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To support and to be supported

A Qualitative Study of Peer Support Centres in Cancer Care in Norway

Abstract

Objective: To explore what peer supporters, patients and their relatives want and gain from peer support in cancer care.

Methods: Focus group interviews with peer supporters, and in-depth interviews with peer supporters, patients and relatives (N=38) and observations of daily activities in a Vardesenter (“Cairn Centre”).

Results: Peer supporters helped cancer patients and relatives with coping in and outside the hospital in several ways: (1) conveying hope and providing ways to cope in situations where despair would often be prevalent, thus protecting against unhealthy stress; (2) being someone who had had the same experiences of disease and treatment, and thus providing a framework for positive social comparisons; and (3) to be an important supplement to family and health care providers. To be working as a peer supporter was also found to be positive and important for the peer supporters themselves.

Conclusion: The peer support program represented a valuable supplement to informal support from family and friends and healthcare providers, and gave the peer supporters a new role as “professionally unprofessional”.

Practice implications: Organised peer support represents a feasible intervention to promote coping for cancer survivors.

1. Introduction and aims

To be diagnosed with cancer and to go through treatment, follow-up and often rehabilitation, can be a traumatic experience with physical, psychological and social implications. Many patients report psychological distress related to the uncertainty of the disease, adverse effects of treatment and impaired quality of life [1-3]. Some experience loneliness, uncertainty, depression, unmet informational needs, and a fear of relapses, and may need support to handle these challenges [4-9]. Follow up procedures are most often limited to medical examinations to check for recurrences, and patients often report unmet support needs for years after they have completed treatment [10].

A number of studies have investigated the effects of social support for **people diagnosed with cancer** [11,12], with positive results. A review of peer support interventions for cancer patients indicated both emotional and informational support through shared personal experiences [13]. For breast cancer patients, it has been shown that being anchored in a safe social network may have a positive impact on a number of outcomes, including disease progression [14].

Recognising unmet needs for social support, several peer support programs have been developed for patients under treatment, and cancer survivors. RCTs have shown improvements in self-efficacy for patients with breast cancer and prostate cancer, respectively [15,16]. In a review of 44 studies on peer-support programs in cancer care, Hoey et al. concluded that one-on-one face-to-face, and group internet, peer-support programs were the most effective [9].

Lahey and Cohen have suggested three important theoretical perspectives on why social support has positive effect on patients [17]. First, according to the stress and coping perspective, social support promotes coping and protects individuals

against unhealthy stress. There is evidence that a peer support intervention may alleviate distress [18], but there are no systematic studies on the stress reduction effect of peer support programs.

Second, the social constructionist perspective proposes that social support has a positive effect for increased self-esteem and self-regulation. According to social comparison theory, people suffering from acute or chronic medical conditions use comparisons to cope, to reduce the threat, and to find ways to meet challenges [19]. A specific quality in peer support different from other interventions, is the function of the peer supporter as a role model. The encounter with the peer supporter gives an opportunity for upwards comparison, i.e. meeting another person who has lived through and mastered similar stress [18].

Finally, the relationship perspective on social support claims that positive health effects of social support cannot be separated from other more general aspects of social interaction [17].

Peer support programs may also be helpful and represent a positive and important experience for the peer supporters. Brooks et al. explored emotional gains among peer supporters from participating in such programs, and found higher confidence, pride and enhanced self-esteem, as well as a greater sense of connection with others [20]. However, supporters also reflected on the negative emotions that could be evoked, and the importance of a clear understanding of roles.

In Norway, so called “Vardesentre” (Cairn Centres) were established by the Norwegian Cancer Society and associated patient organisations in collaboration with hospitals. The concept of a cairn, a man-made pile of stones, is well known in Norway, in particular as trail markers on mountain routes. The Cairn Centres, localised within hospital premises, provide a setting for peer support programs in

Norway.

The present study was conducted to investigate the experience of patients and peer supporters at the Cairn Centres. Few, if any, studies have compared both the patients' and the peer supporters' viewpoints. The aims of the present study were therefore:

- 1) To explore what peer supporters, patients and their relatives want and gain from peer support in cancer care.
- 2) To compare the challenges and needs of living with cancer among peer supporters, patients and their relatives.
- 3) To explore what motivates peer supporters, patients and their relatives to enrol in peer support programs.

2. Methods

2.1 Setting and sample

Qualitative methods were applied, including site observations, in-depth interviews and focus groups. The setting for the study was a Cairn Centre at the Norwegian National Cancer Hospital. It was opened in 2009 to provide peer support for patients and their relatives regardless of cancer diagnoses. The centre consists of a common room with several sitting groups and a kitchen, and rooms for conversations and various activities. Peer supporters are available every weekday, both in the common room, and more privately in the adjacent offices. There is large variability regarding how often patients visit the Cairn Centre. Most often, they talk to peer supporters who happen to be available on the day of the visit. Continuity in the patient-supporter relationship is relatively rare. Peer supporters receive training provided by their

patient association.

Purposive sampling was used to select peer supporters, patients and close relatives. Peer supporters were recruited through the Norwegian Cancer Society (NCS). Patients and relatives were recruited by us while visiting the Cairn Centre.

A total of 38 persons were interviewed individually or in focus groups. We conducted five focus groups with 19 peer supporters (3-6 participants in each), 12 in-depth individual interviews with patients (N=10) and spouses (N=2, interviewed separately), and 7 individual in-depth interviews with peer supporters. As we wished to interview patients and relatives without planned visits to the Cairn centre, individual interviews were chosen rather than focus groups. Their age varied between 27 and 73 years, mean 52 years. Age and gender were reasonably representative of the users of the Cairn Centre [21]. We also conducted site observations over five days at the Cairn centre to get a better understanding of how peer supporters interacted with patients and family. This provided valuable background information. A separate observation guide was not applied. The use of different methods helped us validate our findings through triangulation [22].

2.2 Interviews

All interviews (both individual and focus groups) followed an interview guide. We encouraged discussions upon phenomena that were of interest to the interviewees. Topics in the interviews included 1) background/history (disease, work and demographic data), 2) how they got to know of the Cairn Centre (important for the NCS), 3) when did they come here, 4) what were their expectations, 5) why did they come here, 6) what did they do here, 7) who did they talk to, 8) improvements (very varied). Following the approach known as active interviewing, the participants in the

interviews were considered to be part of a common process of meaning-making [23,24]. This meant that both the informant and the interviewer were considered to be epistemologically active. The patients, relatives and peer supporters were encouraged to reflect upon, assert their own opinions and tell their own stories concerning the phenomena discussed.

2.3 Ethics

The work was undertaken conforming to the provisions of the Declaration of Helsinki. Interviewees were in advance informed about the purpose and design of the study. All informants gave written consent. The project and the handling of recordings and transcriptions was approved by the Data Protection Offices at both Oslo University Hospital and the Norwegian Social Science Data Services.

2.4 Analysis

Analyses followed an approach known as systematic text condensation [25,26]. The method represents a feasible process for managing intersubjectivity and reflexivity in content analyses, while maintaining a responsible level of methodological rigour. During the first stage of the analyses, we identified units of meaning and patterns in interviewees' descriptions. Categories were developed in collaboration with a panel of user representatives. The patients' and relatives' need for hope and conversation partners were identified very early during analysis. To explore these and other themes, we condensed and summarised them. Remaining interviews were reviewed in order to find both supporting and opposing interpretations [27]. At this stage several topics were elaborated, especially regarding how conversations evolved in the peer support centres.

2.5 User involvement

User representatives were involved both when we discussed our aims and interview guides, and when we analysed our early findings.

3. Results

Based on the analysis of the data, the findings were organised according to four major themes: a) Peer supporters provided hope and inspired coping for the patients and relatives, b) peer supporters shared similar experiences as the patients and their relatives, c) peer supporters were conversations partners, supplementing family and healthcare providers, and d) peer supporters formed a new and important semi-professional role within the healthcare system.

3.1. Hope and coping

A major theme among patients and their relatives was the feeling that conversations with peer supporters represented a source of hope, and inspired coping. Almost all the patients and relatives made positive remarks about the friendly atmosphere of the peer support centre, praising the people working there. Several informants remarked that they felt the peer supporters “looked happy” to see them. Others emphasised the light atmosphere: “I have never laughed as much as here”. Some patients appreciated conversations where sensitive issues were discussed in ways that were more uplifting and sometimes more humorous than what was the norm in the hospital setting. Some patients even preferred a joking tone when discussing risks.

A number of patients indicated that peer support was important because living with cancer had led to drastic changes and stressful events for many, both at home

and at their workplaces. Quite a few patients and peer supporters said that they had been uncaringly treated by their (former) workplaces, and some had lost their jobs. Others experienced that they could not function in the same way that they used to with their families.

Many patients told stories of how they and their relatives had gained hope by seeing and talking with peer supporters. Emotionally charged terminology, indicating positive emotions and reduction of distress, was often used. One patient put it like this:

It is comforting to hear someone say 'I did that yesterday!' It becomes less scary.

For many, being a peer supporter and “feeling useful” became a way to compensate for the sense of meaning employment or active family lives no longer could provide. Peer support thus represented a source of hope and coping also for peer supporters. One peer supporter said the peer support centre was “at least as important for the peer supporters as for the patients”, and another indicated with pride that he was highly aware of the energy and knowledge he could provide for the patients and their relatives: “It makes me strong and happy to do something for others”.

Some peer supporters said they worked in the centre because they had a wish to reciprocate for the help they themselves had received during treatment. One emphasised a sense of community through his Christian beliefs:

It feels good to use my experiences to the benefit of others ... People don't live and die on their own, to quote the Bible. We have to help each other.

Some said that peer support made them feel a need to focus on the patients' needs, and not just their own. Although all peer supporters had to be free from symptoms to qualify for the peer support courses, many of them lived with the risk that the cancer might return. They said that peer support helped them to cope by avoiding to think about their own diagnoses, and instead to help others.

3.2. Shared experiences

Peer supporters, patients, and to some extent relatives, had been through similar experiences of living with cancer and cancer treatment. The peer supporters' tacit knowledge of life with cancer made them "someone to talk to without having to explain so much". For patients, the peer supporters were living proof that treatment worked, and thus they embodied a notion of "life even after a cancer diagnosis". Moreover, the peer supporters provided role models through a mixture of humour and seriousness, providing "energy" for many patients and relatives. These qualities of peer support appeared to be of great importance to many patients and relatives, as one patient pointed out:

In the ward, everybody talks about the disease, but it could drive you mad. It's important to get away from that. Those [peer supporters] who are here have good social antennas. They know when one wants to talk and when one does not.

Peer support was especially important for patients who did not know anyone else with similar diagnoses (because of rarity or mortality). For these patients, the

peer support centre was their only option to meet others in similar situations as themselves, to talk to “a person who had felt the same inside”. One patient said that “it gives me more to talk to someone who has experienced something similar”, but a few seconds later he added, “type of cancer does not matter.”

The peer supporters’ tacit knowledge could also be important when discussing sensitive issues such as death. One patient said that peer supporters “understood [the patients’] fears and problems without talking about them”. Several peer supporters emphasised how they felt less afraid when speaking with dying patients than many others would be:

“Having been through a cancer treatment gives me security when I speak with terminally ill people.”

One peer supporter used a very strong metaphor when he described the same phenomenon:

It is an advantage to have been through the concentration camp [...] You become a different person afterwards.

The peer supporters told us that they knew what the patients and relatives lived through, something patients and relatives confirmed. Peer supporters knew that it was hard to talk about life with cancer, that it was sometimes more important to listen than to speak, and they had the time to do it. The peer supporters “were willing to give of themselves and their experiences” according to one patient, not giving the impression that the patients had to “pull themselves together” to present a seemingly

more acceptable facade.

3.3. Peer support as a supplement to family and healthcare providers

Another major theme for patients and their relatives, was the importance of conversation partners. During interviews, it became clear that peer supporters represented an irreplaceable supplement and an alternative to both family and healthcare providers.

Patients and relatives frequently expressed how important it was to have someone to talk to about their concerns and daily struggles. Conversations with family members and friends met this need for many of our interviewees, but not all. One patient said: “I don't want to be a burden to my friends and family”, expressing a concern that was shared by several patients. It was quite common among the patients to feel that they had “to put their act together” when they spoke with their family members, something they did not always find the strength for. Another patient expressed how family members sometimes were unable or unwilling to talk: “My husband can't bear to talk about diseases.” Some patients also expressed how problematic it was that friends and family were often unavailable when patients wanted to talk, for instance during daytime when family members were working.

Among the relatives visiting the peer support centre, these difficulties were often acknowledged. Several relatives said that they wanted to be conversation partners for the patients, but admitted it was not always possible. Some said that they did not feel that the patients trusted them to talk about sensitive issues regarding diagnoses, treatment and emotions.

Many patients and relatives had experienced that healthcare providers gave good medical treatment, but did not fulfil the need for someone to talk to about

personal concerns. Three unmet needs regarding communication with healthcare providers were emphasised: the need to be seen, the need for more time, and the need to talk about issues beyond the strict medical ones. One patient said:

Well, you often sit there with a lot you want to say inside. [...] So you want to empty yourself somewhere. Not just at home, but why not in front of a peer supporter who can sit and listen to what I say? And sort of “thanks for the help”, and “bye, bye” afterwards

Some patients said they felt that healthcare providers did not see the patients as “whole human beings”. Instead they “just saw the diagnoses”. Some relatives had experienced that even when elderly patients had expressed clearly that they did not want any more treatment and just wanted to die peacefully, they were “put on aggressive treatment regimes”. One relative said that “doctors always spoke about further treatment, even when I knew that it was too late”. This had led some of the relatives in our study to be angry at the doctors for “giving false hopes”.

Several patients said that they felt that the healthcare providers were too busy to talk with them, rarely having time to sit down. One patient claimed healthcare providers were “trying to avoid me, trying not to talk to me”. The peer supporters, on the other hand, made the patients and relatives feel like they were not in a hurry. One patient said about the peer support service:

There are always persons here with time to talk. I don't need a queue number and then be called in.

Whereas healthcare providers tended to restrict communication to medical issues, peer supporters were open for discussions on just about any topic. Most often, conversations with peer supporters started with small talk about normal, non-invasive topics, such as handicrafts or food. Some patients indicated that they used these conversations as a way of “testing” which peer supporters they liked and trusted, and they went on to discuss sensitive issues with these peer supporters in the smaller offices.

Conversations with peer supporters were further helped by the surroundings in the peer support centre. For many patients and relatives, the contrasts between the peer support centre and the “sterile” cancer hospital was in itself inspiring. They enjoyed the exercises, yoga lessons, handicrafts, free advice from volunteering lawyers, and they often commented on the food and drinks that were on offer. One patient even described the peer support centre as “three stars in the Michelin guide”.

3.4. A new role as helpers

In the interviews, peer supporters indicated that they saw themselves as carers for the patients and relatives, someone whose job it was to see the “whole human beings”.

One peer supporter said:

I look forward to coming here [...] Perhaps I will meet someone and do some good, instead of going to a café and eat with friends. [Our daily lives] become more filled with light. It is good to give something back; it is my job, in a way. And I can see how my family enjoy that I am a fellow human being and peer supporter who really enjoys what I am doing.

The peer supporters seemed to have developed a set of semi-professional norms to act as boundaries in their interactions with the patients and relatives. Many peer supporters pointed out that it was a challenge to balance between their own need to help and the patients' need for help. When balancing these needs, many peer supporters said that it was important to remind oneself that they were "professional helpers". Most peer supporters saw themselves as more professional than what volunteers or fellow patients could be. They said they had received training to balance the distance and proximity to the patients. One peer supporter described her role as "professionally unprofessional".

Several peer supporters emphasised the importance of being sensitive of when the patients wanted to talk about their disease, and when they did not. **According to the peer supporters, the patients' and relatives' stories** should always be the focus of conversation. The peer supporters said they discussed how finding the right balance for such "professional proximity" was challenging. They wanted to use their knowledge and understanding to help the patients, without too much focus on their own experiences. One said that it was "hard to give of oneself without focusing on oneself".

Peer supporters were also careful about what topics they did not want to talk about with the patients, especially treatment recommendations. The distribution of roles seemed very clear for the peer supporters in this regard: "Only doctors can discuss treatment."

Further, some peer supporters tried to terminate discussions when patients and relatives complained about the healthcare services they had received. Some patients and relatives told stories of maltreatment, or failure to recognise cancer symptoms. A

few peer supporters told us that in such cases they would try to steer conversations towards “any positive experiences” of their stay in hospital.

4. Discussion

In this study of a peer support program for cancer patients, we found that peer support represented hope, inspiration and relief to patients, gave them an opportunity to meet peers who shared some of the same experiences as they had, and as a valuable supplement, both to formal healthcare services, and to informal support from family and friends.

4.1. Benefits for the patients

The functions and benefits of social support as observed in the present study could be understood from all three theoretical perspectives referred to in the Introduction.

First, a number of informants referred to how the Cairn Centre, in general, and the relationship to peer supporters in particular, was associated with positive emotions and functioned to promote coping. The peer supporters contributed to hope among patients and relatives simply by showing and demonstrating that survival was possible, but also through their friendly acceptance of the stories of patients as well as relatives. The peer supporters appeared to be empathic listeners, and in this capacity functioned as containers for the fears and emotional chaos of patients and relatives [28]. The conversations at the Cairn Centre reframed the uncertainties many felt during hospitalisation and treatment. Similarly, in a review of prostate cancer patients’ experiences and unmet needs, King et al. concluded that one-to-one peer support could alleviate uncertainty and normalise patients’ experience of their disease

[29]. Peer support seemed to be an important source for quality of life for many patients [30].

Second, a number of statements could be interpreted within the framework of social comparison theory. By referring to the positive experience of talking to “a person who had felt the same inside”, patients showed how they looked upon the peer supporter as reference person, with whom to compare and validate their own experience, similar to the upward comparison described by Legg et al. [18].

Similarly, the peer supporters in our study seemed to be experts at aligning their own experiences with those of the patients and relatives. They provided necessary talking partners for patients and relatives, with time and knowledge that no one else could provide. Moreover, peer supporters expressed how working as peer supporters also met their own needs for meaningful social interaction and a need to feel useful and understood.

Third, typically, the relationship with the peer supporter filled a gap in the repertoire of relationships. Patients under treatment for cancer, and cancer survivors, often express a need to discuss their emotional reactions; their fears, uncertainties and anger [13, 31]. For instance, Back et al. have discussed how patients need recognition of their personal needs from the doctor when vital news are given, not only the medical details [32]. However, a number of studies have shown how health care providers often do not meet these needs to a sufficient extent and how communication often is focused on medication and other medical issues [31, 33].

On the other hand, patients in the present study reported a need to discuss emotional concerns with other than their closest kin, in order not to burden relatives. The peer supporters thus represented a way to close the gap related to communication needs, thus being an important supplement to healthcare providers, and relatives and

friends.

Relationships between peer supporters and users of the Cairn Centre were, as far as we could see, to a large extent implicitly negotiated. In studies of how trust develops, the boundaries of the “mandates of trust” between patients and healthcare providers were negotiated **implicitly** through discussions of non-invasive topics, and through such conversations the healthcare provider’s judgement was tested [34,35]. In a similar way, we found that chatting about everyday topics in the common room could pave the way for more open mandates of trust to develop. Such discussions could be understood as “tests” of which peer supporters to trust with more sensitive discussions in separate rooms, and a reciprocal understanding of one another and the situation.

4.2. Norms of the “professionally unprofessional”

During the process of providing support, a set of semi-professional norms were developed and negotiated among the peer supporters. These norms, categorised by one peer supporter as “professionally unprofessional”, meant the peer supporters distanced themselves somewhat from other volunteers who worked at the peer support centre. These other volunteers were described as not being professional enough in keeping a distance when talking to the patients and relatives. The healthcare providers, on the other hand, were described as professional, but not necessarily as very caring, and they did not have the unique experience of being a cancer patient.

The peer supporters emphasised the importance of knowing when to talk, and when to listen, of giving of oneself without focusing on oneself, to maintain a positive atmosphere, and to leave discussions of treatment to the healthcare providers. These norms led the peer supporters to sometimes side with the healthcare providers. When

patients complained about treatment and hospitalisation, the peer supporters often focused on whatever positive experiences the patients had. They said they tried to avoid a negative atmosphere, and thus to help the patients and relatives. But it could also be interpreted as peer supporters viewing themselves more as part of the professional healthcare system than other patients or unprofessional volunteers [36].

Many peer supporters expressed a wish for more education and closer discussions with their patient unions. This was explained as a wish to be seen as active participants with a clearly defined role in the cancer patients' treatment. More research is needed on the development of the social role of peer supporters.

4.4. Strengths and limitations

The study was conducted by researchers with different backgrounds (nursing, psychology and sociology), and with active help from user representatives. This helped us gain a variety of perspectives, but it could also make the presentation unfocused and complex. The combined use of interviews, focus groups and observations helped us validate our findings through triangulation, and the observations helped us compare what people say they do, and what people actually do. Furthermore, the observations became an object for discussion and therefore helped us focus on what mattered most for the interviewees.

The study also has a number of limitations. Only two relatives were interviewed, which limits knowledge about the perspective of relatives. Patients and relatives were interviewed individually only, without the opportunity of focus group interviews. Moreover, it would have been beneficial if we had known more about what the peer supporters learned through their training.

5. Conclusion

Our study showed that peer supporters at the Cairn Centre were important conversation partners for cancer patients and their relatives, and important alternatives to healthcare providers and family members. Peer supporters helped cancer patients and relatives with coping in and outside the hospital in several ways:

- a) conveying hope and providing a way to cope in a situation in which despair often would be prevalent, thus protecting against unhealthy stress.
- b) being someone who had had the same experiences of disease and treatment, and who implicitly knew when and how to discuss sensitive issues, thus providing a framework for positive interpretations.
- c) being someone to talk to when no one else, neither friends nor family, nor healthcare providers, were perceived as able to see and understand the patients.

To be working as a peer supporter also represented a positive experience for the peer supporters themselves. The main motivation for peer supporters seemed to be the experience of meaningfulness by being able to help others, and a wish to reciprocate for the help the peer supporters themselves had received. Being peer supporters seemed to replace other roles that were lost or weakened when they were diagnosed with cancer. This helped them to develop their own role as “professionally unprofessional”, distancing themselves from both other volunteers and healthcare professionals.

Practice implications

Organised peer support represents a feasible intervention to promote coping for cancer survivors. Many peer supporters wanted more training, and a clarification of roles could prove beneficial for all parties.

Conflicts of interest:

The study was funded by the Norwegian Cancer Society (NCS), and the NCS provided access to the Cairn Centre. Then NCS did not affect study design, collection of data, analysis and interpretation of data, writing of the article, nor the decision to submit the paper for publication. No authors are affiliated with the NCS, nor have they received any financial benefits.

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