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Peer support for people with advanced cancer: a systematically constructed scoping review of quantitative and qualitative evidence

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Peer support for people with advanced cancer: a systematically constructed scoping review of quantitative and qualitative evidence

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Abstract

Purpose of review: The number of people living with advanced cancer is increasing, and appropriate support to this population is essential. Peer support is increasingly advocated as a component of care, but little is known about how to provide this in the context of advanced cancer. This review describes the experience and impact of different forms of peer support for people with advanced cancer.

Recent findings: Data from 22 papers were reviewed, primarily descriptive studies. They describe three forms of peer support (one-to-one, group and online), reaching primarily those who are female, middle aged and well educated. Only two studies focused on support to people with advanced cancer, but those with advanced cancer were frequent users of all forms of peer support. Benefits of peer support were described, but no data were presented to allow a determination of the best form of support for people with advanced cancer.

Summary: Practitioners can be assured that peer support is likely to be beneficial, and provide care that complements that of clinicians. However there is a need for a comprehensive programme of high quality evaluative research of peer support for people with advanced cancer.

Key words: Advanced cancer, peer support, peer group, volunteer, palliative care

Introduction

The number of people living with and beyond cancer increases by 3.2% each year (1). Whilst some remain disease free, a proportion are living with, and dying from, advanced cancer. One model estimates that there are around 3-4 metastatic breast cancer cases for every breast cancer death(2). It is therefore critically important that services not only support excellence in diagnosis and treatment, but also provide effective and appropriate support for a prolonged period of time, designed to meet the needs of those with advanced cancer (3).

Clinical services are unlikely to meet all the needs of those with advanced cancer. This may be because of their capacity to provide care, or because needs may be best met outside formal healthcare systems. Compassionate support cannot be the responsibility only of health and social care professionals, and wider support, including from peers and the community, may be important (4, 5). Social networks and social capital are important contributors to health (6, 7), buffering the effects of crisis, providing a framework that may prevent burn out, and demonstrating the importance of supportive social contexts (8-10).

One form of support that may have merit is that provided by peers. Peer support involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help, often in a way that is mutually beneficial (11). Peer support is different because the source of support is a similar person with relevant experience, and health policy recognizes the importance of such support (12).

Peer support, within a health care context is:

> *'The provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person' Dennis 2003 (13)p329.*

Peer support is a specific form of supportive relationship, distinctive from ‘embedded’ social networks (such as family members, friends, co-workers or neighbours). Peer support is a ‘created’ social network, provided with a range of professional support and involvement ranging from self-help groups with little outside involvement to ‘paraprofessionals’ who may have extensive training for their peer support role (13). Figure 1 presents conceptual distinctions of different forms of peer support and the effect models and proposed outcomes of peer support.

<Insert Figure 1 around here>

The mechanisms of effect of peer support are theorised to be either direct (direct effect on health outcomes through e.g. decreasing feelings of isolation), buffered (e.g. through reframing threat appraisals and improving coping responses (14), or through mediating (e.g. indirectly influencing health through emotions, cognitions, and behaviours (15).

Previous reviews of peer support for people with cancer are summarised in table 1.

< Insert table 1 around here>

Some focus on describing peer support, providing taxonomies or models of types of support (16, 18), others on outcomes generally (17), or of the effect of specific forms of peer support such as one-to-one support (19, 20) or social media/online support (21, 22). All identify satisfaction with models of peer support from those who receive it, but with criticisms of the descriptive focus of some studies, and methodological weaknesses in the literature.

What none of these reviews offer is an appraisal of peer support for people with advanced cancer. The needs of those with advanced cancer are distinct (3), and there may be differences in their desire for, experience, and impact of different forms of peer support. There is a need for an up to date review that addresses the experience and impact of different forms of peer support for people with advanced cancer.

Methods

This is a scoping review which enables literature to be mapped whilst addressing a broad question. This approach allows overview, identification and mapping of key concepts rather than synthesis of evidence. A formal assessment of methodological quality of included studies is usually not performed (23, 24).

Review question

What is the experience and impact of different forms of peer support for people with advanced cancer?

Inclusion and exclusion criteria

The key concept is the provision of any form of peer support (13), for people with a diagnosis of advanced cancer. This can be in any setting or geographical location. This concept and context guided our inclusion and exclusion criteria (table 2):

<Include table 2 around here>

Search strategy

Key terms from existing reviews of peer support were used to combine terms for ‘peer support’ with terms for ‘cancer’ (Table 3). Citation tracking of key papers in existing reviews was also used, and from a recent broad report on peer support across a number of disease areas (11). Databases searched include PubMed and Cochrane Databases(11).

<Insert table 3 around here>

The process of searching for papers and determining exclusion and inclusion is detailed in figure 2.

<Insert figure 2 around here>

Data extraction

Data were extracted and charted to describe and summarise information relevant to the question, concept and context of the scoping review.

Findings

Twenty two papers were included in this review, two were from the same project. The studies are summarised in table 4.

<Insert table 4 around here>

Studies came from the US (n=8), Canada (n=2), Australia (n=2), Netherlands (n=2) and one each from Norway, Denmark, Finland, Germany, Hungary, Ireland and the UK. Study designs included qualitative (n=8), cross-sectional surveys (n=8), pre-post surveys (n=1), comparative design (n=1) and different forms of trial design (n=4). Only two studies exclusively explored peer support for people with advanced cancer (35, 45), others included people with advanced cancer alongside those at other stages of disease. Themes presented here include the type of peer support, who participates in peer support, and the benefits or risks of peer support.

Type of peer support

Studies investigated three types of peer support: one-to-one support (n=5), group support (n=6), and online support (n=9). One paper compared group support offered either face-to-face or online. No studies compared different types of peer support, so it is not possible to conclude if one form of support is more effective.

Who participates in peer support programmes?

Peer support programmes typically report reaching out to people in middle age, female, and who are well educated. The mean ages of those receiving support, where reported, ranged from 48-62. Some studies only investigated peer support for those with specific diagnoses, often a gendered diagnosis, typically breast cancer (n=11), but also gynaecological cancer (n=1), or prostate cancer (n=1). Two studies only included those with lung cancer; five studies included those with any cancer diagnosis. Of the studies that included those with any diagnosis, most participants were nevertheless female. A study of a Peer Connect programme found that of their 'guides' 66% were female, and their 'partners' were 84% female (28). A similar pattern was found in a social network intervention with 77% female participants (38), and 78% of users of an online lung cancer support community were female (39). Study participants were typically well educated. One study of online social support found that most had a polytechnic or college degree (39%), and nearly one in four (24%) had a university degree (43), while a study of one-to-one peer support found that 51% had a college degree(29).

All studies reviewed have some participants with advanced cancer, but not exclusively so. Only two studies solely examined support for those with advanced cancer (35, 45), but others identified that people with advanced cancer were frequent users of all forms of peer support. A study of a Patient Survivor Advocacy programme found that over 90% of both advocates and patients had invasive cancer (26), the Woman to Woman programme had 19% of women with stage IV ovarian cancer(29), a belly dancing support group had 31% with metastatic disease(31), and 25% of participants in a trial of the Health-Space online intervention had late stage cancer(38).

What are the benefits or risks of peer support?

Most studies were descriptive cross-sectional studies, typically using a qualitative interview or survey design. Satisfaction with peer support was high (26), no risks were identified. Multiple benefits are described, mostly characterised as emotional or informational support.

Emotional support included conveying hope and ways of coping(25, 29), reducing loneliness(27), and improving self-esteem(34). Peer support helps people communicate with partners and family members(29). Depressive symptoms and distress were reduced through group support (30, 33), but a trial of online support found no difference in depressive symptoms(44). A trial of an online support group for women with metastatic breast cancer showed a trend to distress reduction(45). How people interacted was important, with humour important to conveying trust(37). Those who were highly active online, but who managed their emotions less actively, had increased emotional wellbeing (40).

Informational support was also important (31), including health information and navigation(34). Informational needs were particularly noted by users of online support groups (39, 42, 43). However one study comparing online and face to face groups concluded that face to face groups were better for exchanging information and caring for others (46).

Socially, peer support was seen as providing a framework for social comparisons (25), where exchanging thoughts was easier with a peer(27), and with a need for mutual identification(36). Being a peer supporter was felt to be positive and important, giving people a sense of achievement (25, 26). Studies with a specific intervention (such as motivational interviewing), found that peers developed proficiency in the intervention (28).

Discussion

Summary

This review describes a range of studies that investigate different forms of peer support used by people with advanced cancer. Three main forms of peer support are one-to-one support, group support or online support. Those who use peer support, or participate in studies of peer support, are typically female, younger, and well educated. Peer support is well received, with people reporting a range of benefits centred on emotional and informational support, however there are few robust trials or other experimental studies. No risks from peer support were identified. Few studies specifically study peer support for those with advanced cancer, but people with advanced cancer are frequent users of peer support.

Comparison with previous reviews

Past reviews of peer support have been critical of this field of research, identifying issues with a focus on breast cancer, lack of theory, poor or absent specification of peer support interventions, and the lack of robust, high quality comparative studies such as trials (18-20). These issues, broadly, remain. A large proportion of studies reviewed focus attention on those with breast cancer (26, 30, 32-34, 36, 37, 42). Whilst people with breast cancer require support, especially those with advanced cancer (47), so too do people with other diagnoses. Studies reviewed are mostly not underpinned by any form of theory, a trend also identified in a recent review of behavioural theories in end-of-life care research(48). Peer support intervention descriptions were often poor, it was challenging to extract details from many included papers, such as understanding the intervention at 'Cairn Centres' (25), the use of former patients(27), or the form and function of some groups(34). This is an issue both for practice implementation and for study replication.

Research included was typically descriptive, with few trials or other evaluative or comparative studies. Many studies did not use validated measures of outcome e.g.(26, 28, 29). Studies of the perception of peer support are, and have been, overwhelmingly supportive of the benefits of peers. This is no longer the research that is needed. Questions that remain focus on who might benefit most from peer support and what sort of peer support might be most effective. This is particularly true for those with advanced cancer, who were frequent users of peer support programmes, but where the programmes were rarely specifically designed to meet their needs. It is not possible on the basis of this review to recommend a particular form of peer support for those with advanced cancer, and studies are urgently needed to investigate this. Peer support for those with (or by) advanced cancer is likely to have specific issues associated with sensitive appreciation of the disease status, fluctuating health, and likely death of those involved in the programmes. This was rarely acknowledged in the included papers, but is important, with important methodological issues(49). Street (35) found two dominant but separate narratives – those who wished to discuss death, and those deferring such discussions. Any peer support programme needs to acknowledge and accept these different approaches.

Recommendations for policy, practice and future research

Peer support has a sufficient evidence base for policymakers and practitioners to be confident in recommending it in policy and putting schemes in to practice. Whilst care is required in thoughtful use of peer support it is likely to be positively perceived. However, the caveat to this is that there are major unanswered questions and issues that require attention:

a) Peer support interventions should be clearly specified, such that they can be reported using the TIDieR guidelines (50). This does not mean that programmes cannot be responsive and flexible, as this is likely a hallmark of peer support. Rather, care should be taken in planning and describing what is meant by a peer, and how support was given such that practice can be carefully implemented and studies replicated.
b) Robust, adequately powered, theoretically underpinned, comparative and evaluative studies are required. These should compare different forms of peer support, using appropriate validated measures, in controlled conditions such that a clear understanding of what form of peer support may benefit particular people is known. Designs such as wait-list or stepped wedge trials may offer possibilities where it is felt that the intervention should not be withheld from participants(51-53). Embedded qualitative process evaluations are likely to be required to facilitate understanding of programme implementation and response(54).
c) Studies which focus on the peer support of those with advanced cancer are urgently needed. These may be specific studies, or where the needs and responses of those with advanced

cancer are studied within a larger project. Nevertheless, attention must be paid to the type of support mechanism required and how to sensitively and methodologically manage issues of deterioration and death.

Conclusion

Peer support appears important to those with advanced cancer, but has little evidence base. Attention must be paid both in service and project design to incorporating the needs of people with advanced cancer in future studies.

Key points:

- Peer support complements, but is distinctive from, health and social care services.
- People with advanced cancer are frequent users of peer support services, but little is known about how best to provide these services, nor their effect.
- A high quality programme of evaluative research is required to understand what forms of peer support are most effective for people with advanced cancer.

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3. Conflicts of interest. None declared.

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Figure

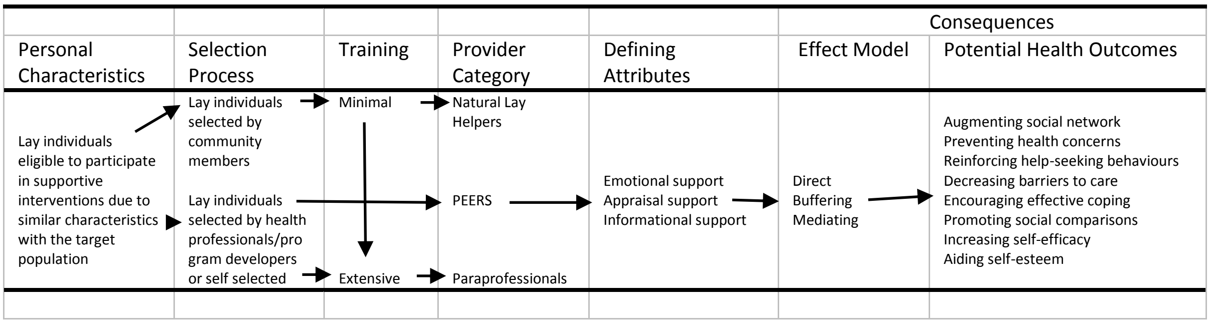

Figure 1. Conceptual distinctions of peer support. Reprinted with permission from (13)

Figure 2. Flow diagram of review process

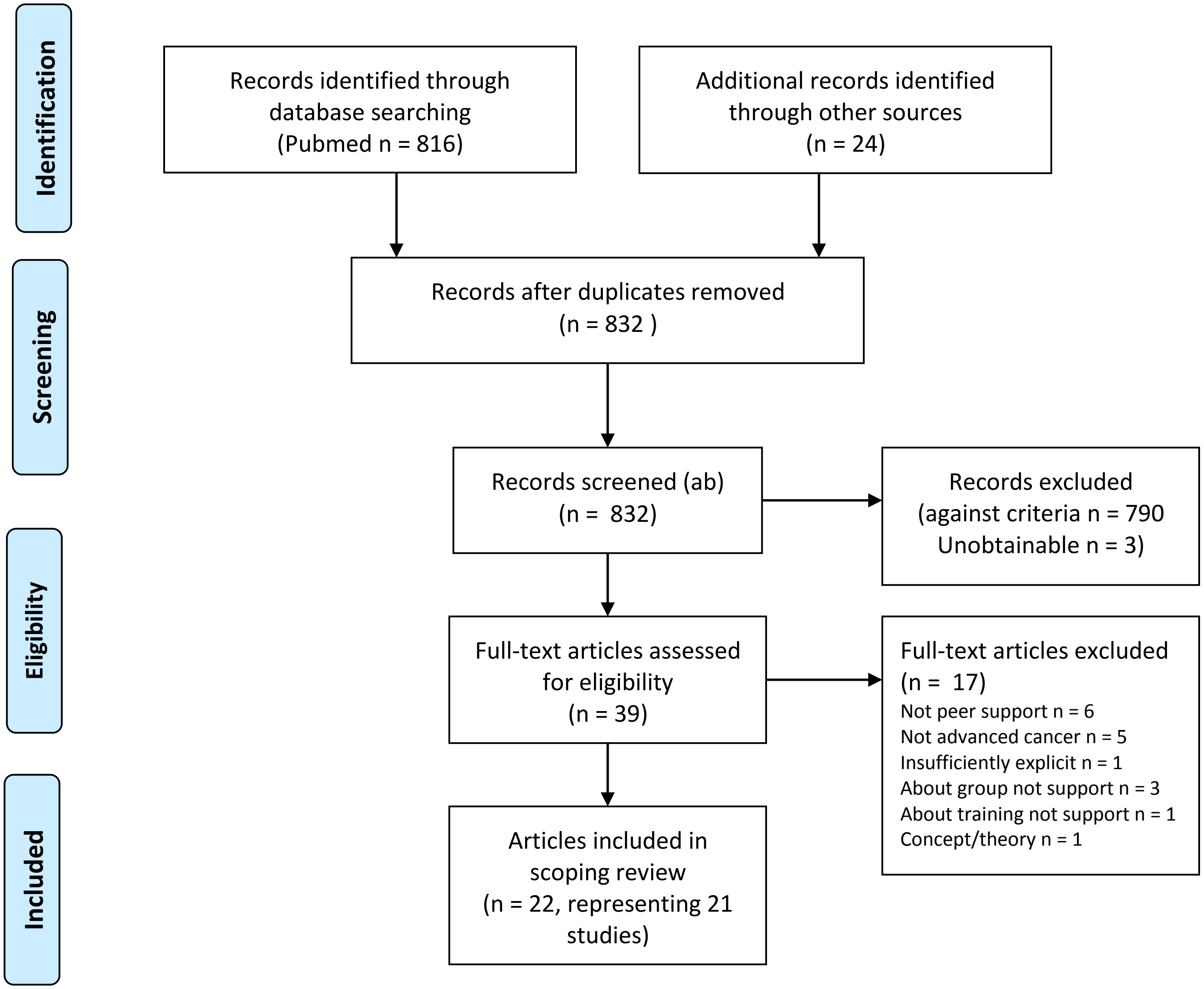

Table 1. Existing reviews of peer support for people with cancer

Author, date	Review question	Dates searched/Inclusion criteria	Included papers	Findings	Comments
Dunn et al. 2003. (16)	To assess the prevalence and contribution of articles on peer support	1990-2001 Cancer programmes, primarily peer support, with evaluation.	25 Descriptive (15), cross-sectional pre-post evaluations (5), case comparisons (1), experimental (1), Trial (1)	Taxonomy: style of supervision, interpersonal context, and mode of delivery. Peer support programs help by providing emotional and informational support from the perspective of shared personal experience	Paucity of studies, especially trials. No specific comment on advanced cancer.
Campbell et al. 2004. (17)	What types of cancer peer support programs have been evaluated? What do we know about participants? What benefits, risks and barriers are associated with cancer peer support programs?	1980-2002 Peer support by survivors to patients, excluding active role of health care professionals. Exclude children or caregivers.	21 Needs assessments (2), interviews (4), observation (1), focus groups (1), pre-post surveys (7), comparison groups (3), trials (5)	Consistent informational, emotional and instrumental benefits were identified	Moderate scientific quality (lacking theory, program descriptions, validated instruments). No specific comment on advanced cancer.
Hoey et al. 2008. (18)	To identify models of peer support for cancer patients and systematically review evidence of their effectiveness in improving psychosocial adjustment	1980-2007 Peer support to people with cancer, where peer had been diagnosed/treated for cancer.	43 papers 26 descriptive papers, 8 non-randomized comparative papers, and 10 papers reporting eight randomized controlled trials (RCTs)	Five models of peer support were identified: one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone, and group Internet Papers indicated a high level of satisfaction with peer-support programs; however, evidence for psychosocial benefit was mixed	Tentative recommendations only due to populations (mostly breast cancer) and few comparative studies. No specific comment on advanced cancer.
Macvean et al. 2008 (19)	To conduct a systematic review of literature reporting on the use of volunteers in support programs for people with cancer.	To 2007 Described a program where unpaid volunteers provided one-to-one support to people with cancer	28 papers:8 papers with no data or only service usage data;10papers with one group descriptive data; 6 papers reporting non-randomized comparative studies;4papers reporting randomized controlled trials	Only 19 papers described peer support programmes. Most volunteer-based support programs are well received and have benefits, including improving well-being and/or reducing anxiety	Methodologically poor or inappropriate. No specific comment on advanced cancer.
Meyer et al. 2014 (20)	To determine whether one-to-one peer support programmes benefit cancer patients.	2007-2014 Empirical studies, one-to-one peer support, cancer, in person or by phone, adults.	13 studies: four randomised controlled trials, one non-randomised comparative study	All studies reported high participant satisfaction with the peer support intervention, and the majority noted positive	No specific comment on advanced cancer.

			and eight one-group descriptive studies.	outcomes regarding psychological adjustment	
Kim and Park, 2015. (21)	1.What are the characteristics of the current web-based self-management support interventions for cancer survivors? 2.What modes of intervention delivery are used for cancer survivors on the Web? 3.Were the web-based interventions for cancer survivors more effective than the standard interventions	2000-2014 People with cancer, or carers, interventions include Web-based self-management support interventions. Only experimental designs.	37 articles were selected for the systematic review, and the meta-analysis included 5 articles for fatigue, 7 for depression, 5 for anxiety, and 5 for overall quality of life	The most popular mode of intervention delivery was “peer-to-peer access” in the communicative functions category, followed by “the use of an enriched information environment” in the automated functions category. The effects across all outcome measures were small to moderate compared to standard care.	Not all included papers were on peer support. No specific comment on advanced cancer.
Falisi et al. 2017 (22)	To provide a systematic synthesis of the current literature on social media in order to inform (breast) cancer health communication practice and cancer survivorship research	2005-2015 Has online or web component that is participatory, breast cancer survivors.	98 publications 13 commentaries and reviews, 47 descriptive studies, and 38 intervention studies	Online support groups were the most commonly studied platform, followed by interactive message boards and web forums. Limited research focuses on non-Caucasian populations. Psychosocial well-being was the most commonly measured outcome of interest	Few assessed impact on people with breast cancer. No specific comment on advanced cancer.

Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Studies exploring the form, experience or impact of any form of peer support for people with cancer. Peer support (13) has to include being supported by someone with personal experience of cancer within a 'created' social network. This may be part of a wider or more complex intervention.	The question is on hypothetical rather than actual support. The focus is on peer support for cancer screening or prevention. The focus is on training people to be peer supporters. The support is provided by 'embedded social networks' (e.g. friends, neighbours), community volunteers, or health and social care professionals.
The population receiving peer support must include adults with a diagnosis of advanced/metastatic cancer.	The population are only those with early stage or curable cancer. The peer support is only provided to family carers, parents or children.
Primary research, any research design.	Review papers
Papers published after 2014 if the focus is on one-to-one support, after 2010 for other forms of peer support, to avoid duplicating existing reviews.	Papers in languages other than English

Table 3. Search terms used

Terms for cancer (MeSH heading or keywords used where possible, truncations allowed, all combined with OR)	**Terms for peer support** (MeSH heading or keywords used where possible, truncations allowed, all combined with OR)
Combined with AND	
Neoplasm Cancer Oncology Terminally ill Advanced cancer	Peer group Peer support Peer volunteer Peer discussion Peer counselling Volunteers Hospital volunteers Voluntary Mentors Cancer survivors Psychosocial support systems Social support Self-help groups Peer mentor support Cancer support Buddy

Table 4. Table of included studies

Author, Date, Country	Research question	Design	Data collection	Participants (	Peer Mentor intervention type	Peer Mentor characteristics	Mentee Characteristics.	Findings
1:1 support								
Skirbekk et al. 2018. Norway (25)	To explore what peer supporters, patients and their relatives want and gain from peer support in cancer care.	Qualitative.	Focus group and in-depth interviews and observation of daily activities. Systematic text condensation.	38 people interviewed in focus groups or individually. Five FGs (19 peer supporters), 12 interviews (10 patients, 2 spouses), 7 peer supporters.	'Cairn Centres', within hospital settings, provide settings for peer support programmes. Peer supporters available every weekday in common spaces. Patients rarely see the same peer supporter. Peer supporter's patient association provides training.	No information, other than recruited and trained by national cancer association, have had experience of cancer.	Mean age 52. Age and gender typical of Cairn Centre users.	Peer support conveyed hope and ways of coping, protecting against stress. Provided a framework for social comparisons. Were an important supplement to family and health care providers. Being a peer supporter is positive and important.
Mirrielees et al. 2017. US (26)	To evaluate patient, advocate and clinician experience with a Patient Survivor Advocacy (PSA) program	Survey.	Survey created to explore experience, impacts and quality of life topics, experience of program.	14 advocates trained, 40 newly diagnosed breast cancer patients referred. 25 matched to an advocate. 14 surveys received.	Patient Survivor Advocate (PSA) program facilitates peer-to-peer support between those who have completed breast cancer treatment and newly diagnosed patients. Advocates who have completed treatment 1+ years ago were recruited if endorsed by a clinician. 2 day training. Matched to patients on basis of age, type of breast cancer and life factors identified by patients. Contact logs maintained (53% email, 36% telephone, 8% text, 2% face to face)	Advocates: Mean age 50, 93% with invasive cancer.	Patients. Mean age 49. 93% with invasive cancer.	Satisfaction with programme reported, 92.9% say helpful, and would recommend, all peer advocates had a sense of achievement. Contact with advocates improved communication with family and the healthcare team, make treatment decisions, provided information.

Borregaard et al. 2018. Denmark (27)	To examine how hospitalised surgical lung cancer patients experience talking to a former patient.	Qualitative, based on text interpretation theory.	Phenomenological qualitative interviews with a narrative structure.	9 Patients, 18+, having surgical lung cancer treatment.	Weekly availability of a trained former patient within the hospital ward setting. Current patients advised of opportunity to talk with him.	Male former patient. Recruited, interviewed, with contract to provide support. 2 years + following own admission. Aged 65.	3 women, 6 men between ages of 22-80.	Four themes: exchanging emotional thoughts easier with a peer, talking to a peer reduces loneliness, being ambiguous about a relationship with fellow patients, being the main person in the conversation with a peer.
Allicock et. al, 2014. US (28)	What is the role of guides, perceived program efficacy, program satisfaction and partner's perceptions about support?	Longitudinal Survey and telephone interviews	Telephone survey, Likert scale exploring perceived efficacy, matching, benefits. Qualitative telephone interviews.	15 trained 'volunteer guides' (3 carers) and 19 'partners' (4 carers). 4 'partners' had been diagnosed for 6+ months. Data not collected on disease status of guides.	Motivational Interviewing based 'Peer Connect' programme. Primarily 1:1 telephone support. 2 day DVD training on MI, with 6 supplemental sessions. Coordinator managed recruitment, matching. Six month follow up.	'Guides' were 18+, either cancer survivor 1 year + post treatment, or caregiver. Females 66% Mean age 56 Breast cancer 46%	'Partners' had a cancer diagnosis or caregiver, 18+. Self-referred to programme. Matched mostly on diagnosis. Females 84% Mean age 60.7 Breast cancer 32%	Guides were proficient at MI. Mean of 5 calls to partner discussing fears, support needs, coping and care issues. Partners valued listening, support, and non-judgemental attitude. Diagnosis matching not necessary.
Moulton et al. 2013. US (29)	To understand experiences of Woman-to-Woman programme, and perceptions of how met psychosocial needs.	Telephone survey	Telephone survey with 17 questions about perceptions of effectiveness (7 point Likert), plus open ended questions on program.	57 women (58% response rate) with gynaecological cancer. Mean age 58. 72% White. 51% college degree. 56% stage III ovarian cancer, and 19% stage IV ovarian cancer.	Woman to Woman provides 1:1 peer support to women in treatment of gynaecological cancers. Matched on patient characteristics. Collaborates with multidisciplinary team at cancer centre. Follow people through treatment, visiting them in hospital settings, typically 10 – 20 minutes long.	15 survivor volunteers, some with recurrent disease. 8 hours of training. Monthly volunteer meetings.	Referred by oncology team, seen by social worker coordinator.	Helped cope emotionally with diagnosis (98%), treatment (97%), and managed anxiety (96%), provided hope. Helped communicate with partner (43%).

Group support								
Mens et al. 2016. US (30)	To identify mediators underlying the effects of an education and peer support intervention for women with breast cancer.	Randomised design comparing early stage vs late stage cancer randomised to education, peer support or a control condition.	Baseline, two weeks, 6 months. Interview or mailed survey. SF36, Center for Epidemiological Studies Depression Scale (CES-D). Life Engagement Test (LET), Confidence scale.	245 women with either first time diagnosis stage I or II breast cancer (180) OR initial diagnosis of stage IV or distant recurrence breast cancer (65).	Education: weekly group meetings to provide information about disease. Peer support: focused on fostering purpose on life by providing opportunity to support and care for each other. Group facilitator present. 1-hour meetings for 8 weeks. Low attendance noted.	NA	NA	Peer support intervention reduced depressive symptoms increased life purpose at 2 weeks for both early and late stage cancer for those who attended a meeting. ITT showed no effect.
Szalai et al. 2016. Hungary. (31)	To clarify channels of social support through a belly dancing peer support group.	Comparative, non-randomised quantitative study comparing belly-dancing support and aged matched controls.	Health related quality of life and overall life satisfaction. EORTC QLQ C30, F-SozU social support questionnaire. Baseline and 1 year follow up. Semi-structured interviews.	51 people interviewed. Mean age 48, educated, 31.4% had metastatic disease.	Belly dance rehabilitation programme, held outside the hospital setting. 3 hours weekly, 90 minutes physical activity, 90 minutes group discussion, without a facilitator.	NA	NA	Belly dancing group scored better at both baseline and follow up. Social support achieved through emotional, practical and informational support by the role model function.

a) Morris et al. 2012. Australia (32) b) Morris et al. 2010 Australia (33)	a) The role of social comparison and social identity based on group membership on posttraumatic growth and distress. b) To understand the lived experience of Breast cancer survivors participating in a peer-support programme	a)Pre-and post peer intervention survey. b) Qualitative	a) Social identity measure, Identification – Contrast Scale for social comparison, Impact of event Scale – Revised (IES-R) to measure distress, Posttraumatic Growth Inventory (PTGI). b) Phenomenological interviews and written narratives.	51 women with breast cancer, mean age 49, average 6.39 years since diagnosis. 14% had recurrent breast cancer. b) 37 women. Demography as above.	A shared 1000 mile motorcycle ride (2 rides in US and Australia), preceded by a 6 month online discussion group.	NA	NA	a) Cancer related distress significantly reduced, but no difference to post-traumatic growth. Challenge based activities may provide a positive peer support environment. b) Peer support is a safe network, providing understanding and acceptance. Overcoming challenge enables bondinig and affirmed a survivor identity.
Ashing-Giwa et al. 2012. US (34)	To examine the impact of support groups among African American breast cancer survivors	Qualitative	Focus groups and questionnaires.	62 African American breast cancer survivors. Mean age 62. 8 stage III, 3 stage IV cancer.	Five different peer support groups.	NA	NA	Themes include: a) comfort and hope, (b) belonging and companionship, (c) health information and navigation, (d) economic and functional relief, and (e) self-esteem and purposefulness. African American BCSs prefer culturally and socio-ecologically embedded support groups.

Street et al. 2012. Australia (35)	To investigate motivations for involvement in technology-based support groups for people with advanced cancer	Qualitative	Telephone interviews, qualitative content analysis.	20 people (10 online group, 10 telephone group). Mean age 49. 14 females. Diagnosis of advanced cancer.	Telephone and online groups facilitated by cancer information and support service. Those for people with advanced cancer are facilitated by nurses who make check-calls to assess availability and see if any issues. Six facilitated sessions fortnightly for each online group (60-90 minutes), with 6-8 participants and 2 palliative care nurses. Online meet in a password protected chat room. Telephone groups meet as a teleconference.	NA	NA	Two dominant narratives: a focus on dying with dignity, or an interests in deferring discussion of death to focus on the present. Groups were accessible and safe environments in which to discuss difficult topics.
Power & Hegarty, 2010, Ireland (36)	To evaluate a facilitated breast cancer peer support program	Qualitative	Pre and post program focus groups. Content analysis.	8 women with breast cancer. Aged 30 – 60, completed treatment.	7 week facilitated peer support programme. Run in a cancer support house. Led by nurse counsellor, with a Reach to Recovery volunteer, trained as a peer supporter. Groups lasted 2.5 hours.	NA	NA	Themes: The need for mutual identification, post-treatment isolation, help with moving on, the impact of hair loss, consolidation of information, enablement/empowerment, the importance of the cancer survivor.
Online support								

Lovatt et al. 2017. UK (37)	To examine how trust develops and influences sharing among users of an online breast cancer forum.	Interpretive, qualitative approach.	Sample from threaded forum posts from a UK based breast cancer charity. Semi structured interviews face to face, skype or telephone.	135 threads across 9 boards. Includes a board called 'end of life'. Interviews with 14 forum users, no information on disease status.	Online forum, moderated by the staff of a cancer charity.	NA	NA	Three dimensions to trust: structural, relational and temporal, which are intersecting. Aspects such as not ranting and using humour were key to assessing and conveying trust.
Owen et al. 2016. US (38)	To evaluate social network characteristics of different forms of social networking interventions, determine who participates, and evaluate whether community membership impacts engagement.	Wait-list trial. Randomised allocation to immediate or 12 week wait intervention. Reported here are data on all those who accessed intervention, regardless of randomised condition.	Baseline and 12 week measures. Depression (CES-D), trauma (IES-R), social support (Yale Social Support survey, YSS), and social constraints (Social Constraints Inventory SCI). Network attributes such as density, clustering, connectedness.	299 participants from larger wait-list study. 77% female, mean age 53.8, well educated. 24.7% had late stage cancer. 45% breast cancer, 14% prostate cancer.	*Health-Space* intervention included access to confidential community of cancer survivors (asynchronous discussion, personal pages, blogs, mail, and real-time 90 minute weekly chat) and professional facilitators and a structured, 12 week coping skills training intervention.	NA	NA	Four different kinds of communication channel that create independent opportunities for people to interact. Multiple channels expands networks and enhances engagement.

Lobchuk et al. 2015. Canada (39)	To describe the content of messages in an online support community for lung cancer.	Descriptive exploratory qualitative case study approach to analyse a sample of online pages.	Convenience sample of archived online threaded messages within an online lung cancer support community over a two month period.	Registered users were 36-65 years old, 78% female. Around 50% were support persons (e.g. family, the others diagnosed with lung cancer.	Secured, monitored online support community. Monitors respond to some postings to correct erroneous information, remove spam, abuse etc. Volunteer peer monitors guided on how to respond to posts and report concerns.	NA	NA	Themes: disease, test, treatment information; symptoms, marked deterioration, advocacy, experiencing healthcare providers, survivorship, making sense of emotions. Predominant focus on symptoms and meeting instrumental and emotional needs.
Batenburg and Das. 2014. Netherlands (40)	Hypothesised an interaction between emotional coping style and intensity of online participation.	Longitudinal cohort study	Survey. Demographic information. Social support (FACT-B), Depression (CESD-10), Emotional coping scale, Profile of concerns about breast cancer, intensity of use of online communities. .	133 people with breast cancer, 109 visited online communities. Mean age 48. Educated. 32.5% had ‘cancer cells’ currently.	Dutch online communities for people with breast cancer.	NA	NA	Increased emotional wellbeing if highly active online, and approach their emotions less actively.

Batenburg and Das. 2014. Netherlands (41)	Hypothesized relationship between active online support group participation and emotional wellbeing, depression, and concerns.	Cross-sectional survey design.	Survey. Demographic information. Intensity of use of online communities. Cognitive avoidance (Dutch mini-MAC), Emotional Approach Coping scale, Depression (CES-D10), Functional Assessment of Chronic Illness Therapy questionnaire (FACIT-B)	175 women with breast cancer. Mean age 48. 12% degree educated. 14.3% stage III, 9.1% stage IV.	Dutch online communities.	NA	NA	Breast cancer patients' ability to cope with emotions and thoughts regarding the illness influence the relationship between online support group participation and psychological well-being
Bender et al. 2013. Canada (42)	To explore the role of online communities from the perspective of breast cancer survivors who are facilitators of face-to-face support groups.	Cross-sectional survey followed by qualitative interviews.	Postal survey exploring use of online communities. Telephone interviews exploring how became aware of online communities, motivations, comparisons to other support forms.	73 survey respondents (16.4% with recurrent disease), 12 interview respondents (8.3% with recurrent disease). Recruited from those attending support group facilitator training.	Any form of online community reported.	NA.	Peers who accessed any form of online cancer support community. Often tested or accessed more than one community.	Online communities used by 31.5% mostly during treatment, for information (91.3%), symptom management (69.6%), emotional support (47.8%). Addressed unmet needs during time of uncertainty. A different form of support and information.

Yli-Uotila et al. 2013. Finland (43)	To identify the initial stimuli and motives of patients with cancer to seek social support on the internet.	Survey	Online questionnaire, demographic details, experience of cancer, use of the internet.	74 adults. Mean age 53. 87% female. Educated. One forum was particularly for people with chronic cancer or palliative care treatment.	Use of discussion forums hosted on a cancer society website.	NA	NA	Initial stimuli to use internet was ease of communication, access to information, need for emotional and informational support. Seeking peer support was important, especially when fearful of expressing self to family. Healthcare systems cannot meet needs.
Klemm. 2012. US (44)	To evaluate the effects of different formats of online group support (moderated vs. peer led) on depressive symptoms and extent of participation in women with breast cancer.	Randomised longitudinal design comparing two forms of online groups. Random allocation to moderated or peer-led online support group.	Depressive symptoms (CES-D), demographic information. Baseline, 6 weeks, 12 weeks.	50 women with breast cancer recruited from breast cancer organisation. Mean age 53 (moderated), 52 (peer led. 16 had metastatic disease.	Moderated or peer-led 12 week online support groups. 15 women recruited in to each group in waves. Four groups in total. Moderated groups included social work trained moderators, trained in online support.	NA	NA	No significant differences in depressive symptoms by group or extent of group participation. Moderated groups posted more often.

Vilhauer et al. 2010. US (45)	To evaluate the feasibility and acceptability of an online peer support intervention for women with metastatic breast cancer.	Pilot randomised wait-list trial (2 months wait).	Baseline and 6 monthly assessments. Satisfaction questionnaires. ECOG performance scales. FACT-B, Perceived social support (MSPSS), Positive and Negative Affect Schedule (PANAS), Depression (CES-D). Logbooks of time taken online, and activities. Post-intervention telephone interviews.	30 women with metastatic breast cancer. 16 immediate, 14 waitlist.	Three online support group for 6 months, or 4 months for waitlist condition. Some groups mixed immediate and waitlist condition participants.			Size of study precluded definitive conclusions about intervention effectiveness. Recruitment was lengthy, but other study procedures feasible. Trends indicate effect on reducing distress and increasing activity.
Comparing forms of support								
Huber et al. 2017. Germany (46)	To identify differences and similarities in anamnestic, medical and psychological characteristics of users of face-to-face and online support groups for prostate cancer.	Cross sectional comparison study.	Quality of life (EORTC QLQ C30), Patient Health Questionnaire (PHQ-2), Generalised Anxiety Disorder Scale (GAD-2), distress thermometer, Control Preferences Scale.	955 patients visiting face-to-face support groups, and 686 using online support groups. F:F 12% metastatic disease, OSG 17%.	Face to face (230 groups) and online groups (with 3357 registered users) organised by the Prostate Cancer Patient Support Organization of Germany. Face to face groups have a trained group leader who organises meetings.	NA	NA	Online used by younger people, more educated, higher income, more likely to have metastatic disease (17 vs. 12% $p<0.001$). OSG report more distress. Face to face better for exchanging information and caring for others.

Editorial Manager MS Check Form, Current Opinion

MS Number	SPC120308
Corresponding Author name *(# of authors?)*	Catherine Walshe
Review title	**Peer support for people with advanced cancer: a systematically constructed scoping review of quantitative and qualitative evidence**
Section	Living with cancer and the consequences of treatment
Author address on MS?	Y
Author email on MS?	Y

Structured abstract	Y
Key words	Y
Introduction	Y
Headings in text	Y
Conclusion	Y
Key points	Y

Word count: abstract	191
Word count: text	2370

Bullets/annotations	Y
Refs. in sequence?	Y

Conflicts of Interest	Y

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