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Experiences of the Distress Thermometer and Problem List

**Patients' and clinicians' experiences of holistic needs assessment using a cancer Distress Thermometer and Problem List: a qualitative study**

## **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.

**(195 words)**

**Keywords: cancer treatment; oncology; distress thermometer and problem list; distress screening and management; patient experiences; qualitative.**

**Conflicts of interest:** none.

### **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 (Authors 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, 2011).

In the UK, clinical guidelines recommend cancer patients undergo ‘systematic psychological assessment’ (National Institute for Clinical Excellence, 2014, 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 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) (Authors et al, 2013) of needs assessment using the widely used Distress Thermometer and Problem List<sup>1</sup> (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 (Authors 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 N et al, 1993).

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<sup>1</sup> Distress Thermometer and Problem List: DT&PL

### **Methods**

We recruited patients undergoing outpatient chemotherapy or radiotherapy at two sites in the southwest of England between October 2009 and February 2011 (Authors 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 minutes 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.

### ***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.

### *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 minutes to over 2 hours, 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.

### *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.

### **Results**

Fifteen patients (P) and seven clinicians (C) (Tables 1 & 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

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under four themes: benefits of needs assessment using the DT&PL, barriers to effectiveness, areas for improvement, and overall effectiveness. There were no discernible differences in the experiences of clinicians according to whether they were radiographers or nurses. This paper focuses on ‘barriers to effectiveness’ and ‘areas for improvement’ since these are the most instructive, identifying opportunities to develop and advance needs assessment using the DT&PL or similar tools. We give a brief summary of the other themes and offer full details as online supplementary materials.

### **Benefits of needs assessment using the DT&PL (Supplementary material)**

Clinicians described the DT&PL as a ‘powerful’ (C1) tool, that could engender a ‘smoother journey’ (C3, C4) for patients through treatment. They perceived benefits more clearly than patients, but there was symmetry between clinician and patient views. Perceived benefits of needs assessment using the DT&PL included detecting, clarifying and legitimising distress; provision of holistic care and improved clinician-patient relationships; and the potential to address problems and deliver outcomes.

### **Barriers to effectiveness**

Several barriers emerged that could undermine some of the benefits outlined above.

#### *Clinician ability to respond to psychosocial distress*

Clinicians were confident at dealing with physical distress and independently delivering solutions. In contrast, they commonly reported feeling: ‘out of depth’ (C6); anxious about their ability to cope with psychosocial issues; and uncertain how to respond.

C3: I’ve found this [DT&PL] quite useful... very satisfying. Especially when there are small [physical] issues that I’ve very easily been able to rectify myself. (...) One interview, the lady had [social problem], it was probably the longest interview I did, I wasn’t able to give her any advice. I mean I said I’d get her information and stuff. So, I kind of left thinking poor lady, you know. Sometimes it’s better to offload and try and share it with somebody but ultimately has that improved things for her?

While mostly able to suggest help sources or information, they expressed uncertainty about the actual utility of this and whether it would meet patients’ expectations:

C6: She [patient] had very real issues and I didn’t want her to think that they were all gonna be solved as a result of this... I didn’t want to be flippant and say, ‘oh go and talk to someone, have counselling, do this’... I could only give broad solutions...

Some practical difficulties seemed to have no solution, which was difficult for the clinician when the tool directly elicited these:

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C7: I find it very hard to discuss finances with patients, especially when it comes to, “they say I’m not entitled to any benefits,” and I’m thinking, “well I can’t do anything about that unfortunately.” I feel inadequate... because a patient could get a false sense from this thinking, “oh they can do something about it”... if it’s on there [DT&PL] ... and you can’t do anything about it.

Similarly, some patients also questioned clinicians’ ability to deal with ‘non-physical’ distress:

P13: If I said, ‘yes, I’ve got a big problem in my relationship with my partner’. What are they going to do about it? I think that plan of action is quite difficult, isn’t it? I think this bit [physical domain] is the easy bit. This bit, family and emotional, maybe spiritual, I don’t know how they handle all that stuff. Who are they going to wheel in for you to talk to...?

### *Clinician appropriateness and training needs*

Some patients perceived elements of the DT&PL content as the remit of other professionals, or even as interfering with the job they thought radiographers and chemotherapy nurses ‘should be doing’ – that is, delivering a specific ‘medical’ treatment:

P15: It’s difficult for someone like a radiographer to gauge just how serious some of them [DT&PL items] might be. You know, if somebody’s saying ‘I’m feeling very depressed’, is this clinical depression or are they just feeling a bit down?... perhaps asking the patient to go back to their own doctor might be a good idea... financial issues and so on might need help from the social work department.

P4: Outside of treatment, whether it would sort of be a different environment to stop and reflect on these things... in the sense of separating out almost the physical, which is having the physical treatment and then being away from it. The breast care nurses sort of sit in between... maybe that’s a better place for some of this.

Consequently, two patients described not reporting ‘non-medical distress’, despite their issues being items on the problem list:

I: Would you have thought of raising that [spiritual concerns]?

P15: I think I could have talked to her [radiographer] about it but maybe I’d have thought perhaps I was wasting her time in a way because somehow that was somebody else’s problem.



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Despite clinicians' concerns about responding to psychosocial distress, only one (C6) questioned the appropriateness of radiographers and chemotherapy nurses delivering needs assessment using the DT&PL:

C6: I'm still not sure whether I was the best person to have that conversation [about emotional distress] with her... I guess if it had all been physical problems, I would have been like, 'yeah, of course I'm the best person to do it' but there's something that when it kind of got to the practical problems, I guess it might have been quite nice to go, "right, okay, you really need to go and speak to so and so who knows all about these kind of things and who will really be able to help you".

Others felt they were the most appropriate personnel on account of their frontline role, the relationships they built with patients, and their expertise in physical health. They saw the question being one of training rather than appropriateness. Most clinicians felt they lacked training to deal with psychosocial distress:

C7: Things like 'feeling guilty'. I mean, how can I help someone who is feeling guilty about having the disease? And you know, hopelessness... when you've not had any kind of psychological training, it's hard to know how to deal with that.

The two clinicians who did not feel like this were experienced at conducting patient reviews. One had pre-existing counselling training, which she pointed to as something that assisted her in using the DT&PL for needs assessment and another (C7) implied effectiveness of the DT&PL hinged around this.

### *Contextual barriers*

#### *Time*

All clinicians experienced time pressures, feeling the need to rush some patients through and struggling to accommodate the follow-up required. Therefore the DT&PL may not be completed 'properly' or issues might be 'missed' (C5).

C3: I'd say to the patient, 'okay, this shouldn't take too long, we've got as long as you need', and in my mind I might be looking at my watch and going, 'I need to be back on service in a minute'.

C7: Once you've had the interview and you say, 'right, okay, I'll go and make these phone calls', ... 'right, ok, I've got to do this, I've got to do that', and no added time was given. [Its] the aftermath as well... if they'd allowed us more time, I think it could have been more effective.

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Where patients recognised these difficulties, this could inhibit disclosure:

P15: They're [radiographers] run off their feet and how long they can spend discussing the more nebular sort of aspects... you're always aware that you're taking up precious time ...

### *Setting*

Barriers associated with setting included: lacking a private room; being interrupted; patients not having time, feeling too unwell, or being accompanied; and there being no pre-existing relationship between patient and clinician. Having a pre-existing relationship was thought to be particularly important because patients were 'more relaxed' (C7) and clinicians felt more able to 'probe' around psychosocial concerns without this seeming 'intrusive' (C6). However, this was not always organisationally possible.

C7: It could be a bit awkward if I hadn't met them before. Had I met them on their very first cycle I could have actually struck up a nice relationship with them in the very beginning. But unfortunately with, you know, the way things are in the chemotherapy bay unit, it was not always possible.

### *When and how to refer*

Although the resource directory provided information about referring to other services, some clinicians felt hampered by a lack of appropriate services, or knowledge about when and how to refer:

C2: There were probably people who would have benefited from counselling and we don't really have that here...

C7: I myself have never had to refer anyone to the psychology. I wouldn't even know how to because no one's told me what I've got to do... It would be nice to actually have some kind of guidelines.

### ***Patient barriers to reporting distress***

Patients tended to define distress in terms of mental health symptoms and extreme difficulties, rather than common concerns. Consequently, many defined themselves as 'low need' or 'not distressed', despite experiencing issues from the problem list. This appeared to inhibit reporting. For instance, one patient described an "overriding sense of fear" about her diagnosis but felt that she had not needed the DT&PL because: "I certainly haven't sat down and sort of broke down in emotions with it all" (P4).

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Reporting emotional distress was particularly problematic. Two patients feared repercussions if they 'admitted' to being emotionally distressed.

P6: ... am I going to be labelled as mad or barmy, are they going to put me on medication. It's one of those things you think, do I answer this how I actually feel or is it going to end up with me in trouble.

Some struggled to decide what 'counted' and was legitimate to report, particularly if feelings/problems were transient, thought to be mild, or apparently unrelated to treatment (e.g. loneliness (P7)). In contrast, physical problems were: "really easy. That was just 'yes, yes, yes, no I didn't have that one, yes...'" (P6).

### **Areas for improvement**

#### ***Timing and frequency of administration***

There was agreement among clinicians that the DT&PL was a futile paperwork exercise if conducted too early since it could pre-date the onset of distress, particularly distress caused by treatment side-effects, which may then be 'missed'.

C3: I had a couple which, it was fairly early... and they generally didn't have much in the way of concerns... so literally it was a case of going through the forms...they probably weren't fifteen minutes

For patients, needs assessment using the DT&PL could also appear less acceptable if presented too soon since many found the start of treatment overwhelming and early administration generated fears about possible difficulties ahead for at least one patient.

P6: It [DT&PL] was on my very first chemo... I was a bit screwy at the time... there was so much to take in and there was so much going on that I sort of looked at it and answered it, but it was the later ones [trial patient outcome questionnaires] that I had time to think about

'Readiness to talk' was a further aspect of timing in relation to emotional distress.

P3: Because this [DT&PL] all happened in the very beginning when you, you're having the treatment, I don't know whether you're quite ready to talk about some of the feelings that you would tick on here. Its just a little bit further along the line that I think you're ready or want to talk to somebody about how you're feeling.

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Clinicians pinpointed mid treatment, or shortly thereafter, as the optimum time for needs assessment. Then physical symptoms are more ‘pronounced and acute’ or have ‘hit their peak’ (C5) and patients may be ‘struggling’ (C6). Patients may also be more ready to address other domains of distress.

C2: At least half way or towards the end. I think that towards the end people have a lot of physical problems because of the radiotherapy and they’re developing the side effects, and I think half way through then at least patients feel comfortable with what’s happened with their treatment...before that people are too worried...and once they’ve got past that they’re focusing on other (non-physical domain) things.

Patients identified mid, late or even end of treatment as points at which they felt most need for reassurance about treatment and when emotional issues became more salient.

P13: I think middle. To start with you don’t really know much about the treatment so you want to give it a go, and then you start thinking ‘this is all a bit weird’ and ‘it would be nice to speak to somebody about it’.

P9: Some of the things [patient scans DT&PL] yeah, because I’ve got one breast bigger than the other, constipation... [continues to list relevant problems]

I: So all that would’ve been during treatment?

P9: Probably more after... it would be a big help after... perhaps now I could do with it more than I did.

Patients and clinicians went on to discuss the complex nature of distress during cancer, how this evolves, and how the physical and psychological may need to be addressed at differing time points.

P12: You would have got different results from me if I was having chemo when I was filling it out... and now it’s different again. So it does change as you go through.

Thus, a common view across patients and clinicians was that the DT&PL should be completed more than once. Clinicians feared time constraints would preclude this ideal.

P10: You have to find out these things [DT items], you have to adjust... you don’t know what your relationship with your partner’s going to be when you’ve got a mutilated breast or... so I’d have thought middle and then again at the end of treatment.

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C5: This should be done at various stages throughout a patient's journey, you know, at the beginning of the diagnosis, at treatment, after treatment is finished... unfortunately, ... I don't think would ever happen. There's just not the manpower or time.

### *Ensure outcome and follow-up*

For a number of patients, the value of needs assessment using the DT&PL was contingent upon a demonstrable outcome, such as referral or a prescribed treatment. This was at odds with some clinicians' belief that the DT&PL could be a therapeutic intervention in and of itself:

P10: I definitely would expect someone to address the issue because otherwise I would feel betrayed... people have to be quite careful about asking questions if they don't want to deal with the answers.

A follow-up appointment was identified as a way of improving the DT&PL, particularly when emotional issues were raised, given these need consideration on "an ongoing basis" (P15) and "seeing through" (P12). Otherwise, the DT&PL could seem like an isolated event with unclear purpose:

P6: We did this thermometer, which she sort of talked me through it and I sort of done it... and then after that I never seen her again.

Patients were positive about needs assessment using the DT&PL where they could identify a useful outcome but several had felt there was no outcome for issues they raised or that there had been no check on whether action plans had been carried out or worked.

I: Do you remember what the outcome of doing this was?

P4: No, other than that I did think actually I should probably do something and I went and bought the [recommended] relaxation tape. There were some booklets that went with it, and I stuffed them on the study floor at home and they stayed there for months...

I: Did it [DT&PL] help you in any way?

P4: I 'spose if I'm honest it probably hasn't, has it?

Six clinicians discussed how lack of follow-up resulting from a single needs assessment could leave them uneasy where patients were particularly distressed. Some informally checked whether referrals had materialised, or returned to issues at subsequent appointments but this required a continuing relationship, which did not always exist.

### **Overall evaluations of effectiveness (Supplementary material)**

Clinicians and patients were uncertain about the overall utility of needs assessment using the DT&PL as implemented in the RCT. While some believed it had the potential to actually

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‘intercept’ or reduce distress, bringing about improved psychological well-being, others suggested the benefits were quite subtle or immeasurable.

The crux of the debate surrounded how much needs assessment using the DT&PL added to usual practice, particularly in relation to physical issues since these were often ‘covered’ (C5) during standard assessments or ‘first day chats’. This led some to suggest the true value of the DT&PL is in addressing psychosocial issues. Such a conclusion was problematic since this was also where several clinicians felt ill-equipped to respond.

## Discussion

While patients and clinicians identified many ways in which the needs assessment could be beneficial during cancer treatment, several important barriers to effectiveness were also evident in this study. Despite training in needs assessment and the use of the DT&PL, most clinicians reported feeling ill-equipped to deal with psychosocial distress. Some patients raised similar concerns and questioned the appropriateness of radiographers or nurses carrying out assessments, leading to under-reporting of psychosocial problems. Moreover, some patients were reticent about reporting emotional distress. Practical barriers such as time constraints and uncertainty about where to refer patients also existed for clinicians. Respondents underlined the importance of appropriate timing and frequency of the tool, and the essentialness of providing follow-up for needs identified by the tool. Overall evaluations of the usefulness of the DT&PL as used in the RCT drew attention to a fundamental difficulty; that the area in which the tool could be most beneficial to patients (addressing psychosocial needs) was also where these clinicians felt ‘out of depth’.

It is widely recognised that diagnosis and treatment can bring significant disruption to patients’ well-being, such that distress during cancer is now conceptualised as a separate entity requiring recognition and intervention (Velikova, 2010). The findings of this study reaffirm this. Patients experienced distress, were positive about the opportunity to explore this and emphasised the importance of outcome and follow-up. Holistic assessment tools such as the DT&PL may legitimise and normalise ‘non-physical’ sources of distress, such as emotional, interpersonal, and spiritual, which patients will otherwise rarely volunteer to health professionals, believing this not to be their job. However, also in keeping with current literature, these findings demonstrate that the process of holistic needs assessment and management in routine care can be problematic (Jacobsen and Ransom, 2007). Many trials of needs assessment and distress screening tools, including the trial within which this qualitative study was nested (Authors et al, 2013), have unclear or negative results indicating no overall benefit for patients (Carlson et al, 2012). To our knowledge, there has been little research using qualitative methods to gather insights from patients and clinicians about the experience and process of needs assessment in order to understand the issues that may lie behind effective implementation.

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We included male and female patients from across centres, with a range of ages, distress scores and cancer types. A potential limitation of our study is that some of the patients interviewed had little or no recall of completing the DT&PL and so only provided hypothetical evaluation, though they did so from the informed position of an individual who had recently undergone cancer treatment. This is likely to be because interviews were conducted at the end of the trial, long after (approximately 13 months) DT&PL administration. Those with recall were mostly female breast cancer patients, though the hypothetical views of the more diverse group without recall were largely compatible with these patients, implying that they represent a broader viewpoint. Poor recall could indicate that the tool was administered seamlessly as part of existing care, or that it was ineffective, passed over briefly, timed inappropriately, or that it blurred with the many other consultations occurring near the start of treatment. One advantage of conducting interviews after the completion of initial therapy was that patients could reflect on the optimal timing and frequency of needs assessment over the course of treatment.

While the findings of this study relate to how the DT&PL was administered within the context of this trial, they serve as important observations about the process of needs assessment. Our findings imply that success is contingent upon i) tailoring mode of delivery to match the nature of distress during cancer; and ii) attending to the context of delivery. Regarding mode of delivery, timing and frequency of administration emerged as fundamental issues. A badly timed DT&PL consultation could be futile and while there was some consensus about ‘good’ timing, it was not possible to arrive at a single optimum time since distress during cancer is dynamic. Patient ‘readiness to talk’ varies with the changing faces of distress, as indicated in other qualitative studies of distress during cancer (Baker et al, 2013; Waldrop et al, 2011). Such complexity could not be captured or managed by a single administration of the DT&PL; to be successful needs assessment should be flexible and readily available at regular intervals during treatment and follow up.

Regarding context, lack of time significantly hampered clinicians’ ability to deliver the DT&PL and follow-up issues raised. Protected time is essential and a sense of this should be conveyed to patients who may otherwise perceive clinicians to be too busy to discuss distress. Second, as indicated elsewhere (Velikova, 2010), clinicians require adequate support services with clear guidelines for referral, to assist with specific practical problems or more complex cases of distress, thus avoiding a situation where distress is uncovered but cannot be managed. More generally, follow-up procedures should be developed so that needs assessment is not a ‘one-off’ event, as this can be self-defeating, confusing or frustrating for patients and clinicians. A further key issue is to respond to barriers surrounding the discussion of psychosocial distress, which were prominent in these data. Furthering others’ suggestion (Carlson et al, 2012; Dolbeault et al, 2011; National Institute for Clinical Excellence, 2014) these data indicate that further training is likely to be crucial towards addressing clinicians’ low confidence and enabling them to deliver

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the psychosocial needs assessments effectively. Patients' understandings of the radiographer/chemotherapy nurse remit should also be tackled. Encouraging an enduring and open patient-clinician relationship is an important step towards removing patient fears about 'admitting' to emotional distress.

The barriers identified in this study suggest that potential benefits of needs assessment and distress management may not be achieved without due consideration of process. Significant investment, for example in staff training, psychosocial support services and dedicated time to conduct needs assessment and follow up may be essential. This is difficult in the context of the current financial pressures on healthcare providers. Additional research is required to explore these findings further since such understanding can identify opportunities for clinicians and policy makers to tailor interventions to optimise potential benefits for patients. This study also indicates the potential insights that can be gained from using qualitative methods within trials of needs assessment in order to understand intervention processes. Our experience underlines the importance of embedding this throughout to avoid difficulties of recall as encountered in this study.



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## Experiences of the Distress Thermometer and Problem List

**Table 1: Patient characteristics**

<b>ID</b>	<b>Centre</b>	<b>Sex</b>	<b>Age group (yrs)</b>	<b>Cancer site and treatment</b>	<b>Recall of DT</b>	<b>DT score</b>
P1	1	Male	50-65	Prostate Surgery, radiotherapy	No	3
P2	2	Male	75+	Prostate Hormone therapy, radiotherapy	Partial	0
P3	1	Female	50-65	Breast Surgery, radiotherapy	Yes	5
P4	2	Female	50-65	Breast Surgery, chemotherapy	Yes	7
P5	1	Female	35-50	Breast Surgery, radiotherapy	No	5
P6	2	Female	35-50	Breast Surgery, chemotherapy, radiotherapy	Yes	5
P7	2	Male	75+	Prostate Hormone therapy, radiotherapy	Partial	1
P8	2	Female	50-65	Vulva Surgery, radiotherapy	No	0
P9	1	Female	35-50	Breast Surgery, radiotherapy	Partial	7
P10	1	Female	50-65	Breast Surgery, radiotherapy	Partial	6
P11	1	Male	65+	Prostate Brachytherapy, radiotherapy	No	2
P12	1	Female	35-50	Breast Surgery, chemotherapy, radiotherapy	Yes	4
P13	1	Female	50-65	Breast Surgery, radiotherapy	Yes	5
P14	1	Male	65+	Prostate Hormone therapy, radiotherapy	No	6
P15	2	Female	65+	Uterus Surgery, chemotherapy, radiotherapy	Yes	5

## Experiences of the Distress Thermometer and Problem List

**Table 2: Clinician characteristics**

<b>ID</b>	<b>Centre</b>	<b>Sex</b>	<b>Role</b>	<b>Patient group(s)</b>
C1	1	Female	Consultant treatment and review radiographer	Gynaecology
C2	2	Female	Treatment radiographer	Varied
C3	2	Male	Treatment radiographer	Varied
C4	2	Female	Research radiographer	Varied
C5	1	Female	Review radiographer	Head and neck, neurology
C6	1	Female	Chemotherapy nurse	Varied
C7	1	Female	Chemotherapy nurse	Varied