

Visiting Community-Based Psychosocial Support Centers for Cancer Patients and Their Relatives: A Buffer for the Decrease in Health Quality of Life.

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Abstract

Introduction: Psychosocial treatments may prevent the decrease of the perceived HQoL of cancer patients with a good medical condition. However, contrarily, psychosocial support may not prevent the decrease their HQoL, but only stabilized it, in case of a bad medical condition. The explanatory factor of the effect of psychosocial support may be the severity of the medical condition of patients. This hypothesis was tested in an intervention among Dutch cancer patients visiting a Community Based Support Centre (CBSC), offering contacts with fellow patients, psychological treatment, and participation in supportive activities (e.g. walking, music and art therapy, mindfulness training, cooking courses).

Methods: A mixed methods study was held among 20 CBSC's, including 24 visitors about the meaning of their HQoL. In a digital survey at two timepoints (T-1, a few months after the first visit) and again after 3 months-5 months (T-2), the HQoL was studied using three questions of the standardized EORTC measure, beside validated questions on the medical condition, fatigue, sleeping, pain, short-breathing, and perceived prognosis. All measures are very reliable showed by Cronbach alpha coefficients between 0.72 and 0.96.

Results: The studies confirmed that visiting CBSCs enable their well-being and the communication about HQoL. In total 203 visitors responded at both time points, revealing that between T1-T2, the HQoL decreased ($p < 0.05$) from 5.3 to 5.1 (seven-point scale). In multivariate analysis the influence of eight confounding factors was studied to explain this result: Social and medical characteristics, medical condition, morbidities, being an (ex) patient or relative with/without cancer, changes in health, stressful life events, number of visits, and perceived meaning of the visits. Only the severity of the medical condition played a role in the decrease of HQoL. For visitors with a better medical condition at T-1 the HQoL decreased, while for visitors with a rather worse medical condition at T1, the HQoL did not change.

Conclusion: The results confirm the hypothesis that a psychosocial intervention (visiting CBSCs) decreases the HQoL over 3 months-5 months as part of their adaptation process. However, for visitors with a poorer medical condition, the HQoL remained stable over time. This implies that psychosocial interventions (e.g. visiting a CBSC) are functioning as a buffer against decreasing HQoL for those in a poor medical condition only.

Keywords: Cancer • CBSCs • Social support • Psychotherapy • HQoL • Medical condition

Introduction

The prevalence of people with cancer is growing due to higher life expectancy and aging populations [1]. This is also the case in the Netherlands where in 2017, 347.121 (prevalence) people were affected with cancer [2], on Jan 1, 2020 this were 604.00 cases. The diagnosis cancer and its treatment may strongly influence the quality of life in practical, physical, emotional, social, and meaning of life terms. This emphasizes the importance of psychosocial care and aftercare for cancer patients and their relatives [3-5].

Psychosocial cancer care

Dutch cancer patients and their relatives may receive support in hospitals from the direct involved oncologists and oncology nurses; however, they are often limited available for support due to work overload

and lacking of skills [4-6]. The primary and secondary health care is broadening the guidance by General Practitioners (GPs), social workers, psychologists, and psychiatrists. However, due to waiting lists, barriers in referrals, and high costs, these forms of supportive care are also often not easily accessible for cancer patients [6,7]. Therefore, patient organizations and health care professionals in several countries took initiatives to found easily accessible patient-oriented support centers [8,9]. Examples of these centers are the Maggie' centers in the UK, Barcelona and Hong Kong, also the MD Anderson Cancer Centre (Houston) and the Memorial Sloan Kettering Cancer Centre (New York) in the USA 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 organisational close related with or in hospitals [9-11]. In the Netherlands, (former) cancer patients and professionals took the initiative to found CBPSCs: Community based psychosocial support centers for cancer patients [8]. About 30%-45% of Dutch cancer patients experience the need of referral to psychologists, public mental health institutions and/or specialized institutions for psychosocial oncology [6]. From here on we only mention cancer patients, although studies may include also a few relatives. This will not influence the described results.

Community-based psychosocial cancer centers

The Dutch CBPSCs are private and independent social driven enterprises, funded by local and country policy institutions, sponsorships, grants, donations, and PR activities. Nowadays more than 35.000 cancer patients (and relatives) are visiting the CBPSCs. These centers are

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mostly led by part-time paid professional directors/coordinators, beside organizational support by specialized trained volunteers, offering to their visitor's participation in social supporting activities as well as in less case, also receiving therapeutic support [8].

Social support are low-threshold psychosocial support activities, 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 and informal talks about their problems, creative expression (painting, photography), and body-mind activities for relaxation (meditation, singing). Therapeutic support may include therapies given by trained professionals in-or outside the CBSCs (but always in close collaboration with the CBPSCs): Cognitive Behavior Therapy (CBT), yoga, mindfulness training, and other forms of individual clinical therapeutically coaching.

The CBPSCs for people with cancer were introduced in the early nineties. Comparable accommodations abroad are often closely linked to hospitals, but this is not the case for CBPSCs. Currently the 80 CBPSCs are joined in the IPSO, Organization of Community-based Support and Psycho-Oncological Centers for Collaboration and Organization. During our study about 35,000 people visited yearly the CBPSCs. People who do not recover from their illness, and whose illness has become instable, for whom death is inevitable, and palliative care may be necessary, will also visit CBPSCs, which are often part of the regional networks for palliative care [12-13].

The whole offer by CBPSCs should fit within the total psycho-social cancer care, at the lowest level of support in a stepped-care model [14]. This may lead to a more convenient offer of informal and formal supportive care to cancer patients, close to their homes [15,16], including also the offered palliative care. This requires, however a fitting and frequent communication with the health care professionals as well as adequate reference of patients. Lacking information about influence of these conditions on the HQoL was the impetus for our study.

Aims of the Study

Despite the increasing number of CBPSCs, not much information was known about the content and quality of their services, especially concerning the aimed influence on the HQoL. More information was needed to initiate a national policy to establish high qualitative CBPSC's for the improvement of the HQoL. In this article we explore if the participation in CBPSCs will raise the health quality of life, taking in account the medical condition of the cancer patients, who are the visitors to CBPSCs, what is the offered support, if the services meet the needs and expectations of the visitors, and how do visitors value these facilities?

Methods

Design

A mixed-method design was used for the study on the CBPSCs' services. To explore the content of the CBPSCs supportive care, 34 semi-structured interviews among visitors of 20 CBPSCs was conducted (Study 1) [17]. Additionally, visitors of 25 CBSCs filled out a web-based questionnaire (Study 2) [18]. In a part of this study, also a group of participants filled out the questionnaire for a second time after 3 months-5 months (Study 3) [18,19].

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 ask one or two patients to participate in the study.

The visitors of the CBPSCs were recruited for semi-structured face-to-face 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 visitors needed to consent to participate.

Study 2 aimed to include 30 centers, approximately 50% out of the 60 CBPSCs 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 by email or 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 months-5 months (T-2). The changes in well-being were researched using three health quality of life questions (HQoL) of the EORTC [20] and ten validated questions about health complaints, e.g. fatigue, sleeping, pain and breathing [18].

Data collected

For the interviews in Study 1 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. A researcher (MVH) conducted the interviews, while trained research assistants observed this process and made notes (RHAB). The interviews, usually lasting between 45 minutes-60 minutes, were held in separate rooms. Details of this part of the study are reported by Vahedi Nikbakht -Van der Sande et al. [17].

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-Cancer 30 [20], 6: Psychosocial distress measured by the Dutch version of the Distress Thermometer and palliative care needs questions developed by Osse et al. [21-23]. These are the measures, later called as T-1. Details of this part of the study are reported by Van der Stege et al. [18].

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 [18] on general body condition, health condition and quality of life. Further, ten validated questions about health complaints were applied, e.g. fatigue, sleeping, pain and breathing [20].

All used measures are reliable, based at Cronbach alfa coefficients variation between 0.72 and 0.96.

Data analysis

The interviews in Study 1 were transcribed verbatim and the deductive coding was discussed in the research team [17]. We used the qualitative data-analysis software ATLAS. The data in Study 2 were analyzed with SPSS, using appropriate statistics (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

Participation was voluntary and the respondents also gave their written consent prior to the interviews. 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. The members of the advisory board and the scientific committee of the Dutch Cancer Society both approved the research protocol to guarantee proper ethical procedures confirming the rules of the regional Medical Ethics Review Committee (METC).

Results

Reference to and visiting CBPSCs

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 (Table 1).

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

Type of contacts	Answers in % of N = 963 *	Answers in % of number of 711 visitors
I By own initiatives and networks		
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 neighbourhood	2,9	4,0
I By own initiatives and networks		
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

Note: * Multiple answers possible.

** Physiotherapist, psychologist, social worker, health care company, hospice, home care organisation, patient organisation, other psycho-oncological centres

Once patients did find their way to a CBPSC, 28% visit the CBPSC once a week or more frequently (44%), like several times a month. A visit takes about 2 hours-3 hours. Many visitors are only tempted to stop visiting when circumstances that require e.g. their health and invasive treatments, preventing to reduce their HqoL.

The 25 CBPSCs in Study 2, easily to visit, cover eight representative regions, existing on the average for 8.2 years, with a mean number 49 local volunteers involved and mainly coordinated by paid staff. The background characteristics of the participants in Study1 are presented in (Table 2).

Table 2: Overview of characteristics of visitors (study I); N lower than 34 due to missing answering.

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

Most respondents were (ex) patients and women with breast cancer. Less than 5% suffered from other types of cancer. The average age was 58 years (SD = 10.6). In 58% of the cases, the diagnosis was made four years or longer ago.

In addition, the background characteristics of the participants in Study 2 show that 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 woman (81%) than man (19%) was 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 the (pre) pension and one fifth received disability benefits.

The offered support by the CBPSCs 2

The offered support 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 3) 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. From here on, mainly results from study 2 will be reported

Table 3: Participation in supportive care activities and the evaluation (Study 2). Means; scale of (0-10) and SD.

Supportive care activities	Number	Percentage (%)	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	(Ex) patients/ relatives	(Ex) patients/ relatives	(Ex) patients/ relatives	(Ex) patients/ relatives
46	7,0	7,4	2,2	(Ex) patients/ relatives
Partner meetings	41	6,2	8,1	2,0
Documentation centre	32	4,9	7,8	1,8
Playing 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 * multiple answers possible	2305	350,8*		

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 improving their HQoL. The participation in therapeutically support is presented in (Table 4).

Table 4: Participation in the therapeutic support and the evaluation; 10-point scale (study 2); mean & SD.

Therapeutic support	%	Mean	SD
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	

The main therapeutically activities are individual therapy talks, groups discussions. Creative therapy, mindfulness, body-oriented groups, and bereavement therapy (less than 10%). In the already presented tables 3 and 4, 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.

The medical condition of the visitors

Forty percent (40%) of the visitors in study 2 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.

Effects on health quality of life

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

To explore this 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 medical condition did play a role in the decrease of the HQoL. For all visitors the HQoL decreased significantly, also for visitors with a good medical 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 of Community-Based Support Centres for Cancer Patients (CBPSCs). This part of the 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].

Conclusion

The CBPSCs offer social support activities as well as forms of psychotherapies 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 number of visitors is 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 3e Study shows 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 stress the need of more fundamental effect studies on the service of CBPSCs.

Limitations

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 [1, 2]. 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 limitation is that international comparison is rather limited, because only a few comparing 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 specific forms of support, distinguishing social activities from therapy, is in practice 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.

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