

*Support Services for adolescents and  
young adults with cancer or a blood  
disorder:*

**Measurement Properties and  
Validation of Quality of Life  
Instruments for Adolescents and  
Young Adults with Cancer or a  
Blood Disorder**

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A thesis submitted in fulfilment of the  
requirements for the Degree of  
Master of Science in  
Mathematical Sciences (Thesis)

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July 2006

### ***Certificate of Authorship/Originality***

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Candidate

Jane Elizabeth Ewing

## ***Dedication***

I dedicate this thesis to my family, David my husband and our beloved children Elizabeth, William and Victoria for their support, love and encouragement. Also, in memory of my Mother, Heather for her patient and self-less love as always and in helping me nurse Elizabeth in her final stage of life; in memory of my Father, Lance who has keenly watched my progress in this neglected field of healthcare; in memory of my cousins Donald, Tracey and Judith whose lives were also cut short by cancer.

In particular I dedicate this thesis to the memory of my elder daughter, Elizabeth, a vivacious, gifted, generous, loving, courageous, community spirited individual with a passion for encouraging cultural harmony. She achieved much and inspired many in her 19 years. Her cancer gave her family an unwanted personal introduction to the huge gap in the health system for adolescents and young adults and the impact that cancer has on them, their siblings, parents, families and friends.

This horrendous tragedy is the driving force behind my work to help reduce the burden of illness for adolescents and young adults living with cancer, and their families. Elizabeth laid the initial challenge before me to help make the system fairer for these young people. I work and live in the hope that her untimely death will not be in vain.

Finally, I dedicate this thesis to my beloved New Zealand, Aotearoa.

## *Acknowledgments*

I wish to thank my initial Supervisor, Peter Petocz for encouraging me to embark on this Masters thesis. Thank you to Narelle Smith who took on the role of Supervisor some time into the thesis, for her interest and support from the beginning, and being a great source of guidance in the analysis stage, and in helping me through the UTS Ethics process in the early stages of the research.

I am indebted to Madeleine King for agreeing to become my Co-supervisor. I am grateful for her understanding and appreciation of my vision, seeing the potential in my ideas, and helping me refashion and strengthen my long-term plan in this area of youth health. My learning curve has been very steep in many areas, such as, critical and precise thinking, building conceptual models, working with clinicians, developing project budgets, writing funding applications, politics, and maintaining focus.

The field-testing of this study was done with the co-operation of the Centre for Children's Cancer and Blood disorders (CCCBD) at Sydney Children's Hospital (SCH), Randwick. I am grateful to Belinda Goodenough, Hospital Scientist for her on-going support and encouragement in helping me through the many hoops in gaining access to the required patients, smoothing the research process at the coal face, and assisting and refining funding applications, presentations and items for publication. Belinda's ability to make things happen in the hospital environment complemented Madeleine and Narelle's expertise. I am grateful to Glen Marshall, Director of the CCCBD, for permitting me to work closely with the staff at his Centre, particularly clinicians: Richard Cohn, Marcus Vowels, and Sue Russell for allowing access to their patients.

I am grateful to Michael Friedlander, Rob Lindeman and Neville Hacker for their interest and support at the Prince of Wales Hospital (POWH), SEALS (POWH) and the Royal Hospital for Women (RHW) respectively, in giving access to their units and potential participants. I wish to also thank clinicians: Scott Dunkley, Craig Lewis, and David Goldstein from POWH, and Donald Marsden and Grant Robertson from RHW for permitting access to their patients.

I wish to thank Les White, CEO of Sydney Children's Hospital, for his encouragement and advice in pursuing my vision.

Also I wish to thank Anne Senner (CCCB) and Sally Francis (SCH/POWH); the data managers Pam Edhouse, Cecilia Oswald and Brigitte Richmond of CCCB; Therese Malone (RHW), and Sue Vachalec (POWH); and the hospital staff for their support in the clinics and wards, particularly Phil Grant (NUM), Helen Knox (NUM), Judy Warren (NUM), Anne Rich (Secretary) and Tali Foreman (Social Worker).

Special thanks to my husband, David and our younger children William and Victoria for helping, supporting, advising and encouraging me.

Special thanks go to my sister-like cousins Shona Kramer and Lynne Hume, and special friends Sue Wood, and Barbara and Lynton Bates. I also wish to thank my many friends and colleagues from Westlake Girls' High School, in particular, Jackie Prestige, Helen and John Rimmer, Jo McKenzie, Elizabeth Redwood, Judy Woods.

Very special thanks to Elizabeth's wonderful group of friends.

I acknowledge the support, and kindness shown by many staff at various NZ hospitals for their kindness and support in particular, Cindy, Lucy, Andrew, Jenny, Marjorie and John; and the encouragement shown by members of NZAAHD, Youthline, and CanTeen.

I acknowledge the support received in formatting and proofing this thesis from Jo Watson, Josh Tow, Joel Tow and Paul Drury.

Finally, I specially want to thank the adolescent and young adult aged Australian patients, and their nominated proxy's who participated in this research, and the young New Zealanders living with cancer, and their siblings and parents who helped put in the foundation from which this research developed. Without their support in the first instance this work would not have developed.

Thank you,

Jane Ewing.

December 2005.

## ***List of Abbreviations***

<b>AHS</b>	Area Health Service
<b>AIHW</b>	Australian Institute for Health and Welfare
<b>AYA</b>	Adolescents and young adults
<b>ALL</b>	Acute lymphatic leukaemia
<b>CAAH</b>	Centre for Advancement of Adolescent Health
<b>CCCB</b>	Centre for Children's Cancer & Blood Disorders at SCH
<b>CHERP</b>	Centre for Health Research & Psycho-oncology
<b>CNC</b>	Clinical Nurse Consultant
<b>CRASH</b>	Centre for Research into Adolescents' Health
<b>DHB</b>	District Health Board
<b>DHN</b>	District Health Nurse
<b>EEMF</b>	Elizabeth Ewing Memorial Framework
<b>EEMCVAFH</b>	Elizabeth Ewing Memorial Conceptual View of AYA Family Health
<b>EFA</b>	Exploratory Factor Analysis
<b>GMCT</b>	The Greater Metropolitan Clinical Taskforce
<b>GMTT</b>	The Greater Metropolitan Transition Taskforce
<b>GP</b>	General Practitioner
<b>HRQOL</b>	Health-Related Quality of Life
<b>IAAH</b>	International Association for Adolescent Health
<b>IPOS</b>	International Psycho-Oncology Society
<b>MSAS</b>	The Memorial Symptom Assessment Scale
<b>NAAH</b>	NSW Association for Adolescent Health
<b>NGO</b>	Non-Government Organisation
<b>NHMRC</b>	National Health & Medical Research Council
<b>NZAAHD</b>	New Zealand Association for Adolescent Health & Development
<b>OT</b>	Occupational Therapist
<b>PMCC</b>	Peter Macallum Centre for Cancer
<b>POWH</b>	The Prince of Wales Hospital, Randwick, NSW, Australia
<b>QOL</b>	Quality of Life, in general
<b>RCT</b>	Randomised Clinical Trials
<b>RHW</b>	Royal Hospital for Women, Randwick, NSW Australia

**SCH** Sydney Children's Hospital, Randwick, NSW, Australia

**SCNS** Supportive Care Needs Survey

**SEALS** South Eastern Area Laboratory Services

**SESAHS** South Eastern Sydney Area Health Service, NSW, Australia

**TCYPCCI** Transition Care for Young People with Chronic Childhood Illnesses

**UNCROC** United Nations Convention on the Rights of the Child

**UTS** University of Technology, Sydney

**WHO** World Health Organisation

**WINZ** Work and Income New Zealand

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## ***Abstract***

Health-Related Quality of Life (HRQOL) is an important outcomes measure in cancer and there are specific issues depending on the site, stage, treatment and patient age. Although numerous instruments are available for cancer HRQOL, most are designed for adults, some for children, but none for adolescents and young adults (AYA) who have special age-specific concerns and poor improvement in survival compared with other age groups.

An existing HRQOL instrument was modified to ensure its suitability for AYA, its validity, reliability and sensitivity were tested in Australians aged 16 to 25 years old diagnosed with cancer or a blood disorder. Varni's PedsQL<sup>TM</sup> Measurement Model (13-18 year olds) was selected, modified then administered to families recruited from haematology/oncology clinics and wards at three Sydney Metropolitan Hospitals in person or by telephone. The Memorial Symptom Assessment Scale was used to categorise participants into groups reflecting sensitivity of symptom severity (slight, moderate and severe).

The instruments demonstrated excellent internal consistency reliability, making them suitable for both group and individual comparisons. Clinical validity, construct validity, and discriminant validity were demonstrated by "known-groups" analysis, exploratory factor analysis and correlations, respectively.

These new versions of the PedsQL Generic Core and Cancer Module are reliable, valid and sensitive measures of HRQOL in patients aged 16-25 years diagnosed with cancer or a blood disorder. The measures will soon be available for use as outcome measures in clinical trials and clinical practice with this age cohort in Australasia and internationally.