Babeş-Bolyai University

The Faculty of Sociology and Social Work

The role of psychosocial factors in the oncologic background.

Theoretical and interventional implications for patients and caregivers

Scientific coordinator:	PhD student:
Conf. Univ. Dr. Dégi László Csaba	Florina Pop

The content of the doctoral thesis

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THESIS SYNTHESIS

The paper approaches high occurrence present-day themes, debated in the range of researches focusing on psychosocial field. By analyzing the selected dimensions for patients and caregivers, this paper aims at putting this domain into a new perspective, within the Romanian oncologic background.

The sickness-life relation is multidimensional, having as much physical implications, as psychological and social ones. Due to the impact of the neoplastic disease, new research patterns are needed, which will integrate other dimensions, such as the fear of recurrence, fatigue, in case of patients, but also psychosocial factors related to caregivers. These aspects are emphasized more and more often by experts in international specialised literature, so that the information deriving from them needs to be acknowledged and, especially, valorised.

This research has chosen a methodology that focuses on paired samples (patient-caregiver) with the purpose of providing a broader image.

The purpose of the research is to reveal a contextual understanding of the oncologic patients and caregivers registered in the Institutional Register of „Prof. Dr. Ion Chiricuță" Institute of Oncology, by measuring their own perceptions and evaluations in distinct matters of life quality, psychological dimensions (depression, anxiety, fear of relapse), psychosocial needs, fatigue, of caregivers` reactions related to social-demographic factors (age, gender, educational level, financial status, marital status, professional status).

In the theoretical part of the paper I intended to perform a synthesis of the main studies available in psychosocial research, in the oncology field, at international level, by emphasizing the analysis of quantitative studies and used instruments, thus highlighting the important psychosocial factors (patients` and caregivers` psychosocial needs, fear of relapse and fatigues, in case of patients, distress, depressive and anxiety symptoms, life quality of patients` and caregivers` and the role of social-demographic factors over the psychosocial implications within the oncologic context).

I mention the fact that a part of the research instruments used in the paper are validated by Romanian population, and another part have been already used and validated in case of various researches which have focused on neoplastic patients and their caregivers, in different parts of the world.

The paper is structured in 2 big sections: the first section includes six chapters, which present the physical theoretical, psychological and social framework referring to oncologic patients and their caregivers, by trying to summarize the main frameworks and tendencies available at this point at international level, as well as in Romania and afterwards, to focus on the chosen key-elements. This fact has been carried out by explaining the concept and presenting the epidemiology, the main clinical features and signs, the evaluation and intervention means.

The second section refers to the actual empirical research and includes four chapters which focus on testing, verifying and interpretation of scopes and hypotheses of the paper.

The population of this exploratory, longitudinally designed study is represented by the oncologic patients and their caregivers.

This research which is centred on psychosocial aspects in the oncologic background, by associative analyses and initial correlations, yet also through multifarious statistic analyses, proves that the social-demographic and psychological factors have an obvious significant influence on the life quality of the patients and their caregivers.

According to the purposes of the research, the constant social-demographic variable having an influence on the life quality of patients and their caregivers is the *financial situation and income*. It seems like an associative relation and when the caregivers achieve an income above the average wage, they score higher at life quality. The results are in accordance with other researches in the specialized literature which have studied this variable in oncologic background. Among the used terms for this hidden cost of cancer is that of "financial toxicity". The consequence of a low wage roots deeply to the poor life quality and to high anxiety, in case of patients and their caregivers. The psychological impact (higher levels of anxiety, depression and fear of relapse) in the context of financial issues of patients has been asserted in a series of studies in specialized literature. We can simply refer to the Maslow`s pyramid of needs, only after a person manages to satisfy his/her basic needs, then he/she can focus on the top needs, such as self-development, so that, in case of a cancer patient, whose physical integrity has already been threatened, who says he/she has a low income or so low he/she can`t even afford the necessary items and the lack of financial security may constitute a real hurdle in one`s way to adapt to a serious problem, such as cancer. Another social-demographic variable emphasized by results is the *educational level*, namely the study sustains a significant correlation between the level of education and life quality (patients with university degrees/post-university studies have a higher life quality compared to those who have graduated only from high school/secondary school) and also the post-test analysis has revealed a significant difference between the levels of depression and anxiety in case of patients with high school studies versus those having university degrees/post-university studies. Even the fear of relapse level is much higher in patients with a lower education degree. The results are also asserted by other specialized literature studies.

Another emphasized correlation is related to the *professional status* of the caregivers – a higher life quality in case of employed caregivers versus the professionally inactive ones. This association explains that the financial aspects are important. When the family confronts with a neoplastic disease and the caregiver doesn`t have a job, the resources needed for facing this challenge are limited, fact reflected in the life quality of the caregivers.

The environment (urban or rural) – patients coming from the rural environment have scored higher at anxiety level compared to those in the urban environment. Following the same idea of limited resources, a diagnosis such as a malignant pathology, interpreted as a death sentence, may generate a higher level of anxiety.

The marital status – according to the results shown, the average depression score has been lower to married patients, as opposed to other marital categories. This association is explained by the family support of the married people. This protective factor is also argued by other specialized literature studies.

Age and gender have been emphasized in this study in relation to the life quality and the level of depressive symptoms – female patients under 60 years old have a lower quality life level and also the average depression score was significantly lower in case of caregivers under 60 years old versus those over 60. These variables are asserted by a series of studies. The patients` age has also a significant impact on the social dimension of life quality, meaning that the elder have fewer social relations than the younger. Regarding the age, the studies show that the single young female patients report more practical issues. In what concerns the gender, the results of this current study have shown a higher need for help, higher fear of relapse at female patients and a positive association with a low level of life quality in case of patients under 60, whereas at male patients, a negative association with a low level of life quality. According to cancer information provided in literature, there are some studies asserting that females report more physical symptoms, such as nausea/vomiting, fatigue and especially a lower global functioning and lower well-being. In what concerns the fear of relapse, a study from 2009 carried out by researchers Simard & Savared shows that female patients report a more frequent fear of recurrence.

Referring to the clinical variables (stage of the disease, the moment of diagnosis, type of cancer), it has been emphasized in this study that *the fear of relapse was significantly* *higher in case of mammary cancer patients versus those with thyroid pathology*. Although the fear of recurrence is considered universal, in cancer there are certain risk categories mentioned in specialised literature, such as: young patients, those suffering from general anxiety or confronting with a series of adverse effects of the oncologic treatment, including long-term ones, or those having informational needs may experience a higher level of fear of recurrence. Therefore, even if the literature doesn`t provide clear explanations on the fear of recurrence in case of thyroid cancer versus mammary cancer, the difference in the intensity of the fear of recurrence in this study may be explained precisely by the fact that breast cancer patients have followed the entire treatment scheme and face a much lower life quality, as opposed to thyroid cancer patients, whose life quality is not so much affected. Adverse effects of the oncologic treatment have been stated as an important risk factor in experiencing the fear of recurrence, according to the above-mentioned studies.

In what concerns the *psychological variables*, some correlations have been highlighted between depressive and anxiety symptoms and fear of recurrence, fatigue and life quality of the patients. It`s natural for the life quality, more precisely, functionality, to be affected by the psychological variables. The association between the mentioned variables is asserted also by a series of studies in the specialized literature. Identifying the depressive and anxiety symptoms, the fear of recurrence and fatigue is important because, on the long term, the life quality is significantly affected if not intervened upon. Furthermore, at longitudinal evaluation, distress remains unaltered, whereas the life quality decreased and there have been showed lower scores at fatigue subscale, which measures low motivation, proving that the risk factor remains active and psychosocial intervention measures are to be imposed.

The comparative analysis of *depression and anxiety* at patients and caregivers show that both affective symptoms are higher among the patients than the caregivers, fact that may be interpreted that, in case of caregivers, the key-element is lacking, namely the neoplastic disease, and the daily functionality, an important aspect of the life quality, is not so much affected.

The chapter entitled “Conclusions” refers to issues related to theoretical and practical utility of the data, after which it is presented the self input to the development of the research theme, the limits of the paper and future research directions, outlined based on the achieved results.