REPRESENTAÇÕES SOCIAIS DE FAMILIARES E PACIENTES COM CARCINOMA EPIDERMÓIDE DE BOCA E OROFARINGE SOBRE PREVENÇÃO E DIAGNÓSTICO DE CÂNCER

SOCIAL REPRESENTATION OF RELATIVES AND PATIENTS WITH ORAL ANDOROPHARYNGEAL SQUAMOUS CARCINOMA ON THE PREVENTION AND DIAGNOSIS OF CÂNCER

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The most significant causes of oral and oropharyngeal cancer delay on diagnosis are the oligosymptomatic initial manifestations, lack of knowledge about the disease among patients and health professionals, fear of the diagnosis, and difficulties to access medical assistance. The aim of this survey is to study social representations of patients and relatives on the prevention and diagnosis of these cancers. This study started on 1999 and was concluded on July, 2000, with the accrual of 130 patients and 130 relatives. The research instruments to collect data were questionnaires and semi-structured interviews. We investigated data on sources of information about health, how they access medical and odontological assistance, possibilities of prevention, treatment and cure. All data are analyzed using qualitative and quantitative data analysis. The information obtained from the first 38 patients and 41 relatives were used to construct a data matrix that was submitted to statistical analysis. The initial patients of the study were 32 males (84%) and 34 were white (90%). Ages varied from 34 to 87 years (median, 60 years). Two patients were illiterate, 22 had only grade school, 4 high school, and 10 college; among the relatives, none was illiterate, 16 grade school, 8 high school, and 17 college. The most frequent information sources on health were radio and television that were mentioned by the vast majority of patients and relatives. The reported frequency of visits to a medical or dental office was higher among the relatives than among the patients. Only 6 patients reported a regular visit to the dentist at least once a year. Most patients (66%) only seek medical assistance due to the persistence of unexplained symptoms. A total of 19 patients (50%) and 27 relatives reported the use of automedication. The majority of the patients had a negative view of cancer (fatal, dangerous, malignant, painful, etc.). According to the patients, tobacco and alcohol were the most significant a risk factors for cancer (18, 47%; and 7, 18%, respectively). Thirty-six patients (95%) were tobacco users, of whom 6 quitted smoking after the diagnosis of cancer, and 13 had tried several times before (with no success). The investigation of the image of cancer, showed that cancer was frequently associated to objects that can cause harm or death, such as guns, knifes, etc. Concerning the association with animals, the most frequent were with wild predators like lion, tiger, crocodile, etc. The main reason for the choice was the ability to cause harm or death. There was a predominance of dark colors in the association with cancer. Black was the choice of 16 patients and 22 relatives, due to it is considered ugly, cause fear, and is associated to death and funeral. The data showed that only 14 patients (37%) expected that cancer would be cured. Death was a common topic associated to cancer, independent on the tumor site, stage or other prognostic factors.

Unitermos: *Câncer prevenção, diagnóstico, representação sociais*
Keywords: *Cancer, prevention, diagnosis social representations.*

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Introduction

The most significant causes of oral and oropharyngeal cancer diagnosis delay are the oligosymptomatic initial manifestations, lack of knowledge about the disease among patients and health professionals, fear of the diagnosis, and difficulties to access medical assistance. [2-4,9-11] The emphasis on health promotion and disease prevention has focused the control of

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risks (tobacco, diet, alcohol, etc.), and social representations has not been usually applied to the prediction of change in behavior.[6] A social representation is a particular modality of knowledge that deal with behavior elaboration and communication between individuals.[7] The social representations have the functions of behavior and attitudes orientation, allowing to understand how one take a position on specific subjects. [8]

The aim of this survey was to study social representations of patients on the prevention and diagnosis of these cancers. The results can be useful to establish prevention programs, using more realistic strategies, based on the social representations of patients.

Methods

This study started on 1999 and was concluded on July, 2000, with the accrual of 130 patients and 130 relatives.

The following eligibility criteria were used to include the patients:

- histologic confirmation of squamous cell carcinoma of the oral cavity or oropharynx,
- no previous treatment,
- acceptance to participate as a volunteer,
- sign the informed consent.

All eligible patients were invited to participate on the study after the initial medical evaluation at the Hospital do Cancer A C Camargo, Sao Paulo, Brazil. The research instruments to collect data were questionnaires and semi-structured interviews. The methodological procedures were carried out in two phases: questionnaire (130 patients and 130 relatives) followed by a face-to-face interview (19 patients and 19 relatives). We investigated data on sources of information about health, how they access medical and odontological assistance, possibilities of prevention, treatment and cure. All data were analyzed using qualitative and quantitative data analysis.

The information obtained from the first 38 patients and 41 relatives were used to construct a data matrix that was submitted to statistical analysis (presence/absence of one category, association indexes, correlations).

Results

The initial patients of the study were 32 males (84%) and 34 were white (90%). Ages varied from 34 to 87 years (median, 60 years). Tumor sites were the mouth in 19 patients (50%) and the oropharynx in 19 patients (50). Tumor stages were: Tis, 1 case (3%); T1, 8 cases (21%); T2, 4 (11%); T3, 11 (29%); T4, 14 (37%); N0, 22 (58%); N1-3, 16 (42%). The relatives were more frequently females, younger than the patients, and usually with a higher educational level. Two patients were illiterate, 22 had only grade school, 4 high school, and 10 college; among the relatives, none was illiterate, 16 grade school, 8 high school, and 17 college.

The most frequent information sources on health were radio and television that were mentioned by the vast majority of patients and relatives. On the other hand, magazines and newspaper were more frequently cited by the relatives than from the patients (Table 1). The

Table 1: Distribution of patients according to the usual health assistance when there are symptoms of any disease.

Variables	Categories	# Patients	# Relatives
Automedication	No	18	14
	Seldom	16	25
	Frequently	3	2
Pharmacy salesclerk	No	19	21
	Seldom	10	18
	Frequently	8	2
Physician or dentist	No	6	0
	Seldom	18	12
	Frequently	12	28
	Physician no/Dentist yes	1	1
Religion	No	29	23
	Yes	8	18
Alternative treatments	No	35	35
	Yes	2	6

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reported frequency of visits to a medical or dental office was higher among the relatives than among the patients. Only 6 patients reported a regular visit to the dentist at least once a year. A total of 25 relatives and only 4 patients went to a medical office at least once a year. Most patients (66%) only seek medical assistance due to the persistence of unexplained symptoms. A total of 19 patients (50%) and 27 relatives reported the use of automedication.

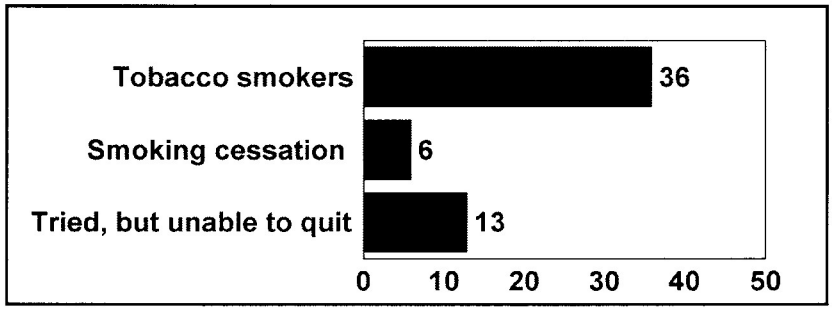

Figure 3: Distribution of patient´s responses according to tobacco consumption and attempts of smoking quitting

The majority of the patients had a negative view of cancer (fatal, dangerous, malignant, painful, etc.) (Figure 1). Fifty percent of the patients reported recent losses (in the family, of friends or financial problems) within a short period before the diagnosis. According to the patients, tobacco and alcohol were the most significant risk factors for cancer (18, 47%; and 7, 18%, respectively). Ten patients had no idea on the possible risk factors (Figure 2). Thirty-six patients (95%) were tobacco users, of whom 6 quitted smoking after the diagnosis of cancer, and 13 had tried several times before (with no success) (Figure 3).

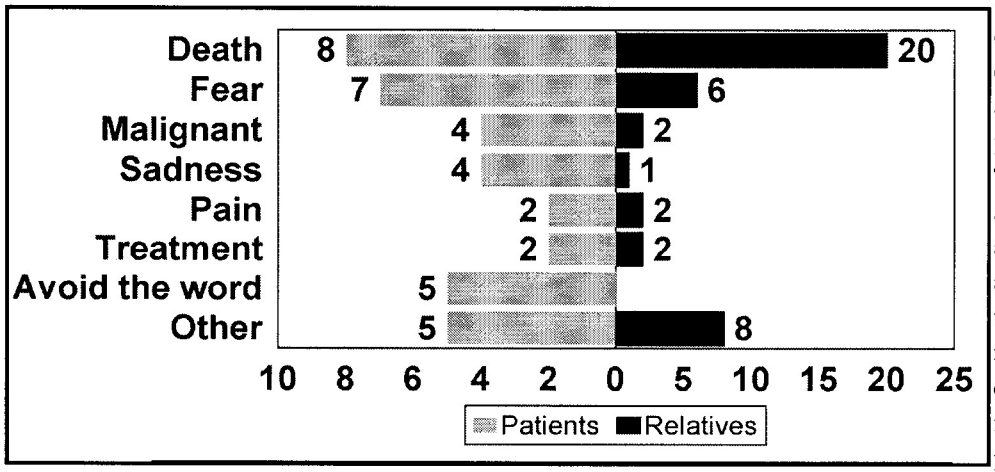

Figure 1: Distribution of patients and relatives according to the first inpression of patients about cancer

The investigation of the image of cancer, showed that cancer was frequently associated to objects that can cause harm or death, such as guns, knifes, etc. Concerning the association with animals, the most frequent were with wild predators like lion, tiger, crocodile, etc. The main reason for the choice was the ability to cause harm or death. There was a predominance of dark colors in the association with cancer (Table 2). Black was the choice of 16 patients and 22 relatives, due to it is considered ugly, cause fear, and is associated to death and funeral. The data showed that only 14 patients (37%) expected that cancer would be cured. Death was a common topic associated to cancer, independent on the tumor site, stage or other prognostic factors (Figure 4).

Comments And Conclusions

The planning of a health promotion program requires a sequence of epidemiologic, behavior and environmental diagnosis to achieve a clear understanding of the actions and life conditions affecting a population´s health problem. The education and organizational diagnosis identifies factors that must be changed to initiate and sustain the process of behavior and environmental change. [2-5,9-11] Individual and collective behavior is remarkably influenced by different factors:

- predisposing (motivation, awareness, beliefs, attitudes, confidence, knowledge),
- enabling (antecedents, availability and accessibility of health resources),

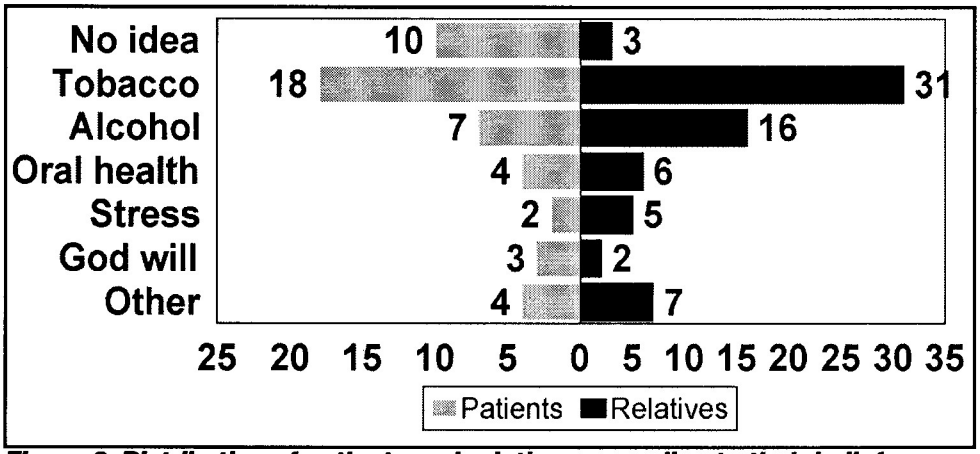

Figure 2: Distribution of patients and relatives according to their beliefs on the cause of cancer

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Animals	# patients	# relatives	Colors	# patients	# relatives
None	3	4	Black	16	22
Wild animals	19	19	Violet	9	7
Snakes	8	10	Red	9	6
Domestic animals	3	3	Brown	1	1
Acquatic animals	2	3	Blue	1	0
Monsters	2	2	Green	1	0
			Yellow	0	1

Table 2: Cancer image: associations between cancer, animals and colors.

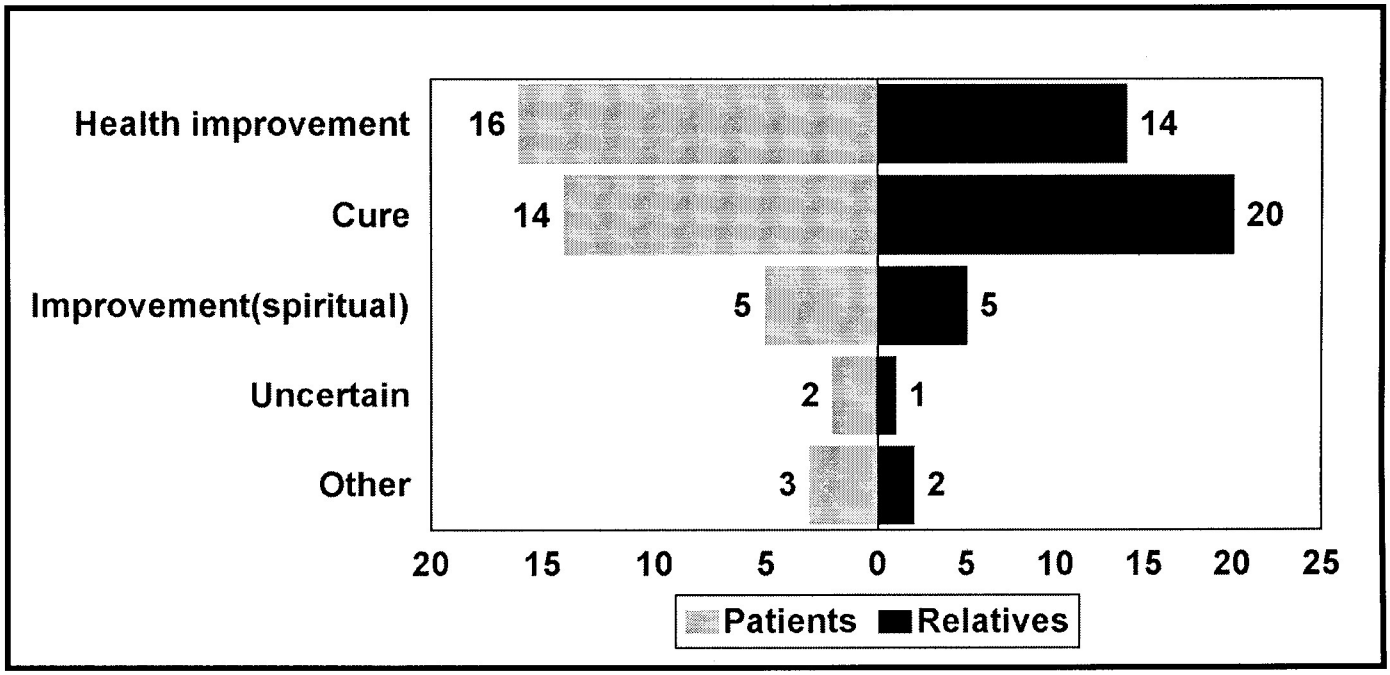

Figure 4: Patient´s and relative´s expectations of treatment results

- reinforcing (incentive, family, peers, teachers, health providers, community leaders).

An increase in knowledge alone does not always cause behavioral or organizational change. Predisposing factors include knowledge, attitudes, beliefs, values, needs and abilities. Most of them fall in the psychological domain and include cognitive and affective domains of knowing, feeling, believing, valuing and having self-confidence. [1,5]

The identification of social representations of mouth and oropharyngeal cancer is useful for highlighting patient´s beliefs and behaviors. Our study confirmed that socioeconomically disadvantaged population presents the diagnosis of oral cancer established at advanced stages. This can be attributed to the differences found in educational and information level (and low frequency of preventive health behavior), delay in seeking health care and non availability of health services. Most patients ignore their risk of cancer, even when signs of advanced disease are evident. Automedication and search for prescription of drugs by pharmacy salesclerk are frequent and cannot be ignored.

The negative image of cancer among people needs further consideration because those who feared cancer and did not believe on the possibilities of cure, also adopted lower preventive behavior.

Our preliminary results can be useful to establish prevention programs, using more realistic strategies. But, we do need to learn more about those representations before we can effectively establish a prevention program.

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Resumo

As causas mais importantes de atraso no diagnóstico do câncer de boca e de orofaringe é a evolução inicial oligosintomática, pouco conhecimento sobre a doença entre pacientes e profissionais da saúde, medo do diagnóstico e dificuldades para acessar o sistema de saúde. O objetivo deste trabalho é estudar as representações sociais de pacientes e familiares sobre prevenção e diagnóstico de câncer. Este estudo foi iniciado em janeiro de 1999 e concluído em julho de 2000, com a inclusão de 130 pacientes e 130 familiares. Os instrumentos de pesquisa para coleta de dados foram questionários e entrevistas semi-estruturadas. Investigamos dados sobre fontes de informação sobre saúde, como acessam assistência médica e odontológica, possibilidades de prevenção, tratamento e cura. Todos os dados foram analisados usando técnicas de análise qualitativa e quantitativa. As informações obtidas dos primeiros 38 pacientes e 41 familiares foram usadas para construir uma matriz de dados que foi submetida a análise estatística. Os pacientes iniciais do estudo eram 32 homens (84%) e 34 (90%) eram brancos. A faixa etária variou de 34 a 87 anos (média de 60 anos). Dois pacientes eram analfabetos, 22 tinham apenas cursado o primeiro grau, 4 o segundo grau e 10 tinham nível universitário; entre os familiares, nenhum era analfabeto, 16 tinham primeiro grau, 8 segundo grau e 17 nível universitário. As fontes de informação sobre saúde mais freqüentemente utilizadas por pacientes e familiares foram rádio e televisão. A freqüência de visitas médicas ou odontológicas foi maior entre os familiares que os pacientes. Somente 6 pacientes relataram consultas regulares ao dentista pelo menos uma vez ao ano. A maioria dos pacientes (66%) somente procura assistência médica devido persistência de sintomas inexplicáveis. Um total de 19 pacientes (50%) e 27 familiares referiram automedicar-se freqüentemente. A maioria dos pacientes tinha uma visão negativa sobre o câncer (fatal, perigoso, maligno, doloroso, etc.). De acordo com os pacientes, tabaco e álcool eram os fatores de risco mais significativos para câncer (18, 47%; e 7, 18%, respectivamente). Vinte e seis pacientes (95%) eram tabagistas, dos quais 6 haviam parado de fumar, e 13 tinham tentado parar várias vezes sem sucesso. A investigação da imagem do câncer, mostrou que a doença era freqüentemente associada a objetos que podem causar ferimentos ou a morte, como armas, facas, etc. Com respeito a associação com animais, os mais freqüentemente citados foram predadores selvagens como leão, tigre, crocodilo, etc. As maiores razões para a escolha também foram a capacidade de ferir ou matar. Houve predominância de cores escuras na associação com câncer. O preto foi a escolha de 16 pacientes e 22 familiares, porque foi associada com medo, morte e funeral. Os dados mostraram que somente 14 pacientes (37%) esperavam que o câncer pudesse ser curado. A morte foi um tópico associado ao câncer, independente do local do tumor, estádio ou outros fatores prognósticos.

Referências Bibliográficas

1. Breakwell GM, Canter DV. Empirical approaches to social representations. Oxford: Oxford University Press; 1993.
2. Butler JT. Principles of health education and health promotion. Englewood: Morton; 1994.
3. Ghiglione R, Bonnet C, Richard JF. Traité de psichologie cognitive. Paris: Bordas; 1990.
4. Green LW, Krueter MW. Health promotion planning and educational and environmental approach. Mountain View: Mayfield; 1991.
5. Holland JC. Psycho-oncology. New York: Oxford University Press; 1998.
6. Jodelet D. Folies et représentations sociales. Paris: Presses Univesitaires de France; 1989.
7. Moscovici S. A representação social da psicanálise. Rio de Janeiro: Zohar; 1978. 293p.
8. Moscovici S. Psychologie socieale. Paris: Presses Universitaries de France; 1984.
9. Nettleton S. The sociology of health & Illness. Cambridge: Polity Press; 1995.
10. Ogden J. Health psychology. Buckingham: Open University Press; 1996.
11. Tones K, Tilford K. Health education: effectiveness, efficiency and equity. London: Chapman & Hall; 1994.