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# Changes in psychosocial distress and the number and types of problems reported by patients with cancer when routine screening is integrated within cancer services

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**Abstract**

**Background:** The impact of patient-reported outcome measures on patient outcomes in longitudinal clinical studies is poorly understood. This observational study explored longitudinal changes in distress and problems reported by cancer patients screened and managed in accordance with a clinical pathway for anxiety and depression (ADAPT CP), implemented over 12 months.

**Methods:** Patients reported distress using the Distress Thermometer and indicated reasons for distress using the 39-item Problem List across five domains: practical, social, emotional, spiritual/religious, and physical. Repeat screening occurred on average 3 monthly (quarterly).

**Results:** Six hundred sixty patients from 10 participating services completed 1,256 screening events over 12 months, reporting 8,645 problems. On average, more emotional (27–34%) and physical (19–22%) issues were reported across all quarters than practical (7–9%) and social (8–9%) issues. Distress and emotional, physical, practical, and social problems reduced from initial to follow-up screens, although the decrease in emotional problems over time was not significantly different than that of the other problems. Worry, fatigue, sleep difficulties, health of family members, and insurance/finances were more persistent problems.

**Conclusions:** Although distress and the change in the number of emotional concerns over time did not differ from other problems, rescreening is recommended within oncology settings to allow patients to indicate new or persistent problems and hospital staff to monitor and assess needs. Emotional concerns are high in oncology patients, suggesting the need for the prioritization of psychosocial care. These problems can persist over time due to their clinically challenging nature or because access to, or implementation of, evidence-based interventions are not yet widespread.

**Keywords:** Patient-reported outcomes, oncology, psychosocial, clinical pathway, patient care management, NCCN distress thermometer

## 1. Introduction

A cancer diagnosis is often accompanied by uncertainty and high levels of distress; one in two cancer patients experience significant distress.[1] Distress can arise from physical symptoms or treatment side effects, practical and social issues, or existential concerns eliciting fear, worry, or depression.[1,2] Because healthcare

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professionals' (HCPs') assessments of patient well-being often diverge from patients' own assessments,[3,4] it is important to capture information from patients directly (patient-reported outcomes [PROs])[5] to accurately assess distress and provide appropriate care. Non-concordance may be due to patient non-disclosure of distress or HCP misattribution of symptoms arising from distress (eg, nausea, issues with sleep) to the disease or treatment side effects.[6]

Patient-reported outcome measures (PROMs) are validated tools used to capture PRO information[7] at single[8] or multiple time points.[9] Routinely screening patients using PROMs is one component of patient-centered care where patients' preferences and needs are valued.[10] Capturing PRO data systematically over time can improve the safety and quality of oncology care at a population level.[11]

PROMs have been shown to facilitate communication between patients and HCPs, allowing patients to elaborate on their concerns and encouraging HCPs to routinely raise and review issues.[12,13] Information from PROMs enables the early detection and management of symptoms and treatment side effects, which patients may not have otherwise raised.[14] The use of PROMS has been shown to improve adherence to treatment, and disease and treatment outcomes, with the potential to reduce health service utilization and hospital length of stays.[15–18]

Although PROMs can enhance clinical care, the evidence is mixed regarding the impact of PROMs on patient outcomes.[19] Some studies found clinical improvements in health-related quality of life (HRQoL), psychosocial functioning, and physical functioning[8,15,20] after PROMS were introduced, whereas others have not.[8,21] This may in part be due to methodological limitations. A recent systematic review of randomized controlled trials (RCTs) (n = 22 studies) investigating the effectiveness of PROMs noted that of the cancer-related studies reviewed (n = 6), those failing to find an impact of PROMs administration on health outcomes had relatively small sample sizes.[22] Conversely, one of the very few larger-scale studies, a 4-year longitudinal evaluation of the effectiveness of PROMs in reducing pain and distress in outpatients at an oncology clinic[9] involving analysis of 26,385 screening occasions from 9,133 patients, reported a significant reduction in both pain and distress over time. However, this study was based in only one oncology clinic, and it is unclear how these findings would generalize across multiple sites and varying patient outcomes.

The impact of PROMs is likely to depend on clinical actions that follow such monitoring, rather than assessment alone. Very few of the studies reviewed had implemented PROMs within a clinical pathway (CP). As CPs provide standardized, evidence-based, detailed management plans, the use of PROMs without a CP may not be as impactful. We aimed to address these gaps by examining the impact of PROMs administered longitudinally within a CP to coordinate care, in multiple sites to a large cohort of cancer patients, on multiple patient outcomes.

Based on recommendations to integrate routine screening into cancer care,[23] an evidence-based CP for screening, assessing, and managing anxiety and depression in adult cancer patients (ADAPT CP) was developed in Australia.[24] An online portal operationalized the ADAPT CP,[25] providing a platform for patients to complete routine screening, alerting HCPs about patients requiring follow-up assessment when high distress levels were indicated, providing evidence-based recommendations for care, and sending alerts when patients were due to rescreen. The ADAPT CP was implemented as part of a large-scale cluster RCT (CRCT) across 12 cancer services within New South Wales, Australia, over a 12-month period.[26] The aim of the CRCT was to evaluate the appropriate "dose" of 2 implementation strategies in facilitating adherence to the ADAPT CP over 12 months. Services were randomized to receive a standard health service approach (core) or a supported approach (enhanced).[26] In all participating services, cancer service staff were invited to attend education sessions about the ADAPT CP and the portal and had access to online education modules on the importance of psychosocial screening, how to introduce and screen for anxiety and depression, triaging patients based on screening results, and making appropriate referrals based on symptom severity. In enhanced services, staff had more ongoing support in reviewing implementation success and addressing barriers across the implementation period.

For screening, patients initially completed the Distress Thermometer (DT) and Problem List (PL)[27] or the revised Edmonton Symptom Assessment Scale with the Canadian Problem List (ESAS-r)[28] (selected by service preference). Where cutoff scores were met, they also completed the Hospital Anxiety and Depression Scale (HADS)[29] to determine whether the distress was associated with symptoms suggestive of anxiety or depression or related to other areas of concern. The PROs collected included distress level (through DT) or anxiety and depression symptoms (through ESAS-r), and areas of concern (through PL or ESAS-r Canadian Problem List) categorized into domains. The DT is only an assessment of general distress, and the source of the distress may be related to physical, practical, social, emotional, or spiritual/religious concerns.

This study aimed to examine the changes in distress and the number and types of problems reported within the context of an observational study design. In a qualitative investigation into staff perceptions of the ADAPT CP,[30] staff expressed that ADAPT raised their awareness of psychological issues and provided them with the skills and confidence to be able to raise mental health concerns in routine practice and to manage psychological issues. Therefore, as routine screening became established and oncology HCP's awareness of distress and their skills in preemptively addressing and responding to these symptoms improved, we hypothesized that there would be a reduction in the average distress level and emotional concerns captured over each 3 months of screening over the 12 months in which ADAPT was implemented.

Second, as patients' identified concerns should have been addressed in accordance with the ADAPT CP, we hypothesized that distress and emotional concerns in subsequent screens would be less than that in initial screens.

Third, we hypothesized that there would be an association between the length of time that the ADAPT CP has been implemented within the service (ie, across each 3 months of screening) and screening occasion (ie, initial or subsequent screening) for distress and emotional concerns as HCPs' responses improved over time.

Finally, with cancer care consistent among patients, and the ADAPT CP focused on assisting services in identifying and managing anxiety and depression only, we hypothesized that the decrease in the number of emotional issues over each 3 months of screening (ie, quarter) would be greater than that in other issues (ie, physical, practical, and social).

## 2. Methods

### 2.1. Study setting and design

The ADAPT CP was implemented as a part of a CRCT for 12 months in 12 cancer services using staggered recruitment start

dates between November 2017 and December 2020. As most services (n = 10) chose to use the DT and PL and to eliminate confounding effects of slight differences in measurement approach, the two sites that elected to use the ESAS were excluded from this analysis and we report data collected from those 10 services only (Supplemental Digital Content, Figure 1, Table 1, http://links.lww.com/OR9/A58).

### 2.2. Site and patients

Seven services were in a major city, and three were in inner regional areas. Nine services were publicly funded, and one privately funded. Four services were classified as small (<100 new patients/year) and six as large (≥100 new patients/year). Four services had one psychosocial staff member onsite, four had 2–4 psychosocial staff, and two services had eight or more. Four services indicated that they had existing psychosocial screening processes in place before ADAPT CP implementation.

Three services chose to implement the ADAPT CP in a single department (medical, hematological, radiation, or surgical oncology), with other services implementing the ADAPT CP across two (n = 2) or more (n = 5) departments. Seven services opted to rescreen patients 3 monthly, whereas the other three services rescreened patients 2 monthly, 4 weekly, or initially 6 weekly for the first 6 months of the trial, then 3 monthly.[31] Seven services chose to screen new patients only, with the remainder including both new and existing patients. Patients were ineligible to screen if they were <18 years of age, unable to provide informed consent, deemed too unwell, had a cognitive impairment, or had insufficient English to complete the screening questions, although the use of interpreters or family members to assist patients was permitted.

### 2.3. Measures

The DT is a validated and reliable single-item measure of global distress level. Participants indicate level of distress on a visual analogue Likert scale ranging from 0 (no distress) to 10 (extreme distress).[27] Meta-analysis confirms that a cutoff score of ≥4 provides an acceptable balance between sensitivity and specificity in identifying cancer patients with high levels of distress.[32] The associated PL comprises 39 items of concern, which may contribute to distress, organized into five domains: practical (6 items), social (4 items), emotional (6 items), spiritual/religious (1 item), and physical (22 items). To identify possible cases of anxiety and depression, those who scored ≥4 on the DT were then prompted to complete the HADS.[29] As two-thirds of screening events were below cutoff scores on completion of the DT, and so did not trigger the HADS; the focus of the current analysis was solely on the findings from the DT and PL.

Patient demographic and clinical information were obtained from patient medical records and from information required for registration in the ADAPT Portal.

### 2.4. Procedure

Screening (through email, phone, in clinic) was integrated into routine cancer care as a key component of the ADAPT CP. Nominated staff at each service introduced patients to screening, registered patients in the ADAPT Portal, and followed up on screening results to triage patients for additional support where indicated.

### 2.5. Statistical analysis

Descriptive statistics for screening events were calculated with regards to the following: patient demographic (gender, age) and clinical (cancer diagnosis, cancer stage, time since diagnosis) characteristics, distress level on the DT, and the number and types of problems reported on the PL. As the number of items within each domain in the PL differs (eg, 6 vs 22 items in the emotional and physical domain, respectively), the mean number of problems reported across domains were standardized by dividing the total number of problems endorsed by the number of problems listed within that domain, converted into a percentage.

Although screening schedules varied across services, to examine the impact of the implementation of the ADAPT CP on patient outcomes as a function of time and screening event, screening events were first grouped according to 3-month blocks (ie, quarters), regardless of the service. Each quarter was composed of initial and subsequent screening events. Average distress levels and the average percentage of items selected within each PL domain over all screens were then calculated for each 3-month block. Within each quarter, screening events were further differentiated based on whether the screening event was an initial or a subsequent screen.

To test whether an association between quarter and screening occasion exists, a multilevel, mixed-effects, linear, regression model was run with cancer service and subjects as random effects, with potential confounders (age, gender, cancer stage, and time since diagnosis), and the interaction terms of quarter and screening occasion as fixed effects. Separate analyses were conducted for each outcome, specifically, distress level and the number of problems per domain. In the absence of a significant association, the same analysis was run but with quarter and screening occasion entered as fixed main effects. Chi-squared tests were used to determine whether there were significant differences in distress level and the proportion of problems in each domain from initial to subsequent screens.

The spiritual/religious domain was excluded from all analyses due to low frequencies. Statistically significant results were those where $p<.05$. All analyses were performed using Stata, version 17.0.

## 3. Results

### 3.1. Screening events and sample characteristics

Over the 12-month period across the 10 participating cancer services, 660 of the 1,212 patients (54%) registered onto the ADAPT Portal completed PROMs. The most common reasons for not screening were that the patient did not respond to the screening invitation (39% of non-screeners) or explicitly declined to screen (23% of non-screeners), although specific reasons were not captured. Some patients completed screening on multiple occasions (n = 342, 52%), with 178 completing screening twice, 107 three times, and 57 ≥4 times. In total, there were 1,256 screening events (Quarter 1 = 173; Quarter 2 = 311; Quarter 3 = 395; Quarter 4 = 377). There were more initial than subsequent screens in the first quarter and more subsequent than initial screens in the final quarter (Table 1).

Across all quarters, women made up 54–60% of the screening events (Table 1). Average age at screening ranged from 62.7 to 64.8 years. Breast and gastrointestinal cancers were common, with approximately one-third of participants having Stage IV cancers. On average, time since diagnosis was <6 months in half of patients at initial screening. As the focus is on screening events

and not on individual patients, patient characteristics are not reported here but are available in Supplementary Digital Content, Table 2, http://links.lww.com/OR9/A58.

### 3.2. Prevalence of distress as measured by distress thermometer

The average level of distress was 2.7 of 10, and averaged 3.1, 2.9, 2.7, and 2.5 per screening event in quarters 1–4, respectively. Distress level for initial and subsequent screens for each quarter is presented in Figure 1, with distress averaging 3.2 for initial screens and 2.3 for subsequent screens. The proportion of screening events with above-threshold (≥4) distress levels was 39% for initial screens and 27% for subsequent screens.

A multilevel, mixed-effects, linear, regression analysis was conducted to examine whether there were changes in distress over time, controlling for cancer service and subjects, and potential confounders. Because information on cancer stage and time since diagnosis was unable to be obtained for 236 of 1,256 screening events (19%), the analysis was conducted with 1,020 screening events. There was no significant association between quarter and screening occasion ($P = .95$), and thus, hypothesis 3 was not supported for distress: the reduction in amount of distress from initial to subsequent screens was not influenced by the length of time that the ADAPT CP had been implemented (ie, across the 3 month blocks; eg, there was no significant difference in the reduction of distress from initial to subsequent screens observed in the first quarter vs the last quarter). The same analysis was conducted but with quarter and screening occasion entered into the model as main effects (Table 2). There was no significant association between quarter and distress. Thus, hypothesis 1 was not supported for distress because distress did not decrease over the 12 months of ADAPT CP implementation. There was a significant association between distress and screening occasion as severity of distress decreased from initial to subsequent screens (MD = −0.51, 95% CI −0.86 to 0.16, $P < .01$), supporting hypothesis 2.

Across all screening events, younger age was associated with higher distress (MD = −0.03, 95% CI −0.04 to −0.01, $P = .001$). Distress levels decreased at 6–12 months since diagnosis (MD = −0.54, 95% CI −1.00 to −0.08, $P = .02$).

### 3.3. Frequency of problems reported as measured by problem list

In total, there were 8,645 problems reported, with an average of 6.9 problems per screening event. On average, more emotional (26.8–33.8%) and physical (18.5–22.2%) issues were reported than practical (6.8–9.4%) and social (8.0–9.4%) in each quarter (Fig. 2). The decrease in the number of emotional issues over each 3 months of screening did not differ significantly from the decrease in problems reported in the other domains ($P = .08$); therefore, hypothesis 4 was not supported.

Table 2 presents the results of the multilevel, mixed-effects, linear, regression analysis conducted separately for each domain, adjusting for the same potential confounders as in the analysis of distress. There was no significant association between quarter and screening occasion in the number of emotional problems reported ($P = .09$); thus, hypothesis 3 was not supported. There was also no significant association between quarter and screening occasion in the number of problems reported in the other domains ($P$ range .09–.71). Therefore, quarter and screening occasion were entered as main effects. There was no association between the number of emotional problems reported and quarter ($P = .86$); thus, hypothesis 1 was not supported. There was also no significant association between the number of social, practical, and physical problems reported and quarter ($P$ range .27–.94). The number of emotional problems was associated with screening occasion such that there was a decrease from initial to subsequent screens, supporting hypothesis 2. The number of problems reported in the *physical*, *practical*, and *social* domains also showed a significant decrease from initial to subsequent screen (Table 2).

Younger patients reported on average more problems in the *emotional* (MD = −0.55, 95% CI −0.76 to −0.35, $P < .001$), *practical* (MD = −0.35, 95% CI −0.44 to −0.26, $P < .001$), and *social* (MD = 0.19, 95% CI −0.29 to −0.09, $P < .001$) domains, with no effect of age on the average number of *physical* problems reported ($P = .15$) (Table 2).

### 3.4. Types of problems reported

To examine the changes in the number and types of problems, the proportion of the types of problems reported at initial and subsequent screens was calculated (Fig. 3). There was a significant decline from initial to subsequent screening for all items in the *emotional* domain. Worry was the most prevalent concern across both initial and subsequent screens. In the *practical* domain, the most common concerns were related to insurance/finances and treatment decisions, although there was a significant reduction from initial to subsequent screens in the reporting of issues relating to treatment decisions (16.5%–8.9%). In the *social* domain, the health of family members was the most persistent concern but declined in subsequent screens (17.1%–12.9%). There was a significant decline in the reporting of most *physical* concerns (Fig. 3). Reporting of tingling in hands/feet was the only issue that showed an increase from initial to subsequent screening (24.8%–29.9%). Sleep and fatigue were the most persistent problems. The results are also summarized by quarter in Supplementary Digital Content, Table 3, http://links.lww.com/OR9/A58.

## 4. Discussion

This study examined longitudinal changes in distress and the number and types of problems reported by patients with cancer following routine screening with PROMs as part of the ADAPT CP at 10 cancer services over a 12-month period. We thought that as staff were trained, became more confident, practiced, and received more feedback from their patient cohort regarding responding to common concerns, they would discuss and preemptively address concerns more effectively, and thus, distress and emotional concerns reported by patients would decrease over time (quarters). Although we could not formally test this hypothesis without a control group who did not participate in ADAPT, a decrease in patient distress over time would have supported this notion. However, this hypothesis was not supported, with no changes found in distress or the number of emotional issues reported over quarters.

Training in enacting the ADAPT CP was provided to all staff before implementation, and referral pathways for psycho-oncology support and resources available to support patients were clarified and amplified by the ADAPT CP. Staff themselves reported finding that the ADAPT CP increased their awareness of and confidence in managing psychosocial issues.[30] However, this study did not assess the actual impact of the training provided to

**Table 1**

**Sample demographic and clinical characteristics for screening events.**

| Characteristics[c] | Entire cohort (N = 1,256) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Quarter 1 (N = 173; 14%) | | | Quarter 2 (N = 311; 25%) | | | Quarter 3 (N = 395; 31%) | | | Quarter 4 (N = 377; 30%) | | |
| | Initial (N = 162) | Subseq.[a] (N = 11) | Total[b] | Initial (N = 222) | Subseq.[a] (N = 89) | Total[b] | Initial (N = 172) | Subseq.[a] (N = 223) | Total[b] | Initial (N = 104) | Subseq.[a] (N = 273) | Total[b] |
| Gender[b] | | | | | | | | | | | | |
| Male | 68 (42) | 7 (64) | 75 (43) | 88 (40) | 35 (39) | 123 (40) | 65 (38) | 97 (44) | 162 (41) | 57 (55) | 115 (42) | 172 (46) |
| Female | 94 (58) | 4 (36) | 98 (57) | 134 (60) | 54 (61) | 188 (60) | 107 (62) | 126 (57) | 233 (59) | 47 (45) | 158 (58) | 205 (54) |
| Age (in y) | | | | | | | | | | | | |
| Average (SD) | 65.1 (12.5) | 61.0 (10.9) | 64.8 (12.4) | 63.6 (12.5) | 63.5 (12.7) | 63.5 (12.6) | 63.9 (11.9) | 64.1 (12.1) | 64.0 (12.0) | 61.4 (13.1) | 63.2 (11.6) | 62.7 (12.0) |
| Cancer diagnosis[b] | | | | | | | | | | | | |
| Breast | 45 (27.8) | — | 45 (26.0) | 64 (28.8) | 25 (28.1) | 89 (28.6) | 64 (37.2) | 60 (26.9) | 124 (31.4) | 21 (20.2) | 82 (30.0) | 103 (27.3) |
| Gastrointestinal | 52 (32.1) | 8 (72.7) | 60 (34.7) | 65 (29.3) | 32 (36.0) | 97 (31.2) | 37 (21.5) | 70 (31.4) | 107 (27.1) | 30 (28.9) | 84 (30.8) | 114 (30.2) |
| Genitourinary | 17 (10.5) | 1 (9.1) | 18 (10.4) | 16 (7.2) | 10 (11.2) | 26 (8.4) | 15 (8.7) | 22 (9.9) | 37 (9.4) | 17 (16.4) | 26 (9.5) | 43 (11.4) |
| Gynaecological | 6 (3.7) | 2 (18.2) | 6 (3.5) | 16 (7.2) | 4 (4.5) | 20 (6.4) | 10 (5.8) | 12 (5.4) | 22 (5.6) | 2 (1.9) | 11 (4.0) | 13 (3.5) |
| Hematological | 7 (4.3) | — | 7 (4.1) | 9 (4.1) | — | 9 (2.9) | 6 (3.5) | 9 (4.0) | 15 (3.8) | 12 (11.5) | 14 (5.1) | 26 (6.9) |
| Head and neck | 13 (8.0) | — | 15 (8.7) | 14 (6.3) | 8 (9.0) | 22 (7.1) | 15 (8.7) | 18 (8.1) | 33 (8.4) | 2 (1.9) | 18 (6.6) | 20 (5.3) |
| Lung | 16 (9.9) | — | 16 (9.6) | 29 (13.1) | 7 (7.9) | 36 (11.6) | 17 (9.9) | 24 (10.8) | 41 (10.4) | 11 (10.6) | 23 (8.4) | 34 (9.0) |
| Melanoma and skin | 5 (3.1) | — | 5 (2.9) | 5 (2.3) | 2 (2.3) | 7 (2.3) | 4 (2.3) | 6 (2.7) | 10 (2.5) | 4 (3.9) | 8 (2.9) | 12 (3.2) |
| Neurological | — | — | — | — | — | — | 1 (0.6) | — | 1 (0.3) | — | 1 (0.4) | 1 (0.3) |
| Sarcoma | — | — | — | 2 (0.9) | — | 2 (0.6) | — | 1 (0.5) | 1 (0.3) | 1 (1.0) | 1 (0.4) | 2 (0.5) |
| Other | — | — | — | 2 (1.0) | — | 2 (0.6) | 1 (0.6) | 1 (0.5) | 2 (0.5) | 3 (2.9) | 3 (1.1) | 6 (1.6) |
| Cancer of unknown primary | 1 (0.6) | — | 1 (0.6) | — | 1 (1.1) | 1 (0.3) | 2 (1.2) | — | 2 (0.5) | 1 (1.0) | 2 (0.7) | 3 (0.8) |
| Cancer stage[b] | | | | | | | | | | | | |
| Stage 0 | 2 (1.2) | — | 2 (1.2) | 3 (1.4) | — | 3 (1.0) | — | 4 (1.8) | 4 (1.0) | 2 (1.9) | 2 (0.7) | 4 (1.1) |
| Stage I | 23 (14.2) | 2 (18.2) | 25 (14.5) | 22 (9.9) | 16 (18.0) | 38 (12.2) | 24 (14.0) | 26 (11.7) | 50 (12.7) | 11 (10.6) | 40 (14.7) | 51 (13.5) |
| Stage II/III | 55 (34.0) | 2 (18.2) | 57 (33.0) | 72 (32.4) | 31 (34.8) | 103 (33.1) | 58 (33.7) | 72 (32.3) | 130 (32.9) | 35 (33.7) | 81 (29.7) | 116 (30.8) |
| Stage IV | 61 (37.7) | 1 (9.1) | 62 (35.8) | 83 (37.4) | 32 (36.0) | 115 (37.0) | 44 (25.6) | 86 (38.6) | 130 (32.9) | 47 (45.2) | 92 (33.7) | 139 (36.9) |
| Missing | 21 (13.0) | 6 (54.6) | 27 (15.6) | 42 (18.9) | 10 (11.2) | 52 (16.7) | 46 (26.7) | 35 (15.7) | 81 (20.5) | 9 (8.7) | 58 (21.3) | 67 (17.8) |
| Time since diagnosis (in mo)[d,e] | | | | | | | | | | | | |
| <3.0 | 63 (38.9) | 1 (9.1) | 64 (37.0) | 93 (41.9) | 3 (3.4) | 96 (30.9) | 83 (48.3) | 4 (1.8) | 87 (22.0) | 26 (25.0) | 5 (1.8) | 31 (8.2) |
| 3.0–5.9 | 31 (19.1) | 3 (27.3) | 34 (19.7) | 38 (17.1) | 35 (39.3) | 73 (23.5) | 27 (15.7) | 62 (27.8) | 89 (22.5) | 28 (26.9) | 28 (10.3) | 56 (14.9) |
| 6.0–11.9 | 19 (11.7) | 1 (9.1) | 20 (11.6) | 30 (13.5) | 17 (19.1) | 47 (15.1) | 22 (12.8) | 78 (35.0) | 100 (25.3) | 14 (13.5) | 123 (45.1) | 137 (36.3) |
| 12.0–59.9 | 37 (22.8) | 3 (27.3) | 40 (23.1) | 47 (21.2) | 27 (30.3) | 74 (23.8) | 30 (17.4) | 65 (29.2) | 95 (24.1) | 29 (27.9) | 100 (36.6) | 129 (34.2) |
| ≥60.0 | 8 (4.9) | 1 (9.1) | 9 (5.2) | 7 (3.2) | 5 (5.6) | 12 (3.9) | 6 (3.5) | 10 (4.5) | 16 (4.1) | 2 (1.9) | 10 (3.7) | 12 (3.2) |
| Missing | 4 (2.5) | 2 (18.2) | 6 (3.5) | 7 (3.2) | 2 (2.3) | 9 (2.9) | 4 (2.3) | 4 (1.8) | 8 (2.0) | 5 (4.8) | 7 (2.6) | 12 (3.2) |

[a] "Subseq." refers to subsequent screens.
[b] Proportions based on the number of screening events within each quarter.
[c] The figures are presented as frequency (percentage).
[d] This is defined as the length of time (measured in months) between a screening event and the date of diagnosis.
[e] For ease of interpretability, 3.0–5.9 months will be referred to in the text as 3–6 months, 6.0–11.9 months as 6–12 months, 12.0–59.9 months as 1–5 years, and ≥60.0 months as ≥5 years.

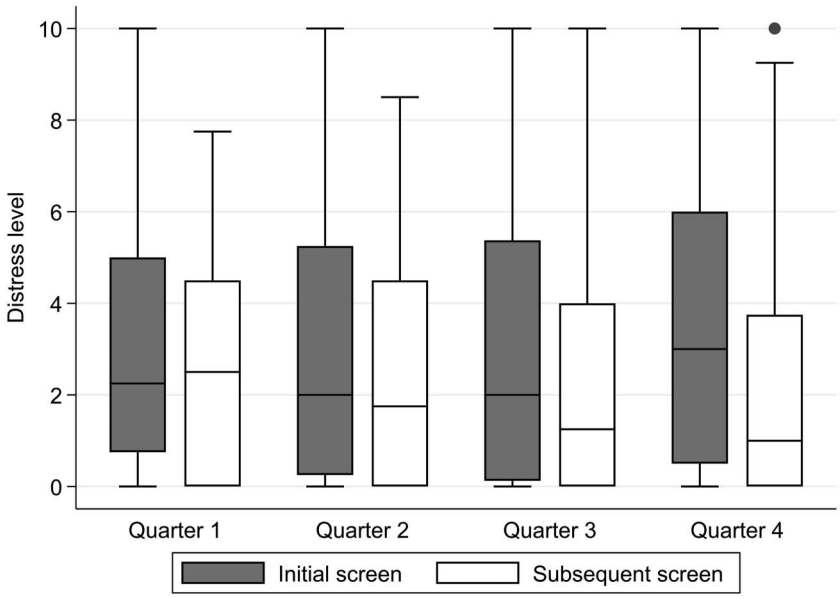


**Figure 1.** Distress level for initial and subsequent screens per quarter.[a] [a]Dot represents an outlier.

staff in being able to identify and address patient psychosocial issues. Furthermore, services motivated to participate in the ADAPT CP may have had a greater focus on psychological care than those who did not, with staff already aware of and addressing psychosocial issues. Finally, the ADAPT CP may have failed to have a sufficient additional impact on staff behavior to impact patients' distress and emotional concerns over time. Indeed, some staff reported barriers to implementation, which reduced their engagement with the ADAPT CP.[30] Identifying and addressing implementation barriers remain vital if such interventions are to be successful, particularly in the discipline of psycho-oncology where implementation has been identified as a research and clinical priority.[33]

Our second hypothesis that if staff were effectively addressing issues identified when patients screened for the first time, patient distress and emotional concerns would reduce in subsequent screens was supported. This provides empirical support for the routine use of PROMs in oncology services to increase discussion and management of psychosocial issues, as has been strongly advocated by psycho-oncology experts.[34] Alternatively, patients' distress and emotional needs may have decreased over time in any case as they adjusted to the diagnosis and completed treatment. However, as one-third of screens were completed by patients with advanced cancer, whose condition may well have worsened over time, this explanation is less compelling. Notably, the difference in distress and emotional concerns between initial and subsequent screens was stable over time (in contradiction to hypothesis 3). An assessment of the effectiveness of the training provided to staff in identifying and managing psychosocial issues may have helped elucidate the impact of the training received on patient outcomes.

There were also significant reductions in the number of physical, practical, and social issues reported from initial to subsequent screens, which were not expected (second hypothesis) because the ADAPT CP does not address these types of problems. In addition, the decrease in the number of emotional problems over time did not significantly differ from that of other problems (hypothesis 4). These results suggest either that the ADAPT CP was ineffective in specifically improving staff management of emotional issues or, indeed, that routine screening provided an opportunity for patients to discuss not only emotional concerns but also to convey information about physical, social, and practical concerns. Indeed, other studies[19,35] have found that routine use of PROMs increases discussion of symptoms and emotional concerns in consultations. This finding is promising for an integrated, wholistic approach to care.

Our inability to demonstrate improved psychosocial outcomes over time for services implementing a clinical pathway for anxiety and depression is in contrast to earlier studies, which did demonstrate such an improvement. Clover and colleagues, for example, found that distress over threshold (4/10) reduced from 28% to 10% over four years of implementing QUICATOUCH, an intervention comprising screening, clinician alert for patients requiring follow-up and a speciality psycho-oncology service, at one hospital.[9] In Clover's single institution study, the on-site availability of a psycho-oncology service may have been a key factor in improving outcomes; in our study of implementing the ADAPT CP in oncology services, many services were operating in hospitals with minimal psychosocial staff, making it more difficult to ensure effective management of identified concerns. The need for adequate psycho-oncology staff has been previously highlighted; Rankin et al,[36] noted in their survey of 26 oncology services in NSW Australia, that 58% of psycho-oncology staff said that they could provide only limited (27%) or very limited (31%) services, due to inadequate resourcing.

The fact that average distress levels remained somewhat elevated for some patients, and some problems remained consistently present while new issues emerged over time, provides strong support for the importance of rescreening. Rescreening allows patients to report new or persistent problems and for staff to monitor and reassess needs.[24] The increase in the number of subsequent screening events over time suggests that there is good uptake of rescreening.

One of the aims of this study was to examine the types of problems reported over time. The most frequently reported problems in this study were those related to worry, treatment decisions, insurance/financial stress, concerns around the

**Table 2**

**Results of the multilevel, mixed-effects, linear, regression analysis.**

| | Distress | | | Emotional | | | Physical | | | Practical | | | Social | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | MD[a] | CI[b] | *P*[c] | MD[a] | CI[b] | *P*[c] | MD[a] | CI[b] | *P*[c] | MD[a] | CI[b] | *P*[c] | MD[a] | CI[b] | *P*[c] |
| Quarter | | | 1.00 | | | .86 | | | .94 | | | .30 | | | .27 |
| 1 | Referent | | | Referent | | | Referent | | | Referent | | | Referent | | |
| 2 | −0.01 | −0.49 to 0.47 | | 0.71 | −4.14 to 5.56 | | −0.34 | −2.78 to 2.11 | | 0.73 | −1.62 to 3.08 | | 1.38 | −1.39 to 4.15 | |
| 3 | −0.01 | −0.54 to 0.51 | | −0.17 | −5.64 to 5.29 | | −0.19 | −2.93 to 2.56 | | −1.02 | −3.62 to 1.58 | | −0.73 | −3.75 to 2.30 | |
| 4 | 0.02 | −0.55 to 0.58 | | 1.31 | −4.71 to 7.32 | | 0.28 | −2.74 to 3.30 | | 0.02 | −2.82 to 2.85 | | 0.48 | −2.78 to 3.74 | |
| Screening occasion | | | **<.01** | | | **<.001** | | | **<.01** | | | **.022** | | | **.022** |
| Initial | Referent | | | Referent | | | Referent | | | Referent | | | Referent | | |
| Subsequent | −0.57 | −0.95 to −0.19 | | −7.65 | −11.61 to −3.68 | | −3.13 | −5.11 to −1.14 | | −2.20 | −4.09 to −0.31 | | −2.56 | −4.76 to −0.36 | |
| Age | −0.04 | −0.06 to −0.02 | **<.001** | −0.55 | −0.76 to −0.35 | **<.001** | −0.08 | −0.18 to 0.03 | .15 | −0.35 | −0.44 to −0.26 | **<.001** | −0.19 | −0.29 to −0.09 | **<.001** |
| Gender | | | .60 | | | .39 | | | .71 | | | .38 | | | **.48** |
| Female | Referent | | | Referent | | | Referent | | | Referent | | | Referent | | |
| Male | 0.12 | −0.31 to 0.55 | | −2.23 | −7.33 to 2.88 | | −0.48 | −3.03 to 2.07 | | 1.009 | −1.25 to 3.27 | | −0.90 | −3.40 to 1.59 | |
| Cancer stage | | | .36 | | | .51 | | | .40 | | | .47 | | | .71 |
| Stage 0 | Referent | | | Referent | | | Referent | | | Referent | | | Referent | | |
| Stage I | 0.74 | −1.12 to 2.60 | | 5.19 | −16.79 to 27.18 | | 2.25 | −8.75 to 13.25 | | 0.51 | −9.23 to 10.26 | | −2.83 | −13.58 to 7.92 | |
| Stage II/III | 1.09 | −0.72 to 2.91 | | 8.92 | −12.53 to 30.36 | | 4.92 | −5.81 to 15.65 | | 2.91 | −6.60 to 12.42 | | −4.41 | −14.90 to 6.08 | |
| Stage IV | 1.16 | −0.65 to 2.98 | | 10.18 | −11.30 to 31.65 | | 4.80 | −5.94 to 15.54 | | 1.78 | −7.74 to 11.30 | | −4.28 | −14.78 to 6.22 | |
| Time since diagnosis (in mo) | | | **.04** | | | .24 | | | .02[d] | | | .46 | | | .07 |
| <3.0 | Referent | | | Referent | | | Referent | | | Referent | | | Referent | | |
| 3.0–5.9 | 0.13 | −0.34 to 0.61 | | −0.87 | −5.73 to 3.99 | | 2.24 | −0.19 to 4.68 | | 0.93 | −1.41 to 3.26 | | 2.27 | −0.48 to 5.01 | |
| 6.0–11.9 | −0.50 | −1.010 to −0.007 | | −5.48 | −10.78 to −0.18 | | −1.60 | −4.24 to 1.04 | | −0.30 | −2.81 to 2.22 | | 1.99 | −0.95 to 4.92 | |
| 12.0–59.9 | −0.19 | −0.74 to 0.36 | | −3.61 | −9.81 to 2.59 | | −0.86 | −3.91 to 2.20 | | 0.84 | −1.97 to 3.64 | | 3.30 | 0.11 to 6.48 | |
| ≥60.0 | 0.49 | −0.56 to 1.55 | | −2.73 | −14.83 to 9.38 | | −1.26 | −7.30 to 4.78 | | 3.84 | −1.60 to 9.29 | | 8.17 | 2.09 to 14.25 | |

[a] Mean difference: Positive values indicate on average higher distress/greater number of problems, whereas negative values indicate on average lower distress/fewer number of problems. For categorical variables, these represent the average difference for a category when compared with the reference group. For continuous variables, these represent a 1-unit increase/decrease.
[b] 95% confidence interval.
[c] Statistically significant results were those where $P < 0.05$.
[d] This result was not reliable as the overall *P* value of the main effect was significant ($P < 0.05$), but there were no significant differences between the referent and the other categories.

health of family members, fatigue, sleep, and memory/concentration. Prior research also demonstrates that worry is a predominant issue for cancer patients,[37] due to concerns around treatment and its side effects, disease progression or recurrence, and the impact of cancer on relationships and work.[38] Research shows that one in two cancer patients who exhibit high levels of distress also endorse worry as a concern.[39] Despite emotional morbidity decreasing over time in this study, worry remained high across screening occasions. Although some worry is understandable, the prominence of worry as a concern suggests that screening for clinical levels of anxiety is important. As there are now evidence-based, effective interventions for anxiety[40,41] and concerns such as fear of cancer recurrence or progression,[42,43] the early identification of anxiety-related symptoms and referral to appropriate health professionals for management is recommended. Building capacity of frontline clinicians to explore and respond to underlying worries and concerns is also warranted.

Prior research also highlights that 80% of cancer patients indicate financial issues as a concern, particularly in the later stages of treatment.[44] Recently, there have been calls to better address financial toxicity through greater transparency at all stages of cancer care, promotion of informed choice, and financial advice and support.[45] Our findings indicate persistent financial concerns, further highlighting the need for early integration of such services. Common physical symptoms reported here and in the literature were issues with sleep and fatigue.[46,47] Their persistence as predominant concerns indicate a need for further research to identify effective interventions to better address these common sequalae of cancer treatment.

Demographic and clinical factors were also associated with distress and the number of issues reported. Distress and emotional, practical, and social concerns were higher in younger patients in line with previous research,[48] possibly due to their stage in life with many child-rearing and work responsibilities,

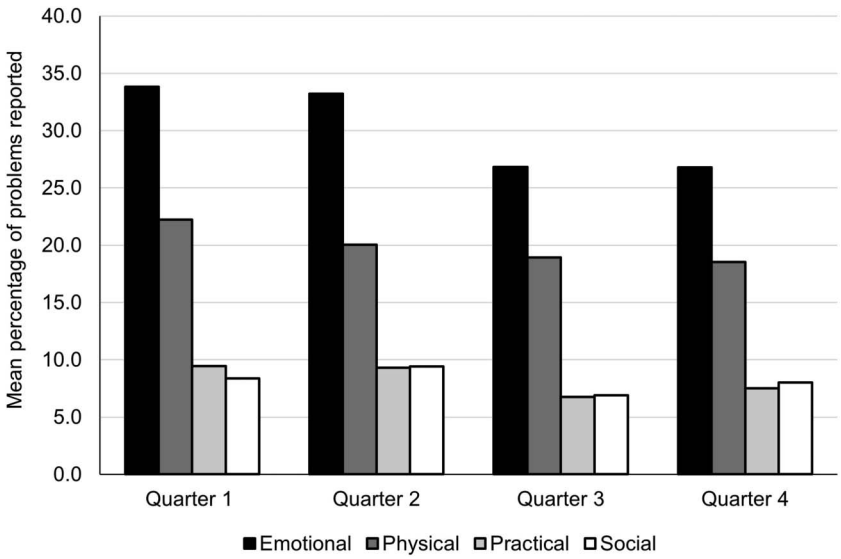


**Figure 2.** Standardized mean percentage of problems reported per domain across each quarter.

and the potential for more years to be lost due to cancer.[46,49] Alternatively, because of having more life experience, older adults may have developed greater emotional resilience and coping strategies to deal with stressful life events, such as a cancer diagnosis.[50] One study reported that every 1-year increase in age was associated with a 3% reduction in distress levels.[51] Thus, young age is a vulnerability factor for distress, signaling the need for additional protective measures for identifying and managing distress in younger patients. However, screening for vulnerabilities more generally to identify those at risk is also important.

Time since diagnosis was related to increased physical problems reported at 3–6 months, when patients are likely receiving active treatment and experiencing diverse physical side effects. Thus, intervention is particularly important at this stage to improve patient HRQoL and decrease the likelihood of reduced adherence and treatment delays due to the impact of side effects.

A limitation of this study was that the patient sample was mostly composed of breast or gastrointestinal cancer diagnoses, and those who were <3 months since diagnosis, and the results need to be considered in light of this. Also, it was not possible to capture data on the distress and concerns of all patients in services where the ADAPT CP was implemented. Because of the nature of some cancers, patients may be too unwell to complete screening questions or discharged from services shortly after surgery. Some patients registered in the portal also declined screening altogether, limiting the generalizability of our findings to the total population of cancer patients within those services. Despite attempts to control for possible confounds, a limitation of this study was the lack of a control group consisting of patients who did not complete the screening. Therefore, the results may only be interpreted as observational rather than causal. However, a major strength is the diversity of participating cancer services, which differed according to public/private care offered, location, and

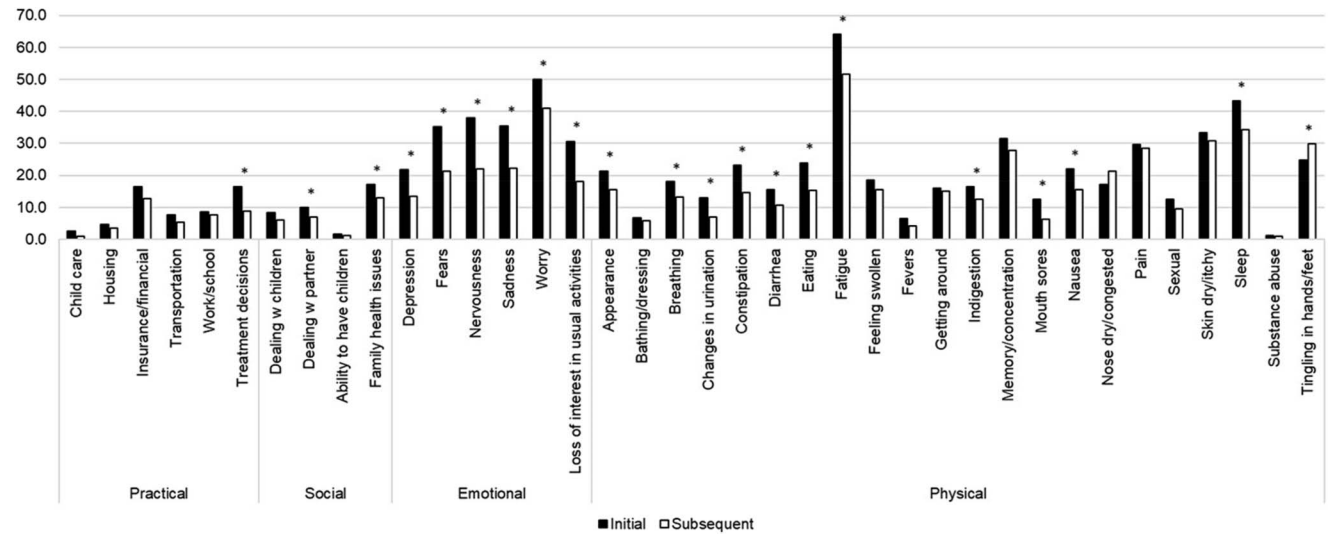


**Figure 3.** Proportion of the types of problems indicated in initial and subsequent screens (asterisks indicates $P < .05$).

patient load, as well as the large number of screening episodes recorded.

## 5. Conclusion

The implementation of routine distress screening within cancer services over a 12-month period was not associated with changes in distress or the number of emotional issues reported. This may be due to the services participating in the ADAPT CP already focusing on the psychosocial care of patients or due to implementation barriers. Regular rescreening and assessment showed reductions in distress and number of issues identified from initial to subsequent screening. This suggests that repeated screening provides opportunity to identify new and persistent issues but also that continuity of care within a cancer service reduces concerns as information and illness experience is gained and shared. However, the number of emotional concerns reported over time did not differ from the reporting of other problems suggests that, although this is a promising finding for a wholistic approach to healthcare delivery, addressing implementation barriers remains a priority in psycho-oncology research and practice.

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Data availability: The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval: This research is being conducted in accordance with the Declaration of Helsinki and Ethical Approval for this study has been granted by Sydney Local Health District (RPAH Zone) Human Research Ethics Committee, Protocol X16-0378 HREC/16/RPAH/522. Research Participation Agreement and Governance Approvals have been obtained from individual participating institutions.

Consent to participate: Patients at each site participate in screening as part of routine care. This research includes aggregated data.

Consent for publication: This research used routinely collected data and does not include individually identifiable data. Consent for publication was not necessary.

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