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Preferences for models of peer support in the digital era: A cross-sectional survey of people with cancer

Running title: Cancer patients' preferences for peer support

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ABSTRACT

Objective: Many people with cancer report an unmet need for peer support, yet participation rates are low. This study examined cancer patients' preferences for participating in peer support, and the characteristics associated with having or wanting to participate in peer support.

Methods: Adult cancer patients were recruited from outpatient oncology clinics at five hospitals in Australia. Participants were invited to self-complete two questionnaires: one at recruitment assessing their demographic and cancer characteristics, and another four weeks later assessing their preferences for participating in cancer-related peer support.

Results: The peer support questionnaire was completed by 177/273 (65%) of participants. Most (59%, n=104) had or wanted to participate in peer support. More than half reported that it was important the people they connected with had the same cancer treatment (56%, n=99) or type of cancer (53%, n=94) as themselves. Half had or wanted to participate in one-to-one peer support (52%, n=92). Half had or wanted to connect with peers face-to-face (53%, n=93). Only 13% (n=23) were receptive to connecting with peers over the internet. Being aged ≤ 65 years was significantly associated (OR=2.3; 95% CI: 1.1 – 5.1) with reporting a preference for participating in peer support.

Conclusions: Cancer patients are interested in participating in peer support, particularly those who are younger. Despite the digital era, traditional forms of peer support continue to be important in supporting people with cancer. Greater understanding of the barriers to cancer patients' involvement in potentially low cost and high reach web-based models of peer support is required.

Keywords: cancer, internet, neoplasm, oncology, patient participation, patient preference, peer group, self-help groups, social support, surveys and questionnaires

BACKGROUND

Reviews of the literature suggest that social support beneficially influences individuals' adjustment to cancer.^{1,2} While there is insufficient evidence to determine which models of social support are best, those that provide reciprocal support through peers (i.e. others going or having been through a similar experience), show favourable outcomes. In contrast to naturally occurring social networks such as family and friends, peers are in the unique position of sharing an insider's perspective of the cancer experience and providing experiential empathy.

Studies have found that cancer patients' unmet needs are greatest in the areas of emotional health and information.^{3,4} 'Finding someone to talk to who understands and has been through a similar experience' is among the top ranked items of unmet need.⁴ Three reviews concluded that peer support is acceptable and useful to people with cancer.⁵⁻⁷ Paradoxically, studies suggest that cancer patients' participation in peer support is low with estimates varying from 5% to 25%.⁸⁻¹¹ Peer support participants are more likely to be female, younger and more highly educated than non-participants.^{9,12,13} Peer support can be provided by a range of providers (e.g. not-for-profit organisations, health services) in a range of modes (e.g. face-to-face, telephone, online) and formats (e.g. one-to-one, group). Most studies examining barriers to participation have focused on traditional face-to-face models. These studies have identified low rates of referrals from health professionals, the regular time commitment, scheduling difficulties, travel constraints, feeling unwell, distress at seeing others' health declining, and feeling uncomfortable speaking in a group format as barriers to participation.¹⁴⁻¹⁶

The internet presents individuals with new choices for accessing peer support. Web-based peer support includes email groups, chat rooms, online forums and social networking. Web-based models may offer cancer patients several advantages over face-to-face and telephone modes of peer support including (a) *accessibility* regardless of geographic location, time of day or health status; (b) *autonomy* to choose with whom, when and how much to communicate; (c) *anonymity* to self-disclose beliefs and experiences without fear of negative consequences; (d) *asynchronous* conversation which allows individuals to take their time to read and compose messages; and (e) *diversity* in the range of experiences, opinions and social ties than would be available in other settings.^{17,18} Recent data indicates that 86% of households in Australia¹⁹ and 73% of adults in the United States²⁰ have internet access at home, suggesting that web-based peer support is accessible.

A tenet of quality cancer care is responsiveness to consumer needs, values and preferences.²¹

However, there is a lack of information about cancer patients' preferences for peer support in the digital era. Therefore, the aims of this study were to:

1. Describe cancer patients' preferences for peer support with respect to a) interest in participating; b) source, format and mode of support.
2. Identify whether patient preference for participating in peer support is associated with sociodemographic and disease characteristics.

METHODS

Design and setting

This study was part of a larger cross-sectional study examining psychosocial issues among patients attending outpatient medical and radiation oncology clinics at five comprehensive cancer treatment centres in New South Wales, Australia. To ensure a diversity of patient experiences and preferences regarding access to support services were represented, treatment centres were located in major cities (n=3) and regional areas (n=2).

Sample

Eligible patients had a confirmed diagnosis of any type of cancer, had attended the cancer treatment centre at least once in the past six months, were aged 18 years or older, and able to read and understand English adequately to provide informed consent. Patients deemed by clinic staff to be too unwell or unable to complete the survey independently were excluded.

Procedure

A structured recruitment and data collection procedure was used. Participants were recruited between October 2015 and April 2016. Each treatment centre had a six-week recruitment period consisting of two weeks of active recruitment, a two-week pause to allow turnover of patients, followed by another two weeks of active recruitment. Outpatient clinic staff screened the medical records of scheduled patients and recorded their eligibility against each criterion on a log sheet. When eligible patients presented for their appointment, clinic staff introduced them to a research assistant in the clinic waiting room. The research assistant used a standard script to give eligible patients a verbal overview of the study, provide a written patient information and consent form, answer questions, and obtain informed written consent to participate. Consenting patients were asked to complete two pen-and-paper questionnaires. The first questionnaire was provided to participants at the time of consent and contained items about demographic and cancer characteristics, quality of life and cancer care experiences. Participants who were unable to

complete the first questionnaire in the waiting room before being called for their consultation were asked to return it to the researchers within one week in the reply-paid envelope provided. In order to minimise clinic disruption and participant burden at a potentially stressful time, a second questionnaire was sent to participants four weeks later. Participants were randomly allocated to receive one of two versions of the second questionnaire with each version containing different items. The peer support items were in one of the versions of the second questionnaire. Two written reminders were sent at two-weekly intervals. The research was conducted according to the protocol approved by the Human Research Ethics Committee of the University of Newcastle (H-2015-0158) and each treatment centre.

Measures

Peer support preferences: Two study-specific items assessed participants' preferences for participating in, as well as the format, mode and sources of peer support. The author-developed items were based on a review of the literature, input from cancer support service providers and feedback from people with cancer. The following explanation was provided: "Peer support involves listening to, exchanging information and sharing experiences with other people who have been diagnosed with cancer. Peer support can be between two people or a group, and can take place in person, over the telephone or the internet." The two items (verbatim) which followed were:

- (i) "Since your cancer diagnosis, have you taken part in any of the following types of peer support: a) meeting with a person face-to-face, b) meeting with a person over the telephone, c) meeting with a person over the internet, d) meeting with a group of people in person face-to-face, e) meeting with a group of people over the telephone, and f) meeting with a group of people over the internet?" For each model of support, participants responded either "yes," "no, but I would like to" or "no and I don't want to." Those who answered either "yes" or "no, but I would like to" to at least one of the six peer support models listed were classified as having a preference for taking part in peer support. Participants who answered "no, and I don't want to" to all six peer support models were classified as not having a preference for taking part in peer support. Additionally, preferences for format (group-based, one-to-one) and mode (face-to-face, telephone, internet) of peer support were derived. Participants who answered either "yes" or "no, but I would like to" to at least one of the group-based peer support models were classified as having a preference for that format of peer support. The same logic was applied to classify participants as having a preference for one-to-one models of peer support, face-to-face, telephone-based, and web-based peer support respectively.
- (ii) "How important is it for peers who may provide you with support to be: a) the same gender as you, b) similar in age to you, c) from the same cultural background as you, d) diagnosed with the same type of cancer as you, and e) having the same type of cancer treatment as you?" For each

characteristic, participants were asked to respond either “very important, “somewhat important”, or “not at all important”.

Demographic characteristics included self-reported age, sex, highest level of education completed, country of birth, current employment status, health insurance status, home internet access, and home postcode. Postcodes were categorised as “urban” (major city or inner regional Australia) or “rural” (outer regional, remote or very remote Australia) according to Australian Bureau of Statistics Remoteness Area classification and Accessibility Remoteness Index of Australia scores.

Cancer characteristics included self-reported cancer type, perceived stage of disease at diagnosis, length of time since diagnosis, current treatment status and treatments ever received.

Social support was assessed by the 6-item MOS Social Support Survey (MOS–SSS-6) which measures global functional social support.²² A mean score was calculated for participants who answered all 6 items. Those with a mean score ≥ 3 were classified as having social support available ‘all/most of the time’ and those with a mean score < 3 were classified as having social support available ‘some/a little/none of the time’.²³

Health status was assessed by the 2-item global health status/quality of life scale of the EORTC Quality of Life Questionnaire-Core 30.²⁴ A mean score was calculated for participants who answered at least one of the two items and transformed to range from 0 to 100.²⁵ Higher scores represent better overall health.

Statistical analysis

Frequencies and percentages with 95% confidence intervals were calculated for the main outcome (preference for participating in peer support). The association between participant characteristics and the main outcome were assessed using logistic regression analyses. Due to the number of independent variables assessed and the modest sample size, four separate multivariable logistic regression analyses were initially conducted. That is, a separate logistic regression examined the association between each of: (i) demographic (age, sex, country of birth); (ii) disease (cancer type, stage at diagnosis, time since diagnosis); (iii) treatment (current treatment status; received surgery, chemotherapy, radiotherapy) and (iv) social (MOS-SSS category, health status score, employment, home internet, remoteness) characteristics with preference for participating in peer support. Demographic characteristics with a p -value < 0.2 and disease, treatment and social characteristics with a p -value < 0.05 were included in the final logistic regression model. A less conservative p -

value was used to identify demographic characteristics to include in the final model to control for potential demographic confounders. Characteristics with a p -value <0.05 in the final logistic regression model were considered statistically significantly associated with a preference for participating in peer support. The final model was assessed for multicollinearity, influential observations, goodness of fit (Hosmer-Lemeshow statistic with p -value >0.05 considered acceptable) and discriminative ability (area under the curve with ≥ 0.7 considered acceptable). For the secondary outcomes (source, format and mode of support), only the frequency and percentage are reported; 95% CI are not reported to avoid multiplicity issues for these descriptive outcomes.

RESULTS

Of the 784 eligible patients approached, 527 consented to participate in the study and of these, 273 were sent the questionnaire containing the peer support items. A total of 177 (65%) participants completed the peer support questionnaire and were included in the analyses. There were no statistically significant differences in the demographic and disease characteristics of those who completed only the first questionnaire compared with those who completed both the first and second questionnaire. Sample characteristics are presented in Table 1.

Cancer patients' preferences for peer support

Participation: A total of 104 (59%; 95% CI: 52% - 66%) participants reported a preference for participating in peer support. Of these, 75 had participated in peer support and 26 had not participated in peer support but would like to. A total of 66 (37%; 95% CI: 30% - 44%) participants reported that they had not participated in peer support and did not want to.

Source: More than half of participants reported that it was very or somewhat important that the people they connected with had received the same cancer treatment ($n=99$; 56%) or were diagnosed with the same type of cancer ($n=94$; 53%) as themselves. Fewer participants reported that it was important that peers were of the same age ($n=74$; 42%), gender ($n=68$; 38%) or cultural background ($n=56$; 32%) as themselves.

Format and mode: Approximately half of participants reported that they had or would like to participate in peer support in a one-to-one format (52%). Half of participants had or would like to connect with peers face-to-face (53%). Few participants had or wanted to connect with peers over the internet (13%) (Table 2).

Factors associated with preference for participating in peer support

The initial logistic regression models identified that age group, country of birth, cancer type, disease stage at diagnosis and having received chemotherapy were associated with a preference for

participating in peer support. A total of 156 participants had complete data for all of these variables and were included in the final multivariable logistic regression model (Table 3). Age group was the only characteristic found to be statistically significantly associated with preference for peer support. Participants aged ≤ 65 years had twice the odds of reporting a preference for participating in peer support, compared to those > 65 years. The final model showed no indication of multicollinearity or influential observations, was an adequate fit to the data (Hosmer-Lemeshow $p=0.095$) and had acceptable discriminative ability (AUC=0.72).

CONCLUSIONS

This study found that the majority of people with cancer are interested in connecting with others who have experienced cancer. More than half of participants (59%) had either participated in or wanted to participate in peer support. These findings correspond with research indicating that many people with chronic disease, including those with cancer, report feelings of loneliness or social isolation,²⁶ and the general trend towards community disconnectedness.²⁷ The rates of demand for peer support identified in this study are considerably higher than that reported by other studies also involving large samples of people with cancer at various stages of the cancer journey.⁸⁻¹¹ This likely reflects that this is one of the first studies to examine participation across a diversity of peer support formats and delivery modes. Nonetheless, a sizeable minority (37%) of participants did not want to participate in peer support and emphasizes the need for people with cancer to have access to a suite of support services.

Connecting with peers with a similar cancer experience is important

Homogeneity in disease characteristics were important criteria for participants' preferred source of support. Participants valued connecting with peers whose cancer type and cancer treatment, rather than sociodemographic characteristics, were similar to their own. These findings are consistent with those of Butow et al²⁸ and Ieropoli et al.¹⁵ Given that identifying with and sharing lived experiences with others who have comparable problems is intrinsic to the principles and processes of peer support, these findings aren't surprising. They also resonate with the notion that support received from fellow cancer patients is different to that received from other supportive relationships.²⁹

Traditional models of peer support are preferred

In contrast to our expectations, participants reported a preference to connect with others using traditional, resource-intensive models of peer support. Participants preferred to be involved in peer support delivered in a one-to-one format. Some studies have found that patients perceive it is easier to establish rapport and mutual understanding with one unfamiliar individual than a group of

unfamiliar people.³⁰ Given that building rapport is the first step towards developing trust and reciprocity in sharing personal experiences, these findings emphasise the importance of patients having the opportunity to be involved in choosing the peers with whom they connect.

In terms of mode, participants preferred face-to-face peer support. Only 13% of participants reported being receptive to using web-based peer support. While these findings may be partly due to one third (34%) of participants not having internet access at home, they are similar to other studies examining peer support preferences among people with cancer^{31,32} and other chronic diseases.³³ However, our findings are in sharp contrast with general population data revealing high and growing levels of internet use for communication,¹⁹ support and health advice.³⁴ It's possible that web-based peer support has not been well explained to cancer patients so they don't have a clear understanding of its advantages over other modes of peer support. These findings reinforce that, despite the emergence of the digital era and use of the internet in daily life, support for people with cancer still needs to be available in a range of different forms. However, given the potential low cost and high reach of web-based peer support, research is needed to examine the barriers that impede cancer patients' participation in this mode of support. This information will be important for guiding innovations in the design, delivery and promotion of web-based peer support to enhance the likelihood of uptake.

While patient preferences are an important criterion for decision-making about which models of peer support are developed and made available to patients, evidence of the effectiveness of the different models of peer support in improving physical and mental health is also important. Interestingly, some studies have found that meeting patients' preferred intervention delivery mode does not lead to better outcomes.³⁵ Evidence from rigorous trials testing the comparative effectiveness of different models of peer support is needed to inform decisions about the composition of cancer-related peer support services.

Age influences cancer patients' interest in participating in peer support

Of the variables examined, age was the only characteristic which significantly influenced interest in participating in peer support. Similar to findings of other studies with cancer patients,^{9,12,13} those who were younger than 65 years were significantly more likely to be interested in engaging in peer support. This may reflect that individuals' appraisal of and coping with potential stressors, such as cancer, varies over the life course. Older adults, including cancer patients, report being more concerned about the death of a spouse or family member than personal illness.^{36,37} They also report a strong need to maintain self-sufficiency and autonomy in the face of cancer.³⁷ This is consistent

with studies suggesting that the use of ‘adaptive’ coping strategies, such as seeking support, decreases with increasing age.³⁸ In contrast, it is well documented that younger cancer patients are more likely than older cancer patients to experience and want help to manage distress.^{39,40} As cancer is an aging-associated disease, it is likely that those diagnosed at a younger age may not know any other individuals in their support network with a similar cancer with whom they can share their experiences.

Study limitations

Despite consecutive sampling of eligible participants, approximately one third of the study sample were diagnosed with breast cancer. Additionally, patients who were not proficient in English were excluded. Although two reminder follow-ups were implemented, the response rate of 65% of those who were sent the second questionnaire is lower than desired. Consequently, the generalisability of the study findings to the diversity of cancer patients may be limited. Due to response burden, we were unable to assess a number of psychosocial characteristics, such as coping style and distress, which may have influenced participant’s interest in connecting with peers. While this study allowed us to identify the proportion of participants who reported the various elements of peer support as being important, it did not allow us to determine their rank order of importance. To address this, we are eliciting cancer patients’ preferences for the configuration of peer support programs in a discrete choice experiment study. Finally, patient preference does not equate with use with studies showing that fewer patients participate in peer support than express interest.¹²

Clinical implications

This study provides valuable information to those involved in organising cancer-related peer support. Our findings suggest that the capacity to link up peers based on criteria such as cancer treatment or cancer type may be a key ingredient to a successful peer support program. Most cancer patients were interested in participating in peer support, particularly those aged ≤ 65 years. This suggests that opportunities for participating in peer support need to be available and promoted to younger people with cancer. Older cancer patients may need more detailed information about the potential benefits of peer support, and encouragement to engage in it as an adjunct to the care provided by health professionals. Although the internet has increased opportunities for peer contact, more cancer patients were receptive to face-to-face and telephone-based support than to web-based support. These findings suggest that traditional forms of peer support continue to have an important place in supporting people with cancer. Promoting greater understanding of web-based peer support may be required to overcome cancer patients’ reticence towards these newer forms of peer support.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

DATA ACCESSIBILITY STATEMENT

Study data are available from the corresponding author on request.

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Table 1: Sample characteristics (N=177)

Variable	Category	Total [†]
		n (%)
Age group	≤65 years	83 (50)
	>65 years	84 (50)
Sex	Male	71 (41)
	Female	101 (59)
Education	High school or less	93 (58)
	Vocational	45 (28)
	University	23 (14)
Country of birth	Australia	130 (77)
	Other than Australia	38 (23)
Employment	Employed	52 (31)
	Not employed	117 (69)
Private health insurance	Yes	77 (46)
	No	92 (54)
Home internet	Yes	112 (66)
	No	57 (34)
Residential remoteness	Urban	153 (89)
	Rural	18 (11)
Cancer type	Breast	63 (38)
	Prostate	24 (14)
	Gastrointestinal	21 (13)
	Lung	16 (9.5)
	Other	44 (26)
Disease stage at diagnosis	Early	93 (56)
	Advanced	51 (31)
	Don't know	23 (14)
Time since cancer diagnosis	<1 year	82 (49)
	1-2 years	25 (15)
	>2 years	62 (37)
Current treatment status	Not receiving treatment	112 (67)
	Receiving treatment	56 (33)
Treatment ever received	Surgery	107 (62)

Variable	Category	Total†
		n (%)
Availability of social support	Chemotherapy	109 (63)
	Radiotherapy	110 (64)
	All/Most of the time	132 (80)
	Some/None/Little of the time	34 (20)
Health status (mean, SD)		67 (21)

† totals may not add to 177 due to missing responses

Table 2: Patients' preferences for format and mode of peer support

	Participated in peer support (n=75) n (%)	Want to participate in peer support (n=26) n (%)	Don't want to participate in peer support (n=66) n (%)	Total[‡] n (%)
Characteristic				
Format [†]				
One-to-one	71 (95)	19 (73)	0 (0)	92 (52)
Group	42 (56)	20 (77)	0 (0)	63 (36)
Mode [†]				
Face-to-face	68 (91)	24 (92)	0 (0)	93 (53)
Telephone	50 (67)	13 (50)	0 (0)	65 (37)
Internet	15 (20)	7 (27)	0 (0)	23 (13)

[†] multiple responses allowed [‡] totals may not sum to 177 due to missing responses

Table 3: Characteristics associated with willingness to participate in peer support

Characteristic	Category	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted p-value
Age group	≤65 years or less	2.3 (1.2 – 4.5)	2.3 (1.1 – 5.1)	0.03
	>65 years	1.00	1.00	
Country of birth	Other than Australia	1.7 (0.77 – 3.8)	1.8 (0.72 – 4.5)	0.20
	Australia	1.00	1.00	
Cancer type	Breast	1.7 (0.78 – 3.9)	2.7 (1.0 – 7.4)	0.12
	Gastrointestinal	3.2 (0.91 – 11.0)	3.9 (0.99 – 15.5)	
	Lung	0.79 (0.25 – 2.5)	0.9 (0.25 – 3.2)	
	Prostate	0.49 (0.17 – 1.4)	1.2 (0.33 – 4.1)	
	Other	1.00	1.00	
Disease stage at diagnosis	Don't know	1.5 (0.59 – 4.0)	2.2 (0.71 – 6.9)	0.06
	Advanced	1.9 (0.91 – 4.0)	3.0 (1.2 – 7.5)	
	Early	1.00	1.00	
Chemotherapy	Yes	2.6 (1.3 - 3.7)	1.6 (0.71 – 3.6)	0.25
	No	1.00	1.00	