



Use of the Distress Thermometer in a cancer helpline context: Can it detect changes in distress, is it acceptable to nurses and callers, and do high scores lead to internal referrals?



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ABSTRACT

Purpose: To improve understanding about; (1) the validity of the Distress Thermometer (DT) as a measure of changes in distress after a cancer helpline call, (2) the impact of a helpline call on callers' distress, (3) caller and helpline nurses' comfort with use of the DT, and (4) the extent to which DT scores over the critical threshold, are associated with referral to internal support services for follow-up psychosocial care.

Methods: Callers (people diagnosed with cancer and their family/friends: $N = 100$) completed a questionnaire that included DT ratings (three time-points), the Depression Anxiety and Stress Scale-21 (DASS-21) and measures of comfort with the DT tool. Nurses recorded referrals to internal services and their comfort in using the DT in each call.

Results: The DT correlated with the DASS-21 depression ($r = 0.45, p < 0.001$), anxiety ($r = 0.56, p < 0.001$) and stress ($r = 0.64, p < 0.001$) subscales demonstrating validity. Callers' self-rated distress was significantly lower after the call, regardless of gender or caller type ($F(2, 97) = 63.67, p < 0.01$, partial eta squared = 0.57). Over 74% of people diagnosed with cancer, 80% family/friends and 89.3% of nurses felt comfortable with DT use. Only 16% of participants were referred on to follow-up internal support services despite 90% of people with cancer and 75% of family/friends' DT scores' suggesting they required follow-up care.

Conclusions: The DT is a valid and acceptable tool for use by cancer helplines. Improved documentation of referrals is required to better understand referral patterns.

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1. Introduction

Psychological distress is now considered the 'sixth vital sign' to be monitored in cancer care, along with temperature, respiration, heart rate, blood pressure and pain (Carlson et al., 2012). Distress in the context of cancer has been defined as "a multifactorial, unpleasant experience of an emotional, psychological, social or

spiritual nature that interferes with the ability to cope with cancer, its physical symptoms, and its treatment" (Holland and Bultz 2007, p.1). It affects the person who experiences cancer as well as their family and friends (Matthews et al., 2003; Lin et al., 2014). Psychosocial interventions that aim to address this distress may be provided at all points of the cancer trajectory (i.e. at initial diagnosis, treatment, survival, palliation or after bereavement) and they can incorporate both ongoing distress tracking and management (Fawzy, 1999). Traditionally, cancer-specific psychosocial interventions for cancer patients have been provided face-to-face (Bowen, 2010). However, due to cost, time and their broader reach, telephone-based services (often called 'helplines') are increasingly important sources of psychosocial information and support, primarily because patients are receiving more of their

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treatment as outpatients and spending less time in hospitals (Guadagnoli and Mor, 1991). These changes to treatment delivery also mean that family members are playing an increasingly complex role in cancer care, often face new and unfamiliar caring responsibilities at home (Guadagnoli and Mor, 1991), and need remote access to information and support.

Cancer helplines provide information, supportive counselling and psychosocial triaging to callers who are impacted by cancer directly or indirectly, regardless of cancer type, stage or prognosis (Harvey et al., 2013). They are typically staffed by oncology-trained nurses. An increasing number of studies suggest that cancer support services delivered by telephone are efficacious and effective in addressing the needs of these groups (Beaver et al., 2006; Livingston et al., 2006; Steginga et al., 2008) and are accessible, convenient, and anonymous (Livingston et al., 2006; Hawkes et al., 2010; Leahy et al., 2013; Lin et al., 2014).

Previous research has highlighted the importance of distress identification and subsequent triaging being carried out on helpline calls (Hawkes et al., 2010; Hughes et al., 2011). Screening for distress at call outset is now considered critical, and guidelines suggest that screening needs to occur in a standardised and supportive way (Snowden et al., 2011). A brief screening tool, the Distress Thermometer (DT), has been recommended for this purpose. The DT is a single question used to identify the level of distress that clients have experienced in the past week (National Comprehensive Cancer, 2003). Clients are asked to report their distress from 0 (*no distress*) to 10 (*extreme distress*). Cancer patients and survivors with DT scores ≥ 4 , and family/friends with scores ≥ 6 require further assessment and support according to Hawkes et al.'s (2010) guidelines.

Most research on the DT to date has focused on the validity of the DT compared to other measures of psychological distress (Snowden et al., 2011) but there has been little effort to ensure that the measure is sensitive enough to detect changes in distress before and after helpline calls, or whether call efficacy varies with caller type (patient, survivor, family, friend) or by caller gender. Moreover, some concerns have been raised about the potential poor acceptability by call centre staff and the discomfort of cancer nurses using the DT measure (Hughes et al., 2011; Meijer et al., 2013; Chambers et al., 2014). It is thought that staff reluctance to use the tool may arise from nurses' lack of knowledge and confidence in its use (Mitchell et al., 2008), time constraints, or the belief that the caller's enquiry did not fit with distress screening (e.g. caller ringing for specific service information) (Hughes et al., 2011). Barriers to use by nurses require further examination (Mitchell et al., 2012a; Mitchell et al., 2012b). Similarly, little is known about how comfortable callers feel when asked to rate their distress.

This study aimed to determine (1) the validity, sensitivity and acceptability of the DT as a method of measuring change in distress following contact with a cancer helpline, (2) the impact of calling a cancer support helpline on callers' recollected levels of self-reported distress as measured by the DT (and whether or not there are differences between genders and caller types), (3) the extent to which callers and cancer helpline nurses are comfortable with use of the DT, and (4) how frequently callers who score over recommended referral thresholds are referred to follow-up, internally sourced support (i.e. counselling, financial, practical or legal assistance programs).

2. Method

2.1. Participants

Adult callers to Cancer Council SA's telephone-based information support service (Cancer Council 13 11 20) between 12th May

and 18th July 2014, who identified themselves as having been diagnosed with cancer or as being the family or friend of someone diagnosed with cancer, were invited to participate. Cancer Council 13 11 20 is a free, confidential information and support service available to anyone in South Australia. Calls are not-time limited and are answered by experienced cancer nurses who are normally part-time employees who are also encouraged to continue working in direct cancer care control (e.g. a hospital). A total of 1809 calls were received by Cancer Council 13 11 20 in South Australia during this period (see Fig. 1 for the study's flow diagram). Only 718 of these calls were made by people who were eligible to participate. Non-eligible callers include health professionals and members of the general population. Enrolled participants who completed all parts of the survey equated to 14% of eligible callers during this period ($n = 63$ people diagnosed with cancer, $n = 37$ family or friends).

Eligible participants ($n = 197$), which included all those who agreed to receive the survey (100 people who completed it plus the 97 who agreed to receive it but did not complete it), were compared to eligible non-participants ($n = 512$) and found not to differ by gender ($\chi^2(1, 718) = 0.002, p = 0.97, \phi = 0.005$), caller type (people affected by cancer or their family/friends) ($\chi^2(1, 659) = 0.196, p = 0.66, \phi = 0.021$), DT ratings (if requested by the cancer nurse) ($t(409) = -0.08, p = 0.94$) or age range (as determined by median split; ≤ 59 years; > 60) ($\chi^2(1, 643) = 0.187, p = 0.67, \phi = 0.02$; see Table 1). However, the two groups did differ by the length of the call, (with longer calls being held with participants compared with eligible non-participants) ($t(716) = 6.81, p < 0.001$, eta squared = 0.06) and by the reason for their call ($\chi^2(4, 718) = 15.32, p = 0.004, \phi = 0.15$). More eligible participants than non-participants called regarding treatment or management issues ($z = 2.3, p < 0.05$).

2.2. Procedure

The study protocol was approved by the University of Adelaide, School of Psychology Human Research Ethics Subcommittee. A pre-recorded message was placed on the Cancer Council 13 11 20's answering facility to inform callers about the research. The caller was then directed to a cancer nurse as per usual operating procedure. The nurse used a study-specific flowchart to determine eligibility and willingness to participate. The nurse also collected caller data including call purpose, diagnosis and if a referral to another internal support service was given. During each call, the cancer nurse was instructed to record the caller's distress, using the DT, and to record their comfort in using the DT. If the DT was not rated, the nurse could indicate "not asked", "not applicable" or "it was asked but the caller declined to answer". Interested callers then received written information about the study and the survey via email or post. All participants provided informed consent. Participants who had not returned their survey after a couple of weeks were re-sent a copy. Surveys took, on average, 20 days ($SD = 21.87$) to be returned.

2.3. Measures

The survey included questions on age, gender, educational background, ethnicity, mental health history (self-rated on a single item; *very poor, poor, average, good, excellent*), history of helpline use and, if applicable, cancer diagnosis, stage and treatment.

2.3.1. Distress Thermometer (DT)

The DT is a single item measure that asks participants to self-rate their level of distress on an 11-point scale from 0 (*no distress*) to 10 (*extreme distress*). It is considered non-invasive,

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