

## PAPER

# Parental cancer: Characteristics of users of child-centred counselling versus individual psycho-oncological treatment

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## Abstract

**Objective:** The aims of this study were to investigate the characteristics of users of a specific child-centred counselling service (COSIP) and to compare those to parents using an individual psycho-oncological treatment (PO).

**Methods:** We conducted a retrospective analysis on data of users of COSIP and users of PO. Database was the routine assessment (demographic and disease-related characteristics, GAD-7, PHQ-9, EORTC QLQ-C30, and current concerns) of an outpatient psycho-oncological clinic with additional child-centred counselling. A total of 151 patients and 49 partners with children  $\leq 21$  years were included. We conducted descriptive analyses and group comparisons.

**Results:** Fifty-nine patients and partners used COSIP only or additionally to individual psycho-oncological service. PO users were more depressed and were more anxious than COSIP users. Patients using PO reported worse emotional functioning than patients using COSIP. Partners using PO reported worse global quality of life and more symptoms of fatigue than partners using COSIP. With regard to current concerns, patients using COSIP reported child-related issues more frequently than PO users. PO users reported symptoms of anxiety, depressive symptoms, or exhaustion more frequently than COSIP users.

**Conclusions:** The findings demonstrate that patients and partners self-referring to PO or COSIP are highly burdened. COSIP users experience different psychosocial burden than PO users. As poor mental state of parents is a risk factor for the development of mental problems in children, parents using only PO may benefit from additional child-centred support. Accordingly, the need for COSIP should be assessed continuously during PO of patients with children  $\leq 21$  years.

## KEYWORDS

cancer, child, counselling, oncology, parent

## 1 | BACKGROUND

Cancer diagnosis, treatment, and treatment side effects can lead to physical consequences such as pain or functional limitations for the patient.<sup>1,2</sup> Further, both the patients as well as close relatives can experience elevated levels of distress as well as fear and anxiety.<sup>3,4</sup> A particular patient group are patients parenting children: According to current estimates, from the United States and Norway, about 14% of cancer patients have at least one minor child.<sup>5,6</sup> Parents with cancer report a decreased quality of life (QoL), experience changes in daily life,<sup>7,8</sup> and are concerned about the impact of their disease on their children.<sup>9</sup> At the same time, they struggle to accomplish their parental responsibilities<sup>10</sup>

and are challenged by communicating with their children about the disease.<sup>11</sup> Children as relatives report elevated levels of distress and are at risk for developing internalizing or externalizing problems.<sup>12-14</sup>

Current international guidelines for oncological care explicitly recommend to involve the parental role of the patient and to involve minor children in supportive and psycho-oncological care, if necessary.<sup>15,16</sup> In Scandinavian countries, children of parents undergoing treatment should be considered routinely in healthcare clinical practice.<sup>17</sup> Tailored support can help cancer patients during the course of the disease to reduce emotional distress and to enhance their QoL.<sup>18</sup> Up to today, several interventions have been developed for families affected by parental cancer.<sup>19,20</sup> Still, in a population-based study, only

9% of included cancer survivors with children  $\leq 21$  years used any kind of family-centred support,<sup>21</sup> whereas 73% expressed the need. There may be several barriers for using family- and child-centred support, eg, no perceived need or practical difficulties.<sup>19</sup> Additionally, parents may underestimate the impact of the disease on their children.<sup>22</sup>

To the best of our knowledge, studies on users of psycho-oncological care among families affected by parental cancer in routine care are non-existent. For this reason, our aim was to investigate the characteristics of cancer patients with children  $\leq 21$  years using a child-centred supportive counselling and to compare those to patients with children  $\leq 21$  years using individual psycho-oncological treatment in routine care to gain information about differences in demographic and psychosocial variables.

## 2 | METHODS

### 2.1 | Data and sample

We conducted retrospective analyses based on data of the psycho-oncological outpatient clinic of the University Medical Center Hamburg-Eppendorf. The clinic offers individual psycho-oncological treatment (PO) as well as child-centred counselling (COSIP) for cancer patients with children  $\leq 21$  years and their family members. Patients referring to the psycho-oncological outpatient clinic independently elect and apply for any of the interventions. All users of any service of the psycho-oncological outpatient clinic are routinely screened with regard to demographic and medical information as well as psychological symptoms (PHQ-9, depression; GAD-7, anxiety) and QoL (EORTC QLQ-C30) prior to counselling. According to the local ethics committee of the Medical Associations of the Free and Hanseatic City of Hamburg, ethical approval by the ethics committee was not required since the analysed data were gathered in routine psycho-oncological care and were provided anonymized for the presented analyses (WF-63/17).

For this study, we used data of the routine assessment of the years 2014 and 2015. In total, data of 711 users were available. Of these, 30.5% ( $n = 217$ ) had minor or young adult children ( $\leq 21$  years), 32.1% ( $n = 228$ ) had children  $> 21$  years, and 37.4% did not have any children ( $n = 266$  including  $n = 15$  with missing information about children). We excluded relatives with children where another relative other than the parent (eg, grandparent and sibling) was diagnosed with cancer. This led to a final sample of  $n = 200$  patients and partners with minor and young adult children ( $\leq 21$  years). Of these, we compared COSIP users ( $n = 59$ ; COSIP only [ $n = 51$ ] or both interventions [ $n = 8$ ]) to those patients and partners using PO ( $n = 141$ ).

### 2.2 | Interventions

#### 2.2.1 | Child-centred counselling for families affected by parental cancer (COSIP)

The concept of child-centred counselling for families affected by parental cancer was developed based on the work of the COSIP group (Children of Somatically Ill Parents),<sup>23,24</sup> which is a short-term intervention to prevent psychological consequences for the children. The intervention comprises a diagnostic phase, an interventional phase (3-8 sessions), and a closing session or a flexible after care phase.

The aims of the intervention are tailored according to the needs of the families and can focus on the family level (eg, facilitate open communication), on the parental level (eg, enhance self-perceived parenting competence), and on the child's level (eg, enhance child's active coping).<sup>25</sup> A child and adolescent psychotherapist or a psychotherapist with training in the COSIP concept conducts COSIP counselling.

#### 2.2.2 | Individual psycho-oncological treatment (PO)

The psycho-oncological outpatient clinic offers supportive psychotherapeutic care for cancer patients and relatives coping with cancer. The facilitators are mostly certified psychotherapists with training in behaviour therapy, humanistic therapy, or psychodynamic oriented psychotherapy. The individual psycho-oncological treatment mainly consists of individual sessions with cancer patients or relatives, but also couple sessions, relaxation training, group sessions, as well as art and music therapy.

### 2.3 | Measures

#### 2.3.1 | Demographic and disease-related variables

Demographic and disease-related information were obtained by self-report questions. Demographic variables included age, gender, age of children, education, and employment status. Disease-related variables included cancer diagnosis, occurrence of metastases, and time since diagnosis.

#### 2.3.2 | Anxiety and depression

Depressive symptoms were assessed using the PHQ-9.<sup>26</sup> All 9 items can be rated on a 4-point Likert-scale (0-3). The PHQ-9 has good reliability and validity with higher sum scores indicating higher severity of depressive symptoms (total score range 0-27). A total score of 10 or higher indicates possible depressive disorder.<sup>26,27</sup> The internal consistency in this study was good (Cronbach  $\alpha = .86$ ). To assess anxiety the GAD-7 was used.<sup>28</sup> The questionnaire uses a 4-point Likert-scale (0-3). The GAD-7 shows good psychometric properties. In our sample, the internal consistency was high (Cronbach  $\alpha = .89$ ). Higher sum scores indicate higher severity of anxiety symptoms (total score range 0-21). A total score of 10 to 14 indicates moderate anxiety symptoms, and a total score of 15 and higher indicates severe symptom levels.<sup>28,29</sup>

#### 2.3.3 | Health-related quality of life

Health-related QoL was assessed using the German version of the EORTC QLQ-C30.<sup>30</sup> The self-administered questionnaire consists of 30 items, which can be rated on a 4-point Likert scale (except the scale global QoL with a 7-point Likert scale). The items can be aggregated into one global QoL scale, 5 functional scales, and 9 symptom scales. The raw scores of the scales were linearly transformed to a scale from 0 to 100. A high score in the functional scales indicates high level of functioning; a high score in the symptom scales indicates high problems. The questionnaire shows satisfactory to good psychometric properties.<sup>30-32</sup> In our sample, the internal consistency for the subscales ranged from Cronbach  $\alpha = .61$  to  $.91$ .

### 2.3.4 | Current main concerns

Current main concerns were assessed with the open-ended question "Which problems are most stressful to you at the moment? Please describe the most stressful problems shortly". Answers to the open-ended question regarding main concerns of the patient or partner were categorized with regard to theme and content.

## 2.4 | Analyses

Statistical analyses were conducted using Statistical Package for Social Sciences (version 18.0, SPSS Inc, Chicago, Ill). We conducted descriptive analyses to examine the sample characteristics.

Group differences between PO users and COSIP users were analysed using chi-square tests and Fisher exact tests for categorical variables and 2-sample *t* tests for metric data. All analyses were conducted for the total group as well as for patients and partners separately.

To rate QoL in partners, we compared QoL in our sample with age- and gender-adapted norm values from a representative sample of the German population.<sup>33</sup> For this, we assigned an age- and gender-adapted norm value for each patient, computed the mean value, and included it as reference value in one-sample *t* tests.

Two-tailed significance was examined using a significance level of  $p < .05$ .

## 3 | RESULTS

### 3.1 | Sample characteristics

In total, 70% ( $n = 141$ ) of the patients and partners with children  $\leq 21$  years used PO, while 30% ( $n = 59$ ) used COSIP. About 72% of patients and 54% of partners were female. Mean age of patients was 46 years ( $SD = 7.4$ ), and mean age of partners was 45 years ( $SD = 8.2$ ). COSIP users were significantly younger and had younger children than PO users (Table 1).

### 3.2 | Anxiety and depression

Approximately 50% of the sample showed moderate to severe depressive symptoms, and 54% showed moderate to severe anxiety symptoms.

Patients using PO showed significantly higher depressive symptoms and higher symptoms of anxiety disorder than patients using COSIP (Table 2). Partners using PO reported significantly more

**TABLE 1** Demographic and medical characteristics of the sample

Variable	Total (n = 200)				Patients (n = 151)				Partners (n = 49)			
	Total n (%)	COSIP n (%)	PO n (%)	<i>P</i> <sup>a</sup>	Total n (%)	COSIP n (%)	PO n (%)	<i>P</i> <sup>a</sup>	Total n (%)	COSIP n (%)	PO n (%)	<i>P</i> <sup>a</sup>
Age (M, SD)	46.0 (7.6)	44.0 (7.6)	46.9 (7.4)	.011	46.4 (7.4)	43.8 (7.4)	47.3 (7.2)	.011	44.8 (8.2)	44.3 (8.2)	45.3 (8.3)	.678
Female	135 (67.8)	38 (64.4)	97 (69.3)	.510	109 (72.2)	28 (75.7)	81 (71.1)	.586	26 (54.2)	10 (45.5)	16 (61.5)	.265
Living with partner	154 (78.6)	44 (77.2)	110 (79.1)	.763	111 (74.5)	26 (72.2)	85 (75.2)	.719	43 (91.5)	18 (85.7)	25 (96.2)	.202
Number of children (M, SD)	1.8 (.77)	1.8 (.74)	1.8 (.78)	.730	1.8 (.79)	1.7 (.78)	1.8 (.80)	.526	1.7 (.68)	1.9 (.67)	1.6 (.64)	.042
Age of child <sup>b</sup>												
0-6	59 (29.5)	21 (35.6)	38 (27.0)	.001	39 (25.8)	12 (34.2)	27 (23.7)	.003	20 (40.8)	9 (40.9)	11 (40.7)	.078
7-11	40 (20.0)	17 (28.8)	23 (16.3)		30 (19.9)	12 (32.4)	18 (15.8)		10 (20.4)	5 (22.7)	5 (18.5)	
12-17	64 (32.0)	20 (33.9)	44 (31.2)		54 (35.8)	13 (35.1)	41 (36.0)		10 (20.4)	7 (31.8)	3 (11.1)	
18-21	37 (18.5)	1 (1.7)	36 (25.5)		28 (18.5)	-	18 (24.6)		9 (18.4)	1 (4.5)	8 (29.6)	
Education												
$\leq 10$ years	62 (32.5)	18 (33.3)	44 (32.1)	.872	47 (32.9)	13 (39.4)	34 (30.9)	.363	15 (31.3)	5 (23.8)	10 (37.0)	.327
>10 years	129 (67.5)	36 (66.7)	93 (67.9)		96 (67.1)	20 (60.6)	76 (69.1)		33 (68.8)	16 (76.2)	17 (63.0)	
Employed full- or part-time	141 (70.9)	40 (67.8)	101 (72.1)	.920	101 (67.3)	23 (62.2)	78 (69.0)	.813	40 (81.6)	17 (77.3)	23 (85.2)	.489
Diagnosis												
Breast	71 (35.5)	22 (37.3)	49 (34.8)	.842	58 (38.4)	14 (37.8)	44 (38.6)	.844	13 (26.5)	8 (36.4)	5 (18.5)	.681
Digestive organs	35 (17.5)	11 (18.6)	24 (17.0)		24 (15.9)	6 (16.2)	18 (15.8)		11 (22.4)	5 (22.7)	6 (22.2)	
Haematological	14 (7.0)	4 (6.8)	10 (7.1)		10 (6.6)	2 (5.4)	8 (7.0)		4 (8.2)	2 (9.1)	2 (7.4)	
CNS	16 (8.0)	3 (5.1)	13 (9.2)		8 (5.3)	1 (2.7)	7 (6.1)		8 (16.3)	2 (9.1)	6 (22.2)	
Other	52 (26.0)	14 (23.7)	38 (27.0)		41 (27.2)	10 (27.0)	31 (27.2)		11 (22.4)	4 (18.2)	7 (25.9)	
Unknown	12 (6.0)	5 (8.5)	7 (5.0)		10 (6.6)	4 (10.8)	6 (5.3)		2 (4.1)	1 (4.5)	1 (3.7)	
Metastasis	76 (43.4)	20 (40.0)	56 (44.8)	.563	61 (45.5)	14 (43.8)	47 (46.1)	.817	15 (36.6)	6 (33.3)	9 (39.1)	.702
Time since diagnosis, months (M, SD)	20.6 (30.9)	24.1 (35.9)	19.2 (28.5)	.311	21.5 (32.4)	24.3 (38.3)	20.6 (30.4)	.545	17.7 (25.1)	23.8 (31.9)	12.8 (17.2)	.150

Abbreviations: COSIP, child-centred counselling service (children of somatically ill parents); M, mean; PO, individual psycho-oncological treatment; SD, standard deviation.

<sup>a</sup>Chi<sup>2</sup>-test, Fisher exact test, or *t* test.

<sup>b</sup>Age of the youngest child.

**TABLE 2** Psychosocial burden of cancer patients and relatives using psychosocial support

Psychosocial Burden	Total (n = 200)				Patients (n = 151)				Partners (n = 49)			
	Total	COSIP	PO	P <sup>e</sup>	Total	COSIP	PO	P <sup>e</sup>	Total	COSIP	PO	P <sup>e</sup>
Depressive symptoms <sup>a</sup> (M, SD)	10.1 (6.0)	7.8 (5.9)	11.1 (5.8)	.001	10.7 (5.9)	8.6 (5.7)	11.4 (5.8)	.013	8.2 (6.2)	6.4 (6.2)	9.6 (5.9)	.082
Moderate to severe depressive symptoms <sup>b</sup> (n, %)	96 (50.3)	20 (35.7)	76 (56.3)	.010	79 (54.1)	16 (44.4)	63 (57.3)	.180	17 (37.8)	4 (20.0)	13 (52.0)	.028
Symptoms of anxiety disorder <sup>c</sup> (M, SD)	10.3 (5.6)	8.5 (5.7)	11.4 (5.4)	.001	10.6 (5.7)	8.7 (6.0)	11.3 (5.5)	.017	10.3 (5.6)	8.3 (5.3)	11.9 (5.3)	.024
Moderate to severe symptoms of anxiety <sup>d</sup> (n, %)	105 (54.4)	22 (38.6)	83 (61.0)	.004	82 (55.4)	15 (40.5)	67 (60.4)	.036	23 (51.1)	7 (35.0)	16 (64.0)	.053

Abbreviations: COSIP, child-centred counselling service (children of somatically ill parents); PO, individual psycho-oncological treatment.

<sup>a</sup>According to PHQ-9;

<sup>b</sup>PHQ-9 score  $\geq 10$ ;

<sup>c</sup>According to GAD-7;

<sup>d</sup>GAD-7 score  $\geq 10$ ;

<sup>e</sup>Chi<sup>2</sup>-test, Fisher exact test, or *t* test.

often moderate to severe symptoms of depression and higher symptoms of anxiety disorder than partners using COSIP (Table 2).

### 3.3 | Health-related quality of life

The PO users reported significant lower global QoL than COSIP users ( $p = .004$ ). Partners using COSIP reported better global QoL than

partners using PO ( $p = .035$ ; Table 3). However, this difference was not found for patients.

Highest functioning was reported with regard to physical functioning (M = 78.9) and cognitive functioning (M = 60.4). Patients using COSIP reported significantly better emotional functioning than patients using PO (43.0 vs 32.9,  $p = .045$ ). In the total sample, significant differences were found for cognitive functioning ( $p = .022$ )

**TABLE 3** Quality of life in cancer patients and partners<sup>a</sup>

	Total (n = 200)				Patients (n = 151)				Partners (n = 49)			
	Total	COSIP	PO	P <sup>b</sup>	Total	COSIP	PO	P <sup>b</sup>	Total	COSIP	PO	P <sup>b</sup>
Global quality of life	45.9 (21.9)	52.9 (23.4)	43.0 (20.7)	.004	43.7 (21.6)	48.6 (23.5)	42.0 (20.8)	.107	53.3 (21.6)	60.8 (21.6)	47.4 (19.9)	.035
Functional scales												
Physical functioning	78.9 (24.9)	82.1 (24.7)	77.5 (24.9)	.242	73.6 (25.7)	72.9 (26.3)	73.8 (25.6)	.870	96.4 (8.8)	99.0 (4.3)	94.4 (10.8)	.082
Role functioning	50.3 (32.0)	55.6 (33.8)	48.1 (31.1)	.138	46.2 (31.0)	48.2 (34.4)	45.5 (29.9)	.652	63.7 (32.0)	69.2 (28.2)	59.3 (34.4)	.312
Emotional functioning	34.4 (26.4)	41.5 (26.5)	31.4 (25.8)	.015	35.4 (26.6)	43.0 (24.7)	32.9 (26.8)	.045	30.9 (25.6)	38.6 (29.9)	24.7 (20.1)	.069
Cognitive functioning	60.4 (32.6)	68.7 (30.4)	57.0 (33.0)	.022	58.3 (32.2)	64.9 (31.1)	56.2 (32.4)	.156	67.4 (33.5)	75.8 (28.3)	60.7 (36.3)	.133
Social functioning	47.9 (34.5)	57.3 (35.1)	44.0 (33.6)	.014	40.2 (31.7)	45.9 (30.8)	38.3 (31.9)	.207	73.3 (31.3)	78.3 (33.4)	69.3 (29.5)	.343
Problem scales/items												
Fatigue	60.1 (30.0)	50.3 (32.1)	64.2 (28.2)	.003	64.4 (28.4)	58.3 (31.0)	66.4 (27.4)	.132	49.9 (30.9)	35.6 (29.4)	54.2 (30.1)	.043
Nausea/vomiting	11.6 (20.2)	9.7 (15.1)	12.5 (21.8)	.375	13.8 (20.9)	13.1 (17.2)	14.0 (22.0)	.807	4.4 (15.7)	3.3 (6.8)	5.3 (20.3)	.675
Pain	35.0 (34.1)	27.5 (32.8)	38.2 (34.3)	.046	40.7 (33.9)	33.8 (34.6)	42.9 (33.5)	.156	16.3 (27.6)	15.8 (26.2)	16.7 (29.3)	.921
Dyspnoea	27.0 (31.9)	21.6 (30.5)	29.2 (32.3)	.131	32.4 (32.8)	30.6 (32.8)	33.0 (32.9)	.699	8.9 (20.6)	5.0 (16.3)	12.0 (23.3)	.262
Insomnia	56.5 (38.9)	50.3 (38.4)	59.0 (39.0)	.156	59.6 (38.2)	54.9 (37.0)	61.1 (38.6)	.396	45.9 (20.6)	41.7 (40.3)	49.3 (39.8)	.527
Appetite loss	28.6 (37.0)	24.6 (34.8)	30.2 (27.8)	.332	31.8 (38.0)	27.9 (36.4)	33.0 (38.5)	.479	17.8 (31.5)	18.3 (31.4)	17.3 (32.1)	.917
Constipation	13.9 (28.0)	11.7 (25.6)	14.7 (29.0)	.493	17.3 (30.6)	18.0 (30.0)	17.1 (30.9)	.876	2.2 (11.0)	.000 (.000)	4.0 (14.7)	.230
Diarrhoea	13.3 (26.3)	14.6 (28.2)	12.8 (25.6)	.662	14.9 (27.7)	16.2 (30.0)	14.5 (27.1)	.738	8.1 (20.3)	11.7 (24.8)	5.3 (15.8)	.304
Financial problems	35.2 (37.6)	25.6 (36.0)	39.2 (37.6)	.022	41.3 (38.1)	34.3 (37.8)	43.5 (38.1)	.205	15.6 (28.1)	10.0 (26.7)	20.0 (28.9)	.239

Abbreviations: COSIP, child-centred counselling service (children of somatically ill parents); PO, individual psycho-oncological treatment.

<sup>a</sup>According to EORTC QLQ-C30;

<sup>b</sup>*t* Tests.

**TABLE 4** Current concerns of cancer patients and partners receiving psychosocial support<sup>a</sup>

Current Concerns	Total (n = 200)				Patients (n = 151)				Partners (n = 49)			
	Total n (%)	COSIP n (%)	PO n (%)	<i>p</i> <sup>b</sup>	Total n (%)	COSIP n (%)	PO n (%)	<i>p</i> <sup>b</sup>	Total n (%)	COSIP n (%)	PO n (%)	<i>p</i> <sup>b</sup>
Child-related issues	59 (29.5)	29 (49.2)	30 (21.3)	<.001	37 (24.5)	16 (43.2)	21 (18.4)	.002	22 (44.9)	13 (59.1)	9 (33.3)	.071
Finances	10 (5.0)	2 (3.4)	8 (5.7)	.499	8 (5.3)	2 (5.4)	6 (5.3)	.973	2 (4.1)	–	2 (7.4)	– <sup>c</sup>
Physical symptoms	24 (12.0)	2 (3.4)	22 (15.6)	.015	23 (15.2)	2 (5.4)	21 (18.4)	.056	1 (2.0)	–	1 (3.7)	– <sup>c</sup>
Anxiety	39 (19.5)	3 (5.1)	36 (25.5)	.001	29 (19.2)	1 (2.7)	28 (24.6)	.003	10 (20.4)	2 (9.1)	8 (29.6)	.152
Disease progression	51 (25.5)	14 (23.7)	37 (26.2)	.710	42 (27.8)	10 (27.0)	32 (28.1)	.902	9 (18.4)	4 (18.2)	5 (18.5)	1.0
Concerns about future	33 (16.5)	7 (11.9)	26 (18.4)	.253	23 (15.2)	19 (16.7)	4 (10.8)	.389	10 (20.4)	3 (13.6)	7 (25.9)	.288
Depression	28 (14.0)	3 (5.1)	25 (17.7)	.019	25 (16.6)	3 (8.1)	22 (19.3)	.112	3 (6.1)	–	3 (11.1)	– <sup>c</sup>
Exhaustion	22 (11.0)	2 (3.4)	20 (14.2)	.026	20 (13.2)	2 (5.4)	18 (15.8)	.105	2 (4.1)	–	2 (7.4)	– <sup>c</sup>
Coping	47 (23.5)	15 (25.4)	32 (22.7)	.678	30 (19.9)	8 (21.6)	22 (19.3)	.758	17 (34.7)	7 (31.8)	10 (37.0)	.703
Work situation	10 (5.0)	2 (3.4)	8 (5.7)	.499	8 (5.3)	–	8 (7.0)	– <sup>c</sup>	2 (4.1)	2 (9.1)	–	– <sup>c</sup>
Partner	17 (8.5)	8 (13.6)	9 (6.4)	.097	14 (9.3)	5 (13.5)	9 (7.9)	.306	3 (6.1)	3 (13.6)	–	– <sup>c</sup>

Abbreviations: COSIP, child-centred counselling service (children of somatically ill parents); PO, individual psycho-oncological treatment.

<sup>a</sup>Themes coded from open-ended answers, multiple answers possible;

<sup>b</sup>Chi<sup>2</sup>-test or Fisher exact test;

<sup>c</sup>No significance due to small number of answers.

and social functioning ( $p = .014$ ). In both scales, COSIP users reported significant better functioning than PO users.

With regard to the symptom scales, highest symptom burden was found for fatigue ( $M = 60.1$ ) and insomnia ( $M = 56.5$ ). Significant differences between COSIP users and PO users were found for partners in fatigue ( $p = .043$ ).

Comparing partners in our sample to reference values from a representative sample of the German population, partners reported significantly lower QoL in global QoL and all functioning scales but physical functioning (Table S1).

### 3.4 | Current concerns

We identified the following current main concerns of patients and partners: child-related concerns (30%), fear of disease progression (26%), coping (24%), anxiety (20%), concerns about future (17%), depressive symptoms (14%), physical symptoms (12%), exhaustion (11%), partner-related issues (9%), job-related concerns (5%), and financial concerns (5%) (Table 4).

Patients and partners using COSIP reported child-related concerns such as communicating about cancer with the children and concerns about the children more frequently than users of PO ( $p < .01$ ). In the total sample, PO users described physical symptoms, anxiety, depressive symptoms, and exhaustion ( $p < .05$ ) in the open-ended answers more often than users of COSIP (Table 4).

## 4 | CONCLUSIONS

As an integral part of cancer care, psycho-oncological interventions support patients and relatives in coping with the disease.<sup>18</sup> Interventions for affected families are often not included in routine care; in particular, findings derived apart from study populations are limited.

Based on a naturalistic design using data from a routine assessment of an outpatient psycho-oncological support (PO) and child-centred support for cancer patients (COSIP), we found that all COSIP users have children younger than 18 years, whereas about a quarter of the PO users have children between 18 and 21 years. Possibly, parents rather consider their young adult children to be responsible to seek help independently, although the design of the COSIP counselling provides support for children up to 21 years. At the same time, adolescent and young adult children may be better in hiding their emotions, staying functional in daily duties regarding school and household and may even support their parents. Hence, the parents might believe that their adolescent and young adult children are less distressed.

In our study, patients and partners using PO reported significantly higher depressive symptoms and higher anxiety symptoms than COSIP users. Higher mental burden may impair the parental attention on the mental state of the children, and parents may be less emotionally attentive towards their children.<sup>34</sup> Therefore, parents might not notice the full extent of their child's burden. This is an important finding since parental depression and emotional burden have been identified as risk factors for the development of mental problems in affected children.<sup>12,14</sup> Therefore, particularly these parents and their children could benefit from specific child-centred support, and COSIP could be a valuable complement to individual PO.

Compared to others studies,<sup>35,36</sup> the sample of this study reported poorer QoL. As we included a sample of users of psycho-oncological care, this is not surprising. A study on breast cancer patients with minor children in inpatient rehabilitation reports slightly better functioning than our sample.<sup>37</sup> In our sample, patients using PO reported significantly poorer emotional functioning than patients using COSIP. Partners using PO reported poorer QoL and more symptoms of fatigue than partners using COSIP. The comparisons of partners in our sample to reference values from the general population<sup>33</sup> indicate that cancer diagnosis can lead to high burden in partners. Those partners self-referring to psycho-oncological or family-centred support are impeded

in their emotional functioning, role functioning, cognitive functioning, and social functioning.

Patients and partners using any of the interventions report a high range of current concerns. Whereas PO users report more physical and depressive symptoms, anxiety, and exhaustion, COSIP users focus on child-related concerns. Still, in patients using PO 18% and in partners using PO 33% report child-related issues explicitly. Possibly, child-related concerns are not prioritized because of the parent's mental burden. Therefore, it is especially important for psycho-oncologists to pay attention to their patients' familial background and the possible burden of the children.

#### 4.1 | Study limitations

This study has some limitations. With a total of 141 PO users and 59 COSIP users, the sample size of the subgroups (patients and partners) is limited. Further studies with larger sample size and longitudinal design are necessary to identify factors influencing the use of child-centred support and to evaluate such services. Data analyses were based on a single psycho-oncological outpatient clinic. Still, the naturalistic design of the study minimized the selection bias. We have no information about the actual content of the individual psycho-oncological support and, hence, cannot exclude the possibility that child- and family-related issues were a main topic in individual psycho-oncological treatment. However, this is unlikely, since patients usually are referred to COSIP counselling if child-related issues play a major role.

#### 4.2 | Clinical implications

As child-centred issues do not only request expertise in developmental issues and knowledge about coping strategies in children, but also additional time and possibly the involvement of the children themselves, cancer patients with children  $\leq 21$  years and their families should be offered a specific child-centred counselling. Not only to prevent the children from developing mental problems in the long term, but also to reduce a potential additional burden in parents caused by the challenge of navigating through the course of cancer and parenting issues simultaneously.<sup>9,38</sup> Our results provide relevant information for clinical practitioners and indicate the need for specific child-centred interventions for cancer patients and their families. Still, not only patients applying for such a service on their own, but also patients using individual psycho-oncological treatment should be offered child-centred support to address child-related concerns.

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#### CONFLICT OF INTEREST STATEMENT

The authors have no conflicts to declare.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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