

## Patients' Experiences with the Degenerative Process of Cancer: A Content-analysis Study in Iran

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### Abstract

**Background:** This study sought to provide a comprehensive understanding of cancer treatment refusal based on the experiences of patients, caregivers, and health care providers.

**Methods:** In this qualitative research study, we enrolled 21 cancer patients, their caregivers, and health care providers. We conducted in-depth interviews of the participants to obtain the necessary data about treatment refusal. The data were coded, and data analysis was performed via the inductive analysis method.

**Results:** There were three main categories in this study: “coexistence of hope and denial”, “treatment complexity and repeated complications”, and “treatment is in vain”. The first main category had five subcategories: ‘lack of symptoms, a way to denial’; ‘misconception’; ‘hope’; ‘hiding the disease’; and ‘insistence on maintaining one’s lifestyle’. Subcategories of the second main category included: ‘fear: shared experience’; ‘sign and symptom exacerbation; end of denial’; ‘duality in life quality’; ‘side-effects: a barrier to treatment’; ‘side-effect reliever’; and ‘tendency for alternative medicine’. Subcategories of the third category included: ‘degenerative course of cancer’; ‘acceptance of death’; and ‘remorsefulness: the shared experience’.

**Conclusion:** In this study, participants provided different explanations for forgoing or avoiding treatment. During the initial cancer stages, denial was an effective factor for patients to not seriously consider the appropriate diagnostic and therapeutic interventions. As the disease advanced, alternative treatments and complications were the main factors for treatment refusal. Identification of the main motives for treatment refusal during the course of the disease would be effective for cancer management.

**Keywords:** Neoplasms, Caregivers, Treatment refusal, Qualitative research, Content analysis

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## Introduction

Next to cardiovascular disease, cancer is the third leading cause of death in Iran.<sup>1</sup> Newly diagnosed cancer patients undergo different treatment modalities that include surgery, chemotherapy, and radiotherapy. Most patients accept the initial treatment recommendations by their physicians and undergo treatment. However, factors such as prolongation of the disease, invasiveness of therapies, complications that arise from treatments, and repeated recurrence of the disease significantly affect the quality of life of both patients and their relatives.<sup>2</sup> Factors that include physical and work disabilities, as well as treatment costs also enhance the complexity of this process.<sup>3,4</sup> Despite progress in conventional treatment, patients have increased suffering during the last year of their lives.<sup>5</sup> However, over the disease course, some patients decline a portion or all of the treatment recommendations. Although few patients refuse treatment, this matter should be explored due to its significant effects on disease outcome. Studies have shown that 1% of the patients decline all conventional medical interventions, and 3% to 19% refuse a portion of these conventional medical interventions.<sup>6</sup>

Quantitative and analytic studies comprised the majority of studies that assessed treatment refusal. These studies investigated the relationship between different factors and treatment refusal. The results indicated that increased age, low level of education, Eastern Cooperative Oncology Group score, low income, depression, absence of social support, and probable lack of compliance led to treatment refusal.<sup>7-13</sup> Researchers have suggested that patients' experiences and their beliefs effectively play a role in refusing treatment.<sup>14-19</sup>

In this area, qualitative studies can be useful because forgoing treatment is a subjective and experiential matter. The recent literature points to the relationship between individual experiences and treatment refusal. In exploratory studies on cancer patients, negative experiences with mainstream medicine, deaths of friends or relatives from cancer despite conventional therapy, history

of complementary and alternative medicine (CAM) use, belief in mind-body healing, and hesitancy in decision-making are among the effective factors in patient refusal of conventional therapies. Results from a similar study have shown that spirituality practices such as religious ceremonies, meditation, and prayer had an impact on changing treatment plans or forging conventional treatment.<sup>17,20</sup>

The interaction between cancer and the patient is a complex process that results in various outcomes. Some studies have concluded that the patients' beliefs and characteristics are responsible for treatment refusal. According to research, the patients' attention to self-competence, belief in a supernatural power, distrust in the health structure, lack of belief in the efficiency of therapeutic procedures, and living with a lack of certainty were main reasons for treatment refusal.<sup>21,22</sup> The results of a cross-cultural study on oncologists have shown that existential reasons were effective in patients' decisions for treatment refusal.<sup>15</sup>

Patient autonomy is an important factor in the decision-making process for treatment refusal. However, decision-making based on autonomy does not necessarily mean that the patient has considered any possible benefits or harms of this decision. Some patients decline treatment that is absolutely necessary. Patient reasoning vastly differs from standard medical approaches and has its own integrity. These patients' approaches are often value-oriented and physicians only agree when the curative treatment does not match the patient.<sup>4,18,23</sup>

Quantitative analytic studies have not dealt with the mental aspects of treatment refusal; whereas, this issue is based on individual experiences, complex, and culture bound. Qualitative studies have mostly investigated one type of cancer or one dimension of treatment refusal. In the current study, we intend to provide a comprehensive understanding of treatment refusal based on experiences reported by patients, caregivers, physicians, and nurses.

## Materials and Methods

### *Study design*

This study was an inductive qualitative content analysis of cancer patients in Iran who have refused treatment. A qualitative study is a proper method to determine the factors that make patients refuse oncologists' therapeutic recommendations.

In this study, we used in-depth individual interviews to explore the experiences of patients, their relatives, and health care providers. We have defined refusal as not starting treatment at all, forgoing treatment, or refusing some of the key oncology recommendations (e.g., starting chemotherapy but refusing to undergo surgery). We avoided any prejudgments about these behaviors throughout data collection. In this study, we have used memo writing strategies and experts' views. This study is a part of a grounded theory study, whose initial findings have been presented through content analysis which uses constant comparison analysis as recommended by Corbin and Strauss.<sup>24</sup> Based on this model, we have analyzed each part of the data from the interviews, observations or other strategies by open coding and category development. This study attempted to present some part of open coding to determine the factors involved in this process.

### *Participants and study setting*

Participants consisted of patients, caregivers, physicians, and nurses who had direct and extensive experiences with treatment refusal. Patient participants were selected from hospitalized patients who met the inclusion criteria. They were given the necessary explanations about the study and we interviewed those who agreed to participate. The other participants were selected by strategic sampling. After the initial interviews, if necessary, the next participants were selected and interviewed. Data analysis was conducted after the patient interviews. Once completed, we continued with the next set of participants. Then, based on the research questions and data requirements, the next participants were selected and interviewed, followed by data analysis.

### *Data collection and analysis*

We gathered the data for this study through individual in-depth interviews conducted between March 2016 and October 2017. The interviews were performed by the first researcher, an expert in collecting qualitative data based on an interview guide approach. Patient interviews began with patients telling their stories and the reasons for treatment refusal. By using the interview guide approach, the researcher asked the patients open-ended questions. Next, based on the responses, the interviewer asked exploratory questions to gain additional information about the issue.

The interview guide questions were decided based on a literature review and observations of patients in oncology wards, in addition to specialists and research team's viewpoints. All interviews were recorded after the patients provided permission. After each interview the audio files were reviewed several times and transcribed. Each interview was analyzed as a unit. The transcribed text was read numerous times to identify the meaning units. After aggregation and integration, the meaning units became more abstract and each meaning unit was labeled with a code. Then, based on similarities and differences, we compared the meaning units and arranged them into categories and subcategories.

Considering the issue under discussion, the researcher developed an informal rapport with the participants. At the end of the interview, the researcher asked the participant: "Is there anything else you want to talk about?" to supplement the issues not discussed during the interview.

### *Trustworthiness*

This study followed the suggested criteria for qualitative data assessment. The principal investigator spent approximately one year for data collection and analysis, and prolonged engagement with the data to insure credibility and acceptability. The data underwent peer and member check as a measure of dependability. The initial analysis of data that included the preliminary concepts and codes were given to two outside colleagues, and we considered their

**Table 1.** Theme, categories and subcategories of the study.

Theme	Category	Subcategory
Degenerative process of cancer	Coexistence of hope and denial	Lack of symptoms, reason for denial Misconception Hope Hiding the disease Insistence on maintaining one's lifestyle
	Treatment complexity: Repeated complications	Fear: Shared experience Severity of signs and symptoms, end of denial Duality of life quality Treatment side-effects: A barrier to treatment Reducing the side-effects of treatment Tendency for complementary and alternative medicine (CAM)
	Treatment is in vain	Remorsefulness: Shared experience Degenerative course of cancer Acceptance of death

views. The principal investigator repeatedly presented the findings to the research team and the team checked and surveyed each case.

Once we achieved the preliminary codes and concepts, we used the findings from other studies for conformability. Finally, by presenting a comprehensive description of the issues, participants, process of data collection, analysis, and the study limitations, the researchers provided a proper transferability for further research on this issue.

### *Ethical consideration*

The Ethical Committee at Shiraz University of Medical Sciences approved this study (IR.SUMS.REC.1395.S1063, 1396/2/17). Participants received detailed explanations of the purpose and stages of the interview. Each participant provided informed consent for inclusion in the study and received assurances about data confidentiality, the choice to discontinue the interview, and withdrawal of participation in the study.

### **Results**

We interviewed 21 participants – 10 patients, six caregivers, and five physicians and nurses. Of the 14 patients who met the inclusion criteria, three did not agree to be interviewed, and one was unable to be interviewed due to poor health. The

patients and caregivers had a mean age of  $43.6 \pm 3.1$  years and the health care providers mean age was  $49.1 \pm 3.1$  years. The 16 patients and caregivers had the following marital status: single (n=4), widowed (n=2), and married (n=10). Patients' level of education was as follows: elementary school (n=1), middle school (n=2), high school diploma (n=5), B.Sc. (n=3), and M.Sc. (n=1).

Analysis of the data on patients' experiences with treatment refusal indicated three main categories: 'coexistence of hope and denial'; 'complexity of treatment: repeated complications'; and 'treatment is in vain'. These categories and subcategories are discussed in the following sections. Table 1 lists the categories and related subcategories.

### *Coexistence of hope and denial*

The participants' experiences suggested that the patients had both hope and denial when declining treatment. While some of their behaviors suggested hope, the patients talked about decisions which denoted denial of the disease. Based on the findings of the study, one reason for such paradoxical feelings was the one-sided view patients had of their condition.

### *Lack of symptoms, a reason for denial*

The patients attributed limited systemic signs and symptoms to cure or misdiagnosis and

declined treatment. One patient who had forgone chemotherapy claimed:

“My chemotherapy was terminated 11 months ago and it was recommended that I undergo surgery, but I did not. I have not had any pain, signs or symptoms. I think I did not have cancer at all. Otherwise, the cancer would have spread throughout my body.”

### *Misconception*

The patients' motives for treatment refusal denoted their beliefs and subjective judgment which did not comply with scientific evidence.

“When I was diagnosed with cancer, I turned to vegetarianism. After two months, the sonography results showed no tumor increase. I was relieved and continued to be a vegetarian and did not consider any other treatments.”

### *Hope*

The patients discussed their hope for cure in different ways, which were not medically probable.

“I am provided with a lot of facilities. I have enough money and know a lot of physicians. I knew whenever I decided to treat myself, I would manage to do it, undergo follow-up, and get good results....”

### *Hiding the disease*

Interviews with the patients revealed that those who declined treatment usually hid their diagnosis from family members, friends, and, in some cases, from physicians.

“Dr. A. referred me to a surgeon to undergo an operation a year ago, but I did not. I told my family that my doctor said I had recovered.”

### *Insistence on maintaining one's lifestyle*

The patients pointed to their successful experiences to ignore their disease at the time of treatment refusal. They believed that when they decided to decline treatment, they managed to escape worry, and continue their normal lifestyles without having to go to the hospital, visit their doctors, or see other patients. They considered this experience to be a disease-free lifestyle. One of

the caregivers who considered treatment refusal as a way to maintain one's lifestyle pointed out:

“From the time my sister was diagnosed with cancer, we continued our usual lifestyle while her physical condition allowed it. This was what she preferred: no pills, no doctors, no hospitals, no pain, and no discomfort. We took trips, walks, and visited our relatives and friends. There was no indication of disease in her routine life. This continued for 21 months. Only the last two months was my sister disabled.”

### *Treatment complexity: Repeated complications*

Cancer creates a long and challenging journey for patients. Recurrent complications necessitate diagnostic and curative interventions. The patient experiences fear and, with disease advancement, a marked influence on patient quality of life. Although different types of cures are effective, the resultant complications cause problems such that some patients turn to CAM or even forgo conventional treatments.

### *Fear: Shared experience*

The interviewed patients suggested that they felt fear after the denial stage. The individuals' presumptions and beliefs together with memories of those with cancer, particularly those who died despite various therapies, affected patients' experiences. Some patients avoided conventional treatments in order to not repeating the experiences of friends and relatives.

“I felt severe pain in my breast and armpit. I had a sonography and was told I had a cyst in my breast. At the same time, my mother was suffering from ovarian cancer. Although she was under chemotherapy, she was not in a good condition. When I found that I had cancer, I cried a lot.”

### *Severity of signs and symptoms, and end of denial*

The patients' experiences suggested that the process of disease denial continued in some patients. The disease manifestations and outcomes of diagnostic interventions did not affect denial and acceptance of this disease. However, with the advancement of disease and emergence of

signs and symptoms such as pain, dyspnea, coughing, and tumor enlargement, the patients had to accept their diagnoses. A patient who had forgone treatment after a course of chemotherapy stated:

“I did not follow any treatment for one year; I did not even consult a doctor. But when I started coughing, I felt what I had been told a year ago was right. Then I decided to visit my doctor again.”

Another caregiver stated: “I took my husband for leech therapy. He did not want to undergo chemotherapy, but when his pain increased, he begged me to take him to a doctor to undergo chemotherapy.”

### *Duality of life quality*

The patients' experiences suggested that some patients declined treatment due to the unpleasant effects of treatment on the quality of their individual, family, and social lives. On the other hand, treatment refusal diminished the disease-free period and subsequently had a significant impact on various aspects of life. A patient who declined treatment and experienced a hip fracture expressed her experience and loss of independence in this way:

“I broke my leg simply by falling down. I cannot walk. When I go for chemotherapy, three people should help me walk ...”

Another patient expressed his reason for quitting the treatment by arguing for the quality of life:

“I prefer to have a short life with high quality rather than a long life with pain and discomfort ...”

### *Treatment side-effects: A barrier to treatment*

The patients' experiences suggested that concern about treatment side-effects affected their decision to decline treatment. Some patients did not like to receive chemotherapy or radiotherapy because of hair loss and drug toxicity. They had rigid views about surgical interventions.

“I was afraid of a scar on my breast, so I declined surgery.”

“After a biopsy, I was told to undergo a leg amputation. I did not have any pain. I could walk

easily, so why should I lose my leg! So, I did not continue.”

### *Reducing the side-effects of treatment*

Some patients' experiences suggested that there were factors which led to the reduction of complications. These factors, together with improvements to quality of life and easier tolerance of complications could likely enhance patients' desires to undergo therapy and reduce treatment refusals.

“My doctor told me that I should undergo surgery. Then, I can have a prosthesis or undergo corrective surgery....”

### *Tendency for complementary and alternative medicine (CAM)*

The common experience of the patients revealed that they tended to turn to CAM. Some patients thought that CAM was effective enough and did not like to continue conventional treatment. Belief in CAM, closer relationship between the patient and therapist, feeling of well-being with CAM, and fear of invasive therapies were among the factors that encouraged patients to turn to such therapies.

“When I talked to my doctor, he told me I should trust God. He said he would help me overcome my cancer through different therapies, including leech therapy, bloodletting, etc.”

The side-effects of conventional therapies, despite some positive effects, have some negative influences on patients' well-being. On the other hand, CAM tends to improve their well-being.

### *Treatment is in vain*

Throughout the course of the disease, the patient may face metastasis and disease recurrence. Most patients have this conception of cancer, which can affect their decision to continue treatment.

### *Remorsefulness: Shared experience*

When the signs and symptoms of cancer exacerbate, patients who have declined all or part of their therapeutic interventions at the initial or

middle stages of their disease become remorseful. The severity and recurrence of the disease makes patients challenge their beliefs and experience on treatment refusal.

One of the patients who had postponed her treatment for months and had accepted treatment after metastasis said:

“I regret that I did not agree to undergo chemotherapy at the right time due to fear and misunderstanding. My disease is serious and I do not know what might happen”.

### *Degenerative course of cancer*

Cancer develops over time and has adverse physical, mental, and psychological effects on patients, as well as relatives and friends. The patient experiences diminishing physical ability and its impact on all aspects of life. This condition and fear affect the patient's decision for treatment refusal.

### *A nurse in a chemotherapy department described her experience:*

“The patients under chemotherapy are gradually losing their lives. Here, you witness people dying little by little.”

### *Acceptance of death*

With the advancement of cancer, treatment refusal and acceptance of death might occur simultaneously or sequentially. Loss of physical strength and severity of signs and symptoms make the patients tired and unwilling to continue therapy. Less communication with relatives and friends, avoidance of eating, and refusal to take medications can be seen in these patients.

## **Discussion**

Patients either forgo or avoid treatment because of the degenerative nature of cancer. Based on the findings of this study, we have observed that cancer patients are initially in the phase of “coexistence of hope and denial”. With the advancement of disease, they experience “treatment complexity and repeated complications”. Finally, they believe that

“treatment is in vain”. Cancer patients often continue treatment; however, a few who decline treatment follow these stages. Patients who decline recommended therapies have their own reasons, although physicians and nurses may consider these reasons to be irrational. Patients' reasons and beliefs to forgo treatment are completely different from the typical approaches and decisions in medical practice; however, they have their own special conceptual structures.

In our context, a significant factor for treatment refusal was the prolongation of the denial process. Denial partly originates from patients' misconception. Limited signs and symptoms in the initial stages of the disease intensify denial and make patients hide their cancer. Patients try to follow the lifestyle they had prior to their disease. Simultaneously, hope for cure with therapeutic interventions is present. This condition can be traced in patients who did not start treatment in the initial phases of their disease or declined treatment after a period of time. After declining treatment, the disease advances with exacerbation of signs and symptoms. Patients who forego treatment due to denial refer to doctors to begin treatment. Denial causes transient treatment refusal by these patients. Despite temporary treatment refusal, the patient loses the opportunity for an effective treatment and the chances for a cure. There is no mention of the relationship between misconception and treatment refusal in the literature;<sup>25</sup> studies have focused mostly on the relationship between lack of signs and symptoms and treatment refusal, particularly in the elderly.<sup>26</sup> Denial was a common reaction among such patients; however, there was no finding on the relationship between denial and treatment refusal.

With the exacerbation of signs and symptoms and “treatment complexity and repeated complications”, the condition of treatment refusal changes. The patients' experiences have suggested that a significant factor for treatment refusal was fear. The findings of this study showed the experiences of patients' relatives with cancer played a role in the development of fear in these patients. The patients had observed the long

process of treatment and complications in their relatives, which increased their fear. Some studies have found that cancer patients with this background were more likely to refuse treatment.<sup>17,20,27-33</sup>

In our context, patients' belief in CAM and lack of its side-effects was an important factor in declining treatment. Patients turn to CAM because of the fear of chemotherapy side-effects and their relatives' experiences with cancer. However, few patients declined treatment due to CAM. The reasons for patients' resort to CAM could be a close rapport between the physician and patient, the compliance of this type of treatment with patients' beliefs, and the sense of well-being throughout treatment. Other studies have mentioned a relationship between CAM use and treatment refusal. Most of these studies have investigated only one type of cancer.<sup>22,28,34-37</sup> Their findings agreed with our results.

Despite the seriousness of cancer, some patients decline treatment because of the physical and non-physical treatment side-effects. Previous studies have mentioned these side effects, although most investigated only one type of cancer.<sup>9,17,37,38</sup> The patients in our study mentioned certain treatment interventions that diminished complications and helped them to lead better lives. Thus, they continued the new treatment. This issue was less investigated in previous studies.

With the advancement of cancer, patients come to the conclusion that "treatment is in vain". In this stage patients have mentioned various reasons to decline or avoid treatment. The severity of cancer causes loss of physical and mental abilities. As the treatment interventions prolong the process, the patients conclude that treatment is in vain. Therefore, they tend to decline treatment and turn to palliative care. Usually, treatment refusal does not significantly affect the disease prognosis. Insistence on treatment may increase futile interventions. Few studies have dealt with treatment refusal when interventions can be futile and decision-making involves existential issues.<sup>15,21</sup>

## Conclusion

The issue of treatment refusal has been investigated in many studies. However, most studies focused on patients with one specific type of cancer. For a better understanding of treatment refusal, researchers should investigate patients with different cancer types and in different cultural, social, and health structural contexts. A model should be presented to the health care providers based on the grounded theory beyond the type of cancer or signs and symptoms and medical data. This is necessary for proper interaction between the health care providers and patients.

Regarding treatment refusal, the major findings of this study could be expressed in the three main categories. For patients who declined treatment in the initial stages or refused to start any treatment, "coexistence of hope and denial" most aptly explained their condition. However, with the advancement of the disease, treatment refusal was mostly attributed to "treatment complexity and repeated complications". Finally, for patients with metastasis, refusal resulted from the idea that "treatment is in vain".

## Limitations

The fact that some patients were not able to go through a second interview due to the progressive nature of their condition and/or poor health might have somewhat affected the obtained results.

## Clinical implications

The results of this study have indicated that cancer patients temporarily or permanently refuse treatment because of denial, misconception, and fear. However, over time and with cancer progression, most regret their decision. Awareness of these factors can help oncologists and nurses in their rapport with such patients, assist with removal of patients' misconceptions, and encourage patients to undergo the best treatment interventions. Finally, despite patient autonomy, a proper understanding of the patient's cognitive capacity can help health care providers with proper patient intervention.

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## Conflict of Interest

None declared.

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