

Voluntary organizations supporting patients with cancer: A qualitative exploratory study into their experiences

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Abstract

Purpose: Both the incidence of cancer and cancer survival rates are increasing. Cancer patients can experience distress and have higher needs for psychosocial care. While voluntary organizations can support cancer patients' needs, many patients have little awareness of them. We aimed to explore the experiences of cancer voluntary organizations in one region of the Netherlands, how familiar they are with each other's efforts, and how eager they are to collaborate with each other. **Methods:** Thematic analysis of three one-to-one semi-structured interviews and two focus group discussions (FGDs) with members of seven cancer voluntary organizations. **Results:** The main themes identified were: (1) objectives of the participating cancer voluntary organizations, (2) patients' and healthcare professionals' familiarity with the existence of the voluntary organizations and their reach, (3) challenges recruiting volunteers, (4) messages to healthcare providers, and (5) eagerness to collaborate. Participants shared many tips and ideas during the FGDs, and demonstrated a wish to collaborate. **Conclusions:** The prime objective of cancer voluntary organizations is to decrease the impact of cancer on the personal life of patients and their loved ones. However, awareness of what they can offer is poor amongst both patients and their clinicians. Participants became keen to collaborate, which may result in both the sharing of ideas and expertise, and an increased use of these cancer support services.

Keywords: cancer; oncology; voluntary organizations; cancer patient support services; psychosocial support; collaborations

Introduction

In the Netherlands, one out of every three people will develop cancer in their lifetime [1]. Cancer is often a devastating, life-changing diagnosis. Due to the ageing population, the incidence of cancer is expected to have increased by 40% between 2007 and 2020 [2]. As a result of diagnosis at an earlier stage, partly due to population screening and better treatment options, patients with cancer now have a higher chance of surviving [2, 3], leading to a rise in the number of people living with cancer [4, 5]. In line with this, the number of people indirectly affected by cancer, such as loved ones and bereaved, is also increasing. Thus, the disease increasingly impacts not only individuals, but also society as a whole. Cancer is increasingly being viewed as a chronic disease [6].

The quality of life of people living with cancer tends to be lower than that of people living with other chronic conditions [7]. Cancer and its treatment have consequences for various of aspects of patients' personal lives, including psychological problems, physical problems and work-related issues [5]. It may affect patients' social lives and their relationships with loved ones [5]. Common physical complaints include fatigue, poor physical condition, sexual problems, problems with eating and bodyweight,

neuropathy and hormonal imbalances [8]. According to the National Comprehensive Cancer Network (NCCN), the burden that patients with cancer experience can be summarized by the word "distress": "Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety, panic, social isolation and existential and spiritual crisis" [9].

Patients with distress need psychosocial support. However, research shows that four out of every ten patients with cancer do not receive information about supportive care

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Received 10 February 2022 Revised 29 April 2022 Accepted 14 May 2022
Published 23 May 2022

Citation: van Langen B, Harris M, Nafzger R, Dinant GJ. Voluntary organizations supporting patients with cancer: A qualitative exploratory study into their experiences. J Cancer Res Ther. 2022; 10(1):1-7. DOI: [10.14312/2052-4994.2022-1](https://doi.org/10.14312/2052-4994.2022-1)

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[10]. Psychosocial support now receives more attention [11], and can reduce the effect of symptoms or help patients learn how to cope with their consequences [10]. Signaling and regularly discussing distress can result in a better quality of life, greater satisfaction with received care and less consumption of medical care [11].

Voluntary organizations are bodies that operate on a not-for-profit basis, are funded by donations or grants, and are typically assisted by volunteers. In the Netherlands, voluntary organizations, such as drop-in centres or patient support groups, are active in supporting patients with cancer. They organize peer support groups, information events and many other activities, and they aim to decrease the impact of cancer and thus preserve quality of life [12, 13]. There is an expectation that the use of drop-in centres will grow considerably, which may reduce the pressure on expensive professional care [13]. However, patients and their loved ones tend to have little awareness of these organizations [14], in addition to which the organizations themselves are not always aware of each other's existence. Other barriers may be important: in a survey of cancer and cancer-related charity helplines in the United Kingdom, very few had phone numbers that were free to call, half had no provisions for callers with additional needs, and over half had no clinical staff available to callers [15]. There have been concerns that some charities transform into commercial enterprises [16].

This study aimed to explore the experiences and objectives of cancer voluntary organizations in one region of the Netherlands (South Limburg), gain insight into barriers they encountered in reaching their objectives, and find out how familiar these organizations were with each other's efforts. We also investigated whether these organizations were interested in collaborating together, so that they could take advantage of each other's expertise and increase their reach. By doing so, we can learn how to stimulate the valuable work of these organizations and increase the awareness that cancer patients and their loved ones have of them.

Materials and methods

We carried out an inductive thematic analysis with an open-ended qualitative approach, to allow more in-depth exploration of participants' experiences and ideas than would be possible using more structured methods. After a search for these organizations to identify possible participants for our interviews and focus group discussions (FGDs), we conducted three one-to-one semi-structured interviews. Topics identified in the interviews were explored in more detail in two FGDs.

Identification of voluntary organizations and recruitment of participants

To find out which voluntary organizations were active in the field of cancer, we performed an on-line search, and contacted the Maastricht University Medical Center (MUMC), Oncology Department, specialized nurses in oncology, and social support organizations. More voluntary organizations were identified used snowballing [17].

Our inclusion criteria for interviews and participation in FGDs were that organizations had to be: (1) mainly

staffed by volunteers, (2) offer help to patients with cancer and their loved ones, and (3) either be located in South Limburg or having a specific department/representative responsible for the province of Limburg. We invited directors, founders or regional representatives, as they would be best informed about the functioning of their organizations. The principal investigator (BL) contacted representatives of these organizations either by phone or face-to-face, followed by a formal e-mail invitation with more detailed information about the study.

Interviews and focus group discussions

We conducted one-to-one semi-structured interviews with representatives of some of the voluntary organizations, to get a broad picture of some of the organizations' functioning and experiences, and to get an "insider's" perspective. The interview topic guide was designed following examination of cancer voluntary organizations' websites, reading their annual reports and objectives, as well as discussions with volunteers and other primary care researchers.

We chose the FGD method to encourage interaction and discussion between the participants, and to explore how much they recognized each other's experiences. The topic list was based on sensitizing concepts that derived from a study of the literature and analysis of the interview data. BL discussed the topic list with the FGD moderator and G-JD, to achieve consensus on the topics to be covered (Table 1). The moderator read transcripts of the interviews to get familiarity with the key issues. We reviewed the topic guide after the first FGD, but no changes were considered necessary.

Table 1 Topic guide for FGDs.

Topic 1	The overall objectives of participating organizations.
Topic 2	Experiences of participating organizations: satisfaction with reaching their objectives and encountered pitfalls or barriers.
Topic 3	Familiarity with the existence and efforts of each other's organizations.
Topic 4	Familiarity with the existence of these organizations amongst patients and medical workers (oncologists, general practitioners and nurses).
Topic 5	Volunteer recruitment and education/training.
Topic 6	The use of social media.
Topic 7	Collaboration between the participating organizations.

Data collection

Data collection took place from October to December 2019. Interviews were conducted by BL and took place either at the locations of the organizations or at Maastricht University. The FGDs took place at Maastricht University. An independent and experienced moderator, with a background as a behavioural scientist, led the FGDs. The moderator was accompanied by BL, a medical student, who observed the discussion and made field notes on non-verbal communication and interaction. The interviews and FGDs were audio recorded and transcribed verbatim.

Data analysis

BL analysed interview transcripts and field notes, by

marking important information and adding comments. The FGD data and the analysis were managed using NVivo. A process of open coding, axial coding and selective coding was used. Gradually, themes were obtained inductively from the data. Two researchers independently analysed the first FGD transcript, then compared their analyses for inconsistencies and agreement. BL analysed the second transcript.

Trustworthiness of data

Methodological triangulation was done by combining data from one-to-one semi-structured interviews, FGDs and the observer's field notes. Investigator triangulation was accomplished by working with two independent analysts and regular meetings and debriefs within the research team, characterized by persistent observation. Transcripts of the interviews were checked by the interviewees. We performed a member check of our findings with all the study participants. Participants signed informed consent regarding publishing their data anonymously in this article.

Ethical considerations

All participants provided written informed consent before the start of the interviews and FGDs. Data were used and analysed anonymously. Participants did not receive any form of compensation. The study was approved by the Medical Ethics Committee of the Maastricht University Medical Centre (METC 2019-1380). A statement was obtained that the study was not subject to the Medical Research Involving Human Subjects Act (WMO).

Results

Sample size and characteristics

We identified ten relevant voluntary organizations. Included organizations were either charities, local drop-in centres, or national patient associations with local members. One organization focused on providing practical or financial assistance to people with cancer. The organizations' ages varied from five to forty years.

Members of three organizations took part in the one-to-one semi-structured interviews. Two participants were directors, who received a small payment for their work. One participant was the founder of his organization and worked on a voluntary basis. The three interviews lasted for 45 minutes, one hour, and one hour and 50 minutes.

All ten organizations were invited to participate in an FGD. Two organizations were unable to allocate time to participate. We split the remaining eight organizations over two FGDs. Three organizations cancelled their participation at the last minute, and were unable to provide replacement colleagues. Five organizations participated in our FGDs, with a total of seven participants, four in the first FGD and three in the second FGD. All FGD participants were volunteers within their organizations. Their mean age was 60 years (range 49-77), five were male and two were female. Participants had either finished Masters degrees, or completed degrees at universities of applied sciences. All participants had at some time been diagnosed with cancer, but were cancer-free at the time of the FGDs. Both FGDs lasted for one hour and 50 minutes. Member

checking after the analysis supported the findings of the study.

FGD participant interaction

None of the FGD participants knew each other beforehand. The relatively small numbers of participants resulted in more in-depth answers. Group dynamics were characterized by feelings of solidarity. Participants listened attentively to each other, contributed actively in discussions, and made each other think more critically, resulting in considerable interaction. Many ideas, tips and strategies were shared. It was notable that, at the end of the FGDs, all participants shared their contact information.

Categories

The coding process yielded five categories: (1) objectives of the participating voluntary organizations, (2) patients' and healthcare professionals' familiarity with the existence of the voluntary organizations and their reach, (3) challenges recruiting volunteers, (4) messages to healthcare providers, and (5) eagerness to collaborate. Each category is described below, with participant quotations identified by participant (PCP) number, and FGD or interview number.

Objectives of the participating voluntary organizations

Defined objectives varied from providing information, bringing cancer patients into contact with each other through peer support groups, improving the quality of care, preventing dismissal from work, supporting rehabilitation, providing practical or financial assistance, creating awareness, social understanding and improving aftercare, to providing simple psychological support. All organizations shared the objective of improving the quality of life of patients with cancer:

You see guests bloom again, they get positive energy to fully feel alive again, to mostly look ahead, and that's what we stand for as well of course, and also to improve that quality of life (Interview 2).

Participants felt it was important to recognize that they could offer psychological support, for example by offering an experienced volunteer who carefully listens to the patient's story and sympathizes with him/her:

What we also absolutely need to keep in mind: there's a whole lot between a justified indication to get psychosocial support in a professional way and nothing at all (PCP6, FG2).

Information events were reported to be well organized and attended. Sometimes cancer peer support groups were well attended, sometimes not at all. Participants were particularly proud of the quality and comprehensiveness of information that they provided, in print and especially on their websites:

There's a fantastic website! Where they can find genuinely everything (PCP2, FG1).

Several voluntary organizations worked with quality assessments for hospitals. They believed this was appreciated by patients, while resulting in improvement of healthcare regarding oncology:

The quality label worked very well, because in the beginning maybe only half of the participating hospitals met the criteria, however in the end every hospital met the criteria (PCP2, FG1).

Participants perceived that there were barriers to patient use of drop-in centres, for example the distance to or location of a drop-in centre, or unfulfilled expectations, even though they tried to reduce these:

So, even though we want to be approachable, we aren't always (Interview 1).

Patients' and healthcare professionals' familiarity with the existence of voluntary organizations and their reach

Familiarity with the existence of voluntary organizations amongst patients was variable. Participants reported that it was hard to make contact with medical specialists to give them information about their voluntary organizations, or to ask them for help. While most medical specialists were aware of voluntary organizations, they often lacked time to discuss this with patients, and did not consider it to be their priority:

"Time is money". Those specialists have a very busy schedule. (...) Then there's not enough time to discuss everything (PCP6, FG2).

Recently "case managers" (specialized nurses) had been employed in hospitals, and they were able to help in giving information about the voluntary organizations:

More and more case managers are employed in hospitals. (...) And those are often the people that compensate for the cases the specialist didn't or couldn't discuss. And if this works out, they've made a good move, because that's in fact someone who will guide you as a cancer patient through the entire process (PCP6, FG2).

The importance of increasing familiarity of voluntary organizations amongst home care workers, district nurses and general practitioners (GPs) was also emphasized. As they visited patients at their homes, they had a better perception of what sort of help was needed:

Home care workers and district nurses, who really visit patients at their homes, who can really see: hey, that's for example an isolated person that doesn't know who to approach. Home care workers see the problems, and could ask us to help out. (...) And also with a GP that visits patients at their homes (PCP5, FG2).

Each organization had its own website and actively used social media, though this had the disadvantage of reducing personal interaction with patients or their loved ones:

I think that social media is a gigantic big force on one hand, but on the other hand it's also a really big barrier. Because especially social media can inform people quickly about a subject and they don't have to leave their house to go to a theme evening, because they can already find it immediately on their mobile phone (PCP5, FG2).

Participants recognized that requests for help often came from loved ones, which made it important to raise awareness of their work with that group as well as with patients. To reach the entire intended target group was challenging:

So, I just want to say that it also doesn't reach a lot of men, even while we're doing the best we can by any means to increase the familiarity with our organization (PCP7, FG2).

Look, you can expect people to ask a question, but they should know they can ask a question to begin with, and if yes, which question (PCP6, FG2).

Challenges recruiting volunteers

Voluntary organizations encountered difficulties in recruiting volunteers:

However, we also encounter the fact that getting new members is less and less easy and especially volunteers; active members. It's very hard, our province in particular (PCP2, FG1).

One participant stated that subdividing the organization over regions, each with an individual representative, worked very well as it gave a clear task division for the volunteers. It was also found useful to have contacts with professors or oncologists who assisted in further professionalizing and recruiting volunteers. One participant advised asking a friendly doctor for assistance in recruiting volunteers:

Yes, can I immediately give a tip? (...) I looked back on how I became a volunteer at the organization. And that was because I was asked by a medical specialist. (...) If you go back, via a befriended doctor in a hospital you know and ask: "Don't you know a patient that's ready to become a volunteer at this patient organization"? (PCP1, FG1).

Reaching adolescents was a shared challenge. To be able to do this, organizations needed younger volunteers, but these were particularly hard to recruit:

If we, as an organization, want to reach those adolescents, we have to make sure we have an adolescent volunteer, because that person knows how the target group thinks and works (PCP1, FG1).

Most volunteers had experienced cancer in a relative or themselves. Some voluntary organizations offered training. While the quality of volunteers varied as they reflected the entire population, most volunteers were motivated, passionate and committed:

I'm not talking about the engagement and how driven they are; I can feel that from every volunteer. They all want to do it right in their own way (PCP1, FG1).

It's a reflection of the entire society. However, they do share the common characteristic that they're very passionate once they become a volunteer. Moreover, once they volunteer they're motivated, they're committed and they're often people who have work experience, who are used to perform well. So, yeah, they're very, very good, in general (PCP2, FG1).

For some, volunteering helped them reintegrate into society after recovering from cancer:

One of the volunteers was affected by cancer; very much, I have to say. For her it's a huge outlet to be engaged in this work. So, yes, once again, it works both ways. We've been helped and she has been helped as well (PCP5, FG2).

Messages to healthcare providers

Participants felt that doctors should share decision-making with their patients, look beyond their disease, and take their patients' life and work situation into account:

Well, I should say: look beyond the disease. Look at the position of the patient that is sitting in front of you. What about his or

her life? And take this into account. This already plays a role in shared decision-making for example (PCP2, FG1).

They also felt that there was a need for discussions about the need for psychosocial assistance earlier in patients' disease processes. To assist with this, one voluntary organization visited hospitals to discuss their approach to referring patients needing psychosocial support:

And what we then do in hospitals, is discuss: "To whom do you transfer this patient? Do you sufficiently inform the GP? Are there any other assistants who can help this patient to fill that gap?" (PCP2, FG1).

Doctors were perceived as being skilled in treating patients and providing practical support, but not in providing or referring for psychosocial support:

Also from the experience that the doctors' awareness often does cover practical support, however does not cover psychosocial support so much (PCP7, FG2).

Eagerness to collaborate

Collaborations between voluntary organizations and hospitals already existed. Voluntary organizations were part of a variety of networks and partnerships:

We organize various projects in collaboration with care partners. (...) We're affiliated with different networks (Interview 2).

Nevertheless, most participants were not even familiar with the names of each other's voluntary organizations, and they felt that there was room for improvement:

Also the contact with other foundations or organizations, yes, that could be way, way better (Interview 3).

Many tips and pieces of advice were shared during the FGDs, and new ideas about collaborating arose. Participants suggested, for example, providing workshops at each other's events, organizing theme evenings, sharing announcements on Facebook, informing each other of opportunities or interesting events, and lowering the barriers for cross-referral of patients.

Participants valued the FGD encounter and planned to take advantage of each other's expertise:

Collaboration, learning from each other, to make the most out of it for each other and for the people we're doing it for. (...) You need each other and that's the power of meetings like these. (...) Well I think we concretely have to look with each other what we can actually do for each other. I will give you our folder, I'll give you my business card and we'll see what we can do for each other (PCP6, FG2).

Discussion

Main findings

Our research questions were exploratory and not tied to formal hypothesis testing [18]. Participants gave us insight into their experiences and the functioning of their voluntary organizations. Voluntary organizations have a shared aim of improving the quality of life of patients with cancer. They can provide psychosocial support, and they are proud of the quality of the information that they provide on their websites and during planned events. Particular

challenges include attracting patients to use their drop-in centres, and difficulty in recruiting volunteers, particularly younger ones. They find that the volunteers who work for them are passionate and committed, and have usually experienced cancer in a relative or themselves. Medical specialists are usually aware of the existence of the voluntary organizations, though lack of time to discuss this with patients. Most participating organizations are not familiar with each other's efforts, but FGD participants become keen to collaborate.

Strengths and weaknesses

This is the first qualitative study to explore the experiences of voluntary organizations themselves that support people with cancer and their loved ones in the Netherlands, offering a unique insight into their successes and challenges. We achieved methodological and investigator triangulation and performed a member check.

While the focus groups were small, this gave participants more time to voice their views and give more detailed information. However, a larger group might have generated greater variety of information [19]. Due to the short timescale for the study, it was not possible to arrange more interviews or FGDs, and data saturation was not achieved. While we sampled representatives of these organizations, neither their volunteers, nor clinicians or patients, were included in the study. This study took place in a single region, and we do not know the extent to which our findings are applicable elsewhere.

Comparison with existing literature

While we did not find comparable studies that reported the experiences of representatives of organizations that provide psychosocial support to patients with cancer and their loved ones, we did find studies that investigated effects of drop-in centres in the Netherlands. One study showed that 96% of respondents (patients or relatives that visited one of the many drop-in centres) experienced a positive effect in at least one health domain and 89% in at least three domains [13], which maps across to our finding that cancer voluntary organizations aim to improve patients' quality of life. All the participants in our study had at some time been diagnosed with cancer, and this may go some way to explaining the success of these organizations, as research shows that patients want to know where they can go to share their experiences with others who have had similar experiences [20]; to get in touch with peers and feel heard have been found to be the most important reasons to visit a drop-in centre [21]. Our participants' wish to increase familiarity of voluntary organizations amongst healthcare professionals fits with a study which found that patients would like to be referred by the latter more often [21].

Studies have shown that almost a third of patients with cancer have an unmet need for psychosocial support [22, 23], which suggests that our voluntary organizations' prioritization of offering psychological support is valuable. Another study found that oncologists perceive that there are barriers in communicating about psychosocial issues with patients [24], which may link with our finding that

specialists did not consider giving information about voluntary organizations to be a priority. Patients also experience barriers to using support services, particularly lack of awareness of those services, and lack of provider referral [25, 26].

Future research

Research is necessary to investigate the attitude of clinicians regarding their feelings towards cancer voluntary organizations, in particular to find out their views on recommending the use of these organizations. A study in the Netherlands showed that partners of cancer patients consult their GPs 6-24 months after diagnosis significantly more often with both somatic and psychosocial problems [27], which emphasizes the importance of also including the views of loved ones in future research. There is also a need to identify ways to increase patients' and relatives' use of existing services. Another area of study would be to focus on the interactions between representatives of these organizations, volunteers, clinicians, as well as patients and their loved ones. Matching their perspectives and recommendations about these services would provide empirical evidence for knowledge of, and the actual use of, cancer support organizations.

Conclusions

This study identified experiences of voluntary organizations that support people with cancer and their loved ones in South Limburg. These organizations share a prime objective of reducing the impact of cancer on the personal life of patients and their relatives. However, awareness of what they can offer is suboptimal amongst both patients and their clinicians. There is scope for collaboration between these voluntary organizations, and study participants became keen for this to happen; this would allow these organizations to share ideas and increase their expertise by learning from each other. Future research combining the perspectives and recommendations of representatives of these organizations, volunteers, clinicians, patients and their loved ones could help in finding more efficient ways to optimize the use of cancer voluntary organizations.

Acknowledgments

We would like to thank the following individuals for their contributions in this study: Henk Goettsch, Yvonne Koolen, Roel Sillen and all participants.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Availability of data and material

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Author contributions

BL, G-JD and RN contributed to the study conception and design. Data collection and analysis were performed by BL. The first draft of the manuscript was written by BL. G-JD commented on all versions of the manuscript. MH contributed to the data analysis and writing the manuscript.

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