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ORIGINAL ARTICLE

Beliefs of Turkish cancer patients on the genesis of cancer: "Why do I have cancer?"

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Summary

Purpose: *To determine the beliefs of Turkish cancer patients about the etiology of carcinogenesis.*

Methods: *The study was carried out at Istanbul Bilim University, European Florence Nightingale Hospital, Department of Medical Oncology. The data were collected during April-June 2008 from 39 women and 23 men. Sociodemographic data form and beliefs on the reasons of carcinogenesis rating scale were used while collecting the data.*

Results: *Of the patients recruited in this study 29 (47%) took it as fate, 28 (45%) as a rightful punishment, 28 (45%) as a result of air pollution and toxins in food, 26 (42%) because of losing a beloved person, 26 (42%) as a result of wrong nutrition, smoking and alcohol consumption. In women the most common belief was fate (n=20, 51%), while in men it was air pollution and toxins in food (n=12, 52%). In primary school graduate patients or patients with no education the most common belief was rightful punishment (n=17, 62%), whereas in university graduate patients it was wrong nutrition, smoking and alcohol consumption (n=12, 63%).*

Conclusion: *A considerable proportion of patients behaved in a fatalistic manner. This may cause a risk of taking the responsibility of treatment and control of disease not by the doctor but by other persons. It seems that sex and educational status are important factors in relation with the beliefs of the patients. Meanings attributed to the disease by the patients should be found in order to increase their treatment compliance and be helpful to face off the disease. Patients should also be encouraged to change thoughts that affect treatment process negatively.*

Key words: beliefs, cancer, fatalistic approach, loss, rightful punishment

Introduction

The way of perceiving and understanding cancer has a crucial role in psychopathology and also for compliance to treatment. People generally try to find a reason when they face unfortunate or scary incidents. Questions like "Why me?", "Why did this happen to me?" preoccupy the minds. There are lots of possibilities in such situations. People can blame themselves; blame other people or can act fatalisticly [1]. Cancer patients tend to assert theories to perceive and understand their disease and its reasons and generally they barely talk about their beliefs [1]. However, it's also an important situation experienced in our daily practice that the beliefs of patients on the reasons of the disease significantly affect the way and power of dealing with the disease. Therefore, it is very important to determine the beliefs and help changing them when required.

Methods

Sixty-two cancer patients with no mental retardation or psychotic characteristics, informed about their participation in the research and asked for tacit consent, who were treated at Istanbul Bilim University, European Florence Nightingale Hospital, department of Medical Oncology between April and June 2008, were recruited for the study.

Sociodemographic data survey

The survey prepared included questions about the patients' demographic and descriptive characteristics. Questions looked into age, education, occupation, date of marriage, number of children, income evaluation, information about treatment and whether the patient received professional psychological support or not.

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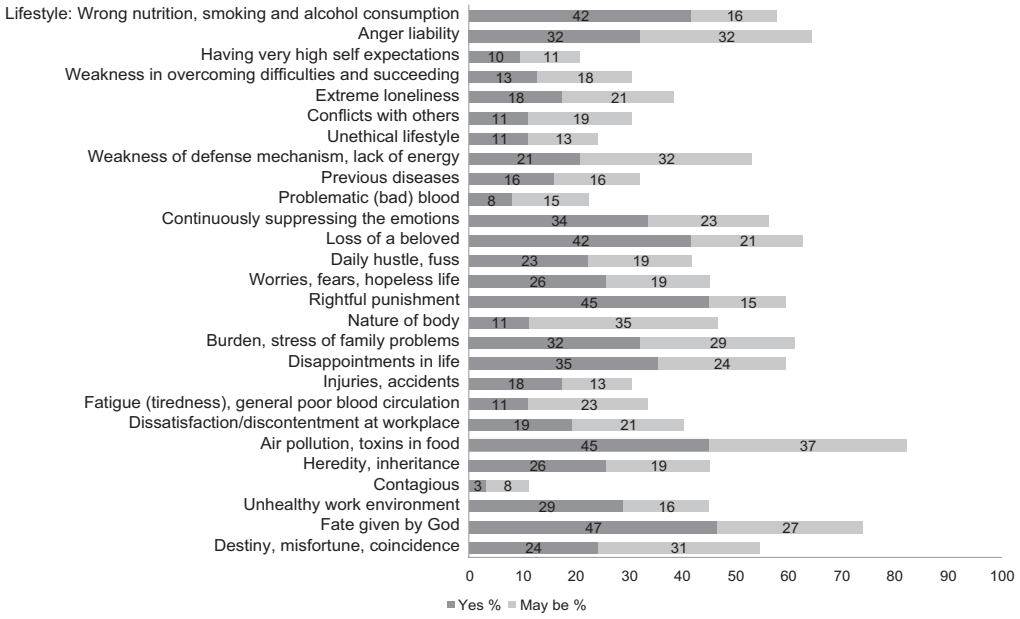
Table 1. Beliefs on the reasons of cancer of all patients (n=62)



Beliefs on the reasons of Cancer Rating Scale

This scale was created by Verres in 1986 [2] and translated into Turkish for this research. Before developing this scale, Verres talked to cancer patients and asked them in the right time why "they" had cancer. As a result of his clinical interviews with patients, he developed his "3-step Self-Rating Scale" consisting of 27 items. Then 101 patients were examined for their beliefs on the reasons of cancer using this scale [2]. Verres asked these questions:

"Do you have any assumptions/predictions about why some people get cancer and some others don't?"

"How does a person have cancer?"

"In this list, there are some possible factors that can cause cancer. These factors are developed in the light of patients thoughts. People may have various opinions about these factors. Do you think these factors can play any role on the genesis of cancer? (yes / no / may be)".

In that study, 23 (23%) out of 101 patients thought that lifestyle (wrong nutrition, smoking, alcohol consumption) was responsible, 12% air pollution and toxic agents in food, 10% heredity and 6% by nature.

The data of the present study were collected through face-to-face interview with 62 patients. The items in the Turkish version of the scale were read step by step to the patients who were asked to think out loud and give spontaneous answers. Then, patients were asked whether they wanted to add any items to the existing list.

Language validity of beliefs on the reasons of Cancer Rating Scale

The beliefs on the reasons of Cancer Rating Scale were translated into Turkish by a clinical psychologist who had good command of the German language and two German linguists. Translations were discussed on and compared carefully to maintain the best equivalent possible in Turkish in order to develop the scale in Turkish. Then the scale was given to 10 people who were asked what they had understood from every single item and to analyze the language structure and comprehension of the scale. It was observed that the scale was clearly understood by those people.

Results

Sociodemographic findings

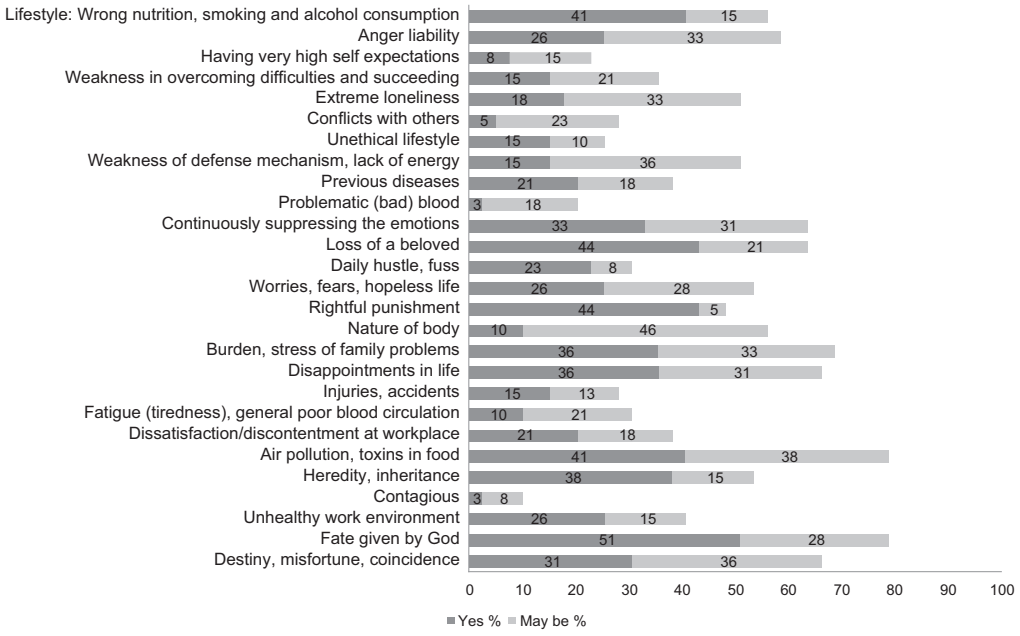
Thirty-nine (62.90%) patients were women and 23 (37.10%) men. Twelve patients (19.35%) were in the 65 years and above age group; 32 (51.61%) in the 45-64 age group; 12 (19.35%) in the 35-44 age group; and 6 (9.68%) in 25-34 age group. Twenty-seven (43.55%) of the patients were primary school graduates or without education, 16 (25.81%) were secondary or high school graduates and 19 (30.68%) were university graduates.

Beliefs on the reasons of Cancer Rating Scale findings

The beliefs on the reasons of Cancer Rating Scale findings of 62 patients who participated in the research are shown in the following Tables.

Beliefs about getting cancer of all 62 patients are shown in Table 1. The most common beliefs were fate (47%); rightful punishment (45%); air pollution and

Table 2. Beliefs on the reasons of cancer in women (n=39)



toxins in food (45%); loss of a beloved person (42%); and wrong nutrition, smoking and alcohol consumption (42%).

When we examined the beliefs in relation to sex, fate (51%) and rightful punishment (44%) were the most common beliefs in women (Table 2), whereas air pollution and toxic agents in food (52%), wrong nutrition, smoking and alcohol consumption (48%), inclination to anger (43%) and loss of a beloved person (43%) were more prominent in men (Table 3).

Beliefs about having cancer according to patients' level of education are shown in Tables 4-6. In primary school graduates or those with no education, the most common beliefs on the reasons of the disease were rightful punishment (62%) and fate (59%), whereas in secondary or high school graduates the most common beliefs were air pollution and toxic agents in food (44%), loss of a beloved person (44%), suppressing the emotions continuously (44%) and fate (44%). In university graduates, wrong nutrition, smoking and alcohol consumption (63%) and air pollution and toxic agents in food (53%) were the most common beliefs.

Table 3. Beliefs on the reasons of cancer in men (n=23)

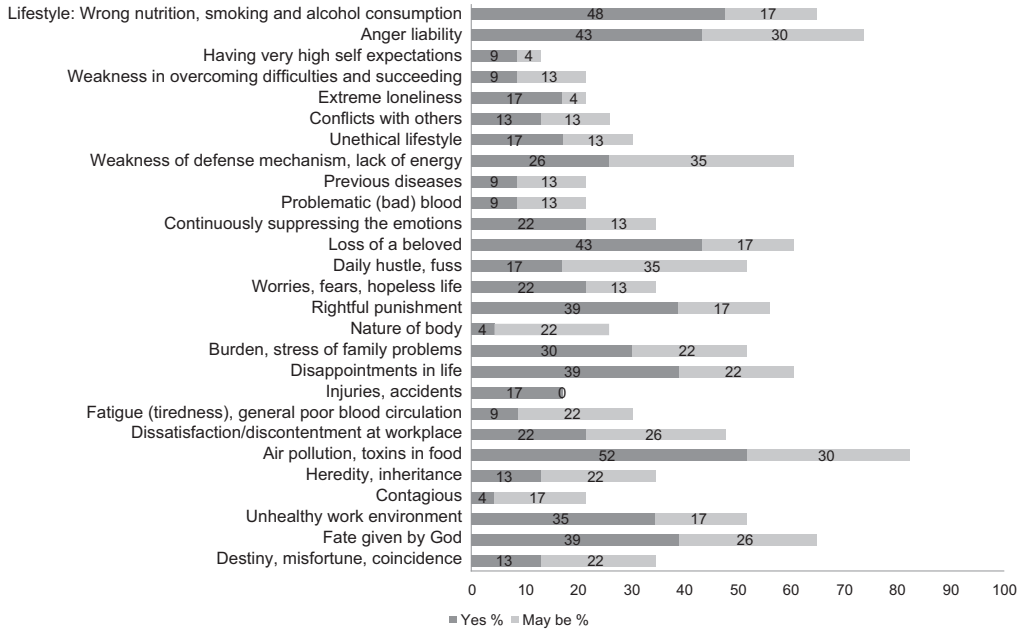


Table 4. Beliefs on the reasons of cancer in primary school graduate patients or patients with no education (n=27)

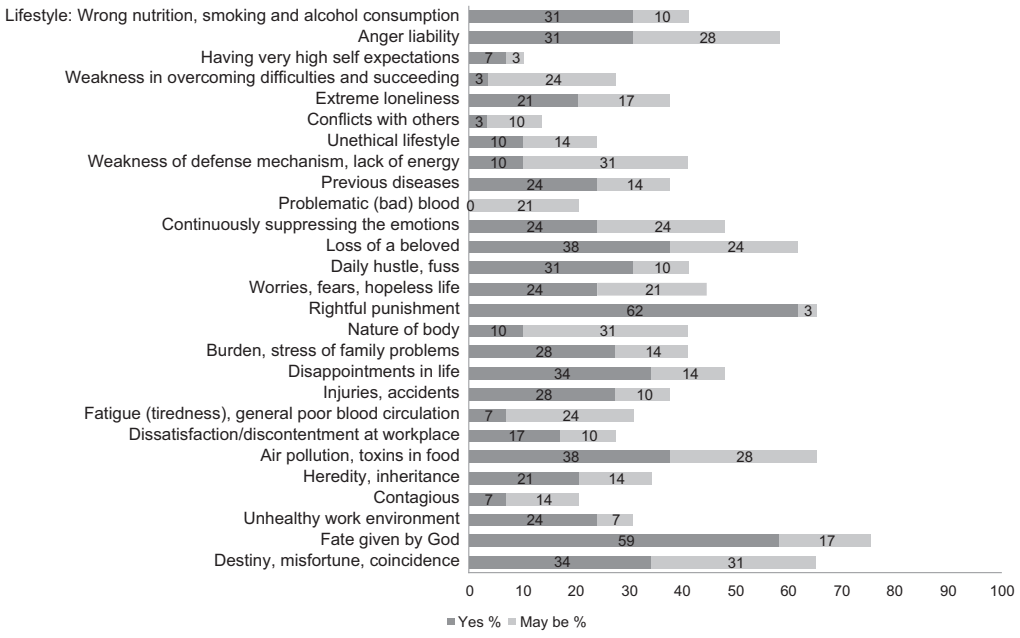
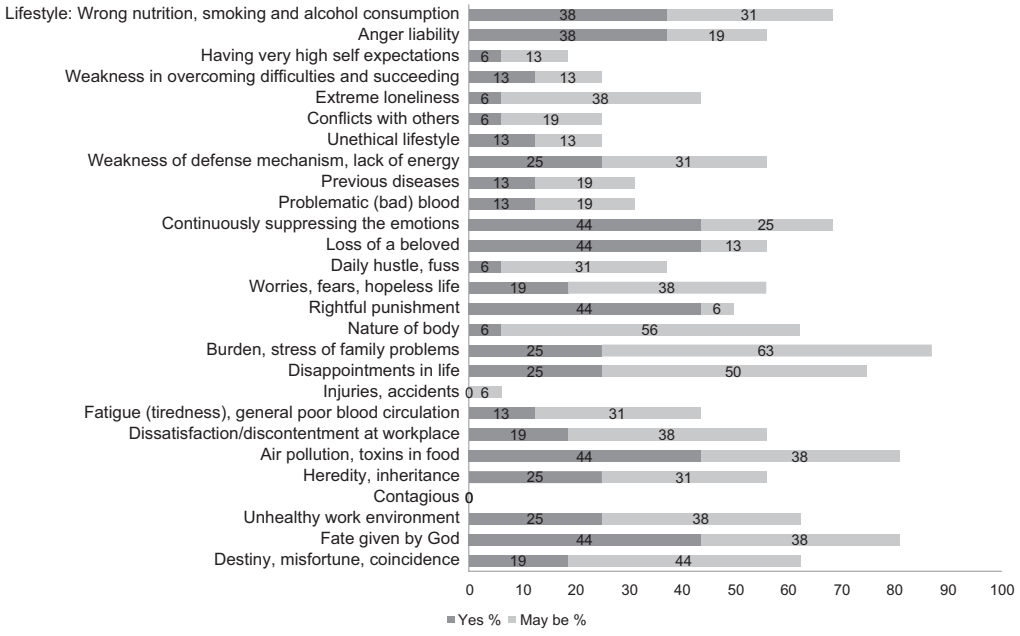


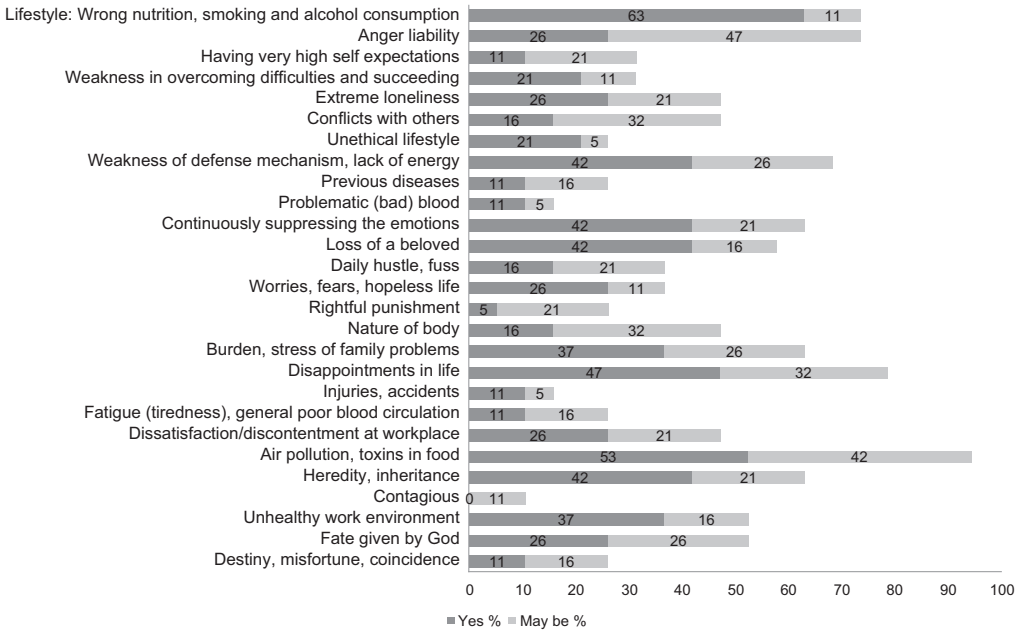
Table 5. Beliefs on the reasons of cancer in secondary or high school graduate patients (n=16)



Discussion

A number of studies carried out in Turkey and Europe have shown that patients' understanding of cancer affects their adjustment to treatment and their mood during treatment. Therefore, it is very important to understand how a cancer patient perceives the disease, and what his/her family and relatives tell him. Great conflicts between the patient, his family and doctors may cause serious stress [3]. According to a research carried out by Kerr et al. [4] young cancer patients want to get more detailed information than old ones, while patients who are in poor condition prefer to know less and do not get his involved in the decision-making process. Ptacek and Ptacek [5] have shown that doctors' being in a comfortable and convenient place while telling the patient about the diagnostic and treatment process, without disturbing elements present, sitting next to the patient and

Table 6. Beliefs on the reasons of cancer in university graduate patients (n=19)



addressing his emotions, positively affect the patient's adjustment to disease reconciliation.

The patient must be accepted by the doctor with all his/her emotions, feelings and needs. As each patient's feelings, emotions and needs will differ from each other, the doctor needs to adopt a different attitude against each patient. Some patients need to acquire lots of information regarding their disease, while some do not want to know any details. The doctor must adapt to the emotional state and the demands of the patient. For the doctor to be able to understand and distinguish the emotions, feelings and the needs of the patients, the environment should be comfortable and free from disturbing or inconvenient elements (such as being interrupted by someone entering the room, phone calls, etc) and also, the doctor should not act hastily or impatiently [5].

Kallergis [6,7] emphasized that the process of informing the patient should be realized taking into consideration the patient's personality traits. This way, it will be clear which words should be used and when, how often and how they should be used.

Cancer patients develop subjective beliefs during the course of their illness. The patient provides himself/herself with explanations regarding the disease. The reason why each individual lives his/her process of illness distinctively is due to the fact that the explanations they develop (the meanings they attach) originate from their own personal experiences, knowledge, values, beliefs and needs [8]. Leventhal and colleagues [9] speak of "disease representation model".

According to this model, patients create schemes regarding the disease in their minds. These schemes are created in line with the information the patient gathers from his/her own experiences and resources. These schemes are fantasies about the reason, course, treatment and termination of the disease. Therefore, they perceive their disease with a disease representation model. This model determines the patient's reaction and attitude towards treatment [9].

Lazarus and Folkman [10] found out that different people respond differently when they encounter the same stress-causing situation. This might be the same for cancer patients. One of the reasons why cancer patients respond differently is because of different meanings they attribute to the disease. For instance the reaction and adjustment to disease are different between a patient who perceives cancer as a rightful punishment for his/her former mistakes and a patient who perceives his/her disease as a coincidence. For this very reason, as Kallergis stresses [11], while informing the patient about his/her disease or condition, the patient's level of denial and his/her personality traits should be taken into consideration and information about the patient's family and family dynamics should also be gathered beforehand.

Fatalistic approach: "Fate, misfortune, coincidence"

Approximately one half of the patients who participated in the research believed that their disease is determined by God. This thought could result in patients becoming submissive and passive, and lose their motivation in fighting the disease by way of treatment.

The fatalistic approach may take both the control and responsibility regarding treatment away from the doctor and patient. Moreover, in the event of recovery from the disease the patient may attribute this to other factors outside himself/herself. These factors can be the following: "God saved me", "This was my destiny; to suffer all this pain and then recover", "The amulet I wore protected me", "I had melted lead poured in cold water over my head, so I drove away the evil eye" (an old superstition to drive away the evil eye that is believed to do harm). These factors vary according to culture, level of education and belief system.

The fatalistic approach may make people postpone their decisions, avoid responsibilities and risks for decisions [12]. The idea of perceiving cancer as fate may symbolize "constancy". This leads the patient to think that "It is not in my hands, I can not do anything" and makes the compliance to treatment difficult.

If patients understand that they can influence the treatment process, they would stay away from the fatalistic approach and start to behave more cooperatively.

Rightful punishment

Forty-five percent of the patients characterized their disease as "rightful punishment". This is a factor which makes the adjustment to treatment difficult. Perceiving cancer as rightful punishment may be related to patients' feeling guilty and responsible because of their faults or sins in the past. Some patients believe that having cancer is their own fault. Ideas like "I did not appreciate myself enough", "I was never a positive person", "I was too stressed out", "If I hadn't got divorced, I would not have had cancer" make patients believe that they are responsible for having cancer and become more angry. Anger of a patient towards himself is an important factor affecting treatment [1]. Of course people can not be expected to be positive all the time not only before developing cancer but also during the disease. Being told "Be positive, do not care about anything" can stress out the patients. "The positive thinking" expected from patients all the time, as mentioned above, leads them to take all the responsibility on their shoulders; as a result anxiety would rise [13].

"Unintentionally, all I could think of today were negative and bad, will my cancer relapse?"; "I am always in poor morale and out of spirits, I will never recover"; "If I feel bad, my tumor may grow and it's all and only my fault".

An efficient explanation can be done by doctors that would decrease the level of the "punishment approach". Educational level and social environment are also associated with this belief. In our study, 62% of the patients graduated from a primary school or without education, 44% of secondary or high school graduates and only 5% of university graduates perceived their disease this way. This shows that doctors should give more careful explanation to a patient with low educational level.

Loss of a beloved

Losing someone beloved increases the depression tendency level. In the present study, 42% of the patients mentioned that they got cancer just after they lost someone they loved, in other words, they related their disease with that loss. Depression, grief, sadness can make someone vulnerable against cancer; however, in the literature there is not enough data to support this idea.

Volkan and Zitl argue that each loss drives people into an inevitable grief and flashes back all the losses left behind [14]. Cancer patients also enter into a mourning period when they are informed over the diagnosis. They experience losing their past healthy lives and sometimes an organ removed by a surgical operation. This loss and the mourning period that follows may remind them of their losses in the past and even make them relive the experience. For that reason, the patient may perceive the reason for his/her disease as the "loss of a beloved" [14].

If a person mourns enough for his/her losses in the past, each mourning, each grief can serve as a mean of personal growth and an instrument for the person to renew.

If this theory is applied on cancer patients, if patients grieve properly and take the disease period as "change", they might increase their awareness, look into life from a different perspective they have never looked before and enjoy the moment. Patients could prefer to use their whole potential to live a high quality (or "happy") "now". Volkan in his book states that, as William Niederland also points out, "losing or facing a threat of losing body parts, channel people to develop other skills and talents and fix offences" [14].

In conclusion, we analyzed the beliefs of cancer patients regarding carcinogenesis and found that these beliefs are associated with gender and educational status. Further studies are needed to assess the relations between these beliefs of cancer patients and relationships with family members, marital status, stage of disease, and level of compliance to treatment. In this context, we suggest that patients must be encouraged to ask more about their treatment. Patients should be led to know more about cancer and its treatment and given the chance and enough time to express their emotions and thoughts. In addition, meanings attributed to the disease by the patient should be found out and beliefs

affecting the treatment period in a negative way should be changed; at this point patients should be given information on where to get support. This is the best possible way to increase the treatment compliance and strength to fight the disease.

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