

A nurse-assisted screening and referral program for depression among survivors of colorectal cancer: feasibility study

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Inadequate attention has been given to the psychosocial care of patients with cancer who have completed active treatment and are identified as survivors.^{1,2} Cancer survivors are vulnerable to distress on completion of treatment because of the reduced frequency of clinician visits, the change in daily routines, adjustment to treatment-related side effects, unease about the future and concern about potential recurrence of the disease.³

To be effective, screening for distress requires a systematic approach.⁴ In the absence of formalised screening procedures, studies have shown that health professionals were unskilled at recognising clinically significant distress in patients with cancer and cancer survivors.^{5,6} Distress in patients with cancer and cancer survivors is often under-recognised by health professionals,⁷ and remains unexamined unless symptoms or signs are observed in a troubled patient or disclosed by patients themselves.

To guide the development of a systematic approach to screening for distress, a screening and referral program was developed making use of the cancer helpline, operated by the Cancer Council Victoria. It was envisaged that this program could improve the psychosocial care of survivors of cancer after their treatment. Linking an existing telephone information and support service to survivors who have recently completed their treatment is a model of care that carries potential for real change in the delivery of services to post-treatment survivors.

Colorectal cancer (CRC) was chosen for three reasons. First, it is the second most frequently diagnosed cancer in Australia.⁸ Second, it is often stigmatised because it involves more intimate parts of the body, bodily functions and potential changes in quality of life with a reorientation of bowel habits.⁹ Third, limited research has been undertaken to address the unmet psychological needs of people affected by CRC, particularly in the period beyond completion of treatment.¹⁰

The aim of this study was to test the feasibility and acceptability of screening for distress among patients with CRC who had completed active treatment. Patients identified as having elevated levels of distress were

ABSTRACT

Objective: To test the feasibility and acceptability of a telephone-based program to screen survivors of colorectal cancer (CRC) for distress, and to refer distressed patients to their treating health service.

Design, setting and participants: A prospective, multicentre study involving 59 patients with CRC recruited from six public and private health services in Melbourne, Victoria, from 15 June 2008 to 22 September 2009. Patients who had completed adjuvant chemotherapy for CRC were contacted (7–10 days after recruitment [outcall one] and again 4 weeks later [outcall two]) by the Cancer Council Victoria's helpline nurse, and screened for distress with the Distress and Impact Thermometer (DIT); participants were given tailored information and support and those with distress scores of ≥ 5 , and impact scores of ≥ 4 , were referred for follow-up. Telephone interviews were conducted 4 weeks after outcall two. Participating helpline and health service staff were surveyed on the feasibility and acceptability of the service.

Main outcome measure: Anxiety and depression, measured by the Hospital Anxiety and Depression Scale (HADS).

Results: Of the 59 patients (87%) who agreed to participate, 63% were men; their mean age was 59 years (SD, 9.5 years). HADS depression decreased significantly from baseline (mean score, 4.93; SD, 4.22) to follow-up (mean score, 3.84; SD, 4.10; $Z = -2.375$; $P = 0.02$). However, there was no significant difference in HADS anxiety between baseline (mean score, 5.29; SD, 4.11) and follow-up (mean score, 4.78; SD, 3.65). Outcall one generated two referrals (4% of participants) and outcall two generated four referrals (8%); five of these six participants took up the referrals. Satisfaction with the program among participants was high; 82% found outcall one "quite or very helpful" and 79% found outcall two "quite or very helpful". Helpline and health service staff reported a straightforward process that did not adversely affect workloads.

Conclusion: This model of care carries the potential to meet ongoing psychosocial needs of survivors of CRC.

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referred to psychological or social work services at their treating health service.

METHODS

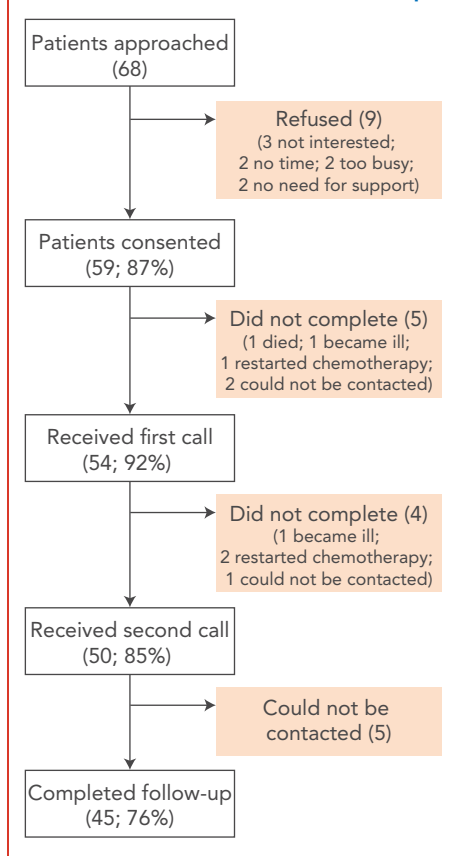
This was a prospective, multicentre study, involving patients with CRC from six public and private health services across Melbourne, Victoria.

Eligible patients had potentially curable CRC, and were aged 18 years and over, able to speak and read in English, and nearing completion of postoperative adjuvant chemotherapy. Patients were identified from ambulatory chemotherapy units by oncology nurses assigned to recruit eligible patients from 15 June 2008 to 22 September 2009. Recruitment nurses were provided with standardised recruitment procedures to follow, and were contacted each week by the project coordinator to monitor the recruit-

ment process. At the second-last chemotherapy cycle, the oncology nurse asked eligible patients if they were willing to receive a call from the cancer nurse at the Cancer Council Victoria's helpline. At the final treatment cycle, patients completed the consent form, demographic and baseline questionnaires. Participant details were then passed on to the helpline nurse assigned to the project.

Cancer helpline nurses have postgraduate qualifications in oncology, palliative care or both, including counselling, and have a minimum of 5 years' clinical oncology experience. The helpline information and support program is structured on the clinical practice guidelines for the psychosocial care of adults with cancer by the National Breast Cancer Centre and National Cancer Control Initiative,¹¹ and focuses on a patient-centred approach.¹² An ongoing training and education program is provided to staff. All calls

1 Recruitment and loss to follow-up



are recorded and reviewed for quality assurance.

The helpline nurse assigned to this project was trained in research methods and the intervention protocol, including completion of records and standardisation of telephone calls. A single helpline nurse was assigned to the project to ensure consistency with the protocol.

Following the standardised intervention protocol, the nurse telephoned participants 7–10 days after recruitment (outcall one) and 4 weeks later (outcall two). During both calls, the helpline nurse administered the Distress and Impact Thermometer (DIT),^{13,14} provided tailored information, support and resources, and referred participants with distress levels of 5 or higher to psycho-oncology services at the patient's health service. The DIT is a brief screening tool for the detection of distress and/or major depression.^{13,14} It is a two-item self-rated scale that rates the level and impact of distress. Each "distress" and "impact" question is scored along an 11-point scale, and the scores range from zero to 10, with scores of 5 or higher for distress and 4 or higher for

impact reflecting moderate to severe distress that warrants follow-up care.¹⁴ This tool has shown high performance¹⁴ and is feasible for use by community-based cancer helpline operators to screen callers for distress.¹⁵ The cancer nurse at the Cancer Council Victoria's helpline referred participants with elevated distress levels to their treating health service's psycho-oncology service for follow-up care, and requested permission from the participant to send a letter to the patient's nominated general practitioner to advise of the screening process and outcome. The helpline nurse telephoned the psycho-oncology staff, with a follow-up email, advising them of the patient's contact details and DIT score. The project coordinator was in regular contact with the helpline nurse and health service psycho-oncology staff to monitor the intervention and discuss specific issues.

Before the intervention, psycho-oncology staff (the social worker or psychologist employed at each of the health services) were approached and agreed to participate in the study. Follow-up outcomes were documented on a health service outcome form that was completed by the psycho-oncology staff on completion of the contact and forwarded to the project coordinator. Outcomes comprised recommendations including referrals to the patient's GP or psychologist, one or more follow-up counselling sessions with health service psycho-oncology staff or referral to a local welfare agency.

Study questionnaires were self-administered at baseline and administered through a telephone interview by an experienced interviewer one month after outcall two. The main outcome measure was anxiety and depression, measured using the Hospital Anxiety and Depression Scale (HADS).¹⁶ The HADS consists of two subscales, one assessing depression (seven items) and the other assessing anxiety (seven items), with scores ranging from zero (no distress) to 21 (maximum distress) for each scale. Scores of 11 or higher on either subscale are considered to indicate a significant "case" of psychological morbidity, scores of 8–10 represent borderline morbidity and 0–7 reflect a normal range.^{17,18} The HADS has been used in many research settings and clinical studies, particularly for patients with cancer.¹⁹

Telephone interviews included questions with both open-ended and forced-choice responses. The open-ended questions were

concerned with participants' experience of the referral process, timing, and overall expectations of the outcall program. The forced-choice responses asked participants to rate the helpfulness of the calls using a three-point scale. Postintervention questionnaires were sent to the helpline and the health services, to determine the feasibility and acceptability of the program.

Ethics approval for the study was received from Deakin University, the Cancer Council Victoria and each of the participating public and private health services before commencement of the study.

Statistical analysis

Patients' demographic characteristics, including age, sex, country of birth, employment status and marital status, were obtained at baseline. Descriptive statistics were used to describe the sample demographic characteristics and levels of distress, anxiety and depression. Due to the dispersed nature of the data, non-parametric tests were used: Wilcoxon signed ranks test compared baseline and follow-up levels of anxiety and depression, and Mann-Whitney U tests and χ^2 tests compared the demographic characteristics and baseline outcome scores of those who did and did not complete follow-up. Thematic analyses were used to identify the main themes from the open-ended questions. All statistical analyses were performed using SPSS, version 17.0 for Windows (SPSS Inc, Chicago, Ill, USA).

RESULTS

Overall, 59 (87%) of the 68 patients with CRC who were approached agreed to participate. Forty-five participants completed both interventions and the follow-up interview. Reasons for loss to follow-up included: significant illness; could not be contacted; deceased; and restarted chemotherapy (Box 1). There were no significant differences between those who did and did not complete follow-up in terms of age, sex, baseline anxiety and depression, and distress.

Box 2 shows that there were more men than women. Participants' ages ranged from 33 to 77 years, the average being 59 years (SD, 9.5 years). Three-quarters of participants were married or in a de facto relationship, and most participants were born in Australia and were either retired or working full-time (Box 2).

Anxiety and depression at baseline and follow-up

Although mean levels of anxiety and depression at baseline were within the normal range, HADS depression decreased significantly from baseline (mean score, 4.93; SD, 4.22; $n=45$) to follow-up (mean score, 3.84; SD, 4.10; $n=45$; $Z=-2.375$; $P=0.02$). At baseline, nine participants scored 8–10, representing borderline clinical levels of depression, and a further five scored 11 and over, representing significant psychological morbidity. At follow-up, one participant had borderline clinical levels of depression and five had significant psychological morbidity.

2 Demographic characteristics of the 59 people who agreed to participate

Characteristic	Number
Sex	
Male	37 (63%)
Female	22 (37%)
Age	
30–39 years	2 (3%)
40–49 years	7 (12%)
50–59 years	17 (29%)
60–69 years	26 (44%)
70–79 years	7 (12%)
Current employment status	
Retired	16 (27%)
Working full-time	13 (22%)
Not working (but not retired)	11 (19%)
Working part-time	9 (15%)
Home duties	5 (8%)
Permanently unable to work or ill, or other	5 (8%)
Marital status	
Married/de facto	45 (76%)
Separated/divorced/widowed	9 (15%)
Single	5 (9%)
Living arrangements*	
Living with partner and/or family	47 (81%)
Living alone	11 (19%)
Country of birth†	
Australia	42 (79%)
Other	11 (21%)

* Data for 58 participants only.

† Data for 53 participants only.

There was no significant difference in HADS anxiety between baseline (mean score, 5.29; SD, 4.11; $n=45$) and follow-up (mean score, 4.78; SD, 3.65; $n=45$). Eleven participants scored 8–10, representing borderline clinical levels of anxiety and a further six scored 11 and over, indicating significant psychological morbidity. At follow-up, six participants had borderline clinical levels of anxiety and four had significant psychological morbidity.

Intervention

At outcall one, two participants (4%) were referred back to their treating health service, and, at outcall two, four participants (8%) were referred. Five of the six participants took up the referral, with the participant who refused reporting that he had sufficient counselling and support from family and friends and that additional support from the health service was unnecessary. Four participants had two consultations, and one participant had one consultation, with their hospital-based social worker or psychologist, with subsequent follow-up when necessary.

At outcall one, 94% of participants discussed psychological and emotional issues, 93% discussed management of side effects, 89% discussed partner and family issues and 84% discussed cancer survivorship. At outcall two, 94% of participants discussed psychological and emotional issues and how to manage side effects, 88% discussed cancer survivorship and 82% discussed partner and family issues.

Survivor response to the intervention

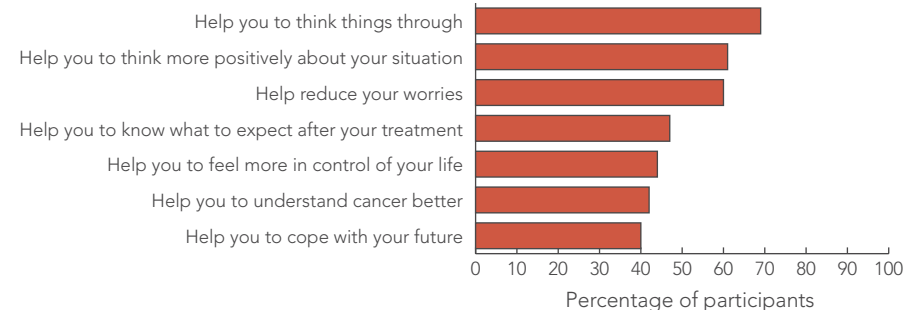
Overall, 60% of the 45 participants who completed the follow-up survey reported that the calls positively affected how they felt about their condition. All participants reported that they were “not at all” worried

about receiving the calls and most (77%) said they felt better after the calls.

Satisfaction with the program among participants was high, with 82% reporting outcall one “quite or very helpful” and 79% reporting outcall two “quite or very helpful”. With regard to outcall one, participants reported that they “took comfort” in the support provided by the call, that it was “good to have someone to chat to” and also that it was helpful “to discuss issues that I was uncertain about”. Overall, 30% of participants took action as a result of this call, including joining a support group, increasing or decreasing physical activity and contacting their oncologist about physical symptoms. Participants reported that outcall two was particularly important, as they had had no contact with medical practitioners since completing their treatment, had a “feeling of abandonment” and welcomed the emotional support and reassurance of discussing issues with the cancer nurse. Participants also reported that they “did not want to burden family and friends” with their problems. Participants were asked in what ways the calls helped them. As shown in Box 3, most reported that the calls helped them think things through (69%) and helped them think positively about their situation (61%).

The helpline nurse who delivered the intervention found the DIT easy to administer and the referral back to the patient's health service uncomplicated. Eight of the nine social workers and psychologists involved in the study returned the questionnaires. They reported that the program did not adversely affect their workloads because the number of referrals was small. One staff member suggested that the telephone helpline might be appropriate for clients who find it difficult to travel back to their health service. It was also reported that making appropriate resources available would be

3 Perceptions of the 45 participants who completed follow-up about outcalls



necessary to ensure the sustainability of such a program.

DISCUSSION

Our study trialled a systematic approach to screening patients who had completed their treatment for CRC for distress, and referring distressed patients back to their treating health services. This simple model of care offers great advantages in terms of ease of access and reach to survivors of cancer. The additional benefit of the program we trialled was that awareness of the Cancer Council Victoria's helpline among patients with cancer (and potentially their families) was increased. Our study also provides valuable information for health care providers involved in the planning and implementation of health service delivery aimed at decreasing the psychological distress after active treatment for CRC.

Although most participants did not have anxiety or depression, the screening program identified a group of severely distressed patients who required additional psychosocial support from a social worker or psychologist at their health service. Without a service such as the one we tested, people with significant levels of distress may not have made use of psychosocial services for follow-up care. However, a larger controlled trial to determine whether the intervention improves psychological adjustment is needed, and assessing whether subgroups, such as men or people with limited social support, would benefit significantly from the screening program, as well as determining the cost-effectiveness of providing this service, is warranted.

More than 80% of participants at both outcalls responded to the opportunity to discuss psychological and emotional issues, management of side effects, cancer survivorship, and partner and family issues. Most participants reported that receiving the calls from the helpline was a positive experience; the calls enabled them to think more positively about their cancer diagnosis and helped to reduce their worries. Participants also reported that the second call was particularly useful because of the reduced number of clinician visits they experienced since the completion of treatment. The outcalls appeared to fill a need for survivors of CRC.

This was a feasibility study, hence the sample was small. Although the response rate was high, the number of eligible patients recruited into the study was lower than anticipated. Although we monitored recruitment across the sites and requested

that all eligible patients be approached to participate, we cannot be certain that the oncology nurses adhered to this request at all times. As not all health services have patient databases and some patients in the private system completed treatment without the oncology nurses being told of their final completion date, we were unable to ascertain the number of patients with CRC who completed their treatment within the recruitment period, and therefore cannot determine potential selection bias. While there was high participation at both outcalls, demonstrating the feasibility and acceptability of the intervention, there was also a moderate attrition rate over time with participants either too ill or unable to be contacted during the follow-up period. Other studies have demonstrated similar decreases.²⁰ A future trial would need to take into account these recruitment and attrition issues.

Despite these limitations, as a feasibility study, the study demonstrated important findings. Screening for distress was achievable and acceptable for post-treatment survivors of CRC, with referrals taken up by most patients with elevated levels of distress. Moreover, more than 80% of patients responded to the opportunity to discuss psychological issues.

This model of care has potential for real change in the delivery of services to patients with cancer, with this intervention identifying those who are at risk of severe distress after treatment and who require assistance with their ongoing psychological needs, which do not cease on completion of active treatment. This study also provides valuable insights for the planning of a larger randomised controlled trial and, more generally, for researchers planning intervention programs for posttreatment cancer survivors.

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COMPETING INTERESTS

None identified.

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