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## *Research Article*

# **Community-Based Psychosocial Support Centers for Cancer Patients and Their Relatives: Use, Evaluation and Effect**

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## **Abstract**

**Aim** Community-Based Psychosocial Support Centers for cancer patients and their relatives (CBPSCs) offer easily accessible contacts with fellow patients and support by trained volunteers in the Netherlands. We studied the characteristics of visitors of CBPSCs, which social support and/or therapy they receive, if these services meet their needs, how satisfied they are with the help, and if it does affect their Health Quality of Life (HQoL).

**Methods** The role of 20 CBPSCs was explored in semi-structured interviews among 34 visitors. Regarding their contacts with CBPSCs (Study 1), additionally, in 25 CBPSCs, 701 visitors filled out a web-based questionnaire about their experiences with CBPSCs (Study 2). Within this second study, 203 participants filled out a questionnaire again after 3-5 months (Study 3).

**Results** The studies confirm the significance of CBPSCs contacts, resulting in increased communication about their illness, talks with fellow patients about their problems. Most visitors are not referred to CBPSCs by health care professionals, but visit on their own initiative and contacts. Patients often visit CBPSCs once a week or monthly. The visitors are mainly highly educated women with breast cancer over 60 years of age. The social support involves especially creative and leisure time activities. The therapies are individual therapy sessions, groups on creative therapy, mindfulness, body-orientation, and bereavement. Evaluation of activities and therapies is positive, varying from 7.2 to 8.6 on a 10-point scale. Study 3 shows that after a few months the HQoL decreased significantly for all other visitors, but did not change for serious ill patients.

**Discussion and Conclusion** CBPSCs play an important and highly evaluated role in psycho-oncology. Insight in effects of visits is still limited. Differences in the health care organization restrict the comparability with the CBPSCs in other countries. More studies are needed to show the effects of CBPSCs.

## **Keywords**

Cancer, Community-based psychosocial support centers, Effect, Evaluation, Psychosocial care, The Netherlands

## Introduction

World-wide the number of people with cancer is growing due to higher life expectancies and aging populations [1]. This is also the case in the Netherlands where in 2017 3,47,121 (prevalence) people were affected with cancer [2]. The diagnosis cancer and its treatment may strongly interfere with their life in practical, physical, emotional, social, and philosophical terms. This emphasizes the importance of psychosocial care and aftercare for cancer patients and their relatives [3-5].

### Psychosocial Cancer Care

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 is needed [6]. From organizational point of view, cancer patients and their relatives may receive support in hospitals from the direct involved oncologists and oncology nurses; however, they are often limited available due to work overload [4-6]. The secondary health care is broadening the guidance, including support by General Practitioners (GPs), social workers, psychologists, and psychiatrists. Due to waiting lists, barriers in referrals and high costs, the mentioned forms of supportive care in the secondary care are often not easily accessible for cancer patients [6,7]. Therefore, patient organizations, but also health care professionals in several countries took initiatives to found patient-oriented support centers [8,9]. Examples of these centers are the Maggie' centers in the UK, Barcelona and Hong Kong, In the USA the MD Anderson Cancer Centre (Houston) and the Memorial Sloan Kettering Cancer Centre (New York) offer support groups. In Germany the psychological support is organized by the Lebenswert Institute (Life valued Institute) in Koeln and by the Krebsgesellschaft (Cancer Society) in Bayern (München). Comparable initiatives exist in Australia, Belgium, Canada, Denmark, Norway, and Israel, often organizational close related with or in hospitals [9-11]. Former cancer patients and also professionals in the Netherlands took the initiative to found CBPSCs: Community based psychosocial support centers for cancer patients [8].

### Community-Based Psychosocial Cancer Centers

The CBPSCs are private and independent social driven enterprises, funded by: local and country policy makers, sponsorship, grants, donations, and PR activities organized by the centers themselves. Nowadays more than 40,000 cancer patients (and relatives) are visiting the CBPSCs. These centers are mostly led by part-time paid professional directors/coordinators, beside organizational support from specialized trained volunteers. People who do not recover from their illness and whose illness has become instable may also be visitors for whom death is inevitable palliative care is necessary. Considering the increasement of people surviving from cancer, it is likely that a larger part of the visitors of CBPSCs will be confronted with palliative care, a reason that CBPSCs have often become part of the regional networks for palliative care [12,13]. The support that CBPSCs offer to their visitors can be participation in social supporting activities and in less cases, also receiving therapeutic social support [8].

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

*Therapeutic support* includes therapies given by in principle trained professionals in- or outside the CBPSCs (but always in close collaboration with the CBPSCs): Cognitive Behavior Therapy (CBT), yoga, mindfulness training, and forms of individual therapeutical coaching.

The offer by CBPSCs should in fact fit within the whole of the psycho-social cancer care, as the lowest level of support in a stepped-care model [14]. This may lead to a more convenient offer of informal and supportive care to cancer patients, close to their homes [15]. This requires, however a fitting communication with the health care

professionals and adequate reference of patients. Lacking information about these conditions was the impetus for our studies.

The CBPSCs for people with cancer were introduced in the early nineties. Comparable accommodations abroad are often closely linked to hospitals. Currently the 80 CBPSCs are joined in the Organization of Community-based Support and Psycho-Oncological Centers for Collaboration and Organization [16]. During our study about 35,000 people visited the CBPSCs.

The governmental policy during the years 2014-2020 aims at providing the patients optimal care by an integral multidisciplinary team of caregivers, professionals and volunteers, integrated within the regular care as much as possible [14]. This means that the offered social support and professional care need to be integrated in a form of stepped care model, offering a different intensity of supportive care for patients in different stages of their disease. For patients for whom basic psychosocial care is sufficient, a CBPSC may fit within the whole of the available psychosocial cancer care. This may lead to cost reduction and a more convenient and connected service of care and support to patients close to home [15].

### **Aims of The Study**

Despite the increasing number of CBPSCs, not much information exists about the content and quality of the services. More information is needed to initiate a national policy to establish high qualitative CBPSC's. In this article we explore: who are the visitors to CBPSCs, what is the offered support, do the services meet the needs and expectations of the visitors, how do visitors value these facilities, and will the participation in CBPSCs raise the health quality of life?

## **Methods**

### **Design**

A mixed-method design was used for the research on the CBPSCs' services. To study the content of the CBPSCs supportive care, 34 semi-structured interviews among visitors of 20 CBPSCs were conducted (Study 1). Additionally, visitors of 25 CBSCs filled out a web-based questionnaire (Study 2). In a part of this study, also a group of participants filled out a part of the questionnaire for a second time after 3-5 months (Study 3).

### **Populations and Samples**

For study 1, a heterogeneous sample of 20 CBPSCs was selected according to geographical location, urban vs. rural areas, the year of founding of the CBPSCs, and possible membership the CBPSC of a national cancer support foundation. The coordinators of the CBPSCs received an invitation to participate in the study. If they did not respond within a week, they were called [17].

The visitors of the CBPSCs 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 participate.

Study 2 aimed to include 30 centers, approximately 50% out of the 60 CBSPCs available and willing to participate. The same selection criteria were used as in Study 1. The visitors of the CBPSCs were recruited for a web-based questionnaire, based on visitors from eight years ago (from 2012-2013). The visitors were informed about the study by email, regular post, and through information flyers about the CBPSCs. 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 790 participants could be included in the analysis due to incomplete filled out questionnaires.

Study 3 did include selected participants of Study 2, answering standardized questions about several aspects of the visit again after 3-5 months (T-2). The changes in well-being were researched using three health quality of life questions (HQoL) of the EORTC [18] and ten validated questions about health complaints, e.g., fatigue, sleeping, pain and breathing [17].

### **Data Collected**

For the interviews in Study 1 no instruments were available regarding psychosocial issues specifically applying to CBPSCs. Therefore, we adapted a topic list used in a previous study on CBPSCs (8) as well as questions from more general studies in this field [19]. This resulted in six themes covering visitor's expectations and experiences with regard to: (1) support and guidance needs, (2) referrals to and from the CBPSCs, (3) provision of information, (4) perceived expertise of the (mainly) voluntary workers, (5) the cooperation of the CBPSCs with other professionals, and (6) the perceived health. Two experts were consulted to comment on the final topic list. A researcher (MVH) conducted the interviews, while trained research assistants observed this process and made notes (RHAB). The interviews, usually lasting between 45-60 minutes, held in quiet, separate rooms in the CBPSC and were audio-recorded. Details of this part of the study are reported by IPSO [16].

The web-based questionnaire in Study 2 consisted of questions about seven topics: (1) biographical and medical characteristics, (2) reasons and needs for visiting CBPSCs, (3) activities and support that were attended, (4) appreciation and significance of the social activities and therapeutic support received, (5) well-being, including perceived health, emotional well-being, and symptoms (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Cancer30) [18], (6) psychosocial distress measured by the Dutch version of the Distress Thermometer [20], and (7) palliative care needs questions developed by Osse et al. [21]. These are the measures, later called as T-1. Details of this part of the study are reported by Van der Stege et al. [22].

In study 3, the selected visitors answered again standardized questions about several aspects of their visits after 3-5 months (T-2). The changes in well-being were researched using three questions of the EORTC [17] and ten validated questions about health complaints, e.g., fatigue, sleeping, pain and breathing [22].

### **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 (RHAB) independently labeled the data using these main codes. Another researcher (HTS) confirmed this action of the student-assistants. 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 Study 2 were analyzed with SPSS (2000), using frequencies, means, crosstabs, construction of sum scores, Pearson correlations, and Anova's. Changes between T1 and T2 in Study 3 were tested by dependent T-tests, F-tests and Manova's.

### **Ethical Approval**

The respondents were informed orally as well written on the studies. Participation was voluntary and, in the interviews, the respondents 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 a 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

### Reference to CBPSCs

Most visitors of a CBPSC did not know what a CBPSC was, or where to find a CBPSC in their area. The idea that visitors may be inhibited to talk about cancer, showed not be the case. **Table 1** shows how visitors contacted the CBPSCs.

Type of contacts	Answers in % of N = 963 answers*	Answers in % of number of 711 visitors
<b>I. Own initiatives and by networks</b>		
family, friends, acquaintances	16.2	22.1
Brochure, leaflet, announcement board, newsletter	15.7	21.4
Newspaper, radio, TV	11.3	15.4
Visitors, volunteers of CBPSCs	9.0	12.3
Internet, social media, patient associations	7.5	10.2
Own initiative	3.5	4.8
Living near a CBPSC, known in the neighborhood	2.9	4.0
<b>II. By health care professionals</b>		
Oncology nurses	15.8	21.5
Specialists and oncologists in hospitals	4.5	4.0
General practitioners	3.5	4.0
Other health care providers/institutes **	4.0	5.5
* Multiple answers possible.		
** Physiotherapist, psychologist, social worker, health care company, hospice, home care organization, patient organization, other psycho-oncological centers.		

**Table 1:** How cancer patients contacted the CBPSCs (Study 1).

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 were rarely mentioned, such as specialists (6%) and general practitioners (5%) Visitors often stated that much more attention should be paid to referrals to a CBPSC by the professional circle [1]. *"Realize that referrers are more informed, 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 did find their way to a CBPSC, 28% visit the CBPSC once a week or more frequently (10%). A third (34%) did visit the CBPSC once or several times a month. A visit takes about 2 to 3 hours. Almost half (44%) want to continue visiting the CBPSC in the coming years. Two-thirds (69%) of the visitors even report that they visit the

CBPSC for more than a year. Many visitors are only tempted to stop visiting when circumstances that require e.g. their health and invasive treatments. To continue visiting the CBPSCs by visitors who are familiar with cancer themselves is stronger than for relatives ( $p < 0.001$ ).

### Characteristics of The CBPSCs

The 25 CBPSCs in Study 2 cover eight representative regions, existing on the average for 8.2 years. The mean number of local volunteers involved was 49. In eighteen CBPSCs paid staff was available. Most CBPSCs were open three to five days a week and some were also open in the evenings.

### Background Characteristics of Participants

The background characteristics of the participants in Study1 are presented in **Table 2**.

<b>Type of visitors</b>	<b>N =34</b>
(Ex) patients/relatives	24/10
Female/male	24/10
<b>Age (year)</b>	
Mean (SD); range	58,4 (10,1); 41-78
<b>Marital status</b>	
Married/cohabit/living alone	14/20
<b>Education</b>	
Lower vocational education	6
Secondary and higher education	7
Secondary, higher vocational education, university	20
<b>Types cancer</b>	
Breast cancer	11
Lung cancer/colon cancer	4/3
Other type of cancers	12
<b>Treatments (combinations possible)</b>	
Operation	24
Chemotherapy	23
Radiation	15
Hormone therapy	6
<b>Prognosis</b>	
Cured, healed/bad prognosis	9/6
Partner died	7

Uncertain	12
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**Table 2:** Overview of characteristics of visitors (study 1; N lower than 34 due to not answering).

Important characteristics are that most respondents were (ex) patients and women with breast cancer. Less than 5% had colon cancer, lung cancer, lymphoma, prostate cancer, skin cancer or cervical cancer. The average age was 58 years (SD=10.6). In 58% of the cases, the diagnosis was made four years or longer ago. Forty percent (40%) of the visitors suffered from a (chronic) condition in addition to the diagnosis of cancer. About 52% of visitors say they were cured or free of cancer, or that there was a good chance of recovery; this are patients with a good medical condition. Indications of a worse condition are that nearly half (46%) stated that they were still under medical supervision and a quarter was being treated. For many patients, the prognosis was uncertain. More than half of the visitors (51%) used a form of complementary or alternative treatment outside the CBSPC.

The background characteristics of the participants in Study 2 are presented in **Table 3**.

<b>Overview of characteristics of the visitors</b>		
<b>Gender</b>		
Female	574	80.7
Male	137	19.3
<b>Country of origin</b>		
Netherlands	668	94.0
<b>Level of education</b>		
Lower	119	16.7
Middle	344	48.4
High	238	33.5
<b>Socio-economic status</b>		
Paid work	230	32.3
Not-active in paid work	472	66.4
Total	711	100

**Table 3:** Overview of characteristics of the visitors (Study 2).

Of the 711 respondents, 72% had cancer (presently or in the past) and 28% were relatives. Of the relatives, 62% had experienced the death of a family member they were close to. More women (81%) than men (19%) were visitors and the mean age of the whole group was 58 years. Most visitors (94%) were born in the Netherlands. One-third had completed university or higher vocational education; 17% was educated at a lower level. One third of the visitors had a paid job. A large number of visitors enjoyed (pre)pension and one fifth received disability benefits.

## The Offered Support by The CBPSCs

The support that CBSC's offer their visitors are 'social activities' and 'therapeutic support'.

Social support activities: The offered activities are sufficiently diverse, according to the expectations of the large majority (69%). The need to diversify activities is reflected in the fact that 56% of participants emphasize the importance of contact with fellow patients, whereas 53% finds activities with patients of a comparable age very important. In addition, for almost half (46%) of the participants, the motivation to visit these facilities is that there is someone willing to listen, as well as to meet other people to have a conversation about what has happened to them (33%).

**Table 4** contains an overview of the participation in other activities, such as creative and leisure activities (respectively 47% and 36%) and many other social activities related to massage, sport, cooking, etc.

Supportive care activities	Number	Percent (%)	Mean	SD
Meeting activities (walk-in morning, coffee, tea, eating together, etc.)	429	65.3	8.3	1.2
Creative activities (painting, choir, photography, etc.)	307	46.7	8.5	1.1
Theme meetings, lectures, presentations	238	36.2	8.3	1.2
Leisure activities (yoga, meditation, tai chi, moving with music, aromatherapy, etc.)	233	35.5	8.4	1.2
Massage	209	31.8	8.6	1.4
Information	149	22.7	8.3	1.5
Sports activities (walking, swimming)	145	22.1	8.2	1.6
Event (fashion show, Christmas market etc.)	130	19.8	8.4	1.3
Cooking	126	19.2	8.4	1.5
Mindfulness group	80	12.2	8.1	1.8
Bereavement group	69	10.5	8.2	1.6
Reiki	38	5.8	7.6	2.2
To sell items in store	46	7.0	7.4	2.2
Partner meetings	41	6.2	8.1	2.0
Documentation center	32	4.9	7.8	1.8
Play games	14	2.1	7.5	2.5
Youth meetings	13	2.0	7.6	2.8
Telephone consultations	6	0.9	7.2	2.9
Total	2305	350.8*		
* multiple answers possible				

**Table 4:** Participation in supportive care activities and the evaluation (Study 2); Mean (scale of 0-10) & SD.

Furthermore, other answers indicate that almost half (47%) of the visitors talk about the contact with the therapists, their work (37%), their family and friends (33%), mourning (32%), and contact with their partner (30%).

Most visitors clearly state that the main purpose of visiting a CBPSC is to experience contact with fellow patients, to find peace, information and participation in activities [2].

*“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, living together).*

Participation in therapies: The participation in therapeutical support is presented in **Table 5**.

<b>Therapeutic support</b>	<b>Percent %</b>	<b>Mean</b>	<b>SD</b>
Individual talks	70.5	8.4	1.4
Group discussions	35.6	7.6	1.6
Creative therapy (visual)	16.8	8.5	1.2
Mindfulness	16.1	8.0	1.1
Body-oriented therapy	13.4	8.1	1.9
Bereavement group	13.4	8.8	1.0
Guidance of partner relationship	8.1	8.9	1.2
Physiotherapy	6.0	7.9	2.0
Supervision of (grand) children	5.4	8.5	1.1
Music therapy	4.7	9.1	0.9
Haptonomy	0.7	8.0	-

**Table 5:** Participation in the therapeutic support and the evaluation; a 10-point scale (Study 2); mean and SD.

The main therapeutical activities are individual therapy talks, group discussions, creative therapy, mindfulness, body-oriented groups, and bereavement therapy (less than 10%).

### **Evaluation of Activities and Therapy**

In the already presented **Tables 4 and 5**, 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 highest for music therapy.

Effects on health quality of life: The EORTC health quality of life (HQoL) measure decreased significantly at T-2 ( $p < 0.05$ ) from 5.1 to 5.3 on a seven-point scale. The also measured health complaints did not change at T-2 in comparison with T-1.

To explain the decrease in HQoL, the influence of eight possible confounding factors were studied using multivariate analysis: social/medical characteristics, medical condition, co-morbidities, being a (ex)patient or relative with/without cancer, health changes, stressful life events, number of visits to the CBPSC, and perceived meaning of the visits. Results showed that only the severity of the perceived health condition did play a role in the decrease of the HQoL. The data show that for all visitors the HQoL decreased significantly, also for visitors with a good health condition at T-1, except for more seriously-ill visitors for whom the HQoL did not change.

## Discussion

The offer of adequate social support for cancer patients is a complex organizational task in health care [3-5]. The needs of cancer patients require a patient-centered approach, which is often not very well developed in the mainly instrumental-technical oriented medical care in hospital [6]. Consequently, cancer patients are frequently struggling to find fitting psycho-oncological care. The available psychosocial care is often difficult accessible due to waiting lists and financial costs. Patients and professionals in the Dutch psychosocial cancer care tried to solve the offer of fitting support by the founding community-based support centers for cancer patients (CBPSCs). This Dutch psychosocial cancer care is a rather uniquely approach in international perspective. This is a first extensive study on CBPSCs in the Netherlands. It confirms the results of smaller, earlier studies [8].

## Restrictions

The samples are biased by the high number of women with breast cancer and a low number of men with prostate cancer, as compared to national statistics. The number of participants was lower than the number of visitors we planned, while the CBPSCs count the number of visits. The limitations of the cross-sectional character of Study 2 are compensated by the repeated measurement model in study 3.

A further restriction is that international comparison is rather limited, because only a few studies were performed in other countries [9,10]. The comparison is also more limited due to differences between countries in the organization of health care and CBPSCs. The Dutch CBPSCs function independently of hospitals. In Germany, the USA, the UK, Canada, Australia, Israel and Denmark, that is not the case [9-11]. Two more comparable initiatives in Belgium were liquidated due to financial restrictions, while two other Belgium initiatives are part of a broader social welfare organization.

Another limitation is that although CBPSCs try to offer support, distinguishing social activities from therapy, in practice this is often not possible or difficult, such as when offering mindfulness groups and massages.

The reference to CBPSCs is a last restriction, because the references are rather limited from the health care, especial references by oncologists or medical doctors and GPs. Other and recent studies show that this situation is not much improved [23,24]. An effective PR for CBPSCs should be especially concentrated on hospitals and the primary health care to improve their acquaintance, while in the meantime, the number of Dutch CBPSCs is raising, although the financial conditions are still limited.

## Conclusion

The CBPSCs offer social support activities as well as forms of psycho-therapies which are important for cancer patients who are confronted with a lot of physical, psychological, social, financial and spiritual problems. We explored in qualitative and quantitative studies the characteristics of the visitors, whether the offered services met their needs and expectations, how they valued the facilities, and if effects on the HQoL could be found. A mixed-method design was used by interviews and filling out questionnaires.

The studies confirm the strong significance of visiting CBSCs for a strong diversity of cancer patients. The main numbers of visitors are not referred to CBPSCs by the health care system, but on their own initiative and contacts. They participate in a lot of supportive social care and in a variety of therapies. The evaluation of activities and therapy is predominantly positive. The studies show that after a few months, the HQoL did not change for serious ill cancer patients. The visits to CBPSCs seems to function as a buffer for further decrease of their HQoL, which fits to the decrease of the HQoL by a small, but significant level for the visitors with a better health condition at T-1, which may

not need the support in the CBPSCs. This stresses the need of more fundamental effect studies on the service of CBPSCs.

## Notes

1. From here on we only mention cancer patients, although it includes also a few relatives.
2. Citations from interviews in study1.
3. We mainly report data from study2.

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