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**Research Article**

# Perception of Iranian Patients with Cancer, Their Relatives, and Health Care Professionals Towards Length of Life and Quality of Life: A Local Survey

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## Abstract

**Background:** Recently, therapeutic decision-making in oncology is changed to a big challenge for both patients and involved oncologists due to an increase in available treatment modalities with a variety of benefits or adverse effects.
**Objectives:** The current study aimed at comparing the perception of treatment priorities regarding lengthening of survival time or maintenance of the quality of life (QoL) among patients with cancer by health care professionals (HCPs).
**Methods:** The current cross-sectional study was conducted on patients with cancer, their relatives, and healthcare professionals in the referral cancer center of Omid affiliated to Isfahan University of Medical Sciences. To identify treatment choices, priority, and related variables influencing their opinions, all participants were interviewed using a standard and valid questionnaire in Persian. The collected data were analyzed using the SPSS software version 20, and the P-value less than 0.05 was considered statistically significant.
**Results:** A total of 299 participants, including 100 patients, 109 relatives, and 90 HCPs (74.2% nurses, 20.2% physicians, 5.6% others) participated in the study. The priority of treatment between survival time (66.1% for relatives vs. 47.9% for patients and 21.3% for HCP) and QoL (33.9% vs.52.1% and 78.7%) was significantly different between the three groups ($P < 0.001$). Most of the HCPs, patients, and their relatives believed that the physician is the only person who should accept the responsibility of treatment choices and process (98.9% vs. 100% and 98%, respectively; $P = 0.002$).
**Conclusions:** Among the Iranian population, both the length of life and QoL were valuable; however, it was observed that patients with cancer and HCPs preferred mostly to expand the QoL, while the length of life was more valuable for relatives. Also, all patients, their relatives, and HCPs preferred to choose the physicians as the decision-makers. The results of the study can be helpful in choosing treatment regimens and designing clinical trials.

*Keywords:* Cancer, Overall Survival, Quality of Life, Treatment, Length of Life

## 1. Background

In the last quarter of the 20th century, substantial advancements in oncology were made concerning well-designed clinical trials. However, there is a similar primary goal among all modalities: to live longer or live better. In reality, by considering different treatment planning, the term clinical benefit is defined in different ways in clinical practice, as well as to those receiving the treatment and the ones providing the health care services (1).

The broad spectrum of available therapies with potentially different adverse and beneficial effects makes therapeutic decision-making a big challenge to healthcare providers and patients. Especially in the case of cancer, getting involved in treatment-chose and considering personal and family preferences and values can be complicated and problematic.

Under such circumstances, knowing the concept of patients with cancer of the main goals of treatment, including an extension in survival time and/or improving the quality of life (QoL), is a matter of debate.

Several studies assessed patient expectations in making treatment decisions in different cancer types (2, 3). For example, in the US, a survey study on 181 female patients affected by metastatic breast cancer reported that most patients were willing to value overall survival, regardless of potential risks of adverse effects (2).

Also, the characteristics of patients may influence the evaluation of treatment decisions and recommendations. A study on treatment alternatives for early prostate cancer showed that although both patients and urologists preference was the same, anxious/depressed patients preferred to choose radical treatment courses instead of active surveillance (3, 4).

An accurate understanding of the disease condition is another factor affecting patient expectations of treatment. If patients do not know their exact prognosis, their decisions about treatment choices and priorities may not completely reflect the real values.

For instance, a large prospective study on patients with non-small-cell lung cancer stages III and IV or colon cancer declared that patients seeking a better prognosis preferred receiving life-extending therapies (4).

Concerning diversity among features, such as religion, culture, demographic characteristics, or social class, patient opinions may vary; however, 98% of patients rely on the physician as a trusted person and leave treatment decision-making to them.

Iran has a vast population with very different characteristics and cultural varieties in comparison to other countries. The Iranian population has complicated relationships, especially family relationships, which can directly affect treatment decision-making. A previous Iranian study announced that 85.2% of 980 patients with cancer wanted to receive detailed information about their disease. Likewise, 56.9% wanted to leave treatment decision-making to their physicians (5). Information about s patient expectation of cancer treatment is low in Iran, and there are limited data regarding the influence of patients‘ demographic characteristics.

## 2. Objectives

The current study aimed at assessing the treatment prioritization of patients with cancer, their relatives, and healthcare professionals (HCPs) by differentiating their preferences between the extension of survival time and improvement of QoL. Moreover, it was tried to find out the factors affecting the treatment choices and if physicians were the key players in their treatment decision-making in our local hospital or not.

## 3. Methods

### 3.1. Study Design

The current study was conducted on patients with cancer referred to the Outpatient Ward at the Hematology-Oncology Center in Omid Hospital affiliated to Isfahan University of Medical Sciences. This 200-bed hospital is one of the referral and well-equipped centers in Iran, allocated to oncology-hematology patients. Besides, information was collected from relatives accompanying their patients.

Data were also collected from HCPs working in the hospital (the HCPs group), including physicians, nurses, and other related staff. All patients aged 18 years or older referred to the outpatient ward were enrolled in the study.

### 3.2. Exclusion Criteria

Participants under 18 years old or those with any kind of psychiatric illnesses or cognitive disorders were excluded from the study.

The local institutional review board approved the study protocol, and a signed written consent form was obtained from all the participants.

### 3.3. Sample Size Calculation

Since the study had a survey design aimed at determining several ratios (proportion) in terms of application, the following formula was used to determine the required sample size.

$$n = \frac{(Z)^2 \times p\ (1-p)}{d^2} \tag{1}$$

where Z was a 95% confidence interval for the distribution of the P index; taking into account the alpha error of 0.05 (type 1 error = 0.05), given that a similar study was not available to determine the maximum, it was considered 50% or 0.5 to obtain the maximum sample size. Therefore, Z was 1.96, and P as a relative frequency or estimated probability was considered 20% in the present study based on the expected proportion in a previous study (6). As a result, 100 patients, 100 relatives, and 100 HCPs could be a good sample size.

### 3.4. Sampling

In order to create uniformity in the sampling method of participants, random sampling was performed using the Excel software. Samples were randomly selected from patients daily referring to the outpatient ward for chemotherapy and their relatives. For this purpose, on daily visits, the list of patients referring for chemotherapy on that particular day, as well as their companions, was taken. Then their numbers on the list were transferred to the software, and 5 - 10 individuals per day were selected as a sample. In addition, HCPs were selected by simple random sampling.

### 3.5. Data Collection

Demographic and socioeconomic data, such as gender, age, education level, marital status, number of family members, occupational status, level of income, etc., were gathered from all participants as part of the questionnaire. Other related data, such as cancer type, was extracted from medical records.

An international questionnaire with a fictitious case was used in previous studies (6, 7). The questionnaire consists of two parts. The first part includes demographic information, such as age, gender, education level, and occupational status. In the second part, patients were asked about the view of all three groups and their preference for survival time versus QoL. Participants were also asked about their preference to be involved in the treatment decision-making process.

The validity and reliability of the questionnaire were assessed and confirmed in previous studies (6, 7). To assess the validity of the Persian version of the questionnaire, it was evaluated by a group of specialists, including two psychologists, one literature expert, two oncologists, and 10 pharmacists. Then, a forward-backward translation method was employed for translating the questionnaire, and the same questionnaire was given to 30 matched patients within two weeks. And finally, the reliability of the questionnaire with an intraclass correlation coefficient (ICC) was assessed.

A pharmacy student was responsible for interviewing the participants. They were given sufficient time to read the Persian-language consent form prior to answering the questions.

Based on the questionnaire, participants were asked about their treatment priorities over each fabricated case. One of the main questions was about treatment decision making. Participants were asked to comment on the person who has more weight in treatment decision making. In several closed-ended questions, the priority of treatment regarding QoL versus survival time was assessed according to fictitious scenarios. In the scenarios described, a patient has just been informed about his/her malignancy, and to choose the best treatment option, the physician explains the treatment types and possible adverse effects, and then the subject was asked what treatment priority should be taken. The participants were only allowed to choose one answer out of three, including "the treatment modality that prepares a longer survival time, instead of a higher QoL", "the treatment procedure that provides the highest QoL, regardless of the impact on survival time prolongation", and "I do not know or prefer not to answer".

If participants selected more than one option for each question, the answers were considered invalid. Questions on treatment priority were also assessed based on three different fictitious scenarios for age groups, including a five-year-old child, a 16-year-old teenager, and a 70-year-old person, if clarification was requested for each case, an open-ended question was raised.

The decision-making procedure was examined with another closed-ended question: "Imagine that a patient just finds out that he/she has cancer. In your view, who is the best person for decision-making?" Participants could choose one or more options provided in the questionnaire: the physician, the patient, the family, or other HCPs.

Examiners were responsible for all aspects of the process, such as implementing the questionnaire, checking completion, and ensuring the quality of data received from the questionnaire.

Patient's perception was defined as the manner in which something is regarded, understood, or interpreted through the senses by a patient.

### 3.6. Statistical Analysis

To assess the reliability of the questionnaire, ICC was performed for each question. ICC inter-rater agreement measures above 0.6 was considered good and acceptable. The total sample size was determined based on a similar study in another country and feasibility (7). The student t- and Mann-Whitney U-tests were utilized for numerical variables; the chi-square test for categorical variables and differentiation of demographic characteristics between and within patients, their relatives, and HCPs were also accomplished. Pearson correlation and ANOVA were also employed to assess the relationship between quantitative variables, such as age, gender, and education level, and answers. In the last question (see the English version of the questionnaire in the supplementary file. Appendix 1 in Supplementary File extracted from the study by Marta et al. (6), candidates could choose between six scenarios. Therefore, all information was gathered to analyze the relative frequency for each scenario.

Statistical analysis was performed using SPSS version 24 (SPSS Inc, Chicago, IL). In all cases, a P-value of less than 0.05 was considered statistically significant.

## 4. Results

From July to September 2019, a total of 299 participants were selected (100 patients, 109 relatives, and 90 HCPs). The demographic information of the study participants was provided in Table 1. The median age was the highest in patients (42.6 ± 20.2 years old), relatives (41.2 ± 12.14 years old), and HCPs (33.7 ± 6.7 years old). As shown in Table 1, patients mostly had hematologic (28%), breast (18%), or gastrointestinal (11%) cancers. The HCPs group consisted of 74.2% nurses, 20.2% physicians, and 5.6% others.

### 4.1. Decision-making Question

The chief responses to the decision-making question are summarized in Figure 1. The relatives group more often declared that "the physician alone should be in charge of treatment choices" rather than patients and HCPs (100% vs. 98%, and 98.9%).

### 4.2. Therapy Priorities

Figure 2 manifests the distribution of responses to the related items on the questionnaire.

The second question was asked to understand the participants' views on survival time and QoL indirectly. In this question, the participants could choose across various therapies considered for a fabricated case recently diagnosed with malignancy. As shown in Figure 2, treatment priorities for 69.5% of the patients and 94.3% of the HCPs were QoL and for 66.2% of the relatives the survival time; however, 13.7% of the patients, 9.5% of the relatives, and 2.3% of HCPs were uncertain or unwilling to respond.

Survival time in 3.4% and QoL in 94.3% of the HCPs were the treatment priorities; however, 2.3% were uncertain or unwilling to respond. Also, QoL in 24.3% and survival time in 66.2% of the relatives were the treatment priorities; however, 9.5% were uncertain or unwilling to respond.

After analyses, a statistically significant difference was observed in treatment priorities among the three groups ($P = 0.002$).

In statistical analysis, there was no significant difference in prioritizing survival time or QoL between genders, according to the second question of the questionnaire. However, there was a significant difference among the age ranges in the three groups in prioritizing survival time versus QoL ($P = 0.004$).

Additionally, the participants were asked to choose the best option across three therapeutic strategies for the fabricated case in three age ranges. As shown in Table 2, all the three groups of patients, relatives, and HCPs chose the improvement of QoL instead of survival time prolongation (i.e., a less invasive therapy) for a 70-year-old person. However, there was a significant difference between the conception of patients and relatives for a 16-year-old fictitious case ($P = 0.004$) in a way that relatives preferred a more invasive treatment compared to patients. Also, there was a significant difference between relatives and HCPs for a 16-year-old fictitious case ($P = 0.0018$), so that relatives preferred a more aggressive treatment as well. In addition, there were no different views among the three groups in treatment priorities for a five- and 70-year-old fictitious case. All groups preferred invasive therapies for the five-year-old case and less invasive one for the 70-year-old case.

In the current study, therapeutic options were categorized as follows:

Therapy X: It is toxic, and the patient needs to stay in the hospital for one month to recover. Visiting the patient has restrictions due to the patient's fragile immune system, but the chance of cure is high.

Therapy Y: It may cause gastric problems, such as nausea, vomiting, and some others such as fever and tremors, but the toxicity is less than the therapy X. The patient should get this therapy in the hospital once a week for one year without requiring hospitalization. This therapy is not curative but can extend the length of life for months.

Therapy Z: The patient should get it monthly in a hospital within 30 minutes. It has mild side effects and is probably less effective than the therapy Y.

Finally, six scenarios were presented in the last question of the questionnaire. For the length of life and QoL, different scores were applied in each row. Score zero demonstrated the worst case. Table 3 shows the answers in the three groups. But it should be considered that the data in Table 3 were analyzed in only two categories, life span and QoL, or in one that considered survival time as the only priority among participants (i.e., scenarios A to C, for which the minimum survival time was six months) and the one that considered QoL as their preference (i.e., scenarios D to F). The results revealed that QoL was more frequently important among patients and HCPs and length of life among relatives. There were significant differences among the three groups ($P < 0.001$).

Table 3 shows six scenarios. Each scenario contains a value for survival time and one for QoL. Under both circumstances, survival time and QoL, the score of zero indicates the worst possible situation (immediate risk of death and extreme suffering from the disease), whereas a score of 10 indicates the best possible situation (an expectation of living a life for many years with no suffering from the disease). The other figures reflect intermediate situations.

## 5. Discussion

In the current cross sectional study, the majority of oncology HCPs and patients preferred a higher QoL outcome while most of the relatives preferred an increase in the length of life. However, patients with cancer, in comparison with HCPs, were more willing to choose a treatment, which could prolong their lifespan. There were no variables to significantly influence participants' choice- e g, gender, age, or the type of baseline cancer. In comparison with the study by de Araujo Toloi et al. (7), in the current study, both patients and HCPs believed that the physi-

**Table 1.** Demographic Characteristics of Participants

| | Patient | Relative | Healthcare Professional |
|---|---|---|---|
| **Age, y, mean ± SD** | 42.6 ± 20.2 | 41.2 ± 12.14 | 33.7 ± 6.7 |
| **Gender, %** | | | |
| Female | 62 | 48.6 | 88.9 |
| Male | | | |
| **Marital status, %** | | | |
| Married | 69.7 | 63.3 | 54.4 |
| Single | | | |
| **Level of education, %** | | | |
| Under and lower | 58.5 | 55 | 0 |
| Bachelor’s or master’s degree | 40.5 | 40.3 | 81.1 |
| PhD and higher | 1 | 4.6 | 18.9 |
| **The income per month, US$, %** | | | |
| < 35 | 1.2 | 0 | 0 |
| 35 - 80 | 28.4 | 0.9 | 2.3 |
| 80 - 160 | 40.7 | 37 | 59.3 |
| 60 - 390 | 27.2 | 51.9 | 34.9 |
| > 390 | 2.5 | 10.2 | 3.5 |
| **Cancer type, %** | | | |
| Gastrointestinal | 11 | | |
| Breast | 18 | | |
| Hematologic | 28 | | |
| Other[a] | 43 | | |
| **Healthcare professional** | | | |
| Physician | 0 | 0 | 20.2 |
| Nurse | 0 | 0 | 74.2 |
| Others | 0 | 0 | 5.6 |

[a] Mostly included gastric, pancreatic, lung, bladder, ovarian, and sarcoma cancers.

cian alone should be responsible for treatment decision-making and the proportion in the HCPs group was higher than that of patients. Besides, in another study by Motlagh et al. (5), in Iran, most patients believed that the physician is the most reliable person for treatment decision-making and wanted that in difficult situations, the decisions be made by their physician rather than themselves or their relatives.

In a British survey study on 1441 participants, analyses revealed that patients with cancer prioritized therapies with a minor chance of cure or extending the life, as opposed to HCPs (8). In another large study published in 2001, data indicated that patients more frequently welcomed a lower chance of benefit than HCPs (9). A recent review confessed that patients more often tend to choose to live longer compared to HCPs and healthy individuals (10).

There were controversies among the reported data; for example, in a US survey of 1000 patients with prostate cancer, patients preferred to have a higher QoL (45%), whereas more than 90% of 200 urologists preferred extending life (7). Furthermore, various factors, such as being supported by family or having different cultural backgrounds, can affect patient prioritization. For example, in the latter survey, most of the patients with prostate cancer received supportive care. It is not quite clear to what extent this factor is influential, but it is believed that factors, such as financial and non-financial support, definitely affect patient preference. Since the treatment of patients with prostate cancer is an effective therapeutic modality, and most of the patients respond well to the applied treatment, it can justify

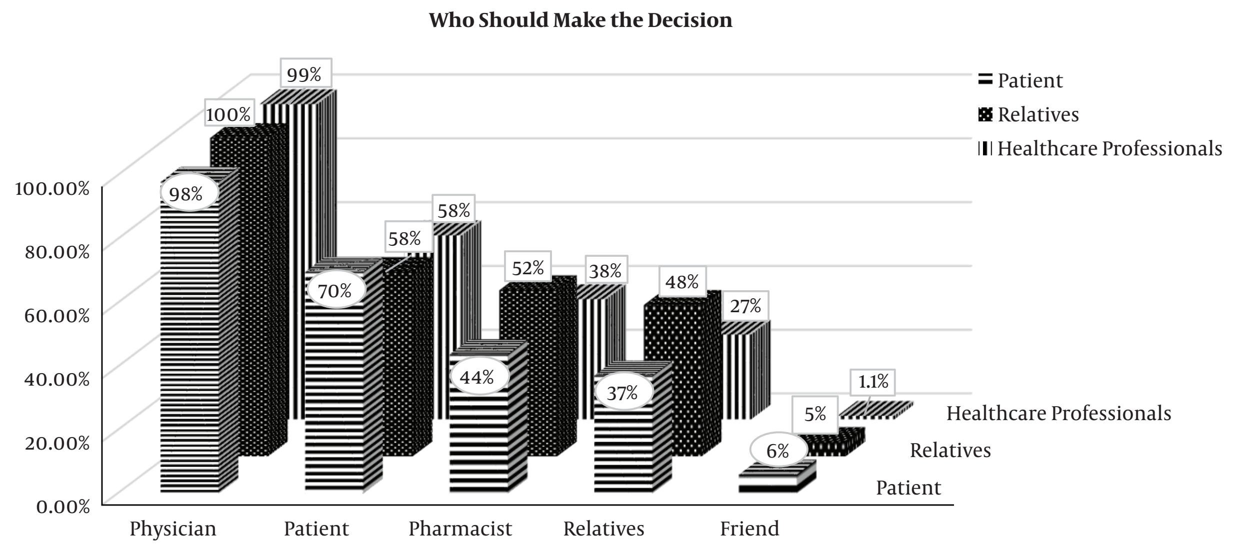

**Figure 1.** Decision-making question

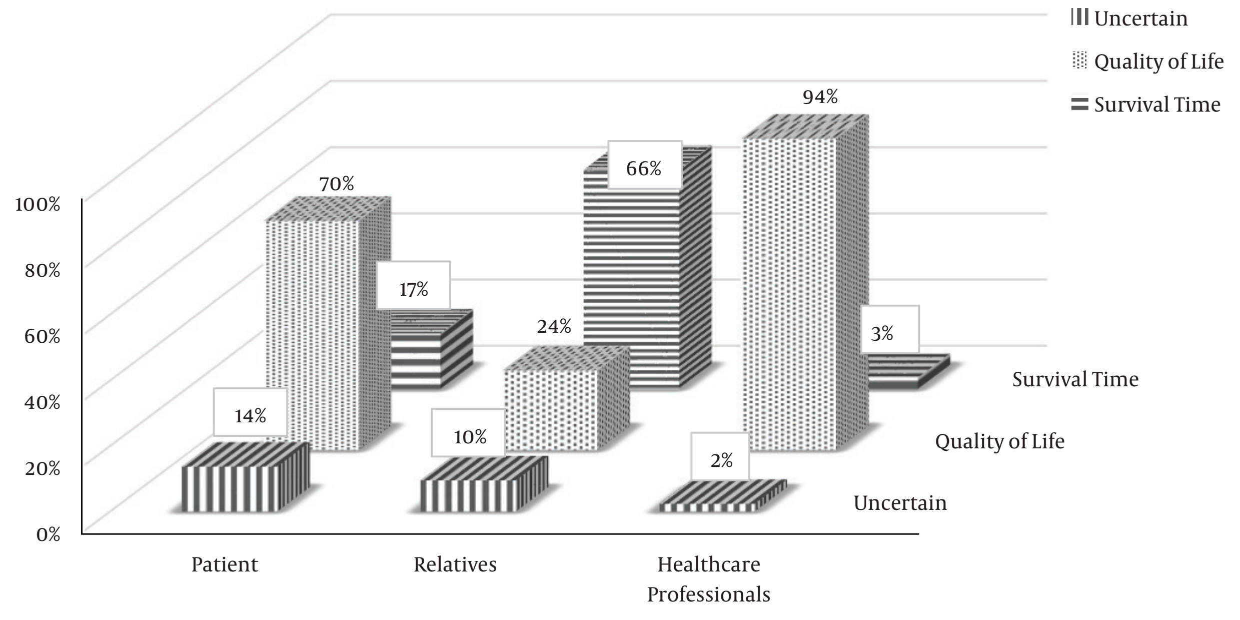

**Figure 2.** Priority treatment question

the preference of HCPs for extending survival time versus QoL in this case (7). Probably, larger-scale studies can detect the impact and overcome the sample size limitations.

Two similar studies were performed in Brazil, one of them was conducted in a private hospital and the other in a public institute. They involved patients, HCPs, and laypersons, investigating treatment priorities in cancer management (6, 7). The results of both studies were inconsistent with the current study findings, suggesting that QoL was more favorable than living longer among patients and HCPs. The Brazilian studies suggested that the healthcare services were funded by two separate organizations, private and state insurances, and those with lower income are under the state insurance coverage, which had more limi-

**Table 2.** The Priority of Decision-making by the Age of Participants in Fabricated Cases

| Age, y | Therapy X, % | Therapy Y, % | Therapy Z, % |
|---|---|---|---|
| **(A) Patient** | | | |
| **5** | 53.6 | 26.8 | 19.6 |
| **16** | 56.4 | 24.5 | 19.1 |
| **70** | 28.4 | 23.2 | 48.4 |
| **(B) Healthcare Professionals** | | | |
| **5** | 39.8 | 24.4 | 36.7 |
| **16** | 55.1 | 34.8 | 10.1 |
| **70** | 10.1 | 23.6 | 66.3 |
| **(C) Relatives** | | | |
| **5** | 52.3 | 22.9 | 24.7 |
| **16** | 74.3 | 20.2 | 5.5 |
| **70** | 21.1 | 26.6 | 52.3 |

tations in treatment options and medicines, encountering them to problems they do not expect. Although patients prefer treatments extending their survival time, physicians prefer treatments that increase their QoL, and since patients rely on physicians as their treatment decision-makers, it could be essential for the physician to know patient perception (7). In Iran, the majority of medication and health system facilities for cancer treatment are fully supported by insurance companies; however, patients and their relatives still experience a variety of financial problems and bear a drastic economic burden (7). Besides, most patients experience many chemotherapy side effects leading to numerous physiological and psychological problems. In fact, most patients and their relatives are advised to see a psychologist in order to better deal with the cancer situation but refuse it due to economic problems, and the cultural taboo of consultation with a psychologist is not helpful. Therefore, numerous problems of patients with cancer and the persistence of their relatives on the length of life raised many arguments among the three groups. In fact, most patients and HCPs preferred QoL to survival time, whereas relatives preferred survival time.

Interestingly, in most studies, including the current one, HCPs prioritized QoL more often than patients. Based on previous studies, this kind of study is a dynamic process, and patient perception may depend on his/her medical condition or change in different stages of the disease, so they may have various comments by reaching a closer view of death. A study conducted in Canada reported the same result and indicated changes in patient perception in different conditions. The current study was conducted in an outpatient ward in which most patients are still in a good health condition, and their views may change if they experience a drastic situation (7). Furthermore, the potential implication might be prioritizing views of both sides involved in treatment modalities. Probably, conducting a clinical trial with the primary endpoint of overall survival may be more demanded than t designed to improve QoL.

The comparison of the overall outlook of patients, HCPs, and relatives towards QoL showed that to choose the best modality for a child or adolescent patient with cancer, they selected an invasive treatment modality that had toxic side effects with more cure chance but chose less toxic ones without toxic side effects for old patients. The difference in outlook among the three groups for the three age ranges rises from the fact that younger patients are stronger than older ones and can tolerate side effects better than the older patients. Also, they believed that the risk of death was lower in younger patients.

The selection of the best person for choosing the treatment plan completely depends on information about prognosis, diagnosis, and therapies given to patients and their families. One of the systemic reviews published in the field of cancer demonstrated that patients with cancer prefer to have meticulous information about their prognosis, and they truly appreciate physician support for providing information about prognosis and therapeutic alliance (11).

The current study observed that the majority of patients with cancer, their relatives, and HCPs relied on oncologists for treatment decisions. Interestingly, it was more emphasized in the relative group. Such attitudes are influenced by the social and ethnic characteristics of Iranian people. Physicians in Iran have a good social status; they could be really trusted and honored in Iranian society. It seems that due to factors, such as lack of clarification on the disease and available therapies, emotional fragilities of the patients, and denial of cancer, physicians are mostly preferred as a person in charge of choosing the treatment plan. Another study conducted in Brazil also showed similar results (7). There were some restrictions in the current study. First of all, the cross sectional design for this dynamic process. It was anticipated that patient opinion differs across the stages of the disease or drug administration. Besides, the current study was performed in an outpatient ward where most of the patients were in a better general health condition to respond to the questions. The selected patients were hospitalized for hours in the outpatient ward to receive their daily medication; furthermore, it was hard to access patient records and information on the stage of the disease in a limited time. A second limitation was the sample size of the study, although it was similar to those of some published studies, no detailed/significant relationships/information was found on the demographic analysis. It was probably due to inade-

**Table 3.** Participants Priority Between Quality of Life and Survival Time, Using the Scenarios

| Scenario | Life Span, % | Quality of Life | Patient, % | Relative, % | HCP, % |
|---|---|---|---|---|---|
| **A** | 10 | 0 | 17.9 | 15.6 | 1.1 |
| **B** | 8 | 2 | 13.7 | 31.2 | 5.6 |
| **C** | 6 | 4 | 15.8 | 19.3 | 14.4 |
| **D** | 4 | 6 | 27.4 | 14.7 | 36.7 |
| **E** | 2 | 8 | 10.5 | 16.5 | 33.3 |
| **F** | 0 | 10 | 13.7 | 2.8 | 7.8 |
| **Participants Priority Between Survival Time and Quality of Life, Using the Scenarios** | | | | | |
| A, B, or C | | | 47.9 | 66.1 | 21.3 |
| D, E, or F | | | 52.1 | 33.9 | 78.7 |

quate sample sizes. As the median age of HCPs was 33, there might be a possible bias in answering the questions in the healthcare team. Altogether, further studies with larger sample sizes are recommended.

### 5.1. Conclusions

Treatment priorities and decision-making were greatly different among patients with cancer, their relatives, and HCPs in the population surveyed in the current study. Survival time was a priority for both patients and HCPs, relatives preferred treatments extending patient QoL. Most of the HCPs focused on QoL. Moreover, the studied patients and their relatives relied on physicians for treatment decision-making. Prospective studies are necessary since treatment modalities may alter across different stages of the disease as treatment decision-making is a dynamic process. It is hoped that the results of such studies can be helpful in oncology drugs and regimen development, as well as designing clinical trials.

## Supplementary Material

Supplementary material(s) is available here [To read supplementary materials, please refer to the journal website and open PDF/HTML].

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## Footnotes

**Authors' Contribution:** All authors contributed to the study concept, design, data collection, statistical analysis, and drafting of the manuscript.

**Conflict of Interests:** The authors declared no conflicts of interest.

**Ethical Approval:** The study was approved by the Ethics Committee of Isfahan University of Medical Sciences (ethical code: IR.MUI.RESEARCH.REC.1398.721).

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**Informed Consent:** All subjects read and signed the informed consent forms.

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