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

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BArts(Hons) in Psychology

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

The University of Newcastle
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A more amazing husband there never was.
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<td>ALL</td>
<td>Acute Lymphoblastic Leukaemia</td>
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<tr>
<td>AQoL</td>
<td>Adolescent Quality of Life Instrument</td>
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<td>AYA</td>
<td>Adolescent and Young Adult</td>
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<tr>
<td>CaSUN</td>
<td>Cancer Survivors’ Unmet Needs measure</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<tr>
<td>CML</td>
<td>Chronic Myeloid Leukaemia</td>
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<tr>
<td>CNQ</td>
<td>Cancer Needs Questionnaire</td>
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<td>CNQ-YP</td>
<td>Cancer Needs Questionnaire – Young People</td>
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<tr>
<td>CNS</td>
<td>Central Nervous System</td>
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<td>CPNQ</td>
<td>Cancer Patient Need Questionnaire</td>
</tr>
<tr>
<td>CPNS</td>
<td>Cancer Patient Need Survey</td>
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<tr>
<td>CSF</td>
<td>Cerebrospinal Fluid</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>HPV</td>
<td>Human Papillomavirus</td>
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<td>HRQOL</td>
<td>Health Related Quality of Life</td>
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<tr>
<td>ICC</td>
<td>Intraclass Correlation Coefficient</td>
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<tr>
<td>MMQL</td>
<td>Minneapolis-Manchester Quality of Life Instrument</td>
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<tr>
<td>NCI</td>
<td>National Cancer Institute</td>
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<tr>
<td>NCRI</td>
<td>National Cancer Research Institute</td>
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<td>NEQ</td>
<td>Needs Evaluation Questionnaire</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
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<td>NMSC</td>
<td>Non-Melanoma Skin Cancer</td>
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<td>NSW</td>
<td>New South Wales</td>
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<td>PCA</td>
<td>Principal Components Analysis</td>
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<td>PCQL</td>
<td>Pediatric Cancer Quality of Life Inventory</td>
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<td>PedsQL</td>
<td>Pediatric Quality of Life Inventory</td>
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<td>PFA</td>
<td>Principal Factor Analysis</td>
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<td>PIE</td>
<td>Perceived Illness Experience Scale</td>
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<td>PNAT</td>
<td>Patient Needs Assessment Tool</td>
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<td>PNI</td>
<td>Psychosocial Needs Inventory</td>
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<tr>
<td>POQOLS</td>
<td>Pediatric Oncology Quality of Life Scale</td>
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<tr>
<td>QLD</td>
<td>Queensland</td>
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QOL–CS  Quality of Life - Cancer Survivors
RCT    Randomised Controlled Trials
SA     South Australia
SCNS   Supportive Care Needs Survey
SEER   Surveillance, Epidemiology and End Results
SES    Standardised Effect Size
TCU    Teenage Cancer Unit
TYA    Teenage and Young Adult
UK     United Kingdom
US     United States
VIC    Victoria
WA     Western Australia
WHO    World Health Organization
Synopsis

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