Quality of life in a cancer caregivers sample in Albania

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Abstract

Aim: This study aims to explore the quality of life of cancer caregivers and the impact of socio-demographic factors.

Methods: A quantitative approach was used to conduct the study. The sample selection was based on a quota strategy and resulted to a total number of N=377 cancer caregivers. The study took place in the Oncology Hospital, at the "Mother Teresa" University Hospital of Tirana. The research tool was a questionnaire starting with socio-demoghraphic questions for the caregivers followed by the Quality of Life Scale of Flanagan (1982). Data analysis was conducted using SPSS 16. Validity of the QoLS was satisfying (Cronbach alpha=0.882).

Results: Findings indicated that the caregivers were mainly women, unenmployed, of different ages and different types of families. Most of them offered care for more than five hours per day. QoL of the participants were at most low to medium. Age had a negative correlation with QoL (r_s = -0.362, P<0.001). Participants with secondary education reported lower levels of quality of life (U=3334.5, P<0.001, r = -0.33). The married participants had higher levels of QoL, compared to the widowed (U=1117, P<0.001, r = -0.23). The mean values were m=169.07 for the caregivers with children and m=244.20 for the ones without children.

Conclusion: Quality of Life can be influenced by certain life stressors like having a family member with cancer and being a caregiver. Further research with a cancer caregiver focus is needed in the Albanian context.

Keywords: cancer, caregiving, quality of life, socio–demographic factors.

Introduction

According to statistics, every year almost 5000 individuals are diagnosed with cancer. Tumoral diseases are the second cause of death in Albania after cardiovascular diseases. In 2009, 64 persons (per 100.000 inhabitants) died because of cancer, a number that represents 16% of deaths (1).

On the other hand, nowadays many kinds of cancer can be described as chronic illnesses, which require a long lasting treatment and an ongoing caregiving. Changes in the patients ability to function as before diagnosis, on his/her appearance, on body functions, employment as well as on self perception have a direct impact in caregivers (2). Early diagnosis, advances in treatment, prolonged survivorship and the tendency for an outpatient treatment demand from cancer caregivers to offer a more complicated care for a longer period of time. Literature and studies in the field of caregiving had in focus family members of patients with mental health problems, like schizophrenia or dementia, while there is a trend towards exploring the issues faced by the chronic patient's caregivers, including cancer patients' caregivers (3).

In developed countries, changes in the health care system have resulted in an early out of the hospital treatment (4). Hence, a considerable number of patients that suffer from cancer get their care in home settings from other family members (5). Even though the requirements for cancer caregiving are not unknown for the families, the cancer caregiver's role has changed significantly the last years: from an emotional support and a focus in healing the cancer caregiver's role has been transformed to offering specific psychosocial help in home settings. As a result, family members become of a crucial importance, when it comes to fulfilling the complex needs of caring for a cancer patient (6).

Who is a caregiver?

An overall definition of a caregiver is: "it is the individual responsible for caring for another person, whom suffers from mental health problems or has special needs or has a poor health because of his/her disease or age" (7).

Aim and objectives of the study

The aim of this study rises from the need to conduct studies in the Albanian context in the field of caregiving for patients with tumoral diseases. This study aims to explore the quality of life of cancer caregivers and the impact of socio-demographic factors.

Quality of life (QoL)

QoL can be defined as a subjective wellbeing. The subjectivity of quality of life is the key to understand the concept. QoL reflects the change and the gaps between hopes and expectations of an individual and his/her actual life. The individual's adaptation is such that his/her life expectations change, in order to fall within his/her perceived possibilities. Likewise, people can face many problems and difficulties, but they can have a satisfying perceived quality of life (8).

World Health Organization (9) defines quality of life as "individual's perception about their life positioning, in the context of culture and values' system in which they live, as well as in relation to their aims, expectations, standards and concerns". This is the operationalization of quality of life in this study.

Methods

This study employed a quantitative approach for data collection and analysis. It was conducted at the "Oncology Hospital" of the University Hospital Center "Mother Teresa" in Tirana in the Radiotherapy, Chemotherapy and Gynecology Department. These were the sections were patients received a more prolonged care and stayed longer in the hospital, so caregivers were more easily reached. The sampling of the study was non probability, quota and convenient.

Inclusion criteria

Individuals that could take place in this study fulfilled the criteria of being above 18 years old, having the main responsibility to offer a direct care to a cancer patient for at least one hour per day for a minimum of one month. They were not paid caregivers.

Exclusion criteria

Individuals excluded from this study were the ones that although they were caregivers, they didn't have more than a month in this role (n=31). Another exclusion criterion was age, but no individual were excluded because of his/her age. A third criterion was mental health, were one person was excluded because of his mental problems (n=1). Data collection lasted eight months and the final sample was n=377. The research instrument consisted in 18 general questions and four different questionnaires. For the purpose of this paper only the Quality of Life Scale results will be presented (10).

Quality of Life Scale

The Quality of Life Scale (QoLS) consisted in 16 items with a Likert scale responses. It has been developed from the American psychologist Flanagan (1982). The questionnaire is scaled through the sum of the items to conclude in a total result. The subjects should be encouraged to fill all the items even if they are not actually doing some of the activities mentioned (e.g. they can be satisfied even if they do not actually take part in organizations). Missing values are replaced with the mean value of the scale. The scale had good validity according to its author (α=0.82 until 0.92) and test-retest reliability (r=0.78 until r=0 .84) (11). The categories of this scale were:

- Material and physical wellbeing
- Other people relationships
- Social, community and citizenship activities
- Personal development and self - fulfillment
- Creativeness
- Independence

The QoLS subscales based on the results of this study were:

- Low QoL: 35-58.3
- Medium QoL: 58.4-81.7
- High QoL: 81.7-105

Statistical analysis

Data analysis was conducted in SPSS 16. This analysis starts with frequencies, correlations and continues with more advanced tests like: non parametric tests (Kruskal-Wallis, Mann-Whitney, Spearman correlation).

For the QoLS the Cronbach's alpha was: 0.882 while the intraclass correlation coefficient (ICC) was: 0.827.

Results

Caregivers's characteristics

The sample of this study consisted in N=377 cancer caregivers, 31% of which were male and 69% female caregivers. Their age varied from 18 until 66 or more years. Most of the caregivers had elementary and secondary education (68.9%) and were married (71.4%) with kids (73.5% of the married sample). Of the 377 caregivers only 37.4% of them were employed, a percent that indicates that caregivers's employment may be hampered by the role of a caregiver. Being unemployed influences the monthly income of the family, where only 11.4% of the caregivers had a monthly income above 60000 lek, while a very large percent of the caregivers lived with minimal family monthly income of under 30000 lek (48.3%). One of the most mentioned needs of the caregivers was the financial one.

The role of the caregiver can be challenging regarding the time needed to fullfil it. In this study, caregivers assisted the patient in offering psychosocial and emotional support, in coordinating different activities related to the patient like e.g. medical visits and exams, activities that prior to the disease the patient conducted. That is why most of the caregivers devoted seven or more hours/per day in this role (49.9%), then 3-5 hours/per day (22.5%), and 1-3 hours/per day (8.8%) until 5-7 hours/per day (18.8%).

Caregivers' quality of life

Regarding caregivers' quality of life the mean value was $m = 69.45$ with $SD = 1.5189E1$. The median was M=70, with $min = 35$ and $max = 205$. Table 1 presents the frequencies of quality of life according to the three

categories. As it is seen in the table only 21% (*n* = 79) of the participants reported a high QoL, most of them had a medium QoL (*n* = 199, 52.8 %) and there was a part that reported low QoL *n* = 99 (26.3%).

Table 1. Quality of Life frequencies (N=377)

	Frequencies	Percent	Cumulative percent
Low	99	26.3	26.3
Medium	199	52.8	79.0
High	79	21.0	100.0
Total	377	100.0	

Relationship between socio-demographic factors and QoL

In an effort to explore and identify the socio-demographic factors influencing the QoL of cancer caregivers several parametric and non-parametric tests were conducted. Following are the statistically significant tests for these factors.

Age and QoL

Age had statistically significant differences in relation to the quality of life, within three groups: the group of "18-35" years (*M*=75.87, *SD*=13.57) and the group of "36-55" (*M*=67.24, *SD*=14.05) and that of "56- 65" (*M*=61.91, *SD*=15.38) as well as between the last two groups (Table 2).

Table 2. Relation between age and QoL (ANOVA, N=377)

		Sum of Squares	df	Mean Square	F	P
Quality of Life	Between groups	11621.087	2	5810.543	28.924	<0.001
	Within groups	75132.526	374	200.889		
	Total	86753.613	376			

Table 3 shows the correlation between age and quality of life. The results are in the same direction as the ANOVA results indicated in Table 2. Age had a negative correlation with quality of life (r_s = -0.362, P<0.001).

Table 3. Correlations between age and QoL (N=377)

Age	QoL
Correlation Coefficient	-.362[*]
Sig. (2-tail)	.000
N	377

* Correlation is stastically significant at the level 0.01 (2- tail).

Education and QoL

A more distinct difference resulted in the case of the participants with secondary education compared to the higher education. Participants with secondary education reported lower levels of quality of life (*U*=3334.5, P<.001, *r*= -0.33).

Civil status and QoL

Other studies indidated statistically significant differences in QoL in relation to civil status in cancer caregivers. In order to confirm or not these differences the non-parametric test of Kruskal-Wallis was conducted, which resulted statistically

significant: $H(3) = 47.3$, $P<0.01$. Further tests (Mann-Whitney with Bonferroni correction at $P<0.017$) revealed that the statistically different categories were the ones of the married participants, whom had higher levels of QoL, compared to the widowed ($U=1117$, $P<0.001$, $r = -0.23$).

Table 4. Comparison between married and widowed participants (N=377)

	Quality of life
Mann-Whitney U	1117.000
Wilcoxon W	1288.000
Z	-3.826
Significance level (2-tailed)	<0.001

Children and QoL

Having children can influence the everyday care load and can have a negative impact in mental health and quality of life of cancer caregivers. In this study, cancer caregivers with children compare to the ones without children had satistically significant results regarding quality of life ($z = -5.912$, $P<0.01$). The mean values were $m=169.07$ for the caregivers with children and $m=244.20$ for the ones without children. It is evident that raising and caring for children can have adverse effects in cancer caregivers.

Discussion

Cancer caregivers quality of life is an important aspect of psychosocial, financial and physical wellbeing of caregivers. Furthermore, caring for cancer patients can have an impact in family functioning and in caregivers' burden (12). Family caregivers usually start their caregiving role without any training. It is expected that they will fulfill several needs of the patient without any experience or other help. Caregivers can neglect their own quality of life in an effort to care for the patient (13).

Perceived quality of life of cancer caregivers participants in this study had a mean value of $m=69.45$, $SD = 1.5189E1$, $min = 35$ and $max = 105$ respectively. Most participants reported that they had a medium quality of life (52.8%). These values indicate lower quality of life compared to other studies. A study focused on quality of life of the general popullation, that used the same instrument showed that the mean value of QoL was higher $m = 88.5$, $SD=9.5$ (14). Flanagan (15), the author of QoLS, has offered comparison values for QoL. The mean value of QoL in a healthy sample was 90, which is much higher that the ones of this study. Furthermore, in special samples, according to the author, there is a decline in the QoL, but their values are still much higher compared to the caregivers' sample of this study. For example, in the sample of reumatism diseases the mean value is 83, in a systemic lupus erithematosum it is 84, in an osteoarthrit sample it is 87.

The cancer caregivers QoL can be influenced in several dimensions: psychological, physical, social and financial. Psychological distress is the most common effect in QoL. In this study, the relevant questions were not further analysed because in the original scale the different dimensions were not treated separately, but as an overall QoL score. On the other hand, in this scale there were items that assessed psychological distress, which can be experienced because of the practical demands of the caregiver's role as well as of the emotional ones, such as seeing the patient suffering (Sales, 2003). Family members that see the patient suffering can experience higher distress that the patient himself.

Besides psychological distress another important aspect of QoL is physical health. Cancer patients often have a need for physical help during their illness and treatment, e.g. using the toilet, feeding, changing bed positions, using medical equipment and the like (16). The level of help that the patient

needs depends on the: ability of the patient to conduct the everyday activities without help (like dressing, walking etc.), the level of the patien't fatigue, the cancer stage, patient's symptoms and their seriousness as well as cancer treatments side effects (17).

Cancer caregivers can enjoy little relaxing time and they don't usually care for their own health. Healthy habbits, like healthy eating, or physical exercises can be neglected. This is the reason why caregivers themselves can have new health issues arisen or worsen during the caregiving journey (18). A major effect in QoL is attributed to the caregivers income, particularly when they are part of the family and live with the patient. Cancer treatment can be very expensive in Albania, even though the hospital service is for free.

Conclusion

Cancer caregivers can face many challenges in their role. Very little is known about this group in Albania. Further research is recommended in order to explore the role of other important factors to the caregiver's quality of life.

Conflicts of interest: None declared.

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