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Enabling mutual helping? Examining variable needs for facilitated peer support

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Abstract

Objective: To examine uses of peer support among people living with a urological cancer.

Methods: 26 qualitative interviews investigating experiences of needing and receiving information and support among people who had and who had not used a new urological cancer centre and its various peer support opportunities.

Results: Study participants reported varied needs for engagement with facilitated peer support, and suggested these depended on the severity and burden of their disease and treatment, the support they derived from existing networks, and their sense of coping. A minority reported avoiding speaking with other patients in order to protect their own or the other patients' emotional wellbeing.

Conclusion: Desire for facilitated peer support is variable, and both giving and receiving support may have negative as well as positive consequences. These may depend on the nature of social comparisons that peer support interventions prompt, and the varying ways people interpret these.

Practical Implications: Services offering facilitated peer support should recognise people's variable and contingent needs for support, and acknowledge the potential disadvantages of facilitated peer support for some patients.

1. Introduction

In recent decades, many health services have started to facilitate peer support for people with various conditions, including cancer [1]. Broadly speaking, they all seek to promote social and communicative exchanges between patients, but they do this in diverse ways and with a range of aims. Peer supporters might be encouraged to listen to problems, try to understand feelings, share experiences, discuss practical ways of dealing with physical effects of diseases or treatments, and provide practical help, for example with transportation [2]. The forms of support they aspire to offer have been variously categorised, for example as focusing primarily on ‘emotional,’ ‘informational’ or ‘instrumental’ support [3], although these categories are not necessarily mutually exclusive (e.g. informational support could also help on an emotional level).

An extensive literature demonstrates that facilitated peer support interventions that enable people with cancer to talk with others with similar experiences can create a sense of empowerment and community [4-7] and influence a range of outcomes including morale, psychosocial functioning and quality of life [8].

Studies of peer support initiatives in the context of cancer have tended to focus on the views of those who accept offers of peer support [4,9,10]. However, accepters may be in a minority and drop-out rates are sometimes high [5,11]. Few studies have

considered the views of those who do not participate, or those who subsequently drop out [for a notable exception see 12], resulting in limited understanding about why people do not use these services [4].

We examined issues relating to peer support among people living with a urological cancer (prostate, bladder, kidney, testicular, or penile), as part of a qualitative evaluation of a new centre that was established to provide newly diagnosed patients with information, guidance and support. The centre's main facilities are located just off a cancer ward in a major hospital. It facilitates communication between patients in several ways, including: offering a comfortable seating and conversation space; providing access to an online discussion forum for patients in the region; and offering to introduce new patients to more experienced patient 'buddy' advisors. Since it opened in January 2008, most people who have been newly diagnosed with a urological cancer have been introduced to the centre and its support services.

2. Methods

Eligible participants had been treated for a urological cancer at the hospital where the centre's main facilities are located. For the evaluation, we sought to interview a diverse sample including men and women with different urological cancers who had and who had not used the centre and its peer support services.

The study was approved by the North of Scotland Research Ethics Committee. All participants gave written consent before participating.

2.1. Recruitment and consent

We used two recruitment strategies to help ensure we included patients with diverse perspectives on the centre. Both required people to 'opt in' to the study by contacting a researcher.

First, as we wanted to recruit both those who had and had not been introduced to the centre at diagnosis, hospital staff used a hospital database to identify eligible patients diagnosed in either the 6 months before or the 6 months after the centre opening. They mailed a study information leaflet and an invitation letter from a consultant explaining that his research team wanted to hear from people about their views of the centre and issues relating to their care and treatment.

Second, in order to ensure we attended to the views of people who had engaged actively with at least one of the centre's support services, people who attended a meeting for people registered with the centre as 'buddy' advisors were informed of the study and asked to opt in if willing to take part in an interview.

We monitored the sample of people who responded, and as interviews progressed, to check participants varied in terms of key characteristics and experiences of interest. We took care to ensure we included people who had and had not participated in the various peer support services as 'givers' and/or 'recipients' of support (recognising that there is often reciprocity between the people who are viewed primarily as providing and those viewed primarily as seeking help).

2.2. Data collection

We used telephone interviews to minimise participant burden and to avoid excluding people who lived in remote areas. At the start of the interviews, participants were encouraged to provide a narrative account of their cancer journey. They were then asked about their reactions to their diagnosis, information and support needs (around diagnosis and subsequently), interactions with health professionals, and views about the care they experienced. Participants were also asked to discuss any experiences they had of using the centre or its peer support services. Those who seemed not to know about the centre were informed of its services and asked what they thought about these as ideas. Interviews lasted 40-80 minutes and were audio-recorded and transcribed.

2.3. Data analysis

Transcripts were analysed thematically [13]. Following initial familiarisation with the transcripts, a priori and emergent themes and sub-themes were identified, discussed and agreed by the authors and a thematic coding framework developed. Initial codes (including codes relating to facilitated peer support) were then systematically applied to the data using text management software (NVivo 8), and this software was used to help organise the data to facilitate further analytic consideration.

3. Results

3.1. Sample size and characteristics

72 people were approached by hospital staff: 22 contacted the researcher and 19 were interviewed. 14 people contacted the researcher after attending the 'buddy' meeting and 7 were interviewed.

Brief descriptions of the participants are provided in Table 1. They include 20 men and 6 women, aged from 37 to 80 years, who had been diagnosed with cancers of the prostate (6), bladder (6), kidney (8) or testes (6). They had first been diagnosed between 1986 and 2008. All were white British and lived in Aberdeen city, Aberdeenshire, Moray or Orkney.

Seven participants remembered being introduced to the centre by a specialist nurse when they were first diagnosed: five of these had not used it since. Six participants indicated that they had been frequent visitors. Six participants were registered as 'buddy' advisors, and three of these had given support to other people with cancer. Three participants had sought support from a buddy advisor (2 via the centre and 1 via ward staff). Seven had used the centre's online forum at least once.

3.2. Valuing communicating with other people with cancer

In their narrative accounts, people mentioned various sources of communicative support including health professionals, family and other people with cancer. These others included people whom participants knew prior to their own diagnosis, people met while using health services and people met through facilitated contact. Most participants spoke appreciatively about a) hearing about other people's experiences and b) being able to share their stories or offer advice to others.

Experiential information sharing with others with cancer was valued as an important complement to communicative support from other sources. It appeared to serve several positive functions relating to different forms of support, including: 1) receiving/demonstrating understanding and empathy; 2) reducing feelings of

isolation; 3) alleviating worries and promoting 'hope'; and 4) receiving/giving practical tips and advice (Box 1).

Box 1. Valuing communicating with other people with cancer

1) Receiving/demonstrating understanding and empathy

“with the deepest respect to [cancer specialist nurse] he’s never suffered from this [cancer], he’s studied it clinically but he’s never been there and worn the t-shirt...” (Bill, Prostate)

2) Reducing feelings of isolation

“...I did actually find staying in the hospital... surrounded by other people, most of whom were... in a worse place than I was, there is a degree of comfort that you take from ...I'm not alone here there's hundreds and thousands of people going through this ...” (Daniel, Testicular)

3) Alleviating worries and promoting 'hope'

“...someone in the very early stages who is really going through the mill...if you can present yourself as a healthy active person then they’ll be saying...‘Hey, it can’t be too bad, that guy’s managed and look at him now.’”(Geoff, Prostate)

“...I think to get somebody whose come out the other end ...make you feel a bit better, like it's not all doom and gloom...”(Nick, Testicular)

4) Receiving/giving practical tips and advice

“...[another patient] had a very sore mouth and I said...I cleaned my mouth every night and morning with sodium bicarbonate and... it got rid of it really...just sort of simple tricks that you’ve learned to cope with things...” (Jennifer, Kidney)

3.3. Avoiding communicating with other patients

A minority of participants reported avoiding communicating with other people with cancer (or at least some people with cancer). They said this was to prevent anxiety, guilt or envy in themselves or the others. For example, Lynn had become friendly with another cancer patient around the time of her diagnosis, but had been distressed by the woman's death. She wanted to avoid repeating that experience:

"...the first time I went in for a bladder examination, there was this woman there... And she had exactly the same as I had...and I got quite friendly with [name]...Well that woman died...and I just said that's it, I'm not going to speak to anybody ever again about it...because it was worrying for me, it was obviously very, very sad also."
(Lynn, Bladder)

Lynn also chose to avoid sharing her experiences with others for fear that she might upset them:

"... if somebody comes in with the same problem as me I try and not discuss it because I wouldn't like to worry anybody about it...." (Lynn, Bladder)

Queenie said she had enjoyed taking part in a support group with other people with cancer. However, when a friend suggested she could volunteer to make tea at a hospice, she declined because she anticipated that contact with people with less good prognoses would trigger distressing guilt and anxiety:

"... I'd feel a bit guilty if I was recovering and somebody else was terminal... I'd feel... ashamed and stuff... I can't go and watch other people...that are terminally ill...I find that distressing...I said I just don't think I could face that..." (Queenie, Kidney)

Neil described actively avoiding communicating with other patients around the time of his diagnosis for fear that it would give him 'false hope' with regard to his own prognosis, or lead him to feel envious:

"...I didn't really want to know about other people ... especially when someone says oh yes everything's perfectly okay and then... you probably get that in your mind and if someone was to suddenly tell you something different, it's a bit harder to take... I think it would make you a little bit envious of them as well...why did it go all right for him and not for me." (Neil, Testicular)

Neil had subsequently made a good recovery but was wary of sharing his 'positive' story with recently diagnosed patients in case it gave *them* false hope.

3.4. Varied needs for facilitated peer support

Some non-users of facilitated peer support services discussed not feeling the *need* for these services. Their reasons included a) they were getting adequate support from elsewhere; b) the severity of their cancer and treatment at the time did not warrant it; and c) they had adjusted well enough to having cancer. For example:

3.4.1. Support from existing support networks

Our sample reflected on the support they had received from members of their existing social networks (e.g. friends/family). This support could be 'emotional' (e.g. attempting to improve psychological well-being) 'informational' (e.g. accessing treatment information) and/or 'instrumental' (e.g. helping with changing dressings; travel to hospital; attending consultations).

3.4.2. The burden of illness and treatment

Several people described having had a fairly 'straightforward' cancer journey. They reported having been given a good prognosis, sometimes undergoing a 'one-off' treatment (e.g. surgery to remove a kidney) which resulted in few or no side effects and was followed by periodic non-invasive monitoring. Some did not think they had been 'ill enough' to need support beyond that obtained from their existing support networks:

"...as [far as] I was concerned I had to have an operation to remove the kidney and the cancer and then I had to get fit for work ... and I never needed any support to do that, I had my family around me supporting me and my doctor and my consultant and I didn't really need any more support than that." (Joseph, Kidney)

3.4.3. Adjustment and acceptance

Non-participation in facilitated peer support for others seemed to relate to how they had psychologically adjusted to having cancer, along with their coping style:

"I'm afraid I don't really take a lot of interest, I just go up, they give me a check up, if I'm clear that's fine, if I'm not clear I know I'll be in within six weeks and they'll take it out ...So I just look on the bright side of it and not a chore, you know?...I'm not really that bothered, I'm having a good life..." (Albert, Bladder)

Some people who had not used the centre or its peer support services clearly regarded their own lack of need for it as contingent on their particular circumstances. Several said that they might have found these services useful if their situation had

been worse – and that they might appreciate them if their condition or circumstances changed in the future. Several also acknowledged that other people with cancer might be more likely to benefit from facilitated peer support if, for example, they had poor prognoses, limited supportive networks to draw on, and/or different personalities and attitudes towards cancer.

3.5. Factors moderating perceived usefulness of facilitated peer support

Even among those who had engaged or would consider engaging with facilitated peer support there was recognition that its usefulness could be variable. Participants expressed concerns about the accuracy of information shared and the appropriateness of any influence that others may have. They also suggested that offers of facilitated peer support needed to be timed appropriately to stages of illness and treatment journeys to ensure patients were able to benefit from them.

4. Discussion and conclusion

4.1. Discussion

We examined views about various forms of peer support amongst people with urological cancer who had and had not participated in facilitated peer support services as givers and/or recipients of support. A majority described valuing hearing about other people's experiences of cancer and being able to share their own stories or offer advice, although not all had felt the need to participate in facilitated peer support. A minority had chosen to avoid communicating with other people with cancer – especially those who were better or worse off than themselves at the time in terms of disease prognosis status. People's needs for facilitated peer support depend

on their 1) 'usual' sources of social support; 2) disease and treatment burden and; 3) sense of adjustment and acceptance.

4.1.1. Potential benefits of helping others

Our findings that people often valued experiential information sharing in the context of cancer were consistent with a number of previous studies [e.g. 4,5,14,15,16].

However, most published research into peer support in the context of cancer has investigated the effects of engagement on those receiving rather than those giving support. Our sample included people with experience of giving and receiving support through peer support interventions. Our findings tend to confirm that some people value being able to share their own stories or offer advice to others, and that helping others may impact positively on their own wellbeing. This observation, which seems consistent with 'helper-therapy' theory (17), has been hinted at before [4] and supports findings from various studies in non-cancer contexts [18,19,20].

4.1.2. Variable desire to participate in facilitated peer support

Some people did not want to hear about other people's cancer experiences or to share their own. A minority of participants reported avoiding speaking with other patients for reasons that included concern about possible negative outcomes as well as a lack of felt need for additional support. These observations resonate with findings from the few previous studies that have explored reasons for non-engagement in facilitated peer support [12,21].

The people who did not engage with facilitated peer support interventions could still value the existence of such services. Some thought their usefulness might vary across the phases of their cancer journey, and some regarded them as an important 'safety

net' should their circumstances change in the future (this was perhaps particularly true for people who considered their cancer journey had been fairly 'straightforward' and people who had been given a good prognosis). Previous research has also suggested that people's engagement with peer support services may alter with changes along health and illness pathways [12,22].

4.1.3. Opportunities for social comparison

Social comparison theory can help us to understand and explain variations in the extent to which different people are inclined to participate and likely to benefit from different forms of peer support. This theory suggests people are motivated to compare themselves with others in order to feel better about themselves [23]. The social comparisons that people engage in can be based on various dimensions (e.g. coping and/or illness severity) and can be in either an 'upward' or a 'downward' direction. People may benefit from social comparisons in various ways. They may, for example, learn and derive hope from making 'upward' comparisons to people who seem to be coping better than they are. They might also feel better about their own plight if they make 'downward' comparisons with people whose prognosis is worse than their own [24].

However, the meanings people derive from any social comparisons they make are important, and some interpretations may be unhelpful [25,26]. For example, a person who encounters others who are coping better than they are might interpret the 'upward' comparisons negatively if they do not believe they could be like those others. A person who encounters someone with a worse disease prognosis status might become anxious about how their own condition might deteriorate. Thus, both 'upward' and 'downward' comparisons can have both positive and negative

interpretations and implications. The ways in which people interpret comparisons in different directions may relate to individual variables such as levels of anxiety about symptoms and self esteem [25]. They may also vary over stages of illness.

Social comparison theory has been used to explain some of the potential benefits and harms of peer support interventions among people who use them. They may help some people with cancer because the opportunity they provide for social comparison can be important for promoting self enhancement and self improvement [25].

Our data contained examples of social comparisons made in both 'upward' and 'downward' directions on different dimensions (e.g. treatment side effects; treatment burden; prognosis). It illustrated the potential of such comparisons to impact positively and negatively on people's self-evaluations. Some people with cancer interpreted 'downward' comparisons positively and valued the opportunity to make (or enable others to make) 'positive' upward comparisons. Several people who reflected on their roles as buddy 'advisors' thought they could help more recently diagnosed patients by offering reassurance, helping to alleviate specific worries, and presenting a 'positive' image that could foster hope. Others described how they had valued or *would* have valued speaking to people who they perceived had 'beat' cancer to help 'cheer themselves up' and give them hope.

However, a few seemed hesitant to make either 'upward' or 'downward' comparisons with others (and/or to encourage others to make comparisons with them). These people tended to interpret such comparisons in a 'negative' light. They discussed wanting to avoid communicating with (some) others with cancer as they

anticipated making comparisons that would be unhelpful or have negative implications.

Social comparison theory can thus shed light on some of the reasons for variations in people's preferences to engage with peer support, and on the circumstances in which peer support may have negative consequences. People's preferences may (implicitly) reflect their self-anticipated tendencies to interpret comparisons in ways that are or are not personally helpful, and the interpretations they make in practice may shape the benefit (or disadvantage) they derive.

4.1.4. Study strengths and limitations

Our study is one of only a few that has explored views about peer support amongst people who have not (as well as those who have) participated in facilitated peer support, and we have considered the provision as well as the receipt of support.

Our sample included men and women with a diverse range of cancers, across a wide age range and who were at different 'phases' in their cancer journey. Within our diverse sample, we found that themes relating to experiential information sharing were similar across urological cancers and broadly consistent with previously published research. However, research focussing more narrowly on one specific cancer 'group' might reveal more particular issues in terms of views and experiences of peer support.

We reflected on social comparison theory and found it useful for furthering understanding into reasons for and against participation in peer support interventions. However, our study was not specifically designed to 'test' this theory.

Further research might usefully explore the differential benefits that people might gain from participation in facilitated peer support that offers opportunities for different types of social comparison, with greater or lesser demands for communication, and among people who are inclined to interpret and use comparisons in varying ways.

4.2. Conclusion

Our investigation of views about peer support within the context of urological cancer confirms that enabling people with cancer to talk with others with similar experiences may influence a range of outcomes including emotional well-being by facilitating learning, enhancing coping strategies and creating a sense of 'connectedness.' However, people's desire for facilitated peer support is variable and there may be potential negative as well as positive consequences associated with both giving and receiving peer support. To some extent these depend on the nature of social comparisons that peer support interventions prompt, and the variable inclinations of people to interpret and use these comparisons positively or negatively.

4.3 Practice implications

Our paper provides important insights into why people with cancer vary in terms of both their desire and their potential to benefit from participation in facilitated peer support. Understanding the reasons why people might and might not choose to participate in facilitated peer support services is important for designing effective interventions and for identifying and offering them to people who could benefit.

Organisations interested in developing and promoting peer support services should bear in mind that desire for engagement may be variable and contingent upon a range of factors including specific support needs and existing support networks. Perceptions about the composition of any peer support group or the characteristics of a prospective 'buddy' advisor might have implications for participation. People who do not wish to engage in social comparisons and/or interpret comparisons with others negatively may be less likely to gain benefit from engaging in peer support opportunities. The potential disadvantages to taking part in peer support interventions need to be acknowledged, and risks appropriately managed. For some people, and perhaps depending on circumstance, the opportunities they provide for social comparison may be unhelpful.

Our study suggests reasons why the composition of peer support groups and the 'matching' of patients with 'compatible' peer supporters may impact on participation and retention levels, but also suggests that the variables of age and gender which are usually considered may not be the most important ones.

There may be scope to 'target' services more effectively towards people most likely to benefit by considering patients' psychological functioning, existing sources of support, coping style (e.g. avoidant rather than positive coping behaviour) [28] and inclination to place positive or negative interpretations on comparisons with others. Furthermore, as our findings also suggest that desire for engagement in facilitated peer support interventions may change over the course of an individual's cancer journey, health care providers may need to consider assessing patient need at various time-points. These ideas warrant further attention in research.

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