

SOCIAL SUPPORT AND QUALITY OF LIFE

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ABSTRACT

Post – socialist societies face many challenges regarding health care and caregiving. Albania, as one of these countries, has only sporadic studies related to the tumor diseases and their psycho – social effects that focus on the patients themselves, but also on their caregivers. In western societies, patients themselves and caregivers are studied and provided services. The aim of this study was to assess the levels of perceived social support of cancer caregivers and their quality of life, as well as to find out the possible relations with socio – demographic factors. The research was conducted at the Oncology Hospital, which is part of the “Nene Tereza” University Hospital in Tirana. The instruments used to assess the perceived social support was the “Quality of Life Scale” and “Multidimensional Scale of Perceived Social Support” which divided social support according to the sources from which it was received: a special person, family or social network. The sample of this study was $n = 377$.

Results indicated that half of the participants had high levels of perceived social support and medium levels of quality of life. Although, when these levels were divided according to the source of social support there were differences: the levels of social network were lower compared to the other two. Finally, age and gender were negatively related to social support, while being single had a positive effect. Quality of life declined with age and men were far better than women. Further studies are necessary in order to explore the impact of other factors.

Keywords: *perceived social support, quality of life, caregiving, socio – demographic factors*

JEL Classification: *I12, I14*

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 diseases as a leading cause for deaths, which resulted in 64 deaths per 100,000 thousand in 2009, and 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

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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 caregiving 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.

Operational definitions of caregiving, social support and quality of life.

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) Quality of Life (QOL) may be defined as subjective well-being. Recognizing the subjectivity of QOL is a key to understanding this construct. QOL reflects the difference, the gap, between the hopes and expectations of a person and their present experience (Jansenn, 2007). Social support can be defined and measured in many ways. It can loosely be defined as feeling that one is cared for by and has assistance available from other people and that one is part of a supportive social network. These supportive resources can be emotional (e.g., nurturance), tangible (e.g., financial assistance), informational (e.g., advice), or companionship (e.g., sense of belonging). Social support can be measured as the perception that one has assistance available, the actual received assistance, or the degree to which a person is integrated in a social network. Support can come from many sources, such as family, friends, pets, organizations, coworkers, etc. (Cohen and Syme, 1985).

Aim and research questions of the study.

The aim of this study was to assess the role of perceived social support in cancer caregivers and its relation to quality of life. For this reason the following research questions were addressed:

- What were the levels of perceived social support and quality of life in cancer caregivers?
- How social support influences the quality of life in cancer caregivers?

2. Literature review

Cancer caregiving. Cancer diagnosis is a unique living experience, the consequences of which often persist after diagnosis or treatment. The impact of this disease can be just as strong in the individual, in his/her family and social network; people around the patient may find it difficult to accept it European or maybe are not aware of the ways to help. The kind of the relationship as well as the attitudes and perceptions of cancer affect the way of experiencing the disease and caregiving. Some of the most common problems of physical and mental health caused to caregivers are: physical exhaustion, low levels of energy, insomnia, excessive appetite or lack of

appetite, pain in different body sites, stress, frustration, depression, bad mood, melancholy, anger towards the person of caring or others, reduction of social contacts with friends and family, lack of interest in favorite activities or activities with other family members and the feeling that they have no time for themselves (http://www.medlook.net/article.asp?item_id=1894).

Perceived social support. With the increasing demands of caring for cancer patients the need for social support network of caregivers can be enhanced, especially for the socio – emotional aspects of support. Caregivers who perceive that such support is available and accessible can use it as a method to have close relationships, which may have lost due to cancer relatives. A number of studies refer that perceived social support is an intermediate factor for psychological symptoms to freedom and the level of QOL (Nijboer et al., 2001). Different forms of social exchange (negative support, daily emotional support, etc.) have different effects or not in distress of caregivers. Different types of social support mediate or not the care results in non - formal cancer (Gaugler, 2005).

According to Kim et al. (2006), the majority of caregivers received support from their employers (77%) or from their peers (85%), while none was reported to have used child care services and little (1%) wished to use them. These findings imply that the support in the work environment is very frequent and caregivers can benefit from it. For caregivers with children, finding or providing child care services in the community or encouraging caregivers to receive assistance from other family members and friends / close / or child care may be very useful.

Quality of Life. Quality of life is a term often used to refer to the general wellbeing of the individual. Studies conducted in Western countries have revealed factors related to quality of life during the period of caregiving for a patient with cancer. They can be divided into four categories: (i) socio - demographic characteristics, (ii) the demands of caregiving, (iii) resources available, psychological and social, and (iv) the caregiving situation (Lu et al., 2010). In a research study on quality of life for caregivers of patients with cancer three aspects of this concept were reported. These were (a) descriptions of the quality of life of caregivers, (b) impacts associated with the quality of life and (c) interventions to enhance quality of life of caregivers.

Positive expectations, performing protective behaviors, self-efficacy and self-esteem had a positive correlation to their quality of life. Using avoidance as a stress coping strategy caused poorer mental wellbeing, but lower use of self-blaming correlated with a higher life quality of the caregiver. Individual aspects of the quality of life of the caregivers influence the overall quality of life. Good life quality at the beginning of the disease, good health, marital satisfaction and feeling of safety and meaning, were positively correlated to the life quality of caregivers (Axelsson & Sjoden, 1998). On the other hand, loss of physical strength, the feeling of burden, emotional tension, psychological distress, confusion, sadness, anxiety, depression, concerns and lack of hope were important factors on reducing the quality of life (Gaston-Johansson *et al.*, 2004).

The time devoted to caregiving, negative appraisal of caregiving and the impact of caregiving in the life of caregivers were strongly correlated to the quality of life of the caregiver (Axelsson & Sjoden, 1998). Good relationships with patients, marital satisfaction, contacts with friends, family resilience and social support contributed to a better quality of life (Axelsson & Sjoden, 1998).

3. 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.

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. The other part of the research tool comprised of 4 different scales; for the purposes of this paper only two of the scales will be analyzed: the "Quality of Life Scale" (Flanagan, 1982) and the "Multidimensional Scale of Perceived Social Support" (Zimet, Dahlem, Zimet and Farley, 1988). All research scales were originally in English; they were translated forward and backward and then adapted for the Albanian context. At the final instrument Cronbach alphas were in satisfying levels for all scales ($\alpha > 0.7$).

Data analysis was conducted in SPSS 16 after data cleaning.

4. Results

Characteristic 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%).

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. 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 %) .

Table1. Participants' characteristics

| <i>Participants characteristics</i> | | |
|--------------------------------------------------------|------------------|-------|
| Age | 16 - 25 | 18.3% |
| | 26 - 35 | 21.2% |
| | 36 - 45 | 20.2% |
| | 46 - 55 | 18.0% |
| | 56 - 65 | 17.8% |
| | 66 and above | 4.5% |
| Sex | Male | 31.0% |
| | female | 69.0% |
| Level of education | illiterate | 0.8% |
| | elementary | 3.2% |
| | secondary | 24.1% |
| | high school | 44.8% |
| | higher education | 24.9% |
| | postgraduate | 2.1% |
| Civil status | Other | 0.0% |
| | married | 71.4% |
| | divorced | 1.6% |
| | widower | 4.8% |
| | separated | 0.0% |
| Employment | single | 22.3% |
| | Yes | 37.4% |
| Family monthly income of your family (in Albanian lek) | No | 62.6% |
| | >30000 | 48.3% |
| | 30000 - 60000 | 37.7% |
| | 60000-90000 | 6.4% |
| | 90000-120000 | 2.7% |
| | 120000-150000 | 1.6% |
| | 150000 and above | 3.4% |

Perceived social support. As seen in Table 2 perceived social support as a total was in fairly satisfying levels; the major part of the participants reported having high social support (49.9%) while the rest a medium one (46.9%). A very small percentage didn't have any significant support (3.2%).

Table 2. Social support overall

Social support overall (Total)

| | <i>Frequency</i> | <i>Percent</i> | <i>Valid Percent</i> | <i>Cumulative Percent</i> |
|--------|------------------|----------------|----------------------|---------------------------|
| Low | 12 | 3.2 | 3.2 | 3.2 |
| Medium | 177 | 46.9 | 46.9 | 50.1 |
| High | 188 | 49.9 | 49.9 | 100.0 |
| Total | 377 | 100.0 | 100.0 | |

In relation to the sources of support it seems that the participants received a considerable support from a special other (80.6%), whom could be a best friend, the spouse or another relative (Table 3). Table 4 indicates the results for family support, which was in even better levels reaching 84.9% and indicating a high level of family support.

Table 3. Social support: special other subscale

Social support: special other subscale

| | <i>Frequency</i> | <i>Percent</i> | <i>Valid Percent</i> | <i>Cumulative Percent</i> |
|--------|------------------|----------------|----------------------|---------------------------|
| Low | 15 | 4.0 | 4.0 | 4.0 |
| Medium | 58 | 15.4 | 15.4 | 19.4 |
| High | 304 | 80.6 | 80.6 | 100.0 |
| Total | 377 | 100.0 | 100.0 | |

Table 4. Social support: family subscale

Social support: family subscale

| | <i>Frequency</i> | <i>Percent</i> | <i>Valid Percent</i> | <i>Cumulative Percent</i> |
|--------|------------------|----------------|----------------------|---------------------------|
| Low | 7 | 1.9 | 1.9 | 1.9 |
| Medium | 50 | 13.3 | 13.3 | 15.1 |
| High | 320 | 84.9 | 84.9 | 100.0 |
| Total | 377 | 100.0 | 100.0 | |

However, when it comes to receiving social support from friends and social network in general then the levels dropped drastically as seen in Table 5. Social support received from this sources were in low (42.2%) or medium levels (37.1%). A very small percentage, which were mainly younger caregivers, reported having support in high levels (20.7%).

Table 5. Social support: friends and social network subscale

Social support: friends and social network subscale

| | <i>Frequency</i> | <i>Percent</i> | <i>Valid Percent</i> | <i>Cumulative Percent</i> |
|--------|------------------|----------------|----------------------|---------------------------|
| Low | 159 | 42.2 | 42.2 | 42.2 |
| Medium | 140 | 37.1 | 37.1 | 79.3 |
| High | 78 | 20.7 | 20.7 | 100.0 |
| Total | 377 | 100.0 | 100.0 | |

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 6 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 6. Quality of Life frequencies

Quality of Life frequencies, N=377

| | Frequencies | Percent | Value percent | Cumulated percent |
|--------|-------------|---------|---------------|-------------------|
| Low | 99 | 26.3 | 26.3 | 26.3 |
| Medium | 199 | 52.8 | 52.8 | 79.0 |
| High | 79 | 21.0 | 21.0 | 100.0 |
| Total | 377 | 100.0 | 100.0 | |

Social support and QoL

As in other studies social support appears to have a relation with QoL. Table 7 indicates the positive correlations between QoL and social support in general as well as with its subscales. Regarding the total of social support it correlates moderately with QoL ($r = .480$, $p < .001$) and the from the subscales the best correlation was the friends and social network ($r = .463$, $p < .001$), followed by special other subscale ($r = .272$, $p < .001$) and family ($r = .249$, $p < .001$).

Table 7. Relation between Social support and its subscales and QoL.

Relation between Social support and its subscales and QoL

| | QOL | Social Support, total | Special other, social support | Family social support | Friends and social network, social support |
|---------------------|-----|-----------------------|-------------------------------|-----------------------|--------------------------------------------|
| Pearson Correlation | 1 | .480** | .272** | .249** | .463** |
| Sig. (2-tailed) | | .000 | .000 | .000 | .000 |
| N | 377 | 377 | 377 | 377 | 377 |

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

5. Discussion and conclusions

In this study an effort was made to assess the levels of social support of cancer caregivers and its subscales, the levels of QoL and the relation between all these variables. As indicated at the results social support was in satisfying levels, besides the one from friends and social network, and quality of life was mainly in medium levels, which is lower compared to other studies conducted with different populations. On the other hand, QoL and social support had different positive correlations. According to Nijboer et al. (2001) social support may moderate the psychological symptoms and improve the perception on quality of life. However, this is not confirmed in other studies (Gaugler et al., 2005). Goldstein et al. (2004) conducted a study

focusing on social networks, where they found that caregivers with limited social networks felt more the burden of caregiving. This result is relevant to this study also and confirmed by other studies as well (Stenberg, Ruland and Miaskowski, 2010).

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