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Cancer Palliative Care: Technology Support for Quality of Life Assessment of Family Caregivers

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Abstract

Family caregivers (FCs) are fundamental for quality of life (QoL) optimization and well-being of cancer patients, contributing to the quality of palliative care services. The present study aimed to evaluate the QoL of FCs caring for oncological patients admitted to the Palliative Care Service of the Portuguese Oncology Institute of Porto. It was also intended to identify multidimensional problems that could guide strategies to provide support to FCs. Two measurement instruments, translated and validated for the Portuguese population, were administered to FCs (n=150): World Health Organization Quality Life - WHOQOL-BREF and WHOQOL-SRPB questionnaires. The Platform for QoL Assessment in Oncology (OpQoL) was used for data collection. Most FCs were female (n=97, 64.7%), catholic (n=137; 91,3%), married (n =106; 70,7%), 7%), professionally active (n=147; 98,0%), having a daily care of less than 6 hours (n=88; 58,7%) and for less than 6 months (n = 87; 58,0%). The most frequent schooling years was between 8 and 11 (n =67; 44,7%) and the most common affective relationship with the patient was being son/daughter (n =63; 42,0%). FCs education and age influenced QoL results, with the worst impacts occurring in all dimensions evaluated in the age ranges 18-30 and 46-60 years. Women score worse in physical, psychological, social, and total domains of the WHOQOL-BREF. FCs from patients with 3 and 4 level on the ECOG scale have a greater negative overall and social impact. Worst results were observed in FCs who take care more than 6 hours/day. QoL systematic assessment is decisive for FCs QoL optimization in cancer palliative care. Technology support contributes to overcome technical, methodological and logistical constraints, allowing the use of QoL results on the shortest time. This study identifies FCs needs and signal affected domains – it provides guidance to the implementation of strategies that can optimize QoL.

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1. Introduction

Previous studies show that the integration of family caregivers (FCs) into an interdisciplinary care network, promotes the quality of palliative care services – evidence reveals that FCs are determinant for the optimization of the well-being and quality of life (QoL) of cancer patients. However, FCs often face distress that has been essentially attributed to their lack or poor experience as caregivers, to communication deficiencies with the care services and to the reduced number of professionals integrated in the team care [1].

Published studies assessing QoL and Health status in FCs reveal significant physical, psychosocial and emotional problems with multidimensional impacts, all related to their caregiver experience. Physical problems include: fatigue, exhaustion, insomnia, lack of appetite, nausea, vomiting, spinal affections, arterial hypertension, dyspnoea, and lower limb vascular disorders; psychosocial disorders are related to anxiety, depression and stress; emotional problems involve: feeling useless, feelings of uncertainty, guilt and lack of hope. Financial problems, productivity reduction and social isolation have also been reported [1-3]. These negative effects are felt in family relationships and, since the experience of caring for cancer patients crosses several generations nowadays, they impact the most diverse age groups [4]. On the other hand, studies that analyze the positive effects associated with the act of caring, designated posttraumatic personal growth, seem to indicate a protective role with positive impact on QoL [5]. Caring can be thus an enriching experience, providing feelings of personal and social valuation [6].

According to reviewed literature providing FCs with comfort and support, as well as, physical, psychosocial and educational support results in the improvement of their QoL [7,8]. The definition of strategies to support FCs benefit from the appreciation of their perspectives and, self-reported outcomes evaluations like QoL assessment, should be implemented at the earliest stages of the process. Electronic models for QoL assessment have been developed in the last decade. Our Quality of Life informatics platform is a powerful and effective tool, allowing a real time assessment, processing and analysis of a large Quality of Life data obtained by self-response. Meaningful data can support healthcare decisions, identify potential needs, and support a stepped-care model [9-11]. The collected information can thus be used on the shortest time, favoring a successful communication between FCs and palliative care services that can minimize the risk of disease development [12].

The present study aimed to evaluate the QoL of FCs of oncological patients admitted to the Palliative Care Service of the Portuguese Oncology Institute of Porto (IPO-Porto) using technology support for QoL assessment.

It was also intended to identify multidimensional problems in FCs of oncological patients related to physical, psychological, environmental and social dimensions. Spiritual connection, spiritual strength, inner peace, faith, hope & optimism, meaning in life, awe and wonder, wholeness and integration were analyzed according to their socio-demographic characteristics. This comprehension should guide strategies to provide support to FCs.

2. Method

2.1 Ethics

The study was developed in accordance with the Helsinki Declaration. The method was previously approved by the Ethics Committee IPO-Porto. All participants gave their written and informed consent and agreed to participate in the study.

2.2 Participants

The study included 150 FCs from cancer patients admitted to the Palliative Care Service of the Portuguese Oncology Institute of Porto. Inclusion criteria were: being the patient FC, ability to understand written and spoken Portuguese and filling the informed consent.

Socio-demographic data considered included: age, gender, presence of distant metastases, current treatment - palliative and curative / exclusive palliative - degree of kinship with FCs and performance status scale "Eastern Cooperative Oncology Group" (ECOG). ECOG hierarchizes the functional limitations resulting from the disease - the scale goes from 0 - asymptomatic patient, without functional limitations - to limit 5, deceased patient. In ECOG 1 the patient has some symptoms that limit their performance in some work, but they are able to perform daily activities, while in ECOG 2 the symptoms already require them to stay in bed several hours during the day (less than 50% of the time), being able to perform most of their needs. In the ECOG 3, the patient needs to stay in bed more than 50% of the day and needs help for most of their daily activities [13]. Socio-demographic data of the evaluated FCs were: age, gender, religion, degree of kinship, marital status, offspring, activity related to the profession, education (expressed as schooling years), daily care and duration of care as FCs.

2.3 Questionnaires

Two measurement instruments - translated and validated for the Portuguese population - were administered: *World Health Organization Quality Life* - WHOQOL-BREF and WHOQOL-SRPB questionnaires. WHOQOL-BREF assesses QoL, health, culture, values, personal goals and concerns. It was developed in 1991 by the *World Health Organization Quality of Life* with the objective of creating an international and cross-cultural instrument for the evaluation of QoL. The WHOQOL-SRBP assesses beliefs, spirituality, religiosity and QoL.

Prior to the completion of the questionnaires, all FCs were informed about the nature, pertinence and objectives of the study and then filled the written consent. The Platform for QoL Assessment in Oncology (OpQoL) developed in IPO-Porto was used for data collection,

2.4 Data analysis and statistics

Questionnaire scores (WHOQOL-SRPB and WHOQOL-BREF) were obtained according to the procedures manuals provided by the authors [14].

The continuous variable *age,* was described using central distribution measures, namely the mean, standard deviation, minimum and maximum. Variables with non-parametric distribution (total scores of the questionnaires), the median and the interquartile range 25-75 were used.

As for the categorical variables (gender, religion, kinship, marital status, whether or not they have children, schooling, time of caring and how long they have taken care of the patient), absolute and relative frequencies were used. To test for normality, the Kolmogorov-Smirnov test was applied.

New categorical variables were created for some of the continuums, such as age, which was categorized into three categories (less than 40 years, between 40-60 years and over 60 years), schooling, categorized in less than 8 years of study, between 8-11 years of schooling and over 11 years of study, the time available to take care of the patient (up to 6 hours, between 6-12 hours and over 12 hours a day) and finally, how long have they taken care of the patient (up to 6 months, between 6-12 months and 12 months or longer).

The total scores of the questionnaires were considered as continuous variables. For the missing data, value substitution technique was used as follows: for the normal variables, the total mean of the participants was used and for the non-parametric, it was used the median.

The data obtained were analyzed using the computer application *Statistical Package for the Social Sciences* (IBM ® SPSS © vs. 22) and Microsoft Office Excel (2010).

3. Results

The non-parametric variable *age* of FCs manifested normal distribution (Kolmogorov-Smirnov normality tests with significance of 0.200 and 0.051 respectively since p> 0.005), presenting a minimum of 18, a maximum of 84, a mean of 49,34 and a standard deviation of 15,02 and the most represented age group included individuals between 46 and 60 years old (n = 48; 36,0%).

Table 1 – Socio-demographic characteristics of Family Caregivers (n = 150)

Characteristics	n (%)
Age (years)	
18-30	21 (14,0)
31-45	44 (29,3)
46-60	48 (32,0)
> 60	37 (24,7)
Gender	
Male	53 (35,3)
Female	97 (64,7)
Religion	
Catholic	137 (91,3)
Atheist or agnostic	11 (7,3)
Other	2 (1,3)
Degree of kinship	
Son / daughter	63 (42,0)
Spouse	29 (19,3)
Sibling	16 (10,7)
Parent	3 (2,0)
Other	39 (26,0)
Marital Status	
Single	28 (18,7)
Married	106 (70,7)
Widower	7 (4,7)
Divorced	9 (6,0)
Offspring	
Yes	112 (74,7)
No	38 (25,3)
Work Activity	
Active	147 (98,0)
Inactive	3 (2,0)
Stopped working?	
Yes	60 (40,0)
No	90 (60,0)
Education (schooling years)	
< 8	41 (27,3)
8-11	67 (44,7)
> 11	42 (28,0)
Daily care (hours)	
Up to 6	88 (58,7)
6-12	46 (30,7)
More than 12	16 (10,7)
Duration of care (months)	
Up to 6	87 (58,0)
6-12	23 (15,3)
More than 12	40 (26,7)

As indicated in Table 1, most FCs were female (n = 97; 64,7%), catholic (n = 137; 91,3%), married (n = 106; 70,7%), with offspring (n = 112; 74,7%), professionally active (n = 147; 98,0%), provided daily care for less than 6 hours (n = 88; 58,7%) and for less than 6 months (n = 87; 58,0%). The most frequent schooling years was between 8 and 11 (n = 67; 44,7%) and the most common affective relationship with the patient was to be their son or daughter and (n = 63; 42,0%).

Patients were predominantly males (n = 82; 54,7%), older than 60 years (n = 102; 68,0%), had distant metastases (n = 140; 93,3%), were receiving exclusive palliative treatment (n = 141; 93,3%) and had an ECOG greater than 2 (n = 143; 95,3%) as indicated in Table 2.

Table 2 – Socio-demographic and clinical characteristics of patients (n = 150)

Characteristics	n (%)
Age (years)	
< 40	9 (6,0)
40-60	39 (26,0)
> 60	102 (68,0)
Gender	
Male	82 (54,7)
Female	68 (45,3)
Presence of distant metastases	
Yes	140 (93,3)
No	10 (6,7)
Current treatment	
Palliative only	141 (94,0)
Palliative and others	9 (6,0)
ECOG	
1-2	7 (4,7)
3	70 (46,7)
4	73 (48,7)

The total scores of the questionnaires showed a non-normal distribution since the Kolmogorov-Smirnov test was <0,01 (0,000 and 0,001). It was confirmed that, for total scores groups, the distribution was not normal.

As the data distribution of the sociodemographic variables was not normal, the Kruskal-Wallis test was used to compare the categorical sociodemographic variables with the total score of the two measures. The age distribution was not normal when considering the total scores of the two measures (WHOQOL-BREF and WHOQOL-SRPB), even when tested for the three age categories in relation to the total score of the two measures. Considering the WHOQOL-BREF questionnaire, gender differences were found with statistically significant differences between the medians relative to the *physical* domain (p = 0,006) being the scores were always better in men (Table 3).

Table 3 – WHOQOL-BREF scores obtained by the FCs according to their socio-demographic characteristics as well as the ECOG status of the patient being cared for (expressed in median and interquartile range, IC; n=150).

Characteristics	n	Physical (median, IC)	Psychological (median, IC)	Environmental (median, IC)	Social (median, IC)	Total (median, IC)
Age (years)						
18-30	21	14,7 (13,4-17,1)	14,0 (11,7-15,0)	16,0 (14,7-16,0)	14,0 (13,0-15,0)	16,0 (14,0-16,0)
31-45	44	16,6 (14,9-17,7)	15,0 (13,3-16,0)	16,0 (14,7-16,0)	14,5 (13,0-15,5)	16,0 (12,5-16,0)
46-60	48	14,7 (13,8-16,6)	14,0 (12,7-16,0)	16,0 (13,3-16,0)	14,3 (13,5-14,8)	14,0 (12,0-16,0)
>60	37	15,4 (13,7-16,6)	14,0 (12,3-15,3)	16,0 (13,7-16,7)	14,0 (12,8-14,5)	14,0 (12,0-16,0)
Gender						
Male	53	**16,6*** (14,9-17,1)	15,3 (14,0-16,0)	16,0 (14,7-17,1)	14,5 (3,8-15,5)	16,0 (14,0-16,0)
Female	97	**14,4*** (13,1-16,6)	14,0 (12,0-15,3)	16,0 (13,3-16,0)	14,0 (13,0-14,5)	14,0 (12,0-16,0)
Degree of kinship						
Son /daughter	63	15,4 (14,3-17,1)	**14,0*** (12,7-16,0)	16,0 (13,3-16,0)	**14,0*** (13,0-15,0)	**14,0*** (12,0-16,0)
Spouse	29	14,9 (12,6-16,6)	**14,0*** (9,7-14,0)	16,0 (14,0-16,0)	**13,0*** (12,5-14,0)	**14,0*** (10,0-14,0)
Sibling	16	16,0 (13,2-16,9)	**14,7*** (13,0-16,0)	16,0 (13,3-16,7)	**14,5*** (12,8-15,0)	**14,0*** (12,0-16,0)
Parent	3	15,4 (13,7-16,1)	**13,3*** (11,3-13,0)	13,3 (10,7-15,0)	**14,0*** (13,5-14,0)	**14,0*** (10,0-13,0)
Other	39	16,6 (15,4-17,1)	**15,3*** (14,0-16,0)	16,0 (14,7-17,3)	**14,5*** (14,0-15,6)	**16,0*** (14,0-16,0)
Education (schooling years)						
< 8	41	**14,7*** (12,3-16,6)	14,0 (12,0-15,3)	16,0 (14,3-16,0)	13,5 (12,5-14,5)	14,0 (12,0-16,0)
8-11	67	**16,0*** (14,3-17,1)	14,7 (12,7-16,0)	16,0 (14,7-16,0)	14,0 (13,0-15,5)	14,0 (12,0-16,0)
> 11	42	**16,0*** (15,3-16,7)	14,0 (12,7-16,0)	16,0 (13,3-16,3)	14,5 (13,5-15,1)	16,0 (14,0-16,0)
Daily care (hours)						
Up to 6	88	16,0 (14,3-17,1)	**14,7*** (13,3-16,0)	16,0 (14,7-16,0)	**14,5*** (13,5-15,4)	**16,0*** (14,0-16,0)
6-12	46	15,1 (14,1-16,7)	**14,0*** (5,3-18,7)	16,0 (13,3-16,0)	**13,5*** (12,5-15,0)	**14,0*** (12,0-16,0)
More than 12	16	14,7 (13,3-17,4)	**13,0*** (9,8-14,0)	16,0 (14,7-17,8)	**13,5*** (13,0-14,9)	**14,0*** (10,0-15,5)
Patient ECOG						
1-2	7	15,2 (13,7-17,1)	14,0 (12,7-16,0)	14,7 (13,3-18,7)	15,0 (14,5-16,0)	16,0 (14,0-16,0)
3	70	15,4 (14,1-16,6)	14,0 (12,7-16,0)	16,0 (13,3-15,0)	14,0 (13,0-15,0)	14,0 (12,0-16,0)
4	73	16,0 (14,3-17,1)	14,0 (12,7-15,7)	16,0 (14,0-16,0)	14,0 (13,0-15,0)	14,0 (13,0-16,0)

Note: * when p<0,05; ** when p<0,01.

It was verified that the degree of kinship had an impact on the total QoL reported (p = 0,001) particularly in the *psychological* domain (p = 0,001) in which the parents scored worse and in *social* domain (p = 0,000) where siblings scored better (table 3).

FCs with higher education scored better overall, with statistically significant differences in the *physical* domain (p = 0,043). The time spent on daily care adversely influenced the total QoL reported by FCs (p = 0,019), highlighting in particular the contributions of the *psychological* (p = 0,001) and *social* (p = 0,005) domains - a better QoL was identified in FCs who spent up to 6 hours of daily care (Table 3).

In the WHOQOL-SRPB questionnaire it was identified an impact of the degree of kinship – the *hope & optimism* domain revealed statistically significant differences among the medians (p = 0,043). Worst sores were found in parents and best scores were found in siblings (Table 4).

Table 4– WHOQOL-SRPB scores obtained by the FCs according to their socio-demographic characteristics as well as the ECOG status of the patient being cared for (expressed in median and interquartile range, IC; n=150).

Characteristics	n	Hope & optimism (median, IC)	Spiritual connection (median, IC)	Faith (median, IC)	Total (median, IC)
Degree of kinship					
Son /daughter	63	14,0* (13,0-16,0)	12,0 (7,0-15,5)	13,5 (8,8-16,0)	14,1 (11,9-15,8)
Spouse	29	14,0* (12,0-17,0)	13,0 (11,5-15,0)	15,0 (12,0-16,0)	14,4 (13,3-16,0)
Sibling	16	15,0* (14,0-17,0)	13,0 (9,0-15,0)	14,0 (6,5-16,0)	15,0 (12,3-16,4)
Parent	3	12,0* (11,0-16,0)	11,0 (4,0-12,0)	7,0 (6,0-17,0)	12,6 (11,0-14,38)
Other	39	15,0* (14,0-17,0)	12,0 (10,0-15,8)	13,0 (8,3-15,0)	14,6 (13,5-15,8)
Education (schooling years)					
< 8 years	41	15,0 (13,0-16,5)	14,0* (11,5-16,0)	15,0* (13,0-16,0)	15,4 (13,6-16,0)
8-11 years	67	15,0 (13,0-16,0)	12,0* (5,0-14,5)	12,0* (7,0-15,0)	14,3 (12,3-15,3)
> 11 years	42	14,0 (12,0-16,0)	12,5* (10,0-15,8)	13,0* (9,0-16,0)	14,6 (12,4-15,8)

Note: * when p<0,05; ** when p<0,01.

It was also observed that education also influenced the QoL reported in particular in the *spiritual connection* domain (p = 0,009) and *faith* domain (p = 0,005) where FCs with lower levels of education always score better followed by those with maximum schooling (over 11 years), such as shown in Table 4.

4. Discussion

The experience of caring is multigenerational nowadays. However, several studies indicate that FCs are mostly between 40-65 years old, such as the tendency evidenced in the sample studied. Clearly, the age of FCs is related to the age of the cancer patient. Considering that 68% of cancer patients were older than 60 years, justifies the fact that the percentage of CFs with younger ages (14%) is lower [4,15]. It is also observed that for all dimensions, the worst impacts assessed were associated with FCs with the age ranges 18-30 and 46-60 years.

Hongjuan *et al* (2017) [16] found that younger FCs presented the worse results in the physical, social and environmental domains and Shahi and collaborators (2014) have demonstrated that the FCs of older cancer patients have worse QoL in the various domains [17]. The results vary according to the parameters analyzed, such as the health status, the number of daily hours as a caregiver or the duration of the caring experience but they all agree that there are significant differences in the QoL results associated with different age groups [16,17].

The provision of care relies preferentially on the closest female element, even in the case of the active population, it is usually the woman who stops working [18]. In the present study, approximately 65% of FCs were women, corroborating the literature. It was also verified that 40% of the sample interrupted their professional activity to assume the role of caregiver. This socio-cultural tendency does not allow an equitable distribution among genders favoring the development of problems with impact on QoL and health status. There is, however, a reversal of this tendency with the increase of schooling in women as well as with the achievement of greater economic resources in the feminine gender [19].

It was observed that women scored lower in the *physical, psychological, social* and *total* domains of the WHOQOL-BREF, but they scored higher on all WHOQOL-SRPB domains, with the exception of *hope & optimism*. In fact, several studies denote the trend of worse impacts felt by the female gender, associated with fatigue, frustration, isolation, anxiety, stress and depression, supporting the results found [20,21]. According to the literature, spouses are the predominant FCs. The offspring is followed, when the patient is female, or widow or when is older (over 60 years). These evidences may justify the results of the present study - 61% of the studied sample consisted of FCs with degree of spouse (19.3) or son/ daughter (42%) [22].

As described in the literature, different levels of education determined different impacts on QoL in the studied sample. The *physical* and *social* domains revealed worse impacts on the participants with lower educational, with statistically significant differences. Several studies have shown that low levels of education contribute to worse QoL results, presenting as a risk factor for psychosocial disorders, such as depression and increasing dissatisfaction with health services [23,24]. Domains related to spirituality presented inverse results, with significant differences for *spiritual connection* and *faith*. In this study, the increased education is also related to better results in the *psychosocial* domain. It has been demonstrated by literature that religious practice and the experience of spirituality depends on education, presenting individuals with lower educational level greater religious experience [25].

Regarding the ECOG Performance Status scales, it was verified that levels 3 and 4 evidenced a greater negative global and social impact, however, they presented better results in the *physical* and *environmental* domains. The results for WHOQOL-SRPB are globally worse in ECOG patients with levels 1-2, pointing to a possible adaptation of FCs to the new reality with negative evolution of the disease, and can also be related to greater individual and/or institutional support. Studies report that a worse performance status represents a severe burden for FCs and is associated with their decline in functional status [26,27]. No differences were found in our sample when considering the relation of ECOG values in the psychological domain, but it is suggested that levels 3-4 are more likely to progress to a depressive condition [28].

When considering the daily hours spent with caring, the 6 hours per day determined an important milestone. All outcomes appear to be better in FCs who daily cared for 6 hours or less, with significant differences in the *psychological*, *social* and *total* domains in the WHOQOL-BREF. No significant differences were found when using the WHOQOL-SRPB questionnaire. Effendy *et al.* (2015) concluded that the daily time spent as FCs did not influence the QoL [29], while Maguire *et al.* (2017) found that FCs often indicate feeling lonely, feeling spending too much time as FCs, presented greater financial difficulties associated with experience of a caregiver and reported more negative impacts [30].

5. Conclusion

The age of FCs influences QoL results, with the worst impacts occurring in all dimensions assessed in the age range 18-30 and 46-60 years. Most FCs are women who scored lower in the *physical*, *psychological*, *social*, and *total* domains of the WHOQOL-BREF questionnaire. Higher education of FCs competes for better QoL results, with low schooling being a risk factor for the development of psychosocial disorders. Regarding the ECOG Performance Status scales, it was verified that levels 3 and 4 present a greater negative global and social impact. All scores are worse in FCs who care for more than 6 hours a day.

QoL systematic assessment is decisive for FCs QoL optimization in cancer palliative care. Technology support contributes to overcome technical, methodological and logistical constraints, allowing the use of QoL results on the shortest time. This study recognizes some FCs needs, signalizing the most affected domains.

The main goal of our team research is to identify multidimensional problems systematically. Our previous experience in oncology research indicates that this kind of assessment often reveal unmet needs that may contribute to optimize strategies to FCs QoL and Health protection. Our future work will assure the FCs continuous evaluation enabling thus FCs continuous support.

Acknowledgements

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