that influence caregiver health literacy. The stakeholder perspective has been identified as essential to progress healthcare organisations that are supportive of health literacy (Brach et al., 2012). Thus, results from the stakeholder-driven conceptual model have the potential to inform development of health literacy initiatives, at organisational, community, and policy levels.

The HLCS-C provides an opportunity to gain insight into caregiver health literacy within the cancer setting at individual and population levels. The 10 constructs included in the tool provide insights related to individual, interpersonal, as well as systemic factors that influence caregiver health literacy. Thus, results from the HLCS-C can identify target areas for intervention across several key areas. At the clinical level, identifying caregivers with low health literacy assists clinicians to tailor communication and delivery of information to best suit the needs of the caregiver. Clinicians may also be alerted to the need for implementing necessary
supports or procedures to enhance caregiver knowledge and skills. From the research perspective, the information generated by the HLCS-C can be used to guide development of education programs or interventions tailored to caregivers, healthcare providers, and the wider community. It has been argued that individuals with inadequate levels of health literacy, compared to those with adequate health literacy, may require different approaches to meet their needs (Frosch & Elwyn, 2014). Thus, the HLCS-C can assist in the development of tailored approaches for individuals with various levels of health literacy. At the policy level, HLSC-C data have the potential to identify target areas for resource allocation and to guide promotion of a ‘health literate’ healthcare organisation.

With increased recognition that health literacy is an interaction between an individual’s skills, and the demands placed on individuals by healthcare providers and the healthcare system (Brach et al., 2012), there are calls for research that examines how healthcare systems can effectively address health literacy to create a ‘health literate’ organisation (Koh, Baur, Brach, Harris, & Rowden, 2013; Koh et al., 2012). Koh and colleagues identified several effective healthcare provider and organisational strategies for improving health literacy, which included: simplifying written information for clarity, improving healthcare provider communication skills, and improving individual self-management skills. Further, the Institute of Medicine (Brach et al., 2012) proposed 10 attributes that exemplify a health literate organisation. These attributes included embedding health literacy in its mission, and all areas of planning, implementation, evaluation, and quality of care activities (Koh et al., 2013). As part of the key attribute for effective communication, one actionable strategy included “Educating patients and their caregivers and confirming understanding throughout their hospital stays” (p.17). The use of the HLCS-C in routine practice to assess caregiver health literacy has the potential to: contribute to

Chapter 9. Discussion
creating health literate organisations, to assist healthcare providers identify caregiver skills and needs, and to inform planning regarding the level of intervention or strategies required to increase caregiver knowledge and skills.

**Strengths and Limitations of the Studies**

While there are a number of strengths of the studies conducted within the thesis, they are not without limitation, many of which have already been identified in the ‘Discussion’ section of each of the manuscripts. The following sections outline the key strengths and key limitations of the studies.

**Key strengths**

An important component of the research was the systematic review of peer-reviewed publications that assessed health literacy of caregivers of adult care recipients. To the author’s knowledge, this is the first known critique of such literature. A strength of the study was the use of a structured assessment criteria to assess the quality of included studies.

The development of the conceptual model of caregiver health literacy was guided by results of consultations with key stakeholders. A strength of the systematic and grounded concept mapping approach ensured that the conceptual model was grounded in the stakeholder perspective, with minimal influence of prior theory. Thus, the resultant model comprehensively captured the breadth and depth of elements important for caregivers when finding, understanding, and using health information to promote and maintain the health of the care recipient. Inclusion of a broad range of stakeholders also enhanced the potential usefulness of the conceptual model to inform healthcare and public policy initiatives.

A major strength in the process of developing the HLCS-C was the use of a conceptual model to guide identification of key content areas. The importance of a conceptual model in
questionnaire development has been articulated in best practice guidelines for questionnaire
development (Streiner & Norman, 2008; FDA, 2009). The conceptual model guided the
identification of key concepts for inclusion, and assisted with determining the scope of the scale
(what it is, and is not measuring; DeVellis, 2011). Although the use of conceptual models has
been recommended in scale development literature, this is not common practice. A review of
measures used to assess health literacy reported that few measures were derived from a
conceptual model (Jordan, Osborne, et al., 2010).

Further, statements generated by participants during the concept mapping workshops
guided item writing for the ten domains. This ensured that items were written using language that
was relevant, and easy to understand for prospective caregivers. Another strength was the use of
the revised Bloom’s taxonomy (Anderson & Krathwohl, 2001; Krathwohl, 2002) to guide
generation of items to ensure that items within each domain could distinguish between low,
moderate, and high levels of health literacy (i.e., scale sensitivity).

An additional strength in the development of the HLCS-C was combining both Classical
Test Theory (Crocker & Algina, 1986) and Item Response Theory (Hambleton et al., 1991)
approaches to select items for inclusion in the measure. The use of the classical test theory
approach enabled identification of items that were unidimensional and had low measurement
error. The use of item response theory processes in item analysis enabled identification of items
with disordered thresholds for exclusion. It has been argued that combining classical test theory
and item response theory, whilst seldom practiced in questionnaire development, enables a more
rigorous assessment of a scale, and can lead to a more psychometrically robust instrument (Ellis
& Mead, 2002). Another strength of the thesis was the sample size for the validation study that
was sufficient to provide robust results.

Chapter 9. Discussion
Key limitations

A limitation in the development of the conceptual model (Chapter 6) was that caregivers and people with cancer who participated in the concept mapping workshops were recruited from clinics from one metropolitan health service. Caregivers and cancer patients from rural and regional areas, whose experiences may have differed from individuals from metropolitan areas, were under-represented in the study. Thus, the concepts included in the model may not be representative of the caregiver population, particularly for those from rural and regional areas. Further, with the response rate of 20% and 24% for caregivers and people with cancer respectively, the educational, informational, and psychosocial differences between those who did, and not, participate are unclear.

A requirement criterion of caregivers and cancer patients who participated in consultations was they be fluent in English. Thus, it is not known whether the conceptual model is applicable to caregivers from culturally and linguistically diverse (CALD) backgrounds who have been identified as having lower health literacy than mainstream populations (Barton et al., 2014; Sentell & Braun, 2012). While the need to address health literacy in CALD populations has been acknowledged (McKee & Paasche-Orlow, 2012), time and resource constraints precluded inclusion of these populations in the current thesis. Another limitation was that people with cancer (those participating in the consultations, and the care recipients of participating caregivers) all received traditional cancer treatments. As such, the conceptual model may not identify needs unique to caregivers of care recipients managing their cancer exclusively with complementary and alternative therapies. The above limitations suggest the conceptual model may not be generalisable to the caregiver population. However, the purposeful design of including three stakeholder groups in the concept mapping workshops was to minimise the
impacts of these limitations and to ensure elements of health literacy was comprehensively captured in the model.

As outlined in Chapter 6, processes used to guide item writing for the HLCS-C were chosen to maximise the item difficulty in the scales. However, the scale Understanding the care recipient contained items with lower difficulty levels than anticipated. As such, the scale’s sensitivity to detect small changes across differing levels of health literacy capacity may be limited (Osborne et al., 2013).

For the validation study, a large proportion of participants had commenced caregiving at least two years prior to completing the questionnaire. Thus, their health literacy needs and skills may differ to caregivers with less caregiving experience. In addition, as identified in Chapter 7, the low response rate (12.4%), although typical in the recruitment of caregivers through the cancer patient, could mean that non-responders differed significantly from responders on key study variables. Such variables include demographic factors, relationship with the care recipient, psychosocial wellbeing, or physical functioning. As it was not possible to assess differences between respondents and non-respondents, there is the potential for sampling bias in the study.

**Future Directions**

**Suggestions for future validation and refinement of the HLCS-C**

Although the HLCS-C presents as a comprehensive new measure of caregiver health literacy with high content validity, acceptable construct and discriminant validity, and adequate internal consistency, further evaluation of its construct validity and utility in different settings, and in different caregiver samples is warranted. Further, evaluation of the HLCS-C’s test-retest reliability and sensitivity to change is required.
A number of items underwent revision or were included in the scale. As discussed in Chapter 7, 17 items underwent revision and nine new items were included in the scale following expert review, to improve clarity of items and to ensure domains were adequately represented by their items. Two additional items underwent revision following cognitive interviews with caregivers to improve item clarity. As presented in Chapter 8, following psychometric analyses, two items underwent revision to improve item difficulty, and one item was revised to minimize cross-loading on a factor other than its intended factor. These new and revised items should undergo cognitive interview assessment with caregivers to ensure that respondents interpret and respond to these items in the way the researcher intended.

A scoring system for the HLCS-C will need to be empirically developed. There is the potential to use an averaged domain score as a cut-off score. A score at or below the average domain score could suggest that an individual may require additional support in that area.

As there are currently no other measures that assess caregiver health literacy in the cancer setting, it is difficult to assess the convergent and discriminant validity of the HLSC-C. As discussed in Chapter 7, a first step would be to compare the HLCS-C with other indicators such as measures designed to assess caregiver communication with the care recipient (Siminoff, Zyzanski, Rose, & Zhang, 2008), and existing measures of health literacy (Davis et al., 1991; Osborne et al., 2013; Parker, Baker, Williams, & Nurs, 1995; Weiss et al., 2005). Comparing the HLCS-C with other developed measures of health literacy could assist in determining similar and different domains assessed in the current measure.

**Exploring the prevalence and impacts of caregiver health literacy**

An important area for future research is to clearly and accurately understand the prevalence of suboptimal caregiver health literacy using comprehensive, psychometrically
robust, and population-specific measures. In addition, future studies should examine how factors such as caregiver burden, depression and anxiety are associated with caregiver health literacy. These studies have the potential to provide a more comprehensive understanding of the impacts of caregiver health literacy on the health outcomes of the caregiver and to assist in the development of tailored interventions and initiatives to address inadequate caregiver health literacy. Longitudinal studies that examine associations between caregiver health literacy and patient health outcomes following existing and newly developed caregiver interventions will assist to identify effective strategies that target inadequate health literacy.

Within the cancer setting, further consultations with a broad range of caregivers are also recommended to ensure that the breadth of elements that influence caregiver health literacy are captured and adequately assessed in caregiver health literacy measures. Such caregivers include those who are: caring for people who exclusively use complementary and alternative medicine, from culturally and linguistically diverse backgrounds, from Indigenous populations, and from rural and regional areas.

Also recommended for future research is the exploration of the validity and utility of the HLSC-C to caregiver populations outside of the Australian setting. Prior to validation studies, it is essential to assess the content validity of items to ensure that item wording is relevant within the broader cultural context.

Future research should also develop the HLSC-C into a more generic measurement tool suitable for application within other chronic disease contexts. To achieve this, consultations with caregivers from different chronic disease populations are recommended to identify elements that influence their capacity to access, understand, and enact on health information and make health decisions. There is the possibility that some domains identified in the HLCS-C will be applicable...
across different caregiving contexts, while some domains will be context specific. If this is the case, then derivatives of the measure could be developed for specific chronic disease populations.

**Conclusion**

The current thesis is a unified body of work that has provided substantial and original contributions to the conceptualisation and measurement of health literacy of caregivers of people with cancer. The dearth of literature on caregiver health literacy and lack of a specific and validated measure to assess health literacy of caregivers of adult care recipients was identified through a systematic process. A conceptual model was developed through consultations with key stakeholders to identify the key elements important to caregivers when accessing, understanding, and applying information to make health decisions when providing care. The conceptual model provides new insights for the field of caregiver health literacy, including identification of: key elements for inclusion in a comprehensive measure of caregiver health literacy and potential areas that can be addressed at broader healthcare system and policy levels to improve caregiver health literacy at individual and population levels.

The development of the HLCS-C, which is comprised of 46 items across 10 domains, constitutes the first available and validated measure of caregiver health literacy. The scale was developed to measure concepts identified in the conceptual model of caregiver health literacy. The HLCS-C was designed to comprehensively assess health literacy of caregivers of people with cancer and extends beyond functional health literacy skills to assess broader elements such as interpersonal relationships and support from healthcare providers. Evidence from psychometric assessment indicated that the HLCS-C has adequate construct validity and high
reliability. Although these findings suggest that the HLCS-C is a promising new scale for assessing caregiver health literacy in the cancer context, further research is required to validate the HLCS-C across different populations and settings. Evaluation of the HLCS-C’s test-retest reliability, sensitivity to change, and development of a scoring system are also required. It is anticipated that further research that employs the refined HLCS-C will assist in understanding the magnitude and prevalence of health literacy in caregiver populations. Such research will assist in informing the development of education programs, interventions, healthcare initiatives, and public health policy to enhance caregiver knowledge and skills to provide optimal care, and potentially improve both care recipient, and caregiver health outcomes.
References


References


References


References


Frosch, D. L., & Elwyn, G. (2014). Don't blame patients, engage them: Transforming health systems to address health literacy. *Journal of Health Communication, 19*(Suppl.2), 10-14.


Gibson, J. T. (2013). *Correlation of health literacy to the stress level of informal caregivers for people with Type 2 diabetes.* (Doctor of Philosophy), Walden University, Minneapolis, MN. Available from EBSCOhost psyh database.


References

Given, B. A., Given, C. W., & Sherwood, P. R. (2012). Family and caregiver needs over the course of the cancer trajectory. *The Journal of Supportive Oncology, 10*(2), 57-64.


References


References


References


Likert, R. (1932). A technique for the measurement of attitudes. *Archives of psychology*.


References


References


References


References


References


References


References


References
Appendix A
Recruitment letters to people with cancer related to Study D

Appendix A1

Recruitment letter to people with cancer identified from cancer support groups

Dear Sir / Madam

Re: Study to understand the health information experiences of caregivers

We are writing to you as a partner, family member or friend of a person with cancer, to invite you to take part in a research study.

This study is for people who are providing help to someone diagnosed with cancer. Eastern Health and Deakin University are undertaking the study.

This study is part of a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. A/Professor Jacquie Chirgwin from Eastern Health is an associate investigator on this study.

The purpose of this study is to understand how well a new questionnaire measures the needs that caregivers might have when finding and using information about health and healthcare.

We understand that people receiving services within the healthcare system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) are important sources of physical, emotional, and informational support during this process.

We seek your participation in completing a questionnaire.

The questionnaire explores the challenges that caregivers may face when: accessing healthcare services, talking with doctors and healthcare providers and learning about the health condition, treatments, and supports for themselves and person they are caring for.

If you choose to participate, it will involve:
1. Completing the enclosed questionnaire via pen and paper.
2. Returning the questionnaire in the enclosed reply paid envelope
   OR
3. Completing the questionnaire online at

   www.deakin.edu.au/psychology/research/cancer_caregivers/

Appendix A1. Recruitment letter to people with cancer identified from cancer support groups
This questionnaire will take approximately 35 minutes to complete.

The information you provide will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

**Your participation would be highly valued in this research.**

Please find enclosed a Participant Information Form with more information about the study. Information can also be found via the web link listed above.

Please contact Eva Yuen via email at eva.yuen@deakin.edu.au if you have any questions. Alternatively, you are welcome to contact Tess Knight at tess.knight@deakin.edu.au.

Thank you very much for your interest in the study.

Yours sincerely

Signature Redacted by Library

Eva Yuen  
PhD Candidate  
School of Psychology  
Deakin University

A/Professor Tess Knight  
School of Psychology  
Deakin University

Appendix A1. Recruitment letter to people with cancer identified from cancer support groups
Appendix A2

Recruitment letter to people with cancer identified from a public health service

22nd May 2014

Dear Sir / Madam

I am writing to you with regard to a study undertaken by Eastern Health and Deakin University that is looking to better understand the information needs of family members and friends of people with cancer.

The study is for your family members and friends who might attend appointments with you, drive you to treatment sessions, help manage symptoms and side effects at home, and help out when you need it.

This is a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. Associate Investigators on the study include Associate Professor Jacquie Chirgwin and Dr Phillip Parente from Eastern Health.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

We understand that people receiving services within the health system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) can be important sources of physical, emotional, and informational support during this process.

We seek your family member or friend’s participation in completing a questionnaire.

Your family member or friend’s participation will involve completing the enclosed questionnaire. The questionnaire explores the challenges that caregivers may face when: accessing healthcare services, talking with doctors and healthcare providers, learning about
Cancer and available treatments, and finding supports for themselves and person they are caring for.

The information your family member or friend provides will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

Please find enclosed a questionnaire package to give to your family member or friend. The package includes an information letter, and information form that explains the study in more detail.

Please ask your family member or friend to read these carefully. If they wish to participate in the study, please ask them to complete the attached questionnaire and return it in the provided reply pre-paid envelope.

Your family member or friend also has the option to complete the questionnaire online at:

www.deakin.edu.au/psychology/research/cancer_caregivers/

All the information is included in the questionnaire pack for your family member or friend.

If you have any questions please contact the student researcher Eva Yuen on 03 9251 7221 or email at: eva.yuen@deakin.edu.au. Alternatively, please contact Associate Professor Tess Knight at 03 9251 7221 or via email at: Tess.knight@deakin.edu.au.

Thank you very much for your assistance with this study.

Yours sincerely

Dr Phillip Parente
Director of Medical Oncology
Department of Clinical Haematology & Medical Oncology

Appendix A2. Recruitment letters to people with cancer identified from a public health service
Appendix B

Recruitment letter to caregivers related to Study D

Appendix B1

Recruitment letter to caregivers of cancer support group members

TO A FAMILY MEMBER OR FRIEND OF SOMEONE WITH CANCER

Dear Sir / Madam

Re: Study to understand the health information experiences of caregivers

We are writing to you as a partner, family member or friend of a person with cancer, to invite you to take part in a research study.

This study is for people who are providing help to someone diagnosed with cancer. Eastern Health and Deakin University are undertaking the study.

This study is part of a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. A/Professor Jacquie Chirgwin from Eastern Health is an associate investigator on this study.

The purpose of this study is to understand how well a new questionnaire measures the needs that caregivers might have when finding and using information about health and healthcare.

We understand that people receiving services within the healthcare system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) are important sources of physical, emotional, and informational support during this process.

We seek your participation in completing a questionnaire.

The questionnaire explores the challenges that caregivers may face when: accessing healthcare services, talking with doctors and healthcare providers and learning about the health condition, treatments, and supports for themselves and person they are caring for.

If you choose to participate, it will involve:

1. Completing the enclosed questionnaire via pen and paper.
2. Returning the questionnaire in the enclosed reply paid envelope

Appendix B1. Recruitment letter to caregivers of cancer support group members
3. Completing the questionnaire online at

www.deakin.edu.au/psychology/research/cancer_caregivers/

This questionnaire will take approximately 35 minutes to complete.

The information you provide will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

**Your participation would be highly valued in this research.**

Please find enclosed a Participant Information Form with more information about the study. Information can also be found via the web link listed above.

Please contact Eva Yuen via email at eva.yuen@deakin.edu.au if you have any questions. Alternatively, you are welcome to contact Tess Knight at tess.knight@deakin.edu.au.

Thank you very much for your interest in the study.

Yours sincerely

Eva Yuen
PhD Candidate
School of Psychology
Deakin University

A/Professor Tess Knight
School of Psychology
Deakin University

Appendix B1. Recruitment letter to caregivers of cancer support group members
Appendix B2

Recruitment letter to caregivers of patients from a public health service

FOR A FAMILY MEMBER OR FRIEND OF SOMEONE WITH CANCER

Dear Sir / Madam

Re: Study to understand the health information experiences of family members and friends of people with cancer

I am writing to you as a partner, family member or friend of a patient from the Oncology Department at Eastern Health, to invite you to take part in a research study.

This study is for family members and friends who provide support to someone diagnosed with cancer. Support for the person with cancer can include attending appointments, driving them to treatment sessions, managing symptoms and side effects at home, managing medications, cooking and cleaning, and helping out when they need it.

This study is part of a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. Associate investigators on the study include Associate Professor Jacqueline Chirgwin and Dr Phillip Parente from Eastern Health.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

We understand that people receiving services within the healthcare system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) are important sources of physical, emotional, and informational support during this process.

We seek your participation in completing a questionnaire.

The questionnaire explores the challenges that caregivers may face when: accessing healthcare services, talking with doctors and healthcare providers, learning about cancer and available treatments, and finding supports for themselves and person they are caring for.

If you choose to participate, it will involve:

1. Completing the enclosed questionnaire via pen and paper.
2. Returning the questionnaire in the enclosed reply paid envelope, OR
3. Completing the questionnaire online at:

www.deakin.edu.au/psychology/research/cancer_caregivers/

The questionnaire will take approximately 35 minutes to complete.

The information you provide will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

**Your participation would be highly valued in this research.**

Please find enclosed a Participant Information Form with more information about the study. The information can also be found via the web link.

If you have any questions please contact the student researcher Eva Yuen on **03 9251 7221** or via email at eva.yuen@deakin.edu.au. Alternatively, please contact Associate Professor Tess Knight at 03 9251 7221 or via email: Tess.knight@deakin.edu.au.

Thank you very much for your interest in the study.

Yours sincerely

---

Signature Redacted by Library

Dr Phillip Parente  
Director of Medical Oncology  
Department of Clinical Haematology & Medical Oncology  
Eastern Health

---

Appendix B1. Recruitment letter to caregivers of patients from a public health service
Appendix C

Participant Information Forms for caregivers

Appendix C1

Participant Information Form - Cancer Support Groups

Version 1, dated 25th February 2014

Project Title: Understanding the role and impact of health literacy on caregiver health outcomes

Student Researcher: Ms Eva Yuen – PhD Candidate
School of Psychology
Deakin University
Email: eva.yuen@deakin.edu.au

Supervisory Committee: Associate Professor Tess Knight
School of Psychology
Deakin University
Email: tess.knight@deakin.edu.au

Associate Professor Lina Ricchiardelli
School of Psychology
Deakin University
Email: lina.ricchiardelli@deakin.edu.au

Dr Sue Burney
Cabrini Psycho-oncology Unit
Cabrini Health
Email: sue.burney@monash.edu

This Participant Information Form is 4 pages long. Please make sure you have read all of the pages.

1. Introduction

You are invited to participate in this research project as a person who is caring for someone with cancer. We are asking partners, family members and friends (also known as caregivers) of people who have been diagnosed with cancer to complete a new questionnaire about finding, understanding and using health information.
This Participant Information Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. You are welcome to ask the student researcher questions about anything that you do not understand about the project or want to know more about. The researcher’s details are on Page 4 of this Participant Information Form. Before deciding whether to take part, you might want to talk about it with a relative, or friend.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

2. What is the purpose of this research project?

The purpose of this study is to develop a new questionnaire that looks at issues that caregivers might have when finding and using information about health and healthcare.

The questionnaire explores the issues that caregivers’ may face when:

- Finding and using healthcare services
- Talking with doctors and learning about health conditions
- Understanding information about the disease and treatments for the person they are caring for
- Caring for someone with cancer

This information will help researchers make the questionnaire more useful for understanding how caregivers in the community find and understand information about health. This information will also assist us to develop better ways to help caregivers their caring role.

This project is part of Ms Yuen’s PhD project and is supervised by Associate Professor Knight, Associate Professor Ricciardelli, and Dr Burney.

3. What does participation in this research project involve?

To participate in this research project simply:

1. Complete the enclosed questionnaire
2. Post the questionnaire back to the research team using the reply paid envelope
   OR
3. Complete the questionnaire online at:
   www.deakin.edu.au/psychology/research/cancer_caregivers/

For most people the questionnaire will take 35 minutes to complete.
You will not be reimbursed for taking part in this project.

4. **What are the possible benefits?**

There are no direct benefits to you if you take part in this study. However, your participation will help us improve tools that we are developing to assess how people who care for someone with cancer understand and use health information.

5. **What are the possible risks?**

There are no major risks in completing the questionnaire. Some people might find some questions repetitive. There is a small chance that some participants may find it distressing participating in the interview. If you do find answering the questions distressing you may like to take a temporary break. If you feel you would like to speak with someone about your experience, we can refer you to services that are available or your treating health provider. Alternatively, you make like to contact the Cancer Helpline, 131 120, a telephone helpline staffed by cancer nurses who can assist you in finding the help you require.

6. **Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to.

7. **How will I be informed of the results of this research project?**

At the end of the project and when the new questionnaire is finalised and published, a summary of the project will be available at Deakin University. We expect that this will be made available by the end of 2014.

8. **What will happen to information about me?**

The anonymous information you provide in the questionnaire will be stored electronically. The electronic files will be password protected and only the research team will have access to this data. The questionnaire data will be retained for 7 years. At the end of this period, all electronic files with data connected with this project will be permanently deleted.

The results of the research might be published in journals or presented at conferences. You will not be identifiable in any publication or presentation.

9. **Can I access research information kept about me?**

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. We
will not ask you for any identifying information, thus, we will not be able to link you to any data you provide.

10. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committees of Eastern Health (Project ID: E41-1011) and Deakin University (Project ID: 2011-115).

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following contact persons:

For further information or appointments:

If you would like further information about this project, you are welcome to contact the student researcher (Eva Yuen) via email eva.yuen@deakin.edu.au.

Alternatively, you are welcome to contact Associate Professor Tess Knight via email: tess.knight@deakin.edu.au.

For additional support:

If you feel upset or distressed as a result of receiving this information, you are welcome to contact the student researcher Eva Yuen at eva.yuen@deakin.edu.au who can refer you to appropriate support networks.

Alternatively, you can contact the following helplines for telephone support:

Cancer helpline on 13 11 20, or

Lifeline on 13 11 14

For complaints:

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Appendix C1. Participant Information Form – Cancer Support Groups
If you would like to participate in this study, please complete the questionnaire and return it to the researchers using the reply paid envelope.

Thank you very much for your participation.
Appendix C2

Participant Information Form - Caregivers of people from the public health service

Version 3, Dated 10th March 2014

Project Title: Understanding the role and impact of health literacy on caregiver health outcomes

Student Researcher: Ms Eva Yuen – PhD Candidate
School of Psychology
Deakin University
Email: eva.yuen@deakin.edu.au

Eastern Health Investigators: Associate Professor Jacquie Chirgwin
Medical Oncologist
Box Hill and Maroondah Hospitals
Eastern Health

Dr Phillip Parente
Director of Oncology / Cancer Services
Eastern Health

Supervisory Committee: Associate Professor Tess Knight
School of Psychology
Deakin University
Email: tess.knight@deakin.edu.au

Associate Professor Lina Ricchiardelli
School of Psychology
Deakin University
Email: lina.ricchiardelli@deakin.edu.au

Dr Sue Burney
Cabrini Psycho-oncology Unit
Cabrini Health
Email: sue.burney@monash.edu

This Participant Information Form is 4 pages long. Please make sure you have read all of the pages.

Appendix D.
1. **Introduction**

You are invited to participate in this research project as a person who is caring for someone with cancer. We are asking partners, family members and friends (also known as caregivers) of people who attended Eastern Health for their treatment to complete a new questionnaire about finding, understanding and using health information.

This Participant Information Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. You are welcome to ask the student researcher questions about anything that you do not understand about the project or want to know more about. The researcher’s details are on Page 4 of this Participant Information Form. Before deciding whether to take part, you might want to talk about it with a relative, or friend.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

2. **What is the purpose of this research project?**

The purpose of this study is to develop a new questionnaire that looks at issues that caregivers might have when finding and using information about health and healthcare.

The questionnaire explores the issues that caregivers’ may face when:

- Finding and using healthcare services
- Talking with doctors and learning about health conditions
- Understanding information about the disease and treatments for the person they are caring for
- Caring for someone with cancer

This information will help researchers make the questionnaire more useful for understanding how caregivers in the community find and understand information about health. This information will also assist us to develop better ways to help caregivers their caring role.

This project is part of Ms Yuen’s PhD project and is supervised by Associate Professor Knight, Associate Professor Ricciardelli, and Dr Burney.

3. **What does participation in this research project involve?**

To participate in this research project simply:

4. Complete the enclosed questionnaire
5. Post the questionnaire back to the research team using the reply paid envelope

OR

Appendix D.
6. Complete the questionnaire online at:

http://www.deakin.edu.au/psychology/research/cancer_caregivers/

For most people the questionnaire will take 35 minutes to complete.

You will not be reimbursed for taking part in this project.

4. **What are the possible benefits?**

There are no direct benefits to you if you take part in this study. However, your participation will help us improve tools that we are developing to assess how people who care for someone with cancer understand and use health information.

5. **What are the possible risks?**

There are no major risks in completing the questionnaire. Some people might find some questions repetitive. There is a small chance that some participants may find it distressing participating in the interview. If you do find answering the questions distressing you may like to take a temporary break. If you feel you would like to speak with someone about your experience, we can refer you to services that are available or your treating health provider. Alternatively, you make like to contact the Cancer Helpline, 131 120, a telephone helpline staffed by cancer nurses who can assist you in finding the help you require.

6. **Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with Deakin University or Eastern Health.

7. **How will I be informed of the results of this research project?**

At the end of the project and when the new questionnaire is finalised and published, a summary of the project will be available at Deakin University. We expect that this will be made available by the end of 2014.

8. **What will happen to information about me?**

The anonymous information you provide in the questionnaire will be stored electronically. The electronic files will be password protected and only the research team will have access to this data. The questionnaire data will be retained for 7 years. At the end of this period, all electronic files with data connected with this project will be permanently deleted.
The results of the research might be published in journals or presented at conferences. You will not be identifiable in any publication or presentation.

9. **Can I access research information kept about me?**

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. We will not ask you for any identifying information, thus, we will not be able to link you to any data you provide.

10. **Is this research project approved?**

The ethical aspects of this research project have been approved by the Human Research Ethics Committees of Eastern Health (Project ID: E41-1011) and Deakin University (Project ID: 2011-115).

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. **Who can I contact?**

The person you may need to contact will depend on the nature of your query. Therefore, please note the following contact persons:

**For further information:**

If you would like further information about this project, you are welcome to contact the researchers:

**Ms Eva Yuen**  
PhD Candidate  
Telephone: 03 9251 7221  
Email: eva.yuen@deakin.edu.au.

**Associate Professor Tess Knight**  
School of Psychology  
Deakin University  
Telephone: 03 9244 6595  
Email: tess.knight@deakin.edu.au.
For additional support:

If you feel upset or distressed as a result of receiving this information, you are welcome to contact the student researcher Eva Yuen at eva.yuen@deakin.edu.au who can refer you to appropriate support networks.

Alternatively, you can contact the following helplines for telephone support:

Cancer helpline on 13 11 20, or

Lifeline on 13 11 14

For complaints:

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Ethics Chair
Eastern Health HREC
Telephone: 9895 3398
Email: ethics@easternhealth.org.au

The Manager
Office of Research Integrity
Deakin University
221 Burwood Highway
Burwood, Victoria 3125
Telephone: 9251 7129
Email: research-ethics@deakin.edu.au

If you would like to participate in this study, please complete the questionnaire and return it to the researchers using the reply paid envelope.

Thank you very much for your participation.
Appendix D

Health Literacy of Caregivers Scale – Cancer (HLCS-C) completed by caregivers for Study D
Appendix D.
Appendix D.
Appendix D.
Appendix D.
Appendix D.
Appendix D.
Appendix D.
Appendix E

Follow-up letters related to recruitment for Manuscript C

Appendix E1

Follow-up letter to cancer patients from the public health service

23rd June 2014

Dear Sir / Madam

This is a follow-up to a letter that I wrote to you four weeks ago about a study undertaken by Eastern Health and Deakin University.

We are seeking your partner, family member or friend’s participation in completing a questionnaire.

Apologies, please disregard this letter if you, or your family member or friend, have already completed and returned the questionnaire.

Please also disregard this letter if you feel that the study does not apply to you.

To recap, the study is for your family members and friends who might attend appointments with you, drive you to treatment sessions, help manage symptoms and side effects at home, and help out when you need it.

This PhD project is undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. A/Prof Jacquie Chirgwin and Dr Phillip Parente from Eastern Health are associate investigators on this study.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

We understand that people receiving services within the health system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) can be important sources of physical, emotional, and informational support during this process.

Your family member or friend’s participation will involve completing the attached questionnaire. The questionnaire explores the challenges caregivers’ face when: 1) accessing healthcare
services, 2) talking with doctors and 3) learning about the health condition and treatment options for the person they are caring for.

The information your family member or friend provides will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

Please find enclosed a follow-up letter to give to your family member or friend.

Please ask your family member or friend to read the letter carefully. If they wish to participate in the study, please ask them to complete the previously sent questionnaire and return it in the provided reply pre-paid envelope.

Your family member or friend also has the option to complete the questionnaire online at:

www.deakin.edu.au/psychology/research/cancer_caregivers/

This information is included in the enclosed letter for your family member or friend.

If you have any questions please contact the student researcher Eva Yuen on 03 9251 7221 or via email at eva.yuen@deakin.edu.au. Alternatively, you are welcome to contact Tess Knight on 03 9244 6595 or via email: Tess.knight@deakin.edu.au.

Thank you very much for your assistance with this study.

Yours sincerely

Dr Phillip Parente
Director of Medical Oncology
Eastern Health
Appendix E2

Follow-up recruitment letter to caregivers of patients from the public health service

Dear Sir / Madam

Re: Understanding the health information experiences of family members and friends of people with cancer

This is a follow-up to a letter that I wrote to you four weeks ago about a study undertaken by Eastern Health and Deakin University.

Apologies, please disregard this letter if you have already completed and returned the questionnaire.

I am writing to you as a partner, family member or friend of a patient from the Oncology Department at Eastern Health, to invite you to take part in a research study. This study is for people who are providing help to someone diagnosed with cancer.

This study is part of a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight. Associate Professor Jacquie Chirgwin and Dr Phillip Parente from Eastern Health are associate investigators on this study.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

We understand that people receiving services within the healthcare system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) are important sources of physical, emotional, and informational support during this process.

We seek your participation in completing the questionnaire that was sent to you four weeks ago.

The questionnaire explores the challenges that family members and friends may face when: accessing healthcare services, talking with doctors and healthcare providers and learning about the health condition, treatments, and supports for themselves and person they are caring for.

If you choose to participate, it will involve:

1. Completing the pen and paper questionnaire that was previously sent to you
2. Returning the questionnaire in the enclosed reply paid envelope
   OR
3. Completing the questionnaire online at

Appendix E2. Follow-up letter to caregivers of patients from the public health service
www.deakin.edu.au/psychology/research/cancer_caregivers/

This questionnaire will take approximately 35 minutes to complete.

The information you provide will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

**Your participation would be highly valued in this research.**

Please contact Eva Yuen on **03 9251 7221** or via email at eva.yuen@deakin.edu.au if you have any questions. Alternatively, you are welcome to contact Tess Knight on 03 9244 6595 at tess.knight@deakin.edu.au.

Thank you very much for your interest in the study.

Yours sincerely

Dr Phillip Parente  
Director of Medical Oncology  
Department of Clinical Haematology & Medical Oncology  
Eastern Health

**Signature Redacted by Library**

Appendix E2. Follow-up letter to caregivers of patients from the public health service
Appendix E3

Follow-up recruitment letter to cancer support group members identified through Leukaemia Foundation

Dear Sir / Madam

This is a follow-up to a letter that I wrote to you four weeks ago about a study undertaken by Deakin University.

We are seeking your family member or friend’s participation in completing a questionnaire about their health information needs.

Please disregard this letter if your family member or friend has already completed and returned the questionnaire.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

This PhD project is undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight.

We understand that people receiving services within the health system face a number of practical and personal challenges. We also understand that partners, family members, and friends can be important sources of physical, emotional, and informational support during this process.

Your family member or friend’s participation will involve completing the questionnaire that was previously mailed to you.

The information your family member or friend provides will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

Please find enclosed a follow-up letter to give to your family member or friend.

Please ask your family member or friend to read the letter carefully. If they wish to participate in the study, please ask them to complete the previously sent questionnaire and return it in the provided reply pre-paid envelope.

Your family member or friend also has the option to complete the questionnaire online at: www.deakin.edu.au/psychology/research/cancer_caregivers/

Appendix E3. Follow-up recruitment letter to cancer support group members identified through Leukaemia Foundation
If you have any questions please contact the student researcher Eva Yuen on 03 9251 7221 or via email at eva.yuen@deakin.edu.au. Alternatively, you are welcome to contact Tess Knight via email: Tess.knight@deakin.edu.au.

Thank you very much for your assistance with this study.

Yours sincerely

Eva Yuen
PhD Candidate
Deakin University
Appendix E4

Follow-up recruitment letter to caregivers of Leukaemia Foundation cancer support group members

TO A FAMILY MEMBER OR FRIEND OF SOMEONE WITH CANCER

Dear Sir / Madam

Re: Understanding the health information needs of family members and friends of people with cancer

This is a follow-up to a letter that I wrote to you four weeks ago about a study undertaken by Deakin University. Please disregard this letter if you have already completed and returned the questionnaire.

I am writing to you as a partner, family member or friend of someone with cancer, to invite you to take part in a research study. This study is for people who are providing help to someone diagnosed with cancer.

This study is part of a PhD project undertaken by Ms Eva Yuen from Deakin University and is supervised by Associate Professor Tess Knight.

The purpose of this study is to understand how well a new questionnaire measures the needs that family members and friends might have when finding and using information about health and healthcare.

We understand that people receiving services within the healthcare system face a number of practical and personal challenges. We also understand that partners, family members, and friends (also known as caregivers) are important sources of physical, emotional, and informational support during this process.

We seek your participation in completing the questionnaire that was sent to you four weeks ago.

If you choose to participate, it will involve:

1. Completing the pen and paper questionnaire that was previously sent to you
2. Returning the questionnaire in the enclosed reply paid envelope
   OR
3. Completing the questionnaire online at
   www.deakin.edu.au/psychology/research/cancer_caregivers/

This questionnaire will take approximately 35 minutes to complete.
The information you provide will help us to develop better ways to assist caregivers in the community when they need to find, understand, and use information about health and health services.

**Your participation would be highly valued in this research.**

If you have any questions, please contact Eva Yuen on 03 9251 7221 or via email at eva.yuen@deakin.edu.au. Alternatively, you are welcome to contact Tess Knight at tess.knight@deakin.edu.au.

Thank you very much for your interest in the study.

Yours sincerely

Signature Redacted by Library

Eva Yuen  
PhD Candidate  
Deakin University

Appendix E4. Follow-up recruitment letter to caregivers of Leukaemia Foundation cancer support group members
Appendix F

Tables of results from concept mapping workshops with key stakeholders

Appendix F1

Statements and clusters from workshop #2 with caregivers

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cluster 1: Information gathering and access to accurate information</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Understanding the situation and where to get accurate and up to date information</td>
</tr>
<tr>
<td>7</td>
<td>Caregiver needs to take initiative to search for information</td>
</tr>
<tr>
<td>15</td>
<td>Access to whole research papers (not just abstracts)</td>
</tr>
<tr>
<td>21</td>
<td>Someone you can call at any time of day to ask questions and get information (e.g. palliative care team)</td>
</tr>
<tr>
<td>22</td>
<td>Information specific to the specific disease</td>
</tr>
<tr>
<td>36</td>
<td>Accessing information about disease from non-Health Care Professional sources (e.g. internet)</td>
</tr>
<tr>
<td>37</td>
<td>Knowing right websites to access good and reliable information</td>
</tr>
<tr>
<td>41</td>
<td>Extra people (e.g. family members) to attend appointments to help understand and gather all the information</td>
</tr>
<tr>
<td>10*</td>
<td>Asking questions of the health care professional</td>
</tr>
<tr>
<td><strong>Cluster 2: Understanding and deciphering and clarifying information</strong></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Good listening skills to listen to patients and clinicians to make sure both patient and caregiver understand the information given</td>
</tr>
<tr>
<td>11</td>
<td>Need capacity (clear head) to take in the information and decipher what’s important and what the most relevant questions are</td>
</tr>
<tr>
<td>34</td>
<td>Getting “straight answers” from Health Care Professionals</td>
</tr>
<tr>
<td>40</td>
<td>Literature that supports information that has been given by your Health Care Professional</td>
</tr>
<tr>
<td><strong>Cluster 3: Integrated information on complementary and alternative therapies (with traditional)</strong></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Complementary therapies: Health Care Profession more open to homoeopathic and alternative remedies</td>
</tr>
<tr>
<td>18</td>
<td>Would like Health Care Professional to combine alternative and complementary medicines with traditional medicines</td>
</tr>
<tr>
<td><strong>Cluster 4: Effective processes and systems support</strong></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Attending appointments with patient</td>
</tr>
<tr>
<td>28</td>
<td>Acknowledging and nurturing the self-esteem of caregiver - important for both the caregiver and patient</td>
</tr>
<tr>
<td>29</td>
<td>Respect from Health Care Professional about caregiver’s knowledge of patients and patient’s knowledge of themselves</td>
</tr>
<tr>
<td>39</td>
<td>Objective, independent psychological support for both patients and caregivers to provide supportive care</td>
</tr>
<tr>
<td>49</td>
<td>Good guidance about progress of disease</td>
</tr>
<tr>
<td><strong>Cluster 5: Personal support for caregivers from people who understand</strong></td>
<td></td>
</tr>
</tbody>
</table>

Appendix F1. Statements and clusters from workshop #2 with caregivers
Talking to others (e.g. family, friends) who are in similar situation to get a bit of perspective

**Foundation support for both caregiver and patient**

Support groups for specific disease to be able talk to others in similar situations

Support groups particularly after surgery / treatment (or someone to talk to)

Support groups made and accessible times for people in workforce

Cluster 6: Practical and financial support

**Experts giving one on one personal attention even right until the end**

Better financial support for patients and caregivers especially from government

Homecare help for patients who live on their own

Homecare support for people at all ages (young and old) not just old

Cluster 7: Mutual respect and honest communication from Health Care Providers with caregivers and patients

Good honest communication with patient in order for patient to share with caregiver the information about the health condition

Sense of frustration and demeaning feeling (belittled / trivialized) when asking health care professionals questions

Counsellors available to caregivers specifically to provide information and support

Cluster 8: Caregiver life skills (e.g. time management, caregiver self-care)

How to deal with the situation (e.g. the illness)

Time to process, schedule and understand what to do in any given day

Making sure there is time for yourself (e.g. to think things through)

Balancing your time – so being available to the patient but also having “time out”

Making sure you have a close relationship with patient

Caregivers need to ensure own life is in order to be able to take on the additional roles (as a caregiver)

Sense of feeling alone if there is no one to relate to (similar situation)

Try to include patients in normal activities (living life like before cancer) (e.g. painting house and choosing colour)

Working out the fine line between caregiving and stepping back

Taking the role and sharing the journey and trauma together with the patient

Cluster 9: Balance, Relationship, intimacy (togetherness and closeness) along the journey

When the person is very sick rather than protecting “now you are living with cancer” and that you have to live differently (caregivers need to project a positive attitude)

Trust family to be honest about how they are feeling

Focus your energy on what you can do, not what you can’t do

Caring for your loved one can bring you closer together

Fear of the loved one dying

Cluster 10: Attitudes, intellectual and emotional challenges of the caregiver

Objectivity at a sensitive time

Acceptance is the hardest thing BUT life is uncertain and need to keep positive

Putting situation into perspective and thinking your loved one is ill – BUT we are trying to help them and doing everything we can

Don’t disallow the negative and acknowledge that the negative does exist

Appendix F1. Statements and clusters from workshop #2 with caregivers
Cluster 11: Uncertainty and making sense of the future

42 Questions and thoughts on the future (e.g. where to from here after treatment)
47 Respect of patients and accepting when it is the time to let go
48 Courage in final stages to let patients decide and take control of the situation for themselves
56 Sense of freedom and finding sense of self (after loss of loved one)

* Statement moved to cluster 3 to cluster 1 due to group consensus that this statement related more to statements in cluster 1
** Statement moved from Cluster 6 to Cluster 5 due to group consensus that this statement related more to statements in cluster 5
*** Statement moved from Cluster 5 to Cluster 6 due to group consensus that this statement related more to statements in cluster 6
**** Statement moved from Cluster 7 to Cluster 8 due to group consensus that this statement related more to statements in cluster 8
***** Statement moved from Cluster 9 to Cluster 8 due to group consensus that this statement related more to statements in cluster 8
Appendix F2

Statements and Clusters from Workshop #3 with people with cancer

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cluster 1: Doctor / Patient relationship in appointments</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Caregiver to attend appointments</td>
</tr>
<tr>
<td>15</td>
<td>Doctors need to provide more than the basic information</td>
</tr>
<tr>
<td>16</td>
<td>Allowed to repeat questions on different occasions</td>
</tr>
<tr>
<td>27</td>
<td>Feel as though the health provider is concentrating on your individual case</td>
</tr>
<tr>
<td>17*</td>
<td>Need to be able to ask any questions without being made to feel foolish (even basic questions)</td>
</tr>
<tr>
<td>Cluster 2: Gathering information and understanding /processing information/diagnosis</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Information on the disease, expectations with treatment and without, failure of therapy and alternatives</td>
</tr>
<tr>
<td>22</td>
<td>Dot form summary of the information covered during a consultation</td>
</tr>
<tr>
<td>23</td>
<td>Big picture information for the patient and caregiver</td>
</tr>
<tr>
<td>24</td>
<td>Time to process information</td>
</tr>
<tr>
<td>25</td>
<td>Time to rehash information with care providers</td>
</tr>
<tr>
<td>26**</td>
<td>When you attend appointments the health providers are up to speed with your case</td>
</tr>
<tr>
<td>28</td>
<td>Care giver needs the patient to be willing to talk to them and pass information on</td>
</tr>
<tr>
<td>29</td>
<td>Caregivers need someone to talk to about the situation (friends and others)</td>
</tr>
<tr>
<td>30</td>
<td>Being able to get together with people in the same situation</td>
</tr>
<tr>
<td>Cluster 3: Caregiver support</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Support groups for caregivers to share their experiences</td>
</tr>
<tr>
<td>28</td>
<td>Care giver needs the patient to be willing to talk to them and pass information on</td>
</tr>
<tr>
<td>29</td>
<td>Caregivers need someone to talk to about the situation (friends and others)</td>
</tr>
<tr>
<td>30</td>
<td>Being able to get together with people in the same situation</td>
</tr>
<tr>
<td>Cluster 4: Patient information and available services / where to seek help</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Written information about the services available</td>
</tr>
<tr>
<td>20</td>
<td>Support lines to get information about side-effects and drugs</td>
</tr>
<tr>
<td>12****</td>
<td>Practical advice to help during recovery</td>
</tr>
<tr>
<td>19*****</td>
<td>Contact people and numbers if you need help (A little directory to everything)</td>
</tr>
<tr>
<td>38+</td>
<td>List of information on drugs, side-effects and how to deal with side-effects</td>
</tr>
<tr>
<td>Cluster 5: Self – help / self-management</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Information about coping with the side-effects of treatment</td>
</tr>
<tr>
<td>10</td>
<td>Good guidance about what patients can and can’t do – physical capacity</td>
</tr>
<tr>
<td>11</td>
<td>Guidelines for resuming physical activity – recovery and post treatment (e.g. getting back to sport)</td>
</tr>
<tr>
<td>13++</td>
<td>Good guidance to nutrition and diet</td>
</tr>
<tr>
<td>14</td>
<td>Guidelines for effects and physical limitations for specific drugs</td>
</tr>
<tr>
<td>31</td>
<td>Understand what are the ‘must do’ recommendations – to get you motivated</td>
</tr>
<tr>
<td>33+++</td>
<td>Caregivers need to be able to contact medical staff to get information at all times</td>
</tr>
</tbody>
</table>

Appendix F2. Statements and clusters from workshop #3 with people with cancer
34 Caregivers need to understand what drugs the patients need to take and when

**Cluster 6: Hospital Access and parking**
2 Parking – more accessible-discounted
3 Council understanding of oncology needs for parking
4 Hospital access for patients
18 Carers need to be able to get a disability sticker

**Cluster 7: Support services / strategies: non-medical / government**
8 Access to practical support (e.g. day care)
9 Good guidance to services available (e.g. physio, counselling)
35 Information on what support is available from the government and how they can get it
36 Financial support from the government
37 Access to support from social workers

* Item 17 moved from cluster 2 to cluster 1
** Item 26 moved from cluster 1 to cluster 2
**** Item 40 moved from cluster 4 to cluster 2
***** Item 12 moved from cluster 8 to cluster 4
****** Item 19 moved from cluster 3 to cluster 4
+ Item 38 moved from cluster 5 to cluster 4
++ Item 13 moved from cluster 4 to cluster 5
+++ Item 33 moved from cluster 8 to cluster 5
Appendix F3

Concept map generated from workshop #3 with people with cancer*

* Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved.
## Appendix F4

### Statements and clusters from workshop #4 with people with cancer

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cluster 1: Specific and clear guides to illness, treatment and services available (cancer/chronic disease)</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Step by step guide to explain exact cancer, side effects that are applicable and treatments available</td>
</tr>
<tr>
<td>2</td>
<td>See and understand services appropriate to the illness</td>
</tr>
<tr>
<td>11</td>
<td>Usefulness, competency and acceptance of alternative medicines by medical professionals in competition with traditional medicine.</td>
</tr>
<tr>
<td>17</td>
<td>Carers would like health institutions to have a website that provides ‘ad hoc’ information for carers and patients about disease which is easy to navigate and which is appropriate</td>
</tr>
<tr>
<td>18</td>
<td>Understanding short term and long term effects of illness and potential outcomes</td>
</tr>
<tr>
<td><strong>Cluster 2: Information and support programs for family members to cope with diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Adjusting to the initial shock from being well to then being diagnosed</td>
</tr>
<tr>
<td>6</td>
<td>Information and support on how to communicate illness to children</td>
</tr>
<tr>
<td>23</td>
<td>Understanding the balance between philosophical, spiritual and practical with patient’s quality of life (e.g. pain management)</td>
</tr>
<tr>
<td>47</td>
<td>Information about genetic testing for family members</td>
</tr>
<tr>
<td>48</td>
<td>Support services to help family members cope about genetic testing information</td>
</tr>
<tr>
<td>28*</td>
<td>Understanding the ‘schedule of treatment and clinical events and appointments’ so they can support patient (e.g. with driving)</td>
</tr>
<tr>
<td><strong>Cluster 3: Information to meet the needs of all community members (e.g. all ages and all cultures)</strong></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>For younger children, (e.g. grandchildren) need access and understanding and support at their level, i.e., ‘intellectualize’ understanding of illness.</td>
</tr>
<tr>
<td>7</td>
<td>Age appropriate information and applicable, tailored and detailed to the individual</td>
</tr>
<tr>
<td>9</td>
<td>Information from most basic to the more detailed specific to individual and disease</td>
</tr>
<tr>
<td>19</td>
<td>Information that is available to understand the short and long term effects specific and pertinent to the illness</td>
</tr>
<tr>
<td>27</td>
<td>Carers and family get the right information for the right people appropriate and tailored to their cultural needs</td>
</tr>
<tr>
<td><strong>Cluster 4: Financial government support services</strong></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Government financial support for carers and families</td>
</tr>
<tr>
<td>35</td>
<td>Better support from the government for carers caring for patient with all types of illness (e.g. too young, not sick enough)</td>
</tr>
<tr>
<td>20**</td>
<td>For carers and family members in rural region with limited Internet access – relevant information printed about the disease</td>
</tr>
<tr>
<td><strong>Cluster 5: Caregiver practical services/support and community responsibilities</strong></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Lack of compassion from education facilities in caregiver life (e.g. universities) and lenience to extend deadlines</td>
</tr>
<tr>
<td>10</td>
<td>Coping and managing with transport when carer does not drive</td>
</tr>
</tbody>
</table>
Help with housework and practical tasks around the house for both the carer and patients and kids
Access to practical services at a reasonable cost (e.g. housekeeping)

Cluster 6: Sourcing relevant nutritional information – caregiver food support to help the patient

Carers need to know where to source relevant information (e.g. nutrition)
Understanding and information on food and nutrition for patients
Helping patient manage food when taste buds and appetite have changed
Information on appropriate foods to manage symptoms and pain

Cluster 7: N/A. All statements (n = 2) moved into different clusters

Cluster 8: Caregiver attitudes and skills to understand the (changes) patient

Carers should be supported to get appropriate information
Acceptance of changes in patient both physically and cognitively and seriously
Understanding the pain situation for the patient is different for different situations
Support for carers to cope with news of diagnosis
Open the door for opportunities for friends and carers to share their previous experience of cancer and provide specific advice
Imperative to understand medications and ’frequency’ of when to take medications
Carers need good listening skills to understand patients’ situations
Carers need to develop and manage skills to cope with patients’ illness
Provision of outstanding empathetic services to support both carers and patients
Having information to understand that ‘everyone is different and to understand what to expect’

Cluster 9: Carer empathy/insight – caring for the carers

Carers and friends need to understand the abilities doing treatment (e.g. no energy to go out; crankiness)
Carers and family being aware of vulnerabilities of patient
Carers need to know ‘when to let go’ and ‘when to push to motivate patient’
Carers need to take time out for themselves (e.g. taking holidays for themselves)
Carers need to take care of themselves as well as care for patient
Carers need to understand that some patients don’t need to know everything about the illness
Carers need to understand some patients’ need to ‘get on with life; and current affairs / normal life
Availability of counselor or support person to discuss issues with carers and family
Carer sensitivity to information needed of patient
Acceptance of patient as the ’new me’ and coming to terms with changes
Carer understanding and overseeing illness for patients who ‘don’t need to know details’

* Item 28 moved from cluster 7 to cluster 2
** Item 20 moved from cluster 5 to cluster 4
**** Item 45 moved from cluster 5 to cluster 6
**** Item 8 moved from cluster 6 to cluster 8
***** Item 21 moved from cluster 7 to cluster 8
+ Item 13 moved from cluster 8 to cluster 9
++ Item 42 moved from cluster 8 to cluster 9

Appendix F4. Statements and clusters from workshop #4 with people with cancer
Appendix F5

Concept map generated from workshop #4 with people with cancer

* Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved.
Appendix F6

Statements and clusters from workshop #5 with healthcare providers/policymakers

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cluster 1: Carer health and self-care (balancing the care)</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Time to perform the role of the carer while still considering their own health and the health of the person they are caring for</td>
</tr>
<tr>
<td>36</td>
<td>Carers have an understanding of the importance of looking after their own health to enable them to continue in their role</td>
</tr>
<tr>
<td>37</td>
<td>Attitude that their own needs are AS important as the person they are caring for</td>
</tr>
<tr>
<td>51</td>
<td>Able to be aware of their own needs</td>
</tr>
<tr>
<td><strong>Cluster 2: Communication capacity (emotional intelligence) – helped by higher level of education (17)</strong></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Have a level of formal education</td>
</tr>
<tr>
<td>48</td>
<td>Ability to communicate openly with the person with cancer</td>
</tr>
<tr>
<td>49</td>
<td>Openness to asking for help for themselves when needed</td>
</tr>
<tr>
<td>50</td>
<td>Ability to articulate what your own needs actually are</td>
</tr>
<tr>
<td>53</td>
<td>Capacity to cope with the unknowable (especially about the future)</td>
</tr>
<tr>
<td><strong>Cluster 3: Seeking and interpreting information</strong></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Knowing what and how to ask questions</td>
</tr>
<tr>
<td>6</td>
<td>Confidence to be able to ask questions of health professionals</td>
</tr>
<tr>
<td>7</td>
<td>Being able to remember all of the information you are given</td>
</tr>
<tr>
<td>31</td>
<td>Receive information in formats appropriate to their age group</td>
</tr>
<tr>
<td>32</td>
<td>Motivation to seek out information (active rather than passive)</td>
</tr>
<tr>
<td>33</td>
<td>Knowing where to look for trustworthy information</td>
</tr>
<tr>
<td>34</td>
<td>Ability to assess the reliability and validity of information</td>
</tr>
<tr>
<td>35</td>
<td>Able to contextualize information to their personal circumstances</td>
</tr>
<tr>
<td>42</td>
<td>Feel safe and comfortable to ask questions (including on sensitive issues)</td>
</tr>
<tr>
<td>52</td>
<td>Persistence to keep trying until they get the information they need</td>
</tr>
<tr>
<td><strong>Cluster 4: Access to practical social support</strong></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Practical help and support (like day care)</td>
</tr>
<tr>
<td>11</td>
<td>Diversity of support options for the wide range of people who are carers</td>
</tr>
<tr>
<td>27</td>
<td>Need the opportunity to talk to someone who has shared similar experiences</td>
</tr>
<tr>
<td>28</td>
<td>Have access to a mix of professional and peer supports according to their needs</td>
</tr>
<tr>
<td></td>
<td>Assisted to set up their life financially and otherwise, in a way that allows them to fulfil a carer role</td>
</tr>
<tr>
<td>45</td>
<td>Access to good financial and legal advice</td>
</tr>
<tr>
<td>47</td>
<td>Time off / respite</td>
</tr>
<tr>
<td><strong>Cluster 5: Opportunity</strong></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Having a ‘go to person’ to ask questions and explain information</td>
</tr>
<tr>
<td>41</td>
<td>Have the opportunity to ask questions privately with clinicians</td>
</tr>
<tr>
<td><strong>Cluster 6: Diversity of info needs – form and presentation</strong></td>
<td></td>
</tr>
</tbody>
</table>
People need information in a language they can understand (other languages or plain English)

Guidance about what their information needs are or are likely to be

Receive information in a variety of formats

Help to know what they don’t know

Cluster 7: Understanding and navigating the system

Knowing who is responsible for the management of the patient at any point in time

Understanding roles and hierarchies among hospital or health services staff

Carer and patient assisted to deal with the impacts on their life

Help to navigate the hospital and system more widely

Cluster 8: Identity and valuing of the carer role

Understanding that the term ‘carer’ may refer to THEM

Recognition of the importance of what they do (as carers)

Carers understand what their rights are

Wanting to be a carer

Cluster 9: Diversity of info needs –content

Information needs to be repeated to carer and patient so that they hear it when they are ready to process it

Recognition that information needs will change during the course of the illness

Recognition that information needs will be different for different types of cancer and cancer situation

Carers and health professionals are aware of

Cluster 10: Community/societal recognition and understanding

Societal recognition that carers are a diverse group (ages, life stages, situations)

Recognition that there is a wide range of levels of acceptance of the carer role

Recognition that the caring role may not be the number one issue in the carers life

Recognition is given to the financial ramifications of caring

Cluster 11: Patient and family centred practice of health services (formal and informal recognition)

Health care providers understand that people have a wide range of beliefs about health

Carers role is given recognition and acknowledgement by health care professionals (time/information/respect)

Health providers understand what the rights of carers are

Need a mechanism for clarifying and formalizing carers roles and rights

Health professionals avoid making and are aware of the complexity of carer situations and relationships

Clear authority for the carer to be provided with information

Need to be part of the decision-making process (especially if the decision effects them)

* Item 53 moved from cluster 1 to cluster 2

** Item 3 moved from cluster 4 to cluster 6

*** Item 4 moved from cluster 5 to cluster 7

**** Item 23 moved from cluster 7 to cluster 9

***** Item 22 moved from cluster 10 to cluster 11
Appendix F7

Concept map generated from workshop #5 with healthcare providers/policymakers*

*Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved.

Appendix F7. Concept map generated from workshop #5 with healthcare providers/policymakers
Appendix F8

Statements and clusters from workshop #6 with healthcare providers/policymakers

<table>
<thead>
<tr>
<th>Cluster and item #</th>
<th>Statements generated by workshop participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clusters 1 and 2 (merged): Caregiver capability and core skills and caregiver understanding of the impact of illness on the patient</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Cognitive processes: knowledge and understanding of how to access information databases</td>
</tr>
<tr>
<td>4</td>
<td>Understanding of English and if not, access to professional interpreters. Require clearly and accurately understand the physical and emotional effects of cancer as a disease on the patient (e.g. fatigue, nausea, vomiting and fear of the unknown)</td>
</tr>
<tr>
<td>18</td>
<td>CGs need to understand how to be a good help and support</td>
</tr>
<tr>
<td>2*</td>
<td>Willingness of the caregivers to accept information and support provided by health professionals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cluster 3: Understanding and navigating the health care system (8, 9, 10, 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
</tr>
<tr>
<td>9</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td>15</td>
</tr>
<tr>
<td>22</td>
</tr>
<tr>
<td>23</td>
</tr>
<tr>
<td>24</td>
</tr>
<tr>
<td>28**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cluster 4: Direct support for caregivers / caring for the caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
</tr>
<tr>
<td>16</td>
</tr>
<tr>
<td>17</td>
</tr>
<tr>
<td>30</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cluster 5: Health professional education, skills and support</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>11</td>
</tr>
<tr>
<td>13</td>
</tr>
</tbody>
</table>

Appendix F8. Statements and clusters from workshop #6 with healthcare providers/policymakers
<table>
<thead>
<tr>
<th>Item</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Healthcare providers need an understanding of culturally appropriate and sensitive information</td>
</tr>
<tr>
<td>20</td>
<td>Healthcare providers need to understand strategies to help CGs to stop and take care of themselves</td>
</tr>
<tr>
<td>21</td>
<td>Healthcare providers need to address the concerns of patients who think that CGs are doing too much for them (e.g. patient being a burden)</td>
</tr>
<tr>
<td>29</td>
<td>Healthcare providers also need good support networks (e.g. space and time to debrief)</td>
</tr>
<tr>
<td>25</td>
<td>Getting palliative care at the right time</td>
</tr>
<tr>
<td>26</td>
<td>Introducing and understanding palliative care early on in the care, e.g. at diagnosis</td>
</tr>
</tbody>
</table>

* Item 2 moved from cluster 4 to cluster 1
** Item 28 moved from cluster 4 to cluster 3
Appendix F9
Concept map generated from workshop #6 with healthcare providers/policymakers*

*Items that were moved to different clusters are circled with dotted lines and arrows indicating where the items were moved.
Appendix F9. Concept map generated from workshop #6 with healthcare providers/policymakers
Chapter 1. Introduction