Detecting Distress
Introducing routine screening in a gynecologic cancer setting

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BACKGROUND: Cancer results in a wide range of challenges that contribute to patient distress. Detecting distress in patients can result in improved patient outcomes, and early intervention can avoid patients having unmet needs.

OBJECTIVES: The aims were to determine the prevalence of distress in patients with gynecologic cancers, identify specific problems, and explore staff perceptions of distress screening.

METHODS: A mixed-methods design was used. Quantitative data were collected on distress levels and problems. Qualitative interviews were conducted with healthcare professionals.

FINDINGS: Sixty-six percent of women scored 4 or greater on the Distress Thermometer, which was used as the indicator for follow-up or referral. A third reported low distress, and the same proportion was highly distressed. The top five problems identified by participants were nervousness, worry, fears, fatigue, and sleep problems.

ALONGSIDE PHYSICAL SYMPTOMS AND SIDE EFFECTS of treatment, cancer results in psychological, social, and practical challenges, which can contribute to patient distress (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013). The International Psycho-Oncology Society highlights distress as a critical factor affecting patients’ well-being and recommends that distress be named the sixth vital sign in oncology (Holland, Watson, & Dunn, 2011). The reported prevalence rates of psychological distress in patients with cancer range from 35%–49% (Carlson, Groff, Maciejewski, & Bultz, 2010). However, the actual rates of distress are thought to be much higher because of underdetection. Clinician assessments have been shown to be inferior to gold-standard methods, such as validated screening tools and clinical interviews (Werner, Stenner, & Schüz, 2012), and distress is often missed by clinicians (Mitchell, Vahabzadeh, & Magruder, 2011).

Distress encompasses a range of issues, including psychological, spiritual, and existential distress, as well as juggling roles and having financial concerns and practical problems, such as needing help with accommodation or travel. Distress is associated with poorer physical and psychological quality of life (Carlson et al., 2010). Detecting distress in patients with cancer can result in early intervention, which helps avoid patients struggling with unmet or complex needs (Faller et al., 2013). Identifying distress early could also reduce the financial burden on health services (Han et al., 2015). Healthcare professionals (HCPs) must recognize distress so it can be adequately managed (Werner et al., 2012); to do this, HCPs need to screen all patients systematically.

Several organizations and professional bodies state in their standards for quality cancer care that psychosocial support should include routine screening for distress, followed by appropriate referrals targeted to the needs identified by patients (Holland et al., 2011; Werner et al., 2012). Despite this, uptake of routine distress screening in clinical oncology settings has been suboptimal (Mitchell, Lord, Slattery, Grainger, & Symonds, 2012). Many barriers exist to the successful implementation of routine distress screening in clinical settings, including a lack of training, clinicians’ perception of limited skills and confidence in identifying distress, and inadequate referral resources (Absolom et al., 2011). A shortage of private space has also been identified (Ristevski et al., 2013). Many HCPs believe that addressing distress will take too much time. However, appropriate recognition and discussion of emotions can reduce consultation times (Butow, Brown, Cogar, Tattersall, & Dunn, 2002).

Roth et al. (1998) developed a single-item Distress Thermometer (DT), which the National Comprehensive Cancer Network (Vitek, Rosenzweig, &
were interviewed—three nurses, two social workers, and one and the range was 25—94 years (see Table 1). Six oncology HCPs were interviewed—three nurses, two social workers, and one physiotherapist.

**Methods**

A mixed-methods design was used. The current study was approved by the King Edward Memorial Hospital and Curtin University human research ethics committees. Qualitative data were collected on the DT and PL in a cross-sectional study. Qualitative interviews were conducted with HCPs.

The setting was a WA public women’s and newborns’ tertiary teaching hospital, King Edward Memorial Hospital, which is the direct referral pathway for women with gynecologic malignancies in the state. It offers the full range of services for inpatients and outpatients.

**Sample**

Sixty-two patients with gynecologic cancer in the pre-admission clinic, where women are seen prior to surgery, participated in the study during a six-month period. Women were included if they were aged 18 years or older, were diagnosed with a gynecologic cancer, and were able to comprehend and complete the DT and PL. Women who were aged younger than 18 years, had not received a gynecologic cancer diagnosis, were unable to comprehend or complete the DT and PL, or were unable to give informed consent were excluded. The median age was 58 years, and the range was 25—94 years (see Table 1). Six oncology HCPs were interviewed—three nurses, two social workers, and one physiotherapist.

“The current study investigated the impact of screening for distress in patients with gynecologic cancer in WA. The aims were to (a) establish the prevalence and level of distress and determine specific problems identified by patients and (b) explore staff perceptions of the process of using the DT and PL and referring patients.”

**Procedure**

At the pre-admission clinic, the research officer (RO) visited each patient, explained the research project, provided written information, and invited patients to participate. If the patient agreed to participate, she signed the consent form and was asked to complete the DT and PL on her own or with the RO. Following completion, the patient had a consultation with an oncology nurse on duty and, if necessary, the social worker who was present in the weekly clinic. DTs and PLs were evaluated by the oncology nurses who could triage and refer women to appropriate interventions according to distress and psychosocial management guidelines (National Breast Cancer Centre and National Cancer Control Initiative, 2003). The DT has a single item scored from 0 (no distress) to 10 (high distress), and the PL has 39 problems in five domains with “yes” or “no” responses.

At the completion of the project, HCPs were approached directly by the RO, consented, and interviewed at a time convenient to them. These interviews were conducted by a trained interviewer with extensive experience working with vulnerable populations. Interviews were digitally recorded.

**Analysis**

Data were entered into SPSS®, version 22.0. Descriptive statistics were used to describe the DT scores and problems identified. To examine between-group differences, Pearson chi-square test for independence and a one-way analysis of variance (ANOVA) were used. A Pearson product–moment correlation coefficient was used to look at the correlation between the number of problems and distress score.

Qualitative data from interviews conducted with HCPs were analyzed using directed content analysis (Hsieh & Shannon, 2005) because the focus was on how distress screening worked in clinical practice. Deductive category application was used; the text was read, and salient points were highlighted before developing the categories, using the interview questions as a guide. The analysis was undertaken by two of the authors. Rigor for the study was ensured by employing transparency, consistency, neutrality, applicability, and credibility (Emden and Sandelowski, 1998). An
audit trail of decisions was maintained, and the team met to discuss emerging themes and reach agreement.

Findings
Twenty-one participants scored from 0–3 on the DT, 20 participants scored from 4–6, and 21 participants scored from 7–10. For additional descriptive statistics, see Table 2. Of the problems identified on the PL, 207 were physical, 53 were practical, 24 were familial, 147 were emotional, and 2 were spiritual (see Figure 1).

Pearson chi-square test for independence indicated a significant association between age group (three categories: aged 40 years or younger, aged 41–64 years, and aged 65 years or older) and the three different distress score categories (0–3, 4–6, and 7–10) ($\chi^2 = 10.181$ [4, N = 62], p = 0.04, Cramer's V = 0.29 [a medium effect]). Nine participants aged 40 years or younger scored in the 7–10 range on the DT, compared to 10 participants aged from 41–64 years and 3 participants aged 65 years or older.

On average, patients aged younger than 40 years listed 8.31 problems (SD = 4.7), ranging from 2–19; patients aged 41–64 years listed 8.42 problems (SD = 6.35), ranging from 0–22; and patients aged 65 years or older listed 5.89 problems (SD = 5.18), ranging from 0–16. A one-way ANOVA showed no significant differences between age groups on the number of problems listed ($F[2, 54] = 1.2$, p = 0.31).

A Pearson product–moment correlation coefficient was used to determine the relationship between distress scores (continuous) and number of problems. A strong positive association was found between the two variables ($r = 0.53$, n = 57, $p < 0.0005$), with high levels of distress associated with a greater number of problems.

A Pearson chi-square test revealed significant differences between the specific types of gynecologic cancers and the three distress levels ($\chi^2[8] = 21.41, p = 0.006$, Cramer’s V = 0.42 [a large effect]). A larger proportion of participants with a diagnosis of cervical cancer scored in the 7–10 range on the DT (n = 10), compared to participants diagnosed with another gynecologic cancer (endometrial = 4, uterine = 4, ovarian = 3, vulvar = 0).

The main themes that emerged from qualitative data were benefits to patients and staff, challenges faced, and the impact of routine screening on services. Overall, HCPs indicated little impact on services. No increase in overall referrals or referrals to the social work department was noticed, and no extra need for counseling was identified.

Patient Benefits
Several perceived benefits to the patients were found, mainly around validating patients’ concerns and issues: “includes questions they may not have been expecting (allows them to think more broadly),” “gives patients permission [to talk] and includes questions not usually asked (sexual concerns),” and “normalizes

### TABLE 1.
SAMPLE CHARACTERISTICS (N = 62)

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>n</th>
</tr>
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<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Younger than 41</td>
<td>15</td>
</tr>
<tr>
<td>41–55</td>
<td>12</td>
</tr>
<tr>
<td>56–70</td>
<td>20</td>
</tr>
<tr>
<td>71–85</td>
<td>14</td>
</tr>
<tr>
<td>86–100</td>
<td>3</td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>12</td>
</tr>
<tr>
<td>Endometrial</td>
<td>9</td>
</tr>
<tr>
<td>Ovarian</td>
<td>17</td>
</tr>
<tr>
<td>Uterine</td>
<td>19</td>
</tr>
<tr>
<td>Vulvar</td>
<td>4</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
</tr>
<tr>
<td>Time since cancer diagnosis</td>
<td></td>
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<tr>
<td>2 months or less</td>
<td>38</td>
</tr>
<tr>
<td>2–12 months</td>
<td>16</td>
</tr>
<tr>
<td>12 months to 2 years</td>
<td>4</td>
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<tr>
<td>More than 2 years</td>
<td>4</td>
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<tr>
<td>Education</td>
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</tr>
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</tr>
<tr>
<td>Primary school</td>
<td>5</td>
</tr>
<tr>
<td>High school</td>
<td>27</td>
</tr>
<tr>
<td>Diploma, certificate, or trade qualification</td>
<td>18</td>
</tr>
<tr>
<td>University degree</td>
<td>7</td>
</tr>
<tr>
<td>Missing data</td>
<td>4</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Paid employment</td>
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</tr>
<tr>
<td>Pensioner</td>
<td>5</td>
</tr>
<tr>
<td>Self-funded retiree</td>
<td>27</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
</tr>
<tr>
<td>Missing data</td>
<td>11</td>
</tr>
</tbody>
</table>
Detecting Distress

Patient concerns (interview focused on the patients’ needs). It was also seen as a way of introducing a conversation about concerns by offering the patient a prompt and an ice breaker. As stated by one participant, “[Patients are] stoic, not wanting to be a burden, don’t expect help . . . struggle on until crisis.”

Staff Benefits

HCPs saw the tool as adding value in their work by validating what they do, empowering patients to help themselves, asking more detailed questions than routine surgical admission, enhancing normal practice, offering a more holistic approach, giving guidance on what the patients’ needs are, and avoiding missing important issues. One nurse thought it was a good education tool for honing in on what is important to ask, particularly when time is limited, saying, “DT and PL is a good education tool to inform HCPs on what to ask when limited amount of time.”

Another nurse talked about saving time by focusing on salient issues: “Using DT and PL as a prompt for patients can speed up assessment of needs by focusing on the items that matter to them at that moment in time.”

Challenges

Problems and barriers were perceived, mainly around time. The tool requires knowledge, experience, time allocated, and a sensitive approach. Finding time in a busy pre-admission clinic is difficult; extra time may be needed to complete the interview and document, but that may prevent increased distress later. In addition, the HCPs developed strategies to reduce time, including patients prioritizing issues and returning to others later, maybe by phone.

Another issue was when to administer the DT and PL. Participants found this difficult because patients need pain management postoperatively, and sedation may affect them. Participants said that ward staff should be able to administer the DT and PL as part of the discharge process.

Discussion

Screening for distress in this setting was successful, and patients were receptive to completing the DT and PL. This supports previous research demonstrating that the DT was feasible among patients with lung cancer (Lynch, Goodhart, Saunders, & O’Connor, 2011) and acceptable for distress screening in men with prostate cancer (Chambers, Zajdlewicz, Youlend, Holland, & Dunn, 2014). The current study identified challenges, including timing, access to the social worker, and space, but the team found ways around these barriers. The project proceeded in an iterative way, with regular meetings to resolve emerging issues. The researchers succeeded in securing a room to enable a social worker to be present for the pre-admission clinic to address patients’ needs. This modified approach normalized the referral, and patients were able to see the social worker as part of usual care during the same hospital visit.

Twenty-one participants reported low distress, and the same proportion was highly distressed. Forty-one women scored 4 or higher, which is deemed to be the optimal cutoff (Chambers et al., 2014; Donovan, Grassi, McGinty, & Jacobsen, 2014) and an indicator of distress that requires follow-up. This is similar to the 57% of women with gynecologic cancer scoring 4 or higher in a study by Johnson, Gold, and Wyche (2010). Twenty-one participants scored 7 or higher, which has been suggested to be a more appropriate cutoff than 4 (Lambert et al., 2014). This means that high levels of distress are present and need monitoring. The current findings closely mirror those from a WA study with clients of a not-for-profit organization (Watts et al., 2015). Distress was higher than reported in a study from Victoria, Australia (Williams, Walker, & Henry, 2015). This could be partly explained by the profile of participants; participants in the current study were all female patients with gynecologic cancer.

Two hundred twenty-six problems were psychosocial, and 207 were physical; most problems were related to physical and emotional symptoms. Nervousness, worry, and fears were the top three concerns. VanHoose et al. (2014) found that the greatest risk factor for distress was worry and suggested that worry may be a proxy for intensity of distress. Some worries can be allayed by active listening and responding to emotions with empathy, but high anxiety levels need referral. Sadness and loss of interest were in the top 10 concerns, which could be symptoms of depression. Fatigue, problems with sleep and eating, and pain need to be looked at carefully by the team to see how they can be alleviated. The main problems

**Table 2.**

TOP 10 INDIVIDUAL PROBLEMS IDENTIFIED IN THE PROBLEM LIST (N = 62)

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nervousness (emotional)</td>
<td>39</td>
</tr>
<tr>
<td>Worry (emotional)</td>
<td>33</td>
</tr>
<tr>
<td>Fears (emotional)</td>
<td>31</td>
</tr>
<tr>
<td>Fatigue (physical symptoms)</td>
<td>24</td>
</tr>
<tr>
<td>Sleep (physical symptoms)</td>
<td>23</td>
</tr>
<tr>
<td>Sadness (emotional)</td>
<td>21</td>
</tr>
<tr>
<td>Treatment decisions (practical problems)</td>
<td>18</td>
</tr>
<tr>
<td>Eating (physical symptoms)</td>
<td>17</td>
</tr>
<tr>
<td>Pain (physical symptoms)</td>
<td>15</td>
</tr>
<tr>
<td>Loss of interest in usual activities (emotional)</td>
<td>13</td>
</tr>
</tbody>
</table>
identified were similar to the study by Watts et al. (2015), in which the problems identified most frequently were psychological and emotional issues and difficulties with fatigue and memory. The current findings also reflect findings from Williams et al. (2015). Spiritual and religious concerns were reported by only two participants in the current study. Spiritual well-being in patients with cancer is associated with anxiety, depression, and fatigue (Rabow & Knish, 2015), so spiritual and existential fears may be incorporated into these areas. One item relating to spiritual and religious concerns on the PL may be insufficient to capture this issue.

Group differences were seen between older and younger patients for DT score, with a significant association between age group (40 years or younger, 41–64 years, and 65 years or older) and the three different distress score categories. Nine participants aged 40 years or younger scored in the 7–10 range on the DT, compared to 10 participants aged 41–64 years and 3 participants aged 65 years or older. However, no significant differences were seen in the number of problems between age groups. This supports VanHoose et al. (2014), who found that patients most at risk for distress were younger, and Johnson et al. (2010), who found that women aged younger than 60 years were more distressed in a sample of women with gynecologic cancers.

Significant differences also were found between the specific types of gynecologic cancers and levels of distress. This supports previous findings that patients with cervical cancer report worse quality of life than the general population and patients with other gynecologic cancers (Korfage et al., 2009).

Snowden et al. (2011) stated that qualitative data are almost entirely missing from the distress screening literature and few studies investigate how HCPs use the tool. Staff in the current study indicated high levels of satisfaction with the tool and found many benefits. Particularly, it normalized patients’ distress and gave them “permission” to open up. It also proved to be a conversation starter. These findings mirror conclusions by Carlson, Waller, and Mitchell (2012) and Williams et al. (2015), who found that use of the tool promoted communication between the patient and oncology team; Lynch et al. (2011), who suggested that the DT helped patients discuss their feelings and issues with HCPs and recognize the coping skills they already had in place; and Snowden et al. (2011), who highlighted the DT’s function as a facilitator of consultations.

A benefit mentioned by staff members in the current study was that they felt the tool validated what they do and provided guidance, which enhanced usual practice. The key challenge was finding time. However, HCPs were able to identify a range of strategies to overcome this barrier, including making follow-up telephone calls and prioritizing. Continuing professional development could help staff identify ways of managing time (Heyn, Ruland, & Finset, 2012). One HCP stated that using the DT saves time by focusing on salient issues, which contradicts many HCPs’ preconceptions that use of the tool can make consultations longer. Most of the support came from the nurses who were able to talk to the patients about their concerns, listen empathetically, normalize fears and anxieties, and assist in finding solutions. This could partly explain the perception that no additional referrals were needed. Another explanation of this observation was that the social worker was present at the clinic, so she may have been perceived to be part of the clinic team. In the current study, oncology nurses were seen as best placed to conduct the screening, but other models could be applied, such as screening by oncology social workers (BrintzenhofeSzoc et al., 2015).

**Limitations**

Uptake of referrals was not tracked because the patients were difficult to contact. The researchers did not approach everybody who attended the clinic because some people were seen quickly, some were missed because of a busy environment, and, on some days, no one was available to obtain consents. However, most patients were approached and very few women (fewer than 5) declined.

**Conclusion**

Findings will help to address the lack of systematic and formalized routine screening of patients for distress in WA. Screening facilitates conversations, helps normalize patients’ distress, and enables staff to identify issues promptly so that preventive action can be taken. This could prevent later intervention for crisis. Criticism of
the D'T has included that it lacks specificity in identifying problems. However, the current study demonstrates that the tool is useful for initial screening and identifying specific problems that can be followed up by appropriate HCPs. For oncology nurses, the key implications are that screening is useful and acceptable; distress levels are high (particularly in relation to anxiety and nervousness, resulting in the need for anxiety management), and younger patients may be more vulnerable to distress.

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