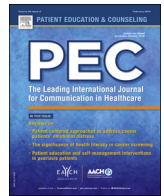




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## Review article

# Skills, knowledge and attributes of support group leaders: A systematic review

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### ABSTRACT

**Objectives:** A systematic review and qualitative synthesis was undertaken to deduce requisite knowledge, skills and attributes of cancer support group leaders.

**Methods:** Medline, CINAHL, and PsychINFO databases were used to identify relevant literature. Inclusion criteria were made deliberately broad after pilot searches produced too few documents and included: adult group leaders who were volunteers, peers or professionals; published in English from database inception to February 2014. Data was extracted on: year of publication; country of authors' origin; study design (if relevant) and methods; group type and group leadership; sample description; and leader qualities.

**Results:** Forty-nine documents met inclusion criteria. Fourteen reported on cancer groups, 31 on non-cancer groups (including four mixed groups) and four did not specify group type. Seven qualities were deduced including group management, group process, role modelling, awareness, willingness, agreeableness, and openness. These were consistent across group type and group leadership.

**Conclusions:** Findings may be relevant to a general model of peer group support and can inform the development of a practical and realistic minimum standard for support group leadership in healthcare.

**Practice implications:** Results can be used to help cancer agencies manage relationships with group leaders. Knowledge of requisite qualities may inform selection, training and support.

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### Contents

1. Introduction	00
2. Methods	00
3. Results	00
3.1. Search results	00
3.2. Description of eligible papers and theses	00
3.3. Qualitative, quantitative and mixed methods studies of cancer groups	00
3.4. Qualitative, quantitative and mixed methods studies of non-cancer groups	00
3.5. Group leader qualities	00
3.6. Cancer groups	00
3.7. Non-cancer groups	00
4. Discussion and conclusion	00
4.1. Discussion	00
5. Conclusion	00

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Acknowledgments .....	00
References .....	00

**1. Introduction**

Cancer is set to become the major cause of morbidity and mortality in the next few decades in every region of the world [1]. With population growth and aging, new cancer cases are expected to reach 22 million in 2030. Survival rates have improved due to increased rates of early detection and better access to effective treatment in high-income countries. The experience of a cancer diagnosis and treatment is also changing; consideration needs to be given to reproductive factors, regional and economic diversity, psychosocial care and management of long-term effects. Around the world, health care systems are struggling with rising costs, and unsatisfactory and uneven quality of care [2]. There is a clear need for improved outcomes that matter to patients and survivors relative to the cost of achieving those outcomes [2]. The focus is moving towards meeting the psychosocial care needs of patients and families across the health trajectory [3]. Significant and swift action is required to develop or adapt solution-based approaches that engage those impacted by cancer with community-based supportive care.

In the 1960s, descriptive case studies of peer support first emerged in the literature. Chambers et al. [4] identified six theoretical approaches (or models) that are specifically relevant to how peer support is expressed and consumed: social support, the helper-therapy principle, experiential knowledge, social learning theory, social comparison theory and social identity theory [4]. The essence of peer support is people seeking out interactions with others who have a similar experience, often as a way of comparison to establish a sense of normalcy (social comparison theory) [5]. Social support theory can further be used to explain how peer support encompasses emotional, practical and informational support in a way that facilitates adjustment and engagement in active coping strategies [6]. Peers with shared experience are perceived as more credible role models (social learning theory) [7], with specialised information and perspectives (experiential knowledge) [8]. With significant life experiences, such as cancer, disruption of one's identity can occur and therefore the groups in which individuals perceive membership to can be derived from these experiences. Part of an individual's self-concept can therefore be derived from membership of a particular peer group [9], with peer support offering a real sense of belonging and identity (social identity theory). Additionally, many who engage in peer support express their desire to help others (the helper-theory principle) and satisfaction with developing interpersonal relationships [10]. However, as yet there is not a specific or all-encompassing model developed for peer support.

Effectiveness of peer support in the context of cancer has begun to be explored through literature reviews. Peer support programs have been found to provide informational and emotional support benefits [11,12], improved wellbeing [13] and high level of satisfaction [14]. Evidence for effectiveness, however, is limited, with challenges in isolating dynamics and other sources of variation. It could be argued that the context in which peer support operates and how it works is not easily defined or measured. In addition, effectiveness of peer support has focused on delivery of programs or one-to-one support, which is different to peer support groups.

The evolution of group work spans several behavioural science disciplines, with most theory grounded in professional delivery of psychotherapeutic and educational programs. In response to the need for support during the lived experience of cancer, support

groups have developed somewhat organically over time and make up part of the broader category of self-help groups.

Theme-centred groups, such as cancer support groups, are considered to be a particularly useful intervention; groups may complement individual treatment and are a cost effective means of delivering support within the broader health care system. General cancer support groups are the most common type of support group, followed by breast and prostate cancer support groups [15]. The purpose of a peer-based support group is to allow a safe place to connect and share with others who have been or are going through a similar experience [16]. Peer groups adopt certain aspects of psychotherapeutic and education programs, but should not provide therapy or education. Members of cancer support groups seek to help themselves and each other to reduce the negative or disabling effect that cancer may have on general health, relationships, coping abilities and daily functioning. More often than not, group leadership is provided voluntarily, mostly by those with a personal experience of cancer.

Group leaders are typically self-selected, and motivated by the desire to help others, while at the same time placing themselves into a role they may know very little about [17]. Within the group, leaders have a considerable amount of power, prestige, responsibility and status, with many not able to manage or even recognise these factors [18]. Not surprisingly, alongside the many benefits, leaders have reported a range of difficulties associated with cancer support group leadership. For example, some struggle to deal with issues like difficult and demanding personalities, maintaining adequate group numbers, disease progression, and death [19,20]. Challenges in maintaining their own quality of life and avoiding burnout are not uncommon, and these issues can contribute to the termination of groups [17]. Difficulties, however, are often outweighed by the rewards. Rewards include feeling part of members' lives, own self-development, and being part of the process that helps members' adjustment and empowerment following a cancer diagnosis [20]. Arguably, the experiences of group leaders, both positive and negative, may be related to some or all of the qualities group leaders bring to the role. But, to date, there has been little focus on the nature of the role itself and who is best suited to it.

While unknown, the total number of support groups in operation globally is thought to be considerable. For example, Macmillian Cancer Support in the UK is linked to over 900 support groups. And, the American Cancer Society is currently developing cancer support networks to provide support to face-to-face, phone and online communities. Many groups, however, operate without formalised structures, policies and procedures. Currently, then, support groups may be an under-acknowledged and under-developed resource in public health. Within Australia, peak cancer agencies have been working to establish relationships with independently run support groups. In recent times, funding, training, resources and support staff have been made available to group leaders as a way of strengthening the delivery of support provided by groups. If support groups are to be formally recognised as one of many solution-based approaches to the delivery of cancer care, further investigation is needed to address the question: who should lead support groups? More specifically, what are the requisite knowledge, skills and attributes of leaders of cancer support groups? There is a clear need to establish an evidence-based framework to inform the selection process of group leaders seeking legitimacy, funding or support from external agencies, regardless of whether the role is undertaken in a paid or volunteer

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