Research paper

		Healthcare
Psycho – Social well-being of Caregivers of Persons with Cancer in Albania		**Keywords:** psycho – social wellbeing, cancer caregivers, anxiety, depression.

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Abstract

This study aims to assess the psycho – social wellbeing of cancer caregivers and their needs in the Albanian context. In Albania studies focused on cancer caregivers are not frequent and have a sporadic character. A quantitative methodology was employed for this study. The number of the participants was N=377. Data collection took place in the University Hospital "Nene Tereza" in Tirana, at the Oncology Hospital. Cancer caregivers were invited to fill the questionnaire concerning their socio – demographic information, their current needs and HADS (Hospital Anxiety and Depression Scale) of Zigmond and Snaith (1983). Results of the study indicated that cancer caregivers were mainly females, of different ages. Their relation to the patient was mainly that of adult children caring for their parents. Their levels of anxiety and depression were high in most of the cases, sometimes indicating for clinical depression. The most reported needs were financial - because of the high cost of cancer treatments - and emotional. It is suggested that further studies should be conducted with this groups. Social policies and particularly employment policies should incorporate this group, as in developed countries, where assistance or a retirement plan is in place for cancer caregivers.

1. Introduction

According to statistical data, it is estimated that every year almost 3500 individuals will be 'given the diagnosis of cancer, ranking as the second cause of mortality in Albania (Lakrori, 2013). Tumor diseases come immediately after cardiovascular disease as a leading cause for deaths, which resulted in 64 deaths per 100,000 thousand in 2009, a figure that represents 16% of deaths (INSTAT, 2010).

Psychosocial studies for chronic illnesses in Albania have been sporadic. As a result of the demographic and epidemiologic transition there is a probability that the cardiovascular and tumor diseases, diabetes and others to become more frequent, while in the industrialized countries these diseases are in decline for the last two decades. These are statistics that indicate a living reality, which means much more than the numbers presented in a table or graphic. Nowadays, early detection of cancer and progress made with existing therapies as well as the reveal of new ones, has resulted in a better prognosis for cancer patients. ("The stages of cancer", 2011).

Early diagnosis, advancements in cancer treatment, extension of the survivorship and tendency for outpatient treatment are associated with complex help given out of the hospital setting mainly from the patient's caregivers. Literature and studies in the care giving field had in focus family members of individuals with mental health problems, e.g. schizophrenia or dementia, while there is a tendency towards exploring the problems of the chronic patients caregivers, including here cancer patients (Schulz, O'Brien, Bookwala & Fleissner, 1995). The caregivers role can be challenging. Caregivers usually have many unmet needs, problems with physical and mental health and they can be indirectly discriminated because of their status. Being a caregiver can be a noble duty, but on the other hand it relates to problems with work, low socio – economic status and low levels of quality of life.

1.1. Definition of caregiving

An overall definition describes the caregivers as "*the individuals, which are responsible for caring for another person, whom suffers from mental health problems, has different physical abilities or has a damaged health because of his disease or age*" ("Being a caregiver", 2012)

The highest proportion of caregivers are spouses, relatives and close friends. A survey conducted in 23 European countries showed that although the benefits from caring for a relative outweigh the costs, the reality can be different (Döhner, Kofahl, Lüdecke and Mních, 2008). Caregivers face many challenges and demands, hence they need more resources and support. According to the survey, the caregivers reported that they needed more information and tips, they were overloaded, were at a high risk of damaging themselves, having difficulty balancing care and paid work, had less income, felt like they just do not feel valued in their work, had a high risk and sometimes hide neglect or physical, psychological, sexual and financial abuse (Deshields et al., 2012).

1.2. Aim of the study

The aim of this study is to assess the psycho – social wellbeing of cancer caregivers in an Albanian context and to identify their main needs.

1.3. Research questions

The research questions of this study are as follows:

1. What are the socio – demographic characteristics of the cancer caregivers in an Albanian sample?

2. What are the levels of anxiety and depression according to HADS?
3. What are the main needs of the cancer caregivers?

2. Background and Methods

This study was conducted in the Oncology Hospital, which is located in the University Hospital Center "Mother Teresa" in Tirana. Although oncologic services are not provided only by the hospital, the highest percentage of cancer patients are in this hospital.

2.1. Sample

This study is based in a convenient sample. An important issue for the selection of the sample for this study was that of defining the status of caregivers. Before taking part in the study, and filling the questionnaire participants should answer "yes" in the following question: "Are you the person that gives care most for this patient or is it someone else?" If the answer in this question was yes then the participants should meet the below inclusion criteria.

Inclusion criteria. Caregivers in this study should be at least 18 years old and they should have the main responsibility of offering direct care to a patient with cancer for at least one hour per day. They should also be unpaid caregivers, like family members, relatives or friends. Only one person for a patient could have the status of caregiver, so for one patient there were only one caregiver – participant. Finally, the last criterion was the time of caregiving: it should be at least one month.
The sample size was calculated based on the confidence level (95%), and for a N = 20.000 because the real number of cancer caregivers is not known. So, the final sample size was n = 377 participants.

The research tool consisted of socio - demographic information for the caregivers (age, sex, education, employment, monthly family income, origin, type of the family etc.) and questions related to the patients and the caregiver's relationship to them: e.g. relation to the patient, type of diagnosis, age, hour per day for caregiving, first or recurrent diagnosis etc. followed by an open ended question regarding the caregiver's needs. Afterwards, participants also completed the Hospital Anxiety and Depression Scale (HADS) of Zigmond and Snaith (1983), which is a very used self – administered scale, with good psychometric properties, applied in a community and hospital environment. This scale was translated forward and backward by independent translators and experts of the field. Validity was in very good levels, Cronbach a = 0.723 for the anxiety subscale and a = 0.865 for depression subscale. The HADS's authors provide the scores of the scale, which is divided to an anxiety and depression subscales, each of which have the same three levels: normal, borderline and abnormal.

3. Results and Discussion

3.1. Characteristics of cancer caregivers

Participants of this study were *N* = 377 cancer caregivers, 31% of whom were male and 69% female. They belonged to six different age groups, ranging from 18 years to 66 years and more. Table 1 shows that the largest percentage of caregivers belongs to the ages of 26-35 years (21.2%) and 36-45 years (20.2%). Then, with an almost equal distribution are ages 18-25 years (18.3%), 46-55 (18%) and 56-65% (17.8%).

Table 1. *Caregivers age*				
	Frequency	Percent	Valued percent	Cumulated percent
18 - 25	69	18.3	18.3	18.3
26 - 35	80	21.2	21.2	39.5
36 - 45	76	20.2	20.2	59.7
46 - 55	68	18.0	18.0	77.7
56 - 65	67	17.8	17.8	95.5
66 and above	17	4.5	4.5	100.0
Total	377	100.0	100.0	

The highest percentage of caregivers had an elementary or secondary education until high school (68.9 %), a small percentage had no education (0.8%), as well as postgraduate education (2.1 %) , and higher education were 24.9%. In relation to marital status 71.4 % of the participants were married, 22.3% single, 1.6% divorced and 4.8% of them were widowed . When asked if they had children, 73.5 % of participants reported "yes" while 26.5% had no children . Number of children and their ages were the following two questions, which addressed only participants who had said " Yes " to the previous question . The average number of children was *M* = 2.7 , *SD* = 1.28. Much of the participants reported having 2 or 3 children (65%). Age of children was divided almost equally between children under the age of 18, who were respectively: 0-12 years old (27.4 %), 12-18 years old (21.3%) and children above 18 years old (51.3%).
Employment of caregivers was in very low levels. Only 37.4% were employed, while 62.6 % were unemployed. Of course, some of them were retired and therefore not expected to be employed. Excluding age category " 66 and older ", the employment rate varied somewhat: 39.2% reported that they are employed, while 60.8 % were not. Of the employed sample (n_e

=141), 39% were employed in the public sector, 38.3% were self-employed, while the rest were employed in the private sector (22.7 %) .

Table 2. *Family monthly income, (in Albanian lek)*				
	Frequency	Percent	Value percent	Cumulative percent
>30000	182	48.3	48.3	48.3
30000 - 60000	142	37.7	37.7	85.9
60000-90000	24	6.4	6.4	92.3
90000-120000	10	2.7	2.7	95.0
120000-150000	6	1.6	1.6	96.6
150000 and above	13	3.4	3.4	100.0
Total	377	100.0	100.0	

As noted in Table 2 and monthly household income of caregivers from self – report resulted in very low levels. Only 11.4% of them had income above 60000lek per month, while a very high percentage of caregivers live with minimum household incomes. Under 30000lek income per month had 48.3 % of them, while from 30000 to 60000 lek were 37.7 % of caregivers . One of the most frequently reported needs of caregivers were financial ones, something that is supported by the level of income they report. Location of caregivers varied . They lived in the city of Tirana (36.6%), in other cities besides Tirana (44.8%), rural areas (15.1%) and in other countries (3.4%, mostly coming from Kosovo). Location can be a problem for caregivers who do not live in the same place with the hospital where patients receive services, because they should accompany them for medical examinations or further treatment, or when they need medical care offered only in hospital.
Type of family can impact the support given to the caregivers. In most cases caregivers were married with one or more children (65.8 %), while others were single persons (8.5%), couples without children (3.2%), one-parent families (5.3%), other family type (17.2%) such as extended family, in which the couple lives with other people, as the parents of husband/wife or other relatives.

3.2. Caregiving relationship

Regarding the relation of the caregiver to the patient, the most featured one was the one were an adult child was the caregiver of a parent. Caregiver with a mother / father patient accounted for 34.5 % of the cases, followed by marital/partners relationship were (28.9 %), while the following were relations other type such as father/mother in law, aunt/uncle, nephew/ niece etc. (14.9 %). In lower percentages were the relationships brother/sister (13.5%), child (7.4%) and friend (0.8%).
The most common type of cancer was breast cancer (23.6 %), then came intrauterine cancer (22.3%) followed by lung cancer with 13.3%.
The time when the diagnosis was made can be an important factor for the adaptation of the caregivers to their new role. In this study, diagnosis varied from 3 months to 2 years and more. Specifically, a diagnosis was made 6 months before in 46.9% of the cases, before 9-12 months in 30.2 % of the cases, before 1 year to 2 years were 10.6 % of the cases and more than 2 years were 12.2%.
Age of the patient can be an important factor for the emotional and physical wellbeing of the caregivers. The age of patients varied from 16 years old to more than 66 years old. The majority of them belonged to the age group 46-65 years old (56.2%), the lowest percentage belonged to the age group 18-25 years old (4.8 %), followed by 26-35 (6.6%), 66 and above (14.9%) and 36-45 (17.5 %).
The following table (Table 3) reports the distribution of hours per day that caregivers engage in their role as a caregiver, in order to provide emotional support as well as to coordinate various activities related to patient, e.g. hospital visits and medical tests, activities previously performed by the patient etc. The highest percentage of caregivers spend seven or more hours per day to fulfill their caregiving role (49.9%), followed by 3-5 hours per day (22.5%), and the rest of the participants varied among "1 -3 hours" per day (8.8%) up to 5-7 hours per day (18.8 %).

Table 3. *Hours of caregiving per day*				
	Frequency	Percent	Value percent	Cumulated percent
1-3	33	8.8	8.8	8.8
3-5	85	22.5	22.5	31.3
5-7	71	18.8	18.8	50.1
7 and above	188	49.9	49.9	100.0
Total	377	100.0	100.0	

One of the final questions related to the patient's characteristics was that of a first or recurrent diagnosis. Patients diagnosed for the first time was 63.4%, while those who had received this diagnosis for the second time or more were 36.3%.

3.3. Caregiver's needs

One of the most frequently reported needs of caregivers was financial ones, something that is supported by the level of income they report. Other needs often reported were those of communication with health personnel, to obtain more detailed information such as social support from the psychosocial staff, but also from their network of family and society.

3.4. Psycho – social wellbeing of caregivers

Table 4 indicates the levels of anxiety for cancer caregivers. According to the HADS and the results of this study, only 5.8 % of caregivers have normal levels of anxiety; 14.9% belong to the borderline anxiety and a very large number have abnormal levels of anxiety (n = 299; 79.3%).

Table 4. *Anxiety categories*				
	Frequency	Percentage	Valid Percentage	Cumulative percentage
Normal	22	5.8	5.8	5.8
Borderline	56	14.9	14.9	20.7
Abnormal	299	79.3	79.3	100.0
Total	377	100.0	100.0	

Table 5 shows the levels of depression, according to the different categories. Specifically, 19.1 % of caregivers had normal levels of depression, 16.4% borderline levels and a considerable percentage had abnormal levels of depression (64.5%).

Table 5. *Depression categories*				
	Frequency	Percentage	Valid Percentage	Cumulative percentage
Normal	72	19.1	19.1	19.1
Kufitar	62	16.4	16.4	35.5
	243	64.5	64.5	100.0
Total	377	100.0	100.0	

4. Conclusions

Cancer diagnosis is a major challenge for the patients themselves, but also for their caregivers. Different studies have reported the psychosocial and health effects that the care giving role has. In this study, cancer caregivers were mostly women, unemployed, with low educational levels, married with children facing two care giving roles: that of the patient and of their children. They had different family relations with the patients, adding emotional load to their role. They had to engage in this role for 5 and above hours per day, which implies for difficulties in employment. Psycho – social wellbeing of cancer caregivers explored through the anxiety and depression was relatively low. The levels of anxiety and depression were frequently abnormal and borderline. Further research is needed in the cancer care giving field.

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