

Treatment priorities in oncology: do we want to live longer or better?

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OBJECTIVES: Despite the progress achieved in the fight against cancer over the past several years, assessing the needs, goals and preferences of patients with cancer is of the utmost importance for the delivery of health care. We sought to assess priorities regarding quantity *versus* quality of life among Brazilian patients, comparing them with individuals without cancer.

METHODS: Using a questionnaire presenting four hypothetical cancer cases, we interviewed cancer patients, oncology health-care professionals and laypersons, most of whom had administrative functions in our hospital.

RESULTS: A total of 214 individuals participated: 101 patients, 44 health-care professionals and 69 laypersons. The mean ages in the three groups were 56, 34 and 31 years old, respectively ($p < 0.001$). The patients had gastrointestinal (25%), breast (22%), hematologic (10%), lung (8%) or other tumors (36%) and the tumor-node-metastasis (TNM) stage was I, II, III or IV in 22%, 13%, 34% and 31% of cases, respectively. Treatment priorities differed significantly among the three groups ($p = 0.005$), with survival time being a higher priority for patients than for the other two groups and with opposite trends regarding quality of life. In multivariate analysis, the age and sex distributions were not associated with the choice to maximize quality of life. In this limited sample of cancer patients, there were no associations between treatment priorities and disease stages.

CONCLUSIONS: Both survival time and quality of life appeared to be important to cancer patients, oncology health-care professionals and laypersons, but survival time seemed to have higher priority for people diagnosed with cancer than for healthy people. Additionally, survival seemed to be more important than quality of life for all three groups assessed.

KEYWORDS: Oncology; Quality of Life; Survival.

Marta GN, Del Nero LG, Marta GN, Mangabeira A, Critchi G, Kovács MJ, et al. Treatment priorities in oncology: do we want to live longer or better? Clinics. 2014;69(8):509-514.

Received for publication on December 2, 2013; First review completed on January 21, 2014; Accepted for publication on February 4, 2014

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■ INTRODUCTION

In recent years, great progress has been achieved in the fight against cancer (1-3). Improvements in systemic therapy have considerably brightened the outlook for patients with the most common types of solid and hematologic malignant tumors. However, much remains to be done and finding the right treatment for the right patient has become the overarching goal of medical oncology (1). Achieving the goal of personalized cancer care will necessarily entail the discovery, development and delivery of systemic agents

that can modify the natural history of the disease in individual patients, according to the specific biological features of these individuals. However, personalized cancer care has also been described more broadly, in the context of advanced cancer, as a need to consider the 'diverse physical, psychological, social and spiritual consequences of cancer for the individual patient' (4). As a result, assessment of the needs, goals and preferences of patients with advanced cancer has been identified as a necessary step toward tailoring the care delivered to these individuals, who frequently face the complex consequences of cancer and its treatment (4).

Despite the achievements of different treatment modalities, a cure has remained elusive for most patients with advanced solid tumors. Therefore, prolonging survival time is the key objective in the treatment of these patients (5-10). However, it is important to assess the priorities of individual patients in clinical practice. Surveys of patients with cancer should be able to assess how survival time and

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No potential conflict of interest was reported.

DOI: 10.6061/clinics/2014(08)02



quality of life, the two chief indicators of treatment benefit (5), rank in terms of patient priorities and identifying what patients value more (quantity or quality of life) has been proposed as an important research topic (11). Apparently, only a few studies have been performed with the objective of assessing patient preferences, all of which were conducted in North America, Europe or Japan (11). To our knowledge, no similar studies have been conducted and published in Brazil. We thus decided to assess the priorities of a sample of Brazilian patients with various tumor types at various stages regarding these two therapeutic objectives, comparing their preferences with those of health-care professionals and laypersons. Our primary hypothesis was that cancer patients would be more likely to prioritize survival time than quality of life, compared to individuals without cancer.

■ METHODS

Study design and groups of participants

The study protocol for this cross-sectional survey was approved by the institutional review board of Hospital Sírio-Libanês and all of the participating individuals provided their written informed consent. We defined three groups of participants: cancer patients seen in the Departments of Medical Oncology and Radiation Oncology at the hospital, health-care professionals working in these departments and laypersons recruited at the hospital. Cancer patients and health-care professionals were consecutively invited, with no selection criteria other than age >18 years old, during periods when the data collectors (GNM, LGDN and GC) were present. The patients' medical records were reviewed after their permission was granted during the consent process. Information on the disease type and stage was collected from these medical records. Laypersons were invited at the hospital according to logistic feasibility and the only selection criterion was the absence of a personal history of cancer or recent cancer cases in close family members. The participants received explanations of the study objectives and methods and they were asked to complete the study questionnaire (after the consent form was signed). Each participant was interviewed only once during the study.

Study questionnaire

The study questionnaire is shown in the Appendix. In brief, four case vignettes were presented, describing hypothetical scenarios that were developed by medical and radiation oncologists and two clinical and research psychologists. All of the participants were told that the cases were fictitious and the hypothetical nature of these scenarios was emphasized in the introduction to the questionnaire. The first question assessed the participants' opinions regarding who should be involved in initial treatment decisions. The second question assessed priorities regarding different treatment strategies with a preferential impact on survival time or on quality of life. The third question presented fictitious patients in four different age groups (child, adolescent, adult and elderly) in an attempt to assess preferences for treatment strategies with different implications in terms of risks and benefits. Finally, the fourth question was an attempt to quantify the weights given to survival time and to quality of life. In addition to multiple-choice options, participants could express their

opinions in textual form, but that information was not analyzed in the present paper.

Statistical planning and analysis

Our goal was to enroll approximately 250 participants over a period of 10 months (100 patients, 50 health-care professionals and 100 laypersons). This sample size was estimated based on feasibility, rather than on statistical assumptions. Statistical analyses were performed in a descriptive fashion for numerical and categorical variables of interest. Comparisons between groups were conducted using the chi-square test for categorical variables that were considered to be of primary importance. Logistic regression models were used to explore the associations among age, sex and the types of response to the second question on the questionnaire. For several of the variables with an exploratory nature, no statistical tests were applied. MedCalc statistical software (version 11.0.0.0, Mariakerke, Belgium) was used for the analysis and a two-tailed significance level of 5% was considered significant.

■ RESULTS

Flow and characteristics of participants

Between January and September 2010, 214 people were interviewed: 101 patients, 44 health-care professionals and 69 laypersons, most of whom had administrative functions in the hospital. The mean (\pm standard deviation) ages in the three groups were 56 (± 15), 34 (± 9) and 31 (± 7) years old, respectively ($p < 0.001$). There were also significant differences in the sex distribution among the groups: the percentages of women were 53% among patients, 67% among health-care professionals and 78% among laypersons ($p = 0.004$). When pathologic diagnosis was considered in the group of patients, 25% of individuals had gastrointestinal tumors, 22% had breast cancer, 10% had hematologic malignancies, 8% had lung cancer and 36% had other tumors. Regarding the tumor-node-metastasis (TNM) disease stage, 22% of patients had stage I disease, 13% had stage II, 34% had stage III and 31% had stage IV. Among the health-care professionals, 35% belonged to the nursing team, 30% were radiotherapy technicians or physicists, 27.5% were physicians and 7.5% were pharmacists or biomedicine professionals.

Responsibility for treatment decisions

When asked who should be involved in treatment decisions for a fictitious patient recently diagnosed with cancer, the responses of the patient and health-care professional groups were practically identical and were only somewhat slightly different from those of the group of laypersons (Table 1).

Prioritization between survival time and quality of life

Prioritization between survival time and quality of life was assessed indirectly, using the second question on the survey (see the Appendix), for which the participants could choose among different treatment strategies for a fictitious patient recently diagnosed with cancer. As shown in Table 2, there were statistically significant differences in the proportions of responses in the three groups, with a graded increase in prioritizing quality of life across the spectrum, from patients to health-care professionals to laypersons. An



Table 1 - Responses to the question about who should be involved in treatment decisions for a fictitious cancer patient (the responses did not add up to 100%).

| Who should be involved? | Patients | Health-care professionals | Laypersons |
|--|----------|---------------------------|------------|
| The physician | 74.7% | 75.7% | 50.7% |
| The patient | 58.2% | 75.7% | 44.9% |
| Relatives | 35.4% | 48.6% | 33.3% |
| Others members of the health-care team | 2.5% | 13.5% | 14.5% |
| All | 21.5% | 21.6% | 46.4% |

exploratory analysis showed no differences in priorities for the patient group according to TNM stage (I to III *versus* IV; data not shown). Moreover, the exploratory analysis suggested that the age and sex distributions were not associated with the choice to maximize quality of life in response to the second question on the questionnaire, whereas being a layperson was significantly associated with that choice (see Table 3).

For the third question on the survey, the participants were asked to select among three treatment strategies for fictitious patients in four age groups. The responses, shown in Table 4, showed an overall pattern that varied relatively little among the participants regarding treatment aggressiveness across the four age groups. Survival was prioritized (i.e., more aggressive treatment) for a 5-year-old child and a 16-year-old adolescent and increasing emphasis was placed on quality of life (i.e., less aggressive treatment) for a 70-year-old person (with intermediate results for a 50-year-old patient).

Finally, the last question on the survey presented six hypothetical scenarios, each with weights for length of survival and quality of life, with zero representing the worst possible situation. Table 5 shows the distributions of answers in the three groups. However, when the data in Table 5 were analyzed in only two categories or in one that considered survival time as the priority (i.e., scenarios A to C, for which the minimum for survival was 6) and one that considered quality of life as the priority (i.e., scenarios D to F), there were statistically significant differences among the groups ($p=0.007$), as shown in Table 6. These results reflect those shown in Table 2, in the sense that an emphasis on survival was more common among patients, whereas an emphasis on quality of life was more frequent among laypersons.

DISCUSSION

Ideally, the provision of cancer care should consider the medical, psychological, social and spiritual consequences of the disease in each individual patient (4). Therefore, systematic and objective assessment of patients via surveys such as that described here can help the clinician and the oncology community to understand patient priorities and

the extent to which such priorities differ from those of health-care professionals and laypersons. Brazilian patients are subjected to specific cultural and social issues that could result in differences when their psychological responses to cancer are compared to those of individuals with different cultural backgrounds. Thus, the current study was a step toward the important goal of achieving personalized and culturally appropriate cancer care in this country. Brazilian investigators have been increasingly influential in the international oncology community from a scientific point of view (12) and studies such as the current one should represent a natural and necessary extension of clinical trials of novel therapeutic modalities.

Our hypothesis that Brazilian cancer patients would be more likely to prioritize survival time over quality of life, compared to individuals without cancer, stemmed from years of clinical practice with patients and from educational activities with oncology health-care professionals. Evidently, this hypothesis emerged based on subjective feelings and non-systematic observation of the reactions of cancer patients and health-care professionals to conversations about issues of survival time and quality of life. Over the years, several of the authors have developed the impression that health-care professionals seemed to be more concerned with quality of life than with the patients themselves, perhaps due to their professional knowledge of the side effects of treatment and the prognostic implications of cancer diagnosis. The results of our survey suggested that there was a graded increase in concern with the prioritization of quality of life (at the expense of survival) along the continuum from cancer patients to oncology health-care professionals to laypersons. Conversely, an opposite trend appeared to exist regarding concern about survival duration (at the expense of quality of life), at least when patients were compared with laypersons. It should be emphasized, however, that survival was the chief priority (compared to quality of life) in all three of the groups assessed.

It is conceivable that the opposite trends in priorities found in our study were due to the diagnosis of cancer in an individual, leading to a clearer perception of life’s finiteness and to a resultant attempt to avoid death at the cost of quality of life. However, patients’ knowledge regarding

Table 2 - Priorities regarding treatment options for a fictitious cancer patient; the differences among groups were statistically significant ($p=0.005$).

| Treatment type | Patients | Health-care professionals | Laypersons |
|---|----------|---------------------------|------------|
| One that prolongs survival, regardless of quality of life. | 21.2% | 2.3% | 11.8% |
| One that provides a reasonably long life, although not necessarily the longest, with few side effects and little impact on quality of life. | 59.6% | 72.7% | 54.4% |
| One that maximizes quality of life, although survival may be shorter. | 15.2% | 22.7% | 33.8% |
| No treatment should be given. | 0% | 0% | 0% |
| Do not know or prefer not to comment. | 4.0% | 2.3% | 0% |



Table 3 - Multivariate analysis of factors predicting the choice to maximize quality of life in response to the second question on the questionnaire

| Variable | Odds ratio | 95% confidence interval | p- value |
|---|------------|-------------------------|----------|
| Layperson (patient as reference) | 3.34 | 1.04 - 10.76 | 0.043 |
| Health-care professional (patient as reference) | 1.379 | 0.37 - 5.22 | 0.636 |
| Age (as continuous variable) | 1.01 | 0.98 - 1.05 | 0.519 |
| Sex (female as reference) | 0.85 | 0.37 - 1.95 | 0.705 |

Table 4 - Treatment aggressiveness for fictitious cancer patients in four age groups, according to participant group (see Appendix for complete definitions of treatment types).

| Fictitious Patient's age | Treatment type | Patients | Health-care professionals | Laypersons |
|--------------------------|---|----------|---------------------------|------------|
| 5 years old | Very toxic, with high chance of cure | 84.7% | 93.2% | 72.5% |
| | Toxic but able to prolong survival | 10.2% | 4.5% | 14.5% |
| | Low toxicity but less effective than others | 5.1% | 2.3% | 13.0% |
| 16 years old | Very toxic, with high chance of cure | 89.9% | 97.7% | 78.3% |
| | Toxic but able to prolong survival | 7.1% | 2.3% | 18.8% |
| | Low toxicity but less effective than others | 3.0% | 0% | 2.9% |
| 50 years old | Very toxic, with high chance of cure | 78.6% | 81.0% | 64.7% |
| | Toxic but able to prolong survival | 16.3% | 11.9% | 27.9% |
| | Low toxicity but less effective than others | 5.1% | 7.1% | 7.4% |
| 70 years old | Very toxic, with high chance of cure | 44.3% | 18.6% | 35.3% |
| | Toxic but able to prolong survival | 23.7% | 30.2% | 17.6% |
| | Low toxicity but less effective than others | 32.0% | 51.2% | 47.1% |

their diagnoses was not assessed in the current study and the extent to which such knowledge contributed to a greater preference for survival time among patients, compared with the other two groups, remained uncertain. It is also conceivable that the preference for quality of life, particularly among laypersons, was due to the emotional remoteness of the hypothetical cases presented in the questionnaire. Finally, it remained possible that age and sex distributions underlay the different response profiles across the three groups, despite our exploratory analyses not suggesting such a possibility.

To our knowledge, studies of this type have been conducted only in North America, Europe and Japan. Overall, the available studies have shown that cancer patients were more frequently willing to face the possibility of major adverse events in exchange for small objective benefits, compared to health-care professionals and laypersons (11). Slevin et al. (13) and Balmer et al. (14), for example, found that UK cancer patients were more likely to accept radical treatment with a minimal chance of benefit than people without cancer, including physicians and nurses. Similar results were reported by Bremnes et al. in Norwegian patients (15). In Japan, patients with lung cancer were more likely to accept treatment for small benefits than were patients with other respiratory disorders (16). In North American women with early-stage breast cancer, McQuellon et al. (17) assessed patient preferences for treatment in hypothetical scenarios of metastatic disease; specifically, the authors attempted to quantify the trade-off between toxicity and a gain in survival and they found that a substantial percentage of women would accept the risk of major toxicity in return for a minimal increase in survival. Other studies of this type have generally reported similar trends in terms of patient preferences (11) and our results were in agreement with those from other countries. However, it is possible that the patient preferences regarding treatment depended on patient and disease characteristics.

Hirose et al. (16), for example, found an association between age and the choice of more aggressive treatment. In the current study, however, we did not confirm this association when all of the participants were analyzed in an aggregate fashion. Regarding disease characteristics, we could not demonstrate that tumor stage was associated with a preference for survival time in our patients, but a lack of understanding regarding patients' knowledge about their diagnosis and prognosis might have confounded these results. Notably, a telephone survey conducted in the US showed that the most frequent therapeutic goal for patients with prostate cancer was preservation of quality of life, followed by extension of life and other objectives, whereas urologists more frequently focused on survival prolongation as the goal of therapy (18). Whether such results, which differed from the overall literature, were due to differences in disease profile or survey methodology remains unknown. Generally, most patients with prostate cancer do not face imminently life-threatening disease, which is a potential explanation for their preference in the survey by Crawford et al. (18).

The present study, which should be considered our first attempt to enhance our understanding of the preferences and attitudes toward treatment among Brazilian cancer patients, suffered from limitations. Although the number of

Table 5 - Prioritization between survival time and quality of life (QOL) using weights.

| Scenario | Weight for lifespan | Weight for QOL | Patients | Health-care professionals | Laypersons |
|----------|---------------------|----------------|----------|---------------------------|------------|
| A | 10 | 0 | 11.6% | 2.3% | 6.0% |
| B | 8 | 2 | 13.7% | 11.6% | 6.0% |
| C | 6 | 4 | 28.4% | 14.0% | 23.9% |
| D | 4 | 6 | 26.3% | 53.5% | 37.3% |
| E | 2 | 8 | 14.7% | 16.3% | 19.4% |
| F | 0 | 10 | 5.3% | 2.3% | 7.5% |



Table 6 - Prioritization between survival time and quality of life using weights and grouping scenarios (see Appendix for definitions).

| Scenario | Patients | Health-care professionals | Laypersons |
|-----------|----------|---------------------------|------------|
| A, B or C | 53.7% | 27.9% | 35.8% |
| D, E or F | 46.3% | 72.1% | 64.2% |

patients investigated in this study was similar to that enrolled in prior face-to-face surveys (13-15,17), our sample size was relatively small. Notably, the number of individuals without cancer, including health-care professionals and laypersons, was smaller than in previous studies (13,18). In fact, enrollment for the current study was more difficult for the latter two groups than for the group of patients, the vast majority of whom readily agreed to participate after being invited by the interviewers. A second limitation, which was already noted, was that we did not ascertain the patients' knowledge regarding their diagnoses. In fact, we made every effort to avoid exposing the patients to psychological distress resulting from study participation. As noted previously, the hypothetical nature of the cases presented was emphasized in the introduction to the questionnaire. It should be noted, however, that the patients' choices might have been related to their knowledge or beliefs about their prognoses (19). A third limitation was that the current study was conducted at a private hospital in the city of São Paulo and the extent to which the observed patient preferences were representative of those of different social classes and regions of the country remains unknown.

In summary, both survival time and quality of life appeared to be important to cancer patients, oncology health-care professionals and laypersons in Brazil. However, the results of our study suggested that survival time was of higher priority to people who were diagnosed with cancer, whereas quality of life appeared to be more important to those for whom cancer (or, for that matter, the perspective of life's finiteness) was a more remote possibility.

ACKNOWLEDGMENTS

This work was funded in part by a grant from the Bioethics Centre of the São Paulo State Medical Council.

AUTHOR CONTRIBUTIONS

Marta GN, Del Nero LG, Mangabeira A and Critchi G were responsible for the definition of intellectual content, literature research, data acquisition, manuscript preparation, manuscript editing and manuscript review. Marta GN, Kovács MJ, Silva JL and Saad ED were responsible for study conception, study design, definition of intellectual content, literature research, manuscript preparation, manuscript editing and manuscript review.

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APPENDIX

STUDY QUESTIONNAIRE (translated from the original version in Portuguese)

1: A patient has just received a diagnosis of cancer. In your opinion, who should be involved in the choice of treatment? Please check as many options as you like.

-
- The physician
 - The patient
 - The relatives
 - Others members of the health-care team (nutritionist, psychologist, physiotherapist, others)
 - Everybody
-

2: A patient has just received a diagnosis of cancer. The physician discusses the therapeutic options and the possible side effects of the treatment with him or her. In your opinion, which therapeutic modality should be chosen?



- The type that prolongs survival, independent of quality of life
- The type that provides a reasonably long life, although not necessarily the longest, with minimal side effects and little impact on quality of life
- The type that provides maximal quality of life, although survival may be shorter
- No treatment should be given to avoid the risk of side effects or a negative impact on quality of life
- I do not know or prefer not to comment

3: A patient is diagnosed with a highly malignant cancer. Imagine that there are three therapies available for this type of cancer, termed X, Y and Z.

Treatment X is quite toxic for the organism and the patient be hospitalized for approximately one month until his or her body recovers. Visits will be restricted due to the patient's low resistance. There is a high chance of cure.

Treatment Y can produce nausea, vomiting, fever and tremors but is less toxic than treatment X. This treatment should be administered at the hospital once per week over a year's time, with no need for hospitalization. This drug does not cure the disease but can prolong survival by several months.

Treatment Z consists of an intravenous medication that must be administered once per month at the hospital. The patient needs to remain in the hospital for 30 minutes after each application. The most common side effects are mild, but this treatment is most likely less effective than treatment Y.

3a): Considering these three treatments, in your opinion, which one would be the most suitable if the patient were a **five-year-old child**? Please justify your answer below.

- Treatment X Treatment Y Treatment Z

3b): What if the patient were a **16-year-old adolescent**? Please justify your answer below.

- Treatment X Treatment Y Treatment Z

3c): What if the patient were a **50-year-old adult**? Please justify your answer below.

- Treatment X Treatment Y Treatment Z

3d): What if the patient were a **70-year-old patient**? Please justify your answer below.

- Treatment X Treatment Y Treatment Z

4: The following table represents six fictitious scenarios. In each one, there is a value for survival time and another for quality of life. Both for survival time and for quality of life, the value **zero** represents the worst possible situation (in each case, an immediate risk of death and major suffering from the disease), whereas a value of **10** represents the best possible situation (an expectation of a life of many years and no suffering caused by the disease). The other numbers represent intermediate situations.

| SCENARIOS | LIFESPAN | QUALITY OF LIFE |
|-----------|----------|-----------------|
| A | 10 | 0 |
| B | 8 | 2 |
| C | 6 | 4 |
| D | 4 | 6 |
| E | 2 | 8 |
| F | 0 | 10 |

Faced with a diagnosis of cancer, if you could choose only one of the scenarios above, which would you choose? Take into account that, for this hypothetical question, we are considering that you would have to choose either the length OR the quality of life. In practice, what the doctor tries to do for the patient is to increase both the lifespan and quality of life. However, imagine that this would not be possible and that you actually would have to choose what you consider to be more important.

- Scenario A
 Scenario B
 Scenario C
 Scenario D
 Scenario E
 Scenario F