Why do oncology outpatients who report emotional distress decline help?

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Abstract

Objective: Many patients who experience distress do not seek help, and little is known about the reasons for this. We explored the reasons for declining help among patients who had significant emotional distress.

Methods: Data were collected through QUICATOUCH screening at an Australian hospital. Oncology outpatients scoring 4 or more on the Distress Thermometer were asked if they would 'like help' with their distress. Those who declined help were asked their reasons. Demographic variables and a clinical measure of anxiety and depression (PSYCH-6) were used to identify factors associated with reasons for declining help.

Results: Of 311 patients with significant distress, 221 (71%) declined help. The most common reasons were 'I prefer to manage myself' ($n = 99$, 46%); 'already receiving help' ($n = 52$, 24%) and 'my distress is not severe enough' ($n = 50$, 23%).

Younger patients and women were more likely to decline help and were more likely to already be receiving help. Distress score and PSYCH-6 scores were significantly lower among patients who rated their distress as not severe enough to require help. Nevertheless, there were patients who had maximal scores on distress and PSYCH in each group.

Conclusions: Two common patient barriers to help with distress are a preference for self-help and a belief that distress is not sufficiently severe to warrant intervention. These beliefs were held by a sizeable proportion of individuals who reported very high levels of distress. Qualitative research and subsequent interventions for overcoming these barriers are required to obtain the most benefit from distress screening programs. Copyright © 2014 John Wiley & Sons, Ltd.

Introduction

The importance of attending to psycho-social concerns as part of providing optimum care for people with cancer is increasingly recognised [1]. The term 'distress' has been proposed as an umbrella term for negative emotional states [2] and has been promoted as the Sixth Vital Sign [3,4]. Screening programs have been endorsed to improve the recognition and management of distress [5,6]. To be successful, screening programs must not only identify cases but change their subsequent management [7]. However, although 50–70% of patients indicate that they are aware of resources to assist with distress, less than a quarter report using these services [8–11]. We have previously demonstrated that 60–70% of patients who reported experiencing distress declined assistance [12], and we were concerned to investigate the reasons for this.

This study aimed to explore reasons for declining help with distress among cancer outpatients who were experiencing distress. The primary aim was to describe the percentage of patients indicating various reasons for declining help with distress. A secondary aim was to explore the independent predictors of reasons for declining help using available demographic and clinical variables.

Methods

Setting

The Calvary Mater Newcastle (CMN) is a major regional cancer centre. Oncology outpatients completed assessments of their pain, distress and other symptoms on a touchscreen computer (QUICATOUCH) prior to their oncology appointment. Patients over established thresholds for pain or distress were prompted to indicate if they wanted help for pain or distress respectively. Clinicians were alerted by written report if the patient's response was over threshold for pain or distress. Where patients wanted help with their pain or distress, this was indicated on the Clinician Alert. Details of the QUICATOUCH assessment and scoring algorithms have been described previously [13–15].

Study design

The study is a cross-sectional survey of patients undergoing their first occasion of QUICATOUCH screening between March 2010 and September 2011.

Participants

Eligibility criteria for QUICATOUCH screening included age over 18 years, sufficient English language communication skills and being well enough to undertake the assessment, in the opinion of the clinic nurse. Patients were not offered screening at their first oncology appointment, as an overwhelming amount of information is provided and an initial period of distress does not necessarily warrant specialist psychological intervention. Patients are eligible for screening at any subsequent visit to a screened clinic. Resource constraints prevented us from tailoring screening to stage of illness or time since previous occasions of screening.

The study sample ($n = 215$) was drawn from outpatients who completed an initial QUICATOUCH assessment between March 2010 and September 2011 ($n = 3070$). The data were restricted to patients who were over threshold for distress ($n = 310$) (since only these patients were asked about their desire for help with distress) and further restricted to those who declined help ($n = 221$) and provided a reason for declining help ($n = 215$).

Measures

Predictor variables

Demographics and service use characteristics

Information was routinely collected from the patient during the assessment: age, gender and whether the patient was currently undergoing treatment with either radiation therapy or chemotherapy.

Distress score

Distress was measured using the Distress Thermometer which has been widely validated in oncology settings [16,17]. Patients were instructed to 'choose a number indicating how much distress you have been feeling over the past week, including today, where zero means no distress and 10 means the worst distress imaginable'. Distress scores of four or more were considered to be over threshold, as per previous recommendations [2].

PSYCH-6

The PSYCH-6 is a six-item subscale of the Somatic and Psychological HEalth REport (SPHERE-12), which measures aspects of anxiety and depression [18]. Patients are asked if they have been troubled by (1) feeling nervous or tense, (2) feeling unhappy and depressed, (3) feeling constantly under strain, (4) everything getting on top of you, (5) losing confidence and (6) being unable to overcome difficulties. The six items are scored on a three-point response scale from 0 to 2 (minimum zero, maximum 12). Higher scores indicate more pathology. This measure has been validated for use in oncology populations [13]. We previously found substantial agreement (kappa = .73, $p < .001$) between the PSYCH-6 at a cut-off score of three and the Hospital Anxiety and Depression Scale total score.

Outcome measures

Desire for help

The desire for help questions were similar in style to those used in a primary care study in New Zealand [19]. All patients over threshold for distress were asked 'Do you want help with your distress?' with the response options 'yes' or 'no'.

Reasons for declining help

The question on reasons for not wanting help was similar to the question asked in the National Survey on Mental Health & Wellbeing, in which response options were developed by team of consumers and mental health experts informed by literature review [20]. Patients who responded 'no' to the question on desire for help with distress were asked 'What is the main reason you don't want help with your distress?' The response options were: 'I prefer to manage myself'; 'I don't think anything could help'; 'I don't know how or where to get help'; 'I'm afraid to ask for help or of what others would think of me if I did'; 'I can't afford the money'; 'I have asked but didn't get help'; 'I get help from another source' and 'My distress is not severe enough to need help'.

Procedure

Data were obtained during routine outpatient assessment using the QUICATOUCH program [13–15]. A designated 'screening assistant' introduced QUICATOUCH and instructed the patients on using the touchscreen.

Ethical approval

The Hunter New England Research Ethics Committee formally authorised the analyses of these data without the requirement for individual patient consent as a quality improvement evaluation of a clinical service.

Statistical analysis

Data were analysed using SPSS 14 for Windows. Demographic and other variables were described using frequencies, percentages and means as appropriate. Median and interquartile range (IQR) were reported for non-normally distributed variables. Graphs were created using Microsoft Excel.

Regression analysis was used to determine the relationship between the reason for declining help with distress

Table 1. Demographic characteristics of participants by desire for help

	Help wanted (n = 90)		Help not wanted (n = 221)		Chi^2 (df)	p
	n	**%**	**n**	**%**		
Gender						
Male	46	27	123	73	.645 (1)	.422
Female	44	31	97	69		
Cancer site						
Breast	15	44	19	56	8.99 (5)	.109
Lymphoma/leukemia	11	39	17	60		
Prostate	11	29	27	71		
Lung	6	27	16	73		
Bowel, colon, rectum	4	44	5	56		
Other	42	24	137	76		
Current treatment						
No Rx	61	26	177	74	5.40 (1)	.020
Chemo therapy or radiation therapy	29	40	44	60		
Distress score					10.03 (6)	.123
4	9	10	27	12		
5	17	19	57	26		
6	11	12	23	10		
7	12	13	50	23		
8	21	23	36	16		
9	12	13	17	8		
10	8	9	11	5		
Age (mean, SD in years)	59	(14)	62	(14)	t = −1.16	.249

and potential predictor variables. First univariate associations were calculated, in a series of multinomial logistic regressions, each with a single predictor variable and reason for declining help as the dependent variable. These were presented as unadjusted Odds Ratios (OR) with 95% Confidence Intervals (95% CI). To determine the independent predictors of reasons for declining help, two multinomial logistic regression analyses were performed, both with reason for declining help as the dependent variable. In the first analysis the continuous predictor variables were age and distress score, whilst the categorical variables were gender and any current treatment (radiation therapy or chemotherapy). The second analysis was identical except that the distress score was replaced with the PSYCH-6 score.

Results

Participants and desire for help

Demographic characteristics of participants by desire for help are shown in Table 1. Patients currently on treatment were more likely to indicate a desire for help than those not currently on treatment (*n* = 29, 40% vs *n* = 61, 26% Chi-squared = 5.40, *df* = 1, *p* = 0.02). None of the other available demographic variables were significantly related to desire for help.

Reasons for not wanting help with distress

The most common (*n* = 99, 46%) reason for declining help was 'I prefer to manage myself'. Two other common

reasons were getting help from another source (*n* = 52, 24%), and rating distress as not severe enough to require help (*n* = 50, 23%). Infrequently cited reasons were 'I didn't think anything could help' (*n* = 12, 6%), 'I can't afford the money' (*n* = 1, 1%) and 'I'm afraid to ask for help or what people would think of me if I did' (*n* = 1, 1%).

Figure 1 shows the three main reasons for not wanting help by distress score. The percentage of people indicating their distress was not severe enough decreased as distress increased (*n* = 26 (32%) at a score of 4–5 vs *n* = 11 (18%) at a score of 8–10) as did the percentage of people preferring to self-manage (*n* = 33 (53%) at a score of 4–5 vs *n* = 35 (43%) at a score of 8–10). The percentage of people getting help elsewhere increased slightly at higher distress
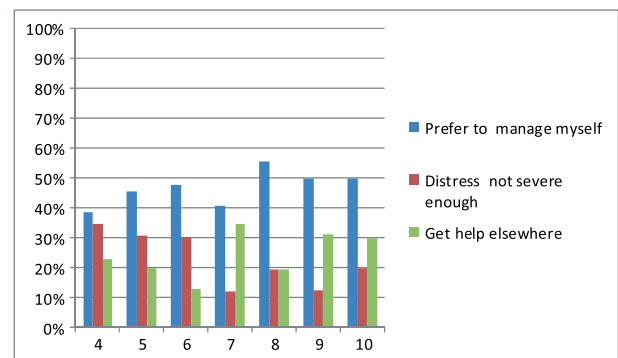

Figure 1. Three main reasons for not wanting help within each level of distress above 3 on the Distress thermometer

Table 2. Characteristics of participants by main reasons for declining help

	Prefer to manage myself (n = 99)		Getting help elsewhere (n = 52)		Distress not severe enough (n = 50)	
	n	%	n	%	n	%
Gender						
Male	65	66	23	44	29	58
Female	34	24	29	56	21	42
Current treatment						
No Rx	76	77	44	85	41	82
Chemo therapy or radiation therapy	23	23	8	15	9	18
Age (mean, SD)	64	(12)	56	(17)	62	(14)
Distress score (mean, SD)	6.61	(1.71)	6.67	(1.71)	6.00	(1.68)
PSYCH-6 score (median, IQR)	2	(1–5)	3	(1–7)	0	(0–2)

SD = standard deviation; IQR = interquartile range.

scores ($n = 17$ (21%) at a score of 4–5 vs $n = 15$ (24%) at a score of 8–10).

Variables associated with reasons for not wanting help with distress

The characteristics of people who declined help by the reason given are described in Table 2. Analyses were restricted to the three most frequently endorsed reasons as the other categories were endorsed by too few patients ($n < 14$) to allow reliable statistical analysis. The reference group was 'I prefer to manage myself' as this was the largest group. In both unadjusted and adjusted analyses distress score, PSYCH-6 score, gender and age were statistically significantly related to the reason for declining help. Those already receiving help were significantly more likely to be female (56% vs 34%) and younger (mean = 64 years (SD = 12) vs 56 years (SD = 17)) than

the reference group (Table 3). Those who considered their distress as not severe enough to warrant help had significantly lower scores on the DT and the PSYCH-6 compared with the reference group (Table 3). The median PSYCH-6 score among people who considered their distress was not severe enough to warrant help was zero (IQR = 0–2) compared with a median of two (IQR = 1–5) for those who preferred to manage themselves (Table 2). Current treatment was not significantly related to reason for declining help (Table 3).

Discussion

This study examined the reasons for declining help with distress among a sample of outpatients with cancer who reported experiencing distress. The three main reasons were a preference to self-manage, already receiving help elsewhere and distress not being severe enough to warrant

Table 3. Multinomial regression analysis of variables associated with reason for declining help with distress. Reference group is 'I prefer to manage myself'

			Get help elsewhere				Distress not severe enough			
			Unadjusted		Adjusted		Unadjusted		Adjusted	
		n	OR	(95% CI)	OR	(95%CI)	OR	(95% CI)	OR	(95%CI)
Analysis 1[a]										
Distress score		201	1.027	(.844–1.249)	1.058	(.862–1.300)	.799	(.647–.987)	.807	(.653–.998)
Age		201	.958	(.934–.982)	.959	(.935–.984)	.988	(.963–1.014)	.990	(.964–1.016)
Gender	Female	84								
	Male	117	.415	(.209–.824)	.431	(.212–.876)	.722	(.359–1.452)	.734	(.361–1.489)
On treatment	Yes	40								
	No	161	1.664	(.686–4.037)			1.379	(.584–3.255)		
Analysis 2[b]										
PSYCH-6 score		198	1.065	(.959–1.183)	1.081	(.965–1.211)	.764	(.647–.902)	.766	(.648–.906)
Age		198	.958	(.935–.983)	.962	(.938–.987)	.988	(.963–1.014)	.985	(.959–1.012)
Gender	Female	83								
	Male	115	.409	(.205–.815)	.387	(.185–.807)	.688	(.340–1.391)	.841	(.405–1.744)
On treatment	Yes	39								
	No	159	1.613	(.662–3.931)			1.304	(.549–3.097)		.

[a]—2LLR = 371.856, chi-squared = 23.495, df = 6, P = .001, Nagelkerke pseudo R squared = .126 [b]—2LLR = 360.160, chi-squared = 36.490, df = 6, P < .001, Nagelkerke pseudo R squared = .192

intervention. Younger patients and women were significantly more likely to already report receiving help elsewhere. Those who indicated that their distress was not severe enough to warrant intervention had significantly lower scores on the DT and on the PSYCH-6, a measure of clinical anxiety & depression. In our previous research we were concerned that, although distress severity was related to desire for help, around half of the patients experiencing very high levels of distress declined assistance. The present study confirmed 71% with distress declined help. However not all such patients have unmet needs as approximately a quarter of those who decline help appear to be already in receipt of help from another source.

The relationship between receiving help and younger age and female gender is consistent with previous work. We have previously summarised findings regarding gender differences in desire for help with distress among oncology patients [12]. We found about half the studies reported an association which consistently indicated higher desire for help among women.

It is encouraging that patients who felt that their distress was not sufficiently severe to warrant help had significantly lower scores on psychological measures. However, it is important to note that 18% of people who reported high levels of distress also felt their distress wasn't severe enough to need help. From a clinical viewpoint, a distress score of 8 or more would warrant further assessment and intervention. It would be of interest to explore the reasons why people with high self-reported distress felt their distress does not warrant assessment, to explore whether psychological or other services would be helpful for this group and to develop interventions to increase use of services, if appropriate.

Some researchers have investigated whether adding a 'help question' to screening tools improves the performance of those tools [21,22]. Ryan et al. [21] found specificity of >88% when the PHQ-2 was combined with a help question, compared with the SCID. However, they noted the low sensitivity (<55%) of this method for identifying people with distress. Baker-Glenn et al. [22] similarly found increased specificity (>96%) but lowered sensitivity (<28%) when a help question was added to a brief screening tool. Van Scheppingen et al. [23] went further and argued that asking about desire for help was a more efficient way of connecting patients with services than asking about distress itself. Overall the literature indicates that while adding a help question increases the specificity of screening for distress the loss of sensitivity is too great for a screening tool.

The main reason for declining help in this sample was the preference to self-manage (46%). It is unclear what underlies this preference, how it reflects 'objective' need and whether self-management is a genuine preference or whether it reflects an underlying reluctance to seek help

for some other reason. It is also not clear what strategies people might be using to manage their distress, and how effective these are. Longitudinal data might better inform our understanding in this regard, as people reporting transient high-level distress can be considered as less in need of professional support than people reporting persistent high level distress.

Three of the reasons for declining help options were chosen by very few (<3%) people. The finding that cost was not a barrier could be specific to our setting where services are free. It is encouraging that people did not indicate a nihilistic attitude to help for distress, in that few said they 'didn't think anything could help'. Although stigma is a known barrier in seeking mental health services more generally, it appears to be less influential in cancer [12,22]. However, we note that the item representing stigma in this study may not adequately capture this concept and that stigma may be subsumed in the desire to self-manage. The low level of endorsement of these barriers might also be a function of the question format, which asked patients to choose one main reason. It is possible these barriers could be important secondary reasons for not seeking help.

A small number of studies have examined reasons for declining psychosocial care in the context of cancer. Plass and Koch [24] found the most common reasons for declining were feeling sufficiently supported by family and friends (40%), preferring to talk with someone else (17%) and feeling they could cope alone (14%). Steele and Fitch [25] found common beliefs that staff were too busy or the problem would go away. Bramsen et al. [26] found common barriers were either no perceived need, not liking the help offered or already receiving care. Unlike our finding Merckaert et al. [27] found that younger people, had a greater desire for psychological support. However, similar to our study, Baker-Glenn et al. [22] found the main reasons for refusal were getting help from family and friends, preferring self-help and not believing the emotional problem was severe enough. van Scheppingen et al. [23] found that the main reasons for declining help were: help had already been received, coping with family and friends, not wanting to talk about emotional problems and the desire to improve by self. From these studies common themes seem to be having already received help, coping alone and/or not believing distress warranted an intervention.

These themes are remarkably similar to findings of a major World Health Organisation study of barriers to seeking mental health treatment [28]. This study included 4582 people from 24 countries who met criteria for selected DSM diagnoses and reported not receiving help. Most (64%) reported a preference to self-manage and the second most common barrier was feeling that the problem was not sufficiently severe (24%). Additionally, women and younger people were more likely to recognise a need

for treatment. Thus the themes identified in cancer-specific studies appear to reflect attitudes common to mental health treatment more generally. Campaigns to improve mental health literacy have been proposed to overcome these attitudinal barriers [28].

Strengths and limitations.

The primary strength of the study is the relatively large sample of patients reporting distress. Previous studies investigating patient-related barriers to psychosocial support have usually surveyed the whole patient population [10,29–31] although some have limited these questions to those who have not used, or who have declined services [8,22]. No previous study, to our knowledge, has recruited as large a sample of distressed patients, making this the first study to examine patient characteristics associated with different types of barriers.

Our clinical approach means that we have no information on help-seeking among people with very mild levels of distress. Another limitation is the restricted number of predictor variables available from the clinical database, thus other potentially important predictor variables including knowledge and attitudes to help seeking have not been explored. We also note that the data were collected from a routine screening program operating in one site and how well these findings may generalise to other settings is not known.

The effect of the particular help question asked and the options offered as barriers must also be considered. We simply asked people if they wanted help with their distress, without specifying or suggesting what form this help may take. Thus it is not certain how patients may have interpreted this question. Patients were offered a limited range of options for barriers and asked to select the main one. Although the options were carefully developed by the Australian Bureau of Statistics for a national survey into barriers to accessing mental health services and our findings reflect the main barriers identified by others [22–24], the options are unlikely to capture all the barriers experienced by patients. A qualitative process would be more suited to developing a list of reasons for declining help but was beyond the scope of our routine screening program.

Clinical implications

The majority of cancer patients with significant distress (71%) declined help and only a quarter of these said it was because they were already receiving help ($n = 52$, 24%). This must mean that over 50% of distressed patients [169/311] decline help without being in receipt of help. Whilst it is true these patients have a slightly lower mean DT score than those accepting help, a full spectrum of distress is present.

To be successful in altering outcomes, screening programs for distress must incorporate further assessment of flagged patients and provide relevant resources and help to affected patients [7]. These programs can be difficult to implement in clinical settings [32]. Our study indicates that even where a distress screening program can be offered, patient-related barriers to obtaining assistance exist among a sizeable percentage of patients, even those reporting high levels of distress. This will of course, reduce the effectiveness of the screening program in altering outcomes.

Most screening tools face a trade-off between sensitivity and specificity and most screening programs face a trade-off between accuracy and acceptability. Settings which value high sensitivity risk misdirecting resources while focusing on higher specificity risks missing cases. Our research and that of others [21,22] suggest that asking people if they want help is likely to be useful in settings where resources are scarce and need to be directed efficiently to people who need and want help. This may be particularly useful in settings considering automatically generating referrals to services based on screening questionnaire information. However responding only to cases receptive to help is somewhat contrary to the purpose of screening programs, which is to flag potential cases which would otherwise go unrecognised and alter the course of the target disorder. A two-step screening process with an instrument with high negative predictive value followed by one with high positive predictive value has been proposed as attempt to resolve the sensitivity/specificity trade-off [14,16].

Psycho-education about distress, its negative side effects and the effective management strategies available may overcome some barriers to accepting services. However, a more in-depth understanding of the desire to self-manage may offer the best avenue for understanding and overcoming patient-related barriers to obtaining help with high levels of distress.

Conclusions

Two common barriers to patient uptake of available services to help with distress are a preference for managing without help and a belief that distress is not sufficiently severe to warrant intervention. These beliefs were held by a sizeable percentage (53% and 18%) of individuals who reported very high levels of distress. Our findings and others' research in psycho-oncology indicate that these barriers to obtaining help for mental health problems are common world-wide and are not specific to the oncology field. Qualitative research and subsequent interventions for overcoming these barriers are required to obtain the most benefit from distress screening programs.

Conflict of interest

The authors declare there are no financial or personal relationships that might bias this work.

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