Title: Toward structured peer support interventions in oncology: A qualitative insight into the experiences of gynaecological cancer survivors providing peer support

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Abstract

*Purpose:* Research into dyadic (one-to-one) peer support has predominantly focused on the *recipients* of peer support, whilst neglecting the impact on the peer support *providers* (*PSPs*). Increasingly, structured/protocolised peer support interventions are employed. The aim of this qualitative study was to explore the experience of providing peer support within a protocolised intervention and how common key characteristics of such interventions (guidelines and checklists, rigourous training and partnerships with health professionals) may influence PSPs’ experiences. This research was conducted within the context of an ongoing randomised controlled trial investigating a protocolised peer support intervention (the PeNTAGOOn trial).

*Methods:* 11 women (gynaecological cancer survivors) providing peer support within the PeNTAGOOn trial participated in semi-structured telephone interviews. Transcribed interviews were analysed using thematic analysis.

*Results:* Five key themes were identified which described the overall experience of providing protocolised peer support: i) fitting oneself to the protocolised PSP role, ii) the impact of personal beliefs about the value of research, iii) protocolisation as both blessing and curse, iv) discussing taboo or sensitive topics, and v) the impact of interactions with study personnel.

*Conclusions:* These insights into the advantages and disadvantages of protocolised peer support can be used to inform future research and social-support programs, and maximise the effectiveness of such programs for patients, PSPs and the healthcare system.

Keywords: cancer, oncology, peer support providers, interventions, qualitative research
Dyadic (one-to-one) peer support occurs when an oncology patient receives emotional, informational and practical care, which is provided by someone who has also had a cancer diagnosis [1]. There is evidence of improved psychological wellbeing for the recipients of such support [2-4], however, findings are inconsistent. It may be that individual characteristics determine who benefits from peer support, and these individual variations may be lost in aggregated data. Further, the mechanisms through which peer support functions and how patients benefit is not well understood.

Research into dyadic peer support to date has focused almost exclusively on peer support recipients, while the peer support providers (PSPs) have been largely ignored [5,6]. There are a few notable exceptions [7-10], including Pistrang et al. [9] who concluded that the benefits of providing peer support include: the satisfaction of giving, a boost in confidence and self-esteem, gaining perspective and coming to terms with emotionally painful issues. Yet challenges of providing peer support were also noted: balancing involvement and detachment, fear of saying something wrong, dealing with others’ negative emotions and poor prognosis, and when support needs were unclear or could not be met. Exploring experiences of PSPs offers a promising way to examine the mechanism by which peer support might function and determine how, in what circumstances and for whom peer support functions well. It will also provide an understanding of how best to support PSPs, and indicate ways to design, deliver and measure outcomes of peer support interventions.

Increasingly, protocolised peer support interventions are used, as opposed to unstructured programs [6,11,12]. Common key characteristics of such protocolised interventions are: i) structured guidelines and checklists for PSPs, ii) rigorous evidence-based training, and/or iii) partnerships with health professionals. A review of the dyadic peer support literature in oncology concluded that such protocolisation is required to ensure consistent delivery of the intervention to systematically address patient needs, so that if the intervention is effective, these benefits for patients can be detected using rigorous empirical methods [6]. A recent feasibility study of a protocolised dyadic peer support intervention, however, found that following guidelines and checklists impeded the development of an authentic connection between PSPs and patients [10]. Indeed, Dunn [13] has recently discussed the challenges of applying scientific methodologies to peer support as it is a naturally occurring phenomena to which such methodologies may be unsuitable or disruptive.

The current study sought to explore how PSPs, as individuals who had experienced diagnosis and treatment of cancer, understood and constructed meaning around their experience of providing peer support. In particular, the study sought to explore how PSPs understood the experience of providing peer support within a structured protocolised intervention and how common key characteristics of such interventions (guidelines and checklists, rigorous training and partnerships with health professionals) may influence these experiences. Therefore, a qualitative thematic analysis methodology, guided by a constructivist epistemology, was selected as the most fitting means of accessing this knowledge.

This research was conducted within the context of an ongoing randomised controlled trial (RCT), the Peer and Nurse support Trial to Assist women in Gynaecological Oncology (PeNTAGOn) [12]. The trial is investigating the efficacy of a psychosocial intervention to reduce psychosocial needs in women receiving radiotherapy.
treatment with the intention of curing gynaecological cancer. The peer support intervention within PeNTAGOn involves a unique peer and nurse partnership. Patients allocated to the intervention receive three face-to-face sessions with a nurse: before, during and after treatment, and a telephone session two weeks after treatment (see Figure 1). Patients are matched with a PSP based on similar demographics and treatment profiles. The nurse contacts the PSP to outline the patient’s needs and recommended self-management strategies. One week after each nurse session, the PSP telephones the patient and discusses a checklist of topics relevant to treatment stage and nurse-recommended self-management strategies. PSPs were identified by their oncologist. Those who agreed and were screened as appropriate participated in a two-day intensive training workshop which covered required skills, including: supportive communication (active listening, responding to emotions and empathy), encouraging adherence to self-care strategies and discussing psychosocial issues. Further details are available elsewhere [12].

Insert Figure 1

Materials and Methods

A thematic analysis approach was used to explore this topic and address the study’s aims [14]. Thematic analyses aim to identify themes and subthemes within interviews in an inductive manner, and the analysis is guided by a coding tree of themes and subthemes which is developed, refined and altered throughout the iterative process [15]. This analysis created a descriptive and explanatory synthesis of PSPs experiences. Thematic analyses have been conducted in inductive and deductive manners, and from positivist and constructivist perspectives [16]. The analysis in the current study was guided by constructivist epistemology. Constructivism assumes that no objective reality exists independent of human understanding, and therefore, individuals’ understanding of the world cannot be independently verified against an objective reality [15]. As such, this methodology allowed PSPs to explain their unique experiences and accounted for the multiple constructed experiences held by participants.

Participants

Participants were 11 PSPs who were providing dyadic peer support within PeNTAGOn. The inclusion criteria were: the ability to read and write English, 18 years or older, and experience of radiotherapy treatment for gynaecological cancer at least 2 years ago. Exclusion criteria included: a current psychiatric or cognitive disorder. Ethics approval was granted by the relevant hospital ethics committees.

Procedure

At the initial recruitment stage, all women currently performing the PSP role within the PeNTAGOn trial were identified as potential participants and invited to participate in the current study. A research assistant briefly introduced the current study and gained verbal permission for these women to be contacted by the researcher (BH). These potential participants were emailed an invitation letter, participant information and consent form, contact preference form and The Depression Anxiety Stress Scale Short Version (DASS-21) [17]. A week later,
the researcher (BH) called each potential participant, to gain verbal consent and schedule a telephone interview. Participants mailed their written consent to participate to the researcher. Semi-structured interviews were conducted by the researcher (BH), a 24 year-old male, as per an interview protocol of open-ended questions and prompts, which was first piloted with two oncology nurses with experience in peer support for their feedback. Audio recordings of the interviews were transcribed verbatim for analysis. This recruitment-interview-analysis-recruitment phase took place over a period of three months. As the current study was conducted, additional PSPs received training and began their role in the PeNTAGOn trial. As no new themes were identified in the final three interviews of the initial recruitment phase, a second phase of recruitment was not conducted and analysis was concluded. Upon completion of data analysis, a member checking process was conducted, during which identified themes were presented to a sub-set of four participants to ensure consistency of these themes with participants’ individual experiences [18].

Data Analysis

The researchers read and listened to interview recordings and transcripts multiple times and made exploratory and conceptual notes about content. Subsequent readings involved efforts to de-contextualise the information and attend purely to the participants’ words. Interview transcriptions were then coded into themes using a thematic analysis method. This method was iterative and involved five key steps: i) the researchers identified an initial set of inductively derived themes, ii) a preliminary coding tree was developed, iii) the remaining transcripts were coded according to this tree and additional themes and revisions to the framework were discussed between authors BH and IJ, iv) themes, supporting quotes and the identification numbers of individual participants from which the themes and quotes came were charted in a matrix, v) the researchers explored the framework across and within themes and participants to discern overarching themes and relationships [14]. This analysis was assisted by NVivo 10 (QSR International Pty Ltd, 2012).

Results

During the initial recruitment stage, 16 women were identified as eligible, 11 participated in the study. Five women declined due to illness, lack of time, or were not contactable. Table 1 provides participant demographic and clinical/trial-related information. Anxiety, depression and stress scores, indicated by the DASS-21 [17], fell in “normal” ranges for all participants. Interviews were an average of 55 minutes long (range: 43-72 minutes)

Insert Table 1 here

Five key themes were identified which described the overall experience of providing protocolised peer support: i) fitting oneself to the protocolised PSP role, ii) the impact of personal beliefs about the value of research, iii) protocolisation as both blessing and curse, and iv) discussing taboo or sensitive topics. The member checking process clarified aspects of themes i) and iv) in particular.
Fitting oneself to the protocolised PSP Role

PSPs commonly described the protocolised PSP role as a good fit with their self-identity, either by describing how well it fit with their personality or their occupation.

*I like [procedures]. I’m a bit of a procedural person.* (ID01)

*I was a teacher… so using questions as a mode of finding out about people is something that is very familiar for me, personally.* (ID10)

Importantly, some PSPs noted the need to put their professional selves aside in order to feel ‘authentic/natural’ in their role while best adhering to the intervention protocol.

*It’s peer to peer and the instructions were written by professionals… I would talk like that [as per the guidelines] as a [health professional] to a patient but I would never talk like that patient to patient…. So I was a bit more freewheeling.* (ID05)

Personal beliefs about the value of guidelines and checklists

Many PSPs held positive beliefs about the value of research to create change, not only for current participants, but gynaecological cancer outcomes generally. PSPs commonly emphasised the importance of closely adhering to the guidelines and checklists, which they were asked to follow while providing peer support to patients, in order to benefit both the research and patient outcomes.

*Well it’s because I know it’s a research study and I worry that if I don’t cover something then that impacts on the research.* (ID01)

Others were less interested in the research aspect of their role. Although these PSPs reported adhering to the guidelines and checklists while talking to patients, they tended to focus purely on whether they were meeting the support needs of individual patients, and less concerned with the success or potential benefits of the research to which they were contributing.

*I think it’s great that this need has been identified and that it’s being researched but for me it’s more about delivering assistance and the help to the people that need it and the mechanism by which I can do that.* (ID07)

One PSP had rather strong negative beliefs about research and was dismissive of the guidelines and checklists she was asked to use when providing peer support. Consequently she prioritised addressing specific needs of individual patients as they arose in conversation. Therefore she did not deliver the structured, protocolised intervention, which was the object of the randomised controlled trial, but instead delivered an unstructured peer support intervention in which patient and PSP decided what to discuss.

*I know how research goes, it pays people’s salaries. They write reports, they put their names on research and they’re famous… My focus is on, if that’s going to be of benefit to the women… It’s
[checklists and guidelines] just a list...I don’t take too much notice of it because I’m guided by what the woman wants to talk about (ID03).

Protocolisation as both blessing and curse

By following the protocol, most PSPs felt more confident and focused, and that they were addressing patient needs and having a positive impact.

“You have to actually cover things off and that makes you much more confident in the call...” (ID02)

Some PSPs, however, noted the need to step outside the bounds of the checklist and procedures in order to truly connect with the patient.

I tried to be guided as much as I could by the notes and the descriptions of the calls... but I would never in a phone conversation with a patient say “so to sum up our conversation we have discussed so and so”...” (ID05)

It was important to some PSPs to allow time to discuss other topics in order to connect and to remind each other that their cancer experience is just one part of their lives.

[Because] you can focus on cancer to a point where it becomes the be all and end all... what we’re trying to do is to acknowledge that our lives still go on around all that... That you’re sort in the same place in life... on the same wavelength.” (ID04)

Discussing Taboo or Sensitive Topics

The protocol requested that PSPs ask patients about progress and potential difficulties with vaginal dilation; a post-radiation rehabilitation technique during which women regularly insert dilators into their vagina in order to promote its patency. Most PSPs believed that dilation was a valuable and essential part of post-treatment rehabilitation.

[Dilation] that’s just to me like a job that you have to do and there is no yes or no about it, it has to be done. (ID02)

In addition, some PSPs believed in the effectiveness of dilation based on their own experiences with side-effects of radiation therapy.

I needed to actually have [vaginal] scar tissue manually broken down and so knowing the pain that that caused... [knowing] the benefits of the continuous use of the dilators is of real importance. (ID06)

PSPs referred to strategies they employed, including humour, to put the patient at ease when broaching this potentially sensitive subject.

I might come up with a suggestion, to “do it while you're having a shower in your own privacy”. But I also say to some of them "I don't know what your situation is like at home and how close you are but
you might like just to sit on the lounge and do it while you're watching TV one night”. They laugh, you know. (ID08)

Conversely, even if a PSP felt vaginal dilation was important, some chose to ignore protocol and not discuss it if they felt uncomfortable with this topic.

That sort of thing [dilating] is necessary for gynaecological cancer. But I’m not in any way experienced to talk [about this] to anyone particularly, particularly patients. (ID12)

Another PSP believed encouraging dilation should be solely the responsibility of the treatment team and should not be part of her PSP role.

I don’t get into any of that [discussing vaginal dilation] because as far as I’m concerned, that’s got to be sorted out with their doctor and no-one ever actually asks that particularly. (ID03)

With regard to psychosexual adjustment issues, some PSPs were concerned that bringing up this topic would make the patient uncomfortable.

The hardest question to do is the sexuality stuff and the intimacy with other people... It’s not that I’m embarrassed talking about it... it’s difficult bringing it up with someone that I don’t know... you don’t know what kind of person they are. (ID02)

PSPs felt comfortable when patients asked them to give advice about sexual issues based on the PSPs’ own experience, such as more comfortable sexual positions to use during recovery. They felt uncomfortable, however, if they felt patients were asking for professional advice, such as relationship counselling.

It felt more comfortable saying “have you gone back to having sex – have you tried it? Perhaps this is something you could try...” But often it’s more than just the functional - having sex - it’s more about a relationship... they were asking for advice on their relationship and I felt really unqualified to do that. (ID07)

One PSP felt talking about sexual issues should not be part of her role and was inappropriate for her to ask about.

I personally don’t think it's appropriate for me to actually discuss it (post-treatment sexuality), particularly if the nurse has already mentioned something about it. (ID10)

**Interactions with study personnel**

Working closely with the intervention nurses made PSPs feel part of a treatment team and united in a common goal.

I feel it’s really important to have that connection [with the nurse] to feel like you’re part of a treatment team for the patient. (ID07)
The patient information the nurse provided helped the PSP feel more confident that they could address the patient’s needs in a targeted and timely manner.

>[Using information from the nurse] I know what to approach and how to approach things and what needs to be discussed [with the patient]. And also how much input to give from my own experience too. (ID04)

When the nurse suggested a PSP share experiential knowledge to help the patient, PSPs felt validated and that their contribution was unique.

> I’ll follow the lead of the nurse. If the nurse hasn’t covered it, then I don’t worry about covering it. (ID01)

A few PSPs, however, described wanting further support and acknowledgement in their role and hoped that the research team might provide this.

> To know that someone's going to contact me... and just have a debrief... an acknowledgement that you've made the call... touch base and see how you're going. (ID03)

Conversely, newsletters from the study team and teleconferences with other PSPs made many feel less isolated in their role.

> I really loved the training... It was quite a bonding session that weekend. And when we had the teleconference and I've heard their voices... "oh is that you [name] from [suburb]" and it's like "yeah!". There's definitely a bond there with the other peers [PSPs]. (ID09)

**Discussion**

The findings suggest that, from the perspective of PSPs, protocolised peer support functioned effectively when PSPs: i) felt confident and able to meet patient needs by following the protocol guidelines and checklists, ii) were able to follow the protocol while also connecting with patients on a personal and genuine level, iii) had positive health beliefs about the value of post treatment dilation to promote sexual adjustment, iv) referred challenging conversation topics such as significant psychosexual difficulties on to the treatment team for further support, v) held positive beliefs about the value of research to affect significant change, and vi) recognised when their personality or professional characteristics could interfere with effectively providing peer support and “put these aside”. The challenges of protocolised peer support which were identified were: i) the need to balance adherence to protocol structure with building an authentic connection with patients, ii) the potential negative impact of PSPs’ personal and professional identities on performing the PSP role, iii) ongoing difficulties broaching taboo topics, and iv) the potential for PSPs to feel isolated within their role.

The positive aspect of a structured protocol was that PSPs felt confident that they were addressing patient needs and making a meaningful contribution. Pistrang et al. [9] reported that, while providing unstructured peer
support, their PSPs found it challenging when patients’ support needs were unclear and were afraid of saying the wrong thing to patients. Although the current study lacks an ‘unstructured peer support’ comparison group, the fact that these difficulties were not found in the current study is consistent with the assertion promoted by Macvean et al. [6] that protocolising peer support would ameliorate such difficulties.

The negative aspect of the structured protocol was that it could interfere with PSPs ability to form authentic connections with patients. This was also found by Chambers et al. [10]. One PSP decided not to adhere to the guidelines and checklists and instead chose to provide an unstructured form of peer support. Others encountered this difficulty but explained that this could be overcome by adapting these guidelines to their own communication style and making time to talk to patients about other shared interests. Future training programs would benefit from encouraging and explicitly teaching such strategies. Further, it may helpful during training to include PSPs in the dialogue about potential benefits and challenges of using a checklist to provide peer support and how they might balance this need for authentic connection, with structured and targeted methods of meeting patient needs.

The finding that PSPs’ personal and professional identities could impact upon their adherence to the protocolised intervention, and their ability to form authentic connections with patients, has important implications for training and ongoing support of PSPs. At initial training, future PSPs could consider the similarities and differences between their PSP role and their professional role, and how this might impact upon their ability to meet patient needs through a protocolised intervention.

Similar to our findings, PSPs in the study by Chambers et al. [10] reported difficulties discussing sexuality with prostate cancer survivors and their partners. This is perhaps unsurprising given that qualified and experienced health professionals also experience difficulty discussing sexuality with patients [20,21]. Around half of women treated for GC report not having had any discussions on sexual adjustment with their doctor or treatment team [22,23]. Indeed, an aim of both the protocolised peer support interventions being investigated by Chambers et al. [11] and Schofield et al. [12] is to address this issue. By guiding PSPs to raise the issue of sexuality with patients and suggesting that they do so on the basis of shared experience, protocolised peer support appeared to give PSPs added authority and encouragement to raise this taboo topic with patients. The difficulties experienced in spite of these efforts make the strength of societal taboos yet more evident. Our findings indicate that while protocolised peer support can assist PSPs to overcome this taboo to some extent, further strategies are required to overcome this pervasive unmet need.

To optimise the protocol given to PSPs in future research or non-research practice, PSPs should be encouraged to understand the principle and rationale for the protocol’s instructions and asked to deliver it to patients in a manner which feels authentic and natural. For example, when following the protocol’s instructions to ask patient about their progress with rehabilitation strategies, a PSP would incorporate their own experience to normalise the experience of difficulties whilst offering ways of overcoming any identified barriers to recommended strategy use.

To our knowledge, the relationship between a PSP and a nurse has not been investigated in the oncology setting to date, with only one study on older people living with cardiac disease exploring such relationships [24].
Consistent with the current study, these authors identified that acknowledging the unique abilities and contributions of each party was useful in a successful partnership between nurse and PSP. Based on our findings and past research, measures taken by health professionals to validate and acknowledge unique abilities and contributions of each part will assist in creating a successful partnership between health professional and PSP. In addition, PeNTAGOn tele-conferences which connected PSPs with each other were particularly valued by PSPs as a way to reduce feelings of isolation from other PSPs and create a sense of being “part of a team”.

As this study was conducted within the context of a single study involving a peer support intervention tailored to gynaecological cancer, the results may not be transferable to other peer support settings. To promote greater transferability across cancer types, future PSP research would benefit from recruiting PSPs from other peer support programs, such as the NSW Cancer Council’s Connect Program.” [25]. Given the gynaecological topic matter, the age and gender of the interviewer (24 year-old male) may have limited the frankness of participant responses. To minimise this, the researcher addressed any potential discomfort when discussing sensitive topics at the start of the interview. The depth and personal nature of women’s responses in this study indicates that this was effective.

Conclusion

By providing the PSPs’ perspective, the current research contributes to the understanding of the impact of protocolisation on PSPs and the intervention they deliver. It also highlights the challenges of protocolised peer support and suggests ways to overcome these. This understanding of benefits and challenges can be used to increase PSP’s satisfaction and adherence to intervention protocols. PSP satisfaction and adherence to interventions is likely to retain PSPs in their role long-term, increase the consistency and efficacy of the intervention being delivered, whilst maximising the benefits for PSPs, patients and the health system.

Acknowledgements

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Conflict of Interest

The authors have no conflicts of interest to declare.
References

19. NVivo Qualitative Analysis Software (2012). 10 edn. QSR International Pty Ltd.,

Table 1
Participant Demographic Information (n=11)

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Figure 1. Overview of PeNTAGOn Trial Intervention