The Unmet Psychosocial Needs of Haematological Cancer Patients and their Relationship with Psychological Wellbeing

Brooke Swash, Nick Hulbert-Williams & Ros Bramwell

Chester Research Unit for the Psychology of Health (CRUPH), University of Chester, UK

Background

Unmet psychosocial needs are a desire for help or support that can relate to a range of patient concerns such as the psychological impact of cancer, body image, spiritual needs, social, support, practical or a need for information and are known to be prevalent within cancer populations (Harrison et al, 2009; Arnes et al., 2009; Morrison et al., 2012). Haematological cancers are notable for their differences in presentation, for the often intensive treatments that can have significant impacts on role functioning and psychological wellbeing, and for the differing settings in which they are often treated. Distress levels in haematological cancer have been found to be as high as 48% (Carlson et al., 2004), yet there is little research fully exploring the specific unmet needs of this patient group, or how patients adjust to their diagnosis over time. This PhD aimed to answer the following key questions relating to unmet need in this patient group:

• What is currently known about the unmet psychosocial needs of haematological cancer patients and where do the gaps in our knowledge lie?
• What do these patients perceive to be their key areas of need and why were those specific needs important during the patient experience of cancer?
• How prevalent are unmet psychosocial needs and distress in newly diagnosed patients and are these two concepts related?
• What are the long-term psychosocial needs of haematological cancer survivors and whether psychological flexibility mediates the relationship between need and psychological outcome?

Systematic Review

Background: Identification of the type and prevalence of the psychosocial needs most relevant to haematological cancer patients is necessary to effectively target and implement clinical services to provide appropriate supportive care.

Aim: To identify and synthesise existing literature relating to the assessment and prevalence of unmet psychosocial needs in haematological cancer patients.

Method: A systematic search of online databases and primary psychosocial oncology journals was conducted to identify all relevant published literature. Papers were selected according to pre-defined inclusion criteria and inclusion was verified by an independent reviewer. Of 14,547 titles identified, 18 were included in the final review.

Results: The key areas of need identified were: (i) psychological need, notably fear of recurrence; (ii) informational needs; and (iii) needs relating to both family and healthcare professionals. Fear of recurrence was the most commonly identified psychosocial need within this literature. The lack of research relating to this patient group was highlighted and provided a rationale for further work.

The Patient Experience

Background: The systematic review highlighted the lack of research relating to unmet needs in haematological cancer; this pilot study was designed to provide a novel insight into the impact of unmet needs in this patient group and to inform later quantitative investigation.

Aim: This study aimed to gain a deeper understanding not just of type of need or how prevalent they are, but of lived experiences of being a haematological cancer patient.

Method: Three small focus groups were conducted with haematological cancer survivors (n=6) recruited from the clinical setting. Data was analysed using an Interpretative Phenomenological Analysis approach.

Results: Key areas of unmet need for this patient group include: availability of psychological support; fear of recurrence; having a positive relationship with the healthcare team; support for family; and, a need for more information. Psychological needs were especially frequently endorsed and reported as being unmet.

This work highlights that the unmet needs that are most relevant to haematological cancer patients are similar to those of other cancer groups. Psychological needs were perceived to be less important than physical needs, as such participants were reluctant to raise their concerns.

Despite the similarities in needs to other patient groups, participants repeatedly expressed the belief that a diagnosis of haematological cancer differed from other cancer diagnoses in terms of support services available, and how well the general population, including family and friends, understands their illness. This was felt to impact upon the acceptability and accessibility of existing support services that are aimed at providing supportive care to cancer patients.

Unmet Needs and Psychological Wellbeing

Background: Little is currently known about how the presence of unmet psychosocial needs may relate to psychological outcomes, such as distress and quality of life. Furthermore, factors that may explain or moderate this relationship have not been examined.

Aim: To identify the unmet needs of haematological cancer patients at both diagnosis and survivorship, and to explore the relationship between unmet need and psychological wellbeing.

Method: Two quantitative studies that assessed both unmet needs and psychological wellbeing using self-report questionnaires were designed. One recruited newly diagnosed patients from the clinical setting, and the other recruited long-term survivors of haematological cancers via internet and newsletter advertisement.

Results: Findings from both studies highlight the prevalence of unmet needs and psychological comorbidity in haematological cancer patients. Clinically significant levels of anxiety and depression were found in a sub-set of all disease groups included within the study.

Unmet needs were most commonly reported in the psychological domain. Significant correlations were found between levels of unmet needs and all three aspects of psychological wellbeing (anxiety, depression and quality of life).

Analysis of data from long-term survivors demonstrated that psychological flexibility moderates the relationship between unmet need and aspects of psychological wellbeing.

Further research is needed to explore this relationship in wider cancer groups and to research the effectiveness of interventions (e.g. Acceptance and Commitment Therapy) that target flexibility as a way of reducing distress in cancer survivors.

Conclusions

Each of the four studies in this PhD thesis highlight that patients with a haematological malignancy have ongoing psychosocial care needs; this includes patients at the time of diagnosis through into the survivorship phase of illness. Furthermore, these findings demonstrate that unmet psychosocial needs directly relate to patient reported psychological wellbeing. Unmet needs assessment, therefore, is important for two distinct reasons. First, as a means to provide information regarding a patient’s psychological adjustment to diagnosis, and second, as a way to personally tailor further support to meet individual patient needs.

The unmet needs of haematological cancer patients were not differ substantially from the needs of other cancer groups, yet the way in which haematological cancer patients perceive themselves as as being different from other types of cancer patients has implications for how support services are targeted in order to optimise acceptability and accessibility to this patient group.

Both in the UK, and indeed in many other countries, psychological support for cancer patients often diminishes at the end of treatment: these findings suggest that needs are also prevalent in long-term survivors, and that further support is needed in order to meet the needs of those living beyond their initial cancer diagnosis.

For further information, please contact:
b.swash@chester.ac.uk