

Palliative Care for Cancer Patients and their Relatives in Dutch Community-Based Psychosocial Support Centers (CBPSCs)

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Abstract

Aim

Community-based psychosocial support centers for cancer patients and their relatives (CBPSCs), developed in the Netherlands, offer easily accessible contacts with fellow patients and support by trained volunteers. We studied the characteristics of visitors of CBPSCs, which palliative support they need and receive, and how satisfied they are with this support.

Methods

The role of 20 CBPSCs was explored in semi-structured interviews among 34 visitors with regard to their contacts with CBPSCs on palliative care (study 1). Additionally, in 25 CBPSCs, 701 visitors filled out a web-based questionnaire about their experiences with the palliative care (study 2). Within this second study, 25 coordinators of CBPSCs also answered questions about the palliative care (study 3).

Results

The cancer patients and proxies stressed the view that palliative support should be a part of the support by CBPSCs. This belief was confirmed by the coordinators. Not only attention to the reduction of symptoms, but also emotional support and information supply should be offered when recovery is no longer possible. Talking about death and dying may be worrying for some visitors in a better condition. Education of the volunteers is needed, taking into account the conditions in the CBPSCs e.g., the already existing experience with the palliative care in the CBPSCs and participation in regional networks.

Practical Implications

Further development of the attention given to palliative support, training and research in that field is needed.

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Introduction

The number of people with cancer is increasing worldwide due to higher life expectancies and aging populations [1]. In the Netherlands, 578,000 people were affected by cancer in 2019 [2]. The diagnosis of cancer and the ensuing treatment strongly interfere with the quality of life of cancer patients, in practical, physical, emotional and social terms, as well as for the meaning of life. This also holds true for their relatives. This emphasizes the importance of psychosocial care and aftercare for cancer patients and their relatives [3-5]. About 30-45% of Dutch cancer patients experiences distress to the extent that referral to a psychologist, public mental health institution, and/or a specialized institution for psychosocial oncology should be needed [6]. Cancer patients and their relatives may receive support in hospitals from the oncologists and oncology nurses directly involved, however, they often have limited availability due to their work overload [3-6]. The primary healthcare system is extending the needed support, including that provided by general practitioners (GPs), social workers, psychologists, and psychiatrists. Due to waiting lists, obstacles in referrals and high costs, these forms of supportive care in the primary and secondary healthcare are often not easily accessible for cancer patients [3-6]. Therefore, patient organizations in several countries, in addition to health care professionals have founded patient-oriented support centers [7 - 11].

In the Netherlands, former cancer patients and committed professionals took the initiative to found so-called CBPSCs: Community based Psychosocial Support Centers for cancer patients [7].

Community-Based Psychosocial Support Centers

The CBPSCs are private and independent socially-driven enterprises, funded by local and national policy makers, sponsorships, grants, donations and PR activities organized by the centers themselves. The CBPSCs were introduced in the early nineties. The 80 CBPSCs are currently joined in the IPSO, Organization of Community-based Support and Psycho-Oncological Centers for Collaboration and Organization [7].

Nowadays more than 40,000 cancer patients and relatives visit the CBPSCs. These centers are mostly

led by part-time paid professional directors/ coordinators, in addition to organizational support from specialized trained volunteers.

The support that CBPSCs offer to their visitors is participation in socially supportive activities and/or in fewer cases, the possibility of therapeutic social support [7].

The social activities are low-threshold psychosocial support facilities, offering contacts with fellow patients who have or have had cancer and who are dealing with their illness, treatment and care. It may include personal meetings with fellow patients (having a cup of coffee together), open discussion groups, informal talks, creative expression (painting, photography), and body-mind activities for relaxation (meditation, singing, etc.).

The therapeutic support includes therapies given by trained professionals within CBPSCs or other outside professionals working closely with the CBPSCs. Such therapies include cognitive behavior therapy (CBT), yoga, mindfulness training and forms of individual and psychosocial therapeutical coaching.

The offered social support and professional care should be integrated in some form of stepped care model, offering different intensities of supportive care for patients throughout the various stages of their disease.

This support is also offered for patients in a palliative condition. As visitors of CBPSCs, people with terminal cancer will do not recover from their illness, whose illness has become instable, and are confronted with death inevitably require palliative care. Considering the increase of cancer patients, it is likely that the majority of the visitors to CBPSCs will be palliative care patients. This is the reason that CBPSCs often form part of the regional networks for palliative care [12-15]. Dutch palliative care is seen as a part of the general care, organized in more than 60 regional networks of palliative care [7,16]. CBPSCs may belong to these networks and may be a part of the entire national palliative care chain on offer. However, this is often not the case because it is unclear what CBPSCs, in fact, offer to palliative care.

Aim of the Study

CBPSCs visitors suffering seriously from their cancer may also need palliative support. However, not much is known about what CBPSCs offer to palliative support and how the visitors and staff assess the palliative support offered. In this article, the following three questions are answered: (a) What is the palliative support offered by CBPSCs? (b) What is the view of visitors and coordinators of CBPSCs with regard to the importance of palliative support, and (c) How is the palliative support experienced and evaluated by the visitors.

Methods

A mixed-method design was used for the study on the significance of CBPSCs' services on palliative support. The attention that CBPSCs pay to palliative support care was studied in study 1 [17] by 34 semi-structured interviews among visitors of 20 CBPSCs (study 1). Additionally, visitors of 25 CBPSCs filled out a web-based questionnaire with questions on the palliative support received and evaluated in study [18]. In a separate study (3) within study 2, also a group of coordinators of CBPSCs filled out a questionnaire about supportive support [13].

Populations and Samples

For *study 1*, a heterogeneous sample of 20 CBPSCs was selected according to geographical, location, urban vs rural areas, the year the CBPSC was founded and the membership of the CBPSC in national cancer support foundations. The CBPSCs received an invitation to participate in the study. If the coordinators did not respond within a week, they were called [17]. CBPSC visitors were recruited for semi-structured interviews based on purposive sampling, reflecting the diversity of the visitors according to (1) patient or relative, (2) gender, (3) age (50 -50+), (4) marital status, (5) western/non-western origin, and (6) type of cancer. The coordinators of the CBPSCs invited one or two of their total visitors to a face-to-face interview. The visitors consented to participation.

Study 2 aimed to include 30 centers, approximately 50% out of the 60 CBPSCs available and willing to participate [18]. The same selection criteria were used as in study 1. The visitors to the CBPSCs

were recruited for a web-based questionnaire, based on visitors from eight years ago. The visitors were informed about the study by email, regular post and through information flyers. In total 3,134 invitations to participate were sent off, 2,436 by email and 698 by regular mail; ultimately, 790 visitors (25%) decided to participate in Study 2. Only 711 of the 790 participants could be included in the analysis due to incomplete questionnaires.

Study 3 did include the coordinators of the CBPSCs in study 2, answering standardized questions about the palliative support provided by the CBPSCs.

Data Collected

There were no appropriate instruments available regarding palliative support in the three studies. Therefore, we adapted topic lists used in previous studies on CBPSCs [7] as well as questions from more general palliative care studies [15,16]. This resulted in six themes covering visitor expectations and experiences regarding palliative care: (1) support and guidance needs, (2) referrals to and by the CBPSCs, (3) provision of information, (4) perceived expertise of the (primarily) voluntary workers, (5) the cooperation of the CBPSCs with other palliative care professionals/organizations, and (6) palliative care needs questions developed elsewhere [17]. Two experts were consulted to comment on the final topic list. A researcher (MVH) conducted the interviews, including selecting the quotations on palliative support, while trained research assistants observed this process and made notes (RH/AB). The interviews, usually lasting between 45-60 minutes, were held in separate rooms in the CBPSC and were audio-recorded [13].

In study 2 [18], the selected visitors answered standardized questions regarding the topics mentioned above.

In study 3 [18], the selected coordinators answered questions about their desire to pay attention to ten aspects of the palliative support, e.g., information supply, contact with palliative care organizations outside the CBPSCs, their last will, financial aspects of the support and requested rituals. The same questions concerned the actual attention given to how dying patients may say farewell to loved ones. Also a few questions concern the

satisfaction with the care during the last stage of life and the participation in National Palliative Care Networks.

In the palliative support part of study 3 specific attention was paid to medical condition of the visitors and the severity of their condition. A variable was developed with two categories: recovered (healed,) free of cancer and a good chance on recovery (52%), and visitors in a less positive medical condition (48%).

Data Analysis

The interviews in study 1 were transcribed verbatim and the process of deductive coding was discussed in the research team. First, one of the researchers (MVH) constructed a list of codes according to the themes in the interview protocol. The research assistants (RH/AB) independently labelled the data using these main codes. Another researcher (HTS) corroborated the student assistants' actions. Secondly, one of the researchers (MVH) reread the transcripts and labelled the data with supplemented codes. The analysis was discussed in the research group. We used the qualitative data-analysis software ATLAS.ti.

The data in the two other studies were analyzed with SPSS [19], using frequencies, means, crosstabs, construction of sum scores, Pearson correlations and MANCOVA's.

Ethical Approval

The respondents were informed verbally, as well in writing, on the studies. Participation was voluntary and the respondents for the interviews also gave their written consent prior to the interview. Confidentiality and anonymity were guaranteed. An advisory board of experts supplied commentary in all phases and for all products (research proposal, data collection and reports) of the study. Approval by the regional Medical Ethics Review Committee (METC) was not applicable because it was non-invasive research, in accordance with the 'Research complying with the Dutch Law on Medical Research in Humans'. The members of the advisory board and the scientific committee of the Dutch Cancer Society both approved our research protocol to guarantee proper ethical procedures.

Results

To participate in the palliative support by CBPSCs, it is necessary that visitors are referred to a

CBPSC. The majority of visitors responded that they were informed about CBPSCs by family, friends and acquaintances (22%), oncology nurses (21%) and/or by written information (21%). Referrals by professionals from primary and secondary health care, such as medical specialists (6%) and general practitioners (5%) were rarely mentioned. Visitors often stated in the interviews that much more attention should be paid to referrals to a CBPSC by the professional circle because they are informed about the regional palliative support.

"Please ensure that referrers are more informed about CBPSCs. I feel that this is often not the case in hospitals, by general practitioners, oncologists and pharmacies." (woman, 48 years, relative, widow).

Visiting CBPSCs

Once patients found their way to a CBPSC, they reported in the interviews that 28% visit the CBPSC once a week, more frequently (10%) or once/several times a month (34%). Many visitors are only tempted to stop visiting when required by circumstances, such as their health and invasive treatments. The desire to continue visiting CBPSCs is stronger in visitors who are familiar with cancer themselves, than for relatives.

The participation in palliative support depends on the organization of the CBPSCs as well. In the survey, the CBPSCs in study 2 covered eight representative regions and had existed for 8.2 years on average. The mean number of local volunteers involved was 49. Paid staff was available in eighteen of the CBPSCs. Most CBPSCs were open three to five days a week and some were also open in the evenings.

Background Characteristics of Participants

Important characteristics of the participants (see study 2) are that most respondents were (ex) patients and women with breast cancer (48%). Less than 5% had colon cancer, lung cancer, lymphoma, prostate cancer, skin cancer or cervical cancer. The average age was 58 years. In 58% of the cases, patients were diagnosed four years ago or longer. Forty percent (40%) of the visitors suffered from a (chronic) condition, in addition to their cancer diagnosis. About 52% of visitors say they were cured or free of cancer, or that there was a good chance of recovery; these are patients with a good medical condition. Nearly half (46%) stated that

they were still under medical supervision and a quarter was still being treated, indicating a poorer condition. For many of these? patients, the prognosis was uncertain.

Most visitors clearly stated that the main purpose of visiting a CBPSC is to experience contact with fellow patients, to find peace, information, and participation in activities [17].

"What I was looking for is a bit of recognition, people who have also experienced it. Because you are very alone in that. You meet people who have had the same experiences and so it's easier to talk" (woman, 49 years old, cohabitating).

Participation in Activities and Therapies

Visitors looking for palliative support usually begin with participation in social supportive activities and/or in fewer cases, by receiving therapeutic social support [7]. The social support and professional care offered should be integrated in some form of stepped care model, offering different intensities of supportive care for patients throughout the various stages of their disease. This includes patients in a palliative condition. As visitors of CBSPCs, people with terminal cancer whose illness have become instable and who are confronted with death, inevitably require palliative care. Considering the increase of people with cancer, it is likely that the majority of visitors to CBPSCs will be palliative care patients. This is the reason that CBSPCs have often formed part of the regional networks for palliative care [9-10]. Dutch palliative care is seen as a part of the general care organized in more than 60 regional networks of palliative care [16]. CBSPCs may belong to these networks and may be a part of the entire national palliative care chain offered. However, this is often not the case because it is unclear what CBSPCs, in fact, offer to palliative care.

The results show that the evaluation of most activities is predominantly positive, varying from 7.2 to 8.6 on a ten-point scale. The same holds true for the therapeutic support, with the least positive evaluation for group discussion and the most positive for music therapy.

View on Palliative care

The interviews in study 1 show that the majority of the participants are (ex) cancer patients (n=24;

71%); One third are woman with breast cancer (n=11; 32%). The mean age is 58.4 years, in a range of 41 - 78 years. Most respondent live alone (n=19; 56%) Most of the visitors followed a medium or higher education (n=24; 71%). Most of the patients followed a combination of treatments, surgery (72%), chemotherapy (68%), or radiation (38%). Patients mentioned that in many cases the prognosis was poor or unknown. (n=18; 53%). Table 1 gives an overview of the importance of the thematic analysis [17].

Most visitors (patients and family members) appreciate the palliative support offered by the CBPSC. It is a part of the general support, relieves the tasks of family members and it may match with what physicians and nurses and the homecare offer. However, not all visitors appreciate the attention to and the discussion about palliative support topics. A few stated that palliative support is not a part of the CBPSCs' function. It is for visitors who do not need support for such a sensitive topic. They also doubt that freelancers have the necessary skills to offer palliative support. Education is therefore necessary.

Needed Attention to palliative support

Table 1 shows which of the ten topics are the most important for the visitors, those being, information about the statistical mean to provide in the last stage of life (52%) and further attention to the needs of partners and children (69%). Information about financial arrangements for the proxies is the least important topic that CBPSCs might offer (36%).

Actual Attention to Palliative Support

Beside the questions on wishes concerning the attention for palliative topics, we asked also about the perceived actual attention. Table 1 also shows (2) that most topics get only a bit of attention. The topic that the visitors perceive as least important, (Financial arrangement for the family) however, receives the most attention. The least important topics are perceived as the most important topic. Information about how to reduce frequent complaints such as pain, nausea and fatigue is seen as so important that it receives a 3.5 out of the four-point scale, but in only 8% of ? (cases/ responders/facilities?) is attention paid to these complaints. Table 1 further shows that more visitors

Table 1. The importance of attention paid to palliative support and end-of-life care (1) and (2) the number of patients who asked questions about that aspect.

Topics ordered on statistical mean of importance on a scale of 1-4 (1) and the actual attention paid to the topics in % (2).	N	M(1)	%(2)
1. Information about the task of healthcare providers to provide in the end-of-life care	560	3,6	11%
2. Attention to partner and children	565	3,6	6%
3.To referred to healthcare providers outside the CBPSC	553	3,6	12%
4. Information about the relief from frequent complaints (pain, nausea, fatigue)	563	3,5	7%
5. Helping to ask questions of doctors and nurses	557	3,5	11%
6. Support around feelings when saying goodbye to loved ones?	556	3,4	11%
7. Helping to cope in the last stage of life (saying goodbye, last wishes, will, euthanasia)	555	3,3	12%
8. A ritual to remember the visitors who passed away (card, flowers, candlelight)	554	3,2	9%
9. The possibility of involving volunteers to arrange common activities	558	3,2	13%
10. Information about financial arrangements for the proxies	549	2,9	16%

(20-30%) express that they appreciate receiving support on more concrete topics such as dying, mourning and terminal care.

Evaluation of Attention to Palliative Support

Given the discrepancy mentioned between the needed support and the support actually received, it is important to study the visitor's satisfaction with the support. The results show that the mean score of the evaluation is 7,1 on a scale of 1 to 10. Visitors who have experience with cancer gave a score of only a 6,9. The satisfaction with the palliative support is the lowest in of all types of support.

A correlation analysis shows that the perceived importance of palliative support positively correlates with the evaluation of the attention given to the palliative care ($r = .37, p < .001; n=458$), but correlates negatively with the actual attention given to this care ($r = -.11; p < .05; n=552$). The actual attention to palliative care also negatively correlates with the palliative support ($r = -.13; p < .01; n=443$). It may be concluded that while visitors appreciate the attention given to palliative support, at the same time, the actual appreciation of this support is low.

The View of the Coordinators

The 25 coordinators interviewed are mainly women ($n=22; 88%$), which have been working an average of 4,3 years in the CBPSCs. In addition to the position of coordinator, about half of the coordinators ($n=15; 60%$) has another function, such as freelancer in a private company, author or volunteer, and a management task.

Table 2 shows that the majority of the coordinators (16/25) states that the CBPSC is a part of the support facilities in the area. Their evaluation of the palliative support given by the CBPSC is 6,4. This confirms the evaluation mentioned by the visitors. So, the coordinators' view is that the palliative support in CBPSCs receives rather low attention.

Coordination with National Networks

On the subject of coordination, it may be concluded that the majority of the CBPSCs works together with national networks for palliative care. The majority has formalized that cooperation. However, the satisfaction with that is not very high, 7,7 (range

7 – 10). Also, the coordinators evaluate this aspect of the CBPSCs as not very high, with a 6,6 (SD: 2,1) on a range of 0 - 8.

Views on Palliative Support

Other results from the interviews describe the attention for palliative support in CBPSCs ($n=25$), as presented in table 3.

Conclusion and Discussion

It may be concluded that palliative support is an important aspect of the stay in the CBPSCs. This includes support and information supply about palliative support. This does not mean that it should be confronting for visitors, but at the same time, this confrontation is particularly important for ethnic minorities and people with a non-Dutch background, as this is frequently a taboo topic for discussion within their own culture. The results also show that palliative support requires a special skill set and training for the volunteers.

Discussion

The study aims at the question of how far visitors and the coordinators believe that attention to palliative support is given and whether that support is actually given and whether it is appreciated. The attention to palliative care is not at the same level in all CBPSCs. The actual attention given may differ from the attention that visitors would like to receive. The appreciation of the palliative support is sufficient in general, but it is lower in comparison to the other types of support provided by CBPSCs.

A comparison to studies elsewhere is rather limited, because CBPSCs are organized differently in various countries [9-11]. There were comparable initiatives in Belgium, but they are also organized differently than the Dutch CBPSCs. In Germany and the UK, there are also initiatives to introduce palliative support in cancer centra, but this occurs in facilities which are closely related to hospitals. No studies have been found concerning the evaluation of palliative support in comparable institutes. [9-11].

The visitors believe that palliative support should be a part of the complete package of support on offer in CBPSCs. The support should be further developed and extended to families, partners and children. Also, the

Table 2. The view of the coordinators on palliative support. (N=20).

Functions of palliative care	M (a)	N (%) (b)
1. Information about what other health care providers may provide in the end-of-life care	3,6	5 (25,0)
2. Attention to partner and children	3,6	3 (15,0)
3. To give referrals to healthcare providers outside the CBPSC	3,6	4 (20,0)
4. Information about relief from frequent complaints (pain, nausea, fatigue)	3,5	3 (15,0)
5. Helping to ask questions of doctors and nurses	3,5	1 (5,0)
6. Support around feelings when saying goodbye to loved ones	3,4	3 (15,0)
7. Helping to cope in the last stage of life (farewell, last wishes, will, euthanasia)	3,3	5 (25,0)
8. A ritual to remember the visitors who passed away (card, flowers, candlelight)	3,2	7 (35,0)
9. The possibility of involving volunteers for visitors to arrange common activities	3,2	6 (30,0)
10. Information about financial arrangements for the proxies	2,9	4.(20.0)

(a) Mean score on four-point scale; (b) in % on N=20.

Table 3. Views on palliative care.

1. Should there be attention given to palliative support?
In general, yes. but it not a specific function of a CBPSC.
2. Reasons to give attention to palliative support
a. There is a shortage of information on palliative support in CBPSCs.
b. It is important for the attention given to family members.
c. Palliative support is a crucial part in cancer care.
d. Palliative care fits very well in CBPSCs.
3. Type of support for the patients
a. Organizing group meetings
b. Education of the volunteers as an important condition
4. Referral to palliative care facilities
The majority of the visitors expressed the opinion that referral by physicians, psychologist, and oncology nurses to palliative care facilities is needed.
5. Confrontation with death and dying
A few of the visitors of CBPSCs state that the confrontation with other visitors who are more seriously ill and may need palliative support is rather confronting. They associate palliative care strongly with end-of-life care. For other visitors, the confrontation with death is too upsetting/traumatic and this should not happen in a CBPSC.
6. Information about palliative care
The majority of the visitors states the importance of volunteers informing them about palliative care. It is seen as part of the CBPSC's task. It is important that this information is given at the right moment. Cultural background may play a role in the information supply about palliative care, because it is still a taboo in some cultures. Therefore, being able to get that information in the CBPSC is then blessing.

information supply requires improvements, such as education, financial possibilities, help when saying goodbye, the possibility to ask more help from doctors and nurses and information on physical complaints in the last stage of life. In comparison with other activities, evaluation of palliative support given is rather low. The coordinators also stress the importance of improvement in palliative care.

Palliative support is often a rather new part of the support by CBPSCs. Therefore, it is important that CBPSCs be part of the regional and national palliative networks. This contact with networks could improve the communication between home care and palliative teams. The connection with palliative networks should be developed further, showing the benefit of it.

The study lays bare the discrepancy between visitors' expectations and the actual attention given to palliative support in CBPSCs. This is especially true for people with incurable cancer and in the end-of-life stage. It clarifies the conflict between what the staff offers in CBPSCs and the wishes of the patients and their families [17-18]. Behind this conflict there may be a lot of unsolved issues between patients and their family in processing the entire situation.

A minority of visitors does not like to be confronted with death and dying in a CBPSC and does not wish to discuss these topics in the CBPSC. These topics may also be difficult for volunteers. On the peripheral are also questions about the training of volunteers in palliative care.

Limitations of the Study

This is one of the first studies about palliative support in CBPSCs. Comparison with other studies elsewhere is limited, also in other countries [9,11]. Another limitation is that the results are based on answers to questions of opinion and not based on factual observations. Another restriction is that this study has not included how palliative networks assess the palliative support in CBPSC. Finally, CBPSCs are often newly developed or recently established, which may mean they have not yet developed the attention to palliative support that is required [20-22]. It is important that further studies about the role of CBPSCs in palliative care are conducted.

Independent of the restrictions mentioned, however, the study also shows that there is room for the development of palliative support, especially if the policy is aimed at cooperation with existing palliative networks and other forms of psychosocial support for people with somatic diseases [3-5]. This is especially the case for CBPSCs which have been recently founded, and where the evaluation of the palliative support is the lowest. Although the coordinators of the CBPSCs support palliative support in CBPSCs, they stress that it is not always easy to realize the palliative in CBPSCs. They realize that the low evaluation of palliative support may be improved by implementing guidelines. Applying the policy of palliative networks may also strengthen the initiatives within CBPSCs. The CBPSCs may play a role in the realization of ambulant palliative care instead of the specialized, intuitional palliative care. This could bring palliative care closer to the patients, which may reduce costs as confirmed by Tanke, De Smit, Groenewoud and Boddaert in their study [23]. An important condition is that CBPSCs specify their aims and tasks more explicitly in palliative support, in order to realize them.

Practical Implications

It may be concluded that visitors of CBPSCs would like more attention to palliative support in their homes. Information supply should be improved regarding this task of CBPSCs. At the same time, it should be clear that some visitors do not like to be confronted with death and dying. In these cases, it is important to consider how to approach the discussion of the end-of-life stage in palliative care. The developmental policy should take into account how long CBPSCs have existed and their size. Finally, it is also important that their provision of palliative support be included as part of existing networks.

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