

*CLINICAL STUDY*

# Impact of Visiting Community-Based Psychosocial Support Centres on the Well-Being of Cancer Patients: Exploration of Evaluation and Effects

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## ABSTRACT

**Aim:** Community-based psychosocial support centres for cancer patients and their relatives (CBPSCs) in the Netherlands offer easily accessible contacts with fellow patients and support by trained volunteers and/or professionals. We studied if the participants in the social support and/or therapy activities are satisfied with these services and if the visits do affect their well-being in terms of bodily and emotional health and their health quality of life (HQoL). **Methods:** In 25 CBPSCs, 701 visitors filled out a web-based questionnaire about their experiences with CBPSCs. Within this sample, 203 participants answered a part of the questionnaire again after 3-5 months about their personal characteristics, the type participation at the visits, their satisfaction with the offered activities, the experienced health complains, and three HQoL questions of the EORTC measure. **Results:** The study confirms the significance of CBPSCs contacts with fellow patients, resulting in satisfaction with the increased communication about their illness and talks about their problems. The results show further that after a 3-5 months the health complains did not change, but the HQoL decreased significantly for all visitors, except for more serious ill patients in comparison with less ill patients. **Discussion and conclusion:** CBPSCs play an important and highly evaluated role in psycho-oncological support. The visit for serious ill patients may function as a buffer for preventing the decrease of their HQoL. Insight in effects of such visits is still limited in other studies. Differences in the health care organization restrict the comparability with the CBPSCs in other countries. More studies are needed to show the long-term effects of CBPSCs visits.

**KEYWORDS:** Cancer, The Netherlands; Community-Based Support Centres; Effects, Health Complains; Health Quality Of Life.

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## INTRODUCTION

Cancer and its treatment cause for a lot of patients and their relatives several problems in terms of practical day life, physical, emotional, social, financial, and meaning of life problems [1]. In general, 90% of the cancer patients is confronted with one of these interruptions in their life [2, 3]. This emphasizes the importance of psychosocial care and aftercare for cancer patients and their relatives as mentioned in several reviews and handbooks on psycho-oncology [3-6]. Beside the support of involved oncologists and oncology nurses in hospitals, people with cancer <sup>(1)</sup> may receive there too support by psychologists, psychiatrists, social workers and physiotherapists [4-6]. The primary health care is broadening this guidance, including support by general practitioners (GPs) and their practice assistances <sup>(2)</sup>. Further, in a lot of countries, psycho-oncological support and therapy is offered in specialized psycho-oncological institutes, independent of hospitals [3, 5]. They offer several types of individual and

group therapy e.g. cognitive behavioral therapy, training in mindfulness, guided imagery, art therapy, and massage [4]. National and international studies show that those therapies may reduce anxiety, solve social problems, reduce feelings of fatigue, and raise the HQoL of cancer patients [7-9].

Due to waiting lists, barriers in referrals and high costs for the patients, the above-mentioned forms of supportive care are often not easily accessible for cancer patients [10, 12]. This was an important reason that patient organisations, but also in cooperation with health care professionals, took initiatives to found private patient-oriented support centres in several countries [13, 14]. Examples of these centres are the several Maggie' centres in the UK (Barcelona and Hongkong), stressing the importance of beautiful and healing architecture, sometimes close related with or in hospitals. These facilities are appreciated and minor effects are reported of acupuncture and cognitive

behavioural therapy on sleeping problems [15, 16]. In the USA the MD Anderson Cancer Centre (Houston), the Memorial Sloan Kettering Cancer Centre (New York), and their related hospitals incidentally offer support groups for cancer patients; so far, effect studies are not reported systematically [17, 18]. In Germany the psychological support is organised by the Lebenswert Institute (Life valued Institute) in Koeln and by the Krebsgesellschaft (Cancer Society) in Bayern (München) [19]. Comparable initiatives exist in Australia, Belgium, Canada, Denmark, Norway, and Israel, often organisational closely related with or in hospitals. In all these before mentioned psychosocial facilities, only marginal evaluation and effects studies are reported [13-21].

Cancer patients and health care professionals in the Netherlands did found CBPSCs: Community based psychosocial support centres for cancer patients and their relatives [13, 22]. A lot of Dutch people with cancer are often visiting one of these 80 available centers (so-called walking-in-homes). These centers offer social contacts with fellow patients/relatives as well as help from trained volunteers by giving several complementary activities and also psychological therapeutical help. Visiting CBPSCs is aiming at more communication about cancer and its treatment, more contacts with co-patients and their relatives, and talking about living with cancer and death. A few studies report the appreciation of the CBPSCs by the visitors, the meaning for the patients, but not reporting effects [13].

#### AIM OF THE STUDY

We firstly studied whether the visits to CBPSCs are appreciated by the patients, and mainly secondly if they may influence the well-being of cancer patients in terms of lowering their health complains and increasing their health-related quality of life, taking in account other factors that also may influence the well-being of the cancer patients.

#### MATERIALS AND METHODS

**Design :** In order to study the content of and experience with the CBPSC's supportive care, visitors filled out a web-based questionnaire. In a subsample of this study, participants were asked to filled out a part of the questionnaire again after 3-5 months [ 22].

**Populations and samples :** The study aimed to include 30 centres, approximately 50% out of the 60 CBPSCs available and willing to participate. The selection criteria were: (a) type of cancer, (b) patient or relative, (c) gender, (d) age (50- and 50+), (e) marital status, and (f) western/non-western origin. The coordinators of the CBPSCs were invited to participate in the study. The visitors need to consent to participate. The visitors of the CBPSCs were recruited for a web-based questionnaire, recruited from the list of visitors from eight years ago (from 2012 – 2013 on). The visitors were informed about the study by email, regular post, and through information in 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 the main study. Of these visitors only 711 could be included in the analysis due to missing data (T-1).

For the second measure after 3-5 months, all participants

were asked to answer standardized questions about several aspects of the visit; 203 were willing to do that (T-2).

**Data collection :** The questionnaire of the web-based questionnaire consisted of questions about seven topics: (a) biographical and medical characteristics, (b) reasons and needs for visiting CBPSCs, (c) activities and support that were attended, (d) appreciation and significance of the social activities and therapeutic support received, (e) well-being, including perceived health, emotional well-being, and symptoms (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Cancer30 [23], (f) psychosocial distress measured by the Dutch version of the Distress Thermometer [24], and (g) palliative care needs at questions developed by Osse et al. [25]. This are the T-1 measures, all of them once tested in former studies. Details are reported by Van der Stege et al. (24).

The invited visitors for the second measure, answered again standardized questions, about background characteristics, changes in living conditions, changes in the perceived health, HQol, experienced health complaints, perceived meaning of visiting CBPSCs, general attitude on CBPSCs, participation in CBPSC activities, and evaluation of their participation (T-2). The changes in well-being were studied by ten validated questions about health complaints, e.g. fatigue, sleeping, pain and breathing [26] and three questions of the health-related quality of life questions of the EORTC [23].

**Data analysis :** The data were analyzed with SPSS-2012 [26], using frequencies, means, standard deviations, construction of sum scores, Pearson correlations, and Anova's. The changes between T1 and T2 were tested by dependent T-and F-tests. To control for confounding factors Manova's were applied. The p-value of < 0.05 is the indication of statistical significance.

**Ethical Approval :** The respondents were informed orally as well written on the studies. Participation was voluntary and the respondents also gave their written consent prior to the measures. 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 due to the 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

All used measures showed to be valid in former studies and reliable, measured by Cronbach's alphas, all being higher than 70. [24]. The answers on the evaluation questions confirms the strong meaning of the visits to the CBPSCs, reporting an increasing attention to communication about life and death, and talks with fellow patients/relatives [22, 26].

**Response at T-2 :** From the total sample of N=711 potential respondents, 60,9% agreed to fill-out the second measure, 25,5% answered no, and 13,6% did not respond. Only about half of the positive responders factual filled out the second measure (N=210). In seven cases it was not

possible to connect the data from T-1 with T-2. So, 203 cases are available for the analysis of the effects.

**Sample characteristics :** In Table 1 we present an overview and comparison of the most important sample characteristic in both measures. Both samples are rather the same, except for age and social status. The medical

conditions at T-1 (N = 619) concerning the type of concern are: breast cancer (47.7%), intestinal cancer (14.1%), lung cancer (9.7%), lymph cancer (8.1), prostate cancer (7.1%), skin cancer (6.3%), cervical cancer (5.7%), and several other type of cancer (< 4.5%).

**Table 1: Background characteristics of the participants in Study 1 and Study 2.**

		Number	Measure 2 (N=203; %)	Measure 1 (N=711; %)
<b>Gender</b>	Female	160	78,8	80,7
	Male	43	21,2	19,3
<b>For who visiting the CBPSC?</b>	Self	158	77,8	71,8
	Family	45	22,2	28,2
<b>Age*</b>	< 49 years	32	15,8	20,4
	50 – 59 years	58	28,6	31,7
	60 – 69 years	68	33,5	33,1
	> 70 years	45	22,2	14,9
<b>Education level</b>	Low	36	18,1	17,0
	Middle	100	50,3	49,1
	High	63	31,7	34,0
<b>Social status*</b>	Working fulltime or parttime, entrepreneur	51	25,1	32,8
	Not paid work	149	73,4	67,2
<b>Status as visitor</b>	Rather long-term visitor	144	71,6	68,8
	New visitor since 2013	57	28,4	31,3
<b>Severity of illness reported by the patients</b>	Less severe (free of cancer, good chance on recovery)	106	53,5	51,9
	Severe ill (prognosis unknown, only still life-lengthening or no further treatment possible)	92	46,5	48,1

\*Statistically significant at P < 0.05.

**Comparison of samples at T-1 and T-2:** Evaluation of the influence of visiting CBPSCs in a repeated measurement design, requires comparable samples at T-1 and T-2. In case of significant differences, statistical corrections should be performed when comparing the effect measures. Statistically, is this however not necessary if the control variables are not related with the effect indicators. The results are presented in table 2.

**Table 2: Comparison of characteristics at T-1 with T-2.**

- A. *Background characteristics. We found that at T-2 that the visitors were older: M=60,7 year; SD = 10,5 vs. M=57,3-year SD=11,1; (F=13,47,df=1, P < .00).*
- B. *Social status. A second difference is that unemployed participants (no paid job) did fill in the questionnaire more frequently than participants with a paid job, like working full- or parttime, and/or entrepreneur (Chi-square= 6,69, df=1, p < .00).*
- C. *Perceived meaning of visiting CBPSCs; a sum score of 10 items on a 4-point scale. Patients filling the questionnaire for the second time are again rather positive about the meaning of visits but less than at T-1. Respective means 3,1 (SD 0,6) and 2,9 (SD 0,6); t = 4.47, 159 df; 159; (p.< .01). The decreased meaning does only apply for cancer patients and not their relatives.*

It may be concluded that in the statistical analysis on the effects, it is necessary to control for age, social status, and the perceived meaning of visiting CBPSCs.

**Conditions at T-1 and/or T-2 :** A second necessary control for analysing the effects of the visits to the CBPSCs are conditions at T-1 or T-2 which may influence the changes in well-being. An overview of those factor is presented in Table 3.

**Table 3: Condition at T-1 or T-2 which may influence the measured effects.**

- A. *Patients vs. relatives with or without cancer. Visitors who are cancer patients did fill in more frequently the questionnaire than relatives (Chi-square = 5,17, df=1, p = 0,0).*
- B. *Co-morbidities. Answers: no 60%; yes 40% (mainly cardiology complaints and diabetes).*
- C. *Medical condition. 1. Unknown (10.6%), 2. Recovered, free of cancer (31,6%), 3. Good chance on cure/recover (17,7), 4. Palliative treatment (3,7%), 5. No more treatment possible. Answers 2 and 3 are considered as indicators of a good medical condition; 4 and 5 as indications of a bad medical condition.*
- D. *Monthly visits to CBPSC at T-1: 17%; T-2: 30%,.*
- E. *Earlier or recent visitors of a CBPSC. Earlier visitors concern N= 139 respondents; recent visitors are N=48.*
- F. *Perceived health condition. Answers at the second measurement: health improved 24,4%; not changed 53,9%; worsen 21,8%.*
- G. *Experienced stressful life events. This concerns life events after T-1, e.g. hospital admission, got another disease, passing away of a relative, divorced, started living together; a new intimate relationship; born of (grand)child; unemployment, new job, and moved. No stressful events:17%; one event: 64%; two 14%; three events 4%; four or more events 0,5%.*

It can be expected that these seven conditions mentioned in Table 2 need to be introduced as control variables in the statistical analysis of the effects.

**Evaluation of the visits and received support :** The results show that the evaluation of almost all 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. Changes in well-being

**Health complaints :** The health complains did not change at T-2 in comparison with T-1, as measured by the health complain total score. The health complaint is a sum score of 10 items on a 4-point scale; e.g. tired, stressed, angry, difficult to sleep, pain, short of breath. At T-1: M=2.0 (SD 0,6); at T-2: M=2.0; SD 2.0; paired T-test  $t = 0.02$  ; df 167;  $p = .99$ .

**Health related quality of life :** The total HQoL measure based on the EORTC items decreased significantly at T-2 ( $p < .05$ ) from 5.3 to 5.1 on a seven-point scale (see Table 4), although the p-value of the single HQoL question (see c) is marginal significant ( $p = .06$ ). (table4)

**Table 4:** General health quality of life during the last week; measures at T-1 and T-2.

	T-1			T-2			T-Tests		
	N	M	SD	N	M	SD	t	df	p
a. General body condition	189	5,2	2,1	189	4,9	1,2	2,80	188	,00
b. General health	188	5,3	1,1	188	5,0	1,1	2,07	187	,04
c. General quality of life	189	5,3	1,1	189	5,2	1,2	1,89	188	,06
Total score QoL of life (a+b+c)	189	5,3	1,1	189	5,1	1,1	2,55	188	,01

**Correction for confounding factors :** Following the conclusions presented in table 1 and 2, for the study of the correction of the ten confounding factors, was applied by using multivariate analysis (MANOVA) with the confounding factors as covariates: social and medical characteristics, health condition, co-morbidities, being an (ex)patient or relative with/without cancer, health changes, experienced stressful life events, number of visits to CBPSCs, and perceived meaning of the visits. The results indicate that only the severity of the medical condition plays a role in the decrease of the HQoL. For visitors with a less severe medical condition at T-1, the HQoL decreased significantly, while for more serious ill visitors the quality of life did not change.

**Determinants of changes in health quality of life :** To attain a final overview of which factors are related with the changes of the HQoL, a difference score was accounted between the HQoL at T-1 and at T-2. as the indicator of the change. A positive score indicates a change towards a higher HQoL score at T-2 than at T-1. A negative score expresses a lower HQoL score at T-2. The correlations between this difference score and all factors in the study showed that the only significant correlation is a negative association with the severity of the medical condition of the patients ( $r = -.20$ ), indicating that if patients feel healed, free of cancer and having a good chance on recovery they have a higher HQoL. A regression analysis (method Enter) with all variables from the study and the difference score as dependent variable showed that the variables indicating a worse medical condition and the severity of the condition, are the main determinants of the HQoL difference score. The total explained variance by all studied factors is 17%. So, the severity of the medical condition does negatively influence the HQoL. See details in Van der Stege et al. (25).

## DISCUSSION

It is one of the first effect studies about the effects of informal psychosocial support on the well-being of cancer patients, like the CBPSC in the Netherlands [22]. Effects of comparable intervention are rather unknown, like the Maggie' centres in the UK and elsewhere, as well as the MD Anderson Cancer Centre and the Memorial Sloan Kettering Cancer Centre in the USA. The same holds true for the comparable initiatives in Europe, Israel and Australia [13, 21]. The comparability of the effects of the interventions at the mentioned institutes is rather limited

due to difference between the applied interventions. Also, organisational factors play a role like the relationship with or in hospitals which may influence the flow, the number and type of patients.

The reported study has several limitations. An important aspect is the design of the study. In the repeated measurements design a control group is missing. It is a study based on one sample. Further, the sample is small and the compared samples may not be representative due to non-response and incomplete data. This situation expresses the strong need of comparable international studies.

## CONCLUSION

The development of the described small, informal organizations for psychosocial support for cancer patients run by volunteers, is a profit for them. These facilities are more easily to access than the national psychosocial foundations. In general, the participants express a positive intention to fill-in the second measure after three to five months (60%). However, only about 30% of those with the intention to fill-in the second measure, did that factually.

The participants in the second measure differ on some variables of the non-respondents in this second measure. The participants in the second measure are a bit older, have less frequently a paid job and are frequently cancer patients instead of relatives. In the second measure the meaning of visiting a CBPSC is a bit lower. This are import factors to control for the effect-indicators.

In the second measure the health complains did not change compared to the measure at T-1. However, the well-being decreased a bit (0.2 point on a seven-point scale), but is statically significant. The regression analysis shows that the most important determinant of the HQoL is the severity of the medical condition, which explains too the changes in the HQoL. The patients who are living with a more severe prognosis report at both measures the same HQoL. The most important determinant of the regression of the HQoL is the severity of the medical condition. The results seem to indicate that for more severe ill visitors their quality of life is maintained by visiting the homes. This could mean that visiting CBPSCs will lead to increasing their communication about their situation, functioning as a buffer against decreasing quality of life.



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