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Information given to cancer patients on diagnosis, prognosis and treatment: the clinical oncologist's perspective ☆

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Abstract

The extent of information to cancer patients is, in general, culture-dependent. Information mainly refers to three aspects, namely diagnosis (Dx), prognosis (Px) and treatment (Rx), but the relative contribution of each domain to the information given overall is not available. To address this issue, we e-mailed a questionnaire to 9893 members of the American Society of Clinical Oncology (ASCO) asking whether they agree that information about Dx, Px and Rx contribute differently to the information given to the cancer patient overall and, if so, to what extent, both in the adjuvant and advanced settings. 857 questionnaires were evaluable. There was no statistically significant difference between the contribution of these 3 domains in the adjuvant setting (33%, 34% and 33%, respectively). In subgroup analysis, medical oncologists and haematologists attributed a significantly higher contribution of Px information compared with other specialists ($P < 0.05$). In the advanced setting, respondents estimated a higher contribution of Px (41%) to patient information overall compared with Dx and Rx (28% and 31%, respectively; $P < 0.05$). This finding was more pronounced in North America than in Europe ($P < 0.0001$), and in Germanic-language than in Romance-language countries ($P = 0.005$). In conclusion, information on Dx, Px and Rx are believed to contribute differently to the information delivered to cancer patients overall, depending on the stage of disease, the cultural environment and the specialty of the physician.

Keywords: Cancer patients; Delivery of bad news; Culture; Information; Diagnosis; Prognosis; Treatment

1. Introduction

In recent years, interest in the process of breaking bad news to cancer patients has grown (Fig. 1). Reports suggest that most cancer patients would prefer to be informed about their illness [1,2]. It is generally taken for granted that patients with cancer are fully informed about their disease, but this may not be true. Patients' attitudes towards cancer are culturally determined and the extent of information is, in general, culture-dependent [3]. In North America and Northern Europe, cancer patients are usually told their diagnosis and prognosis [4]. In Southern Europe, Japan, Central and South America, cancer patients are sometimes only partially informed about their condition [5–9]. In the Navajo community, communication of bad news to patients with cancer is highly discouraged [10,11].

Information given to cancer patients mainly refers to three aspects of their condition, namely diagnosis (Dx), prognosis (Px) and treatment (Rx), and these may contribute differently to the information given overall. Despite an increasing interest in this topic, to date, a standardised evaluation of the relative contribution of

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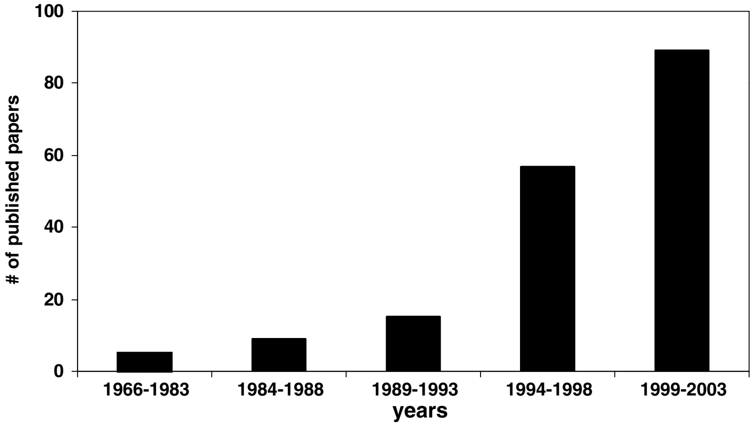

Fig. 1. Trend of number of published papers on information given to cancer patients by date of publication. A Medline search was performed to retrieve publications on this topic in the years 1966–2003 using the string "cancer [TITLE/ABSTRACT] AND patient [TITLE/ABSTRACT] AND (information [TITLE] OR "bad news" [TITLE])". Only pertinent articles were considered.

each domain to the information given to the patient overall is not available.

Accordingly, we surveyed members of the American Society of Clinical Oncology (ASCO) to assess their views on whether they think that information on Dx, Px and Rx contribute equally to the information delivered overall to cancer patients. We asked them to estimate the contribution of each domain to the information given overall and looked for differences between the adjuvant vs advanced settings, Europe vs North America, Romance-language vs Germanic-language countries and medical oncologists vs other specialists.

2. Methods

2.1. Participants included and questionnaire survey

From April 5 to June 26, 2000, we emailed a questionnaire concerning cancer patient information to 9893 ASCO members around the world (Fig. 2). The questionnaire was emailed to the ASCO members listed at that time in the on-line member directory on the ASCO web-site (www.asco.org), provided they had indicated an email address for correspondence. At that time, over 13,000 members were listed in the ASCO directory. We did not send any reminder emails to the non-respondents.

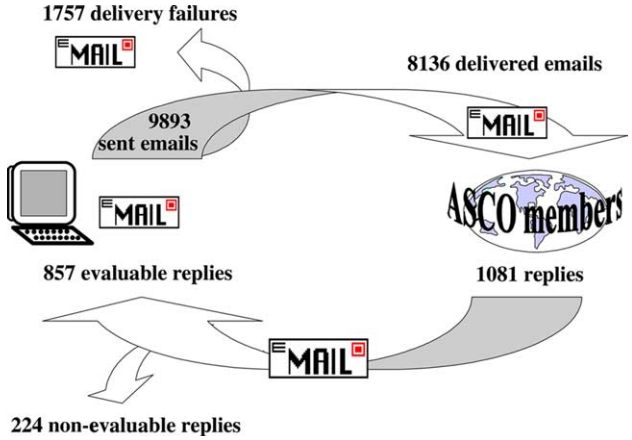

Fig. 2. Schematic representation of the survey. ASCO, American Society of Clinical Oncology.

The questionnaire asked respondents to indicate whether they agreed that information about Dx, Px and Rx contributed differently to the information given to cancer patients overall. If the answer was "yes", we asked them to estimate the relative contribution of each domain to the patient information overall, as a percentage, both in the adjuvant and advanced settings.

Data were handled anonymously. Each respondent was identified by his/her initials, country of residence according to the address indicated in the ASCO directory, and specialty. Depending on their address, respondents were further categorised as either Europeans (i.e. from Austria, Belgium, Bosnia, Croatia, Denmark, Eire, Finland, France, Germany, Greece, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey, United Kingdom), North Americans (from the United States of America (USA) and Canada), or others (from all other countries represented).

In order to assess the impact of cultural background, we also categorised respondents according to the linguistic-cultural background of their country of residence. In particular, we compared Romance-language countries vs Germanic-language countries. Romance-language countries include those where a Romance-language is commonly spoken. Romance languages derive from the Vulgar Latin dialects spoken in different areas after the decline of the Roman Empire. In this study, respondents from Argentina, Belgium, Brazil, Colombia, Philippines, France, Guatemala, Italy, Mexico, Peru, Portugal, Spain and Uruguay were included in the Romance-language group. Germanic-language countries include countries where a Germanic language is commonly spoken. Germanic languages comprise languages spoken in Scandinavia, Central Europe, and in the Anglo-Saxon countries. Respondents from Australia, Austria, Canada, Czech Republic, Denmark, Eire, Finland, Germany, Netherlands, New Zealand, Norway, South Africa, Sweden, United Kingdom and the USA were included in the Germanic-language group. Respondents from Switzerland were categorised according to the language spoken in the Canton of residence.

2.2. Statistical analysis

Differences based on country of practice (i.e. Europeans vs North Americans vs others) and cultural background (i.e. Romance-language vs Germanic-language vs others) were evaluated using the Kruskal–Wallis test for non-parametric data. Comparison between medical specialists (i.e. medical oncologists/haematologists vs other specialists) was done using the Mann–Whitney *U* test for non-parametric data. Significance was accepted as $P < 0.05$.

3. Results

3.1. Characteristics of respondents and response rate to survey

Among the 9893 emails sent, 1757 (17.8%) were delivery failures, therefore 8136 emails were actually delivered. One thousand and eighty one ASCO members replied to our email by December 31, 2001. Two hundred and twenty four questionnaires were excluded due to at least one of the following: (1). incomplete, inappropriate, or non-evaluable answers; (2). respondents not qualified (i.e. not responsible for the delivery of bad news to cancer patients, such as preclinical researchers, pharmaceutical company or government agency employees, clinical psychologists, medical writers, statisticians, nurses, retired or non-practicing physicians). Approximately 10% of non-evaluable respondents reported difficulties in understanding the questions in our survey. Therefore, 857 questionnaires completed by physicians from 49 countries were included in the final analysis (response rate, 10.5%).

Most of these questionnaires (57.3%) were from physicians practicing in the United States, followed by Italian (5.0%), French (4.3%), Canadian (4.2%), British (3.1%) and Japanese (2.9%) physicians. Medical oncologists and haematologists accounted for 64.5%; radiation oncologists, surgical oncologists and gynaecologists accounted for 7.0%, 5.5% and 3.1%, respectively. Board certification was not indicated for 9.6% of the respondents. No analysis was done based on the respondent's gender, age or practicing experience.

3.2. Survey outcomes

Ninety eight percent of the respondents gave an affirmative answer to the question of whether Dx, Px and Rx contributed differently to the information given to the cancer patient overall.

Physicians were asked to indicate the contribution of each domain to the information given, overall as a percentage. Complete results, expressed as the mean percentage of contribution, are reported in Table 1. Overall, there was no statistically significant difference between the putative contribution of each domain in the adjuvant setting. In the advanced setting, most respondents reported a major contribution for Px information. This was significantly different from the contribution of this domain in the adjuvant setting ($P < 0.05$).

To assess geographical differences, we compared the contribution of the three domains as indicated by North American vs European physicians. There was no difference in the adjuvant setting. However, in the advanced setting, respondent physicians from North

Table 1
Perceived contribution of the three domains by ASCO members and comparison by geographical location, cultural background and speciality

	Adjuvant setting (%)			Advanced setting (%)		
	Dx	Px	Rx	Dx	Px	Rx
All respondents ($n = 842$)[a]	33	34	33	28	41[b]	31
Europeans ($n = 200$)	34	33	33	29	36	35[b]
North Americans ($n = 497$)	33	35	31	27	43[c]	30
Germanic language ($n = 597$)	33	35	32	27	42[b]	31
Romance language ($n = 155$)	35	34	31	30[b]	37	33
Medical oncologists/haematologists ($n = 527$)	33	35[b]	32	28	40	31
Others ($n = 214$)	34	33	33	27	43	30

Abbreviations: Dx, diagnosis; Px, prognosis; Rx, treatment; ASCO, American Society of Clinical Oncology.

[a] Fifteen respondents, who answered that Dx, Px and Rx do not contribute differently, have been excluded.

[b] $P < 0.05$.

[c] $P < 0.0001$.

America reported a significantly higher contribution of Px compared with their European colleagues (43% vs 36%, $P < 0.0001$). In parallel, European physicians reported a significantly higher contribution of Rx information (35% vs 30%, $P = 0.0015$).

In order to assess the impact of cultural background, we also compared responses between physicians practicing in Germanic-language vs Romance-language countries. There were no significant differences in the adjuvant setting. However, in the advanced setting, Romance-language physicians reported a significantly higher contribution of Dx information compared with Germanic-language physicians (30% vs 27%, $P = 0.02$), while the latter reported a higher contribution of Px to the information given overall (42% vs 37%, $P = 0.005$).

Finally, we assessed differences between reports from physicians with different medical backgrounds. Medical oncologists and haematologists reported a significantly higher contribution of Px in the adjuvant setting, when compared with physicians with a different specialty (35% vs 33%, $P = 0.04$). No significant differences were observed in the advanced setting.

4. Discussion

Looking at how the information given to cancer patients is perceived among cancer professionals, our survey suggests that information on Dx, Px and Rx may contribute differently to the information given overall. While Dx, Px and Rx contribute equally in the adjuvant setting, information on Px is more predominant than the other two domains in the advanced setting. This is consistent with the fact that facing a life-threatening disease, Px is the most relevant information: “Doc, how much time do I have?” is the issue [12,13].

Breaking down our results by geographical location and linguistic-culture, a slight, but statistically significant difference was observed in the pattern of information given to cancer patients in the advanced setting. North American physicians estimated a higher contribution of information on Px compared with their European colleagues. Such a difference may be explained by cultural heterogeneity between the different European countries. Germanic-language physicians estimated a more relevant contribution for information on Px compared with physicians from the Romance-language countries. In the Romance-language countries, when “cancer” is diagnosed, the patient’s family may play a central role and the Dx and Px are often hidden from the patient, either partially or completely, at the family’s request.

To our knowledge, this is the first survey evaluating the physician’s perception of the relative contribution of the three domains to patient information given overall. There are several limitations to our analysis. First, ASCO members may not be representative of all practicing cancer physicians worldwide. Outside North America, ASCO members account for a small percentage of all cancer physicians in individual countries, whose perceptions may not reflect those of all of their colleagues.

Second, out of approximately 8000 delivered emails we had only 857 evaluable replies (response rate of 10.5%). This is lower than rates reported in other recently published surveys among ASCO members where responses ranged between 49% and 60% [14–16]. However, in these published studies, ASCO directly surveyed its membership and members who failed to respond to the first mailing were sent a second mailing and/or were telephoned in one of these surveys, Authors reported that up to seven attempts were made to reach physicians [15]. The low response rate in our survey may have led to a bias in our results.

Third, in order to limit the time necessary to complete our survey, only a few items were included in our questionnaire. We asked for a general evaluation of the contribution of the three domains to the information given to the cancer patient overall in the adjuvant and advanced settings, irrespective of the type of cancer, stage of disease, time of evaluation during the evolution of the disease and patient characteristics. All these variables may deserve further investigation. Finally, each individual patient has his/her own perception of their disease, and it may not match those of their treating physician.

In conclusion, cancer physicians perceive that the information on Dx, Px and Rx in general contributes differently to the information given to cancer patients overall.

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