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“What about you? How are you doing?”

Impact of caregiving on informal caregivers of oncology patients in follow-up



Eindwerk neergelegd tot het behalen van het getuigschrift
van de opleiding ‘Psycho-oncologie’

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PREFACE

The basis for this research originally stemmed from my affinity and passion for supporting caregivers of brain tumor patients in a pilot care project (2014-2016) in the University Hospitals of Leuven. As oncology nurse, I'm on a daily basis impressed with by the strong companionship and motivation of the informal caregivers. I am convinced of their vulnerabilities and greater need for support as part of the routine care.

Our present oncology care with shorter hospital based treatments imply a shift of responsibilities to home care and to the available informal caregivers. With the increasing cancer prevalence and the evolution of cancer to a chronic disease, there will be a greater need to understand and support the informal caregivers of our oncology patients.

I've got the opportunity to set up a study in the University Hospitals of Leuven, with financial support by Albertfonds in 2017 to evaluate the experiences of caregivers of oncology patients in our hospital. In this research, we investigated the burden, quality of life, satisfaction with care and the preparedness for caregiving in informal caregivers of oncology patients.

This master thesis focuses on the experiences of caregivers of patients who were in follow-up phase, and is part of a larger study, aimed to explore these outcomes in caregivers of patients who were in active treatment (systemic treatment and/ or radiotherapy). I decided to write this master thesis in English, because I want to gain experience in scientific English vocabulary and writing. Secondly, I want to take the opportunity to publish a scientific publication, based on the research presented in this paper.

In truth, I could not have achieved this master thesis without a strong support from my promotor doctor Coolbrandt Annemarie. She provided me a lot of advice and guidance throughout the research project and for the statistical analysis. Secondly, I want to thank my co-promotor professor Andries Caroline and the Cédric Hèle Instituut to give me the opportunity to achieve this master thesis.

Also, I want to thank my husband and my family for their support and their motivation.

Last but not least, thank you to my colleagues of the oncology consultation unit in the University Hospitals of Leuven for their practical help to hand out the questionnaires to the informal caregivers of the patients.

Thank you all for your unwavering support.

Ine Decadt

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ABSTRACT

Objectives: The recent trend toward longer survival and shift to ambulatory care has increased the number of informal cancer caregivers and may have amplified their growing responsibilities in the caregiving role. This study aims at evaluating caregiver distress and quality of life in primary caregivers of cancer patients during follow-up.

Methods: This cross-sectional descriptive study was performed by a questionnaire in 516 caregivers of cancer patients with different cancer diagnoses in the University Hospitals of Leuven. Caregiver reported outcomes were measured by the Caregiver Risk Screen (CRS), Distress Thermometer (DT), and Caregivers Quality of Life Index-Cancer (CQOLC).

Results: Caregivers of oncology patients in follow-up experienced generally a low until moderate risk of caregiver distress and a moderate level of QoL. About 20 % report high distress levels. There was a strong significant correlation between caregiver distress scores on CRS (.847) and on DT (.656) with caregiver's QoL. Distressed caregivers of oncology patients in follow-up faced a low QoL, what is related to several variables. Fewer emotional and practical resources, non-spousal relationship to the patient (e.g. being parent, child or friend), lower education level and living together with patient are predictive factors ($p < 0.05$) for higher distress and worse QoL. Also, the type of cancer diagnosis had a significant effect: caregivers of patients with head-and neck, skin, lung or a brain cancer reported the highest distress and lowest QoL-scores.

Conclusions: These findings encourage recognition of caregivers in follow-up as part of the care team, to improve their knowledge about, access to and the support available.

Keywords:

Informal caregiver, caregiver burden, quality of life, satisfaction, preparedness for caregiving, oncology

TABLE OF CONTENTS

Preface.....	3
Abstract	4
Table of contents.....	5
Introduction.....	6
Methods	11
Design and setting.....	11
Sample.....	11
Procedure	12
Data collection.....	13
Statistical analysis.....	16
Results	17
Description of caregiver and patient characteristics	17
Care network of the caregiver.....	20
Caregiver tasks and their content of their caregiving role.....	22
Caregiver reported outcomes	23
Relationship of caregiver-reported outcomes with caregiver and patient demographic data	25
Interrelationships among caregiver-reported outcomes.....	28
Discussion.....	29
Strengths and limitations	31
Implications for nursing practice.....	32
Conclusion	34
References.....	35
Attachments	39
1/ Approval study by the Ethics Committee	39
2/ Informed Consent for the caregiver	42
3/ Questionnaire for the caregiver.....	47

INTRODUCTION

Countries worldwide face increasing challenges in health care owing to an ageing population and increasing life expectancy. In cancer care, these developments together with an increasing cancer prevalence prove to be an affirming reality (*Hodgkinson, Butow, Hobbs, & Wain, 2007*). Given the trend toward shorter hospital stays and the evolution of some types of cancer to chronic diseases, cancer patients are increasingly left to self-manage their illness, including debilitating side effects of treatment at home (*Ream et al., 2013; Stenberg, Ruland, & Miaskowski, 2010*). At the same time, the ambulatory treatment leaves limited opportunities for healthcare professionals in the hospital to provide not only state-of-the-art cures but also state-of-the-art care (*Ream et al., 2013*).

With improved cancer survival rates, an increasing number of patients is living longer and may experience ongoing or new physical, psychosocial, emotional or cognitive challenges which imply a shift of responsibilities to home care and to the available informal caregivers (*B. A. Given, Sherwood, & Given, 2011; Grant et al., 2013; Krebber et al., 2016; Northouse, Williams, Given, & McCorkle, 2012; Pitceathly & Maguire, 2003; Tan, Molassiotis, Lloyd-Williams, & Yorke, 2017; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999*).

The growing role of family caregivers takes place in the context of high levels of distress. Indeed, a cancer diagnosis has a significant impact not only on patients, but also on their informal caregivers; (*Grant et al., 2013; Matthews, 2003; Stenberg et al., 2010; Weitzner et al., 1999*). It causes a major disruption of the daily lives of patients and their informal caregivers, and produces a new set of challenges for both (*B. Given et al., 2004*) Logically, caregivers are in great need of emotional support themselves (*Applebaum & Breitbart, 2013*). At the same time, the patients for whom they provide care, are sometimes no longer able to provide their caregivers with the emotional support that they once did (*Francis, Worthington, Kypriotakis, & Rose, 2010*).

Informal care is the care performed by family members and/or friends as opposed to health care professionals (*Prue, Santin, & Porter, 2015*). The primary caregiver can be defined as the individual who devotes most of his/her time to care for a dependent person (*Van Durme, Macq, Jeanmart, & Gobert, 2012*) taking on the main tasks involved in care with all the responsibilities that this entails (*Martinez-Rodriguez, Ortiz-Marques, Iraurgi, Carrasco, & Miguel, 2013*). The primary caregivers of cancer patients are often their spouses, partners, children, close relatives or friends (*Tan et al., 2017*). In this paper, informal caregivers or family caregivers are referred to as “caregivers”.

In the context of cancer, 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 (*Lund, Ross, Petersen, & Groenvold, 2015*). On top of that, caregivers may play a significant

role in decision-making processes and facilitate informed choices in their loved one's best interest (Adams, Boulton, & Watson, 2009).

Although caregivers provide more than half of the care needed by patients with cancer, they are largely invisible to the professional healthcare team. Also, they are seldom identified as care partners and healthcare providers have high expectations for these informal caregivers to provide complex cancer care (KomOpTegenKanker, 2015).

Several studies have indeed shown that caregivers face a wide range of unmet needs. (Hodgkinson et al., 2007; Kim, Schulz, & Carver, 2007). Caregivers often assume the caregiving role with little or no preparation and without considering whether they have enough knowledge, resources or skills (B. A. Given et al., 2011; Northouse et al., 2012; Williams & McCorkle, 2011).

The emotional and physical demands of caregiving have a substantial impact on caregivers' physical and mental well-being. Studies have reported high rates of burden, anxiety, depression and distress among caregivers (Martinez-Rodriguez et al., 2013; Pitceathly & Maguire, 2003; Tan et al., 2017). For example, 39% of caregivers from brain tumor patients suffer from depression (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007) and 40 % of caregivers of advanced gastrointestinal or lung cancer patients experienced anxiety disorders (Janda et al., 2007). Remarkably, several studies have reported high levels of anxiety and depression (B. Given et al., 2004; Kris et al., 2006; Rivera, 2009) or distress (Adams et al., 2009; Merckaert et al., 2013; Papastavrou, Charalambous, & Tsangari, 2009; Pitceathly & Maguire, 2003). among caregivers that are comparable or even surpass those of the patients for whom they provide care (Braun et al., 2007; Hodgkinson et al., 2007; McLean, Walton, Matthew, & Jones, 2011).

Besides the mental and emotional impact, caregiving has shown to negatively affect relationships, self-esteem, immune functioning, fatigue and sleep disturbances, hypertension, cardiovascular problems etc. (B. A. Given et al., 2011; Lund et al., 2015; Northouse et al., 2012; Weitzner et al., 1999). Additionally, caring for a patient with cancer places a large financial demand on those providing care (Balfe et al., 2016). Studies have reported a lack of exercise, an increase in alcohol and tobacco consumption and a decreased health service utilization among family caregivers. (Applebaum & Breitbart, 2013)

An important body of evidence shows that several caregiver-related factors such as age, gender, relationship with the patient, caregiving duration and intensity and finally the type of cancer diagnosis may affect the extent to which caregivers experience these negative effects (Northouse et al., 2012; Sorensen, Pinguart, & Duberstein, 2002). Following characteristics 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*).

Besides the negative impact of caregiving, caregiving for patients with cancer has also been associated with positive experiences. By fulfilling their caregiving role, caregivers report a motivating and rewarding feeling (*Coolbrandt et al., 2015; Kim et al., 2007; Sterckx et al., 2013*). In several studies, positive effects of providing care such as companionship, self-esteem, support, enjoyment, uplifts and satisfaction have also been reported, which provide a buffer to the residual negative effects of caregiving. Caregivers report also positive changes: appreciation of life, acceptance, reprioritization of values, increased self-confidence, stronger interpersonal relationships, and strengthened spirituality (*Cohen & Kuten, 2006; B. A. Given et al., 2011*).

The importance of caregiver needs and their high levels of distress have been recognized worldwide and a variety of psychosocial interventions have been developed to address those needs (*Applebaum & Breitbart, 2013*). Most of these interventions have been offered freely to caregivers without assessment of individual needs, interests or circumstances (*Applebaum & Breitbart, 2013; Pitceathly & Maguire, 2003*). Many family members show resistance towards interventions, especially in the initial phase of the disease or when they don't feel in need of help or support (*Pitceathly & Maguire, 2003*).

The systematic review of Applebaum (2013) reports 49 different types of caregiver interventions. 65% of the studies showed positive and significant improvements in functioning for caregivers and/or the patients for whom they provide care. Caregiver interventions can be categorized in several types of interventions: psycho-education, problem-solving/skills building interventions, supportive therapy, family/couples therapy, cognitive-behavioral therapy (CBT), interpersonal therapy (IPT), complementary and alternative medicine (CAM) interventions and existential therapy. The study of Hudson (2008), evaluating the effect of three person-group sessions in caregivers of patients with a heterogeneous cancer type in palliative care, reports a significant positive effect on their preparedness/competence in caregiving, rewards and information needs. A CBT-intervention consisting of 9 group sessions for 100 caregivers of cancer patients, showed significant decreases in psychological distress, an improved sleep and perceived support at the follow-up stage (*Cohen & Kuten, 2006*).

At the University Hospitals of Leuven, a caregiver intervention was designed for family caregivers of patients with glioma (an aggressive type of brain tumor) in 2014 (*Decadt, 2017*). We developed a care pathway to better detect and address the needs of glioma patients and their family caregivers. Since both evidence and clinical experience on collaboration with primary care in oncology were limited, we set-up a pilot project aimed at implementing, evaluating and improving the collaboration between hospital and home care.

At the start of the treatment, patients as well as their caregivers enrolled in a care pathway led by two hospital nurse coordinators and two home care nurse coordinators. On top of the routine oncology care by the regular healthcare professionals, these nurse coordinators offered counseling to the brain tumor patients and their caregivers and were available by telephone and email. Given the heavy burden of living with glioma for caregivers (*Coolbrandt et al., 2015; McConigley, Halkett, Lobb, & Nowak, 2010; Seekatz et al., 2017*) providing caregiver support and preventing caregiver burden were top priorities throughout the care pathway. This was done by actively detecting the needs of caregivers in their home situation and by planning multidisciplinary action in a timely and proactive manner. The additional care was highly valued. Caregivers reported a great source of emotional and practical support, personal attention and empathy. Also, the willingness to listen and the time offered for a conversation from the coordinators were experienced highly valuable by caregivers (*Decadt, 2017*).

Interventions designed to produce psychological benefits should target caregivers at high risk of distress or affective disorders, and be tailored to their specific needs (*Pitceathly & Maguire, 2003*). Logically, further development and implementation of initiatives to improve the well-being of caregivers in cancer care should be preceded by a profound evaluation of the impact of caregiving on family caregivers. In daily oncology care, healthcare professionals such as doctors, nurses, psychologists or social workers do not always know who the caregiver of the patient is. Moreover the content of their caregiving role and their quality of life is often unknown. The first challenge, as described by *Asadi-Lari et al (2004)*, is to define the group(s) of the cancer caregivers and their needs. Understanding caregiver distress, quality of life, satisfaction with care and their skills preparedness is a first step to designing specific interventions to meet their needs and wishes. This can, in turn, improve satisfaction and commitment of care and finally empower the quality of life of both caregivers and patients (*Asadi-Lari, Tamburini, & Gray, 2004*).

Available studies often include caregivers of patients with a specific type of cancer patients (for example lung cancer patients (*Ellis, 2012; Grant et al., 2013*), mostly breast or prostate cancer patients (*Adams et al., 2009*) or colorectal cancer patients (*van Ryn et al., 2011*). Furthermore, many studies

often focus on caregivers from patients during palliative care or end-of-life (*Harding et al., 2012; Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016; Williams & McCorkle, 2011*).

Little is known about caregivers' long-term well-being, while patients with cancer tend to live longer (*Hodgkinson et al., 2007*). More research is needed to explore the experiences of caregivers of patients with different types of cancer and in various stages of disease such as the diagnostic phase, the treatment phase or the follow-up phase (*Francis et al., 2010; B. Given et al., 2004; B. A. Given et al., 2011*). Moreover little is known about caregiver variables in the phase after active treatment such as changes in employment, social support, role strain, anxiety, depression, and quality of care for the patient (*Stenberg et al., 2010*).

The present research entails a questionnaire study including caregivers of patients with any kind of cancer at different stages in the disease trajectory both during treatment (chemotherapy, immunotherapy, radiotherapy or combinations of these) and in follow-up or survivorship. Characterizing the experiences of caregivers of oncology patients is challenging because the patient characteristics can vary widely and the caregivers themselves are a highly heterogeneous group (*van Ryn et al., 2011*).

This study is part of a large research where caregivers of cancer patients during treatment and in follow-up were included. In this paper, we only focus on the caregivers of patients in follow-up and for who the oncology treatment has finished. The aim of this study is to describe the impact of caregiving on the primary caregivers of oncology patients in follow-up at the University Hospitals of Leuven. These insights will help to more pertinently address the experiences of these caregivers and understand the impact of the caregiving role. Even more, it can be a powerful step to target initiatives to those caregivers with the greatest needs.

The following research questions were posed: what is the experience and impact of caregiving in caregivers of adult patients with cancer during follow-up in terms of:

- a. Caregiver distress
- b. Caregivers' quality of life
- c. Caregivers' satisfaction with care
- d. Caregivers' preparedness

METHODS

DESIGN AND SETTING

Since our aim was to quantify the extent of caregiver distress, quality of life, satisfaction with care and preparedness in caregivers of patients with cancer, we performed an observational, cross-sectional study using questionnaires. A panel of caregivers was involved in the preparation of the study protocol. Several aspects of the study protocol (such as the content and length of the questionnaire, the selection procedure and the process of data collection) were discussed with 10 primary caregivers of cancer patients to assure the study's acceptability to the target population. The anonymity and confidentiality of these caregivers were assured.

The study was conducted at the University Hospitals Leuven, Belgium. Thirteen oncology wards were involved in the study, 2 of which were day hospitals and 2 were consultation units. As mentioned above, this study is part of a greater study which focuses on caregivers of patients in active treatment (systemic treatment and/or radiotherapy) and in follow-up. For this master thesis, we focused only on caregivers of oncology patients who were in follow-up. Consequently, the recruitment for this part of the study took place on the two ambulatory consultation units (oncology consultation E 612 and respiratory consultation E 409) of the University Hospitals in Leuven.

Caregivers of oncology patients in follow-up were recruited on 13 working days between December 4, 2017 and January 25, 2018. The study was approved by the Ethics Committee of the University Hospitals of Leuven (study number s60892, approval in attachment 1).

SAMPLE

For this study, we addressed adult caregivers of cancer patients with any cancer diagnosis if they were in follow-up after treatment. Caregivers of pediatric oncological patients (ea. parents, grandparents, brothers or sisters) or caregivers of patients in palliative care were excluded.

Caregivers were eligible if they were (a) caregiver of an adult patient with cancer in follow-up after treatment, (b) the primary caregiver, i.e. the caregiver appointed by the patient as being closest to him/her, (c) adult (18 years and older), (d) Dutch, (e) able to fill out the questionnaire and (f) if they agreed to participate in the study by signing the informed consent. Both caregivers present or absent at the patients' hospital visit were eligible for this study.

The target population of the study consisted of 500-1000 primary caregivers providing care for oncology patients in active treatment or in follow-up in the University Hospitals of Leuven.

PROCEDURE

With the intent of reaching primary caregivers both present and absent at the hospital, we prepared a procedure taking into account several possible scenarios: (1) patient alone at the hospital, (2) patient accompanied by caregiver but not the primary caregiver, (3) patient accompanied by caregiver confirmed by the patient to be the primary caregiver. Logically, we approached the patients first: we shortly explained about the study and asked about his/her primary caregiver. Next, and with the agreement of the patient, we provided the primary caregiver with information about the study. When the latter was not present, we provided the patient with all necessary information to inform his/her primary caregiver about the study and for the caregiver, to consider and complete study participation (a research flyer, study information and informed consent, questionnaire). This recruitment method allowed for a respectful consent of the patient prior to the invitation of his/her primary caregiver to participate in this research. Eligible caregivers were actively informed about the study and invited to participate by one of the researchers. They were also handed study information and informed consent.

Scenario (1) or (2): patient is alone or the primary caregiver is not present in the hospital

When the patient was alone (without primary caregiver) or when the patient was accompanied by another caregiver (not the primary caregiver), the researcher informed the patient about the study. Both oral and written information was provided. The patient was asked if he/she was willing to inform his/her primary caregiver. If so, the patient received a flyer for his/her caregiver at home. This flyer contained an introduction to the research and contact details of the researchers. There was no link between the gathered contact details during the introductory talk and the completed questionnaire of the caregiver. If the patient agreed, the questionnaire for the primary caregiver was offered to the patient.

Scenario (3): patient is accompanied with his/her primary caregiver in the hospital

When the primary caregiver accompanied the patient (on time of recruitment) the researcher provided the caregiver with both oral and written information (flyer) about the research. The primary caregiver was given time to think about his/her possible study participation and to ask for more information. If the primary caregiver wanted to take part in this study, the questionnaire and the informed consent form were given. Respondents were offered the choice to complete the questionnaire during their

hospital visit or at home, and to fill out a paper-pencil questionnaire or to complete the questionnaire online.

DATA COLLECTION

The one-time questionnaire bundled five scales measuring the four outcomes of this study: caregiver distress (2 scales), caregivers' QoL, caregivers' satisfaction and caregivers' preparedness. Three independent researchers performed forward- and back-translation to translate the original questionnaires from English to Dutch. Some scales were shortened to limit the length of the final questionnaire or to prevent overlap between scales. The face validity of the questionnaire was checked and commented on by a panel of 10 caregivers during the period prior to the data collection. Some minor linguistic changes were made, based on their feedback. Completion of the questionnaires took about 20-30 minutes.

Caregiver distress

Primary outcome caregiver distress was measured using the Caregiver Risk Screen (CRS) (*Guberman N., 2001a, 2001b*) The CRS is a tool primarily designed for use by home care agencies at intake, to determine whether a caregiving situation is 'at risk' and the level of urgency required for intervention, but it has also been regularly used in hospital (oncology and geriatric) settings and as a pre- and post-test instrument for caregiver interventions (*Guberman N., 2001a, 2001b*).

This 12-item scale evaluates the physical and mental health of the caregiver. The scale is made up of 12 items with a Likert-type response option from 0 (totally disagree) to 3 (totally agree). The item-scores can be summed up to a total score ranging from 0 to 36. The lower the total score, the lower the caregiver distress. CRS-scores below 11 indicates low risk for caregiver distress. Moderate risk (11-16), high risk (17-22) and very high risk (23-30) were defined by Guberman et al (2001b). Research shows that this instrument has a high level of internal consistency (Cronbach's alpha: 0.86) and has an appropriate convergent validity (*Guberman N., 2001b; Martinez-Rodriguez et al., 2013*).

In addition to the Caregiver Risk Screen (CRS), the caregiver psychological distress was measured by the Distress Thermometer (DT). This measurement instrument is an efficient, low subject burden method to evaluate psychological distress over the past week (*Cutillo et al., 2017; Mazanec, Reichlin, Gittleman, & Daly, 2018*). DT is based on a visual graphic color-coded Likert-scale of 0 (no distress) to 10 (extremely distressed). Zwahlen et al (2008) reports the first validation of the distress thermometer as a screening instrument for symptoms of depression and anxiety in family members of cancer patients. Scores were categorized to low caregiver distress (0-4), moderate caregiver distress (5-6) and

high caregiver distress (7-10). (*Halkett et al., 2017; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008*).

Caregivers' Quality of Life (QoL)

We used the Caregivers Quality of Life Index-Cancer (CQOLC) to measure the primary outcome quality of life among caregivers of cancer patients. The CQOLC a 35-item self-reported instrument capturing four dimensions of caregiver QoL: burden (10 items), disruptiveness (7 items), positive adaptation (7 items) and financial concerns (3 items). In addition, there are eight single items not part of any domain. (*Lafaye, De Chalvron, Houede, Eghbali, & Cousson-Gelie, 2013; Weitzner et al., 1999*). Each item is scored from 0 (not at all) to 4 (very much). Respondents are asked to indicate how "true" each of the statements has been for them over the past 7 days using this scale of 0-4 (*Carter, 2006; Lafaye et al., 2013*). The score for each domain is achieved by summing up the related domain item scores, and the CQOLC total score is calculated by summing up all the 35 items. Higher scores reflect worse QoL (*Carter, 2006; Lafaye et al., 2013; Ozer, Firat, & Bektas, 2009; Weitzner et al., 1999*). The reliability of the CQOLC is good. The CQOLC has been shown to be a valid measure of quality of life in caregivers of persons with cancer and has demonstrated high internal consistency ($\alpha = 0.91$), good convergent and discriminate validity with measures of general quality of life, mood, burden, and social desirability, and good 2-week test-retest reliability ($r = 0.95$). The internal consistency coefficient is 0.91 (*Carter, 2006; Weitzner et al., 1999*). Convergent and divergent validity were proved to be adequate (*Weitzner et al., 1999*).

Caregivers' satisfaction

We used the validated Canadian Health Care Evaluation Project Questionnaire (CANHELP LITE) which aims to measure caregiver's satisfaction with the end-of life care (*Heyland, Jiang, Day, & Cohen, 2013*). The original Canhelp Lite is a 21-item scale, drawn from the validated 38-item CANHELP questionnaire. To avoid overlap with the CQOLC, only 10 items of the CANHELP were used in this study. Five answers are linked to a Likert score from 1 (not satisfied at all) to 5 (completely satisfied). The higher the total score, the higher the satisfaction.

As for the original CANHELP, there are 2 formats available in the CANHELP Lite: an importance/satisfaction version that measures both importance and satisfaction with the care and a version that measures only caregiver satisfaction, the latter we used in this study. The internal consistency is moderate to high (Cronbach's alpha 0.69-0.94) as described in previous studies (*Heyland et al., 2010*). In contrast to the original 21-item CANHELP's total score, the total score in this study ranged between 10-50, with a higher score reflecting higher satisfaction with care.

Caregiver preparedness

Caregiver preparedness was assessed using Archbold and colleagues' Preparedness for Caregiving Scale (PCS). The measure is an 8-item scale of the Family Care Inventory (Archbold, Stewart, Greenlick, & Harvath, 1990). Preparedness is defined as the perceived readiness for multiple domains of the caregiving role, such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving (Henriksson, Andershed, Benzein, & Arestedt, 2012; Henriksson et al., 2015; Nielsen et al., 2017). The PCS has been used regularly in studies of caregivers to terminally ill patients. Items are scored from 0 (totally not prepared) to 4 (very well prepared). A total score for the eight items is calculated, with higher scores indicate more perceived preparedness (Karen L. Schumacher & Mildred Caparro, 2008; Mazanec et al., 2018). Internal consistency of the scale ranges from 0.88 to 0.93 (Archbold et al., 1990; Schumacher, Stewart, & Archbold, 2007; Schumacher et al., 2008).

Demographic data

In this questionnaire, a set of demographical (and clinical) data on both the caregiver himself and the patient were self-reported by the primary caregivers. In addition, caregivers were asked information on the informal care they provided (Activities of Daily Living, ADL and the Instrumental Activities of Daily Living, IADL) and their care network (informal care and professional care) .

STATISTICAL ANALYSIS

The quality of the data input was monitored by checking the missing and extreme values. For missing data, composite scores were rescaled based on the number of missing data for all the end scores and were excluded from the analysis if more than 50% of the items in the instrument had missing data.

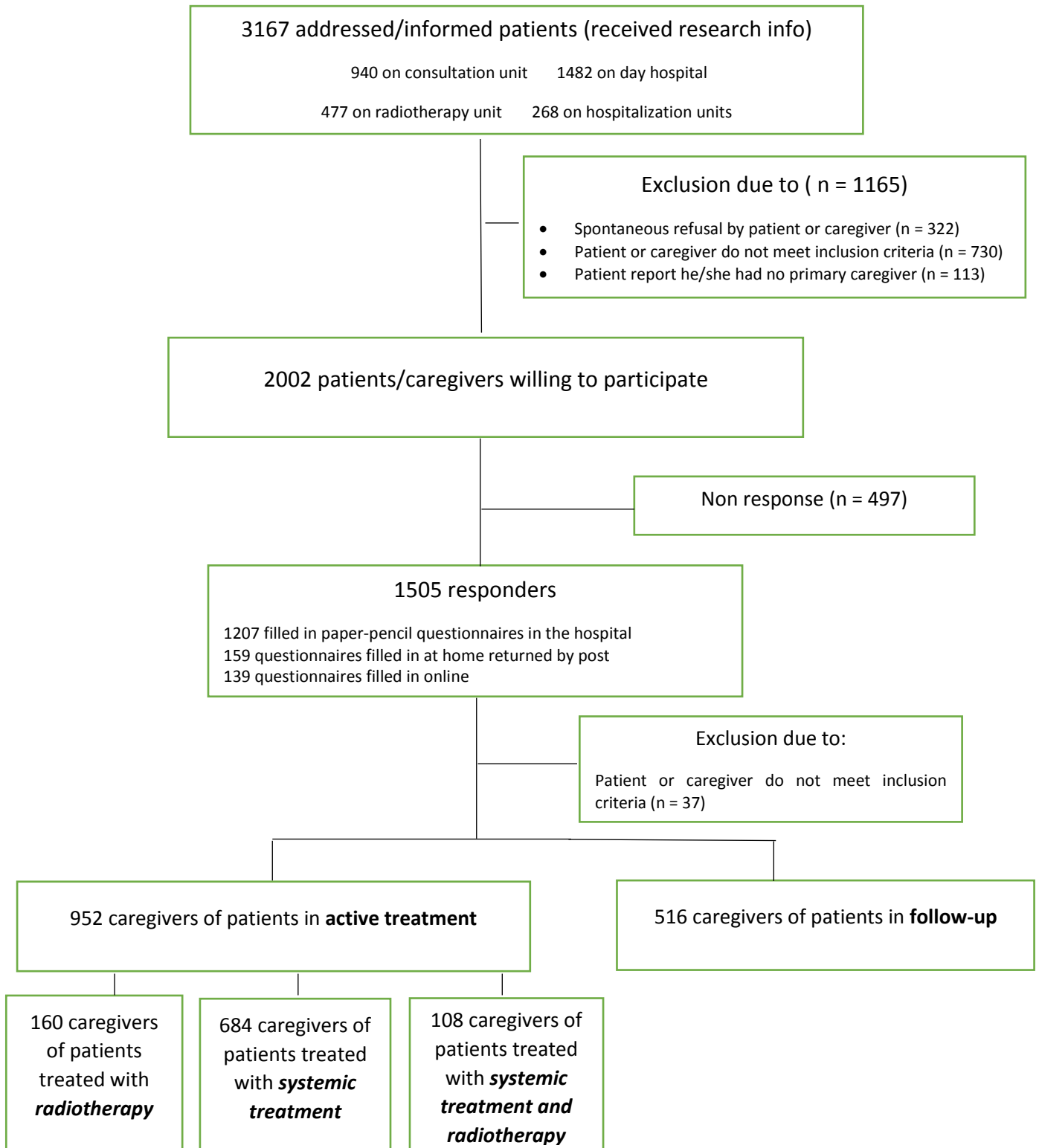
Using SPSS (Statistical Package for the Social Sciences version 19.0 for Windows), in dependence of scale level and distribution different statistical test procedures were applied. Descriptive analyses (i.e. frequencies, means and standard deviations) were conducted to describe demographical and clinical data. Normality tests with Shapiro-Wilk and Kolmogorov-Smirnov approach, visual by the normal Q-Q plots were employed to determine the use of parametric or non-parametric tests. The study sample was normally distributed, so we used the parametric tests.

First, we performed descriptive analysis using the composite scores for primary outcomes caregiver distress and caregiver's QoL, as for secondary outcomes caregiver's satisfaction and caregiver's preparedness.

Secondly, we investigated Pearson correlations (r) to determine the relationships between the primary outcomes on the one hand (caregiver distress and caregiver quality of life) and patient and caregiver characteristics on the other hand. Also, we explored correlation between the primary and secondary outcomes of this study. Finally, analysis of variance (ANOVA) was used to evaluate the relation of the primary outcomes caregiver distress and caregiver QoL to differences in the demographic data of the caregivers. We rejected a null hypothesis at level α , when the p-value was less than or equal to 0.05. A correlation coefficient (r) less than 0.30 indicates weak association, an r between 0.30 and 0.59 indicates moderate association, while an r greater than 0.60 represents strong association (*Martinez-Martin, Serrano-Duenas, Forjaz, & Serrano, 2007*).

RESULTS

DESCRIPTION OF CAREGIVER AND PATIENT CHARACTERISTICS



As mentioned earlier, this master thesis focuses only on caregivers of patients in follow-up, and is part of a larger study (caregivers of patients in treatment and in follow-up). Here, we present the flowchart of the larger study (treatment and follow-up) above. For the larger study, we addressed 3167 patients in the University Hospitals Leuven in the period of data collection. All those cancer patients received research information. Based on the first introduction talk with the researcher, there were 1165 patients excluded because of following reasons: not meeting the inclusion criteria ($n = 730$; for example having palliative treatment or being not an adult), not having a primary caregiver ($n = 113$) or due to spontaneous refusal by patient or caregiver ($n = 322$). From the 2002 patients we addressed in the larger study, there were (approximately) 497 non-responders. Totally, we received 1505 filled in questionnaires from the caregivers. Most of the questionnaires (1207) were filled in by paper-pencil method in the hospital. Next, there were 159 questionnaires filled in at home and there after returned by post to the researchers in the hospital. Finally a small minority ($n = 139$) of the caregivers completed the online questionnaire. Because data-collection on the different wards took place simultaneously and to guarantee the anonymity of the participants, we cannot distinguish how many questionnaires were derived from each ward or were returned by post.

The final sample of the caregivers of oncology patients in follow-up consisted of 516 primary caregivers. 47.1% ($n = 243$) were male and 52.9% ($n = 273$) were female. The mean age of the caregivers was 57.47 (± 14.01).

333 (64.5%) of the study participants were spouses or partners of cancer patients, 101 (19.6%) were their adult child and 81 (15.7%) were other types of close members such as adult siblings, parents or close friends/relatives.

The vast majority of the caregivers (68%) was living together with the patient while about one third of the caregivers (32%) was living apart from the patient. The minority of the caregivers completed elementary school (11.8%). Half of the caregivers had a secondary/high school degree (50%) and another 197 (38.2%) had a college/university degree. 45.5% of the caregivers was currently at work, while 53.7% of the caregivers was not at work at the time of completion of the questionnaire.

The study represents a great variety of cancer diagnoses (Table 1). The main cancer diagnosis, as reported by the caregiver, was breast cancer (19.8%), gastro-intestinal cancer (18.6%) and hematological malignancy (15.5%). 1.2% of the relatives didn't know the main cancer diagnosis of their patient. "Time since diagnosis" refers to the time elapsed since a patient received his/her main diagnosis. A small number of caregivers (15.1%) reported that the cancer was diagnosed more than 10 years ago. Respectively 21.7% and 42.4% of the patients received their main cancer diagnosis more than 5 and more than one year ago. The main cancer diagnosis was given to 20.5% of the patients last year. Caregiver and patient demographic data are presented in Table 1.

Table 1: demographic data of caregivers and patients

N = 516	Total n (%)
Caregiver age – mean = 57.47 ; range: 21 – 90	
Caregiver gender	
Male	243 (47.1%)
Female	273 (52.9%)
Relationship with Patient	
Spouse/Partner	333 (64.5%)
Child	101 (19.6%)
Parent	26 (5.0%)
Brother/Sister	31 (6.0%)
Friend/relative	17 (3.3%)
Other	7 (1.4%)
Missing	1 (0.2%)
Caregiver's home situation	
Living together with the patient	351 (68.0%)
Living apart from the patient	165 (32.0%)
Caregiver education	
Elementary School	61 (11.8%)
Secondary/High School	258 (50.0%)
College/University	197 (38.2%)
Caregiver employment (*)	
Currently at work	235 (45.5%)
Currently not at work	277 (53.7%)
Time of cancer diagnosis of patient	
>10 years	78 (15.1%)
>5 years	112 (21.7%)
>1 years	219 (42.4%)
Last year	106 (20.5%)
Missing	1 (0.2%)
Main cancer diagnosis of patient	
Breast cancer	102 (19.8%)
GI cancer	96 (18.6%)
Haematological cancer	80 (15.5%)
Lung cancer	50 (9.7%)
Cancer of the urinary tract	50 (9.7%)
Gynecological cancer	50 (9.7%)
Brain tumour	22 (4.3%)
Head-and-Neck cancer	19 (3.7%)
Skin cancer	18 (3.5%)
Others (sarcoma's, thyroid cancer,...)	13 (2.5%)
Relative don't know PT's cancer diagnosis	6 (1.2%)
Missing	10 (1.9%)
(*) missing data were detected for these variables	

CARE NETWORK OF THE CAREGIVER

The caregivers varied widely in the corresponding level of care they get (Table 2). The majority of the caregivers (43.6%) reported to get “very much” emotional support, while about one third (32%) received “rather much”. 14.7% indicated to have “very little” emotional support at home and a small minority (3%) said to receive no emotional support at all.

Also, a vast majority (69%) of caregivers of oncology patients in follow-up stated that they have “very much” or “rather much” practical help at home. This practical help at home was mostly offered by their household family or by the family outside the household (43.6%). Further exploration of the practical help at home revealed that 10.5% of the caregivers did not have any resource for practical help at home. Most of them (43.2%) had one resource for practical help at home. One third reported to have 2 resources and a few caregivers (17.2%) indicated they had more than 2 resources in practical help at home (Table 2).

We investigated the professional help at home. 139 caregivers (26.9%) reported their patient did not have professional home care. A vast majority of the caregivers (55.8%) can count on their general practitioner, 18.8% of them on a home nurse and 10.7% on a physiotherapist. Only 17.6% of the caregivers report cleaning help or they can count on help via the service for family care (6.6%) or for delivery of meals (2.5%). Finally, 1.2% of the caregivers indicated their loved one is in a retirement home. Examining all these help resources together, we can conclude that 32.4% of the caregivers indicated to have none professional help at home. 38.4% report to have 1 resource of professional help at home. 17.2% can count on 2 resources at home and only 11.8% report more than 2 resources (Table 2)

Finally, we represent the experienced degree of emotional support in the hospital. The treating physician and the nursing team in the hospital were a resource of emotional support for 33.7% and 28.7% of the caregivers respectively. 6.4% of the caregivers could count on a social worker for emotional support and 6.6% indicated they received emotional support from a psychologist. The majority of the caregivers of patients in follow-up (48.8%) reported to receive no emotional support at all from professional healthcare workers in the hospital (Table 2).

Table 2: Care network of the caregiver

N = 516	Total n (%)
Degree of emotional support at home	
None at all	16 (3.1%)
Very little	76 (14.7%)
No opinion	25 (4.8%)
Rather much	165 (32.0%)
Very much	225 (43.6%)
Missing	9 (1.7%)
Degree of practical help at home	
None at all	25 (4.8%)
Very little	93 (18.0%)
No opinion	33 (6.4%)
Rather much	177 (34.3%)
Very much	180 (34.9%)
Missing	8 (1.6%)
Extent of practical help at home	
None	54 (10.5%)
1 resource	223 (43.2%)
2 resources	149 (28.9%)
>2 resources	89 (17.2%)
Missing	1 (0.2%)
Sources of practical help at home *	
Nobody	40 (7.8%)
My family (inside household)	326 (63.2%)
My family (outside household)	225 (43.6%)
Friends	162 (31.4%)
Neighbors, relatives, (old)colleagues	90 (17.4%)
Volunteers	13 (2.5%)
Others	4 (0.8%)
Extent of professional home care	
None	167 (32.4%)
1 resource	198 (38.4%)
2 resources	89 (17.2%)
>2 resources	61 (11.8%)
Missing	1 (0.2%)
Sources of professional home care *	
Nobody	139 (26.9%)
General practitioner	288 (55.8%)
Home nurse	97 (18.8%)
Physiotherapist	55 (10.7%)
Service for family care	34 (6.6%)
Cleaning help	91 (17.6%)
Delivery of meals	13 (2.5%)
Inapplicable, my loved one/patient is in a retirement home	6 (1.2%)
Others	5 (1.0%)
Extent of emotional support from HCP in the hospital	
None	226 (43.8%)
1 resource	190 (36.8%)
2 resources	77 (14.9%)
>2 resources	21 (4.3%)
Missing	1 (0.2%)
Sources of emotional support from HCP at the hospital *	
Nobody	252 (48.8%)
The oncologist/physician	174 (33.7%)
The nursing team	148 (28.7%)
The social worker	33 (6.4%)
The psychologist	34 (6.6%)
Others	28 (5.4%)

CAREGIVER TASKS AND THEIR CONTENT OF THEIR CAREGIVING ROLE

We describe the care tasks and other role demands experienced by this sample of caregivers of oncology patients in follow-up. Variations in the number and type of caregiver tasks were noted (table 3). Assistance with items of Activities of Daily Living (ADL) and items of Instrumental Activities of Daily Living (IADL) were assessed by asking respondents whether they performed this kind of help for their loved one.

The majority of the oncology patients is independent for Activities of Daily Living such as feeding, transferring at home, dressing, continence and bathing. Approximately one out of ten caregivers indicated to give some assistance to their loved one for the Activities of Daily Living. Only a small number of the patients need full assistance for some Activities of Daily Living such as feeding (6.4%), transferring at home (4.5%), dressing (3.9%), continence (2.7%) and bathing (4.8%).

We also see variations in the assistance for Activities Instrumental Daily Living (IADL). While 220 caregivers (42.6%) indicated their patient is fully dependent for transport, 88 caregivers (17.1%) gave full help with the use of medication. Partly or full assistance with handling finances is provided by 282 caregivers . 147 patients (28.5%) were fully dependent of their caregiver for the housekeeping and 190 patients (36.8%) got full help with shopping. A significant majority reported providing full help for doing laundry.

Table 3: caregiver tasks and content of their caregiving role

N = 516	Independent	Semi-dependent	Fully dependent	Missings
Activities Daily Living (ADL)				
Feeding	408 (79.1%)	64 (12.4%)	33 (6.4%)	11 (2.1%)
Transferring at home	420 (81.4%)	62 (12.0%)	23 (4.5%)	11 (2.1%)
Dressing	423 (82.0%)	61 (11.8%)	20 (3.9%)	12 (2.3%)
Continence	449 (87.0%)	41 (7.9%)	14 (2.7%)	12 (2.3%)
Bathing	415 (80.4%)	63 (12.2%)	25 (4.8%)	13 (2.5%)
Activities Instrumental Daily Living (IADL)				
Mode of transportation	133 (25.8%)	158 (30.6%)	220 (42.6%)	5 (1.0%)
Using medication/drugs	282 (54.7%)	136 (26.4%)	88 (17.1%)	10 (1.9%)
Handling finances	225 (43.6%)	147 (28.5%)	135 (26.2%)	9 (1.7%)
Housekeeping	144 (27.9%)	217 (42.1%)	147 (28.5%)	8 (1.6%)
Cooking	196 (38.0%)	175 (33.9%)	136 (26.4%)	9 (1.7%)
Shopping	141 (27.3%)	177 (34.3%)	190 (36.8%)	8 (1.6%)
Doing laundry	234 (45.3%)	126 (24.4%)	145 (28.1%)	11 (2.1%)

CAREGIVER REPORTED OUTCOMES

The caregiver reported instrument scores are listed in table 4.

The mean CRS score was 8.62 (\pm 8.33), range 0 – 36. This mean score reflects to a low level of distress (< 11), as defined by Guberman et al (2001a). In our sample, most of the caregivers (63.0%) reported this low distress-level (< 11). A moderate level of distress (11-16) was indicated by 15.5% of the respondents, while 9 % have a high risk (17-22) for caregiver distress. Guberman et al (2001a) suggested the above guidelines for interpreting the distress scores. 7.6% of the caregivers had a very high distress (23-30). We noticed that distress scores between 31-36 did not get any interpretation, so we decided to make a new category “severe distress” by calculating the distress scores between 31-36 together. On this way, we can conclude that another 1.2 % of caregivers in our sample was at severe distress risk (31-36).

The mean value on the distress thermometer (DT) was 4.04 (\pm 2.89), which indicates a moderate level of distress. One hundred and ninety two (37.2%) caregivers reported low distress levels (0–3), with another 130 (25.2%) caregivers reporting moderate distress levels (4-6). Nearly one out of five caregivers (18.4%) indicated severe levels of distress (7-10) on the DT. Remarkably, 99 (19.2%) caregivers of this sample did not report their DT-level.

The mean score for the total CQOLC was 48.58 (\pm 22.80). A higher score indicates a worse QOL. The four domains of the CQOLC had respectively mean scores: burden 13.57 (\pm 10.50); disruptiveness 6.16 (\pm 6.50); positive adaptation 15.72 (\pm 5.57) and financial concerns 1.98 (\pm 2.94).

We measured the satisfaction with care by using 10 of the 21 items of the CANHELP Lite. For the reduced scale, the mean satisfaction with care was 37.81 (range 10 – 50), where a higher score reflects more satisfaction. Caregivers of patients in follow-up were very satisfied with the way their patient and themselves were treated and supported by doctors, nurses and other healthcare professionals in our hospital. We note the caregivers’ satisfaction varied as the standard deviation (\pm 7.54) indicate.

The mean score for caregivers preparedness (CSP) 16.20 (\pm 7.31). This 8-item scale had a range 0-32, with higher scores indicating greater perceived preparedness. We concluded a moderate level of preparedness in our sample of caregivers of oncology patients in follow-up.

Table 4: caregiver reported outcomes

N = 516	N (%)	Mean	SD
Caregiver Distress (CRS) (0-3 scale; range 0- 36 ; higher score = more distressed)			
Total		8.62	8.33
Low risk (< 11)	325 (63.0%)		
Moderate level (11-16)	80 (15.5%)		
High risk (17-22)	46 (8.9%)		
Very high risk (23-30)	39 (7.6%)		
Severe risk (31-36)	6 (1.2%)		
Missing	20 (3.9%)		
Caregiver Distress-thermometer (DT) (0-10 scale; range 0-10; 0= no distress; 10 = extremely distress)			
Total		4.04	2.89
Low distress (0-3)			
Moderate distress (4-6)			
Severe distress (7-10)			
Caregiver's Quality of Life (CQOLC) (0-4 scale; range 0-140; higher score = worsen QOL)			
Total (35 items, range 0-140)		48.58	22.80
Burden (10 items, range 0-40)		13.57	10.50
Disruptiveness (7 items, range 0-28)		6.16	6.50
Positive adaptation (7 items, range 0 – 28)		15.72	5.57
Financial concerns (3 items, range 0-12)		1.95	2.94
Caregiver's skills Preparedness (PCS) (0-4 scale; range 0-32 ; higher score = more prepared)			
Total		16.20	7.31

RELATIONSHIP OF CAREGIVER-REPORTED OUTCOMES WITH CAREGIVER AND PATIENT DEMOGRAPHIC DATA

Relationships between caregiver-reported outcomes and demographic data (concerning caregiver and patient) are summarized in table 5.

We found a statistically significant negative correlation ($r = -.223$, $p = 0.000$) between caregiver's age and their distress. Thus, older caregivers experienced more caregiver distress than younger caregivers. There was also a statistically significant association ($p = 0.002$) between the relationship of the caregiver with the patient and their distress. Remarkably, the highest distress was reported in primary caregivers who were a friend or close relative to the patient ($M = 12.93$), while partner or spouses had a mean distress of 7.69. Other relationships with the oncology patients have mean CRS-scores as follows: child ($M = 9.57$); parent ($M = 11.78$) and brother/sister ($M = 11.92$). Caregiver's distress was significantly worse in caregivers living together with the patient ($p = 0.002$). Also, caregiver's education had a significant effect on distress ($p = 0.040$). We noted that high educated caregivers had a lower distress score and a better quality of life.

We found a significant statistically association between the main cancer diagnoses and the caregiver distress ($p = 0.000$) and the quality of life ($p = 0.000$). Caregivers of patients with head-and neck cancer ($M = 15.38$), skin cancer ($M = 15.11$) and with brain cancer ($M = 12.44$) reported the highest levels of distress. The lowest scores on the CRS in this study sample were found in caregivers of breast cancer ($M = 5.72$) and caregivers of patients with gynecological cancer ($M = 6.66$) in follow-up.

Generally female caregivers had relatively higher (but non-significant) scores on distress than male caregivers. There was no statistical significant association between the time of cancer diagnosis and the outcomes distress.

We found a statistically significant negative weak correlation ($r = -.183$, $p = 0.000$) between caregiver's age and their QoL, which indicate that older caregivers experienced a poorer QoL than younger caregivers.

A significant association between the caregiver relation and their quality of life ($p = 0.005$) was found. Caregivers who were brother or sister had the worst score on the CQOLC ($M = 59.61$). Children who were the primary caregiver of the patient report a mean QOL of 49.97, parents ($M = 57.51$), partners ($M = 46.44$) and finally friends/relatives ($M = 54.69$).

As for caregiver distress, caregiver quality of life was significantly associated with caregivers' living situation ($p = 0.024$), education ($p = 0.002$) and the main cancer diagnoses ($p = 0.000$). Scores for QOL were worst in caregivers of patients with skin cancer ($M = 64.23$), lung cancer ($M = 63.82$) and head-and neck cancer ($M = 63.04$). Primary caregivers of patients with breast cancer ($M = 39.76$) or cancer of

the urinary tract (M = 43.86) in follow-up reported the lowest scores on the CQOLC, what reflects to a better QoL.

In contrast with the non-significant effect for distress, QoL was significantly ($p = 0.044$) worse for caregivers at work. This means that caregivers who are employed experienced a lower level of QOL comparing to caregivers who were not at work.

A statistically significant effect was found for the degree of emotional support at home with the level of distress ($p = 0.000$), and with the QoL ($p = 0.000$) of the caregiver.

In this sample, caregivers who have more informal practical help at home have a significant lower burden ($p = 0.004$) and a significant lower quality of life ($p = 0.008$) than caregivers of patients who had no resources for practical help at home.

The majority of the CRS and the CQOLC scores were relatively higher (but not significant) when there were more professional resources (such as the general practitioner, home nurse, physiotherapist, delivery of meals, cleaning services,...) at home. The higher distress and QOL scores in the group of caregivers who had more professional resources, indicate the greater dependence for care of their loved one.

Caregivers of oncology patients in follow-up who can count on healthcare professionals (such as the treating physician, the nursing team, the social worker or the psychologist) in the hospital, experienced a non-significant but lower level of distress and higher level of quality of life than caregivers who didn't have any resource for emotional support in the hospital (Table 5).

Table 5: Associations between caregiver-reported outcomes and demographic data

Variable	Caregiver distress (CRS) ¹		Caregiver's QOL (CQOLC) ²	
	Mean	p-value	Mean	p-value
Caregiver's age^a	8.62	0.000**	8.33	0.000**
Caregiver gender^b		0.147*		0.100*
Male	7.99		46.52	
Female	9.21		50.46	
Caregiver relation with the patient^c		0.002**		0.005**
Partner/spouse	7.69		46.44	
Child	9.57		49.97	
Parent	11.78		57.51	
Brother/sister	11.92		59.61	
Friend/relative	12.93		54.59	
Other	4.28		36.65	
Caregiver's home situation^b		0.002*		0.024*
Living apart	8.06		51.48	
Living together	9.84		47.20	
Caregiver's employment^b		0.772*		0.044*
Currently at work	9.37		50.51	
Currently not at work	8.03		47.18	

Caregiver education^c		0.040**		0.002**
Elementary School	9.17		52.90	
Secondary/High School	9.40		51.03	
College/University	7.41		43.98	
Time of cancer diagnosis of patient^c		0.407**		0.842**
>10 years	7.18		46.60	
>5 years	9.17		49.60	
>1 year	8.87		48.84	
Last year	8.38		48.07	
Main cancer diagnosis of patient^c		0.000**		0.000**
Breast cancer	5.72		39.76	
GI cancer	7.39		47.08	
Haematological cancer	8.46		48.89	
Lung cancer	13.56		63.82	
Cancer of the urinary tract	8.42		43.86	
Gynecological cancer	6.66		45.28	
Brain cancer	12.44		55.46	
Head-and-Neck cancer	15.39		63.04	
Skin cancer	15.11		64.23	
Others	8.08		41.56	
Relative don't know patients cancer diagnosis	7.45		55.87	
Degree of emotional support at home^c		0.000**		0.000**
None at all	12.07		56.89	
Very little	15.77		68.42	
No opinion	6.21		44.74	
Rather much	10.04		51.29	
Very much	5.26		39.53	
Degree of practical help at home^c		0.000**		0.000**
None at all	15.24		69.87	
Very little	13.69		60.42	
No opinion	5.87		42.65	
Rather much	9.12		49.16	
Very much	5.15		40.03	
Resources practical help at home^c		0.004**		0.008**
None	10.85		55.65	
1resource	9.47		50.10	
2resources	7.92		47.09	
>2 resources	6.37		42.98	
Resources professional help at home^c		0.269**		0.122**
None	7.71		45.75	
1resource	8.78		49.41	
2resources	8.94		48.33	
>2 resources	10.10		53.88	
Resources emotional support in the hospital^c		0.108**		0.268**
None	9.50		49.77	
1resource	8.09		48.24	
2resources	2.27		48.36	
>2 resources	5.50		39.28	
Abbreviations:				
a correlation				
b t-test				
c one-way ANOVA				
**. Correlation is significant at the 0.01 level (2-tailed).				

INTERRELATIONSHIPS AMONG CAREGIVER-REPORTED OUTCOMES

We found some significant interrelationships among the caregiver-reported outcomes (Table 6). Moderately to strong correlations were found between the main study variables, with the absolute value of the Pearson correlation coefficients (r) ranging from .360 to .847 (all at $p < 0.01$ level). Caregiver distress score on CRS (.847) and on DT (.656) were positively strong associated with caregiver's score on CQOLC, so we conclude that distressed caregivers of patients in follow-up had a worse QoL. There were moderate negative correlations shown between caregiver's satisfaction with the CRS score (-.500), with DT (-.360) and finally with the CQOLC (-.483). Above negative correlations indicate that distressed caregivers or caregivers with a lower QoL are less satisfied with the care they received from healthcare professionals. In addition, there is a moderate positive correlation (0.468) between caregiver's satisfaction and caregiver's preparedness, indicating satisfied caregivers experience a better preparedness for caregiving.

Caregiver distress scores on CRS (-.507) and on DT (-.409) and QoL-scores on CQOLC (-.554) had negative associations with the preparedness for caregiving. This reveals that distressed caregivers or caregivers with low levels of QoL, had poorer preparedness in fulfilling their caregiving role.

Table 6: Pearson correlations between the main study variables

variable	Caregiver distress (CRS) R	Caregiver distress (DT) R	Caregiver's QOL r	Caregiver's satisfaction with care (Canhelp Lite) r	Caregiver's preparedness (PCS) r
Caregiver's age	-	-	-	-	-
Caregiver distress (CRS)	-	-	-	-	-
Caregiver distress (DT)	,660**	-	-	-	-
Caregiver's QOL (CQOLC)	,847**	,656**	-	-	-
Caregiver's satisfaction with care (Canhelp Lite)	-,500**	-,360**	-,483**	-	-
Caregiver's preparedness (PCS)	-,507**	-,409**	-,554**	,468**	-
Abbreviations: **. Correlation is significant at the 0.01 level (2-tailed). r: 0.1 - 0.3 : weak correlation r: 0.3- 0.59: moderate correlation r > 0.60: strong correlation					

DISCUSSION

Informal caregivers play a crucial role in cancer patient care, representing their principal source of support and their different (disease-related) tasks during cancer care (*Grant et al., 2013; Tan et al., 2017*). The aim of this paper was to evaluate the impact of caregiving on caregivers of oncology patients in follow-up (who are no longer actively being treated). This way, this study contributes to the lack on research examining caregivers in the transition to follow-up or in the survivor period (*B. A. Given et al., 2011; Northouse et al., 2012*).

The 516 primary caregivers of patients with different types of cancer were mainly partners or spouses (64.5%) and were living together with the patient (80%). In this sample, we had about an equal mix between male and female caregivers, between caregivers at work and caregivers who were not at work at the time of data collection. The mean age of our sample is 57.47 years (range 21 – 90). We saw a statistically significant effect between caregiver age and the main study outcomes caregiver distress ($p = 0.000$) and caregiver's QoL ($p = 0.000$). Equally in the study of Grant et al. (2013), caregivers in this study who are older, report higher level of caregiver burden and a lower level of QoL (Grant et al., 2013). This is in contrast to the study of Tan, there was no statistically association between caregiver age and burden or QoL (*Tan, Molassiotis, Lloyd-Williams, & Yorke, 2018*).

Most caregivers reported having at least a degree of secondary/high school (50.0%) or college/university (38.2%). We noted in our sample that high educated caregivers had a significant lower score on distress and report a significant better quality of live. Furthermore, most caregivers were in their caregiving role for longer than one year, which refers to the long-term care they already have provided. There was no statistically significant association found between the duration of caregiving and the major study outcomes.

The majority of the respondents (75.6%) reported they can count on emotional support (rather much or very much) at home, also approximately 70% indicated to have (rather much or very much) practical help at home. Most of the practical help was offered by the household family of the caregiver, from family outside the household or friends. Professional help at home is offered by the general practitioner for more than the half of the caregivers, while about one third had nobody involved in professional home care.

From this study, it appeared that the degree of emotional support and practical help at home had a significant impact ($p = 0.000$) on caregiver distress and caregiver quality of life. We can conclude that caregivers need “very much” emotional support to protect themselves for caregiver distress or for a decrease of their QoL. We showed also that caregivers who had more practical resources at home, experienced a significant lower burden ($p = 0.004$) and a better quality of life ($p = 0.008$). This is similar to the review of Pitcheatly et al (2003), where caregivers have more risk when they lack a support

network at home or when they have relationship difficulties with the patient (*Pitceathly & Maguire, 2003*). This is in line as documented in the study of Chen et al (2009), where higher levels of emotional support have been found to be positively associated with lower caregiver burden and a lower risk for depression, distress and anxiety (*Chen et al., 2009*). Nevertheless, we can conclude that practical help and emotional support at home greatly protect caregivers from the negative effect of caregiving on distress and QoL.

The mean caregiver distress in this study was low, namely $M = 8.62 (\pm 8.33)$ measured by the CRS (0-36). As defined by Guberman et al (2001), total scores on the CRS below 11 indicates a low risk (Guberman N., 2001a, 2001b). We concluded that caregivers of oncology patients in follow-up phase experienced a low risk of caregiver distress. Our findings showed the highest levels of caregiver distress (measured by the CRS) in caregivers of patients with head and neck-cancer ($M = 15.39$), skin cancer ($M = 15.11$), lung cancer ($M = 13.56$) and in patients with a brain tumor ($M = 12.44$).

Generally, the mean QoL as measured by the CQOLC in our study was moderate ($M = 48.58, \pm 22.80$), comparing mean CQOLC-scores found in the literature (*Cubukcu, 2018*)(*Tan, Lim, Kuek, Kua, & Mahendran, 2015; Tan et al., 2017*)(*Tan et al., 2018*).

Caregivers with the worst QoL-scores in our study were caregivers of patients with skin cancer ($M = 64.23$), lung cancer ($M = 63.82$), head-and neck cancer ($M = 63.04$) or brain tumor patients ($M = 55.46$).

As was shown in our results and in literature (*Grant et al., 2013; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Pitceathly & Maguire, 2003*), female caregivers are more distressed and had a poorer quality of life than male caregivers. Female gender had been suggested as a potential predictor for caregiver distress (*Matthews, 2003*). The explanation might be that female caregivers take more roles and tend to be more willing to disclose their difficulties of the caregiver duty and emotional problems (*Northouse et al., 2012*). Also, compared with male, female caregivers tend to be more willing to disclose their emotional problems and their difficulties of the caregiver duty. (*Hagedoorn et al., 2008; Northouse et al., 2012*). In this study, we didn't find a significant effect of gender on the main study outcomes like distress ($p = 0.147$) and QoL. ($p = 0.100$)

Given the conflicting evidence about spouses and partners as having the highest scores on distress (*Mazanec et al., 2018; Pitceathly & Maguire, 2003*), this study highlighted the highest distress levels in friend/relatives, siblings (brothers/sisters) and in parents. Remarkably, we found the lowest distress in the group of partners/spouses of oncology patients in follow-up. In line with the study of Matthews et al (2003), there were equal distress scores between caregivers of spouses and caregivers who provided care to other family members (*Matthews, 2003*).

In our study, we found a strong correlation between caregiver distress scores on CRS (.847) and on DT (.656) with caregiver's QoL, which means that distressed caregivers faced a low QoL. Our results are comparable with the study of Chua et al (2016), where Singaporean caregivers experiencing higher burden are concurrently experiencing reduced QoL (Chua et al., 2016). A higher risk on burden and a poorer QoL among older caregivers in general and caregivers of with a lower education status, is consistent with other results in this field (Weitzner et al., 1999)

The study results showed a moderate statistically significant negative correlation (.500) between perceived preparedness and the mean distress of our caregivers, which infers a healthcare professional can assume that a prepared caregiver had less distress and vice versa. Also in the study of Fujinami et al. (2015), they reported a significant inverse association between preparedness and distress in family caregivers of patients with lung cancer in outpatient treatment and in follow-up. This findings contrasts with the study of Mazanec et al (2018), where there was no statistically significant effect between the perceived preparedness and the distress in male caregivers of oncology patients with gynaecologic cancer (Mazanec et al., 2018).

STRENGTHS AND LIMITATIONS

Major strengths of the study are the large sample size (n = 516) and the quantitative measurement of a wide range of aspects regarding the caregivers' experiences in follow-up care. Another strength of this study is the inclusion of caregivers of patients with different types of cancer. Our results concerning caregivers of patients with a wide range of cancer main diagnosis (>10) contributes to one of the recommendations set up in previous caregiver studies, where only a specific type of cancer patients were included (Adams et al., 2009; Ellis, 2012; Grant et al., 2013).

This study has several limitations. The cross-sectional design made the directional analysis of the study variables impossible. As previously described and as in any survey, non-participation limits the generalizability of the findings. Concerning the characteristics of the different participating caregivers (partners, children, parents, siblings, friends, ...), the study sample seems fairly representative, but we have no knowledge concerning the characteristics of caregivers to patients without participating caregivers. Another important limitation is the effect of multiple testing of the variables, of which the level of significance can increase each time as we test more variables. Consequently, the more variables in our sample, the more difficult it is to differentiate which variables are influencing the primary study outcomes distress and QoL.

We have some recommendations for further research. First, we advise to introduce a statistical correction method (such as the Falls discovery rate) to reduce the probably made false positive or false negative significant relationships between the main study variables. Secondly, we propose to further explore the effect of practical help and emotional help at home containing caregiver outcomes such as burden, distress, QoL. Also, we encourage qualitative studies with caregivers to explore underlying factors affecting these outcomes in depth.

Subsequently, there is a need for future studies with a longitudinal design to follow the main outcomes over time. Also, we encourage longitudinal studies with dyadic analysis to see whether outcomes between cancer patients after treatment and their caregivers are influenced over time. Finally, we think a predictive model with potential risk factors for caregiver distress and QoL impairment must be developed. This model can target supportive services for cancer patients and their caregivers in follow-up phase. In conclusion, our study findings confirm other research in the current cancer caregiver research.

IMPLICATIONS FOR NURSING PRACTICE

Despite the low to moderate levels of caregiver distress and the moderate level of QoL that caregivers of oncology patients in follow-up phase experience, there is strong correlation ($r = .847$) between distress and quality of life. Given this close relationship between our major study variables, it seems reasonable that healthcare professionals take more efforts to relieve caregiver distress and their QoL. This highlights the need to screen these outcomes on regularly base in follow-up care. We advise to start to screen distress with simple tools such as the Distress Thermometer. Despite the individual caregiver interpretation of distress and QoL-scores and the evolution and experience of these scores over time, we suggest to regularly asses these outcomes in caregivers. Distress and quality of life screening may not be limited to the active treatment period, there is a requirement for ongoing evaluation of carer distress and vigilance for poor QoL in follow-up phase. Nurses and other healthcare professionals should screen these outcomes and should be aware that caregiver's distress or QoL may be significantly related. If so, this warrants further evaluation and monitoring, which can be done on regularly base by oncology nurses in ambulatory settings such as the consultation units where patients and their carers have their hospital visit in the context of follow-up of their cancer. We point to the responsibility that cancer-care providers should screen or asses on a regular base how caregivers are doing. Caregivers who report a high level of burden or indicate they need help, should get coaching or –a referral to other healthcare professionals such a social worker or a psychologist. As stated by Ryn et al (2011), since cancer patients and their caregivers may interact with many healthcare providers during active treatment and also in follow-up, it is often not clear which provider should take this

responsibility (*van Ryn et al., 2011*). Thus, we suggest that care systems or oncology wards develop policies and procedures that will result in care coordination, which includes caregiver assessment and caregiver support tailored to their individual needs and expectations.

CONCLUSION

This study contributes to further understanding the impact of caregiving among caregiver distress, QoL, satisfaction with care and preparedness for caregiving in caregivers of oncology patients who were in follow-up. In general, a vast majority of the caregivers reported to have emotional and practical help at home. Practical help at home is mostly offered by household family or family outside the household. We noted that one tenth of the caregivers did not have any resource for practical help at home. Professional help at home is offered by the GP for more than half of the caregivers, while about one third had nobody involved in professional home care. The degree of emotional support and practical help at home had a significant impact on caregiver distress and caregiver quality of life. Remarkably, about half of the caregivers indicated they had nobody from healthcare professionals where they can count on for emotional support in the hospital.

In this study, the mean level of caregiver's distress is low to moderate and the mean level of QoL is moderate. 63% of the patients report a low distress level, 15% of the caregivers had a moderate distress level. We noted that about one fifth report higher distress levels: 9% were at high risk, about 8% were on very high risk and we had 1.2% on severe risk.

We found a strong correlation between caregiver distress scores on CRS (.847) and on DT (.656) with caregiver's QoL. Distressed caregivers of oncology patients in follow-up faced a low QoL, what is related to several variables. Fewer emotional and practical resources, non-spousal relationship to the patient (e.g. being parent, child or friend), lower education level and living together with patient are predictive factors ($p < 0.05$) for higher distress and worse QoL. Also, the type of cancer diagnosis had a significant effect: caregivers of patients with head-and neck, skin, lung or a brain cancer reported the highest distress and lowest QoL-scores. Caregivers of patients in follow-up were generally very satisfied with the way their patient and themselves were treated and supported by doctors, nurses and other healthcare professionals in our hospital. Their perceived skills preparedness was moderate. These findings encourage recognition of caregivers as part of the care team, to improve their knowledge about, access to and the support available.

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ATTACHMENTS

1/ APPROVAL STUDY BY THE ETHICS COMMITTEE

	Leuven, 22 november 2017	
Ethische Commissie Onderzoek UZ/KU Leuven Herestraat 49 B 3000 Leuven (Belgium) Tel +32 16 34 86 00 website: www.uzleuven.be/ec/onderzoek e-mail : ec@uzleuven.be	Mevr. Annemarie Coolbrandt VS EXP PROJ ZONE ONC-ZHBREED	
Ons kenmerk: S60892	EudraCT-nr:	Belg. Regnr:
En u? Hoe gaat het met u?: Ervaringen en noden van naasten van mensen met kanker in UZ Leuven.		
Geachte Collega,		
De Ethische Commissie Onderzoek UZ/KU Leuven heeft vermeld protocol onderzocht en besproken op haar vergadering van 10 november 2017.		
De EC heeft geen bezwaar tegen het project mits vertrouwelijke behandeling van de gegevens en naleving van de Belgische wetgeving omtrent privacy.		
De EC wenst de hoofdonderzoeker/promotor van de studie te wijzen op zijn/haar verantwoordelijkheid betreft de privacy van de persoons-/patiëntgegevens bij contact met de patiënt en/of inzage in het elektronisch medisch dossier, inclusief de correcte implementatie hiervan door medewerkers en studenten. de EC verwijst naar de richtlijnen van ICH/GCP hierover op de website, en benadrukt dat een GCP-opleiding van elke hoofdonderzoeker verwacht wordt. De EC verwijst tevens naar de Belgische wetgeving (Wet van 8/12/1992 ter bescherming van de persoonlijke levenssfeer en Wet van 22/8/2002 betreffende de rechten van de patiënt).		
Dit project valt niet onder het toepassingsgebied van de wet van 7/5/2004.		
Protocol (Versie 1 dd 12-10-2017) Informatieformulier (ICF versie ontvangen 25/10/2017 NI) - Ethische Commissie Onderzoek UZ/KU Leuven heeft geen bezwaar tegen de uitvoering van deze studie op voorwaarde dat de bevraging op een anonieme wijze zal gebeuren en er geen terugkoppeling meer mogelijk zal zijn naar de deelnemer. In die context valt de studie niet onder het toepassingsgebied van de experimentenwet van 7/5/2004 valt en is de no - fault verzekering niet van toepassing.		
De EC bevestigt dat ze werkt in overeenstemming met de ICH-GCP principes (International Conference on Harmonization Guidelines on Good Clinical Practice), met de meest recente versie van de Verklaring van Helsinki en met de van toepassing		
S60892		1 / 4

zijnde wetten en regelgeving.

De EC bevestigt dat in geval van belangenconflict, de betrokken leden niet deelnemen aan de besluitvorming omtrent de studie.

Een ledenlijst wordt bijgevoegd.

Aandachtspunten: (indien van toepassing)

De opdrachtgever is verantwoordelijk voor de conformiteit van de anderstalige documenten met de Nederlandstalige documenten.

*Indien er een **Clinical Trial Agreement** is, kan de studie in ons centrum pas aangevat worden wanneer dit **Clinical Trial Agreement** goedgekeurd en ondertekend is door de gedelegeerde bestuurder van UZ Leuven (en/of desgevallend door bevoegde vertegenwoordiger(s) van KU Leuven Research & Development).*

Studies met geneesmiddelen en sommige studies met "medische hulpmiddelen" dienen door de opdrachtgever aangemeld te worden bij het FAGG.

Studies met geneesmiddelen mogen slechts aanvangen op voorwaarde dat de minister (FAGG) geen bezwaren heeft kenbaar gemaakt binnen de wettelijke termijnen zoals beschreven in art.13 van de Belgische wet van 7/5/2004 inzake experimenten op de menselijke persoon. Voor bepaalde studies met medische hulpmiddelen gelden eveneens wettelijke termijnen (zie KB van 17/3/2009). Voor meer informatie hieromtrent verwijzen we naar de website van het FAGG www.fagg-afmps.be.

Onderzoek op embryo's in vitro valt onder de wet van 11 mei 2003. Voor dergelijk onderzoek is er naast een positief advies van de EC ook een goedkeuring van de Federale Commissie voor medisch en wetenschappelijk onderzoek op embryo's in vitro noodzakelijk vooraleer dit onderzoeksproject kan doorgaan.

Gelieve ook rekening te houden met de regelgeving van het ziekenhuis betreffende weefselbeheer en met de beschikkingen van de wet van 19 december 2008.

Dit gunstig advies van de EC houdt niet in dat zij de verantwoordelijkheid voor de geplande studie op zich neemt. U blijft hiervoor dus zelf verantwoordelijk. Bovendien dient U erover te waken dat uw mening als betrokken onderzoeker wordt weergegeven in publicaties, rapporten voor de overheid enz., die het resultaat zijn van dit onderzoek. U dient ongewenste voorvallen en ernstige bijwerkingen te rapporteren zoals aangegeven door de Belgische Wet aangaande Experimenten op de menselijke persoon van 7 mei 2004 (Art 27 en 28) en de omzendbrief 586 van het FAGG.

Gelieve ons mee te delen indien een studie niet wordt aangevat of wanneer ze wordt afgesloten of vroegtijdig onderbroken (met opgave van reden).

*Indien de studie niet binnen het jaar beëindigd is, vereist de ICH-GCP dat een **jaarlijks vorderingsrapport** aan de EC wordt bezorgd.*

*Gelieve tenslotte het (vroegtijdige of geplande) stopzetten van een studie binnen de door de wet vastgestelde termijnen mee te delen en een **Clinical Study Report** aan de EC te bezorgen.*

Met vriendelijke groet,



Prof. Dr. Minne Casteels
Voorzitter
EC Onderzoek UZ/KU Leuven

“En u? Hoe gaat het met u?”

Ervaringen en noden van naasten van mensen met kanker in UZ Leuven

Onderzoekinformatie en toestemmingsformulier



Beste mevrouw, mijnheer

U wordt uitgenodigd om deel te nemen aan een onderzoek als naaste van iemand met kanker in UZ Leuven.

Voordat u beslist of u al dan niet wilt deelnemen, is het belangrijk dat u begrijpt waarom dit onderzoek wordt uitgevoerd en wat het inhoudt. U kan steeds vragen stellen bij onduidelijkheden of wanneer u meer inlichtingen wenst.

Indien u beslist tot deelname, wordt u verzocht de bijgevoegde toestemmingsverklaring te lezen, te ondertekenen en aan de onderzoeker terug te bezorgen samen met de vragenlijst.

Kanker treft niet alleen de patiënt, maar u ook als naaste.

Doel van het onderzoek

Het doel van deze studie is een beter inzicht krijgen in de huidige ervaringen en noden van naasten van patiënten met kanker in UZ Leuven. Voor dit onderzoek nodigen we de “dichtste” naaste uit, zoals aangegeven door de patiënt zelf.

De resultaten van dit onderzoek zullen ons helpen om:

- * De impact van kanker op naasten beter in te schatten
- * Naasten van patiënten met kanker in de toekomst beter te ondersteunen

Aan deze studie zullen ca. 500–1000 naasten van oncologische patiënten uit UZ Leuven deelnemen.

We hopen met dit onderzoek zoveel mogelijk naasten van mensen met kanker te bereiken om de impact op de naasten beter in te schatten.

“En u? Hoe gaat het met u?”

Ervaringen en noden van naasten van mensen met kanker in UZ Leuven

Wat houdt (deelname aan) dit onderzoek in?

Er wordt u een éénmalige vragenlijst aangeboden.
Deze wordt u persoonlijk bezorgd en toegelicht door de onderzoeker of kan mogelijk ook via de patiënt tot bij u geraken.

U krijgt drie keuzes om de vragenlijst in te vullen:



Op papier op het moment dat u aanwezig bent bij uw geliefde/de patiënt in het ziekenhuis.
U bezorgt de vragenlijst dan terug aan uw verpleegkundige op de afdeling of medewerker van de balie.



Op papier wanneer u thuis bent.
De ingevulde vragenlijst met dit toestemmingsformulier stuurt u via een vooraf gefrankeerde enveloppe terug naar de onderzoekers.



Via een online link.
De link is voor u beschikbaar op www.uzleuven.be/naasten

Alles wat u op deze vragenlijst invult, is anoniem.

Nergens zal u gegevens moeten noteren, waaraan men u kan identificeren zoals bijvoorbeeld uw naam.

Waarom werd ik gekozen?

U werd gevraagd om deel te nemen, omdat u de dichtste naaste bent van iemand met kanker die momenteel in behandeling of follow-up is in UZ Leuven.

Vertrouwelijkheid

De Belgische Wet van 11 december 1998 betreffende de bescherming van het privéleven en de Belgische Wet van 22 augustus 2002 met betrekking tot de patiënten rechten worden gerespecteerd bij uitvoering van dit onderzoek.

Alle persoonlijke informatie die tijdens deze studie wordt verzameld is strikt vertrouwelijk en wordt volledig anoniem verzameld, verwerkt en geanalyseerd. De informatie die u geeft, wordt enkel aangewend voor het doeleinde van deze studie en kan dus geen enkel gevolg hebben voor de zorg voor uw geliefde/de patiënt of op de relatie tussen jullie en de zorgverleners.

“En u? Hoe gaat het met u?”

Ervaringen en noden van naasten van mensen met kanker in UZ Leuven

Wie heeft deze studie gecontroleerd?

Deze studie werd goedgekeurd door de Commissie voor Medische Ethiek van UZ Leuven. Deze studie wordt uitgevoerd volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en volgens de meest recente versie van de verklaring van Helsinki opgesteld ter bescherming van mensen deelnemend aan klinische studies.

In geen geval dient U de goedkeuring door de Commissie voor Medische Ethiek te beschouwen als een aansporing tot deelname aan deze studie.

Bezwaren, suggesties of bedenkingen?

- **Neem zeker contact op met de onderzoekers:**

⇒ **Annemarie Coolbrandt**
(016 34 13 14)

⇒ **Ine Decadt**
(016 34 35 19)

- **U kan contact opnemen met de Ombudsdienst van UZ Leuven**

⇒ **Schriftelijk:** per brief (UZ Leuven, Ombudsdienst, Herestraat 49, 3000 Leuven)

⇒ **Via e-mail**
(ombudsdienst@uzleuven.be)

⇒ **Via het formulier op de website**
www.uzleuven.be/ombudsdienst

⇒ **U kunt ook telefonisch een afspraak maken voor een gesprek via het nummer 016 34 48 18 op werkdagen tussen 8.30 en 16.30 uur.**

Vrijwillige deelname

U beslist vrijwillig of u al dan niet wilt deelnemen.

U heeft het recht deelname aan deze studie te weigeren. Wanneer u beslist deel te nemen, kunt u op elk tijdstip uw goedkeuring intrekken en u hoeft hiervoor geen reden op te geven. Uw beslissing om al dan niet deel te nemen heeft geen enkele invloed op de kwaliteit van de opvolging of behandeling voor uw geliefde/de patiënt, noch op jullie relatie met de zorgverleners.

Mogelijke voor- en nadelen

U zult geen onmiddellijk persoonlijk voordeel halen uit uw deelname aan het onderzoek. Wel hopen wij dat we mede op basis van deze studie en uw deelname eraan beter inzicht krijgen in de huidige ervaringen van naasten van mensen met kanker in UZ Leuven en de ondersteunende zorg voor deze naasten kunnen verbeteren.

Er zijn geen risico's, nadelen of bijkomende kosten verbonden aan deelname aan deze studie, en de deelname brengt geen kosten met zich mee voor u of uw ziekteverzekering.

Wat zal er gebeuren met de resultaten van het onderzoek?

De resultaten zullen in de eerste plaats gebruikt worden om de noden van naasten van mensen met kanker te evalueren en de ondersteuning van naasten te verbeteren. Daarnaast is het mogelijk dat de resultaten van het onderzoek gepubliceerd worden in een verpleegkundig of medisch tijdschrift. Uw identiteit zal in geen van beide gevallen worden vrijgegeven.

"En u? Hoe gaat het met u?"

Ervaringen en noden van naasten van mensen met kanker in UZ Leuven

Toestemmingsformulier

Ik ben gevraagd deel te nemen aan het onderzoek getiteld *"En u? Hoe gaat het met u?"*
Ervaringen en noden van naasten van mensen met kanker in UZ Leuven.

Ik ben geïnformeerd over mijn deelname en het invullen van een éénmalige vragenlijst. Ik verklaar dat ik de informatie ontvangen en zorgvuldig nagelezen heb.

Ik heb voldoende gelegenheid gehad mijn vragen met betrekking tot het onderzoek en mijn deelname met de onderzoeker te bespreken en na te denken over de gegeven uitleg en antwoorden.

Alle antwoorden op de vragenlijsten zullen strikt vertrouwelijk worden behandeld en alleen ter beschikking zijn van de onderzoekers. De in rapporten en publicaties vermelde gegevens zullen zodanig worden beschreven dat zij niet tot mijn persoon kunnen worden herleid.

Het is mij duidelijk dat deelname aan het onderzoek vrijwillig is.

Ik begrijp dat ik, zonder opgave van reden, op elk ogenblik kan besluiten mijn deelname aan het onderzoek stop te zetten.

Ik verklaar hierbij vrijwillig deel te nemen aan bovengenoemd onderzoek.

Handtekening deelnemer:

Datum en plaats:

Ik ondergetekende, bevestig dat ik mondeling de nodige informatie heb gegeven over deze studie, dat ik een kopie heb gegeven van het informatie- en toestemmingsformulier die door de verschillende partijen werd getekend, dat ik bereid ben om zo nodig alle aanvullende vragen te beantwoorden en dat ik geen druk op de naaste of op de patiënt heb uitgeoefend om aan deze studie deel te nemen.

Ik verklaar dat ik werk volgens de ethische principes die worden beschreven in de Verklaring van Helsinki en de Belgische wet van 7 mei 2004 over proeven op mensen.

Naam onderzoeker:

Handtekening:

Datum en plaats:

"En u? Hoe gaat het met u?"

Ervaringen en noden van naasten van mensen met kanker in UZ Leuven

Toestemmingsformulier

Ik ben gevraagd deel te nemen aan het onderzoek getiteld *"En u? Hoe gaat het met u?"* *Ervaringen en noden van naasten van mensen met kanker in UZ Leuven*.

Ik ben geïnformeerd over mijn deelname en het invullen van een éénmalige vragenlijst. Ik verklaar dat ik de informatie ontvangen en zorgvuldig nagelezen heb.

Ik heb voldoende gelegenheid gehad mijn vragen met betrekking tot het onderzoek en mijn deelname met de onderzoeker te bespreken en na te denken over de gegeven uitleg en antwoorden.

Alle antwoorden op de vragenlijsten zullen strikt vertrouwelijk worden behandeld en alleen ter beschikking zijn van de onderzoekers. De in rapporten en publicaties vermelde gegevens zullen zodanig worden beschreven dat zij niet tot mijn persoon kunnen worden herleid.

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Ik verklaar hierbij vrijwillig deel te nemen aan bovengenoemd onderzoek.

Handtekening deelnemer:

Datum en plaats:

Ik ondergetekende, bevestig dat ik mondeling de nodige informatie heb gegeven over deze studie, dat ik een kopie heb gegeven van het informatie- en toestemmingsformulier die door de verschillende partijen werd getekend, dat ik bereid ben om zo nodig alle aanvullende vragen te beantwoorden en dat ik geen druk op de naaste of op de patiënt heb uitgeoefend om aan deze studie deel te nemen.

Ik verklaar dat ik werk volgens de ethische principes die worden beschreven in de Verklaring van Helsinki en de Belgische wet van 7 mei 2004 over proeven op mensen.

Naam onderzoeker:

Handtekening:

Datum en plaats:

3/ QUESTIONNAIRE FOR THE CAREGIVER



“En u? Hoe gaat het met u?”

Ervaringen en noden van naasten van mensen met kanker
in UZ Leuven.



VRAGENLIJST VOOR NAASTEN VAN MENSEN MET KANKER IN BEHANDELING OF FOLLOW-UP IN UZ LEUVEN

Beste meneer/mevrouw,

We willen u danken voor uw bereidheid om deze vragenlijst in te vullen.

In deze vragenlijst worden er eerst enkele algemene vragen over uw rol als naaste en over uw steunnetwerk gesteld. Vervolgens worden er vragen gesteld die peilen naar uw tevredenheid met de gekregen zorg, uw mate van mogelijke belasting, uw voorbereidheid op de zorg, en tenslotte uw kwaliteit van leven. Op het einde van de vragenlijst is er extra ruimte voorzien voor eventuele opmerkingen, bedenkingen of suggesties.

Misschien leest u in deze vragenlijsten stellingen waarin u zich minder of helemaal niet herkent. We hopen dat u in dit geval niet afhaakt maar uw mening laat blijken in uw antwoord op de vraag. De ervaring van elke naaste telt, de deelname van elke naaste is voor dit onderzoek van groot belang!

- Vul deze vragenlijst bij voorkeur in op **een rustige plaats** en **neem uw tijd**.
- Het invullen van de vragenlijst zal ongeveer **15-30 minuten** in beslag nemen.
- De vragenlijst is volledig **anoniem** en uw identiteit zal op geen enkel ogenblik kenbaar worden gemaakt.
- Indien u de vragenlijst **thuis** invult, gelieve **de ingevulde vragenlijst** met het bijhorende toestemmingsformulier zo spoedig mogelijk terug te sturen via de verkregen gefrankeerde enveloppe.
- Indien u de vragenlijst **in het ziekenhuis** invult, gelieve **de ingevulde vragenlijst** achter te laten in de **brievenbus** in de dagzaal op uw afdeling. Deze brievenbus kan u herkennen aan de afbeelding van **de vergeet-me-nietjes**.

Namens het onderzoeksteam, danken wij u voor uw deelname.

Bij eventuele vragen of opmerkingen kan u ons altijd contacteren op het volgende emailadres:

onderzoeknaasten@gmail.com.

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DEEL 1: ALGEMENE GEGEVENS

1.1 GEGEVENS MET BETREKKING TOT UZELF

Geslacht <ul style="list-style-type: none"><input type="radio"/> Man<input type="radio"/> Vrouw
Leeftijd jaar
Relatie met uw geliefde/de patiënt <ul style="list-style-type: none"><input type="radio"/> Ik ben partner<input type="radio"/> Ik ben kind<input type="radio"/> Ik ben ouder<input type="radio"/> Ik ben broer/zus<input type="radio"/> Ik ben een kennis/vriend(in)<input type="radio"/> Andere namelijk.....
Woonsituatie <ul style="list-style-type: none"><input type="radio"/> Ik ben samenwonend met mijn geliefde/de patiënt<input type="radio"/> Ik woon niet samen met mijn geliefde/de patiënt
Wat is de hoogste opleiding die u heeft voltooid? <ul style="list-style-type: none"><input type="radio"/> Lager onderwijs<input type="radio"/> Secundair onderwijs<input type="radio"/> Hoger onderwijs (hogeschool of universiteit)
Wat is uw huidige werksituatie? <ul style="list-style-type: none"><input type="radio"/> Ik ben momenteel aan het werk.<input type="radio"/> Ik ben momenteel niet aan het werk.

1.2 GEGEVENS MET BETREKKING TOT UW GELIEFDE/DE PATIËNT

De huidige diagnose kanker werd gesteld bij mijn geliefde/de patiënt

- Meer dan 10 jaar geleden
- Meer dan 5 jaar geleden
- Meer dan 1 jaar geleden
- Het afgelopen jaar

De hoofddiagnose van mijn geliefde/de patiënt is

- Borstkanker
- Kanker van het maagdarmsstelsel (*maag, darm, pancreas, lever,...*)
- Kanker van het bloed of de lymfeklieren (*leukemie, lymfoom, ziekte van Kahler...*)
- Gynaecologische kanker (*kanker van de eierstokken, baarmoeder, vagina,...*)
- Longkanker
- Kanker in de hersenen
- Huidkanker
- Kanker van de urinewegen (*blaas, prostaat, urineleiders,...*)
- Hoofd-hals kanker
- Andere, namelijk.....
- Ik weet het niet

Mijn geliefde/de patiënt is op dit moment...

- In behandeling
- In follow-up na de behandeling (*mijn geliefde/ de patiënt wordt na de behandeling verder opgevolgd en moet regelmatig op controle komen*)
- Andere, namelijk.....
- Ik weet het niet

Indien uw geliefde/de patiënt in behandeling is, duid dan hier de huidige behandeling aan:

- Chemotherapie
- Immunotherapie of andere kankerbehandelingen met geneesmiddelen
- Bestraling
- Tegelijk chemotherapie en bestraling

Mijn geliefde/de patiënt is op dit moment...

- Opgenomen op een hospitalisatie-afdeling in UZ Leuven
- Op een ambulante afdeling (oncologisch dagcentrum, bestralingsafdeling, consultatie oncologie) in UZ Leuven
- Ik weet het niet

1.3 GEGEVENS MET BETREKKING TOT UW ZORGNETWERK

In welke mate kunt u rekenen op mensen in uw **persoonlijke omgeving** (binnen uw gezin, familie, buren, vrienden,...) voor **emotionele steun**?

Gelieve telkens het antwoord te omcirkelen dat voor u van toepassing is.

Helemaal niet	Eerder niet	Geen mening	Eerder wel	Zeker wel
---------------	-------------	-------------	------------	-----------

In welke mate kunt u rekenen op mensen in uw **persoonlijke omgeving** voor **praktische hulp**?

Gelieve telkens het antwoord te omcirkelen dat voor u van toepassing is.

Helemaal niet	Eerder niet	Geen mening	Eerder wel	Zeker wel
---------------	-------------	-------------	------------	-----------

Op wie kunt u rekenen voor **praktische hulp**?

(Bij deze vraag zijn er meerdere antwoorden mogelijk.)

- Gezinsleden
- Naaste familie (buiten het gezin)
- Vrienden
- Buren, kennissen, (oud)collega's
- Vrijwilligers
- Niemand
- Andere namelijk.....

Wie is **in de thuissituatie** betrokken bij de zorg voor uw geliefde/de patiënt?

(Bij deze vraag zijn er meerdere antwoorden mogelijk.)

- Niemand
- De huisarts
- Thuisverpleegkundige
- Familiehulp
- Poetshulp
- Kinesist
- Maaltijdlevering
- Niet van toepassing, mijn geliefde/de patiënt verblijft in een woon- en zorgcentrum
- Andere namelijk.....

Op wie kunt u rekenen voor **emotionele steun in het ziekenhuis**?

(Bij deze vraag zijn er meerdere antwoorden mogelijk.)

- De behandelende arts uit het ziekenhuis
- Het verpleegkundig team uit het ziekenhuis
- Een sociaal werker uit het ziekenhuis
- Een psycholoog uit het ziekenhuis
- Andere namelijk.....

1.4 INHOUD VAN DE ROL VOOR UW GELIEFDE/DE PATIËNT

De rol van naasten voor patiënten met kanker kan verschillen afhankelijk van de situatie. Aan de hand van onderstaande lijst willen we **de inhoud van uw rol** voor uw geliefde/de patiënt zo goed mogelijk inschatten.

Gelieve telkens één bolletje te kleuren dat voor u van toepassing is als antwoord op deze vragen.

	Ik hoef mijn geliefde/ de patiënt hierbij geen hulp te bieden	Ik bied mijn geliefde/ de patiënt hierbij gedeeltelijke hulp of ondersteuning	Ik bied mijn geliefde/ de patiënt hierbij volledige hulp
Vervoer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gebruik van geneesmiddelen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financieel beheer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Huishouden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Maaltijden bereiden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Boodschappen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kleren wassen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eten	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Verplaatsen binnenshuis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kleden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Toiletbezoek	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wassen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DEEL 2: UW TEVREDENHEID ALS NAASTE MET DE GEKREGEN ZORG

Aan de hand van deze vragen peilen we naar **uw tevredenheid met de gekregen zorg** voor uw geliefde/de patiënt als naaste in de afgelopen weken.

Gelieve telkens één bolletje te kleuren dat voor u van toepassing is als antwoord op deze vragen.

1. Hoe tevreden bent u in het algemeen met de **kwaliteit van de zorg** die uw geliefde/de patiënt in de afgelopen weken ontving?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

2. Hoe tevreden bent u over het algemeen met de manier waarop **u** behandeld werd door de artsen, verpleegkundigen en andere gezondheidszorgprofessionals die voor uw geliefde/de patiënt zorgden?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

3. Hoe tevreden bent u over de **beschikbaarheid** van de arts(en) (via de telefoon of persoonlijk) wanneer u of uw geliefde/de patiënt deze nodig had?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

4. Hoe tevreden bent u met de mate van **vertrouwen** die u had in de arts(en) die zorgde(n) voor uw geliefde/de patiënt?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

5. Hoe tevreden bent u dat de artsen, verpleegkundigen, en andere gezondheidszorg professionals die zorgden voor uw geliefde/de patiënt **medelevend en ondersteunend** waren voor **hem/haar**?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

6. Hoe tevreden bent u dat de artsen, verpleegkundigen of andere gezondheidsmedewerkers die zorgden voor uw geliefde/de patiënt **medelevend en ondersteunend** waren voor u?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

7. Hoe tevreden bent u dat de **zorg en behandeling** die uw geliefde/de patiënt ontving in **overeenstemming** was met zijn/haar wensen?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

8. Hoe tevreden bent u dat de arts(en) zaken uitlegde(n) in verband met de ziekte van uw geliefde/de patiënt op een **oprechte en eerlijke** manier?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

9. Hoe tevreden bent u dat de artsen **luisterden** naar wat u had te zeggen?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

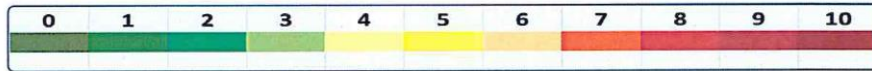
10. Hoe tevreden bent u met uw **rol in het maken van beslissingen** met betrekking tot de medische zorg van uw geliefde/de patiënt?

- Helemaal niet tevreden
- Niet erg tevreden
- Enigszins tevreden
- Heel tevreden
- Volledig tevreden

DEEL 3: UW ZORGBELASTING

Aan de hand van deze vragen willen we de **impact van de zorg voor uw geliefde/de patiënt** in kaart brengen.

Hoe lastig is de **voorbije week voor u als naaste geweest?** Duid dit met een kruisje (X) op de thermometer aan.



Helemaal niet lastig

Extreem lastig

Gelieve telkens één bolletje te kleuren dat voor u van toepassing is als antwoord op onderstaande vragen.

	Helemaal niet akkoord	Eerder niet akkoord	Eerder akkoord	Helemaal akkoord
Zorgen voor mijn geliefde/de patiënt heeft een negatieve invloed op mijn fysieke gezondheid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ga niet goed om met mijn huidige situatie.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben meer geïsoleerd van mijn gewoonlijke sociale activiteiten dan vroeger.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Zorgen voor mijn geliefde/de patiënt heeft voor spanning gezorgd in mijn familiale relaties.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ga niet lang meer in staat zijn om nog voor mijn geliefde/de patiënt te kunnen blijven zorgen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Zorgen voor mijn geliefde/de patiënt heeft voor spanning gezorgd in mijn relatie met hem/haar.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel dat het tegemoet komen aan de behoeften van mijn geliefde/de patiënt niet langer de moeite waard is.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb geen minuut pauze in de zorg voor mijn naaste.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik doe meer dan mijn deel van de zorg in vergelijking met andere familieleden of mensen in mijn sociaal netwerk.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me neerslachtig.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb het gevoel de controle over mijn eigen leven te verliezen door mijn huidige situatie.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In de laatste maanden heb ik mijn gebruik van alcohol, drugs of sigaretten verhoogd.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DEEL 4: UW KWALITEIT VAN LEVEN

Hieronder vindt u een overzicht van een aantal belangrijke uitspraken van andere naasten die de zorg voor hun geliefde/de patiënt met kanker hebben opgenomen.

Door het kleuren van één bolletje per uitspraak geeft u aan in welke mate deze uitspraak de afgelopen zeven dagen het beste voor u van toepassing was.

	Helemaal niet van toepassing	Een klein beetje van toepassing	Een beetje van toepassing	Nogal wat van toepassing	Heel veel van toepassing
Het stoort me dat mijn dagelijkse routine veranderd is.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mijn slaap is minder rustig.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mijn dagelijks leven wordt voor mij bepaald.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben tevreden met mijn seksleven.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Het is een uitdaging om mijn interesses te behouden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik sta onder financiële druk.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben bezorgd over de tegenoetkoming van de verzekering.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mijn economische toestand is onzeker.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik ben bang dat mijn geliefde/de patiënt zal sterven.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik heb een positievere kijk op het leven sinds de ziekte van mijn geliefde/de patiënt.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mijn niveau van stress en zorgen zijn toegenomen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mijn gevoel voor spiritualiteit is toegenomen..	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Gedurende de afgelopen zeven dagen:

	Helemaal niet van toepassing	Een klein beetje van toepassing	Een beetje van toepassing	Nogal wat van toepassing	Heel veel van toepassing
Het stoort me dat ik mijn focus van dag tot dag moet beperken.	0	0	0	0	0
Ik voel me verdrietig.	0	0	0	0	0
Ik voel een toegenomen mentale spanning.	0	0	0	0	0
Ik krijg steun van vrienden en kennissen.	0	0	0	0	0
Ik voel me schuldig.	0	0	0	0	0
Ik voel me gefrustreerd.	0	0	0	0	0
Ik voel me nerveus.	0	0	0	0	0
Ik maak me zorgen over de impact van de ziekte op mijn kinderen of andere familieleden.	0	0	0	0	0
Ik heb het moeilijk om met de veranderde eetgewoonten van mijn geliefde/de patiënt om te gaan.	0	0	0	0	0
Ik heb een hechtere band met mijn geliefde/de patiënt ontwikkeld.	0	0	0	0	0
Ik voel me voldoende geïnformeerd over de ziekte van mijn geliefde/de patiënt.	0	0	0	0	0
Het stoort me dat ik beschikbaar moet zijn om mijn geliefde/de patiënt naar afspraken te vervoeren.	0	0	0	0	0
Ik ben bang voor de nevenwerkingen van de behandeling op mijn geliefde/de patiënt.	0	0	0	0	0
De verantwoordelijkheid die ik thuis opneem in de zorg voor mijn geliefde/de patiënt is overweldigend.	0	0	0	0	0

Gedurende de afgelopen zeven dagen:

	Helemaal niet van toepassing	Een klein beetje van toepassing	Een beetje van toepassing	Nogal wat van toepassing	Heel veel van toepassing
Ik ben blij dat ik me kan focussen op de gezondheid van mijn geliefde/de patiënt.	0	0	0	0	0
De communicatie binnen de familie is toegenomen.	0	0	0	0	0
Het stoort me dat mijn prioriteiten veranderd zijn.	0	0	0	0	0
De nood om mijn geliefde/de patiënt te beschermen stoort me.	0	0	0	0	0
Het maakt me van streek om mijn geliefde/ de patiënt te zien achteruitgaan.	0	0	0	0	0
De nood om de pijn van mijn geliefde/de patiënt aan te pakken is overweldigend.	0	0	0	0	0
Ik ben ontmoedigd over de toekomst.	0	0	0	0	0
Ik ben tevreden met de steun die ik ontvang van mijn familie.	0	0	0	0	0
Het stoort me dat andere familieleden geen belangstelling hebben getoond in het zorgdragen van mijn geliefde/de patiënt.	0	0	0	0	0

DEEL 5: UW VOORBEREIDHEID VOOR HET OPNEMEN VAN DE ZORG

Aan de hand van deze vragen kan u aangeven in welke mate u zich voorbereid voelt op het verstrekken van zorg voor uw geliefde/de patiënt.

Indien u de zorg van uw geliefde/de patiënt al langere tijd opneemt, probeer dan terug te denken aan het moment dat de zorg toenam of veranderde.

Gelieve telkens één bolletje te kleuren dat het best overeenstemt met uw gevoel van voorbereidheid op het verstrekken van de zorg.

	Heel slecht	Eerder slecht	Eerder goed	Redelijk goed	Zeer goed
Hoe goed voelt/voelde u zich voorbereid om te zorgen voor de lichamelijke behoeften van uw naaste?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed voelt/voelde u zich voorbereid om te zorgen voor de emotionele behoeften van uw naaste?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed voelt/voelde u zich voorbereid om informatie in te winnen over hulpverlening en deze te organiseren?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed voelt/voelde u zich voorbereid op de stress van het zorg verlenen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed voelt/voelde u zich voorbereid om het zorg verlenen aangenaam te maken voor u en uw naaste?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed denkt/dacht u voorbereid te zijn om te reageren bij noodsituaties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed denkt/dacht u voorbereid te zijn om die hulp en informatie van uw zorgverleners te verkrijgen die u nodig heeft?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In het algemeen, hoe goed denkt/dacht u voorbereid te zijn om te zorgen voor uw naaste?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DEEL 6: VRIJBLIJVENDE VRAGEN

Welke andere **positieve** of **negatieve ervaringen**, **bedenkingen** of **suggesties** wilt u als naaste van iemand met kanker nog met ons delen?

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Welke **tips** zou u ons als naaste kunnen geven om onze **dagelijkse zorg** voor naasten van mensen met kanker **te verbeteren**?

.....

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.....

Indien u tijdens het invullen van deze vragenlijst bij uzelf gevoeld heeft dat u extra ondersteuning of hulp nodig heeft, aarzel niet om de arts, verpleegkundige of sociaal werker hierover aan te spreken.

Hartelijk dank voor uw deelname!



