



An outreach telephone program for advanced melanoma supportive care: Acceptability and feasibility

Jennifer Fox^{a,*}, Monika Janda^{b,c}, Fiona Bennett^{d,1}, Danette Langbecker^e

^a School of Nursing, Faculty of Health, Institute of Health and Biomedical Innovation, Queensland University of Technology, 60 Musk Avenue, Kelvin Grove, Qld, 4075, Australia

^b Centre for Health Service Research, Faculty of Medicine, Institute of Health and Biomedical Innovation, The University of Queensland, Woolloongabba, Qld, 4102, Australia

^c School of Public Health and Social Work, Faculty of Health, Institute of Health and Biomedical Innovation, Queensland University of Technology, Australia

^d Melanoma Patients Australia, Mater Foundation, 620 Stanley Street, Woolloongabba, Brisbane, 4102, Australia

^e Centre for Online Health – Centre for Health Services Research, The University of Queensland, Ground floor, Building 33, Princess Alexandra Hospital, 199 Ipswich Rd, Woolloongabba, Qld, 4102, Australia

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ABSTRACT

Purpose: People with advanced melanoma face an uncertain trajectory as new treatments now have the potential to provide longer-term survival for some. However, the disease course is variable and unpredictable, with many expressing a need for better supportive care. This study aimed to investigate the acceptability and feasibility of extending an existing melanoma-specific self-referral or ‘passive’ telephone consultation support service to an ‘active’ outreach call to offer a supportive care program tailored to the needs of the patient.

Method: Participants were enrolled by their oncology nurse into a single group pre-post intervention study. Participants received an outreach telephone call focused on knowledge and skill development. Participants completed questionnaires at baseline and four weeks post-intervention. Post-intervention interviews with patients and involved staff were used to explore acceptability and feasibility of the outreach service call.

Results: Of 18 participants approached, 15 enrolled and 14 received the intervention. Staff time required for intervention delivery provided evidence for feasibility. Participants perceived the intervention as acceptable, and beneficial. In interviews, having someone with melanoma-specific knowledge to talk with was a key benefit of the outreach call program. Many participants expressed that they would have wished to receive the outreach call at an earlier stage, for example at the time of recurrence of/progression to advanced melanoma.

Conclusions: Extending an existing self-referral support service model to use a more ‘active’ outreach approach is acceptable and feasible. The next step in the evaluation process for this intervention is a randomised controlled trial to determine effectiveness and cost-effectiveness.

1. Introduction

Treatment options for patients with advanced melanoma have changed dramatically over the past decade. Immune and targeted therapies have led to a transformative change in the patient trajectory. A significant minority of advanced melanoma patients can now expect long-term survival, while other patients will continue to face an incurable illness (Whitman et al., 2019; Luke et al., 2017; Achkar and Tarhini, 2017; Long, 2015; Michielin and Hoeller, 2015). The interface between oncology and palliative care remains difficult and health

systems struggle to support patients and carers as they navigate between these in the context of innovative melanoma therapies becoming available for some patients (Fox et al., 2016, 2019; Von Roenn et al., 2013; Temel et al., 2016). Ongoing uncertainty in relation to disease progression, treatment outcomes and complex side effects makes treatment planning and decision-making challenging (Levy et al., 2019; Wong et al., 2016).

Indeed, the use of immune therapies has seen a rise in consultations in specialties outside of oncology such as cardiology, gastroenterology and endocrinology, for side effects that result from manipulating the

* Corresponding author.

E-mail addresses: jennifer.fox@qut.edu.au (J. Fox), m.janda@uq.edu.au (M. Janda), bennettfiona2018@gmail.com (F. Bennett), d.langbecker@uq.edu.au (D. Langbecker).

¹ Permanent/Current address: 22 Nansen Street, Northgate, Q 4013.

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immune system to treat cancer (Schrag and Basch, 2018). Unmet needs have been reported including psychological and emotional distress, fears about melanoma spreading, uncertainty about the future, physical problems, gaps in care coordination, employment and financial issues (Beesley et al., 2015; Burg et al., 2015; Buzaglo et al., 2017; Fox et al., 2016; Kasparian et al., 2009; Passalacqua et al., 2012). Tailored supportive care interventions are necessary to deliver accessible, low-cost and community-based support (Dunn et al., 2017; Levy et al., 2019).

Recognising and responding to supportive care needs using telephone services can improve patient-reported outcomes in a cost-effective manner and facilitate referrals and linkages with other services (Molassiotis et al., 2014; Schofield and Chambers, 2015). Previous studies with other cancer groups show that a telephone-based intervention can offer callers time to discuss their issues, convenience of access from the caller's home at a time suitable for them, anonymity to allow callers to discuss more sensitive issues, and accessibility for family members (Ekberg et al., 2014). Further studies show that cancer telephone support services empower patients to feel more in control of their illness, more confident about seeking support and assist them in navigation of the health system (Boltong et al., 2017; Livingston et al., 2014).

Despite the reported benefits of cancer telephone information/support services, many patients remain unaware of their availability. Some of the most commonly reported barriers to using these services remain lack of awareness of the service and lack of provider referral (Boltong et al., 2015; Langbecker and Yates, 2016). A Canadian study concluded that health care professionals have an important role in promoting awareness of telephone support services (Kalbfleisch et al., 2015). Furthermore, it was noted that cancer specialists referring their newly diagnosed patients to a helpline and the helpline staff initiating outreach calls to these patients, together may achieve greater engagement of under-served groups (Clinton-McHarg et al., 2014). An outreach model could overcome some of the barriers to engagement with services. This study expands on the work done to date in other cancer groups by investigating an outreach service in the context of advanced melanoma.

The aim of this study was to investigate the acceptability and feasibility of extending an existing melanoma-specific self-referral telephone consultation service model to incorporate an outreach call program. The primary research question asked was: How acceptable and feasible is a supportive care program consisting of referral by an oncology nurse that triggers an outreach call by a social worker/counsellor? The secondary research question in preparation of a possible later clinical trial was: Are the proposed outcome measures acceptable, feasible to complete, sensitive to change, and relevant for the participant group?

2. Methods

2.1. Setting and participants

In a single group pre-post-test design, patient participants completed questionnaires at baseline and 4 weeks post-intervention; at the latter time point, they also participated in qualitative interviews. Patients were recruited from a melanoma outpatient clinic at a tertiary hospital in Queensland, Australia. Recruitment, intervention delivery and follow-up occurred from February to July 2018. Eligible participants were 18 years or older with an advanced melanoma (stage III or stage IV) diagnosis, who could speak, read and understand English and who attended the melanoma outpatient clinic. A sample size between 10 and 20 participants was considered adequate to provide the feasibility data (Thabane et al., 2010).

2.2. Procedures

The melanoma clinical nurse at the melanoma outpatient clinic who

was given an in-depth understanding of recruitment requirements, introduced the study to eligible patients and sought permission to provide their contact details to the research team. A research nurse then contacted patients provided them with written participant information and a consent form. Following informed consent, participants completed the baseline questionnaire (T0). Contact details for consenting participants were provided to the social worker/counsellor who arranged a mutually convenient time for the telephone outreach call. Four weeks following enrolment (T1), the research nurse collected post-intervention data, consisting of a follow-up survey and telephone interviews utilising note taking. At completion of the study face-to-face interviews were conducted with the melanoma clinical nurse with regard to recruitment, and with the social worker/counsellor with regard to the intervention. These interviews were audio-recorded and transcribed to facilitate analysis.

2.3. Intervention

The intervention consisted of an initial single telephone outreach call by a tertiary qualified social worker/counsellor who managed a community-based melanoma-specific telephone support service facilitated by a national melanoma consumer organisation. The intervention was structured around a Social Work Model of Care, which reflects engagement with the person within his/her social context, taking a holistic approach by considering all aspects of a person's internal and external environments including mental, physical, spiritual, psychological, cognitive, relational, social and cultural aspects (Hare, 2004; Kovacs et al., 2006; AOSW Oncology Social Work Standards of Practice, 2012). The core outreach call followed a standardised protocol, which was flexibly tailored to meet the needs of participants. Following the intervention outreach call, the social worker/counsellor recorded the components of care provided to the participant from the intervention toolkit and noted recommendations for future action. Additional calls, delivered as part of the standard practice of the melanoma-specific telephone support service, were scheduled based on participant need. Participants were also advised that they were free to call the melanoma-specific telephone support service at any time (as per usual care).

2.4. Outcome measures

2.4.1. Primary outcomes

Acceptability of the outreach call program was assessed by telephone interviews at follow-up. Open-ended questions explored participants' views of the referral process, timing, expectations and perceptions of the intervention. Suggestions for modifications of recruitment methods and the intervention were explored. Using five-point Likert-type scales (e.g. very unsatisfied to very satisfied), participants rated their satisfaction with program elements (referral process, call content, information received, helpfulness of the call, any problems arising from the call, and outreach call program overall) and their perceptions of the extent to which the outreach call program assisted them (to think things through, think more positively about their situation, reduce their worries, know what to expect after treatment, feel more in control of their life, understand their diagnosis and treatment better, and cope with their future). Views on acceptability of the intervention were also obtained by interviewing the clinical nurse responsible for recruitment and the social worker/counsellor providing the intervention, both at the end of the study.

Feasibility was assessed by collecting data on recruitment, time taken to organise and conduct outreach calls, number of attempted calls that failed to reach participants, incomplete outreach calls, additional follow-up consultations stemming from the initial outreach call, and any deviations from the study protocol. For each call, the social worker/counsellor qualitatively recorded their perceptions of the intervention including participants' receptivity and engagement during

the call. Time spent by the social worker/counsellor in contacting participants, conducting the outreach call itself and any follow-up was recorded to allow estimation of intervention cost.

2.4.2. Secondary outcomes

A number of tools were included in the patient questionnaires to enable assessment of their suitability as outcome measures in a future effectiveness trial. The amount of missing data, variations in scores, and changes between baseline and follow-up were assessed. Tools were chosen on the basis of extensive use for previous research in similar areas, ease of completion and coverage of complementary outcomes. Participants completed the following: the Distress Thermometer, which is a single item, self-report measure of psychological distress consisting of an 11-point scale ranging from no distress (0) to extreme distress (10) (Jacobsen et al., 2005; NCCN, 2016); the Canadian Problem Checklist (CPC), which screens for the most common problems experienced by patients. The CPC lists 21 problems grouped by domain (practical, emotional, physical, social/family, informational, and spiritual) and represents problems frequently reported by cancer patients (Ashbury et al., 1998; Fitch et al., 2012); the Supportive Care Needs Survey short-form (SCNS-SF34), which includes 34 specified need items across five domains (physical/daily living, psychological, patient care and support, sexuality, and health system and information needs) where participants report the extent of need for each item over the past month on a 5-point scale (ranging from no unmet need to high unmet need) (Girgis et al., 2012); the Cancer Care Coordination Questionnaire (CCCQ), which assesses communication and navigation of the health care system and has been shown to be a psychometrically robust patient-report measure of cancer care coordination (Young et al., 2011); and the Functional Assessment of Cancer Therapy – Melanoma (FACT-M), which is a patient-reported outcome measurement system composed of a general health-related quality of life questionnaire coupled with disease-specific module for melanoma (Cormier and Askew, 2011).

2.4.3. Data analysis

Thematic analysis of qualitative data was undertaken by the primary author with input from the whole study team, to identify underlying themes in the open-ended interview data. Themes were grouped, re-examined and refined. Throughout this process, reference was frequently made to the interview data to ensure participants' original meanings were not lost in the analysis.

For quantitative data, the statistics software package SPSS (IBM Corp, 2016) was used for data entry and analysis. Descriptive statistics were used to characterise the sample and summarise the outcome variables at each time point. For all continuous outcomes (e.g. supportive care needs, distress), descriptive statistics were based on averages and associated measures of spread. For categorical variables, numbers and percentages were used to summarise the data. Given the study aims and sample size, statistical testing was not used to assess changes between outcome variables between the two time points.

2.4.4. Ethical considerations

This study was conducted in accordance with the ethical standards of the approving Human Research Ethics Committee (HREC/17/QPAH/719) and Queensland University of Technology (17000010950). All participants provided written informed consent.

3. Results

3.1. Participants

Over four months of active recruitment, the clinical nurse identified 18 patients eligible for the study through the outpatient clinic, and 15 (83%) of these were enrolled in the study. Three patients declined to participate as they did not feel the need for additional support. As shown in Table 1, participants included both women (47%) and men

Table 1
Characteristics of participants, n = 15.

Variable	Categories	N (%)
Gender	Female	7 (47)
	Male	8 (53)
Age	26–49 years	4 (27)
	50–64 years	6 (40)
	65 and older	5 (33)
Marital status	Married/de facto	7 (47)
	Divorced/Separated	7 (47)
	Never married	1 (7)
Location (using ARIA Classification)	Major Cities	9 (60)
	Inner/outer regional	3 (20)
	Remote	3 (20)
Education status	Primary school	2 (13)
	Secondary school	9 (60)
	Certificate/diploma	1 (7)
	University degree	3 (20)
Current employment	Full time work	4 (27)
	Sick leave	3 (20)
	Retired	6 (40)
	Other	2 (13)
	Treatments	Surgery
Psycho-social support	Immunotherapy	15 (100)
	Radiation	8 (53)
	Previous	4 (27)
	Current	1 (7)

ARIA Access/Remoteness Index of Australia.

(53%), all had received immunotherapy (although this was not an eligibility criterion), with the majority having had surgery (87%) and approximately half (53%) radiation treatment for melanoma. One participant consented and provided demographic data but became unwell and withdrew from the study; this participant subsequently did not receive the outreach call or complete the T0 and T1 questionnaires. One participant did not complete T0 and T1 questionnaires, and one further participant did not complete T1 data collection, leaving follow-up data for 12 participants. Thirteen participants completed the interview at T1.

3.2. Acceptability

The majority of participants engaged with and found benefit in the outreach call program. Twelve of the 13 participants who provided follow-up data (92%) were satisfied/very satisfied with the referral process (mean 4.69, standard deviation, SD 0.48), call content (mean 4.69, SD 0.63), and information received (mean 4.54, SD 0.66), while 11 participants (85%) were satisfied/very satisfied with the helpfulness of calls (mean 4.35, SD 0.62) and with the outreach call program overall (mean 4.35, SD 0.62). Mean satisfaction scores ranged from 4.3 to 4.9 (highest score = 5) across items. No participants in the study reported problems arising from the intervention. Mean scores (highest score = 5) for aspects of the outreach call program that were most helpful were: think things through (4.23, SD 0.83); cope with your future (3.77, SD 0.73); and feel more in control of your life (3.69, SD 1.11). Above average scores were also reported indicating the program assisted participants to: think more positively about your situation (3.62, SD 1.19); reduce your worries (3.54, SD 1.05), understand your diagnosis and treatment better (3.54, SD 1.13), know what to expect after treatment (3.38, SD 1.12).

Qualitatively, all participants indicated they would recommend the outreach call program to others with a melanoma diagnosis. Participants' comments indicated the tailoring of the intervention was useful.

'It was very worthwhile and good to talk to someone not emotionally involved and to someone who knows about the issues with melanoma. It was tailored ... I want to know what I want to know.' P11

A number of participants reported that they appreciated knowing they could telephone or email when they had additional questions or needed someone to talk to. One participant found the outreach call discussion reaffirmed the path he was taking.

'The telephone session confirmed I am on the right track. I am doing the right thing.' P12

Helpful aspects of the intervention identified qualitatively were: access to knowledge and resources (including resources for children), having someone to talk to, the normalising of emotions and being linked with a closed Facebook group specifically for those impacted by a melanoma diagnosis.

When asked in what way the intervention could be improved, participants overwhelmingly referred to the timing of the outreach call. In most cases, the preference was for the call to be available sooner, particularly at the time of diagnosis or disease progression.

'I was in a neuro ward at the time of diagnosis. Information was slow in coming ... it was a bit of a minefield' P2

Ten of the 13 participants reported the telephone intervention was preferable to a face-to-face intervention. Reasons for this included convenience and anonymity. No adverse events were reported during the study and all participants reported feeling comfortable and relaxed about receiving the call.

Interviews with the clinical nurse assisting with recruitment and the social worker/counsellor providing the intervention indicated overall acceptability. The clinical nurse reported positive feedback from participants and the social worker/counsellor suggested that participants' receptivity and engagement during the call was positive. This was evidenced by the call duration, and participants' requests for further information and follow up calls.

3.3. Feasibility

The mean duration of outreach calls was 56.5 min (SD 15.72), with 71% of calls lasting 1 h or less. Contact was made with 50% of participants on the first outreach attempt, with all but one of the remaining participants being reached on the second or third attempts. Half of participants requested one or more follow-up calls, and email follow-up (e.g. providing information summaries) was conducted with 11 participants who had internet access.

Intervention components provided to all participants included assessing support systems, risk assessment, de-escalating stress, adjustment therapy, normalising, exploring, informing, emotional support, exploring fear of cancer recurrence, uncertainty, fear and living with a terminal diagnosis. The most common additional components of care delivered in the initial outreach call were: referral to a melanoma-specific closed Facebook group (10 participants); referral to a face-to-face melanoma support group (8); mindfulness information (4); and referral for legal advice (3).

On average, initial screening and enrolment of participants by the clinic nurse and research nurse was estimated to be 20 min per participant. Mean total duration per participant for intervention delivery, including time taken by the social worker/counsellor in contacting participants, the telephone call itself and follow-up with participants including emails was 117 min (SD 35.92).

3.4. Secondary outcomes

While most participants appreciated the relevance of the questions, a number of participants commented that the pilot questionnaire was too long. Exploratory data analysis of the secondary outcomes revealed that participants reported lower scores of distress, fewer problems and improved care coordination with enhanced communication and navigation at post-intervention (Table 2). The Quality of Life (FACT M) tool showed a small decrease in each of the physical, social, emotional,

functional and melanoma-specific subscales.

4. Discussion

The findings suggest that the majority of participants with an advanced melanoma diagnosis engage with and find benefit from an outreach call program. The outreach call was judged to be appropriate, convenient and effective. The ability to personalise and address multifaceted problems by using the outreach call protocol flexibly to address each person's needs may have contributed to this overall acceptability. Further, the outreach call was melanoma-specific rather than generic in terms of a cancer support service. While many of the same concerns and questions were raised by participants and addressed by the social worker/counsellor, such as information about treatment side effects and disease progression, the personalised approach shaped by individual patient need, rather than a global guideline enabled each participant to raise/express topics and issues relevant to them (Kilbourn et al., 2013; Young et al., 2013). Indeed, personalisation and tailoring of topics to individual need were also reported as important strategies of telephone counselling by Marcus et al. (2002). These authors found that while 77% of callers to a cancer information and counselling line initially requested medical information relating to a cancer diagnosis, 67% received psychological support by the time the call was completed. More recently, Ekberg et al. (2014) reported that cancer helpline callers' help-seeking behaviour was multifaceted, in that psychosocial needs were intrinsically intertwined with information and advice-seeking needs. The flexibility of the content of the outcalls in this study enabled participants' needs to be met in terms of psychosocial, informational and supportive care needs.

The data collected in relation to implementing the outreach call program suggests it is feasible. Our results are comparable with those of similar feasibility studies of outreach call interventions with other cancer populations (Young et al., 2010; Macvean et al., 2007; Livingston et al., 2006). The response rate was high, demonstrating the need for additional support among this patient group. The time taken to deliver the intervention for this study, and therefore costs, were minimal as an existing telephone counselling service could be utilised. However, it is recognised that the costs in establishing and providing a service may be higher where an existing service is not available. While this may be resource intensive in the short term, the potential benefits of alleviating acute stress and anxiety may still be cost-effective, by preventing more expensive service needs in the future.

Feasibility in terms of questionnaire completion rates was reasonable. As our sample size was small, a statistical comparison of pre- and post-implementation questionnaire responses was not conducted, however, raw improvements in mean scores for distress, problems experienced and care coordination suggest these may be appropriate constructs to assess the impact of such an intervention in a future randomised controlled trial. Mean scores did not improve in relation to unmet supportive care needs or quality of life. While this may suggest that the outcall intervention may be ineffective in improving these constructs, the ability of the Supportive Care Needs survey to measure change over time is unclear (Carey et al., 2012). Further, given the complex treatment and care trajectory of melanoma, quality of life measures may be relatively insensitive to change from a psychosocial intervention.

The experience of cancer takes the form of a trajectory where patients' understanding of cancer and supportive care needs change as they move from initial diagnosis into survivorship, and then recurrence (McDowell et al., 2010). Study participants suggested that the optimal timing for the outcall would have been at the point of diagnosis/progression to Stage III/IV disease. Adjustment to the reality of an advanced melanoma diagnosis is variable. The need for support may also fluctuate as patients and families enter into relationships with new care providers and confront critical treatment and care management decisions (Komatsu and Yagasaki, 2014; Sanson-Fisher et al., 2019; Thorne

Table 2
Secondary outcome measures.

Construct (measure)	Pre-intervention		Post-intervention		Scale & direction (possible range)
	n	Mean (SD)	n	Mean (SD)	
Distress (DT)	13	4.46 (2.79)	12	3.17 (2.62)	Higher score – worse distress (0–10)
Problems experienced (CPC)	13	6.31 (3.73)	12	4.67 (4.23)	Higher score – more problems (0–21)
Number of moderate or high unmet needs (SCNS)	13	5.31 (6.46)	12	6.25 (6.76)	Higher score – more unmet needs (0–34)
Care coordination (CCCQ)					
communication	13	46.38 (6.41)	11	48.18 (9.46)	Higher score – better coordination (13–65)
navigation	13	20.85 (3.00)	11	22.10 (3.14)	Higher score – better coordination (7–35)
Quality of life (FACT M)					
physical well-being	13	22.46 (4.58)	12	20.17 (5.69)	Higher score – better quality of life (0–28)
social well-being	13	20.10 (5.12)	12	19.97 (5.70)	Higher score – better quality of life (0–28)
emotional well-being	13	17.08 (4.37)	12	16.80 (4.83)	Higher score – better quality of life (0–24)
functional well-being	13	17.00 (4.93)	12	16.00 (6.49)	Higher score – better quality of life (0–28)
melanoma scale	13	48.62 (7.75)	12	47.58 (8.37)	Higher score – better quality of life (0–64)

DT: Distress Thermometer; CPC: Canadian Problem Checklist; SCNS: Supportive Care Needs Survey; CCCQ: Cancer Care Coordination Questionnaire; FACT-M: Functional Assessment of Cancer Therapy - Melanoma.

et al., 2014). Indeed, supportive care needs are dynamic and changing and as such successful models of support should be flexible and readily available (Biddle et al., 2016).

Qualitative data in this study suggest the outreach call program overcame a number of barriers, including patients recognising that services could address their needs and that their needs were valid concerns (Langbecker et al., 2017). This study's findings support the view expressed by Clinton-McHarg et al. (2014), that referral by cancer specialists could overcome the barrier of patients not knowing there is melanoma-specific support and information available. Patients with cancer value the opportunity to discuss a broad range of issues including 'non-clinical' issues, however, these may often be considered by patients to be outside the remit of treating clinicians (Biddle et al., 2016). Practical barriers such as time constraints and clinicians feeling 'out of depth', support the need for a service that provides a timely and flexible response to patients' needs (Biddle et al., 2016). Further, an outreach call can up-skill patients who do not have the knowledge or resources to navigate the healthcare system to access information and support from a trusted source (Thomsen, 1998). The intervention in this study facilitated a patient-centred approach, with referrals to peer support, ongoing counselling, financial planning and legal services.

The intervention trialled in this study has potential to improve psychosocial wellbeing in patients at a time of ever-increasing uncertainty around treatment trajectories (Fox et al., 2019; Schofield and Chambers, 2015). While usual routine follow-up at the hospital plays a significant role in patient wellbeing, it does not allow for flexible scheduling according to the patient need. Therefore the outreach telephone counselling could significantly complement and extend the usual follow-up care. Ekberg et al. (2014) reported that an outreach telephone service complemented the work of treating clinicians who have limited time available to discuss information that may be crucial for future care decision-making. This study reinforces the distinct and complementary role for an outreach call program compared to that of the clinical team (Sledge, 2019; Kalbfleisch et al., 2015).

4.1. Strengths and limitations

The sample size for this study was small, reflecting its aims relating to acceptability and feasibility. A strength of this study was the reach of a broad spectrum of participants in terms of age, education, geographic location, treatment burden and types of treatment. The feasibility of this study may have been enhanced by the existing structure supporting the outreach call intervention. No additional training around melanoma-specific content or telephone delivery was required for this study. Evaluation of an outreach intervention in an unpredictable and complex illness trajectory such as advanced melanoma is particularly

challenging. We used a mixed-methods evaluation which provided valuable, multi-faceted outcome data. Single index measures are unlikely to capture the full breadth of important outcomes for patients and families.

5. Conclusions

This study supports the acceptability and feasibility of extending an existing self-referral or 'passive' telephone counselling service model to an 'active' outreach call program to address the needs of advanced melanoma patients. Telephone-based interventions such as this may extend the accessibility of support to a variety of patients, and as such merit further investigation. The next step in the evaluation process for this intervention would be a randomised controlled trial to determine effectiveness and cost-effectiveness. Incorporating a mixed-methods approach that includes subjective and objective outcomes in addition to qualitative exploration of patient experience and clinical perceptions would be optimal. Supportive care needs screening tools could help facilitate referral of those most likely to benefit from the intervention. In addition, further research is needed to explore the care points where participants may be most receptive to a referral to an outreach call program.

Conflicts of interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

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