Physician, patient and family attitudes regarding information on prognosis: a Brazilian survey

R. R. L. Fumis¹*, B. De Camargo² & A. Del Giglio¹

¹Department of Hematology and Oncology, ABC Foundation School of Medicine, Santo André; ²Post Graduation Program – Cancer Research Center Hospital A C Camargo, Sao Paulo, Brazil

Received 22 June 2010; revised 31 December 2010 & revised 1 February 2011 & revised 2 February 2011; accepted 2 February 2011

Background: Communication between physicians and patients is a fundamental aspect of cancer care, yet most physicians’ perceptions are often inconsistent with the patients’ stated preferences while prognostic information is the most misunderstood.

Patients and methods: Members of the Brazilian Society of Oncology Physicians (n = 609) were identified and asked to complete a mailed questionnaire. Outpatients (n = 150) and their family members (n = 150), oncologists and fellows (n = 55) from a public healthcare hospital and a tertiary cancer hospital in Sao Paulo were also personally invited to participate.

Results: A total of 202 physicians, 150 outpatients and 150 family members were participated. The majority of patients (92%) believe they should know about their terminal stage compared with 79.2% of physicians and 74.7% of families (P = 0.0003). Cancer patients were most likely to support disclosure of diagnosis and terminality (P = 0.001), to consider that this disclosure was not stressful (P < 0.0001) and that this knowledge would improve their quality of life (P < 0.0001).

Conclusions: Cancer patients seen in these centers in Southeastern Brazil prefer to know the truth about their poor prognosis more than their physicians and families think. Further studies with larger samples of patients and physicians are necessary to show if our results are representative of all Brazilian situations.

Key words: doctors, patients and families, prognosis, terminal cancer communication

Introduction

Prognostication is an important clinical skill for all physicians, particularly those who work with advanced cancer patients [1]. In Western countries, there has been among cancer patients an
increasing preference for more involvement in decision making about their care and more detailed information about their illness including prognosis [2].

Recent studies have shown that prognosis is commonly misunderstood [3, 4] and inadequately disclosed, particularly when it is poor [5]. In many countries, while most patients want to be informed about diagnosis of terminal illness, physicians are reluctant to disclose unfavorable medical information to patients with advanced cancer and instead give the bad news to the family [6, 7].

Variation of truth-telling attitudes and practices is worldwide determined by culture as well as the different roles of family members in the information and decision-making process of the cancer patient. Culture also affects patients’ perception of disease and influences the patient–physician relationship [2, 8]. However, there has been very limited research on communication with patients and families regarding diagnosis and prognosis in the developing world, particularly in South America, where they are seldom discussed and many needs of cancer patients regarding communication remain unmet [9].

In fact, over the last 30 years, the importance of communication skills of physicians to break bad news has been increasingly emphasized. There is evidence that this practice has improved but to disclose bad news is still a complex communication assignment. Even though there are some guidelines and recommendations on communicating bad news to help clinicians to disclose diagnosis and prognosis [10, 11], a high proportion of cancer patients continue to receive inadequate information about their disease [12] and the physicians’ perception is often inconsistent with the patient’s stated preferences [13].

The aim of this study was to evaluate attitudes and beliefs regarding communication with terminally ill cancer patients by oncologists working in all the regions of Brazil and to comprise cancer patients and their families in order to better characterize and explore these differences.

methods

The study design was a prospective survey conducted in three different populations: physicians, cancer patients and families.

In order to obtain patients’ and families’ opinions, participants were recruited from two cancer hospitals to take part in the survey. Hospital A.C. Camargo is a tertiary cancer hospital in Sao Paulo and Hospital Mario Covas is a public healthcare hospital in Santo Andre, ABC-Sao Paulo, of which both ethics committees approved this study.

In each hospital, a consecutive series of 75 outpatients and 75 family members present for medical consultations were asked to participate in the study reaching a total of 150 patients and 150 family members. Patients were invited to take part if they had a cancer diagnosis of at least 1 year in duration and if they were Brazilian natives. Regarding the family member recruited for this study, one relative per patient defined either as a spouse, child, parent or sibling in the waiting room was asked to participate in the interview. The same investigator (R. R. L. Fumis) who is a licensed psychologist collected all study data and conducted all interviews with patients and family members. Those who accepted were asked to complete the questionnaire without any assistance to avoid bias.

In order to obtain the opinions of cancer specialists, 609 questionnaires were mailed to physicians from all regions of Brazil, using the mailing list of the Brazilian Society of Oncology Physicians. Oncologists and oncology fellows, who worked in the same hospitals in which the patient and family interviews were conducted (Hospital A C Camargo and Hospital Mario Covas), were also invited to participate in person, regardless of whether they received the mailed questionnaire. Both groups were similar in most characteristics but differed in age and were also analyzed separately to avoid bias (Appendix S1, available at Annals of Oncology online). Regarding these mailed questionnaires, we sent the questionnaire by mail only once in November 2008 and we included in this study the responses that returned until July 2009. Since our aim was to evaluate the effects of conveying overall prognosis information to adult patients, radiation therapists and pediatricians who were also members of the Brazilian Society of Oncology Physicians were excluded.

For this survey, with the author’s authorization, questions derived from a previous study were used [14] to assess the attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients (Appendix S2, available at Annals of Oncology online). Ethical principles were defined as set forth previously by Bruera et al. [14], autonomy being understood as ‘what a patient wants’ and beneficence as ‘what the physician believes is best for patients’. Finally, justice was defined as the ‘fair distribution of healthcare resources for all patients’. All questions were translated into Portuguese and validated before being applied [15]. The instrument was translated from English to Portuguese by two bilingual experts, and then a back translation was made by other two translators who had not seen the original scale, in order to verify the equivalence of terms between the two versions. After translation and adaptation, the authors ensured that the new version included the evaluation properties required for application.

statistical analysis

The analysis of variance test was used for comparison of proportions within all three groups (physicians versus patients versus families). Each variable was analyzed by the chi-square test. A P value of <0.05 was considered statistically significant. Stepwise forward multiple linear regressions were used to determine factors associated with particular attitudes toward Do-Not-Resuscitate orders (DNR orders). SPSS statistical software was used for all calculations in this study.

results

Out of the 609 mailed questionnaires, a total of 212 were returned. Of these 54 were returned due to a wrong address. Five of the 212 questionnaires were not included because physicians answered that they were retired and did not participate in active patient care and an additional 6 were not used because they were incomplete. Thus, 147 questionnaires of the 609 initially mailed were suitable for evaluation. All personally invited physicians agreed to participate (n = 55) and all questionnaires from these physicians were suitable for evaluation.

Table 1 summarizes the characteristics of the 202 physicians suitable for evaluation separated into two groups (interviewed by mail and personally). Most of the physicians (n = 202) were men (76.2%), the median age was 46.5 years (range 25–91) and the median number of years of oncology experience was 18 (range 1–53 years). Brazilian specialists in oncology are predominantly located in reference medical care centers or teaching hospitals and we observed that they were concentrated mainly in the Southeast (64.4%). We did not identify regional differences regarding decision making and practices regarding
The majority of patient interviews had been diagnosed: 158 malignancies. We identified that the median time of initial diagnosis was 3 years (range 1–13). At the time of study entry, the majority had breast cancer (44.7%) followed by gastrointestinal (16%), hematological (12%) and gynecologic (9.3%) malignancies. We estimated that the median age was 53 years (range 22–82); 74% were women, frequently with a high school or college degrees. The majority of patients (92.7%) thought that being informed about their diagnosis of cancer and terminal stage is better/much better than the QOL of a person who ignores their diagnosis and terminal stage is considered to be the worst option. All patients should know the terminal stage of their illness (% who agree) was considered not stressful by 24.7% of patients. In contrast, up to 90% of families and physicians considered this information stressful (P < 0.0001).

Patients were most likely to agree that the quality of life is better for those who know their diagnosis and are aware that they are at a terminal stage (86%, 65.3%, and 50.5% for patients, families and physicians, respectively, P < 0.0001). However, patients’ perceptions about other patients were different from what they replied about themselves. They felt that 31.3% of patients were not aware of the terminal nature of their disease and 68.7% believed that >60% of patients do not know their terminal stage of illness (% who agree).
Physicians' views on communication of cancer diagnoses and decisions: Brazilian perspective

Table 3. Decision-making opinions

<table>
<thead>
<tr>
<th>Decision making</th>
<th>Physician decision</th>
<th>Shared decision</th>
<th>Patient decision</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most frequent in workplace, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients' views</td>
<td>55 (36.7)</td>
<td>95 (63.3)</td>
<td>0 (0.0)</td>
<td>0.009</td>
</tr>
<tr>
<td>Families' views</td>
<td>63 (42.0)</td>
<td>86 (57.3)</td>
<td>1 (0.7)</td>
<td></td>
</tr>
<tr>
<td>Physicians' views*</td>
<td>79 (39.1)</td>
<td>113 (55.9)</td>
<td>10 (5)</td>
<td></td>
</tr>
<tr>
<td>Most appropriate, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients' views</td>
<td>36 (24)</td>
<td>113 (75.3)</td>
<td>1 (0.7)</td>
<td>0.007</td>
</tr>
<tr>
<td>Families' views</td>
<td>42 (28)</td>
<td>106 (70.7)</td>
<td>2 (1.3)</td>
<td></td>
</tr>
<tr>
<td>Physicians' views*</td>
<td>45 (22.3)</td>
<td>143 (70.8)</td>
<td>14 (6.9)</td>
<td></td>
</tr>
</tbody>
</table>

*All physicians interviewed (N = 202).

Table 4. Ethical principles opinions

<table>
<thead>
<tr>
<th>Ethical principles</th>
<th>Autonomy</th>
<th>Beneficence</th>
<th>Justice</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients' views, n (%)</td>
<td>12 (8)</td>
<td>59 (39.3)</td>
<td>79 (52.7)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Families' views, n (%)</td>
<td>16 (10.7)</td>
<td>57 (38)</td>
<td>77 (51.3)</td>
<td></td>
</tr>
<tr>
<td>Physicians' views*, n (%)</td>
<td>64 (31.7)</td>
<td>75 (37.1)</td>
<td>63 (31.2)</td>
<td></td>
</tr>
</tbody>
</table>

*All physicians interviewed (N = 202).

not want to know their terminal stage. However, when questioned about themselves, 88.7% would like to know if they have a terminal cancer.

In our analysis, we found that those with less schooling are more likely to disagree with the item: all patients should know the terminal stage of their illness (68% × 32%, P = 0.021) and also disagree with the item: all patients should have a DNR order (60.6% × 39.4%, P = 0.026). We found that age did not influence patients’ preference.

Families (9.3%) and patients (10.7%) strongly disagree with physicians (52%) that >60% of terminal patients have DNR orders (P < 0.0001). Physicians are more likely to agree to that all patients who die of terminal cancer should have DNR orders written (92.1% versus 61.3% versus 54% for physicians, patients and families, respectively, P < 0.0001). However, patients (92.7%) and families (90.7%) were most likely to agree on the appropriateness of discussing this type of orders with the patient when compared with physicians (70.3%) (P < 0.0001).

We observed that patients from the tertiary cancer hospital are more likely to believe that >60% know their diagnosis when compared with patients from the public healthcare hospital (94% versus 69%, P = 0.0001). However, patients from the public healthcare hospital are more likely to believe that patients want to know if they have terminal cancer than those at a tertiary cancer hospital (40% versus 22%, P = 0.02).

Physicians reported that sharing decision-making responsibilities was the most frequent and most appropriate strategy in their workplace (Table 3).

Brazilian physicians were significantly more likely to support autonomy as an important ethical principle (31.7%) when compared with patients (8.0%) and families (10.7%) that more strongly support beneficence and justice (P < 0.0001) (Table 4).

A multivariate analysis showed that older and more experienced physicians are more likely to disagree with DNR orders and to be against openly discussing them with patients (Table 5).

Discussion

This survey assessed the attitudes and beliefs of Brazilian oncologists, patients and families regarding communication with cancer patients, principally discussing disclosure of the patient's terminal stage. To the best of our knowledge, this is the first report on the opinions of physicians specializing in oncology that covered all regions of Brazil and addressed the opinions of cancer patients and families regarding communication of diagnosis and prognosis.

There is perhaps no more difficult task in all of medical practice than to deliver the terrible news of an unfavorable cancer prognosis. While most physicians in different regions of the world tell patients their diagnosis of cancer, information about prognosis is less common, even when patients indicate a preference for this information [11, 16].

A very important finding of our study was that patients strongly believe that all patients should be aware of the terminal stage of their disease, whereas a substantial proportion of physicians would still like to refrain from communicating this end-of-life information. Our findings suggest that a patient’s diagnosis tends to be more often disclosed than prognosis. In agreement with literature [12], oncologists tended to agree that discussing cancer diagnosis was the least difficult task when giving bad news, whereas discussion of cancer recurrence, failure of treatment or lack of further curative treatment were more difficult.

The patients' desire for information can vary according to treatment and to the stage of their disease [17, 18]. Previous studies suggest that patient’s involvement in the decision-making process concerning treatment also varies with the stage of disease progression [17, 18]. Although this analysis is beyond the scope of the present study, our findings show that patients' preference did not change according to the time since initial diagnosis.

We showed that the nature of communication between Brazilian oncology specialists and their patients reflects Brazilian cultural values. The physicians, some of whom are fellows, think similarly, although there were differences in relation to age and time of practice. Attitudes toward certain issues, such as disclosure of prognosis and discussion of DNR orders were found to vary with the physician’s age. As expected, the years spent in oncology practice were unfavorable for honest disclosure to patients about their terminal stage. The
Disclosure of prognostic information to terminally ill patients has emerged in the last 15 years as a concern in the United States, particularly in the light of the greater demand for patient involvement in medical decision making [19]. The current study indicates that, in spite of the movement toward provision of more information to cancer patients in different countries, Brazilian physicians continue to have difficulties to communicate frankly with cancer patients.

Not surprisingly, our results also indicate that family members prefer their ill relative not to be informed of the terminal stage of their illness, similar to what has been found in other cultures [20]. Patients are willing to hear the truth about their poor prognosis, but the attitude toward such disclosure differs between patients and their families. In the Brazilian culture, there are intense family bonds that lead patients to wish that families be informed [21]. On the other hand, families become united in face of serious disease and view it as their obligation to protect patients from distress and play a major role in decision making about cancer care. Family members frequently ask the physician not to discuss with the patient their diagnosis, prognosis or other aspects related to cancer [12]. Interestingly, for cancer patients’ family members to understand the prognosis was a determinant of satisfaction in an intensive care unit [4]. It was recently shown that family members of critically ill cancer patients have high rates of anxiety and depression and frequently are involved in disagreements with patients [22]. More discussions about the complexities of prognostication in advanced cancer may improve families’ end-of-life experiences by simply helping them to understand the nature of the patients’ illness [23]. Additionally, such discussions with patients and their families may facilitate advanced care planning and improve satisfaction with end-of-life care [24].

The growing palliative care movement in Brazil may have been responsible for many of the changes in the attitude of physicians toward openness about disease and discussion of the quality of life. Attitudes and practices of truth telling to people with cancer have shifted substantially in the past few years. Ten years ago, in a similar study, physicians reported that at least 60% of their patients were aware of their diagnosis and terminal stage of their disease in 52% and 24% of cases in South America [14] in contrast to 84.4% and 38.8% in this study. However, the degree of disclosure still falls short of patients’ expectations. The reluctance to open communication is equally observed in other specialties such as psychiatrists and general practitioners when informing a difficult diagnosis and prognostic scenarios such as schizophrenia and dementia [6]. Indeed, in cases of fatal prognosis, most physicians would tell only the family, whereas only one-third of them would talk directly to the patient [25]. Physicians have previously reported that it was stressful to deal with patient families and to respond to their patients’ emotions, to be honest without depressing their patients and to handle their own negative feelings [12]. Physicians and families believe that to communicate poor prognosis probably leads patients to lose hope and discourages them from fighting the disease and hastens their death [20].

The attitude of Brazilian physicians reflects a more paternalistic pattern of practice. We observed that patients and families agreed with shared decision making and strongly minimized autonomy. Our study shows that physicians replied that they would not involve patients and families in the DNR orders discussion. Patients certainly would wish to further discuss this issue. Our results confirm old problems associated with death in the Brazilian society with the occasional participation of families and patients in the decision-making process [26, 27]. Recently, the Brazilian Federal Council of Medicine, aware of such problems, issued a resolution [28] that reinforces the responsibility of Brazilian physicians to involve families and explain end-of-life care and appropriate life support limitation measures for patients defined as irreversible.

There are limitations to our study. One of the most important is the low return rate (24.1%) of the questionnaires. In previous studies [29, 30], we observed that response rates vary from 60% to 83%. In these studies, the authors send the questionnaire more than once. Interestingly, in a study conducted in Brazil [31] with the questionnaire mailed just once, we also observed a lower response rate (21%). Although representatives from all regions of Brazil answered the questionnaire, the majority of physicians included in this study are from the Southeast because this region accounts for the largest metropolises and hospitals. The low return rate of the questionnaire can jeopardize representativity considering the continental size of Brazil and its regional difference, although we did not find significant difference in their distribution. Also, the sample of patients and caregivers is

Table 5. Significant physicians’ variables associated with disagreement with DNR orders in univariate and multivariate analysis

<table>
<thead>
<tr>
<th>Significant variables all physicians (N = 202)</th>
<th>OR (95% CI) univariate</th>
<th>P</th>
<th>OR (95% CI) multivariate</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree with DNR orders</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.08 (1.04–1.13)</td>
<td>0.0003</td>
<td>1.08 (1.04–1.13)</td>
<td>0.0003</td>
</tr>
<tr>
<td>Time since graduation</td>
<td>1.08 (1.03–1.12)</td>
<td>0.001</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Oncology experience</td>
<td>1.07 (1.03–1.12)</td>
<td>0.001</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Surgical oncology specialty</td>
<td>4.50 (1.37–14.73)</td>
<td>0.01</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Disagree with discussed DNR orders</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.03 (1.00–1.05)</td>
<td>0.03</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Time since graduation</td>
<td>1.03 (1.00–1.05)</td>
<td>0.03</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Oncology experience</td>
<td>1.03 (1.00–1.05)</td>
<td>0.02</td>
<td>1.03 (1.00–1.05)</td>
<td>0.02</td>
</tr>
</tbody>
</table>

DNR: Do-Not-Resuscitate; CI: confidence interval; OR: odds ratio.
unbalanced regarding the distribution according to gender including mostly female patients and caregivers. Furthermore, the median of time physicians spent in palliative care was considerably short (equal to 20% of their total professional time) and therefore, most physicians have limited practice in palliative care, and possibly, these oncologists may have limited experience with terminally ill patients.

Another limitation was that this study did not gather detailed information about treatment content and stage of the disease. The purpose of this survey was to address the opinion of Brazilian oncologists and to compare it with that of cancer patients and their families to better characterize and explore the different opinions. Since the patients’ involvement in the decision-making process was not addressed in this analysis, we only considered important the initial time of diagnosis. Furthermore, the samples of subjects we included in this study are too small to be representative of the Brazilian population, specially regarding physicians. Furthermore, we cannot exclude selection biases that could impact into the generalizability of our conclusions.

Finally, we conducted our study with outpatients. Although we observed that metastatic setting did not influence their preferences, the beliefs of outpatients may differ from those of advanced cancer patients receiving palliative care inside the hospital that have a more restricted life expectancy.

Despite the aforementioned important limitations, the present study suggests that disclosing diagnosis and prognosis is of special importance to cancer patients. In another setting, we have shown that this disclosure does not jeopardize their quality of life and that good communication practices may produce greater satisfaction [32]. Furthermore, our findings add to the evidence favoring open disclosure of prognostic information to cancer patients and help to fill a gap of studies from South America on cultural differences in communication with cancer patients. Our results agree with those of a large study conducted in Korea [33], showing that most patients with terminal cancer and their family preferred disclosure and patients who knew of their diagnosis had a lower rate of emotional distress and a higher health-related quality of life.

funding


disclosure

The authors declare no conflict of interest.

references


