

# Caregiver distress and quality of life in primary caregivers of oncology patients in active treatment and follow-up

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## Abstract

**Objective:** As the number of informal caregivers and their caregiving responsibilities increase, this study aims at evaluating caregiver distress, quality of life (QoL) and their predictors in informal caregivers of cancer patients during active treatment and follow-up.

**Methods:** This cross-sectional descriptive study targeted primary caregivers of patients with different cancer diagnoses. Caregiver-reported outcomes were measured by the Caregiver Risk Screen (CRS), Distress Thermometer (DT) and Caregiver Quality of Life Index–Cancer (CQOLC).

**Results:** Caregivers ( $n = 1580$ ) experienced a low-to-moderate risk of caregiver distress and a moderate QoL during both treatment and follow-up. About 13% reported a high caregiver risk and 20% reported severe distress. There was a strong and significant correlation between caregiver distress and caregivers' QoL (0.793). Predictive factors for higher distress and poorer QoL were: fewer emotional and practical resources, being female, non-spousal relationship or not living together ( $p < 0.05$ ). Caregivers of patients with head-and-neck, skin, lung and brain cancers reported the highest distress and lowest QoL.

**Conclusion:** Caregiver distress is highly variable, but a minority of caregivers is at high risk for caregiver distress. Professional caregivers play an important role at supporting caregivers and detecting high-risk caregivers.

## KEYWORDS

caregiver distress, caregivers, family caregiver, informal caregiver, oncology, quality of life

## 1 | INTRODUCTION

With improved survival rates, an increasing number of cancer patients are living longer with the physical, psychosocial, emotional or cognitive consequences of cancer and its treatment. The shift to ambulatory cancer care implies an increase in responsibilities for informal caregivers (Given, Sherwood, & Given, 2011; Grant et al., 2013; Krebber et al., 2016; Northouse et al., 2012; Pitceathly & Maguire, 2003; Tan et al., 2017; Weitzner et al., 1999). Caregivers

may take on a range of disease-related tasks such as providing emotional support, physical care, symptom management, dealing with nutrition needs and treatment monitoring while being in great need of emotional support themselves (Applebaum & Breitbart, 2013). Moreover, caregivers often assume their caregiving role with little or no preparation (Given et al., 2011; Northouse et al., 2012; Williams & McCorkle, 2011).

Studies have reported high levels of burden, anxiety, depression and distress among caregivers of patients with specific types

of cancer or in a specific phase, mostly the end-of-life phase (Given et al., 2004; Kris et al., 2006; Martinez-Rodriguez et al., 2013; Pitceathly & Maguire, 2003; Rivera, 2009; Tan et al., 2017), that are comparable to or even surpass those of the patients (Braun et al., 2007; Hodgkinson et al., 2007; McLean et al., 2011). Besides the mental and emotional impact, caregiving has shown to negatively affect relationships, self-esteem, health, financial status, alcohol and tobacco consumption (Applebaum & Breitbart, 2013; Balfe et al., 2016; Given et al., 2011; Northouse et al., 2012; Weitzner et al., 1999). Following caregiver-related factors have been associated with higher caregiver distress, higher caregiver burden or higher levels of anxiety: being female (Matthews, 2003; Pitceathly & Maguire, 2003), higher age (Grant et al., 2013), having a history of psychiatric morbidity (Pitceathly & Maguire, 2003), having distressed relationships with patients (Grant et al., 2013), having a more negative view of the patients' illness and its impact on their lives (Pitceathly & Maguire, 2003) and having little social support (Grant et al., 2013). Also, caregiving duration and intensity and type of cancer diagnosis may affect the extent to which caregivers experience these negative effects (Northouse et al., 2012; Sorensen et al., 2002).

Although caregivers provide more than half of the care needed by patients with cancer, they are largely invisible to the professional healthcare team (Neefs, 2015) The study addresses the following research questions:

1. What is the distress and quality of life in primary caregivers of oncology patients in active treatment and follow-up?
2. What are the caregiver- and patient-related predictors associated with caregiver distress and quality of life?

## 2 | METHODS

An observational, cross-sectional study using questionnaires was performed at the consultation, the radiotherapy unit, 2 outpatient clinics and 7 oncology wards of the University Hospitals Leuven. Caregivers were eligible if they (a) were caregiver of an adult ( $\geq 18$  years) patient with any cancer diagnosis in active treatment (systemic treatment and/or radiotherapy) or in follow-up after treatment, (b) were the patient's primary caregiver, (c) were adult ( $\geq 18$  years), (d) were Dutch, (e) were able to fill out the questionnaire and (f) agreed to participate in the study by signing the informed consent. Primary caregivers were appointed by the patient as the closest caregiver. This was not necessarily the caregiver accompanying the patient at the hospital.

All patients who were present on recruitment days between November 2017 and February 2018 were informed about the study. If primary caregivers were present, we provided oral and written study information and invited caregivers to complete the paper-pencil questionnaire at the hospital. When patients were not accompanied by their primary caregiver, they were proposed to introduce the study to their primary caregiver later on. A flyer and the study information form were handed to patients to facilitate this process.

Caregivers were offered the choice to fill out the questionnaire online or return the paper-pencil questionnaire using a stamped envelope.

### 2.1 | Caregiver-reported outcomes

Primary outcomes were caregiver distress and caregivers' QoL. Secondary outcomes were caregivers' satisfaction and preparedness for caregiving.

Caregiver distress was measured using the Caregiver Risk Screen (CRS), a 12-item scale using Likert scales from 0 (totally disagree) to 3 (totally agree). The CRS has shown a high level of internal consistency (Cronbach's alpha: 0.86) and an appropriate convergent validity (Martinez-Rodriguez et al., 2013). In addition, caregiver distress was measured by the distress thermometer (DT), offering a colour-coded Likert scale from 0 (no distress) to 10 (extremely distress) (Cuttillo et al., 2017; Halkett et al., 2017; Mazanec et al., 2018; Zwahlen et al., 2008). The DT was first validated in the context of cancer caregivers by Zwahlen et al and showed good diagnostic utility, sensitivity and specificity (Zwahlen et al., 2008).

The Caregiver Quality of Life Index—Cancer (CQOLC) is a 35-item instrument capturing four dimensions of caregiver QoL: burden, disruptiveness, positive adaptation and financial concerns (Carter, 2006; Lafaye et al., 2013; Weitzner et al., 1999). The CQOLC has demonstrated a high internal consistency ( $\alpha = 0.91$ ), adequate convergent and divergent validity and good test-retest reliability ( $r = 0.95$ ) (Carter, 2006; Weitzner et al., 1999).

We used the validated Canadian Health Care Evaluation Project Questionnaire (CANHELP Lite) for measuring caregivers' satisfaction with care (Heyland et al., 2013). The original CANHELP Lite is a 21-item scale, showing moderate to high internal consistency (Cronbach's alpha 0.69–0.94) (Heyland et al., 2013). To avoid overlap with the CQOLC, only 10 items of the CANHELP were used. We did not evaluate the psychometric properties of the modified CANHELP.

Caregiver preparedness was assessed using the 8-item Preparedness for Caregiving Scale (PCS) (Archbold et al., 1990). Preparedness is defined as the perceived readiness for the multiple caregiving roles (Henriksson et al., 2012, 2015; Nielsen et al., 2017). Internal consistency of the scale ranges from 0.88 to 0.93 (Archbold et al., 1990; Schumacher et al., 2007, 2008).

Finally, caregivers reported on several patient and caregiver characteristics. For the patients, these were as follows: cancer diagnosis, time since diagnosis, stage of disease and type of treatment. For the caregivers, these were as follows: age, gender, relationship to the patient, living situation, educational level, employment status, emotional support, practical help and caregiver roles.

### 2.2 | Statistical methods

Descriptive analysis was performed to report caregiver distress and QoL. Univariate linear models were used to explore their predictors.

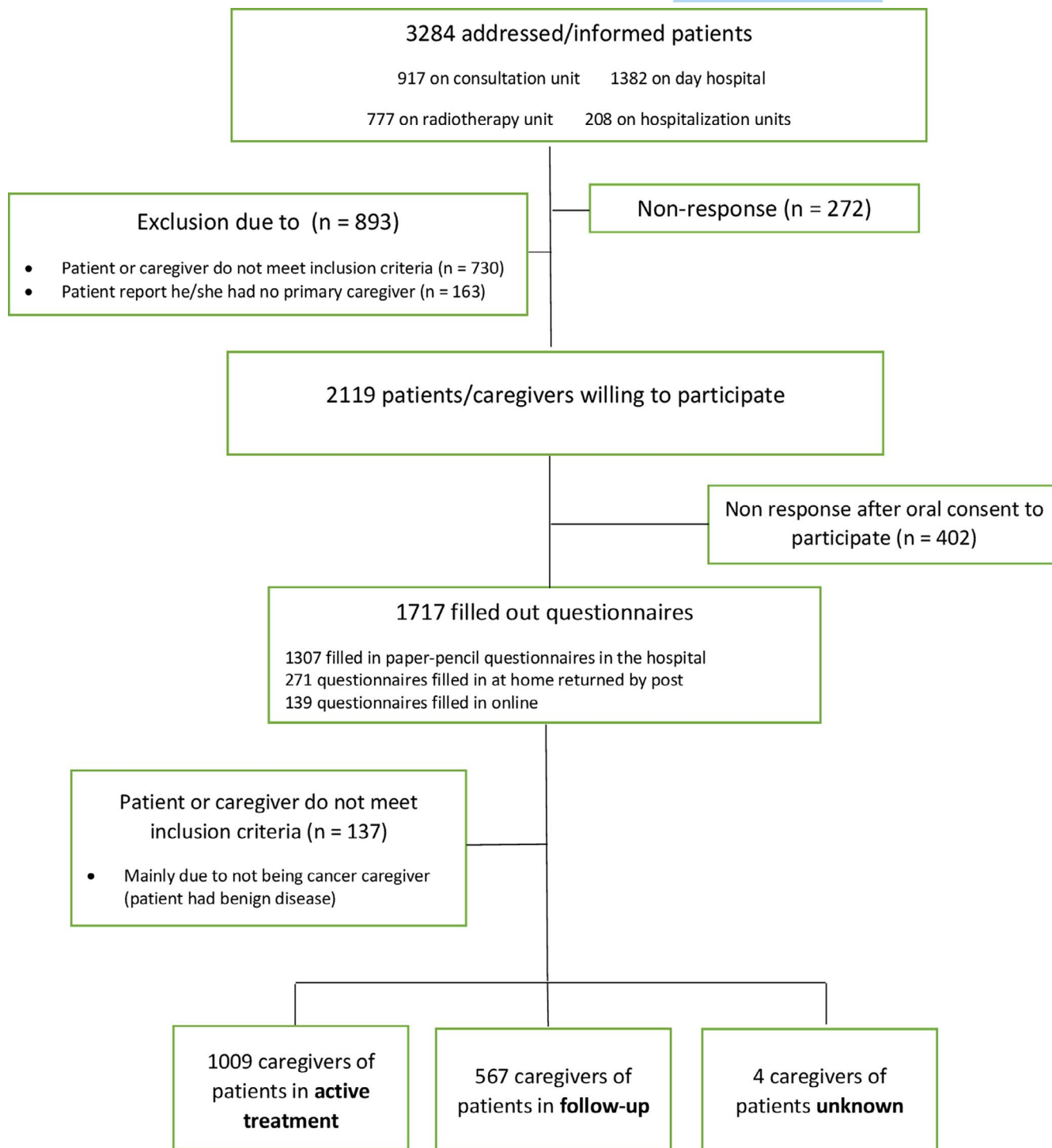


FIGURE 1 Study flow chart

An interaction with the phase of the patients' disease process (under treatment/ in follow-up) was modelled to test whether the associations differ between both groups. Per analysis, we studied the raw  $p$ -values and false discovery rates (FDRs) to account for multiple testing. A null hypothesis was rejected when the  $p$ -value was less than or equal to 0.05. Analyses have been performed using SAS software (version 9.4) for Windows.

### 2.3 | Ethical considerations

The study was approved by the Ethics Committee of UZ / KU Leuven (s 60892). All patients and caregivers received oral and written information to decide on study participation. Study participation was without obligation. All caregivers participating in the study signed informed consent. All data were stored at a secured data server of

the University Hospitals Leuven, and only the researchers had access to these files.

### 3 | RESULTS

Figure 1 presents the flow diagram of this study. The final sample consists of 1580 primary caregivers. The response rate of this study was 70%.

#### 3.1 | Caregiver and patient characteristics

Caregiver and patient characteristics are presented in Table 1. The mean age of the caregivers was 57.8 ( $\pm 13.59$ ) years. About half of the caregivers were male (48%). Participating primary caregivers were mainly spouses or partners (70%) and living together with the patient (74%). The study represents cancer caregivers of patients with a wide variety of cancer diagnoses, of which breast cancer (23%), gastro-intestinal cancer (17%) and haematological malignancy (14%) were the most common. The majority of patients (64%) received active treatment, and the other 36% were in follow-up.

The majority of caregivers (67%) indicated not providing any help for activities of daily living (ADL). Approximately one out of three caregivers provided help for at least one ADL. Concerning the instrumental activities of daily living (IADL), most of the caregivers (91%) offered assistance for at least one of these tasks.

#### 3.2 | Caregiver-reported outcomes

Table 2 presents caregiver-reported outcomes. The mean CRS score was 8.1 ( $\pm 7.06$ ), reflecting a low mean but highly variable level of distress as defined by Guberman et al (2001). A high risk for distress (CRS score  $\geq 17$ ) was noted by 13% of caregivers. The mean value on the DT was 3.3 ( $\pm 3.03$ ), which indicates a low mean level of distress. However, one out of five caregivers (20%) indicated severe levels of distress (7–10). The mean caregiver quality-of-life score was 49.4 ( $\pm 20.04$ ), with a higher score indicating worse QoL. Caregivers reported a mean satisfaction with care score of 38.1 ( $\pm 7.67$ ). Finally, mean caregiving preparedness for caregiving was 17.1 on 32 ( $\pm 6.91$ ).

Generally, caregivers of patients in follow-up had a slightly higher (but non-significant) score on the CRS than caregivers of patients in treatment. Caregivers of patients in treatment had significantly lower mean DT scores than those of patients in follow-up ( $p < 0.05$ ).

Caregivers of patients in active treatment experienced significantly worse QoL compared with caregivers of patients in follow-up ( $p < 0.05$ ). Three of the four domains of the CQOLC (burden, disruptiveness and financial concerns) differed significantly between the follow-up and the treatment group (all at  $p < 0.05$ ), with a significantly higher burden in the treatment group, while disruptiveness and positive adaptation were significantly higher during follow-up. There was no significant difference regarding financial concerns.

There was no statistical difference between the treatment and the follow-up group in terms of caregivers' satisfaction with care. Caregivers of patients in treatment experienced a significantly better preparedness for caregiving compared with caregivers of patients in follow-up ( $p < 0.05$ ).

#### 3.3 | Predictors of caregiver distress and QoL

Relationships between caregiver-reported outcomes and potential predictors are summarised in Table 3. There was a statistically significant but weak correlation between caregivers' age and caregiver risk ( $-0.171$ ) and between caregivers' age and QoL ( $-0.173$ ). Caregivers' gender ( $p < 0.05$ ), relationship to the patient ( $p < 0.05$ ) and living status ( $p < 0.05$ ) significantly influenced caregivers' distress and QoL, with female caregivers, spouses/partners and caregivers living with the patient reporting significantly higher caregiver distress and significantly worse QoL ( $p < 0.05$ ). Caregivers' educational level had no significant impact, and caregiver employment status significantly influenced QoL but not caregiver risk.

Caregiver risk for distress and QoL varied significantly on the basis of patients' cancer diagnosis ( $p < 0.05$ ). Caregivers of patients with lung cancer, head-and-neck cancer, skin cancer or a brain tumour reported significantly higher levels of distress and worse QoL. Time since diagnosis and stage of disease had a statistically significant effect on caregivers' QoL ( $p < 0.05$ ), but had no effect on caregiver distress.

Several caregiver-reported outcomes were significantly related (Table 4). There was a significant, strong and positive correlation between caregiver risk and caregiver QoL, indicating higher caregiver distress is associated with poorer QoL.

Moderately negative correlations were found between satisfaction with care and CRS score ( $-0.370$ ) and between satisfaction with care and QoL ( $-0.374$ ). The same trend was noted for caregiver preparedness, with a correlation of  $-0.454$  and  $-0.492$  between caregiver preparedness and CRS and QoL, respectively.

## 4 | DISCUSSION

The aim of this study was to evaluate caregiver distress and caregivers' quality of life and to explore predictors associated with these caregiver outcomes. Including 1580 caregivers of patients with different types of cancer, both during active treatment and follow-up, this study substantially contributes to the great need for better understanding the impact of cancer caregiving during different phases and among different cancer diagnoses.

Based upon the results of the Caregiver Risk Screen, the mean caregiver distress in this study reflects a generally low caregiver distress, but the standard deviation suggests a great variability among caregivers. In fact, more than one out of 10 caregivers had a high level of distress. Using the DT, one out of five caregivers was in

TABLE 1 Patient and caregiver characteristics

N = 1580	Total n (%)	Mean (SD)
<b>Caregivers</b>		
Caregiver age		57.8 ( $\pm$ 13.59) Range: 18–90
<b>Caregiver gender</b>		
Male	756 (47.9)	
Female	824 (52.1)	
<b>Relationship with patient</b>		
Spouse/partner	1106 (70.0)	
Child	272 (17.3)	
Parent	83 (5.3)	
Brother/sister	69 (4.3)	
Friend/relative	29 (1.8)	
Other	20 (1.3)	
<b>Caregiver's home situation</b>		
Living together with the patient	1167 (73.9)	
Living apart from the patient	413 (26.1)	
<b>Caregiver education</b>		
Elementary school	164 (10.4)	
Secondary/high school	753 (47.6)	
College/university	663 (42.0)	
<b>Caregiver employment</b>		
Currently at work	711 (45.1)	
Currently not at work	865 (54.9)	
<b>Patients</b>		
<b>Main cancer diagnosis of patient</b>		
Breast cancer	361 (23.0)	
GI cancer	292 (18.6)	
Haematological cancer	225 (14.3)	
Cancer of the urinary tract	151 (9.6)	
Gynaecological cancer	145 (9.2)	
Lung cancer	135 (8.6)	
Head-and-neck cancer	75 (4.7)	
Skin cancer	65 (4.14)	
Brain tumour	51 (3.25)	
Others (sarcoma's, thyroid cancer,...) or unknown	70 (2.0)	
Unknown	31 (1.9)	
<b>Time since cancer diagnosis of patient</b>		
>10 years	168 (10.6)	
>5 years	273 (17.3)	
>1 years	519 (32.9)	
Last year	619 (39.2)	
<b>Disease stage of the patient</b>		
In active treatment	1009 (63.9)	
In follow-up	567 (35.9)	
Unknown	4 (0.2)	

TABLE 1 (Continued)

N = 1580	Total n (%)	Mean (SD)
<b>Current treatment of the patient</b>		
Chemotherapy	461 (45.8)	
Radiotherapy	464 (45.9)	
Combination treatment based on radiotherapy	91 (1)	
Combination treatment based on systemic treatment	43 (0.4)	
<b>Caregiver network</b>		
<b>Caregiver's perception of emotional support at home</b>		
None at all	57 (3.6)	
Rather little	152 (9.7)	
Rather much	505 (32.1)	
Very much	789 (50.2)	
No opinion	68 (4.4)	
<b>Caregiver's perception of practical help at home</b>		
None at all	94 (6.0)	
Rather little	213 (13.6)	
Rather much	542 (34.5)	
Very much	630 (40.0)	
No opinion	93 (5.9)	
<b>Sources of practical help at home</b>		
None	138 (8.7)	
1 resource	612 (38.7)	
2 resources	441 (27.9)	
>2 resources	388 (24.6)	
<b>Extent of professional home care</b>		
None	505 (32.0)	
1 resource	584 (37.0)	
2 resources	309 (19.5)	
>2 resources	181 (11.5)	
<b>Caregiver roles</b>		
<b>Caregiver-related tasks for activities of daily living (ADL)</b>		
No help for ADL (patient is independent)	1049 (66.8)	
Assistance for at least one task (patient is semi- or fully dependent)	521 (33.2)	
<b>Caregiver-related tasks for instrumental activities of daily living (IADL)</b>		
No help for IADL (patient is independent)	145 (9.2)	
Assistance for at least one task (patient is semi- or fully dependent)	1433 (90.8)	

(Continues)

TABLE 2 Caregiver distress and quality of life

	Total group (n = 1579)		Treatment (n = 1009)		Follow-up (n = 567)		p-Value
	N (%) <sup>a</sup>	Mean (SD)	N (%) <sup>a</sup>	Mean (SD)	N (%) <sup>a</sup>	Mean (SD)	
Caregiver distress (CRS) (0–36)		8.1 (±7.06)	1005	7.9 (±6.32)	546	8.4 (±6.0)	0.328
Low risk (<11)	1039 (66.8)		673 (66.9)		363 (66.5)		<0.001**
Moderate level (11–16)	311 (20.0)		223 (22.2)		88 (16.1)		
High risk (17–22)	135 (8.7)		85 (8.4)		50 (9.2)		
Very high risk (23–36) <sup>b</sup>	70 (4.5)		24 (2.4)		45 (8.2)		
Caregiver distress thermometer (DT) (0–10)		3.3 (±3.03)	1002	3.0 (±3.04)	467	3.8 (±2.94)	<0.001**
Low distress (0–3)	822 (55.8)		593 (59.2)		228 (48.8)		<0.001**
Moderate distress (4–6)	358 (24.3)		217 (21.7)		139 (29.8)		
Severe distress (7–10)	293 (19.9)		192 (19.1)		100 (21.4)		
Caregiver's quality of life (CQOLC) (0–140)		49.4 (±20.04)	1001	50.2 (±18.64)	541	47.9 (±22.34)	<0.001**
Burden (10 items, range 0–40)		15.0 (±9.86)	1004	15.9 (±9.40)	542	13.3 (±10.45)	<0.001**
Disruptiveness (7 items, range 0–28)		5.9 (±5.58)	1006	5.9 (±5.09)	541	6.0 (±6.41)	0.025*
Positive adaptation (7 items, range 0–28)		15.4 (±5.53)	1004	15.1 (±5.42)	543	15.8 (±5.71)	0.013*
Financial concerns (3 items, range 0–12)		1.8 (±2.76)	1005	1.7 (±2.68)	537	1.9 (±2.89)	0.457
Caregiver's satisfaction with care (CANHELP Lite reduced version) (10–50)		38.1 (±7.67)	1006	38.2 (±7.62)	560	37.8 (±7.75)	0.300
Caregiver preparedness (PCS) (0–32)		17.1 (±6.91)	984	17.5 (±6.64)	537	16.5 (±7.36)	0.025*

Note: Interpretation of the scales: CRS: higher score = more distressed; DT: 0 = no distress; 10 = extremely distress; CQOLC: higher score = worse QOL; CANHELP Lite: higher score = more satisfied; PCS: higher score = more prepared.

<sup>a</sup>Numbers may be deviating from total (sub)sample size are declared by missing data.

<sup>b</sup>Category not conforms with CRS guidelines from Guberman et al., 2001.

\* $p < 0.05$ .

\*\* $p < 0.01$ .

severe distress. These findings correspond to the study of Zwahlen et al showing severe distress levels (7–10) in 18% of the caregivers (Zwahlen et al., 2008). Remarkably, caregiver distress measured by the DT was significantly higher for caregivers in the follow-up phase. Also, according to the CRS, distress was higher (but non-significant) in the follow-up group. Given the time frame of 'the past 7 days' on the DT, this difference may (to some degree) be explained by feelings of anxiety and feelings of stress the days before a follow-up visit at the hospital.

Generally, the mean QoL as measured by the CQOLC in our study was moderate (49.4, ±20.04), when compared to mean CQOLC scores found in the literature (Cubukcu, 2018; Tan et al., 2017). Caregivers of patients in active treatment experienced significantly worse QoL compared with caregivers of patients in follow-up ( $p < 0.05$ ). In our study, we found a strong and significant correlation between caregiver distress and caregivers' QoL (0.793). This strong correlation (0.778) was also seen in

the study of Tan, showing that caregiver distress significantly increases with deteriorating QoL among caregivers (Tan et al., 2017).

Given the high variability of caregiver outcomes, professionals have a major role in detecting caregivers at risk for severe caregiver distress. Our exploration of predictors shows that caregiver risk and QoL are influenced by patients' clinical characteristics, as well as caregivers' demographical and social characteristics. Caregivers of patients with head-and-neck cancer, skin cancer, lung cancer or a brain tumour have the highest distress and worst QoL. Regarding caregiver characteristics, and in line with previous studies (Grant et al., 2013; Hagedoorn et al., 2008; Pitceathly & Maguire, 2003; Tan et al., 2017), female caregivers were more distressed and had a poorer quality of life than male caregivers. The explanation might be that female caregivers take up a larger variety of roles and are more willing to disclose their difficulties concerning the caregiver duty and emotional problems (Hagedoorn et al., 2008; Northouse

TABLE 3 Relationship between caregiver outcomes and patient/caregiver characteristics

	Caregiver distress (CRS)			Caregiver's QOL (CQOLC)		
		p-Value			p-Value	
		Raw	FDR		Raw	FDR
<b>Caregiver characteristics</b>						
Age (correlation)	-0.171**	<0.0001**	<0.0001**	-0.173**	<0.0001**	<0.0001**
Gender (mean)						
Male	7.25	<0.0001**	<0.0001**	46.35	<0.0001**	<0.0001**
Female	8.89			52.28		
<b>Caregiver relation with the patient (mean, CI)</b>						
Partner/spouse	7.55	<.0001**	<.0001**	48.09	0.0012*	0.0018*
Child	9.61			53.32		
Parent	10.09			53.56		
Brother/sister	9.03			52.01		
Friend/relative	9.40			48.02		
Other	7.80			46.35		
<b>Caregiver's home situation (mean, CI)</b>						
Living apart	8.96	0.0046*	0.0070*	51.56	0.0127*	0.0181*
Living together	7.80			48.67		
<b>Caregiver's employment (mean, CI)</b>						
Currently at work	8.46	0.0785	0.0981	50.67	0.0336*	0.0396*
Currently not at work	7.82			48.49		
<b>Caregiver education (mean, CI)</b>						
Elementary school	8.14	0.3662	0.3726	51.22	0.0757	0.0797
Secondary/high school	8.35			50.19		
College/university	7.81			48.11		
<b>Patient characteristics</b>						
<b>Stage of disease of the patient (mean, CI)</b>						
Patient in active treatment	7.94	0.1966	0.2184	50.25	0.0307*	
Patient in follow-up	8.42			47.94		0.0384*
<b>Time of cancer diagnosis of patient (mean, CI)</b>						
>10 years	7.16	0.0893	0.1050	46.71	0.0182*	0.0243*
>5 years	8.45			50.99		
>1 year	8.53			50.95		
Last year	7.81			48.14		
<b>Main cancer diagnosis of patient (mean, CI)</b>						

(Continues)



TABLE 3 (Continued)

	Caregiver distress (CRS)			Caregiver's QOL (CQOLC)		
		p-Value			p-Value	
		Raw	FDR		Raw	FDR
Breast cancer	5.92	<0.0001	<0.0001	42.62	<0.0001	<0.0001
GI cancer	8.05			50.29		
Haematological cancer	8.42			49.15		
Lung cancer	11.01			58.63		
Cancer of the urinary tract	8.02			49.43		
Gynaecological cancer	7.44			48.32		
Brain cancer	11.39			58.64		
Head-and-neck cancer	10.62			55.55		
Skin cancer	9.92			52.85		
Current treatment of the patient (mean, CI)						
Chemotherapy	8.19	0.0070	0.0099	51.25	0.0002	0.0004
Radiotherapy	7.34			46.26		
Combination based on radiotherapy	9.87			55.75		
Combination based on systemic therapy	6.81			43.98		

\*Significant at the 0.05 level (2-tailed).

\*\*Significant at the 0.01 level (2-tailed).

et al., 2012). Subsequently, our finding that caregivers of patients with breast and gynaecological cancers experienced the lowest distress and best QoL compared with other caregivers may in part be explained by the large number of male caregivers/partners in this group.

Evidence on the impact of spousal relationship is conflicting (Mazanec et al., 2018; Pitceathly & Maguire, 2003). This study revealed the lowest distress in the group of partners/spouses and in the group of caregivers who lived together with the patient. Siblings and parents of cancer patients seemed to have the highest risk of caregiver burden. However, most interventional studies target caregivers in a spousal relationship (Kent et al., 2019; Treanor et al., 2019).

Importantly, caregiver distress and QoL are not merely influenced by factors that are easy to detect yet insensitive to change. The caregivers' personal network significantly affected caregiver outcomes as well. Based on the study results, caregivers reporting less practical help and/or emotional support had worse caregiver outcomes ( $p < 0.05$ ). This confirms earlier evidence showing that 'not having alternative caregivers' for practical help was a determining factor for increased caregiver burden and that higher levels of emotional and practical support are associated with lower caregiver burden and a lower risk for depression, distress and anxiety among caregivers (Chen et al., 2009; Pitceathly & Maguire, 2003). Based on this evidence, mobilising social support within the caregivers' personal network holds promise to prevent caregiver burden and is an important topic for healthcare professionals.

We found a strong correlation between caregiver distress and caregivers' QoL, implying that higher caregiver distress is associated with poorer QoL. These findings endorse earlier evidence on the relation between caregiver distress and QoL, both in cancer caregivers (Tan et al., 2017; Weitzner et al., 1999) and in caregivers of patients with other chronic diseases (Martinez-Martin et al., 2007).

A recent Cochrane review on psychosocial interventions for informal caregivers of people living with cancer included 19 interventions, either supporting caregivers directly or supporting caregiver-patient dyads (predominantly spousal dyads) (Treanor et al., 2019). The large majority of these interventions were psycho-educational. Two were psychotherapeutic. There was large heterogeneity in the interventions and outcome measures used for their evaluation, making it difficult to draw conclusions. Overall, Treanor and colleagues did not find clinically meaningful results of the interventions, with only slight improvement in caregiver quality of life and little to no effect on caregiver anxiety and depression (Treanor et al., 2019). The reviewers strongly recommended caregiver involvement for future intervention development.

#### 4.1 | Study limitations

While caregiver outcomes seemed comparable during treatment and follow-up, the cross-sectional design of our study does not allow for conclusions on the evolution of caregiver outcomes along the cancer trajectory. Longitudinal study is needed to learn



**TABLE 4** Correlations between caregiver distress and quality of life

Variable	Caregiver distress (CRS) <i>r</i>	Caregiver's QOL (CQOLC) <i>r</i>
Caregiver distress (CRS)	–	0.793**
Caregiver distress (DT)	0.455**	0.441**
Caregiver's QOL (CQOLC)	0.793**	–
Caregiver's satisfaction with care (CANHELP Lite)	–0.370**	–0.374**
Caregiver's preparedness (PCS)	–0.454**	–0.492**

\*\*Correlation is significant at the 0.01 level (2-tailed).

how caregiver outcomes evolve over time. Having no information on caregivers' burden and quality of life before the patient's cancer diagnosis and given the absence of a control group, our results merely present caregiver outcomes at the time of our study. Secondly, we recommend further research to explore caregiver distress unrelated to close hospital visits. Next, the non-response may limit the generalisability of the findings. While this study exposed several predictors of caregiver distress, some of these predictors may have been interrelated and this was not exposed by bivariate analysis. Finally, our study focused on negative effects of cancer caregiving, except for 7 items concerning positive adaptation in the CQOLC. Limited data are available on the positive aspects of cancer caregiving, such as enhanced intimacy and personal growth (Kent et al., 2016; Li & Loke, 2013).

## 4.2 | Clinical implications

First, our results call upon healthcare professionals to better address the impact of cancer caregiving, not only during active treatment but also in follow-up. Routine distress screening is an approach to detect those caregivers in need for support. A small pilot study introduced electronic distress screening in an ambulatory cancer surgery centre. Caregivers perceived the screening as an acknowledgement of their caregiving roles and a permission to consider their own needs (Shaffer et al., 2019). Further research is needed to explore the feasibility and utility of distress screening for caregivers. Screening is only one step in addressing caregivers' needs. While caregivers' uptake of services is known to be limited because of many barriers (e.g. not wanting to put their needs ahead of the patients' needs, practical difficulties) (Applebaum & Breitbart, 2013; Badr et al., 2016), caregivers in the study of Shaffer appreciated to be referred to available resources targeting their needs (Shaffer et al., 2019). The evolution towards technology-driven approaches may offer caregivers the flexibility of completing interventions at home, and to personalise content based on their individual needs (Sun et al., 2019).

## 5 | CONCLUSION

The aim of this study was to evaluate caregiver distress and caregivers' quality of life and to explore their potential predictors. Overall, caregivers experienced a low-to-moderate risk of caregiver distress and a moderate QoL both during cancer treatment and in follow-up. However, the variability among caregivers is high. About 13% reported a high caregiver risk and 20% reported severe distress. There was a strong and significant correlation between caregiver distress and caregivers' QoL. The results of this study call upon healthcare professionals to detect cancer caregivers at high risk for distress and refer them to appropriate care.

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## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest. The authors have no financial or personal relationships with people or organisations that could inappropriately influence this study.

## DATA AVAILABILITY STATEMENT

Data are available on request from the authors.

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## REFERENCES

- Applebaum, A. J., & Breitbart, W. (2013). Care for the cancer caregiver: A systematic review. *Palliat Support Care*, 11(3), 231–252. <https://doi.org/10.1017/S1478951512000594>
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13(6), 375–384. <https://doi.org/10.1002/nur.4770130605>
- Badr, H., Herbert, K., Reckson, B., Rainey, H., Sallam, A., & Gupta, V. (2016). Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *Journal of Psychosocial Oncology*, 34(4), 336–346. <https://doi.org/10.1080/07347332.2016.1195901>
- Balfe, M., Butow, P., O'Sullivan, E., Goberman-Hill, R., Timmons, A., & Sharp, L. (2016). The financial impact of head and neck cancer caregiving: A qualitative study. *Psychooncology*, 25(12), 1441–1447. <https://doi.org/10.1002/pon.4079>
- Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology*, 25(30), 4829–4834. <https://doi.org/10.1200/JCO.2006.10.0909>
- Carter, P. A. (2006). A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nursing*, 29(2), 95–103. <https://doi.org/10.1097/00002820-200603000-00003>
- Chen, S. C., Tsai, M. C., Liu, C. L., Yu, W. P., Liao, C. T., & Chang, J. T. (2009). Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nursing*, 32(6), 473–481. <https://doi.org/10.1097/NCC.0b013e3181b14e94>
- Cubukcu, M. (2018). Evaluation of quality of life in caregivers who are providing home care to cancer patients. *Supportive Care in Cancer*, 26(5), 1457–1463. <https://doi.org/10.1007/s00520-017-3968-1>

- Cuttillo, A., O'Hea, E., Person, S., Lessard, D., Harralson, T., & Boudreaux, E. (2017). The distress thermometer: Cutoff points and clinical use. *Oncology Nursing Forum*, 44(3), 329–336. <https://doi.org/10.1188/17.ONF.329-336>
- Given, B. A., Sherwood, P., & Given, C. W. (2011). Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology, Biomarkers & Prevention*, 20(10), 2015–2021. <https://doi.org/10.1158/1055-9965.EPI-11-0611>
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., & DeVoss, D. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31(6), 1105–1117. <https://doi.org/10.1188/04.ONF.1105-1117>
- Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S., & Juarez, G. (2013). Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncology Nursing Forum*, 40(4), 337–346. <https://doi.org/10.1188/13.ONF.337-346>
- Guberman, N., Keefe, J., Fancey, P., Nahmiash, D., Barylak, L., Beeman, J., Grenier, A., Robertson, M. L., & Vezina, L. (2001). Development of screening and assessment tools for family caregivers NA 145. Retrieved from Health Transition Fund of Health Canada website: <http://www.msvu.ca/site/media/msvu/healthCanada.pdf>
- Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134(1), 1–30. <https://doi.org/10.1037/0033-2909.134.1.1>
- Halkett, G. K., Lobb, E. A., Shaw, T., Sinclair, M. M., Miller, L., & Hovey, E. (2017). Distress and psychological morbidity do not reduce over time in carers of patients with high-grade glioma. *Supportive Care in Cancer*, 25(3), 887–893. <https://doi.org/10.1007/s00520-016-3478-6>
- Henriksson, A., Andershed, B., Benzein, E., & Arestedt, K. (2012). Adaptation and psychometric evaluation of the Preparedness for Caregiving Scale, Caregiver Competence Scale and Rewards of Caregiving Scale in a sample of Swedish family members of patients with life-threatening illness. *Palliative Medicine*, 26(7), 930–938. <https://doi.org/10.1177/0269216311419987>
- Henriksson, A., Hudson, P., Ohlen, J., Thomas, K., Holm, M., & Carlander, I. (2015). Use of the preparedness for caregiving scale in palliative care: A Rasch evaluation study. *Journal of Pain and Symptom Management*, 50(4), 533–541. <https://doi.org/10.1016/j.jpain.2015.04.012>
- Heyland, D. K., Jiang, X., Day, A. G., & Cohen, S. R. (2013). The development and validation of a shorter version of the Canadian Health Care Evaluation Project Questionnaire (CANHELP Lite): A novel tool to measure patient and family satisfaction with end-of-life care. *Journal of Pain and Symptom Management*, 46(2), 289–297. <https://doi.org/10.1016/j.jpainsymman.2012.07.012>
- Hodgkinson, K., Butow, P., Hobbs, K. M., & Wain, G. (2007). After cancer: The unmet supportive care needs of survivors and their partners. *Journal of Psychosocial Oncology*, 25(4), 89–104. [https://doi.org/10.1300/J077v25n04\\_06](https://doi.org/10.1300/J077v25n04_06)
- Kent, E. E., Mollica, M. A., Buckenmaier, S., & Wilder Smith, A. (2019). The characteristics of informal cancer caregivers in the United States. *Seminars in Oncology Nursing*, 35(4), 328–332. <https://doi.org/10.1016/j.soncn.2019.06.002>
- Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y., & Shelburne, N. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987–1995. <https://doi.org/10.1002/cncr.29939>
- Krebber, A. M., Jansen, F., Witte, B. I., Cuijpers, P., de Bree, R., & Becker-Commissaris, A. (2016). Stepped care targeting psychological distress in head and neck cancer and lung cancer patients: A randomized, controlled trial. *Annals of Oncology*, 27(9), 1754–1760. <https://doi.org/10.1093/annonc/mdw230>
- Kris, A. E., Cherlin, E. J., Prigerson, H., Carlson, M. D., Johnson-Hurzeler, R., & Kasl, S. V. (2006). Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *American Journal of Geriatric Psychiatry*, 14(3), 264–269. <https://doi.org/10.1097/01.JGP.0000194642.86116.ce>
- Lafaye, A., De Chalvron, S., Houede, N., Eghbali, H., & Cousson-Gelie, F. (2013). The Caregivers Quality of Life Cancer index scale (CQoLC): An exploratory factor analysis for validation in French cancer patients' spouses. *Quality of Life Research*, 22(1), 119–122. <https://doi.org/10.1007/s11136-012-0113-y>
- Li, Q., & Loke, A. Y. (2013). The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research. *Psychooncology*, 22(11), 2399–2407. <https://doi.org/10.1002/pon.3311>
- Martinez-Martin, P., Serrano-Duenas, M., Forjaz, M. J., & Serrano, M. S. (2007). Two questionnaires for Parkinson's disease: Are the PDQ-39 and PDQL equivalent? *Quality of Life Research*, 16(7), 1221–1230. <https://doi.org/10.1007/s11136-007-9224-2>
- Martinez-Rodriguez, S., Ortiz-Marques, N., Iraurgi, I., Carrasco, M., & Miguel, J. J. (2013). Adaptation and analysis of psychometric features of the Caregiver Risk Screen: A tool for detecting the risk of burden in family caregivers. *International Psychogeriatrics*, 25(5), 755–764. <https://doi.org/10.1017/S1041610212002426>
- Matthews, B. A. (2003). Role and gender differences in cancer-related distress: A comparison of survivor and caregiver self-reports. *Oncology Nursing Forum*, 30(3), 493–499. <https://doi.org/10.1188/03.ONF.493-499>
- Mazanec, S. R., Reichlin, D., Gittleman, H., & Daly, B. J. (2018). Perceived needs, preparedness, and emotional distress of male caregivers of postsurgical women with gynecologic cancer. *Oncology Nursing Forum*, 45(2), 197–205. <https://doi.org/10.1188/18.ONF.197-205>
- McLean, L. M., Walton, T., Matthew, A., & Jones, J. M. (2011). Examination of couples' attachment security in relation to depression and hopelessness in maritally distressed patients facing end-stage cancer and their spouse caregivers: A buffer or facilitator of psychosocial distress? *Supportive Care in Cancer*, 19(10), 1539–1548. <https://doi.org/10.1007/s00520-010-0981-z>
- Neefs, H. (2015). *Onzichtbaar maar onmisbaar: Welke knelpunten ervaren mantelzorgers van kankerpatiënten?* Retrieved from <https://www.komoptegenkanker.be/blog/mantelzorg-onzichtbaar-maar-onmisbaar>
- Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Vedsted, P., Bro, F., & Guldin, M. B. (2017). Preloss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study. *Psychooncology*, 26(12), 2048–2056. <https://doi.org/10.1002/pon.4416>
- Northouse, L., Williams, A. L., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30(11), 1227–1234. <https://doi.org/10.1200/JCO.2011.39.5798>
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer*, 39(11), 1517–1524. [https://doi.org/10.1016/s0959-8049\(03\)00309-5](https://doi.org/10.1016/s0959-8049(03)00309-5)
- Rivera, H. R. (2009). Depression symptoms in cancer caregivers. *Clinical Journal of Oncology Nursing*, 13(2), 195–202. <https://doi.org/10.1188/09.CJON.195.202>
- Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (2007). Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research*, 56(6), 425–433. <https://doi.org/10.1097/01.nnr.0000299852.75300.03>
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum*, 35(1), 49–56. <https://doi.org/10.1188/08.onf.49-56>
- Shaffer, K. M., Benvenuto, S., Zaleta, A. K., Levine, M., Bellantoni, C., & Dannaoui, A. (2019). Feasibility and acceptability of distress

- screening for family caregivers at a cancer surgery center. *Oncology Nursing Forum*, 46(2), 159–169. <https://doi.org/10.1188/19.ONF.159-169>
- Sorensen, S., Pinqart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*, 42(3), 356–372. <https://doi.org/10.1093/geront/42.3.356>
- Sun, V., Raz, D. J., & Kim, J. Y. (2019). Caring for the informal cancer caregiver. *Current Opinion in Supportive and Palliative Care*, 13(3), 238–242. <https://doi.org/10.1097/SPC.0000000000000438>
- Tan, J. Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2017). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care*, 27(1), e12691. <https://doi.org/10.1111/ecc.12691>
- Treanor, C. J., Santin, O., Prue, G., Coleman, H., Cardwell, C. R., & O'Halloran, P. (2019). Psychosocial interventions for informal caregivers of people living with cancer. *Cochrane Database Systematic Review*, 6, CD009912. <https://doi.org/10.1002/14651858.CD009912.pub2>
- Weitzner, M. A., Jacobsen, P. B., Wagner, H. Jr, Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index-Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8(1-2), 55–63.
- Williams, A. L., & McCorkle, R. (2011). Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliative and Supportive Care*, 9(3), 315–325. <https://doi.org/10.1017/S1478951511000265>
- Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening cancer patients' families with the distress thermometer (DT): A validation study. *Psychooncology*, 17(10), 959–966. <https://doi.org/10.1002/pon.1320>

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