

The effect of the burden of patient care with cancer on family caregivers

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ABSTRACT

Cancer is a major problem that affects today's society. Besides patients suffering from this disease, cancer has also a huge impact on the quality of life of the family. This study aimed to investigate the latest bibliography on the effect of the burden of patient care with cancer on family caregivers. Family caregivers face physical health problems such as physical pain, fatigue, sleep disturbances. Moreover, several psychological effects are shown, in which various disorders such as depression are included. Psychological disorders, also, include adjustment disorder, panic disorder, anxiety, and emotional reactions such as anger, frustration, and fear. In the financial sector, caregivers face several problems due to the coverage of medical needs which are reinforced by reducing or stopping their work because of the

care burden. At the same time, they are confronted with social impacts in which loneliness and isolation are attributable to the limitation of their social activities. As far as the age group of the patient is concerned, the effects of caring for young patients are more psychological than physical in opposite to the older people. The burden experienced by the family of the cancer patient exhausts family and it becomes necessary to identify problems and assess their needs. Health professionals should strength caregivers with actions such as psychological support, training, and participation in social and supportive programs in order to improve their personal health and quality of life.

Keywords: cancer, family, caregivers, burden.

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INTRODUCTION

Cancer is characterized as a "treacherous", "wretched," "scary" disease that sheds fear and panic and inevitably leads to a painful and poignant death. The diagnosis of cancer wreaks chaos. The family is an integral part of the cancer patient's care and the inconvenience caused to the family is great. Care is centered on the patient while the whole family's suddenly paralyzed. Family's breakdown is not evident while the problem is detected even when things are out of control or they are never detected at all. Thus, cancer is a family disease as it greatly affects the quality of life of the family environment as well [1,2]. The family in most cases is the informal caregiver of a cancer patient as they fully assume the support and care of the patient [3]. Furthermore, due to some situations (great social and economic needs, work obligations of all family members and the establishment of the nuclear family as the most common family model), patient's care is distributed among all the members of the family, not just one as it used to be in the past. This has an effect on the confrontation of a variety of problems that have an impact on their psychological well-being and their physical health [1,4].

This study aims to explore the contemporary bibliography that illustrates the effect of the burden of patient care with cancer on family caregivers. Published articles indexed in the PubMed and Google Scholar databases related to the effect of the burden of patient care with cancer on family caregivers were included. The keywords used were "cancer", "family", "caregivers", and "burden."

REVIEW

The patient with the progression of cancer is confronted with a multitude of problems and emotions. The family in most cases takes care of the patient and takes the place of the informal caregiver. They come closer to the patient's psychology and can understand him more [5]. The family will also support, uphold, encourage patient in all aspects and support the patient in all of the problems, without any compensation for the services which are offered. For this reason, the family is the best source of care for the cancer patient. In addition, it has been shown that care provided by the family contributes positively to the patient's health and better dealing with the disease [3].

Family members involved in the patient's care, undertake activities relevant to the care segment. These activities include patient's personal hygiene, mobility, transport, patient's communication, management and coordination of the medical care and

medication, emotional support, assistance in social activities, management of financial transactions, proper nutrition and housework [6]. Family members take on new roles and abandon their old habits [7]. The roles between the members of the family are redistributed and housework is redelegated while everyone acquires more responsibilities and obligations [8]. Suddenly, family members are confronted with a new reality, needs, problems, and obligations [9]. Family members have more obligations than they can handle [6]. Therefore, the care provided by the family members brings them adverse emotional, social, psychological, economic, physical and mental effects [10]. Many studies [1,8,10] report that stress and anxiety experienced by the cancer patient's family are to the same extent or even more than that experienced by the patient himself.

The burden of family caregivers is one of the main problems faced by the family and especially the person who spends most of the time offering the patient's care [10]. The burden of care is defined as the discomfort experienced by family members who administer the care to the patient. It affects the physical, psychological, social and economic dimensions and consequently, the quality of family's life [11].

The burden of care has been seen to increase with the reducing physical functions or reduction of patient's consciousness or both, rendering him unable to self-serve. This situation contributes significantly to the burden of the family but it is not the only factor of deterioration [11]. The burden of caring can affect many aspects of health and socioeconomic life of family.

Physical effects

Along with the burden of care, family members who are responsible for the patient's care face a multitude of health problems associated with their physical deterioration. Such problems relate to sleep disturbance, fatigue, exhaustion, pain in various parts of the body such as legs, shoulders, neck, loss of physical strength, decreased appetite, weight loss or, more rarely, the abrupt increase of the body weight [12,13]. A large percentage of the people taking part in the patient's care are older and therefore have pre-existing health problems. Moreover, relations between members are disrupted as the stress that exists generates tension and conflict between people [6,14]. Sleep disturbance of caregivers is a common phenomenon that is significantly associated with depression and anxiety, two of the main problems that are reflected in the faces of their families and directly affect care provision. Worsening of these symptoms is due to the fact that the patient experiences mobility problems, urinary incontinence, and insomnia. Sleep

disorders include sleeping for less than 7 hours, waking up more than 6 times during the night, resting at noon for more than 2 hours. Situations that may cause insomnia to family members may be the particular characteristics of the patient's disease, the severity of the symptoms and the functional condition. Also, the kinship with the patient, the intensity of care, the mixed treatment are factors that affect the quality of sleep. Sleep disturbances pose a variety of health problems, including depression, anxiety, immune-deficiency, cardiovascular disease, and poor quality of life [4,15].

Psychological effects

The most common psychiatric disorder presented by family caregivers of cancer patients is depressive disorder. The term “depressive disorder” means a disease characterized by persistent discomfort in mood which interferes with the person's daily routine. For caregivers, depression is an emotional reaction to the patient's care and dealing with mortality. It is largely based on the stage of the patient's disease [15-17]. Apart from depression, the family of a cancer patient also suffers from other disorders. Quite a large percentage of them face adjustment disorder. They struggle to adapt to the new situation in both emotionally and behaviorally. In addition, family caregivers whose relatives are at the end stage quite often appear to have panic disorder, followed by depressive disorder, post-traumatic stress disorder, and anxiety [18-20].

Many situations and incidents of a cancer patient's daily life are likely to burden the family caregivers and create anxiety [10,21]. However, they are unaware of the constant and intense anxiety that floods them and begins to impinge on their physical health, resulting in serious mental and physical illnesses [22]. This is because the family members, despite the numerous problems they face, neglect their personal needs, give priority to the care of their family members regardless of their own emotional state [21]. Additionally, the sight of their own family member who suffers from cancer is particularly detrimental and stressful as it is a disease that alters the patient and it is very difficult for the family to see their family member in this state [10]. Therefore, the most important factor of anxiety is thinking about death [8,23].

Another problem that emotionally affects the family environment of the cancer patient is the communication with the patient. Moreover, family members in their efforts to protect and not affect the patient's psychology, avoid discussing issues related to diagnosis and disease. This makes communication between family members and health professionals more difficult due to accidentally hiding information about the patient's condition [24].

Anger is one of the first emotions that dominate the family from the time of diagnosis [7]. Most of the times, anger is directed towards the doctors who make the diagnosis and coexists with a sense of injustice and lack of understanding about everything that has happened. The thought that cancer may return terrifies the family [8,25,26].

Financial impact

During the stages of the disease that the patient faces (diagnosis, treatment, recession, relapse), the family is confronted with changing of roles and coping with many financial burdens [22,27]. The payment of high medical expenses and the cost of treatment and care make it difficult for the family [11]. The financial difficulties that a family may face in conjunction with a low education level and the lack of knowledge about both illness and care, affect the acquisition of the resources needed to care for the patient. This leads to negative influences affecting both the level of care and the health of family members [27-29]. Many times these financial difficulties burden the family for several years after the healing or death of the patient [22].

Despite the cost associated with the treatment and medication needed by the patient, the care of a cancer patient directly affects the professional obligations of family members as it reduces their efficiency and the ability of one or more people involved in the care to work. They are usually forced to work a few hours, get a lower salary, take unpaid leave, and consequently delay their retirement or even lose their work [6,30]. Furthermore, quite often, some members are forced to quit their job due to the many obligations and the constant fatigue arising from the care of their family member [9]. This situation often creates inter-family conflicts but also charges the family caregiver emotionally and psychologically [27].

Social impacts

By stopping or reducing the working hours of family members, another problem that arises is that of social isolation which leads to the loneliness of the caregiver [6]. Social support is an important prognostic factor of health [31]. Several studies indicate that the care may stop social activities since caregivers spend all their time caring for the patient [6]. They are unable to maintain relationships with their friends or participate in recreational activities and hobbies [32]. The effects of this situation often lead to social alienation and loneliness, a sense of sadness and limited time for personal relationships [6]. Nonetheless, they often don't have the sense of being cut off from their social lives as they are focused on the needs and care of their loved ones [22].

Effects depending on age

As far as age is concerned, in cases where the patient is young, it has been observed that while the family members feel a higher psychological burden, they can more easily treat them with optimism. Young patients can communicate better and self-handle more easily than older people, and this makes it easier for caregivers. However, the impact of grief and psychological pressure created when young patients are in the final stage affects family members much worse [33].

The elderly, on the other hand, are more physically vulnerable with increased risk of morbidity, thus requiring additional care and support, which contributes to the burden of caregivers [7].

The effects of death

Family members who eventually lost their patient report that the unpleasant experience of waiting and seeing their patient die without being able to intervene is characterized by shock and intense stress [18]. Death of a loved one is the worst situation a family has to face and adapt to [34]. It is a traumatic experience for the family and the depression and other psychological problems are strongly observed among family members even after the patient's death [17]. However, it has been observed that they often feel relieved by the loss of the patient they had taken care of due to the adverse effects of care on their quality of life [10,35].

CONCLUSION

The burden of care faced by the family does not allow caregivers to fulfill their personal needs for support and leads them to poor quality of life, high levels of anxiety, discomfort, and mental pain. Although the family is in hospital for several hours while accompanying the patient, doctors and health professionals do not give them the proper attention. Medical professionals should recognize the importance of the patient's family's care and the work they perform. In addition, they have a key role in the evaluation of family caregivers, since the health of the patient depends on the quality of the health care they offer. Nevertheless, health professionals cannot force the family to seek support, but they can encourage them. They must also prevent them from neglecting their personal needs as they make their emotional burden more difficult.

Stress and depression can be reduced by providing information addressing it by providing physical, mental, and spiritual support and information. The stress-free relative provides better and more efficient care quality than those anxious and

confused. The strengthening of caregivers can be achieved through support programs from social services, specialized centers, and training which provide knowledge and information. Also, resources should be kept to make the family education available for the role of care. In addition, information can be provided through information leaflets in hospital waiting rooms, pharmacies, respected websites, and by community nurses who may visit the family members.

Conflicts of interest

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