

## The Impact of Cancer in Patient's Caregivers: A Literature Review

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**Abstract:** This paper aims to explore the effects of cancer in mental health and health-related quality of life of the primary caregivers to patients. Cancer can change in many ways the status quo of the family. All the members of the family will change in some way. From a family systems perspective, dysfunction or illness in one family member affects other family members, because a family unit functions as an interconnected whole. Although many research is done having cancer patients in their focus, there is a limited research regarding the impact of a life – threatening disease in the patient's family and especially in the persons that care for them. It makes sense that caring for a cancer patient, can create numerous needs in these individuals, causing various psychosocial or other types of problems. These various problems will be in the focus of this literature review.

**Keywords:** cancer; family; health; mental health; quality of life.

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### Introduction

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 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.

A caregiver's life can change greatly as a result of cancer diagnosis. For example, he/she can quit his/her job in order to care for the patient, someone else may move out to another city or in an area closer to the patient etc. All changes happen due to the demands of caregiving. Important aspects of family life can now take a second place, economic difficulties may arise, which reach up to selling the house to afford health care. In other cases, changes are seen in everyday life, which can create more of a sense of uncertainty and confusion about planning and hopes for the future.

Various studies reveal that the fear experienced by family members is much higher than that experienced by the patient. Different dimensions of distress, anxiety and depression that are reflected in a family where one of its members has cancer are disability, fear and anger, which are referred to as the anxious emotions, especially in the phase of chemotherapy. Individuals closer to a patient with cancer will experience a wide range of responses towards the disease. Their emotions will be complex and difficult to express. Caregivers often neglect their own needs and the health care personnel is also focused on the patient. The caregiver's problems can become more serious if left untreated.

### Definition of caregiver

An overall definition of the caregiver refers to the individual, whom is responsible for caring for another person, that suffers from mental health problems, has physical disabilities or has a poor health because of his/her illness or age.

### Caregiver's needs

Individuals that have the responsibility to care for their sick relatives, can display a variety of problems and negative thoughts. They often overlook the fact that they have undertaken a very important and difficult task: continuous support and care for a very long period of time. In many cases, caregiving provided by the family can last for long periods of time, it is difficult, requires different skills and interferes with their personal lives, increasing the probability of causing physical and mental problems.

It is important to know the problems that arise in persons who care for other persons. Knowing and better understanding the caregivers' experiences is an important step to appropriate support, which will influence everyone positively.

Caregivers' responsibilities to patients with chronic diseases are multiple and numerous. Some of the possible duties and responsibilities of caregivers are: giving medications, shopping, cooking, feeding, bathing, dressing, get the patient

up from the bed, change positions in bed, helping to carry personal needs, changing of clothes, doing other obligations such as payment of bills, emotional support, etc.

In some cases, caregiving can be a traumatic experience for the individual who has undertaken this task. The patient may have lost many of his/her abilities, he/she could also be altered as a personality, may have behavioral changes, can be more aggressive or more passive, etc. For this reason, caregivers often face very difficult situations.

Some of the most common problems of physical and mental health caused to caregivers are:

1. Physical exhaustion;
2. Low levels of energy;
3. Insomnia;
4. Excessive appetite or lack of appetite;
5. Pain in different body sites;
6. Stress;
7. Frustration;
8. Depression;
9. Bad mood, melancholy;
10. Anger towards the person of caring or others;
11. Reduction of social contacts with friends and family;
12. Lack of interest in favorite activities or activities with other family members;
13. Feeling that they have no time to dedicate themselves.

(What happens in individuals that care for sick relatives?, 2009)

### **Cancer Caregiving**

Over the last decade, caregiving for a relative with cancer has increased in terms of the number of individuals involved in this process, as well as in terms of task complexity that caregivers must carry. Between 1997 and 2005, the number of Americans diagnosed with cancer is increasing: from 900.000 (1997) it has reached 1.3 million (2005), but the number of survivors has also increased: from 7.4 million to 9 million (American Cancer Society, 2005). The global burden of cancer continues to increase significantly due to aging and global population growth, "supported" by the adoption of a set of behaviors that cause cancer, especially smoking in developing countries. Based on statistics of GLOBOCAN 2008 (cited in Jemal et al., 2011) in 2008 about 12.7 million new cancer cases and 7.6 million deaths were reported, of which 56% of cases and 64% of deaths were reported in developing countries (Jemal et al., 2011). In 2030, the projected number of deaths from all types of cancer combined is expected to reach 11.5 million, a number almost double the 6 million people in 1990. Moreover, nowadays cancer is not perceived as a rich country disease. Worldwide, the percentage of all new cancer cases emerging in countries with low and average income is increasing: in 1975 it was almost half (51%), reached 55% in 2007 and projected to reach 61 % in 2030 (Thun, DeLancey, Center & Jemal, 2009).

Cancer itself is not only a disease but a constellation of diseases. As a result, informal caregiving for cancer patients follows the same path, and it reflects the diversity of abilities required related to the type and stage of disease, patient's age and the different possibilities and peculiarities of treatment. However, these variables that constitute the process of care are only a part of the picture. What happens to the caregivers? What attributes bring to this experience? What is the impact of the diagnosis in the family? What is the financial situation (O'Mara, 2005)? These are some of the many questions that have been the subject of study and exploration of many years in other countries. In Albania, there are no studies focused on caregivers of cancer patients.

Therefore, the purpose of this review is to summarize the state of knowledge on the following questions:

1. What psychological problems do primary caregivers of cancer patients face? Similarly, do they experience increased levels of anxiety and depression?
2. Does quality of life change for a caregiver? Are there any changes in health – related quality of life?

### **Methods**

The method used in this paper is that of a systematic literature review. For this reason, the author has selected related articles, from 1980 until 2011. Due to limitations in accessing all electronic sources the final articles reviewed reached the

number 30. Inclusion criterion was to find in the abstract one or more of these terms: caregiver, cancer, anxiety, depression, quality of life, health related quality of life. From the first articles, some of them were excluded because, with further reading, it was found that they weren't appropriate for this review.

## Results and Discussion

### *Anxiety, depression and caregiving*

Findings in different studies show an increase in levels of anxiety and depression to caregivers of both genders. Depression symptoms tend to show more often in cancer caregivers, but women have a higher prevalence of depression compared to men. Theoretically, high levels of anxiety to caregivers could be related to their concerns about the future, to coping with a difficult situation, the fear of loss or fear of being alone, to the greater responsibility for children, to coping with unfamiliar tasks at home etc. (Strang & Koop, 2003). These are situational factors, which are perceived as stressors that affect the caregiving situation, as highlighted in the study of Coristine, Crooks, Grunfeld, Stonebridge and Christie (2003). Anxiety is thought as an indicator of negative experiencing of caregiver burden and explains its negative impact on caregiver. However, anxiety can be perceived as a stressful factor, which affects the reactions of caregivers towards caregiving. According to Montgomery, Stull and Borgatta (1985) the direction of the causal link has not yet been found. Findings from different studies show that the psychological burden and that of relationships is more important than the physical one in a caregiving situation. The high level of anxiety may stem from the fact that most caregivers are attached to the patient, and therefore they experience the fear of losing them.

Payne, Smith and Dean (1999) reported that female caregivers experience higher levels in psychological morbidity and strain in the palliative phase. However, this finding is not confirmed in other studies (Grosv, Dahl, Moum & Fossa, 2005). Other studies are focused in different types of cancer and cultural contexts. Grunfeld et al. (2003) found that caregivers of both genders show high anxiety and depression levels in late palliative phase and beginning of terminal phase. In the study of Grov Dahl, Moum and Fossa, (2005) male caregivers experienced more distress in their new role. One reason for that could be the higher possibility that female patients can have a metastasis in brain. Therefore, some vital cognitive and behavioral functions of them are damaged and this increases the difficulties to the caregivers, it is an extra burden. These stress levels should be taken into account from the health care personnel.

In another study, the stress process model was used (SPM), which includes some fields that can predict stress, like for example the context of caregiving, the demands of caregiving and the necessary resources. All these fields influence considerably the variance of primary stress. For example, in the caregiving context there are some indicators that predict role overload of the caregiver. Younger caregivers report feeling fatigue due to the caregiving tasks they have to do. Many studies highlight the possibility that young caregivers have competing responsibilities. In this case, the demands of caregiving conflict with other roles of these individuals as raising children, full time job and other financial responsibilities (loan, cost of child rearing, health security, etc.). All these roles can trigger emotions of fatigue and emotional overload in young caregivers (Clipp & George, 1993). Similar findings came out in employed caregivers, whom due to the job demands felt trapped in their caregiving role.

The importance of competitive roles, especially for those caregivers who face challenges in different socio-economic aspects, might explain the effects of gender on experiencing primary subjective stress. Women more than men tended to show more often feelings of role captivity.

Income may be a buffer to stress, having a negative relationship with perceived role captivity. For caregivers of a low socio-economic status, the opportunity to meet some of the hardest demands of care (e.g. time lost from work) may not exist at all (Oberst, Gass & Ward, 1989).

The personal care that families provide to their relatives with cancer often has negative effects on the emotional distress of caregivers (Given et al., 1993). Another important impact of emotional stress of caregivers are their resources. For example, a multidimensional analysis shows that perceptions of social and emotional support from other family members and friends played an important role in assessing the relationship caregiver - patient (Gaugler et al., 2005).

In another study wellbeing or mental health of caregivers of patients with esophagus cancer was very low and much lower in comparison with caregivers of other patients [Mooney & McNeill, 2001]. Caregivers of esophagus cancer have distress and tension levels comparable to those of caregivers of patients in palliative phase. Also, they reported that they experienced high levels of subjective strain, which is related to experienced emotions (and not so much "objective" strain, which relates to the physical demands of care) (Donnelly et al., 2008)

Specific aspects of the profile of caregivers in cancer chemotherapy patients has emerged in a recent study. The ratio male: female was almost equal, indicating that beyond the traditional beliefs, the probability that a caregiver may be

male was almost the same as for women. This inconsistency may be due to the cultural changes occurring in modern societies. Historically, caregiving has been attributed to women, but nowadays, where labor demands are the same for both genders, men need to spend a considerable amount of time to provide care. Beyond gender, a typical caregiver had an increase in psychosomatic symptoms observed (headache, morbidity, sleep disturbances, anxiety, depressed, fear and irritation) (Pellegrino et al., 2010).

Regarding the profiles of the caregivers, findings from Cipolletta, Shams, Tonello and Pruneddu (2011) resulted in three profiles. The first profile, where there were individuals that had received help from others, was dominated by women. These may have been the wife or daughter of a patient or they could have another kind of relationship with him. These women typically had high levels of depression and anxiety and a poor social network, because it was difficult for them to identify a single important person in their lives. In the second profile, which is characterized by low levels of anxiety and depression, caregivers had a high number of resources, and a dependency level focused mainly on the mother and patient than on the caregiver itself; that is why this was an unexpected profile. It is expected that caregivers should be based mainly on themselves, that is why this was a profile beyond expectations. However, trust in others, and mostly in mother, apparently made them feel less depressive and anxious. In the same study, a third profile of caregivers was characterized by low overall dependence and higher dependence from oneself. This can be an expected profile of caregivers. The high dependence on themselves allows caregivers to have greater confidence in their helping role, which prevented them from high levels of anxiety and depression.

Every field of caregiving experience can be explained by various factors, the total variance ranging from 11 - 46%. Negative experiences related to caregiving correlated with low income, living only with the patient, with an unsatisfactory relationship, with a high dependence to the patient and with a high involvement in the care tasks. Caregivers with a low educational level had greater appraisal for caregiving. Although caregiving can lead to depression, especially in those individuals that experience loss of physical strength, caregivers can maintain a satisfactory quality of life by raising their self – esteem due to the caregiving (Nijboer et al., 1999).

Chinese caregivers of cancer patients experience high levels of depression symptoms and were exposed to many factors related to care, as the characteristics of caregivers, patient's distress, subjective burden of caregivers etc. Moreover, depressive symptoms were predictable by the demographic characteristics of caregivers as well as by their subjective burden, rather than by the patient situation or by objective burden of caregiving (Yang et al., 2011).

### *Depression in partners*

Many studies have explored the level of depression in partners of caregivers. Anxious and avoidant attachment related to more symptoms of depression. The diagnosis of cancer in a partner can activate the attachment system. At this point, individuals attached to an anxious manner were more preoccupied with themselves and provided a non – emotional care. Moreover, because of the seriousness of the disease and the fear of death, these individuals became emotionally alert (Mikulincer & Florian, 2000). Anxious individuals are prone to chronic mourning after the loss due to fear of abandonment (Mikulincer & Shaver, 2007). Consequently, these individuals may have a greater tendency to experience depression when faced with cancer of their partners and their potential loss.

Individuals with an avoidant attachment style have less knowledge about how to support others and have less sense of trust in relationships. Also, they tend to distance themselves from partners in need and from signals of suffering. Avoidance strategies have been effective to reduce stress in neutral situations but not in a threatening and chronic context. Coping with advanced cancer of partners can make them feel confused, because of the awareness of a possible death and separation, which can result in a high-level depression.

On the other hand, problems in marital relationships (marital dissatisfaction) were an important contributor to the depression of caregivers or partners. Furthermore, marital dissatisfaction can sometimes be such a strong source of depression that can be compared to the objective burden of caregiving. Providing care to patients with advanced cancer requires not only the partner to be attuned to the needs of the patient, but also demands from the couple to interact in intimate and difficult situations. In such cases, it may be satisfying for someone to provide care to another individual with whom he/she has a satisfying relationship (Brown & Stetz, 1999).

The role of caregiving is relatively new for those who undertake it, compared to other roles they have (e. g. employee or parent) and providing care to cancer survivors demands a lot of effort. This is the reason why caregivers are a very vulnerable group in many aspects. Employed caregivers and those who care for children while also offering their services to cancer patients were more likely to experience psychological stress and had difficulty in finding the meaning of their new role as a caregiver of a cancer patient (Youngmee, Baker & Spillers, 2006)

## Health related quality of life

Quality of life is a multidimensional concept that includes, but is not limited to, the status of the individual's physical health, psychological wellbeing, social functioning and mental health. Quality of life is subjective, but many studies that use standardized questionnaires have shown that quality of life can be measured in a population of patients with cancer, but also that of their families and caregivers.

Quality of life is a term often used to refer to the general wellbeing of the individual; it is applied for many years in the field of caregiving. Studies conducted in Western countries have revealed factors related to quality of life during the period of caregiving for a cancer patient. They can be divided into four categories: (i) sociodemographic characteristics, (ii) the requirements of caregiving, (iii) available resources, psychological and social, and (iv) the caregiving situation (Lu et al., 2010).

Physical aspects of quality of life during caregiving include fatigue, sleep problems, lack of appetite and need for rest; there were reported in a study of women caregivers for patients with prostate cancer (Kornblith, Herr, Ofman, Scher, & Holland, 1994). Axelsson and Sjoden (1998) found that spouses suffered from insomnia and needed help to care for the hygiene and clothing of patients.

Psychological aspects in quality of life could include an emotional turmoil, stress, anxiety, nervousness, anger, worry about their husbands, destruction and depressive feelings. Vickery, Latchford, Hewison, Bellew, and Feber (2003) reported that levels of anxiety of partners of patients with cancer head and neck were on the border for clinical assessment for mental health problems, but on the other hand, their levels of depression were within the normal intervals. In a longitudinal study, Borneman et al. (2003) found that caregivers had psychological problems that deteriorated after palliative surgery.

Patients in advanced stages had low physical quality of life and their spouses had the lowest emotional quality of life. Poor emotional well-being of spouses in the advanced stages relates to the percent of caregivers that ask for help in mental health services; a reason for this may be the highest threat for life associated with the disease in these stages. Dyads in advanced stages reported more distress, which is linked to lower quality of life. Interestingly, patients who received hormonal therapy reported less social support compared to patients taking other kinds of therapies, perhaps due to lack of awareness of side effects by other people (e.g. low sexual desire, redness, etc.) (Northouse et al., 2007)

## Conclusions

Cancer patients cope not only with their disease, but with many other difficulties. This is the case for their caregivers. Caregivers are individuals that have the duty or the satisfaction to offer care to a relative that suffers. Sometimes, it is not their choice. In many studies, caregiving is associated with high levels of distress, anxiety and symptoms of depression, which are not always related to the objective burden of caregiving, but to the subjective one. Caregiving also influences the perceived quality of life of caregivers. The continuous demands of caregiving can result in fatigue, sleep problems and a poor health. Further studies should be conducted in this field, especially in developing countries.

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