Insights Into Preferences for Psycho-Oncology Services Among Women With Gynecologic Cancer Following Distress Screening

Sylvie D. Lambert, PhD, RN; Brian Kelly, PhD; Allison Boyes, PhD; Alexander Cameron; Catherine Adams, MPych(Clin); Anthony Proietto; and Afaf Girgis, PhD

Abstract
Much attention has been given to implementing routine screening programs in cancer care to improve the management of distress following diagnosis. Although patients might screen positive for distress, several studies have found that most then refuse additional psychosocial support. To inform the development of successful models of distress screening, this qualitative study explored preferences for psychosocial care among 18 women diagnosed with a gynecologic cancer who scored at least 4 on the Distress Thermometer (DT). Participants were recruited from a gynecologic oncology outpatient clinic in Newcastle, Australia, and interviewed. Unanimously, participants felt that completing the DT was an integral part of their cancer care. However, half then refused the referral to see a psychologist. These women typically reported that a referral was not needed, because their rating on the DT reflected transient stressors or physical distress. Many also spoke about their need to cope with the challenges they were facing on their own and the extensive social support they already had in place to help them overcome these challenges. In contrast, women who accepted referral to the psychologist often struggled to cope with several losses they felt had existential and long-term effects. Commonly, these women reported not having the social support they needed, managing several concurrent life stressors, and/or not having the repertoire of coping skills they required to “remain afloat.” Findings from this study begin to bridge the gap between clinicians’ and patients’ expectations of how psychosocial services should be used in response to distress screening. (J Natl Compr Canc Netw 2014;12:899–906)

A cancer diagnosis is associated with a range of physical, psychological, social, and existential challenges. For some individuals, their personal or situational resources are not sufficient to manage these challenges, which in turn contribute to an array of adverse effects, including psychological distress. Psychological distress is a generic term that encompasses the spectrum of feelings from worry, vulnerability, and sadness, to depression, anxiety, and panic. Between 20% and 66% of patients with cancer report high levels of distress. Early identification and treatment of emotional distress are important given its potential negative effects on patients’ short- and long-term illness adjustment. Although distress is recognized internationally as the sixth vital sign, it often goes unrecognized because of health care professionals’ lack of time and confidence in assessing distress.

Throughout the past decade, much attention has been given to implementing routine distress screening programs in cancer care as a way of improving the management of distress. Routine distress screening at periods of increased vulnerability is now an integral part of in-
ternational cancer control plans and best practice guidelines in psychosocial cancer care. Research increasingly supports the effectiveness of distress screening programs in identifying patients with adjustment disorders and of follow-up psychosocial care in improving psychological and physical functioning. However, despite the availability of psychosocial services, many patients who screen positive for distress do not accept referrals for further assessment or psychosocial services. These low rates of referral uptake often raise concerns among health care professionals that patients are not receiving optimal cancer care.

To inform the development and implementation of potentially successful models of distress screening, a qualitative study was undertaken to better understand the preferences for psychosocial care of distressed women diagnosed with a gynecologic cancer, including perceptions of distress screening and women’s motives for accepting (or refusing) subsequent referrals to available psychosocial services.

Methods

Design
This qualitative study involved a thematic survey with the goal of discerning patterns in the data (or themes).

Sample and Setting
Women diagnosed with a gynecologic cancer (primary or secondary) attending an ambulatory gynecologic oncology clinic who scored 4 or more on the Distress Thermometer (DT) and received a referral to see the psychologist for additional assessment and intervention were invited to participate in this study. In addition to scoring at least 4 on the DT, inclusion criteria included sufficient fluency in English and physically and cognitively able to participate in an interview.

Study Procedures
At the participating clinic, the distress screening program is integrated within patients’ cancer care and, in accordance with the clinic’s standard practice, women attending the clinic completed a pen-and-paper version of the DT in the waiting room before their scheduled consultation with the oncologist. The affiliated clinical psychologist then reviewed all completed DTs and spoke to women scoring 4 or more, either in the clinic or by phone after the clinic visit. At this contact, the psychologist informed eligible women about the study, regardless of whether they accepted or refused additional services, and gave or mailed a study pack to those interested in the study. The study pack included an information statement, a consent form, and a brief questionnaire assessing disease and sociodemographic characteristics. Study invitation was independent of future contact with the clinic’s counseling service. Women were asked to return their consent form to the research team directly in the Reply Paid envelope provided. Consenting participants were then contacted by a member of the research team to schedule a semistructured interview. Ethics approval was obtained from the local health district and affiliated university ethics committees.

Data Collection

Distress Thermometer: The DT is a single-item, 11-point visual analogue scale ranging from 0, denoting no distress, to 10, denoting extreme distress (Figure 1). Participants were instructed to select the number that best described the overall distress they experienced in the past week. The DT is one of the best known tools for distress screening. In addition, several studies have supported its convergent validity with the Hospital and Anxiety Depression Scale.

![Figure 1: Distress Thermometer](https://example.com/dt.png)
A cutoff score of 4 typically results in optimal sensitivity and specificity. A total of 28 women diagnosed with a gynecologic cancer who scored 4 or more on the DT were invited to participate in this study. Ten declined participation for common reasons, including too busy (n=4), too ill (n=1), or no reason given (n=5). Of the 18 interviews, 4 were conducted over the phone. On average, interviews lasted 43 minutes (range, 18–117 minutes). Women interviewed were on average 53.9 years of age (range, 30.0–77.5 years) and most were in a de facto relationship or married (61.1%; n=11). On average, women were 20 months from diagnosis (range, 2–108 months). Cancer diagnoses included uterine (38.9%; n=7), cervical (33.3%; n=6), vulvar (11.1%; n=2), ovarian (11.1%; n=2), and fallopian (5.6%; n=1). Nine of the women interviewed accepted the referral to see the psychologist.

### Findings

#### Study Sample

A total of 28 women diagnosed with a gynecologic cancer who scored 4 or more on the DT were invited to participate in this study. Ten declined participation for common reasons, including too busy (n=4), too ill (n=1), or no reason given (n=5). Of the 18 interviews, 4 were conducted over the phone. On average, interviews lasted 43 minutes (range, 18–117 minutes). Women interviewed were on average 53.9 years of age (range, 30.0–77.5 years) and most were in a de facto relationship or married (61.1%; n=11). On average, women were 20 months from diagnosis (range, 2–108 months). Cancer diagnoses included uterine (38.9%; n=7), cervical (33.3%; n=6), vulvar (11.1%; n=2), ovarian (11.1%; n=2), and fallopian (5.6%; n=1). Nine of the women interviewed accepted the referral to see the psychologist.

#### Perceived Usefulness of the DT

Participants found that the DT was useful in communicating their distress to their treating team, and connecting them to the services they might need. As one participant said: “[The DT] was something that succeeded in bringing something to someone’s attention that they thought, you know – because I wondered who would actually be reading it…what kind of question or treatment or attention I might get from that.”

Some participants mentioned that even if they did not accept the referral to see the psychologist, know-
ing that they were “in the system” was comforting, and thought it would facilitate access to this service in the future, if needed. Other participants further expressed that they would not have said anything about how they were feeling to their health professionals otherwise, and thought that “when distressed, the last thing you think about is calling a psychologist.”

Preferences for One-on-One Counseling

Figure 2 provides a schematic summary of the main findings, and emphasizes that the reasons participants gave for accepting or refusing one-on-one counseling focused on the type and length of stressors experienced, and their perceptions of their own internal and external resources to address these. Each of these main categories is reviewed in turn.

Stressors Influencing Rating on the DT

Type and Duration of Stressors Experienced: Approximately half of the women who declined one-on-one counseling said that the stressors influencing their DT rating were transient (or temporary) or physical (rather than emotional), the most common of which were “waiting for tests results” and/or “experiencing side effects.” Given the nature of their stressors, these participants did not feel they needed psychological support (often saying their situation was not “bad enough”); however, they were hoping for additional support from their oncologist/nurse.

In contrast, most of the women who accepted the referral explained that their rating on the DT reflected the extent to which they were overwhelmed by their emotional reactions (eg, fear, uncertainty, worry, sadness, feeling degraded) to the diagnosis and/or treatment. Almost one-third of these women had a history of depression or had depression before the cancer diagnosis. Moreover, only in interviews with women who accepted the referral were codes applied that related to loss, including experiencing unexpected life transitions; forced changes in roles and responsibilities; and negative changes in body image and sexuality. These women also commonly spoke of worrying about the potential long-term impact of these losses on their identity, family, relationships, and life goals. Another type of stressor that was unique to one-third of the women accepting a referral was feeling distressed because of the stigma attached to misconceptions about the cause of gynecological cancer.

Number of Other Life Stressors Experienced: Another unique finding from the interviews with the women who accepted the referral was that they were confronted with several other life stressors, including deceased parents/siblings and/or ill parent, husband, and/or child. Although these participants had been managing these other life stressors, sometimes for many years (or decades), the cancer diagnosis was the “breaking point.” They accepted the referral to see the psychologist, because they felt it was all becoming too much to bear, and they recognized that this additional pressure was putting them at risk of exacerbation. One woman described it as feeling “trapped” between the chronic, noncancer life stressors (eg, death of mother and sister, and sickness of husband) and the new ones caused by the illness (eg, loss of work).

Figure 2 Schematic summary of findings.

Abbreviation: DT, Distress Thermometer.
Perceived Availability of External and Internal Resources

The external resources most often mentioned were availability of emotional support from family and friends and informational support from the treating team. In terms of internal resources, women explained that their ability to successfully cope with the stressors they were facing determined whether they would then accept or refuse additional support.

Availability of External Resources: Central Role of Family and Friend Support: More than three-quarters of the women who refused a referral felt they had an extensive family and friend network that they could readily turn to for emotional (eg, someone to talk to, someone who would listen) or practical support (eg, help with household duties, organizing appointments). As one woman said, “family is key and all you need.” Many of these participants inferred that if this support was lacking, they might have been more inclined to accept the referral to the psychologist. Three-quarters of the women who accepted a referral mirrored this finding; they wanted to see the psychologist because they needed someone to listen to them as they openly talked about the challenges and stressors they were facing. The psychologist was seen as a “neutral” person, who “allows you to say things you normally would not” and could offer a “different perspective” on what was happening to the patient. Before accepting the referral to the psychologist, many of these women often found themselves ruminating about how they were feeling and what they were confronted with, and knew it would be more constructive if they could talk to someone else about it. Many of these women also felt isolated, and the psychologist became their sole source of emotional support. For others, the emotional support they were receiving from family and friends was described as “not what they needed,” or they felt they “needed more.” For instance, one woman said her friends made her feel “like an invalid,” and that she thought that when talking to someone she did not know, she could “talk better”; that she had the freedom to be open and honest, and speak of her experience in a way she could not with friends and family. Women who reported feeling stigmatized were also particularly reticent to turn to family or friends for emotional support. Although some women described an extended network of family and friends, the fear of burdening them meant that the patients hesitated to turn to them for emotional support, and preferred to rely on the psychologist.

Satisfaction With Support Received From Other Health Care Professionals: Experience with other members of the health care team also seemed, for approximately half of the participants, to play a role in whether they accepted the additional psychological support offered. Mainly, if health care professionals (HCPs) met participants’ informational needs and addressed most physical or medical concerns, then participants trusted their core treating team and did not feel they needed support from additional HCPs. In addition, women stated that if their HCPs reassured them that in time “it would be better,” they just accepted that the situation was difficult for the present time and did not think much else could be done. However, for those who did not feel that reassurance, and needed additional information, they valued an opportunity to consult with another member of their health care team who could potentially reassure them that they were “not alone” and normalize their experience.

Perceived Ability to Independently Manage Cancer-Related Challenges: Three-quarters of the women who refused one-on-one counseling highly valued “working through it [herself].” According to one participant, “I’ve just got to work it out for myself…I’m the eldest of 9 children, so it’s sort of like…[when] we were brought up we had to do for ourselves, and I just [learned that] you don’t go asking people to do things for you, you do it yourself.” For some, accepting psychological assistance meant “you can’t cope with the situation” and was admitting a certain level of personal defeat, and they felt that, although they were confronted with several stressors, their situation was “not bad enough.” Approximately half of these participants mentioned that they would be willing to see the psychologist if they felt their coping strategies were ineffective and the situation was getting worse. Common coping strategies these participants described included self-talk, “being positive,” “preparing for the worst and hoping for the best,” setting goals, trying not to dwell on the negativity of the situation, re-framing, minimizing worries/anxieties, distraction (eg, keeping busy, a lot of hobbies), relaxation techniques (eg, deep breathing exercises), engaging in enjoyable activities (eg, part of a social group), and participating in religious activities (eg, praying). These coping strategies were often lifelong skills that had been used during
other stressful life events and were transferrable to current challenges.

Conversely, women who sought counseling often spoke of needing more information on how best to take care of themselves and cope with their overwhelming emotions and worries and the losses they were facing. Some women had tried to cope with the situation, but they felt they just did not have the skills to efficiently and effectively cope with the stressors they were facing. Many spoke of the intensity of the whirlwind of cancer, which had “robbed” them of any internal resources they had (eg, independence), and described feeling little control over the situation and like their ability to cope was “completely depleted.” Thus, usual approaches to coping with life stressors were not applicable or useful, and these women decided to “get help.”

Discussion

This study examined the perceptions of screening for psychological distress and subsequent referral among a group of women experiencing a level of distress generally taken to indicate a need for further assessment. The clinical significance of this issue is based on the concern that, regardless of the efforts directed at improving detection of distress, and the increasing evidence base regarding the effectiveness of psycho-oncology interventions, uptake of these interventions is generally low, raising issues regarding acceptance. The present study offered a better understanding of patients’ motives to accept or decline psycho-oncology services. Key findings of this study are that (1) receptivity to referral is a separate issue from that of distress level, (2) a subgroup of women expressed a strong preference to “cope” on their own, and (3) low social support was a major theme among those accepting the referral.

Although much attention has been given to validating the DT and exploring its acceptability among clinicians, no other study has examined its acceptability among women with gynecologic cancer. Participants in the present study had generally favorable attitudes toward distress screening. However, participants also clearly expressed that then being referred to a psychologist was a different matter, and for some, this referral did not match the main cause of their distress. This finding suggests that instead of offering a referral to a psychologist to all patients scoring greater than 4 on the DT, alternative follow-up services might be offered to improve acceptability, and ultimately use of psychosocial interventions and patient outcomes. For instance, the problem checklist was not used to guide clinical response, which might have led, in part, to a mismatch between the potential cause of the distress and the follow-up care offered, particularly among those who experienced physical rather than emotional distress, or expected their distress to be transient. Another suggestion is to consider whether a cutoff score of 4 or greater is most appropriate. Psychometric studies have suggested that increasing the cutoff score to 5, 6, or even 7 might be more appropriate to detect clinically significant distress. In settings in which a DT score of 4 or greater is still preferred, the suggestion is then to administer to patients scoring above the threshold a test with higher specificity to determine whether additional psychological assessment is needed. This approach acknowledges that the DT is a screening measure, not a diagnostic one. Another suggestion is to consider a stepped approach to care, in which the services offered are tailored to match an individual’s score on the DT. For instance, those with a lower score (4–6) might be offered less-intensive sources of psychosocial assistance (eg, self-help group, self-administered stress management interventions), and higher thresholds are set to justify referral to a psycho-oncology service (eg, DT ≥6 or 7).

Another important finding from this analysis is the preference of those who declined psycho-oncology referral to “cope” on their own, with an underpinning view that their current problems were not sufficiently severe to warrant psycho-oncology intervention, and that they had appropriate support from family and friends in place to help them in this process. This finding is consistent with those of other studies identifying patients’ preference to self-manage. To a certain extent, this finding suggests the perception of a dichotomy between self-care and seeking care (ie, that one is exclusive of the other), whereby expressing a need for support might be perceived as a sign of personal weakness and an admission of an inability to take care of oneself. Additionally, these data emphasize the potential role of self-management or self-directed interventions for this subgroup of patients. These interventions, which focus on empowering patients to effectively manage cancer challenges through the development of a core set of coping skills (eg, stress management, symptom management, problem-solving skills), are
highly acceptable to patients. A recent review by Beatty and Lambert found that Internet-based self-help therapeutic interventions were generally acceptable to patients and hold promise for improving distress and disease control among adults with chronic health conditions. The finding that many women preferred to cope on their own might also be a reflection of the stigma of seeking assistance, or a perception of expectations regarding how a patient with cancer should behave (e.g., stoicism in the face of cancer).

Another noteworthy finding is the extent to which perceived support from friends and family was a major theme differentiating between women who accepted the referral and those who did not. Although social support has not been found to predict completion of a psychosocial program, it is a key predictor of psychological outcomes among patients with cancer and their caregivers. However, measures of distress, such as the DT, fail to take into account the amount and quality of the social support patients receive from their network. This evidence might warrant considering whether combining the DT with a “social support thermometer” or another short measure of social support might help identify those in need of a referral. The theme of seeking support outside their family and friend network because of the concern of being a burden to those close to them was emphasized by women who accepted the referral, and corroborates findings from other studies, especially in the terminal illness literature. Although the partners’ and caregivers’ perspectives were not explored in the current study, other studies have reported that providing emotional support is one aspect of caregiving that is most challenging and anxiety-provoking.

Limitations
The study has several limitations. The context of this clinic and its model of service may limit the applicability of themes to other settings. Similarly, the findings pertain specifically to women with gynecologic cancer, and future work to corroborate and examine these themes across diverse cancer groups and cultural contexts would be beneficial. The focus on patients with moderate to high levels of distress provides information on those most likely to require psycho-oncology services, but limits the study through the absence of views from patients with less distress with whom to compare and contrast these findings. Although 3 interviewers were used throughout the study, no differences were noted in how the interview guide was used. However, differences were noted in the depth of the exploration according to interview length, with longer interviews typically resulting in a more comprehensive description of the phenomenon under study. Because no demographic data are available for those who did not participate in the interview, whether there was a systematic difference between those who participated in the study and those who refused cannot be determined.

Research Implications
Additional studies are needed to further examine, on a larger scale, patients’ preferences for follow-up care after distress screening. Several different approaches to distress screening were discussed, and additional studies should examine their comparative acceptability and efficacy. One particularly promising avenue for future research is to evaluate a stepped approach to care. Although this model of care has long been advocated in cancer care and seems particularly promising in light of the findings of the present study, few studies have examined its appropriateness and efficacy among patients with cancer. Moreover, examining the acceptability of combining the DT with other thermometers to measure key concepts that emerged from this study (e.g., a “social support thermometer”) is another potential focus for future research. Based on the finding that many women preferred to self-manage their distress, more research is needed to determine the kind of services these women would deem more acceptable to help them in their coping efforts.

Conclusions
This study is timely, particularly given that the popularity of distress screening is increasing exponentially, and begins to bridge the gap between clinicians’ and patients’ expectations of how psycho-social services should be used in response to distress screening. Key findings and implications for service delivery were: (1) receptivity to referral is a separate issue from that of distress level, (2) strong preference among those who declined psycho-oncology referral to cope on their own emphasized the potential role of self-management interventions, and (3) low social support was a major theme among those accepting referral, suggesting that assessing family support might further contribute to identifying patients in need of additional psychological assessment.
Lambert et al

References


