



Review

Do cancer helplines deliver benefits to people affected by cancer? A systematic review



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ABSTRACT

Objectives: To determine the: (1) proportion of studies that describe characteristics of helpline service delivery, compared to the proportion that report trials testing efficacy or effectiveness of helplines in changing user outcomes; (2) proportion of efficacy or effectiveness studies that meet EPOC criteria for methodological rigor; and (3) potential benefits of cancer helplines for people affected by cancer based on findings from rigorous efficacy or effectiveness trials.

Methods: Electronic databases (Medline, PsycINFO, EMBASE and CINAHL) were searched to identify English-language studies describing original research published from 1991 to 2011.

Results: Twenty-eight publications met the review inclusion criteria. From these studies, data on: the characteristics of cancer helpline users; call content; and user satisfaction, were extracted. The potential for helplines to improve the psychosocial outcomes of callers was examined for the three intervention trials.

Conclusion: There is a lack of robust evidence regarding the level and types of benefits that cancer helplines may deliver to callers affected by cancer. Given increased emphasis on delivering best-practise supportive care, building the evidence base in this field may assist cancer helplines to increase their service uptake, reach, and benefit to callers.

Practise implications: There is a need for more rigorous intervention-focussed studies in this field across a broader range of cancer populations. Future studies should focus on relevant patient-centred outcomes, such as improved knowledge and greater involvement in decision-making, while incorporating process measures to account for intervention fidelity and clinical performance.

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Contents

1. Introduction	303
1.1. Prevalence of psychological distress and unmet needs among people affected by cancer	303
1.2. Interventions for reducing psychosocial morbidity	303
1.3. Establishment and evolution of cancer helplines	303
1.4. Potential benefits of cancer helplines	303
1.5. Purpose of review	304
2. Method	304
2.1. Design	304
2.2. Search strategy	304
2.3. Inclusion and exclusion criteria	304

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2.4.	Data synthesis	304
2.4.1.	Classification of publications by focus area	304
2.4.2.	Classification of efficacy or effectiveness publications	304
2.4.3.	Data extraction from rigorous efficacy or effectiveness trials	304
3.	Results	304
3.1.	Database search and publication exclusion	304
3.2.	Focus of original research	304
3.3.	Proportion of efficacy or effectiveness publications that met EPOC criteria	305
3.4.	Benefits of cancer helplines for people affected by cancer	305
4.	Discussion and conclusion	306
4.1.	Summary of findings from included studies	306
4.2.	Potential reasons for mixed study findings	306
4.3.	Limitations	306
4.4.	Recommendations for future research	306
4.4.1.	Intervention rather than descriptive studies	306
4.4.2.	Selection of appropriate outcomes of interest	306
4.4.3.	Focus on cancer populations with high unmet needs	308
4.4.4.	Inclusion of process measures	308
4.5.	Conclusion	308
4.6.	Practise implications	308
	Acknowledgements	308
	References	308

1. Introduction

1.1. Prevalence of psychological distress and unmet needs among people affected by cancer

Cancer is the leading cause of disease-related burden worldwide [1–3]. A large proportion of people affected by cancer report psychosocial concerns with high levels of distress reported by: 25 to 62% of patients receiving treatment; up to 40% of cancer survivors [4,5]; and up to 60% of support persons caring for patients with advanced disease [6]. Large-scale studies of cancer-specific supportive care needs reveal that unmet needs for psychological help, information, and assistance with daily living activities are common amongst patients and survivors [7–10], while unmet needs related to financial support and relationships are frequently reported by support persons [11]. Addressing psychosocial morbidity in individuals affected by cancer is important due to its association with decreased social functioning, more intense physical symptoms, cognitive impairment, poor adherence to treatment, fewer health-promoting behaviours, and reduced length of life [12–15].

1.2. Interventions for reducing psychosocial morbidity

According to stress-coping theory, the way an individual responds to a stressful event (such as a cancer diagnosis) depends on how they perceive: (1) the level of burden associated with the event; and (2) the availability of resources to help them cope with that burden [16]. For this reason, research has generally focused on developing interventions which attempt to either alter cancer patients' perceptions of their disease [17] or increase their ability to access resources [18]. Such interventions can be of either high- or low-intensity. Using stepped care as a framework [19], intervention intensity can be defined according to criteria such as accessibility, mode of delivery, number of contacts, length of contact, extent of specialist involvement, and cost. In this context, a high-intensity intervention might include individualised therapy, such as cognitive behavioural therapy (CBT). CBT can require a high patient burden for participation [20], extensive time commitment [21], high costs [22], and is often limited by the accessibility or availability of trained therapists [23,24].

In contrast, a community-based telephone helpline represents a low-intensity intervention [25–27]. A strength of this approach is the ability to assist individuals who may be unable to receive

traditional face-to-face supportive care due to geographical isolation [28] or poor physical health [29]. Telephone-based delivery of support also provides: anonymity to the caller; equity of access; and a cheaper alternative compared to face-to-face services [29].

1.3. Establishment and evolution of cancer helplines

Since its establishment in 1975, the Cancer Information Service in the United States has provided education and support to cancer patients, their family and friends, and health professionals via its telephone helpline service. Provision of uniform, toll-free numbers has improved accessibility, and technological advances has enabled streamlining of up-to-date information and coordinated referrals to other support networks [30]. The cancer helpline has evolved into an international model of care, operating across numerous countries [31], including the United Kingdom [28] and Australia [32]. The aim of the cancer helpline services is to provide callers with cancer-related emotional, informational and practical support from health professionals experienced in oncology [32,33]. Helpline staff do not engage in therapeutic counselling or offer individual medical advice, but instead provide information, reassurance and referral options to callers [34]. Despite these practical advantages, relatively little is known about whether cancer helplines actually deliver psychosocial benefits to people affected by cancer, and if so, what these benefits may be.

1.4. Potential benefits of cancer helplines

Traditionally, the success of cancer helplines has been measured in terms of caller use, satisfaction, and acceptability. Satisfaction surveys [33–37] suggest that the majority of helpline callers are generally satisfied with the information they received, the way their call was managed, and the consultant's knowledge and approach. While evidence of caller satisfaction and acceptability are important indicators of service delivery, these outcomes do not demonstrate whether cancer helplines are effecting a change in the callers' psychosocial well-being. The types of psychosocial benefits a cancer helpline might be expected to confer to people affected by cancer include: reduced information needs and increased knowledge [34,38]; greater involvement in decision-making [39,40]; improved problem-solving skills, self-efficacy and empowerment [41,42]; and reduced psychological distress [43,44].

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