



Patients' and clinicians' experiences of holistic needs assessment using a cancer distress thermometer and problem list: A qualitative study



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ABSTRACT

Purpose: Psychosocial needs assessment is recommended for patients undergoing cancer treatment, but trials of effectiveness of assessment tools provide mixed results. This qualitative study aimed to understand how such tools are experienced by patients and clinicians in order to optimise use in the future.

Methods: Qualitative interviews were used in a mixed-methods sequential design following a randomised controlled trial of needs assessment using the Distress Thermometer and Problem List (DT&PL), and explored patients' and clinicians' evaluations of the needs assessment process.

Results: Benefits of needs assessment using the DT&PL included the potential to detect hidden distress, allow opportunity for distress to be discussed, and to deliver outcomes to address problems. However, effectiveness and patient willingness to report all forms of distress could be hindered by: clinicians feeling ill-equipped to deal with 'non-physical' distress and patients questioning their appropriateness to do so; time constraints; insufficient support services and referral guidelines; inappropriate timing; and lack of follow-up.

Conclusions: The benefits of a holistic needs assessment cannot be realised without matching time and frequency of administration to the dynamic nature of distress during cancer, and making changes to the context of delivery – for instance, providing protected time, increasing referral options and clinician training. Significant investment is needed to optimise potential benefits for patients.

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1. Background

Cancer patients have a high prevalence of distress (20–40%) (National Comprehensive Cancer Network, 2012). This may encompass physical, practical, family, emotional or spiritual problems, and range from moderate feelings to psychiatric morbidity. Most patients report at least one physical or emotional problem (Hollingworth et al., 2013). However, concerns are often not spontaneously expressed by patients or identified by healthcare staff (Bultz and Carlson, 2006), even when severe. Untreated distress may lead to poor treatment adherence, frequent healthcare visits and impaired quality of life (Carlson and Bultz, 2004). Thus, improving the management of distress has been identified as a research priority (Rankin et al., 2011).

In the UK, clinical guidelines recommend cancer patients undergo 'systematic psychological assessment' (National Institute for Clinical Excellence, 2004), but are not explicit about how this should be performed. While many needs assessment and screening tools have been developed (Richardson et al., 2005), there have been few randomised controlled trials (RCTs) evaluating these and results are mixed; not all report improvements in patient outcomes (Carlson et al., 2012). Such findings underline a need to explore issues concerning method of delivery, how the tools function in practice, and to gather patients' and clinicians' experiences of use to guide implementation.

Existing research is limited but indicates that most patients appreciate the opportunity to discuss difficulties and well-being (Kirchheiner et al., 2013), though they may not always identify 'non-physical' issues as within the remit of healthcare professionals (Murray et al., 2004). Training is also pinpointed as important where non-specialist professionals are involved in distress screening and needs assessment (Carlson et al., 2012; Dolbeault

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et al., 2011). Further understanding of such issues is essential to ensure interventions aiming to reduce distress benefit patients.

We used qualitative methods in a sequential mixed methods design (Creswell et al., 2011), following a RCT (ClinicalTrials.gov Identifier: NCT00960466) (Hollingworth et al., 2013) of needs assessment using the widely used Distress Thermometer and Problem List¹ (DT&PL) (National Comprehensive Cancer Network, 2012) to investigate patients' and clinicians' experiences and evaluations of the tool and the process of administration. The DT&PL is a tool that identifies needs and clinically significant levels of distress among people with cancer (Gessler et al., 2008). The trial found no evidence that use of the DT&PL improved patient outcomes or reduced healthcare costs compared to usual care (Hollingworth et al., 2013). The primary trial outcome was psychological distress (Profile of Mood States [POMS], short form) (Baker et al., 2002) up to 12 months. The key secondary outcome was quality of life (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30) (Aaronson et al., 1993).

2. Methods

We recruited patients undergoing outpatient chemotherapy or radiotherapy at two sites in the southwest of England between October 2009 and February 2011 (Hollingworth et al., 2013). In face-to-face meetings with a radiotherapist/chemotherapy nurse at approximately the second week of radiotherapy or second cycle of chemotherapy, all patients randomised to receive the DT&PL used the tool to rate their distress in the past week on a 0 to 10 visual analogue scale. Patients then completed a problem list exploring physical, practical, family, emotional and spiritual concerns (Brennan et al., 2012). An action plan was derived, including immediate staff actions (e.g. providing information), patient actions (e.g. using self-help resources), and referral (e.g. for psychological counselling). At the discretion of the patient, a second DT&PL meeting could be arranged toward the end of therapy. Staff delivering the intervention attended a training session and were provided with a resource directory containing information for each problem, on possible self-management techniques and support groups. They introduced the DT&PL to patients as a holistic tool to explore aspects of distress and administered it in a standardised way, working through the problem list item by item. Time taken ranged from less than 15 min to over an hour.

After the trial, semi-structured interviews were conducted with a sample of patients who had completed the DT&PL during their treatment, and with administering clinical staff at the two centres. Interviews with patients were conducted approximately 13 months after initial administration of the DT&PL and approximately one month after they completed the trial. Methods were approved by the Bath NHS Research Ethics Committee (REC number: 08/H0101/224) and informed consent was obtained from participants.

2.1. Sampling

All patients in the DT&PL needs assessment arm were eligible for interview. Initially, maximum variation sampling was used to recruit men and women from both centres with a range of distress scores. Latterly, patients who had scored highly on the distress thermometer were purposively sampled since this is likely to map onto the primary trial outcome (Profile of Moods State, POMS) (Baker et al., 2002) and it was thought they may have greater recall of the intervention. Sampling continued until diversity had been achieved with respect to age (range 35–77 years), cancer site and

treatment, and distress score (see Table 1), and consistent data emerged. Interviews were conducted with all available clinicians (7 of 10) who had delivered the DT&PL sessions (range from 1 to 30 sessions) during the trial. Clinicians were radiographers and chemotherapy nurses (Table 2). All radiographers were health professionals rather than technicians.

2.2. Data collection

The research was conducted within the interpretive tradition (Schwandt, 2000). Interviews were open-ended, allowing informants to offer full accounts of their experiences with minimal prompting. Fluid topic guides were used to ensure that similar areas were covered and that the research question was addressed. These were generated from pilot data and refined throughout to incorporate emerging themes in an iterative manner. Interviews ranged from 30 min to over 2 h, most lasting an hour. Patients were interviewed by SP or LB at the patient's preferred setting; home, university, or hospital. Although they had all received the DT&PL, five had no recall so were shown a copy of the tool and hypothetical evaluation was sought. This involved asking such participants to draw upon their recent experiences, needs and treatment as a cancer patient and with this in mind to reflect upon the tool's relevance, inclusiveness, acceptability and possible barriers to completion. Thus while hypothetical, answers were grounded in relevant experience. Four had limited recollection so provided a mix of actual and hypothetical evaluation, as above. Recall may have been impaired by the time delay between DT&PL administration and interview (above). Clinicians were interviewed by SH or LB at the service setting. They were encouraged to describe specific examples of DT&PL consultations.

2.3. Analysis

Interviews were audio-recorded with informants' consent and fully transcribed. Thematic analysis (Green and Thorogood, 2003) was conducted by LB for both sets of interviews, transcripts being examined in detail and coded for emerging themes. This approach ensured that categories emerged from the data while preserving detail and individual accounts. Some patient and clinician interviews were double-coded by LB and a second researcher and compared to check for reliability and completeness. The coding frame was revised until a version had been generated which could be applied consistently to all the data. Data relating to specific codes were then pooled from across respondents to explore any patterns in the occurrence of themes (Glaser and Strauss, 1967). All data were useable and considered in the analysis, however hypothetical data were separated from those grounded in actual recall and primacy was given to the latter; hypothetical data being used to support or contrast with emerging ideas rather than to generate analytical categories. The number with actual recall varied between 6 and 10 participants for each theme. Views of patients and clinicians on similar topics were compared. Analysis and data collection were conducted simultaneously, allowing emerging issues to be explored further with later participants.

3. Results

Fifteen patients (P) and seven clinicians (C) (Tables 1 and 2) were interviewed. While some patients had reported little or no distress, most described a range of concerns. Physical problems were prominent. Participants' views of needs assessment using the DT&PL tool are summarised under four themes: benefits of needs assessment using the DT&PL, barriers to effectiveness, areas for improvement, and overall effectiveness. There were no discernible

¹ Distress Thermometer and Problem List: DT&PL.

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