

# MEASURING THE UNMET NEEDS OF THOSE WITH CANCER: A CRITICAL OVERVIEW

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## Abstract

Unmet needs scales are a way of eliciting cancer patients' perceptions of their need for help in order to achieve optimal psychosocial wellbeing. This represents a bottom-up approach to the assessment of psychosocial wellbeing. It may be used in conjunction with traditional top-down, expert driven methods of conceptualising psychosocial status. While there has been an expansion in the development of unmet needs scales for cancer patients, survivors and significant others, there remains a need to ensure that these measures are psychometrically robust. Predictive validity, in particular, has been largely unexamined. More work is needed to establish the clinical utility of unmet need scales and how to define what represents meaningful changes on these measures.

Over the past two decades there has been increasing interest in finding mechanisms to improve cancer patients' and survivors psychosocial wellbeing.<sup>1</sup> Such efforts require robust and effective measures in order to establish prevalence of psychosocial concerns and to evaluate the effectiveness of interventions. This has resulted in increased attention to the development and testing of measures designed to elicit psychosocial wellbeing.<sup>2</sup> Several different ways of conceptualising the impact of cancer on psychosocial wellbeing have been proposed. These approaches may be broadly classified as top-down or bottom-up methods. It is useful to consider unmet needs measures within this context.

## Top-down method of estimating patients' needs

Some attempts to estimate patients' needs have stemmed from an expert driven approach, whereby health professionals take responsibility for determining patient needs.<sup>3,4</sup> This 'top down' approach assumes that health care providers are in the position of expert and therefore are capable of making accurate judgments about the psychosocial wellbeing of a patient. This approach requires the health professional to determine whether or not the individual is depressed, anxious or has other psychosocial concerns requiring intervention. Research in a number of fields including medical oncology, suggests that the ability of health care providers to make judgments which agree with standardised measures of depression and anxiety is questionable.<sup>5</sup>

A variation of the top-down approach is reflected by the use of psychological scales which attempt to mimic clinical judgments. Responses to such scales are used to define cancer patients and survivors as being cases (eg. clinically depressed or anxious), non-cases or borderline.<sup>6,7</sup> The accuracy of this judgment is tested by making comparisons against a psychiatrist's judgement when they are using a standardised interview. Accuracy of the scale is defined by the specificity and sensitivity of the cut point used in the scale in relation to the expert judgement.<sup>8</sup> Commonly used

examples include the Hospital Anxiety and Depression Scale,<sup>6</sup> Depression Anxiety and Stress Scale,<sup>9,10</sup> Brief Symptom Inventory,<sup>11,12</sup> and Beck Depression Inventory.<sup>13</sup> An advantage of the top-down approach is that the use of a gold standard criterion provides a common language.<sup>14</sup> This allows for a person to be defined as depressed or anxious in a standardised way across settings. However, such external definitions do not take into account patient views about their wellbeing or their willingness to accept interventions.

## Bottom-up – an alternative approach

This framework acknowledges the need to involve patients in decision making about their own healthcare and wellbeing.<sup>15</sup> The cancer survivor is accorded 'expert' status alongside the healthcare professional. This approach owes much to the growth in the consumer movement and the acknowledgment that patients have the right to be involved in their care and decision making.<sup>16</sup> An essential element of this approach is not only that the patient indicates that they have a problem, but also their choice about whether they wish to seek assistance for that problem. These two complementary components of the patient perspective: i) expert status and ii) determining whether help is required, differentiate the bottom-up approach from the more usual top-down framework.

While value placed on the patient view in the bottom-up approach is in line with principles of patient-centred care, the approach does have disadvantages. For example, a diagnosis of depression may reduce one's ability to self-identify as depressed and seek help. Additionally, some patients may be unaware of the availability of effective interventions.

## A hybrid approach

There is a potential role for both approaches when attempting to improve cancer patients' psychosocial wellbeing. The need for monitoring and, when necessary, intervening in an effort to assist patients with depression or anxiety is seen as an integral part of cancer care.<sup>17</sup>

A two step process involving a screening tool as an initial mechanism to detect those at risk, followed by a clinical assessment, is often advocated.<sup>18</sup>

However, the need to elicit cancer patients' perceptions regarding what problems they want addressed is increasingly accepted. This acknowledges the respondent's right to make decisions about what is appropriate for them, irrespective of the views of healthcare providers. It also acknowledges that in many domains the patient is arguably the best judge of their need for help. Patient's views about their unmet needs have therefore become increasingly important.

### Some examples of existing unmet need questionnaires

Unmet need scales can be broadly classified in terms of stages of the cancer 'journey'. Some scales estimate treatment related unmet needs, some focus on issues for cancer survivors and others focus on unmet needs relating to advanced or terminal stage issues. Given the differing demands of these phases of the disease trajectory, it is unlikely that measures designed for patients in one of the groups will accurately reflect concerns relevant to the other group. The following is a brief and non-exhaustive overview of some of the more commonly used scales designed to identify patient concerns over a range of domains of need.

#### **Cancer patients undergoing treatment**

Among the scales developed to assess cancer patients' needs during the treatment phase is the Supportive Care Needs Survey.<sup>19</sup> This is a 52 item scale which uses a five point response scale. The questionnaire covers unmet needs relating to health information, psychological wellbeing, sexuality, patient care and support, and physical and daily living needs. Test-retest reliability, face and construct validity have been established.<sup>19</sup> The Patient Information Needs Questionnaire is a self administered, 17 item questionnaire which allows the patient to indicate the need for information about the disease and treatment, as well as issues surrounding access to help and solving practical problems.<sup>20</sup> The Creating Better Health Outcomes by Improving Communication about Patients Experiences questionnaire was designed as an assessment tool for cancer specific symptoms and associated functional problems.<sup>15,21</sup> It can be administered via touch pad computer tablet and has questions and answers tailored to individual responses to problem areas from a potential list of 16 categories. It asks patients to indicate their agreement or views regarding the severity of their symptoms and needs and rate the importance of their problems.

#### **Cancer survivors**

There are two general types of response scales used in the measurement of cancer survivors' needs: i) defining the extent of the perceived problem and ii) exploring patients' desire for help.

The Cancer Rehabilitation Evaluation System is a generic measure of health-related quality of life items which is argued to be specific to cancer.<sup>22</sup> The 139 items can

be completed via computer. The global score is said to indicate overall quality of life and five summary tables reflect important domains - physical, psychosocial, medical interaction, marital and sexual. The scale is presented as being suitable for outpatients with a variety of different cancer types.<sup>22</sup> The Quality of Life Cancer Survivors was developed to measure the specific concerns of long-term cancer survivors.<sup>23</sup> This instrument consists of 41 items representing four domains of quality of life, including physical, psychological, social and spiritual wellbeing, as well as unique areas of concerns for cancer survivors. This scale demonstrated high reliability, reproducibility and validity. The Quality of Life in Adult Cancer Survivors asks cancer survivors to rate their satisfaction on a seven category frequency scale (ranging from never to always).<sup>24</sup> It consists of 47 items tapping into 12 domains, seven generic and five cancer specific. This multidimensional scale enables comparisons to be made between cancer and non-cancer populations. Its domain and summary scores showed good test-retest reliability, internal consistency and convergent validity with other measures designed to assess generic HRQoL measure.<sup>25</sup>

The Survivor Unmet Needs Survey asks survivors to rate 83 items on a scale from zero (having no unmet need) to four (having a very high unmet need).<sup>26</sup> The scale assesses unmet needs in relation to five factors - emotional and mental health, medical care, relationship, jobs and finance, and concerns about the future. It was specifically constructed to be psychometrically rigorous while assessing a range of unmet needs of cancer survivors.<sup>26</sup> The Cancer Survivors' Unmet Needs Measure was designed to assess and identify needs in the general population of cancer survivors.<sup>27</sup> It includes 35 need items covering existential survivorship, comprehensive care, information, quality of life and relationships, and six positive change items. The scale demonstrated good acceptability, internal consistency and validity, although test retest reliability was low.

The findings of studies using these scales suggest survivors do have a range of unmet needs well beyond the treatment phase. For example, it was found that in breast cancer survivors, the highest unmet need was associated with existential survivorship, which addresses concerns with making decisions in the context of uncertainty and existing issues.<sup>28</sup> In long-term survivors, the most frequently reported problems were sexual problems, family related concerns and relationship problems.<sup>24</sup> Concerns about cancer recurrences were high in this population, highlighting the unique needs of cancer survivors.<sup>24,28</sup>

#### **Advanced stage or terminally ill cancer patients**

Limited work has been undertaken to develop unmet need questionnaires for patients with advanced cancer and those who are terminally ill. Among these is the scale developed by Rainbird and colleagues.<sup>29,30</sup> The Needs Assessment for Advanced Cancer Patients was developed, based on a review of available literature and professional opinion. Principal components analysis revealed seven domains assessing patients'

psychological/emotional, medical information/communication, social, symptom, daily living, spiritual and financial needs. The test-retest reliability estimates were within accepted levels, as were all but one of the internal consistency scores.<sup>28</sup> The scale was highly acceptable for this patient group.

## **Cancer survivors' significant others**

There is growing recognition of the impact of cancer on those close to a patient. Significant others may be partners, relatives or friends. Only recently has there been an attempt to identify the unmet needs of this group. The Support Persons' Unmet Needs Survey is a 76 item self report scale to measure the unmet needs of the primary support person of a cancer survivor.<sup>31</sup> As with the Survivor Unmet Needs Survey, iterative consultations occurred with consumers, clinical providers, allied health workers and psychosocial professionals, which led to the initial development of a draft questionnaire for support persons. Six factors were established via principal components analysis: informational needs; personal and family concerns; emotional and mental health issues; medical care needs; concerns about the future; and work issues. The Cancer Survivors' Partners Unmet Needs measure is a 35 item scale with items relating to five factors: relationships, information, partner issues, comprehensive care and emotional support.<sup>32</sup> The scale has high internal consistency, good convergent validity, but moderate test-retest reliability.

## **How well are unmet needs measured?**

There has been a notable expansion in the use of unmet need questionnaires. While there are patient benefits associated with this movement, caution about widespread adoption of the approach and its associated measurement scales must be considered. An overriding concern is whether the existing scales are psychometrically robust, accurate and sensitive measures of unmet needs. A review of needs scales for cancer survivors indicated that few met basic psychometric criteria.<sup>2</sup> Among the problems associated with the scales was the tendency to focus on the internal consistency of the scale as the principal indicator of its reliability.<sup>33</sup> Test-retest reliability of a measure's total score, sub-scale scores, or items, for example, are not often examined.<sup>2</sup> Item test-retest reliability may be particularly informative.<sup>34</sup> It is possible that similar scores at time one and two can be obtained for the sub-scales and overall scores, however the patients have endorsed different items. Item reliability is therefore important but infrequently examined.

It is common for scales to have demonstrable face, content and construct validity.<sup>32</sup> Higher levels of unmet needs are cross-sectionally associated with higher psychological distress, greater complementary and alternative medicine use and poorer quality of life.<sup>24,28,35</sup> While some more recent scales that are applicable to cancer survivors (eg, Survivor Unmet Needs Survey) have been subjected to more rigorous psychometric testing, yet to be considered and tested is whether high unmet need scores predict future outcomes. For example, do high scores on unmet

need measures predict that patients will have depression, consult more frequently with alternative or traditional medicine or visit emergency departments? We know of no studies which have undertaken this difficult task of predicting what a high or low score on unmet need questionnaires might mean for other important outcomes.

## **Issues for the future**

A driving impetus behind the assessment of unmet need is the goal of intervening and reducing needs. There have been several randomised control trials which have attempted to address unmet needs of cancer patients. One found a limited effect for a face-to-face session and follow-up phone call from a breast care nurse in reducing the unmet needs of women with advanced breast cancer.<sup>36</sup> Needs were reduced only on the psychological subscale of the Supportive Care Needs Survey and only for those participants who reported high levels of need at baseline.<sup>37</sup> A recent randomised trial undertaken by White and colleagues (presented at the 8th Biennial Cancer Control Conference, but not yet published) examined the use of well-trained volunteers who attempted to address unmet needs identified by bowel cancer survivors who were within three months of diagnosis, in order to reduce depression, anxiety and unmet needs.<sup>38</sup> The study was one of the largest of its type involving over 300 participants in each group. No intervention effect was demonstrated on the Supportive Care Needs Survey. This finding echoes other research by Boyes et al and a large randomised control trial undertaken by McLachlan and colleagues.<sup>18,39</sup> However, the latter studies were conducted with cancer patients currently undergoing treatment.

In these studies it is unclear whether failure to produce a treatment effect is the result of ineffective treatment strategies, lack of specificity in the unmet needs measure, or unmet needs being a reflection of the endemic uncertainty associated with a diagnosis of cancer. The likelihood that unmet needs naturally decrease during the survivorship phase suggests that at this stage, it is impossible to determine which of these alternatives is accurate. However, the field should continue to attempt to refine the psychometric qualities of unmet needs questionnaires and then use these modified questionnaires to test the effectiveness of intervention strategies with methodologically stringent research designs.

Statistically significant change in an outcome is often the yardstick by which the success of an intervention is measured. However, this criterion fails to take into account whether the intervention has a meaningful impact on patients' wellbeing.<sup>40</sup> Methods for establishing the clinical significance of changes in unmet needs scores have not been well developed. For quality of life measures, methods for assessing clinical significance have included assessment of survivors' views about what constitutes a meaningful change or anchor-based methods.<sup>41</sup> Establishing how clinical significance can be defined for unmet needs could be an important focus of future work.

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