

PERCEIVED SOCIAL SUPPORT AND COPING STYLES AS MODERATORS FOR LEVELS OF ANXIETY, DEPRESSION AND QUALITY OF LIFE IN CANCER CAREGIVERS: A LITERATURE REVIEW

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Abstract:

During the last decades there is a trend in cancer treatment towards giving care at home settings. This trend presents the caregivers, mainly family members, with many difficult and complex tasks. The aim of this study is to explore the impact of perceived social support and coping strategies employed to the levels of anxiety and depression, as well as to the perception for the quality of life to cancer caregivers through a systematic literature review. Perceived social support results in fewer mental health symptoms, like anxiety and depression, and better quality of life, but this is not supported by all the studies. Likewise, some coping strategies, like active coping, have been also considered as important factors influencing quality of life and symptoms of anxiety and depression. Although there are many studies in the area of cancer, the majority of them have the patient in focus. There are few studies focused in the caregiving experience. In an Albanian setting, to the researchers' knowledge, there isn't any other study that targets caregivers.

Keywords: cancer caregiving, social support, coping styles, quality of life, mental health

1. Introduction

According to statistical data (INSTAT, 2008) it is estimated that every year almost 5000 individuals will be given the diagnosis of cancer, ranking as the second cause of mortality in Albania. Tumor diseases are ranked second after cardiovascular diseases as a major cause of deaths, which resulted in 82.2 deaths per 100,000 thousand inhabitants in 2009. Many types of cancer at the present could be described as chronic diseases requiring long-term treatment and posing numerous demands on patients and primary caregivers. Alterations in the patient's functional ability, bodily functions, appearance, employment status, family and social roles, and self-image are reported to have a direct impact on the caregiver (Siegel, Raveis, Houts, & Mor, 1991). With earlier diagnosis, advances in treatment, longer survival times, and a trend toward outpatient treatment, informal caregivers are likely to be involved in providing more complex care for a longer period of time. Research in the field of caregiving encounters mainly concerned family members of patients with mental disorders, such as schizophrenia or dementia (Schulz, O'Brien, Bookwala, & Fleissner, 1995).

The diagnosis of cancer has a strong impact on families. It influences every aspect of family life. Emotional turmoil, role interruption, changes in communication models, ways of living, and existential concerns related to suffering and death are part of the cancer experience. (Hileman, Lackey & Hassanein, 1992). Several types of cancer, previously lethal, already have become treatable and individuals survive for many years. Even so, this kind of success hasn't been achieved yet on some types of advanced cancer. The lives of the persons diagnosed in these cancer stages and of their caregivers change drastically. There are several treatments for them, but chances of survival are low. For example, an individual diagnosed with aggressive or advanced cancer (Stage IV) experiences a series of unpleasant procedures and often needs physical and emotional support. Taking care of this person asks for a lot of time, work and is stressful (Given, Given & Stommel, 1994). Caregivers offer direct help for self-care and activities, such as shopping, transport, money management and coordinating treatments and services they should visit. Caregiving during a serious illness is a new experience for most caregivers and many of them are faced with a new role, while coping with the emotional turmoil, present at the moment of learning of a cancer diagnosis.

Caregiving for an individual with a cancer diagnosis is highly demanding, because of the many responsibilities associated with the disease, especially in the case of advanced cancer

(Longman, Atwood, Benedict & Shang, 1992). For example, the patient may not be anymore able to attend to his/her own physical needs (hygiene, feeding, etc). Furthermore, patients experience symptoms of distress (nausea/vomiting, diarrhea, pain, fatigue, weight loss), which demand assessment and management by the caregivers. They are expected to become ‘health service providers at home’, to know and identify the problems and to reframe their life around the needs of the individual with cancer diagnosis.

Nowadays there is a strong tendency to take care of patients at their own homes and not in a hospital. The positive effects of home care for patients are undeniable, but on the other hand the family members that take care of them can experience high levels of stress and other problems. In order to prevent damages in caregivers health, the health personnel needs to be attentive to symptoms of anxiety and depression. The personality of the individual and stress coping strategies may be important variables in this process.

1.1. 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 poor health, because of his/her illness or age.

A caregiver:

- Arranges things for someone with a chronic illness;
- Manages medications or discusses with doctors and nurses on behalf of someone else;
- Assists someone to carry daily necessities, a person disabled of with limited functionality;
- Cares of household chores, meals, or bills for someone who cannot take care of itself.

(www.nextstepincare.org)

1.2 Operational definitions

Anxiety is an unpleasant emotional state that involves a complex combination of emotions that include fear, apprehension, and worry. It is often accompanied by physical sensations such as heart palpitations, nausea, chest pain, shortness of breath, or tension headache (<http://psychology.wikia.com/wiki/Anxiety>).

Depression may be described as feeling sad, blue, unhappy, miserable, or down in the dumps. Most of us feel this way at one time or another for short periods. Clinical depression is

a mood disorder in which feelings of sadness, loss, anger, or frustration interfere with everyday life for a longer period of time (<http://psychology.wikia.com/wiki/Anxiety>).

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. ([en.wikipedia.org/wiki/Social support](http://en.wikipedia.org/wiki/Social_support)).

1.3 Aim of the study

The aim of this literature review is to explore the impact of perceived social support and coping strategies employed to the levels of anxiety and depression as well as to the perception for the quality of life to cancer caregivers.

1.4 Research questions

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. What is the impact of perceived social support and coping strategies to levels of anxiety and depression and QOL?

2. Literature review

2.1 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

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:

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. The feeling that they have no time for themselves.

(http://www.medlook.net/article.asp?item_id=1894)

2.2 Anxiety and depression

Many studies report an increase in levels of anxiety and depression to caregivers of both genders. The same thing happens in the case of depression, but women have a higher prevalence of depressive symptoms compared to men. Theoretically, high levels of anxiety may be related to caregivers who have concerns about the future, confronting the situation, the fear of loss or fear of being alone, with great responsibility in relation to children, to cope with unfamiliar tasks at home etc. These are situational factors, which are perceived as stressors that affect the care situation, as highlighted in the study of Coristine et al. (2003). Anxiety is thought as an indicator of the burden experiencing during caregiving, a negative way, and explains its negative impact on caregiver. However, anxiety can be seen as a stressful factor, which affects the responses to the challenges of caring. According to Montgomery et al. (1985) the direction of a causal link has not been found yet. In many studies it is thought that the psychological burden and that the kind of relationship is more important than the physical one.

The high level of anxiety may stem from the fact that most caregivers are attached to the patient/s and therefore experience the fear of losing them.

Payne and others (1999) report that women caregivers experience higher levels of morbidity and tension during the palliative phase, though this observation is not confirmed by other studies (Grosv, Dahl, Moum, Fossa, 2005). In these studies, the explanations are oriented towards the types of cancer and cultural differences. Grunfeld et al. (2003) have found that caregivers of both genders show high levels of anxiety and depression during the palliative phase and in the beginning of terminal phase. The study of Grov and others (2005) found that men caregivers experience more distress in their new role. One reason for these results is the tendency in women patient to have more head metastasis. As a result, their cognitive and behavioral functions are damaged, which creates an extra burden for their caregiver. These very high levels of stress must be taken in consideration by the health personnel.

2.2.1 Depression in spouses

Another research has observed the level of depression in caregivers' spouses. Anxious and deviant attachment was connected with more symptoms of depression. The diagnosis of cancer in one partner may activate the attachment system. At this moment, anxiously attached individuals are more likely to be very concerned about themselves and to offer care unfeelingly. Furthermore, because of the seriousness of the illness and the fear of dying, these individuals experience various emotions (Mikulincer, 2000). Anxious individuals have a tendency to experience chronic grief after the loss of a close person, because of fear of abandonment (Mikulincer, 2007). Consequently, these individuals may be more likely prone to depression when faced with spouse cancer and their potential loss.

Individuals with avoidant attachment have less knowledge and understanding of the ways of offering support to others and are less trusting of relationships (Feenay and Collins, 2001). Also, they tend to distance themselves from partner in need and their signals of suffering. Avoidant strategies have been effective in reducing stress in neutral situations, but not in a chronic and threatening context. While facing the advanced stage of cancer of their partner, avoidant individuals may feel confused because of the awareness of a potential death and separations, which may result in frequent depressive symptoms and high intensity.

On the other hand, marital dissatisfaction was an important contributor in the caregiver's/partner's depression. Sometimes, marital dissatisfaction can be a source of depression, as strong as the objective burden of caregiving. Offering care to patients with

advanced cancer asks not only for the partner to be aware of his/her partner's needs, but also for the couple to interact in intimate and difficult situations. In these situations, it may be fulfilling for someone to offer care to another individual, with whom he/she has a satisfying relationship.

Considering the fact that the caregiver's role is relatively new for the ones who undertake it, compared to the other pre-existing roles (employer, parent, etc) and that offering care to cancer survivors is related to attending to many needs, this makes them vulnerable in many aspects. The employed caregivers and those who took care of children, while offering their services also to sick relatives, were more likely to experience psychological stress and difficulties in finding meaning in their new role, as caregivers of a cancer patient (Kim, Baker and Spillers, 2007).

2.3 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 been 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.

2.3.1 Non-formal support

Positive adjustment in caregiving for cancer patients is often connected with the availability of social support and trusted persons (Walker, 1997). On the other hand, a stronger correlation has been found between lack of support and high levels of emotional distress or

affective disorders (Nijboer and others, 1999). Mental health of caregivers usually improved in the first year after the diagnosis, when they felt that support by others increased. Schumacher and colleagues (1993) conclude that social support moderates the functional status of the patient and also the caregiver's depression. Caregivers experience more distress when the patient's level of functioning is low, but this correlation was much weaker when they thought they had social support.

Other studies have not confirmed the correlation between caregiver depression and their perception of social support (Lalos, Eisemann, 1999). Lack of consistency in findings reflects the complications of measuring various aspects of support. One of the influencing factors are gender differences, which may play a role. Ptacek and colleagues (1994) found that patients with breast cancer and their spouses, which required more support, had a better mental health. In another study was found that there is a correlation between spouse support and their better adjustment (Ptacek and colleagues, 1997).

2.3 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.

Influences related to the quality of life of the caregiver of cancer patient: positive and negative influences in caregivers may be grouped in four categories: factors linked with the patient or the treatment, factors linked with the caregivers, factors linked with caregiving and social factors.

Factors linked with the patient or the treatment: various studies have reported that the early stage of the patient's illness, efficacy and quality of life were positively linked to the quality of life of the caregivers (Campbell and others, 2004). Short hospitalizations and the

effects of treatments on the relationship between patient and caregiver had many damaging effects in their psychological wellbeing. Even so, the status of patient functioning and the type of treatment were not correlated with the quality of life of the caregivers.

Factors linked with the caregivers: the demographic factors of caregivers may influence in the quality of their life. Retirement and income level were correlated to a higher life quality in caregivers, while education had a negative correlation. Even so, McMillan and Mahon (1994) found that age and education were not correlated with the quality of life of the caregivers. Personal attributes influenced the quality of life of the 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).

Factors linked with caregiving: 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).

Social factors: good relationships with patients, marital satisfaction, contacts with friends, family resilience and social support contributed to a better quality of life (Axelsson & Sjoden, 1998).

Interventions for the improvement of the quality of life of cancer patients: only in one longitudinal quasi-experiment a connection was found between the type of intervention and the improvement of the quality of life of the caregivers (Smeenk et al., 1998). The study tested a program of offering home services for the caregivers of terminal patients. This program addressed the needs of patients for collaboration, coordination and communication between the family members and professional caregivers. The program consisted in four components: (a) a coordinator nurse, (b) a 24 hours phone service at the hospital, which provided access to a interdisciplinary team, (c) an explanatory file to use at home, and (d) a

protocol especially planned for each person. The caregivers that participated in this program had higher levels of quality of life, a week after the beginning of the program and three months after the death of the patient, compared to the caregivers of those who had a standard service.

2. 4 Coping strategies

When individuals face a traumatic event, they must use a variety of strategies to cope with stress and experiencing change. One of the most popular models for coping with stress is that of Lazarus and Folkman, which is used in the field of stress caused by something life-threatening (Lazarus and Folkman, 1984). Lazarus and Folkman (1984) have defined coping with stress as an attempt to manage the demands of external or internal. External requirements refer to the domestic scene as they refer to an emotional reaction to the event. The difference has led to a differentiation between the problem-oriented coping (responses directed towards the external event) and the emotion-oriented (reactions directed against the individual or emotional reactions to situations of internal). The model suggests that coping with stress is a process and not a single event.

Cancer, as defined by Mages and Mendelsohn (1979) contains the risk of continuous and prolonged stress, because of the discovery of the illness, the process of diagnosing, surgical interventions, monitoring after the treatment and fear of repetition. The adjustment of cancer patients to these changes in their life, caused by continuous stressful experiences, depends on the stress coping strategies (Spencer, Carver dhe Price, 1998).

In other studies (Carver, Scheier dhe Weintraub,1989; Scheier, Carver dhe Bridges, 1994), the coping strategies are grouped according to the adaptive or functional value of their results; their effectiveness is evaluated in terms of eliminating the stressor/distress and maintaining social functioning and the sense of wellbeing (Zeidner M, Saklofske, 1996). Research has shown that problem-oriented coping is more effective than emotion-oriented coping, in terms of emotional reactions and levels of performance in a stressful situation. Problem-oriented attempts are efforts to do something more constructive about the stressful conditions, which may damage, threaten or challenge an individual, while emotion-oriented coping strategies include attempts to regulate the emotional consequences of the stressful event. Taylor (1991) emphasizes that although both strategies may be used in all the stressful cases, the attempts to solve the problem are especially useful to control stressors, while the attempts to regulate emotions are useful to manage the impact of uncontrollable stressors.

Stress coping styles in caregivers

Avoidance has been correlated to poor psychological adjustment in caregivers (Rodrigue and Hoffman, 1994). Those who avoided issues related to the medical condition of the patients or to the treatment, or that gave up passively, were found to be more stressed in the study of Rodrigue and Hoffman (1994). Morse and Fife (1998) studied the partners after receiving the diagnosis, in the first relapse, after returning and when the patients were in an advanced stage. They found that avoidance (for example, not telling other how bad they were feeling, or using alcohol and medications) was linked with a worse adjustment between partners, while denial (minimization of the impact of the disease in their life) was linked with positive adjustment. The way patient coped with stress was linked to the distress experienced by the caregivers. Ey and colleagues (1998) found that male patients, which used avoidance more, had higher levels of anxiety and depression than their wives. Ptacek and colleagues (1994) found that men report less mental health problems when the patients used more the problem-oriented coping strategy and less the avoidance one (Pitceathly and Maguire, 2003)

According to Teschendorf and colleagues (2007), there are two primary ways of coping. One method is that of the personal reflection on specific thoughts related to the caregiving experience and its value or meaning. The second was linked with the use of self-regulating mechanisms to repress unwanted feelings and engage in more positive thinking during the role performance. Using the first coping method, inner reflection and processing, the caregivers continued to be optimistic and tried to transmit this hope to the patients. They talked about the importance of being positive and the conviction that they could bear the responsibility given to them. On the other hand, they felt deprived, a concept linked with limited resources, they had lack of support and less time for themselves and lack of pleasure. They know that they sounded 'selfish', but they compensated for these feelings with hope, patients and a sense of responsibility.

Conclusion

The recent trend in cancer caring towards treating patients at home has many advantages, but also many difficulties. The patients report higher levels of satisfaction with caretaking at home while their caregivers appraise their work and new roles. On the other hand, this trend was accompanied by many new and much more complicated responsibilities for the patient's caregivers. Although, caregivers think of their caregiving mainly in a positive way, there is

always an extra burden in their new lives/roles as caregivers. This could be an objective or subjective one.

Some of the main symptoms caregivers demonstrate are high levels of anxiety and depression during the caregiving period. According to the literature, a social network can moderate the effects that caregiving has to the caregivers, but this is not always true. Also, some coping strategies are related do better outcomes regarding anxiety and depression, like for example, active coping, problem solving coping, or an emotional coping during the palliative phase.

Quality of life is a subjective construct and it one of the most studied in the cancer caregiving field. The reasons that quality of life changes during this period are related to the new role, the lack of social support, the problems with a full time job, the time spent to other relationships (e.g. with children) etc. There aren't any final suggestions regarding coping styles and quality of life. Meanwhile, there is a positive relationship between social support and perceived quality of life. Further studies are needed especially in developing countries, in order to explore the relation of these variables to one another.

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