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Perceived Social Support in Cancer Survivors: Some Preliminary Results

Bilyana Velikova-Tzonkova*[a]

[a] Prof. Assen Zlatarov University, Burgas, Bulgaria.

Abstract

The following article presents the results of a pilot survey focusing on the perception of social support received by people diagnosed with oncological disease. For the purpose of the study the Sources of Social Support Scale (SSSS) by Carver and colleagues was used, combined with the method of psychological interview. The respondents' answers were analyzed on the basis of different kinds of support (emotional, instrumental, informational, and negative) the patients have received from five different groups of support sources.

Keywords: perceived social support, cancer survivors, sources of social support

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*Corresponding author at: Prof. Assen Zlatarov University, 1, Prof. Yakim Yakimov Str., 8000 Burgas, Bulgaria. E-mail: bvelikova@yahoo.com

Topicality of the Problem

Being diagnosed with oncological disease is an extremely traumatic experience that affects every aspect of the everyday life of a person and his encirclement. With the disease some substantial changes occur in the life situation of the individual as the fight for survival becomes of most significance. Cancer diagnosis puts the individuals through serious challenges, forcing them to make radical changes on a physical and mental level. The disease hinders normal social functioning, putting seemingly invisible barriers between the self and other healthy people.

The oncological diseases are a serious challenge for medicine and science in general. Hundreds of different in their nature diseases are identified by the term cancer. Behind every diagnosis there is a real person with his own medical and physiological characteristics (Greenwald, 1992). The combination of clinical, personal and psychosocial dimensions of each individual case of cancer turns it into a multidimensional system of interrelated factors which determine the course of illness, treatment effectiveness and quality of life after the diagnosis.

One of the most researched psychological aspects of a person being diagnosed with cancer is the influence of socio-environmental factors on adaption and coping with the new life situation. Number of studies show significant correlation between the presence of a well-developed social support network and coping with the illness (Billings & Moos, 1981, as cited in Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Dunkel-Schetter, Folkman, & Lazarus, 1987). Cronkite and Moos (1987, as cited in Dunkel-Schetter et al., 1992) found that women deprived of family support in their fight against the disease were more likely to prefer avoiding coping strategies than to actively engage in dealing with the new life situation.

Social support plays a leading role in adapting to and overcoming the life crises. It is a widely accepted opinion today that the diagnosis of early stage breast cancer is a specific life crisis with different possible consequences for the individuals, suffered by patients within a year after being diagnosed (Carver et al., 1993, as cited in Urcuyo, Boyers, Carver, & Antoni, 2005; Spencer et al., 1999, as cited in Urcuyo et al., 2005).

In stressful situations a person usually seeks support and help from family and friends (Kinsinger, Laurenceau, Carver, & Antoni, 2011, p.1572). Studies show that satisfactory family relations correlate with emotional adjustment to the breast cancer diagnosis (Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005).

The social support directly affects the sense of dealing with the disease. The perception that others can and will provide the necessary resources to deal with the stressful event redefine the power of the negative event and also encourages the individual ability to cope with the new needs.

The construct social support refers to the perception of a person for whether he has been taken care of, loved and valued by others (Cobb, 1976, as cited in Corr & Matthews, 2009). It is believed that this sense of support and community in dealing with the uncertainties of life events reinforces the sense of self control (Albrecht & Adelman, 1987, as cited in Corr & Matthews, 2009).

In the context of oncological diseases social support is viewed as multidimensional construct consisting of emotional, informational and instrumental support (Bloom, 1986, as cited in Kinsinger et al., 2011; Helgeson, 2003, as cited in Kinsinger et al., 2011; House, 1981, as cited in Kinsinger et al., 2011). The emotional support includes empathy, listening, feeling comfort, communicating affection and love. The information support includes counseling, referral, and feedback for a given problem. The instrumental support is seen as tangible aid that is offered regarding the disease. It includes transportation to and from the hospital, help with housework, paying the bills (Kinsinger et al., 2011).

At the same time, little research has been done on the impact of unsupporting behavior of the partner and family in dealing with the disease. The behavior can be perceived negatively despite the initial good intentions. Partner’s negative support includes criticizing the way of dealing with the disease or avoiding the cancer topic (Kinsinger et al., 2011, p. 1572).

In the entire psychological profile of a person surviving after cancer diagnosis, sources of social support are one of the most important factors in adapting to life crisis caused by oncological diseases.

Objective

The article presents data from a pilot study that is part of a research project exploring personality and social psychological aspects of being diagnosed and treated for cancer. The ambitious objective of the research project is to set out a possible model for long-term dealing with the cancer disease.

The focus in the present study is on the types of social support received by respondents from different groups of sources defining the specific social network of the individual - partners, parents, children, friends, health professionals, cancer patients.

We assume that there could be some differences between respondents in terms of the used sources of social support regarding the different types and stages of the disease, the different approaches toward the disease and the different marital status. But all these differences are not the subject of the study in this article. The hypothesis is not verified statistically, but the data allow drawing substantive aspects of these differences.

The study in this article is not exhaustive on the subject. It is a pilot project and covers a small number of respondents due to the specifics of the studied problem. Though the research is not representative, the indicated trends are an important element of the hypothesized theoretical model and will be verified or rejected by the official survey.

Methods

Trying to overcome some limitations of the study regarding the psychological aspects of the cancer disease and at the same time striving to meet the requirements for the best possible prognostic value of the analysis, this study combines nomothetic and ideographic approaches for studying personality. These approaches are relevant even today in the discussed scientific field (Grice, Jackson, & McDaniel, 2006).

In this pilot survey, data gathered by *Sources of Social Support Scale (SSSS)* by Carver and colleagues (Carver, 2006) are presented, combined with a structured psychological interview.

Scale of Sources of Social Support (SSSS) evaluates the degree of perceived support from different groups of sources - partners, friends, health professionals, as well as the type of support (instrumental, informational and emotional and negative support). In the version proposed by the authors, the scale consists of ten items describing different aspects of support. In the *Emotional support* subscale six items are included. Two of the items are phrased in the reverse. *Instrumental support* subscale contains one item. The same goes for *Informational support* subscale. The *Negative support* subscale consists of two items (Carver, 2006).

In preliminary discussions with some of the participants in the study, six groups of people were identified, who were perceived as leading components of social support networks in coping with the disease - partner, parents, children, friends, other cancer patients, health care workers.

For the purposes of this study and complying with the requirement for a conceptual clarity of translated in Bulgarian methodology, the claim relating to instrumental support is split into two separate items. The first item studies the support in everyday housework, and the second item the support in organizing and implementing of the healing process (transportation to hospital, paying the bills, getting prescriptions and drugs).

In the original methodology, the author used five-point Likert scale answer format (Carver, 2006). Based on preliminary discussions conducted with cancer patients, it was decided that the scale can be reduced to four answers, ranging from "not at all" to "very much."

In order to examine whether the eleven items formed a reliable scale, Cronbach's alpha is measured. For the different groups of sources of support, alpha ranged from $\alpha = 0.76$ to $\alpha = 0.86$. For the purposes of this study, the psychometric properties of the scale are acceptable.

Participants

In the pilot study, 24 women and 10 men of age of 28 to 84 at the time of being diagnosed with the disease are included. In regard to the rest of the demographic data: 12% respondents with primary education, 27% with secondary and 61% with university education.

6% of respondents stated that they did not have or had not had steady partner during the treatment of the disease. 15% of the respondents informed that their parents were deceased and nearly 18% at the time being diagnosed did not have any children.

Regarding the medical data, the main location of the disease in women is breast and reproductive organs - cancer of the cervix, cancer of the uterus. For men, it is colon cancer, throat cancer, and prostate. There is one case of neuroblastoma, and two cases of brain tumor diagnosed in women.

During the survey, nine of the respondents were in a process of treating the disease (radiation treatment) and upcoming additional therapies - surgery and chemotherapy, while the remaining 74% of survey participants had completed active treatment.

24 of them had been diagnosed within the last 5 years before the study began, and 10 of the subjects were diagnosed between 1993-2004.

The study started in 2012 and continues to the present. It takes place in Burgas, Varna and Sofia.

Results and Discussion

Because of the fact that there were very few respondents, we didn't set the task to test the hypotheses about relationships between variables but we used the descriptive analysis to illustrate the results received from the *Sources of Social Support Scale (SSSS)*.

Based on the descriptive analysis, the data from the respondents are compared in regard to the perceived support received from six sources - partner, parents, children, friends, health professionals, cancer patients.

What is interesting is the following grouping according to the types of social support received from different groups of people.

In regard to the *Instrumental support*, the partner was the one who was most supporting or had been most supporting, compared to the other groups. The responses were distributed in the range of low to moderate degree of instrumental support (*M* = 3.1; *SD* = 0.9), which is somehow a surprising result, given the specifics of the disease, the suffering and difficulties during the therapeutic procedures and the need of partnership in organizational issues related to treatment. The *Instrumental support* refers to assistance in performing household tasks, transportation to a medical facility and arranging of appointments, paying bills. Future studies will search for possible explanations of the results presented.

Children and parents were considered to be giving small to moderate levels of *Instrumental support* (parents *M* = 2.4; *SD* = 1.2; children *M* = 2.9; *SD* = 1.1). The high values of standard deviations could be explained by the wide age range of the surveyed people. It should be kept in mind that this study is a pilot one and outlines possible trends that will be verified or rejected by the official study.

For the other groups, the perceived instrumental support varied in the range of non to small degree (friends *M* = 1.8; *SD* = 0.9; health professionals *M* = 1.7; *SD* = 0.8; other human cancer patients *M* = 1.5; *SD* = 0.6)

The Informational support subscale, according to the method suggested by Carver and colleagues, contains only one item. The data analysis revealed the following results: most of the respondents considered that they mostly received informational support in the form of advices and information regarding the disease from the health care professionals and other cancer patients (health care professionals *M* = 2.9; *SD* = 0.9, other cancer patients *M* = 2.7; *SD* = 0.6). The answers inclined to moderate *Informational support*.

A possible explanation of the result can be found in the specifics of this type of support. It requires knowledge in the field of medicine and requires relevant experience and practice.

The respondents' answers concerning their perception of *Negative support* received in connection with the disease from various sources were within the no level or low levels of such support. Parents, children and friends in general were perceived as uncritical to the way, in which the cancer patient was dealing with the disease and they were willing to discuss the cancer topic (parents *M* = 1.6; *SD* = 0.7; children *M* = 1.4; *SD* = 0.8; friends *M* = 1.3; *SD* = 0.6).

On the other hand, the partner, the health care professionals and other cancer patients were perceived in a very small degree as being involved in *Negative support* (partner *M* = 1.7; *SD* = 0.8; health care professionals *M* = 1.8; *SD* = 0.7, other cancer patients *M* = 1.8; *SD* = 0.7).

A significant aspect of social support is the dimension of *Emotional support*. Number of studies indicated that this type of support was most desired by cancer patients and directly correlated with the positive outcome of the disease (Kinsinger et al., 2011).

The participants' answers pointed to a rather moderate support, implemented in the form of understanding, listening, encouragement, sharing, and trust, offered to them by the people around them - family and health care professionals. First was specified the group of cancer patients and the partner, followed by health care professionals, parents, friends and children (cancer patients *M* = 3.1; *SD* = 0.6; partner *M* = 3.1; *SD* = 0.8; health care professionals *M* = 2.8; *SD* = 0.5; parents *M* = 2.8; *SD* = 0.6; friends *M* = 2.8; *SD* = 0.7; children *M* = 2.7; *SD* = 0.8).

The data analysis showed a large dispersion of responses by dimensions, which would require extensive research and further studies.

To overcome this shortcoming of the pilot study, we compared the data obtained by the scale of social support with the answers from the structured psychological interview.

Main interest was the perception of the personal story of every participant in terms of discovering and going through the process of illness and treatment. The questions from the discourse were about the specific parameters of the disease - type, stage, treatment; type and method of support offered to them by their relatives, friends and health care professionals, as well as preferred strategies for dealing with crisis situation.

Some of the participants, mainly still in active treatment phase of the disease, refused or answered laconically to the questions in the conversation. This reaction was dictated probably by fear and uncertainty of the upcoming medical treatments, causing confusion, shock, hopelessness and depression. One middle-age women, who was about to undergo a major gynecological surgery and was going through a course of radiotherapy for shrinking cancerous growth described this sense of hopelessness with the words "I am too late. And do not know what would happen to me from now on."

Based on the interviews conducted with the participants in the study and given the limited volume of the study, two groups can relatively be distinguished in terms of the support they had received in relation to their disease.

According to the personal perception of the situation, the first group includes people who have received significant support from their friends (partner, parents and children) in the form of listening, sharing, emotional support, willingness to discuss the topic, advice and active commitment to the organization and implementation of treatments.

The second group includes those cancer patients who according to their words were forced to face and fight the disease alone without having emotional, instrumental or informational support from their relatives and friends, or having such support offered to them in extremely rare cases. In addition, this group of respondents described themselves as people avoiding the cancer topic.

Conclusion

By its nature, cancer is a complex disease that puts the patient to many social, emotional and personal challenges in his fight for survival. Being diagnosed with cancer is one of the most stressful events that can happen in one's life. Having cancer inevitably leads to serious long-term psychological consequences (Velikova-Tzonkova, 2011).

What is leading in having such diagnosis is the negative emotion that is triggered by revised questions about death and the meaning of life, shortening of the life perspective, forced change in plans, transformations in the body, self-image and self-esteem, changes in social roles, way of life and complicated social relationships (Murphy, 2003).

In such a crisis situation, social support becomes one of the important factors to adapt to the disease and cope with the new situation.

In order to define a comprehensive model of individual determinants and psychosocial factors affecting the complicated process of accepting and dealing with a cancer diagnosis, extensive research is needed aiming at personality characteristics involved in the process of being ill, treating the disease and long-term coping with cancer.

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About the Author

Assist. Prof. **Bilyana Velikova-Tzonkova**, PhD is a lecturer of Social Psychology, Personality Psychology and Psychology of Communication at Prof. Assen Zlatarov University in Burgas, Bulgaria. Her scientific interests are in the areas of Oncopsychology, Social Perception and Interpersonal Relations.