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## Characteristics of patients in routine psycho-oncological care, and changes in outcome variables during and after their treatment

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**Objective:** The primary aim of this study was to determine the characteristics of clients and interventions in routine psycho-oncological care. The secondary aim was to determine the course of symptomatology during and after the psychological interventions.

**Design:** During a period of nine months, all clients who sought help in one of the seven psycho-oncological care institutes in the Netherlands were approached to participate in the present study ( $N = 483$ ). Information was gathered with respect to demographic and medical characteristics, and type and duration of the interventions. In addition, depression, anxiety, well-being, quality of life, fatigue and daily function were determined before interventions and three and nine months later.

**Results and conclusions:** Compared to the Dutch cancer population, patients in psycho-oncological care were more often young and female. Compared to the general Dutch population, they were highly educated and were more likely to have a partner. Clinical levels of depression, anxiety and/or fatigue were found among 83% of the patients. After three months, only 23% had completed their intervention; this figure was 62% after nine months. Symptoms decreased significantly for all outcome variables. An importance difference with randomised controlled trials is the low session frequency and the long intervention time of patients in clinical care.

**Keywords:** psychological interventions; routine care; psycho-oncology; anxiety; fatigue

### Introduction

#### *Intervention research and clinical practice*

Psychological interventions to help patients with cancer adjust to the disease are a major focus in psycho-oncological research. Their efficacy has been evaluated in hundreds of RCTs, and the various outcomes of these studies have been summarised in dozens of reviews and meta-analyses (Hart et al., 2012; Heron-Speirs, Harvey, & Baken, 2012; Linden & Girgis, 2012; Walker et al., 2014). The internal validity of these studies is often high, yet this focus on optimising internal validity often comes at the

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expense of external validity, because of the often strict inclusion criteria, such as selection of patients within a certain age range, with a specific type of cancer and/or in a specific phase of the disease and the exclusion of people with comorbid somatic diseases and because of interventions that have a predetermined number of sessions and a fixed protocol. In clinical practice, patients with comorbidity and those in all phases of the disease are included, and are offered psycho-oncological care individually tailored with respect to duration and type. Scientific attention has been modest for the regular provision of psycho-oncological care.

### ***Demographic characteristics of clients in specialised psycho-oncological care***

The present study evaluates this form of regular psycho-oncological care by surveying the characteristics of people searching for professional psycho-oncological care with respect to demographic variables, distress levels and medical characteristics. If possible, these characteristics are compared to the general cancer population. Since psycho-oncological health care institutions not only offer help to patients themselves but also to their significant others, this paper will focus on both patients and partners. Partners and other caregivers appear to suffer from distress as much as the patient with cancer (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008), and recent meta-analyses have shown that psychological interventions have a modest though significant effect on reducing caregiver burden (Badr & Krebs, 2013; Northouse, Katapodi, Song, Zhang, & Mood, 2010).

On the basis of earlier studies on routine utilisation of psycho-oncological support services, one would expect that patients with cancer who seek specialised psycho-oncological care are more often young (Ellis et al., 2009; Hewitt & Rowland, 2002; Plass & Koch, 2001), female (Curry, Cossich, Matthews, Beresford, & McLachlan, 2002; McDowell, Occhipinti, Ferguson, & Chambers, 2011; Nekolaichuk, Cumming, Turner, Yushchyshyn, & Sela, 2011), highly educated (Eakin & Strycker, 2001), lacking in social support (Ellis et al., 2009), without a partner (Ellis et al., 2009; Hewitt & Rowland, 2002), show higher distress scores (Curry et al., 2002; Ellis et al., 2009; Plass & Koch, 2001) and suffer more often from comorbid diseases (Hewitt & Rowland, 2002). However, some studies could not demonstrate any effect due to age (Curry et al., 2002; Eakin & Strycker, 2001; McDowell et al., 2011; Nekolaichuk et al., 2011), gender (Eakin & Strycker, 2001; Hewitt & Rowland, 2002; Plass & Koch, 2001), educational level (Ellis et al., 2009; Hewitt & Rowland, 2002; Plass & Koch, 2001) or marital status (Nekolaichuk et al., 2011; Plass & Koch, 2001).

These differences may indicate a certain vulnerability on the part of some subgroups. As such, the consistent finding of an overrepresentation of younger and female participants in intervention studies might indicate not just that these persons are more vulnerable and thus correctly overrepresented, but also that there exist under-served groups and that there is a need to invest more effort in reaching out to specific groups (such as older persons) or to develop specific programmes for these groups.

### ***Medical characteristics, distress levels and need for psychosocial support***

There are some reasons to expect that most patients seek professional support after the end of treatment since the period of diagnosis and treatment may consume most of the

patient's energy. Moreover, one may suppose that patients suffering from a bad or uncertain prognosis, or a recurrence or metastases will experience a higher level of distress than patients without such characteristics, and will more often be inclined to seek professional psycho-oncological care. However, these assumptions have not been unequivocally confirmed. There is some evidence that patients diagnosed with lung, brain and pancreas cancer report higher distress compared to those with other types (Stommel, Kurtz, Kurtz, Given, & Given, 2004), though not always (Schroevers, Ranchor, & Sanderman, 2003, 2006). In addition, some studies have found higher distress levels after a recurrence (Avis, Crawford, & Manuel, 2005; Lu et al., 2009; Qiu et al., 2011), though other studies have not (Carver et al., 2005; Kornblith et al., 2001; Schroevers et al., 2006); some studies found higher distress levels among patients with more advanced stages (Mehnert & Koch, 2008), whereas several studies did not find any difference vis-à-vis stage of the disease (Arndt, Stegmaier, Ziegler, & Brenner, 2006; Cui et al., 2004; Deimling, Bowman, Sterns, Wagner, & Kahana, 2006). So, it is not quite clear what to expect with respect to type, stage and phase of the disease in terms of the reporting of distress and even less so in terms of a need for psychological care.

### *The present study*

The primary aim of the present study is to investigate the characteristics of patients with cancer and of the partners of cancer patients who receive specialised psycho-oncological care with respect to demographic variables, distress levels and medical characteristics, and to describe the type of psychological care they receive and their satisfaction with this care. The secondary aim is to describe the course of symptoms during and after the psychological interventions. This course will reflect a combination of the intervention effect and the effect of the passing of time.

There are several differences between the present study and previous ones. Most of the earlier studies asked patients with cancer whether they had ever made use of psychosocial support services and then determined the demographic and medical characteristics of these patients (Curry et al., 2002; Eakin & Strycker, 2001; Ellis et al., 2009; Hewitt & Rowland, 2002; McDowell et al., 2011; Plass & Koch, 2001), whereas the present study and the study by Nekolaichuk and colleagues (Nekolaichuk et al., 2011) start with patients who are actually receiving psychosocial treatment during the study period. This has the advantage of the absence of any memory bias, and allows additional important information to be provided – though it is not provided by Nekolaichuk and colleagues – about the types of interventions that were followed, intervention duration and number of sessions, satisfaction with the interventions and course of symptoms during the period of psychological treatment. Our study, and the study by Ellis and colleagues (Ellis et al., 2009), has focused on care provided by a psycho-oncological therapist, whereas the 'psychosocial support' in the other studies also included other categories, such as self-help groups (Plass & Koch, 2001), a psychiatric nurse (Hewitt & Rowland, 2002), financial help (Curry et al., 2002) and Internet-based cancer information (Eakin & Strycker, 2001).

## Method

### *Sample and procedure*

All patients who have cancer or have had cancer and who have sought help in mental health care institutes specialised in psycho-oncology in the Netherlands were eligible for this study. These institutions also offer support to relatives of patients with cancer: these include their partners, children parents or other family members, who may come to these institutions together with the patient with cancer or on their own. Of these different types of relatives, only partners were asked to participate in this study because the other categories of relatives (children, parents and/or friends) were expected to be too small for useful analysis. The partners were not necessarily the partners of patients who were included in the present study. They sought support for themselves, sometimes independently from the patient with cancer.

All seven mental health care institutes specialising in psycho-oncology in the Netherlands participated in the study. The inclusion criteria were:

- (1) patients with cancer or partners of patients with cancer, who were seeking help at these institutions;
- (2) age older than 18;
- (3) Dutch speaking.

The exclusion criterion was too much missing data (that is several pages of the questionnaire were not completed). This study was organised and conducted by one of the seven institutions: the Helen Dowling Institute, Center for Psycho-oncology in Bilthoven, the Netherlands.

When patients or partners sought help at these institutions, an information sheet on the study and an informed consent form were sent to their homes. Patients or partners who returned an informed consent form then received the first questionnaire by mail, which they completed before intake (T1), at home with paper and pencil or via the Internet. Successive questionnaires were sent three months (T2) and nine months (T3) later.

It was decided to have the participants complete the questionnaires at fixed time points, instead of at the end of the intervention and at follow-up. The reason for this was the great variation in intervention duration. Moreover, interventions often last longer than nine months, especially in palliative patients who are often supported until they die. This important population would have been missed, had we chosen to measure only at the end of treatment instead of at fixed time points.

The inclusion period lasted nine months. Though the researchers tried to maximise participation by regular visits to and calls to the institutions, a few clients may have been missed through administrative errors. The administrative staff was not asked to take note of any missing patients, so a limitation of the study is that it is impossible to know if there were any patients or caregivers who were missed and could have participated in the study. In total, 611 patients and 166 partners were informed; 384 patients and 99 partners out of this total were included in the study before the start of psychological interventions (see Figure 1). The demographic and medical characteristics that are presented concern these patients and partners. The course of outcome variables has been determined for the 215 patients and 37 partners who had complete data at T1, T2 and T3.

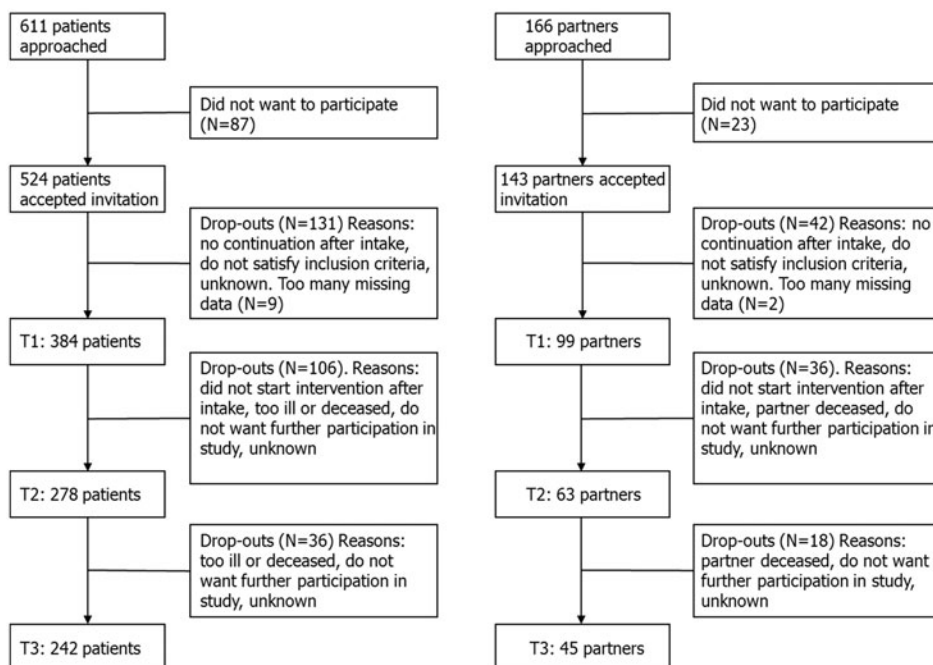


Figure 1. Patient flow chart.

Of the people who refused to participate (87 patients and 23 partners), only information about their age and gender was available. Refusers and participants did not differ with respect to age or gender. Compared to patients with complete data, patients who dropped out after T1 were more often men, more often had metastases and more often perceived their diagnosis as unfavourable. They also scored higher on tension and fatigue, and lower on well-being.

### Questionnaires

Depression, anxiety, well-being, quality of life, fatigue and daily function were measured at all three time points.

Depression in the last week was measured with the 16-item version of Center for Epidemiologic Studies Depression Scale (CES-D). The psychometric quality of the Dutch version of this scale has been proven (Schroevens, Sanderman, Van Sonderen, & Ranchor, 2000). The response categories range from 0 (<1 day) to 3 (5–7 days). A cut-off score of  $\geq 10$  for serious depression was found in a study among patients with cancer (Schroevens et al., 2000). Cronbach's alpha in this study is .88–.91 (separately determined for the three measurement points).

Current anxiety was determined using the short version of the State-Trait Anxiety Inventory, which consists of six items that can be answered in four response categories, ranging from 1 (not at all) to 4 (very much). The psychometric quality of the Dutch version of this scale has been proven (Marteau & Bekker, 1992; Van der Bij, De Weerd,

Cikot, Steegers, & Braspenning, 2003). The cut-off score for serious anxiety is >13, which has been used for cancer patients, though not developed and tested among cancer patients (Henselmans, Coyne, Sanderman, De Vries, & Ranchor, 2009). Cronbach's alpha is .86–.87 in this study.

Well-being in the past four weeks was measured with the Joy-in-Life subscale from the Health and Disease Inventory (HDI), which includes 12 items (De Bruin & Van Dijk, 1996). The HDI is a Dutch questionnaire, designed to assess the adaptation to cancer. The psychometric quality of the Dutch version of this scale has been proven. The response categories range from 1 ('never') to 6 ('always'). Cronbach's alpha is .66–.92 in this study.

Quality of life was assessed with one question, which is part of the reliable and valid European Organization for Research and Treatment of Cancer QoL questionnaire (Aaronson, Ahmedzai, Bergman, Bullinger, et al., 1993): 'How would you on the whole judge your quality of life in the past four weeks?' – to be answered on a scale ranging from 1 ('very bad') to 10 ('very good').

The eight-item subscale of subjective fatigue of the Checklist Individual Strength was used to measure fatigue in the past two weeks (Vercoulen et al., 1994). Items have a response scale, ranging from 1 ('Yes, that is true') to 7 ('No, that is not true'). A score of  $\geq 35$  indicates serious fatigue symptoms based on previous research with chronic fatigue syndrome patients (Vercoulen et al., 1994). This scale and its cut-off score have been used in several studies on cancer patients (Gielissen, Verhagen, Witjes, & Bleijenberg, 2006; Servaes, Prins, Verhagen, & Bleijenberg, 2002). Cronbach's alpha is .91–.92 in this study.

Daily function in the past four weeks was determined with two subscales of the Groningen Social Behavior Questionnaire (Van der Lubbe, 1995): limitations in domestic activities (4 items) and social role function (8 items). This questionnaire has been used before in a study among cancer patients (Henselmans et al., 2010). Items have a response scale, ranging from 1 ('Totally disagree') to 7 ('Totally agree'). Cronbach's alpha was .84–.89 and .91–.93, respectively.

Satisfaction with the interventions was measured with the following, self-formulated question: 'How satisfied were you with the intervention?' (scale from 1 to 10).

### **Statistical analysis**

Several skewed variables could not be transformed to a normal distribution. Therefore, non-parametric statistical tests have been used on the untransformed variables, except for the calculation of effect sizes. Actually, conclusions were similar if parametric statistical tests were applied. For the calculation of effect sizes, the outcome variables of depression and quality of life were square root or log transformed.

For some variables, a comparison could be made between the findings of this study and the Dutch cancer population (five-year prevalence data of the Dutch cancer population in 2012; site of the Dutch Comprehensive Cancer Centre): age, gender and type of cancer. Differences were tested with  $\chi^2$  tests. No comparative information for educational level of patients with cancer was available; a comparison was made with the general Dutch population (2012 data from the Dutch Central Statistical Office).

Differences between patients and partners in baseline symptoms were tested using Mann–Whitney *U* tests. The course of symptoms over the three measurement points

was analysed using Friedman ANOVA. The ANOVA and the following analyses were performed on restricted groups with complete data at all three measurement points ( $N = 215$  for patients and  $N = 37$  for partners). Effect sizes for the changes from T1 to T2 and for T1 to T3, respectively, were calculated, using the formula  $(\text{mean T2 or T3} - \text{mean T1}) / (\text{pooled } [\text{SD T2 or T3 and SD T1}])$ . All analyses were performed with SPSS19.

## Results

### *Demographic characteristics*

Patients with cancer, who seek professional psycho-oncological care, are young (mean age 51 years) in comparison to the population of Dutch patients with cancer: 25% of the clients with cancer and 28% of the partner clients were in the age category below 45 years, which was 8% for the Dutch cancer population. The difference was statistically significant ( $\chi^2$  test;  $p \leq .001$ ); see Table 1. About three-quarters of the patients were female, which is well above the 51% of the Dutch cancer population. Most of them were also highly educated: half of the patients had received a higher vocational or university education, whereas this characterises only about a quarter of the general Dutch population, aged 15–65 years (29%). Eighty per cent of the patients with cancer in this study had a partner (vs. 41% of the general Dutch population). About 60% had a paid job, and 80% of those who had a job had to take sick leave during one or several days in the previous month. The demographic figures for the partners were comparable to those of the patients except for sick leave, which was lower for the partners.

### *Distress levels*

The percentages of patients suffering from clinical levels of depression, anxiety or fatigue before the intervention (T1) are presented in Table 3. Clinical levels of depression, anxiety and/or fatigue were found among 83% of the patients with cancer. It is, of course, to be expected that patients who seek professional support score high on distress measurements. It is perhaps more noteworthy that 17% of the patients did not report any clinical level of depression, anxiety or fatigue.

Partners had as many psychological symptoms as patients with cancer. Clinical levels of depression, anxiety and/or fatigue were reported by 85%. Level of depression, fatigue, well-being, quality of life and domestic activities were similar for both groups, but partners reported significantly more anxiety and more problems in social role function (in the group with complete T1 data; Mann–Whitney  $U$  test;  $z = 2.46$ ,  $p = .01$  and  $z = 2.11$ ,  $p = .03$ , respectively).

### *Medical characteristics*

The mean time since diagnosis was three years, but the range was large (0 to 435 months; median 14 months). Few of the patients (10%) had applied for support from psycho-oncological therapists in the first three months after diagnosis, and about half of the patients (47%) were in the first post-diagnosis year. Half of the patients with cancer in this study were still undergoing medical treatment.



Table 1. Demographic and medical characteristics of participants at baseline.

		Cancer patients ( <i>N</i> = 384)	Partners ( <i>N</i> = 99) <sup>a</sup>	Cancer patients in the Netherlands <sup>b</sup>
Age in years	Mean (SD)	51 (11)	50 (12)	
	Range	25–79	23–76	
	Missing	0%	2%	
	<45 years	25%***	28%***	8%
	≥60 years	22%	23%	71%
Gender	Female	76%***	68%***	51%
	Missing	0%	0%	
Educational level	Low	11%	8%	
	Middle	39%	42%	
	High	49%	50%	
	Missing	4%	1%	
Relationship	Yes	80%	100%	
	Missing	3%	0%	
Children at home	Yes	39%	43%	
	Missing	3%	1%	
Paid job	Yes	59%	68%	
	Missing	3%	1%	
Absenteeism due to illness in past month	Yes	80%	51%	
	Missing	2%	0%	
Time since diagnosis in months (determined at T1)	Mean (SD)	37 (63)	26 (50)	
	Median	14	12	
	Range	0–435	0–354	
	Missing	29%	37%	
Cancer type	Breast cancer	45%***	14%	20%
	Digestive system cancer	10%***	13%	18%
	Lung cancer	5%	16%***	6%
	Hematologic cancer	11%	13%	9%
	Head and neck cancer	6%**	8%**	3%
	Gynaecological cancer	7%	4%	5%
	Other types	16%***	32%	39%
	Total	100%	100%	100%
	Several types of cancer	10%	15%	
	Missing	1%	0%	
	Medical treatment	Surgery	78%	65%
Chemotherapy		64%	67%	
Radiation		49%	60%	
Hormone treatment		25%	14%	
Immunotherapy		5%	2%	
Bone marrow transplant		2%	0%	
Other type of treatment		16%	20%	
Missing		6%	7%	
Still under medical treatment	Yes	52%	66%	
	Missing	10%	14%	

(Continued)

Table 1. (Continued).

		Cancer patients ( <i>N</i> = 384)	Partners ( <i>N</i> = 99) <sup>a</sup>	Cancer patients in the Netherlands <sup>b</sup>
Recurrence	Yes	15%	23%	
	Missing	0%	0%	
Metastases	Yes	37%	57%	
	Missing	1%	1%	
Perceived prognosis	Favourable	47%	24%	
	Uncertain or do not know	36%	33%	
	Unfavourable	17%	42%	
Comorbid diseases	Missing	0%	0%	
	Yes	45%		
	Missing	3%		
Psycho-oncological intervention at T2	Completed	20%	12%	
	Missing	29%	39%	

<sup>a</sup>The medical characteristics mentioned in the 'partners' column concern the diseased partner.

<sup>b</sup>Five-year prevalence data of the Dutch cancer population in 2012 (site Dutch Comprehensive Cancer Centre).

\*\*Difference with respect to the Dutch cancer population;  $\chi^2$  test;  $p \leq .01$ .

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Most patients suffered from breast cancer (45%), which coincides with the high participation rate of women and the high incidence of breast cancer. Though 45% had a recurrence and/or metastases, only 17% of the patients considered their prognosis as unfavourable. Many patients also suffered from one or more other chronic diseases (44%), most often COPD, intestinal disorders, spinal disorders, joint problems, migraine (6–9%) or 'other disease' (20%).

The picture is somewhat different for the partners. Lung cancer was most often the disease that had struck their loved ones (16%): three times more often than among patients (5%), and 2.5 times the rate among Dutch patients with cancer in general. Of their diseased loved ones, 66% had a recurrence and/or metastases, and prognosis was considered unfavourable by 42%. Thus, most of the partners who sought psychosocial support had a husband or wife who was in bad medical condition.

### ***Psychological interventions***

The institutions for psycho-oncological cancer care offer various forms of psycho-oncological interventions. Clients (patients and partners) most often received 'therapy for individual clients' (84%), including individual therapy (75%) and partner or family therapy (23%). A quarter of the clients participated in group therapy (25%), sometimes in combination with individual therapy. Group interventions often focused on learning to cope with the disease and its consequences or mindfulness-based cognitive therapy (MBCT). Mindfulness and mindfulness meditation both focus on becoming aware of all incoming thoughts and feelings and accepting them, but not attaching to them or

Table 2. Types of psychological interventions and number of sessions followed during the first three months, and satisfaction with these interventions at T2 and T3 (and number of clients who gave a score for a specific intervention).

	Type of intervention T1–T2 % <sup>a</sup>	Number of sessions T1–T2 <i>M</i> (SD)	Satisfaction with interventions			
			T2		T3	
			<i>M</i> (SD)	<i>N</i>	<i>M</i> (SD)	<i>N</i>
Interventions for individual clients	84	4.6 (2.1)				
Individual therapy	75		7.9 (1.8)	255	8.3 (1.8)	166
Partner and/or family therapy	23		7.8 (2.0)	77	8.1 (1.9)	45
Group interventions	25	6.8 (5.5)				
Mindfulness/distress management	13		7.4 (1.8)	45	7.6 (2.2)	42
Coping with the disease	15		7.3 (1.5)	50	7.5 (2.0)	36
Physical activity regulation	4		6.6 (2.2)	14	7.1 (2.5)	12
Physical and psychological rehabilitation	5		7.8 (.9)	15	8.0 (1.0)	5
Other forms	21	3.7 (2.8)				
Haptonomy	14		8.0 (1.6)	48	8.1 (2.1)	42
Creative therapy	2		8.4 (2.1)	5	8.7 (.8)	10
Various other forms	3		8.4 (2.2)	11	8.9 (1.1)	9

<sup>a</sup>The sum of percentages is larger than 100% because clients may have followed various types of psychological interventions.

reacting to them. The goal of MBCT is to interrupt automatic processes that may lead to negative cognitions, and teach the participants to focus less on reacting to incoming stimuli, and instead accepting and observing them without judgement. Less often, group interventions focused on regulating physical activities or were a combination of psychological and physical rehabilitation. Some clients (21%) followed ‘other forms’, which included mainly haptonomy. Haptonomy teaches a person what the body is saying about one’s feelings.

At three months, interventions had been completed by only 23% of the clients, whereas this number had increased to 62% after nine months. After three months, the number of sessions (as remembered by the clients) was five for individual therapy and seven for group therapy. Such information was not available for the interval T2–T3 (See Table 2).

### Satisfaction

Most patients highly valued the intervention(s) they had received. The individual contacts with a psychotherapist, partner and/or family therapy and haptonomy were the most highly valued, with mean report marks of about 8 (on a scale from 0 to 10) (see Table 2). The appreciation of group interventions was somewhat lower with report marks of about 7.5. Physical activities’ regulation received the lowest report marks

(6.6). Clients who were still following a particular type of intervention between T2 and T3 were similarly satisfied at T3, compared to T2.

### **Course of symptoms**

Depression, anxiety, fatigue and daily function limitations decreased over the three time points, while well-being and quality of life increased. See Table 3. The effect sizes for the changes from T1 to T3 varied from .55 to .59 for depression, anxiety and quality of life, and were somewhat lower for well-being (.40) and fatigue (.35). The changes in partners were comparable to these of the patients, but for the partners, the change in fatigue was not significant.

At T3, the number of patients with clinical levels of depression, anxiety or fatigue had decreased compared to baseline levels (see Table 3). However, the number of patients with clinical levels of depression, anxiety and/or fatigue was still rather high nine months after the start of therapy, decreasing from 87% at T1 to 67% at T3 (among patients with both T1 and T3 data). Nearly the same data were found for partners: 89% at T1 and 69% at T3. The decrease in number of patients with serious problems was significant for all three outcome variables (Cochran's  $Q$  test: depression  $Q = 38.1$ ,  $p = .000$ ; anxiety  $Q = 31.0$ ,  $p = .000$ ; fatigue  $Q = 13.0$ ,  $p = .001$ ), whereas it was never significant in the much smaller group of partners.

### **Discussion**

The group of patients who seek professional support appeared to be relatively young, more often female, highly educated and often had a partner and a paid job. They also often suffered from clinical levels of depression, anxiety and/or fatigue (83%). These findings will not come as a surprise, as most of these characteristics were generally seen among clients of psycho-oncological therapists (see Introduction section). One could consider this outcome as inevitable, but could also consider it as an impetus for trying to be more appealing for elderly and lower educated people, and males.

Though the number of clients with clinical levels of depression, anxiety and/or fatigue was high, there is also a minority of clients without these symptoms. Some other studies also reported a discrepancy between level of psychological symptomatology and the wish for supportive therapy in a subgroup of patients (Garssen & Kok, 2008). Sollner and colleagues, for instance, reported that of the cancer patients who suffered from moderate to severe anxiety or depression, only 58% accepted counselling (Sollner, Maislinger, Konig, DeVries, & Lukas, 2004). On the other hand, of those patients who fell below the cut-off criterion, 45% actually received counselling. The latter group and the minority group in the present study probably sought professional help for reasons other than a high level of psychopathology. This assumption is supported by an earlier study in which we asked therapists which were the predominant psychological problems they had dealt with during their five most recently completed interventions (Garssen & Van der Lee, 2011). These were therapists employed at the same institutions as were approached in the present study. In about one half of the cancer patients, anxiety and/or depression were not the focus during their therapy. Other predominant problems often encountered by therapists during therapy were relational problems and saying farewell to life.

Table 3. Course of psychological symptoms over time.

	T1		T2		T3		Friedman test			
	M	SD	% <sup>a</sup>	M	SD	% <sup>a</sup>	M	SD	χ <sup>2</sup>	p <sup>c</sup>
Depression	15.0	7.9	69	11.8	7.7	54	10.3	7.9	53.0	.000
Anxiety	14.3	3.6	57	12.7	3.4	42	12.4	3.5	55.1	.000
Well-being	44.6	9.9		47.5	9.6		48.7	10.4	49.5	.000
Quality of life	6.0	1.6		6.8	1.3		6.9	1.7	98.9	.000
Fatigue	35.9	12.5	55	33.7	12.4	49	31.5	12.6	25.7	.000
<i>Daily function<sup>d</sup></i>										
Domestic activities	10.2	3.7					8.9	3.9	18.0	.000
Role function	20.2	7.5					17.4	7.5	17.1	.000
							Patients (N = 215)			
							0.42		0.64	
							0.46		0.54	
							0.30		0.40	
							0.55		0.55	
							0.18		0.35	
							Partners (N = 37)			
Depression	13.3	8.4	62	9.1	6.3	49	8.5	6.1	15.5	.000
Anxiety	14.3	3.1	54	12.8	2.4	37	12.3	3.1	8.9	.011
Well-being	45.9	10.0		49.7	8.6		51.6	9.5	16.6	.000
Quality of life	6.1	1.6		6.8	1.1		7.1	1.4	13.8	.001
Fatigue	32.0	9.2	44	30.2	10.8	39	29.4	10.6	1.8	.414
<i>Daily function</i>										
Role function	20.8	7.3					17.3	6.7	7.4	.009

<sup>a</sup>Percentage of clients who scored above the cut-off criterion.

<sup>b</sup>Effect size for the change from T1 to T2, or from T1 to T3, respectively.

<sup>c</sup>Exact probability.

<sup>d</sup>Daily function was not measured at T2, and domestic activities were not measured among partners.

Quite unlike the findings reported in the literature was the relatively high number of patients having a partner in our study. We do not know the explanation for this discrepancy. However, an acceptable explanation can be offered for both findings. On the one hand, not having a partner could mean lack of support, help and comfort which would constitute a reason for trying to find this support in professional care providers. This reasoning is supported by the finding that the absence of a partner appeared to contribute to distress in some studies (Ben-Ezra et al., 2011; Chae & Seo, 2010; Gotay, Isaacs, & Pagano, 2004). On the other hand, having a partner may imply the presence of someone who provides encouragement to seek professional help.

Nearly half of the patients also suffered from other chronic diseases. Comorbidity is a general and sometimes neglected problem in cancer. Elliott and colleagues found in a population study that 43% of patients with various types of cancer suffered from other chronic diseases (Elliott et al., 2011), and another study showed that comorbidity was the strongest predictor for anxiety and depression among several potential medical and demographic factors (Rosenfeld, Roth, Gandhi, & Penson, 2004). So, although comorbidity was often found among the cancer patients in this study, their number was not clearly different from what is generally found in a cancer population. Comorbidity is still an important aspect to take into account as a therapist because of its overwhelmingly negative influence on well-being.

Time since diagnosis showed a large variation, from directly after diagnosis to tens of years after diagnosis. The mean time was about three years and the median value was about one year. About half of the clients were in their first post-diagnosis year, but only a small minority (10%) sought professional support in the first three months after diagnosis. About half of the patients were still undergoing medical treatment, which implies that the suggestion that patients with cancer most often seek professional help after the end of treatment ('falling into a limbo') does not apply for many patients in our study.

In line with the overrepresentation of women, a large proportion of patients had breast cancer. Nearly half of the patients (45%) had a recurrence or metastases, which may be considered an unfavourable phase of the disease, but only 17% of them considered their prognosis to be unfavourable.

The demographic characteristics of the partners were comparable to those of the patients, but the medical condition of the diseased loved ones of these partners seemed more serious. Level of psychological symptoms of partners was comparable to those of patients. The level of anxiety and social role dysfunction, however, was actually higher among partners. One might assume that the threshold for seeking professional support is higher for partners than for patients. Another interpretation for these differences could be that the patients are more inclined than their partners to deny the seriousness of their disease (Vos & De Haes, 2007; Vos, Putter, Van Houwelingen, & De Haes, 2008) and/or to repress negative emotions (Kreitler, Chaitchik, & Kreitler, 1993).

The intervention time was remarkably long for many patients. After three months, the mean number of sessions followed was only four to seven, and only 23% of the patients had completed their intervention. This number had increased to 62% after nine months. One reason for the long intervention time is that several of the patients being treated in psycho-oncological centres were in the last phase of their disease and were being therapeutically followed until their death.

With respect to change of symptoms during and after psychological treatment, decreases in depression, anxiety, fatigue and function limitations were found, and increases in well-being and quality of life, which were significant, except for the change in fatigue in partners. The effect sizes were substantial, and the number of patients with severe symptoms dropped about one-third for depression and anxiety and one-fourth for fatigue. However, because a no-intervention control group was lacking, one cannot be certain whether these changes should be attributed to therapeutic activities or merely reflect the passage of time. The implementation of such a control group is impossible in a naturalistic setting, where patients with cancer come to an institute seeking psychological support.

### ***Limitations***

The present study has several limitations. First, our findings may be only indicative of the situation in the Netherlands. However, several studies described in the Introduction have also determined the demographic characteristics of patients who seek psycho-oncological care. Some of these studies found no difference between those who had participated in such care and those who had not. However, if a difference was demonstrated, it was in the same direction as found in the present study. The only exception was the percentage of partners, which was remarkably high in our study.

A second limitation concerned the illness-related variables, including cancer site, time since diagnosis and treatments, which were collected by self-report, rather than chart review. A third limitation is the lack of a control group, which is inevitable in a study on clinical practice.

### ***Conclusions and suggestions for future studies***

The main conclusions from this study are: (1) Clients in regular psycho-oncological care have characteristics similar to those of participants in intervention studies; clients are often female, young and highly educated. (2) The number of clients with clinical levels of depression, anxiety and/or fatigue is high in regular care, which is also in agreement with earlier naturalistic and experimental intervention studies; there is also a minority of clients, however, without these symptoms. (3) The level of psychological problems of partners of patients with cancer who seek professional help for themselves is similar to that of patients with cancer, and they seem to profit similarly from the interventions. (4) Many patients with cancer are in a serious phase of their disease (recurrence and/or metastases) when they seek professional help, and the same applies to the diseased beloveds of partners. (5) The structure of the interventions in regular care differs greatly from the set-up in research projects in terms of its low frequency of sessions and its long intervention time.

More studies are needed for the evaluation of specialised psycho-oncological care in clinical practice, especially with regard to (a) the motives of patients in seeking this type of care, (b) the problems that are the focus of care according to therapists and (c) the type and length of interventions offered to clients. These are relatively understudied topics, while the demographic and medical characteristics of clients are relatively well known (see the Introduction). Motives and focal points for care in terms of what topics should be dealt with in therapy represent the viewpoint of clients and therapists,

respectively. This information will make clear whether intervention research and clinical practice correspond with respect to their therapeutic focal points. Information about type and length of interventions will reveal whether clinical practice corresponds to empirically supported therapies. In case of major differences, the question needs to be discussed as to whether clinical practice should adapt to research practice, or the other way around.

A major drawback of clinical studies like ours is the lack of a control group of patients who do not receive any psychological treatment. This hinders a comparison of therapeutic outcomes in clinical practice and in intervention studies. Such a comparison would be extremely relevant; in case of clear differences, adaptation of clinical practice would appear mandatory. One possibility would be to compare data obtained in a no-treatment control group from an earlier intervention study. This is certainly not an ideal situation, but admissible or even advisable in the light of the clinical relevance. However, the group of patients in the clinical therapy study should be comparable to the patients in the control group of an intervention study, at least with respect to the most important variables, which seem to be the initial level of the outcome data, intervals of measurements and time since diagnosis. The most appropriate control group could be newly constituted, if patient-based registries of intervention studies were accessible for researchers who study the effects of psycho-oncological interventions in clinical practice. Therefore, we call for a discussion among psycho-oncological researchers about the possibility for development of patient-based registries of intervention data.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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