

Perspectives of oncology nurses on peer support for patients with cancer

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ABSTRACT

Purpose: To understand the perspectives of oncology nurses on peer support for patients with cancer and the role of oncology nurses in its provision.

Method: Thematic semi-structured interviews of 10 oncology nurses working in a single university hospital were conducted. The data were analysed using content analysis.

Results: Oncology nurses thought that peer support promotes the psychosocial wellbeing of patients with cancer by increasing their social contact and strengthening their emotional resources. In their daily work, oncology nurses engaged in several activities that promote the interactions between patients with cancer and informal forms of peer support. However, directing patients with cancer to formal peer support services outside specialised health care was not an established practice. Oncology nurses expressed several concerns about the availability of support and the coping ability of peer supporters and expressed scepticism about the reliability of information shared in peer support groups.

Conclusions: The awareness of oncology nurses regarding formal peer support services appears rather limited. This knowledge gap should be reduced, such as through closer collaboration between hospitals and third sector cancer organisations, which does not appear effective at present based on the results. In addition, patients with cancer should be systematically informed about peer support.

Keywords: specialised health care; oncology nurse; patient with cancer; peer support

1. Introduction

The life changes and physical symptoms caused by cancer and its treatments often lead to anxiety and depression in patients with cancer. These adverse emotions may result in the need to connecting with other patients in a similar life situation. (Finnish Institute for Health and Welfare, 2014; Kowitt et al., 2019.) Evidence has shown that through peer support, patients can experience empowerment, a sense of belonging, mutual caring and a sense of hope for the future (Shin and Park, 2017; Skirbekk et al., 2018). In addition, peer support from patients with the same illness can enrich the information provided by health care professionals (Ministry of Social Affairs and Health, Finland, 2011). Peer support serves as a unique opportunity to connect with peers (Ussher et al. 2006; Skirbekk et al., 2018). However, patients may not be aware of the available peer support options (Stickel et al., 2015), which emphasises the role of professionals as mediators of information. Patients themselves expect to receive knowledge regarding peer support during nursing care,

particularly when their disease is progressing or when they are undergoing a major surgery (Tuominen et al., 2020).

Peer support can be provided through patient and cancer organisations as an organised one on one or group support service; this can be done face to face, over the phone or via the internet (Pistrang et al., 2012). It can also be provided informally through spontaneous communication between patients. Although peer support is provided by one patient to another and is often facilitated by organisations, health care professionals also play a key role in enabling access to peer support. Professionals play a central role in sharing information, encouraging patients and guiding them to seek peer support (Legg et al., 2018; Stickel, 2015). Studies have shown that health care professionals make various assumptions based on which they offer peer support to patients or they do not mention peer support at all. Aldaz et al. (2016) suggested that patients with a family are seldom offered peer support compared with patients who are alone. In addition, professionals may rely on patients with cancer to receive peer support from one another during treatments and from online discussion groups. This may lead to the assumption that peer support services are not required and that patients do not need to be informed individually about peer support (Harju et al., 2019). On the other hand, it must be recognised that not all patients wish for or need peer support. For instance, some patients with cancer might feel distressed when they perceive the prolonged process ahead (Tuominen et al., 2020). However, this does not eliminate the need for information or referral to peer support services.

Oncology nursing is a field of specialised health care in which care is provided in cancer outpatient clinics or wards (Cancer Societies of Finland, 2019). Oncology nurses meet patients having different stages of cancer on a daily basis (Watts, 2010). It is recommended that health care professionals inform patients about peer support services at the diagnosis stage (MSAH, 2011). Legg et al. (2018) suggested that the positive attitudes of health care professionals towards peer support help patients seek this form of support. The division of responsibilities, (i.e. what different organisations or employees should do) should also be clear. Peer support is generally approved, but it is not distinctly seen as part of one's work in oncology nursing (Harju et al., 2019). Although the incidence of cancer is increasing worldwide, few reports on peer support for patients with cancer have specifically focused on the perspectives of nurses.

The present study aimed to provide a better understanding of the perspectives of oncology nurses on peer support for patients with cancer. The research questions were as follows: (1) How do oncology nurses perceive the role of peer support in cancer treatments? (2) How do oncology nurses describe their own role in the provision of peer support? The information provided through this study can be used to develop peer support services and holistic care for patients with cancer.

2. Methods

2.1. Design

In this study, a descriptive qualitative research design was used. Research data were collected by interviewing individual participants as part of a larger multidisciplinary psychosocial cancer research project in March and April 2018. Snowball sampling was used to reach the potential participants (Kynge, 2020).

Two researchers first contacted the chief physicians and head nurses of the oncology wards and out-patient clinics, who then named potential participants. These selected oncology nurses were sent written information by email about the study and asked by email or phone about their willingness to participate in the interview. Some participants were recruited based on other participants' recommendations. Eventually, a total of 10 oncology nurses were included in the study. The interviews were arranged to be conducted in the hospital during the participants' working hours. Two researchers conducted them. The interviews were semi-structured thematic interviews; the interview frame was developed by the research team based on prior research knowledge (McIntosh and Morse, 2015). The themes of the interview frame focused on the need for psychosocial support of patients with cancer and their family members, the detection of this need, the services provided by organisations and the collaboration between public health care centres and organisations. At the beginning, the participants were asked about their biographical information. In this paper, the focus will be on the aspect of peer support. The duration of the interviews ranged from 30 to 60 min. These interviews were audio recorded with the participants' permission, then transcribed verbatim (Sutton and Austin, 2015) and anonymised. The obtained data were used for data analysis.

2.2. Data analysis

The data were analysed by the first author in consensus with the research group using inductive content analysis based on the data-driven reasoning process (Bengtsson, 2016). The analysis began with a familiarisation with the data to obtain a sense of the whole. After the familiarisation phase, meaning units, in which oncology nurses described their views on peer support for patients with cancer, were extracted from the data. These meaning units were condensed by shortening them whilst preserving their core meaning. In total, 240 condensed meaning units were formed, and they were subsequently grouped into sub-categories based on their content (Table 1). Finally, following discussions with the research team, the first author combined similar categories according to commonalities in their content and formed three themes (Table 2) (Bengtsson, 2016; Vaismoradi et al., 2013).

2.3. Ethical considerations

Permission for conducting this study was obtained from the university hospital where the participants were recruited. The participants were informed both orally and in writing about the purpose of the study, their voluntary participation, and the confidentiality of their data. Prior to the interviews, they signed the informed consent forms.

3. Results

In total, 10 oncology nurses participated in this study. Nine participants were female, and one was male. The age of the participants ranged from 26 to 62 years, and their work experience at the time of the interviews ranged from 1 to 30 years.

The results are divided into three themes. The first theme describes the oncology nurses' perceptions of the effects on peer support on psychosocial wellbeing. The second theme describes

the role of oncology nurses as facilitators of peer support for patients with cancer. The third theme scrutinises oncology nurses' concerns and scepticism about peer support services outside of the hospital (Figure 1).

3.1. Peer support as a promoter of psychosocial wellbeing

Oncology nurses thought that peer support helped improve the psychosocial wellbeing of patients with cancer. Through peer support, the social contact of the patients increased (e.g. through patient interaction and online interaction). Oncology nurses also emphasised the role of peer support in strengthening patients' emotional resources. They identified that peer support could be obtained through formal networks, such as the services provided by patient organisations, and informally through patient interaction. Whilst receiving treatment in the hospital, patients with cancer had the opportunity to have spontaneous meetings that could lead to the exchange of contact information and sharing of experiences:

'You can see in the patients' rooms, as we have single and double rooms, and sometimes, when a patient gets discharged, they leave their contact details on the table for the patient whose bed was next to theirs'.

In the previous excerpt, a nurse described how spontaneous interactions can occur between patients with cancer during treatments, through which they can share their experiences. Some patients with cancer even tried to adjust their own treatment schedules in order to receive treatment at the same time as other familiar patients do. Oncology nurses were able to support the relationships between patients by, for example, facilitating the coordination of their treatment schedules. Peer support was thought to empower and strengthen patients' emotional resources, as they gained hope and support from one another by comparing and sharing experiences. The oncology nurses' descriptions also highlighted the idea that during intensive cancer treatments, patients with cancer might need encouragement and support, especially from a peer who has experienced the same situation:

'So, if you have no close contacts or if you find these treatments terribly distressing, for example, then someone who has gone through these medical treatments is often good for encouragement so that you can manage your stress'.

Oncology nurses were positive about the spontaneous support between patients with cancer and thought that it had several benefits in terms of patient coping. They also experienced satisfaction in observing interactions and even friendships develop between patients during treatment periods. However, oncology nurses not only described peer support as a spontaneous interaction between patients with cancer but also recognised the importance of their own role as facilitators of peer support.

3.2. Oncology nurses as facilitators of peer support

As mentioned above, oncology nurses had positive attitudes regarding peer support. They thought of peer support as a beneficial form of support as it gave patients with cancer new perspectives on their illness, amongst other things. With their positive attitudes, oncology nurses facilitated peer support for patients through different types of practical arrangements. For instance, the hospital

organised activities that made patients gather in the same space, providing opportunities for interactions:

'...our aim is that when we organise this communal supper for which patients would go to our patient kitchen, which is an open space... a bit like a bar, there's a buffet where they can go. Also, there's a table where people actually gather sometimes. For example, a group of men of the same age in a similar life situation can get together. Suddenly, you can start hearing their cheerful conversation and they also start discussing their illnesses'.

In addition, oncology nurses worked concretely to implement peer support in the hospital, including placing young patients with cancer in the same rooms during their treatment. These practical arrangements aimed at facilitating informal peer support between patients with cancer. Oncology nurses also worked to facilitate formal peer support by providing information to patients with cancer about the services provided by organisations and welcomed such organisations' trained peer support personnel to the hospital:

'We have peer support workers sometimes where medical treatments are provided. When a patient comes for cytostatic treatment, they have a peer support worker with them if they have no one else to escort them, if they don't want to bring anyone with them or if they are lonely and there is no one to bring. We welcome them to come along'.

On the other hand, oncology nurses brought up formal peer support only when patients with cancer did not have other forms of support. Oncology nurses also perceived the need to launch peer support services in the hospital, and they supported voluntary peer support services and the formalisation of peer support groups in the hospital setting. These ideas were primarily related to oncology nurses' belief that all services during acute care should be provided at the same place:

'Of course, there are peer support groups provided by the cancer association, but when the treatment is going on, it's not that easy to attend them. So, it would be better if they could be arranged here'.

The employment of a peer support worker in the hospital created enthusiasm amongst oncology nurses. They were also in favour of compensating peer support workers. They felt it was fair and could motivate, encourage and engage a peer support worker in their job. On the other hand, oncology nurses suggested that paid peer support workers could work in the hospital either part-time or based on a scheduled appointment. Although oncology nurses' attitudes towards peer support were generally positive and they wanted to facilitate it, they were prone to scepticism and they identified various difficulties associated with patients' access to peer support.

3.3. Concerns and scepticism about peer support

Despite the positive attitudes mentioned above, oncology nurses felt that referring patients with cancer to peer support varied from nurse to nurse. The guidance was irregular, and in some cases, it was completely bypassed. For example, younger patients were not necessarily referred to peer support services, as they were expected to find out about these services independently. Oncology nurses also thought that patients with cancer would particularly need support from persons of their own age, whose availability was uncertain. The guidance related to peer support services was partly hampered by the fact that oncology nurses did not have a directory of support persons in the area.

On the other hand, they could not share patient information with organisations. Oncology nurses also felt that electronic services replaced the services provided by peers. As highlighted previously, oncology nurses did not automatically discuss the need for peer support during their interaction with patients with cancer. They either relied on patients to independently find out about the service they needed, or they tried to detect signs in patients to determine that they needed peer support:

'Peer support workers should know how to identify a patient who needs peer support when there are patients who do not give any clear indication that they need it'.

On the other hand, oncology nurses observed the voluntary exclusion of patients with cancer from peer support services. The interviews highlighted that some patients did not need additional support and were satisfied with their existing support network. In addition, peer support was not necessarily suitable for everyone or could be perceived as frightening:

'After all, not everyone is ready; they are afraid to face that they could receive help or talk about things. Some may be afraid to open up about their illness. That subject is just too scary'.

When discussing the formal peer support provided by organisations, oncology nurses raised other concerns regarding the coping of peer support persons. Oncology nurses expressed their concern that dealing with depressed or withdrawn patients with cancer could be too burdensome for peers. Moreover, a peer support person was required to meet certain requirements and have certain abilities to face patients with cancer. They nurses did not have these expectations concerning spontaneous peer support between two patients with cancer. However, oncology nurses raised scepticism towards the information shared in peer support groups, specifically nasty experiences, which might instil doubt amongst patients with cancer regarding their treatments. Patients were told to be particularly critical of the information received from internet groups:

'... Regarding Facebook and other social media groups, I emphasise, most of the time that, it's a patient who maintains the group and not a professional. So, you should find out how truthful the information being shared there is. To understand, somehow filter the information... '.

Oncology nurses proposed the development of electronic discussion forums. Such forums already exist though, several organisations maintain and moderate both open and closed discussion forums. Oncology nurses viewed peer support services outside the hospital with more caution than activities related to specialised health care, which they identified as part of their work and which they also tried to promote in practice.

4. Discussion

In this study, oncology nurses appeared to be facilitators of peer support; however, their reservations about formal peer support seemed to act as a barrier for patients with cancer to access peer support. Health care professionals do not appear to be particularly active in their referrals to peer support services as shown in earlier research (Aldaz et al., 2016), but the present results suggest that oncology nurses consider peer support services in their own specialised care framework and rarely look beyond. A previous study on the psychosocial wellbeing of patients with cancer by Harju et al. (2019) obtained similar results, in which the oncology nurses considered the provision of peer support to require specialist expertise and more resources. However, this should not prevent patients with cancer from being informed about available peer support services, emphasized by

Dilsworth et al. (2014). According to this study, suspicion and hesitant attitudes in health care professionals may originate from a lack of knowledge, which is also backed up by the study of Pavolini and Spina (2015).

The oncology nurses in the present study were uncertain about the coverage of peer support services, and they had concerns with the peer support persons of patient/cancer organisations. They were not fully aware that organisations train their support persons, that these support persons need to adhere to the organisation's rules and that they provide completely voluntary work. In addition, the nurses assumed that the work of peer support persons is challenging, as patients with cancer could be difficult to work with. Surprisingly, the findings were not the same in the case of peer support provided during spontaneous interactions between patients with cancer. In this context, oncology nurses did not have any concern about the mental strain on patients with cancer. By contrast, they thought of the interaction as a positive phenomenon. It seems possible that oncology nurses rely too much on spontaneous support and on patients' own activity in relation to peer support and therefore do not refer patients individually to peer support services.

Oncology nurses also tried to direct patients with cancer to genuine peer support websites and wished to increase the availability of relevant peer discussion forums because they were concerned about the authenticity of the information circulating in existing groups. This finding is not new, however, as evidence has shown such concerns earlier (Steginga et al., 2006). It should be noted that increasing the number of discussion forums may not be the solution to the problem, because various moderated and research-based peer support services are already available. Instead, it may be necessary to provide more information about these forums for specialised health care personnel (e.g. about those provided by organisations in their territory). These actions might decrease oncology nurses' scepticism.

In addition to the lack of knowledge, oncology nurses' reasons for not directing patients with cancer to peer support services were even more diverse. According to this study, oncology nurses tried to observe the need for peer support in patients with cancer. They stated that it was challenging, and they wished that patients would provide a sign that they needed peer support. An explanation for this result may be that the nurses are unclear about their own role in guiding patients with cancer. They did not directly ask the patients if they were interested in peer support. Instead, they expected signals, which can be problematic, as previous research has pointed out that some patients leave their need for support unexpressed if they feel it is not serious enough (Clover et al., 2015). Thus, oncology nurses should avoid playing a passive role and should directly address peer support issues by talking to patients with cancer. Active guidance and encouragement by health care professionals have been proven to increase patients' access to peer support services (Legg et al., 2018; Stickel et al., 2015),

In light of the present study's results, it seems that oncology nurses' attitudes and their assumptions about peer support may prevent them from guiding patients towards peer support services.

However, there may be major differences nationally and even globally in how the needs of patients with cancer are responded to and how much resources are allocated in the support services for them.

5. Strengths and limitations

The data were analysed using inductive content analysis. The research phenomenon was examined only from the basis of the data obtained, and the researchers' own preconceptions about the topic did not influence the analysis (Bengtsson, 2016; Elo et al., 2014). The research was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013). The analytical phase and results were returned to the original material on a regular basis to strengthen the credibility of the study. Therefore, evaluating whether the formed categories were in

harmony with the data was possible (Elo et al., 2014). The authors also regularly discussed the progress of the analysis, which increased the confirmability of the analysis.

A limitation of the present study is that the participants belonged to a single university hospital, which decreases the transferability of the results. The participants were also predominantly female, so generalizing the results to male or transgender oncology nurses was not possible.

6. Conclusions

The attitudes of oncology nurses towards informal peer support are much more straightforward than their attitudes towards formal peer support services outside specialised health care.

Oncology nurses consider themselves as active facilitators of informal peer support; however, they adopt a more passive role when guiding patients with cancer to services outside the hospital (e.g. those provided by organisations).

In summary, collaborative efforts between social and health care centres and the third sector, as called for by the Finnish Ministry of Social Affairs and Health, are important. In practice, this means common education and workspaces between healthcare professionals in the voluntary sector and specialist cancer services. Clear instructions on the systematic guidance of patients to peer support services should also be given to personnel in specialised health care.

Declaration of competing interest

The authors declare that there are no conflicts of interest.

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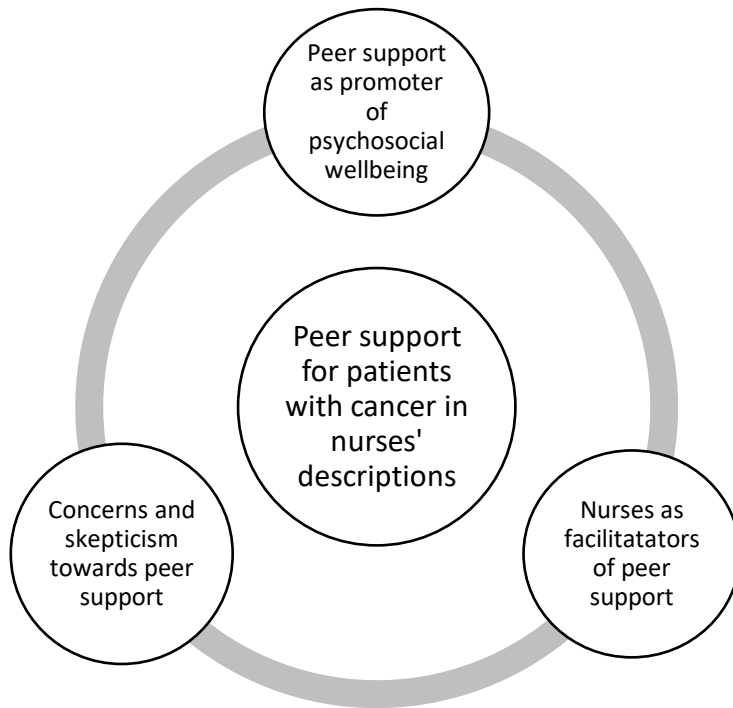


Figure 1. Peer support for patients with cancer, as described by oncology nurses

Table 1. Example of the data analysis process from the meaning units to a sub-category

Meaning units	Condensed meaning units	Sub-category
<i>“I don’t really know if there are any barriers to the co-operation with peer support persons, when it’s free of charge, but...no, I don’t see any barriers to it.” (n8)</i>	There are no barriers to co-operation with peer support persons, unless this service remains free of charge. (n8)	Advocating voluntary peer support services in the hospital
<i>“Yes, it would definitely be, and especially if it is based on like voluntariness, then yes, there could be peer support services in the hospital.” (n7)</i>	Voluntary peer support services could be organised in the hospital. (n7)	
<i>“Let’s say, yes, there has been a need for possible voluntary and other help, that it would be useful from time to time.” (n2)</i>	A volunteer peer support person would be needed in the hospital. (n2)	
<i>“Volunteer peer support persons here, yeah, it would be great.” (n13)</i>	It would be great to have volunteer peer support persons in the hospital. (n13)	
<i>“I don’t know if there are volunteer peer support persons coming to the hospital, but it would sound like a good thing.” (n14)</i>	Volunteer peer support persons in the hospital would be a good thing. (n14)	

Table 2. Oncology nurses' perspectives on peer support for patients with cancer

Themes	Categories	Sub-categories	
<i>Peer support as a promoter of the psychosocial wellbeing of patients with cancer</i>	<i>Increased social contact through interaction amongst patients</i>	Spontaneous acquaintance with other patients	
		Discussion with other patients in connection with cancer treatments	
		Exchange of contact information with other patients	
		Sharing experiences arising from equality	
		Spontaneous form	
		Patients' spontaneous actions to obtain peer support during treatment	
	<i>Increased social contact through online interactions amongst patients with cancer</i>	Possibility to act as a peer support person after the cancer treatments	
		Realised on social media	
		Realised in closed discussion groups	
	<i>Strengthening the emotional resources of patients with cancer</i>	Realised through the hospital's web applications	
		Opening up emotionally to other patients	
		Empowering patients	
<i>Nurses as facilitators of peer support</i>	<i>Positive attitudes of the nurses towards peer support</i>	Creating hope for patients	
		A tolerant atmosphere towards peer support in the hospital	
		A diversely beneficial form of support	
		Motivating patients to communicate with other patients	
		Concrete actions by nurses to achieve peer support for patients in the hospital	
		Informing patients about peer support services	
	<i>Identifying the need for peer support services to be launched in the hospital</i>	Allowing the presence of a peer support person next to patients	
		Advocating voluntary peer support services in the hospital	
		Advocating for peer support groups to be set up in the hospital	
		Advocating for a peer support person to be employed in the hospital	
		<i>Concerns and scepticism about peer support</i>	Informing peer support on a nurse-to-nurse basis
			Informing peer support services irregularly
Bypassing the elderly patients' need for peer support			
Failure to take advantage of peer support persons			
Difficulty in detecting the need for peer support			
<i>Insufficient provision of peer support services</i>	Problems in obtaining peer support		
	Low chances of peer support for rare cancers		
	Lack of peer support services in the hospital		
	Uncertainty of the peer support services in the hospital		
	Leaving the development of peer support services to the responsibility of organisations		
	<i>Challenges in peer support services</i>	The need to increase cooperation with organisations	
The need to make greater use of peer support persons			
Nurses' concern about the coping of peers			
Nurses' views on the conditions of working as peers			
Advocating for the compensation of peers			
The need to increase relevant electronic discussion services			

<i>Reliability of the information shared in peer support services</i>	The experiences heard in peer support groups being a concern for patients
	Nurses' concern about the content of peer support sites
<i>Voluntary exclusion of patients from peer support</i>	Patient negativity towards peer support
	Patient withdrawal from peer support
	Adequate support from loved ones for some patients
