



Research Paper

Interview in a random and not ill population: If you have cancer would you like to know?

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ABSTRACT

The incidence of cancer is increasing in absolute and proportional number of cases. Despite major advances in diagnoses and treatment, disclosure bad news is often inevitable during the course of the disease. Several protocols have been developed to increase effectiveness and standardize communication with patients; however, they are usually based on experiences and reaction of individuals with known cancer. This study aims to evaluate in a random population of individuals without the known exposure factor (cancer diagnosis) the predictive factors and preferences on how to receive the bad news. A survey, containing questions about demography and formulated by the authors, was applied to passers-by in the city centre of the countryside of Rio de Janeiro, Brazil, from 2014 to 2015. Subsequently the data was compiled into a Microsoft Excel® version 97 - 2003 table and later exported to the Epi Info® program version 3.5.2 of December, 2010. Of the 1, 201 people interviewed, 1181 met the inclusion criteria. A majority of 1, 089 (92.6%) would like to be informed of a possible diagnosis of cancer. Advanced age, low purchasing power and low level of schooling seems to be related to a greater tendency and preferred not to be informed of the diagnosis of cancer, as well as, occupations such as human sciences etc ($p < 0.05$). On the other hand, for occupations such as students, biological and exact sciences, they prefer to be informed ($p < 0.05$). There was no significant difference for sex ($P = 0.9222$) or religion ($P = 0.8752$). Three hundred and twenty-five individuals (27.51%) reported some reasons to omit the diagnosis of cancer to any patient due to: 130 (40%) probable deleterious psychological effects; 60 (18.46%) might compromise the patient clinical status, 42 (92%) may cause embarrassment or discrimination, 30 (9.23%) for pity and 63 (19.38%) other opinions ($P < 0.05$). Our study was a pioneer to show that nearly one in fourteen healthy individuals would prefer not to receive the diagnosis of cancer (7.4%). Factors associated with this preference were schooling level, purchasing power, job occupation and age range. An expressive 27.51% of respondents believe there is a reason to omit the diagnosis of cancer to a patient. Further investigations are required to improve the effectiveness in the communication between clinicians and potential patients.

Key words: Cancer diagnose, diagnose disclosure, bad news.

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INTRODUCTION

The incidence of cancer is increasing in absolute number of cases (GLOBOCAN, 2018). Effective communication is the key for the management of cancer patients (Fallowfield and Jenkins, 1999); despite the fact that the community is more

aware of the disease, the new century is marked by active discussion between the patient and the oncologist (Saraiya et al., 2010). For an expressive portion of patients, despite the tremendous advances made in the many therapies

available, bad news can be given (Upreti and Kasireddy, 2015). Recently, as patients actively participate in their treatment decisions sincerity substituted the old fashioned practice called “silence conspiracy” (Costantini et al., 2006).

According to Buckman (1992), bad news is defined as “any information which adversely and seriously affects an individual’s view of his or her future”. It can occur from the time of diagnosis to the most advanced phase of treatment (Eng et al., 2012).

One of the most recognized tools, which works as a prototype, the SPYKES six-step protocol, developed by the collaboration of the University of Texas MD Anderson Cancer Centre and the Toronto-Sunnybrook Regional Cancer Centre, showed that flexibility in communication process depending on individual preference appears to be a good alternative (Baile et al., 2000). An Asian study aimed to evaluate perceptions when disclosing a diagnosis of cancer using a BAS tool (breaking bad news assessment schedule) through the interview of 134 patients and the findings indicated body language, time management and identification of the main fears and concerns of patients (Back et al., 2005). In Germany, a reassessed study of 350 cancer patients assessed preferences in receiving bad news using the Marburg Breaking Bad News Scale based on sub-classifications of the SPIKES protocol. The results showed that only 46.2% are completely satisfied with how they received the bad news. The overall quality of receiving the news is significantly related to the emotional state of the patient receiving it. The author concludes that the SPIKES protocol may require adjustments for this population (Seifart et al., 2014).

There are three specific concerns regarding a cancer diagnose disclosure: physician belief, patient preferences and family preferences (Montazeri et al., 2009). This is worthwhile to highlight that for many cultures cancer diagnosis is often interpreted as death sentence (Montazeri et al., 1993), while some studies reported better psychological outcomes in patients “spared of the bad news” (Chandra et al., 1998; Bozcuk et al., 2002). Other authors reported that this might be a matter of cultural preferences once the disclosure did not have any impact in the quality of life (Barnett, 2006; Centeno-Cortés et al., 1994; Janbabaei et al., 2014).

Several protocols are available to guide the health team on how to disclose the bad news (Miyata et al., 2017). On the other hand, it is important to notice that they are result of a group analysis and therefore lacking on current standard personalized care. Furthermore, the literature shows studies with variable numbers of individuals in different countries using different methodologies, most of which originated from convenience samples, based on patients already diagnosed and possibly at different stages of treatment, including cultural contrasts between Oriental and Occidental countries leading to conflicting results (Fine, 1991; Pereira et al., 2017). Therefore, a considerable rate of not ideal scenarios, such as phone calls and hostile

environments, as well as, cultural preferences are reported and thus reinforcing the challenge faced when we try to personalize the diagnosed disclosure for cultural, spiritual and religious believes (Alexander et al., 1993 ;Jawaid et al., 2010).

The authors proposed and conducted a field study based on a survey with pre-defined questions in a randomized population with a sample calculation to verify if there are predictive factors for preferences in receiving news related to the diagnosis of cancer.

MATERIALS AND METHODS

Sample calculation was performed using a finite sample and standard deviation formula (Supplementary appendix S1). The income criterion was used in the studied population divided into economic classes from A1 to E according to the study carried out by IBGE - Brazilian Institute of Geography and Statistics (2009). The calculation of the sample revealed a number needed to reach the confidence interval of 1125 subjects (Al-Amri, 2016).

This study was conducted in compliance with the Good Clinical Practice Guidelines and the Declaration of Helsinki. The Ethical Committee of the UniFOA – University Center Oswaldo Aranha Foundation approved the study. All participants had to be at least 18 years of age, be able to read or write or being accompanied with a relative. The subject informative consent was written in Portuguese and signed by the investigator and the subject before the subject start to fulfil the survey. The right to withdraw the consent at any time was guaranteed in all circumstances.

The survey was produced by the first and last authors based on previous surveys available on literature, and then discussed with the other authors before approval. Language in the containing text was adopted for better subject understanding after the evaluation of 20 surveys returned from subjects circulating in the OncoCentro clinic, such as patients, employees and health professionals. The final version contained 9 questions, while eight of them allowed only yes/no answers, one allowing one choice between 5 options and two containing a space for free text if the subject would like to express his concerns subjectively. This concise version was specially idealized to optimize answers and increase the subject compliance. Twelve surveys were returned unanswered and excluded from final analysis.

Statistical analysis

The data was compiled into a Microsoft Excel® version 97 - 2003 table and exported to the Epi Info® program version 3.5.2 as of December, 2010. The mean, variance, standard deviation and confidence intervals were calculated. For binary comparisons the Yates test was used. When multiple comparisons that required statistical significance with P-value, the Bartlett's test was used depending on its result.

For the Bartlett's chi-square <0.05 test the two Mann-Whitney / Wilcoxon tests (two groups of Kruskal-Wallis test) was selected and the Bartlett's chi-square > 0.05 was used in the ANOVA test (Parametric test for comparison of means).

RESULTS

The presentation of individuals by economic class was: class A1 68 individuals (5.8%), class A2 137 individuals (11.6%), class B1 155 individuals (13.1%), B2 203 individuals (17.2%), C2 17 individuals (18.1%), C2 176 individuals (14.9%), D 92 individuals (7.8%), E 25 individuals (2.1%) and 111 individuals (9.4%) who opted not to report. In terms of schooling: illiterates were 20 individuals (1.7%)(Table 1 - Sample characteristics).

Answer yes to question 1 involved 92.6% of the subjects (Table 2-Survey Answers). For age, individuals between 18 to 25 years and between 26 to 35, answered no to question 1 (4.7 and 5.4%) and on the other hand individuals aged 66 to 75 years and over 76 years (15.8 and 16.7%) ($P < 0.05$ - Kruskal-Wallis test) (Table 3-Relevant Results). Economy class A1 and A2 reported 92.6 and 98.5% of the answer yes to question 1 and class D and E indicated 88.0 and 91.9%, respectively ($P < 0.05$ - Kruskal-Wallis test). For schooling, 25% of illiterate individuals and 16.8% with complete elementary school answered no to question 1. 1.8% had incomplete graduation course, while 4.8% had complete graduation ($P < 0.05$ - Kruskal-Wallis test) (Table 3).

For occupations related to biological sciences, exact sciences and students presented respectively 97.0, 96.5 and 97.9% of answer yes to the first question, whereas human sciences and other occupations without defined area (commerce and general services) responded with 91.3 and 89.1% ($P < 0.05$ - ANOVA test) (Table 3).

For religion, 75% of atheists and 90.1% of evangelicals answered yes to the first question, but there was no significant difference for religion ($P = 0.8752$ - Kruskal-Wallis test). For sex, 92.4% of the women and 93% of the men answered yes to question 1 ($P = 0.9222$ - Kruskal-Wallis test). Individuals who answered yes to question 1 have a relative risk of 2.33 to answer yes to question 2 $RR = 2.33$ (95% $CI = 1.81 - 2.99$). This presentation corresponds to 96.6% of the individuals interviewed, ($P < 0.05$ - Fisher's exact test) (Table 3). For individuals who answered yes to question 1, 82.1% answered no to question 3 ($P < 0.05$) - Fisher's Exact Test) (Table 3).

For question 4, 27.51% of the individuals who answered no to question 1 answered yes to question 4, ($P < 0.05$ - Fisher's Exact Test) (Table 3). The reasons were related: 40% probable psychological effects deleterious to the patient, 18.46% clinical state compromised, 12.92% patient may suffer embarrassment or discrimination, 9.23% for charity to the patient and 19.38% other opinions (Table 2).

For question 5, there was no relation with the answer yes to the first question ($P = 0.2393747892$ - Fisher's exact

test) (Table 3). For question 6, 87.1% of those who answered yes also did so for question 1 ($P < 0.05$ - Fisher's Exact Test) (Table 2). For question 7, 42.7% were reported for the doctor, family and patient followed by 30.6% of the interviewees who reported the doctor and the patient; this was also followed by 25.8% physician and family in a first contact, finally, 0.9% believed that they should not be informed. 91.1% of subjects answered yes to question 8 and 98.1% for question 9.

DISCUSSION

From our point of view, this survey is the first in literature that evaluated individuals randomly, with no known confounding factor and in a calculated sample size reached. The study showed that in the evaluated population almost one in fourteen people prefer not to be informed of the diagnosis of cancer.

A similar paper in Tokyo accounting with 246 subjects published in 2004 was one in thirty-three (Fine, 1991). He also highlights the growing necessity and aim to inform patients noticed in oriental comparative studies. This contrast with Pakistan data shows that 19% of respondents of the questionnaire refused to have knowledge of the diagnosis of cancer (Bedikian et al., 1985).

The comparison between means was significantly different in age group, economy class, schooling and occupation. Old age, low purchasing power and low level of schooling seems to be related to a greater tendency not to prefer to be informed of the diagnosis of cancer, as well as, occupations such as human sciences etc. Young people, high purchasing power, high schooling and occupations such as biological sciences, exact test and students tend to prefer to be informed of the diagnosis of cancer. There was no significant difference for sex or religion. A retrospective study of 121 patients evaluated the patients' reports when they received the news. Young women tended to find the experience more stressful in contrast to the elderly (Gonçalves et al., 2011). In a Saudi Arabia and an Iranian paper, illiterate patients appear to prefer not to know their diagnosis (Hagerty et al., 2004; Montazeri et al., 1993). On the other hand, retrospective studies of the same theme and country shows that half of the patients did not know their diagnosis as well as, 31% of their relatives (Otani et al., 2011; Konstantis and Triada, 2015).

In the Iranian study, half of the patients were not informed about their diagnosis (Montazeri et al., 1993). There was no significant difference for religion and sex in this study. However, a Saudi Arabia study of 420 patients showed significant difference of more than 20% of men preferring to know their diagnosis versus women; in addition, similar differences were also observed in illiterate patients which did not want to know their diagnosis (Ibrahim et al., 1991). This association is variated in literature, whereas several studies did not report any

Table 1: Sample characteristics.

Characteristic	Value	Percentage (%)
Economic classes		
A1	68	5.80
A2	137	11.60
B1	155	13.10
B2	203	17.20
C1	217	18.10
C2	176	14.90
D	92	7.80
E	25	2.10
NR	111	9.40
Schooling		
Unliterate	20	1.70
Elementary school	173	14.60
High School	407	34.50
Graduation Ongoing	228	19.30
Graduation/Post-graduation	353	29.90
Age range (years)		
18-25	321.00	27.20
26-35	297.00	25.10
36-45	230.00	19.50
46-55	189.00	16.00
56-65	88.00	7.50
66-75	38.00	3.20
> 76	18.00	1.50
Occupation		
Biological and health sciences	100	8.50
Exact sciences	170	14.40
Human sciences	104	8.80
Students	193	16.30
Others	599	50.70
NR	15	1.30
Gender		
Women	735	62.20
Men	446	37.80
Religion		
Catholic	616.00	52.20
Spiritism	171.00	14.50
Evangelic	232.00	19.60
Not Revealed	77.00	6.50
Others	63.00	5.30
Atheist	20.00	1.70
Baptist	2.00	0.20

Table 2: Survey answers.

S/No	Question	Answer	Rates
1	If you were diagnosed with cancer would you like to know?	Yes	92.60% (1094)
		No	7.40% (87)
2	If your relative were diagnosed with cancer would you like to let him know?	Yes	92.50% (1091)
		No	7.50% (88)
3	Do you think you might feel embarrassed to reveal your diagnosis in case it is cancer?	Yes	19.70% (233)
		No	80.30% (948)
4	In your opinion, is there a reason not to disclose a diagnosis of cancer for someone?	No (we should disclosure)	72.40% (854)
		Yes (avoid psychological disturbance)	11.00% (130)
		Yes (mixed reasons)	5.30% (63)
		Yes (it will worsen the clinical status)	5.10% (60)
		Yes (avoid cause shame/embarrassment)	3.60% (42)
		Yes (for pity)	2.50% (30)
5	Do you have a relative with cancer?	Yes	47.50% (561)
		No	52.50% (620)
6	In the case of yes for question 6, would he/she disclose the diagnosis to him/her?	No	15.01% (85)
		Not remember	0.52% (3)
		Yes	84.47% (479)
		Not applicable	(614)
7	What is the best scenario to disclose a cancer diagnosis?	Only patient and physician	25.80% (293)
		Physician, family and physician	30.60% (348)
		We should not tell the patient	0.90% (10)
		Physician and family, then the family disclosure to the patient	42.70% (485)
8	Should we disclose a cancer diagnosis for the patient before the start of treatment?	Yes	91.10% (1076)
		No	8.90% (105)
9	Do you think it should be a multidisciplinary team to disclose a cancer diagnosis for a patient?	Yes	98.10% (1158)
		No	1.90% (23)

difference, and this seems to be linked to cultural characteristics (Otani et al., 2011).

The relative risk of 2.33 of those who answered yes to question 1 also indicate yes to question 2 suggesting agreement between decisions to family members and individual opinions, although we did not ask this specific question in Pakistan where 25.2% of respondents of a questionnaire prefer to inform the family of the patient and not the patient himself (Al-Amri, 2016). This raises an ethical issue between what should be told, what must be told, what people want to be told and what the patient would like to be informed.

Approximately, 18% of those who answered yes to question 1 did answer question 3. This fact reinforces that

social constraint is still an important barrier for potential patients. This question is not so simple even for health professionals as pointed out in a Japanese study in which there was a significant relationship with the difficulties reported with the feeling that the news will take away the hope of the patient and concern that the family will blame the doctor, the patient will ask for self-control and may not have enough time for the news to be given (Konstantis and Triada, 2015).

The results of the analysis of the responses of 27.51% of the individuals believe there is a reason not to tell the patient of the diagnosis, and the reasons were: 11.00% believed on probable deleterious psychological effects to the patient, 5.10 and 3.60% believed that the patient may

Table 3: Relevant results.

Question/comparison	Test	P-value
Question 1 - Age Range (years old) (NO/NO)		
18 - 25 and 26 - 35 4.7% and 5.4% versus 66 - 75 and > 76 years 15.8% and 16.7%.	ANOVA	P = 0,0001
Question 1 - Economic class (YES/YES)		
A1 and A2 reported 92.6% and 98.5% versus class D and E indicated 88.0% and 91.9%	ANOVA	P = 0,0039
Question 1 - Schooling level (NO/NO)		
25% of illiterate individuals and 16.8% elementary school versus 1.8% incomplete and 4.8% complete graduation	ANOVA	p < 0,0001
Question 1 - Occupation area (YES/YES)		
Biological sciences, exact sciences and students 97.0, 96.5 and 97.9% versus human sciences and other occupations 91.3 and 89.1%	Kruskal-Wallis Test	P = 0,0001
Question 1 - Religion (YES/YES)		
75% of atheists versus 90.1% of evangelicals	ANOVA	P = 0,7746
Question 1 - Gender (YES/YES)		
women 92.4% versus men 93%	ANOVA	P = 0,6701
Question 1 (YES) and 2 (YES)		
96.7% of the individuals that answered Yes for question 1 also answered yes for question 2	Yates Test	P < 0,0001
Question 1 (YES) and 3 (NO)		
82.1% of the individuals that answered Yes for question 1 also answered no for question 3	Yates Test	P < 0,0001
Question 1 (NO) and 4 (YES)		
27.51% of the individuals who answered no to question 1 answered yes to question 4	Yates Test	P < 0,0001
Question 1 (YES) and 5 (NO)		
52.8% of the individuals who answered yes to question 1 answered no to question 4	Yates Test	P = 0,4790
Question 1 (YES) and 6 (YES)		
87.1% of those who answered yes also did so for question 1	YATES test	P < 0,0001

suffer embarrassment or discrimination, while 2.50% is for charity to the patient and 5.30% for other opinions. A Greek study aimed at investigating the experience of giving a diagnosis of cancer, with a sample number of 59 physicians showed that residents are involved in a lower rate than specialists and only 21 had specific training in this area, while 20 were unaware of the techniques and protocols available (Surbone et al., 2004).

On the other hand, the majority had a pre-established disclosure plan, they tried to do it in a quiet place, they guaranteed not to interrupt the conversation with the patient. Over 77% allowed family members to determine how much the sick relative should know about the severity and / or existence of the disease. In Saudi Arabia, clinical status compromised is only communicated by 47% of the doctors (Al-Amri, 2016).

In a Japanese study compromised clinical status influenced responders in a questionnaire. Additionally, full, partial or gradual disclosure topics were highlighted, as is frequent in clinical practice (Fine, 1991). Having a relative with a diagnosis of cancer does not seem to correlate with the personal acceptance of the diagnosis by the interviewee if it occurred. However, there is a significant correlation between a family member having been informed of the cancer diagnosis and the interviewee being in favor of being diagnosed with cancer. Although several studies report a poor disclosure in the decade of eighty to ninety, for instance in Italy 40% of subjects reported that his relative was not informed about his diagnosis (Costantini et al., 2006) and there is a growing effort being noted in practice changing (Surbone et al., 2004).

There was a preference in receiving the diagnosis of cancer among the individuals of the sample being present in the conversation of the doctor, the family and the patient (42.7%). However, 30.6% of the interviewees believed that the doctor and the patient alone would be the best scenario, followed by 25.8% physician and family in a first contact and then the family would tell the patient; finally, 0.9% believed that they should not be informed. These results corroborate what has been reported in other studies highlighting two. A study of 100 patients with gynaecological tumours shows a variation of forms of contact, while 24% received the diagnosis by telephone call. The best satisfaction rates were achieved with significant difference when the news was given with a professional present in a private place, with a time greater than 10 min of conversation. In this study, a multivariate analysis showed that the physician's ability correlated with better patient acceptance (Kuroki et al., 2013).

Another study using a logistic regression analysis revealed predictors of satisfaction were the calm environment, the way the doctor speaks and what he says (Cheah et al., 2012). The majority of individuals are propensed to disclose the diagnosis to the patients before they start receiving treatment (91.1%). This data is corroborated by an Arabian paper in which 100% of the patients rejected the idea of begin treatment without knowing their illness; additionally, 99.52% would like to be informed about the side effect of chemotherapy (Al-Amri, 2016).

Before starting the treatment, 98.1% of the individuals believed a multidisciplinary team of support to the cancer patient is necessary in all stages of diagnosis and treatment. This conduct is even recommended by the oncology societies. The challenges are so relevant that in Japan a study was conducted through a questionnaire sent to 620 oncologists with a 67% response rate that aims to know the difficulties in communicating to the patient the interruption of anti-cancer treatment, theoretically acting as the bad news. High difficulty was reported in 47% of respondents, including 17% reporting that they frequently or always feel like stopping activities for these reasons (Otani et al., 2011).

This is corroborated by a Brazilian study in which doctors with more than ten years of experience tends to feel more comfortable and confident, transmitting more wisely bad news. On the other hand, none of the participants were aware of instruments/protocols regarding disclosure of a diagnosis and most of them learned by watching other specialists (Pereira et al., 2017).

Although our data is interesting this study has limitations. We conducted a single center survey in the countryside of a middle-income country by interviewing passers-by in a central neighborhood during a year. Despite the limited resources to perform the study and relative small scale compared to the country population, this is one of the largest samples ever evaluated without a known confounder factor which might influence these results.

Conclusion

Disclosure of a cancer diagnosis is a challenge in clinical oncology. If one in fourteen individuals might prefer not to have the diagnose revealed and there is evidence of predictive factors for this behaviour suggested by this study, it is important to foment further investigations to improve the approach to the recently ill patients.

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