

# Perception of cancer causes and risk, family history and preventive behaviors of users in oncogenetic counseling\*

PERCEPÇÃO DE CAUSAS E RISCO ONCOLÓGICO, HISTÓRIA FAMILIAR E COMPORTAMENTOS PREVENTIVOS DE USUÁRIOS EM ACONSELHAMENTO ONCOGENÉTICO

PERCEPCIÓN DE CAUSAS Y RIESGO ONCOLÓGICO, HISTORIA FAMILIAR Y COMPORTAMIENTOS PREVENTIVOS DE PACIENTES EN ASESORAMIENTO ONCOGENÉTICO

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## ABSTRACT

The aims of the present study were to describe cancer causes and risk perception, and to associate behaviors adopted for the prevention of tumors and cancer family history in individuals with suspect of hereditary cancer syndromes. A convenience sample of 51 individuals was selected from an oncogenetic counseling outpatient clinic in a university hospital in the countryside of the state of São Paulo. An instrument adapted to Brazilian culture was used. The respondents considered their own risk as being the same as the population's risk, and family history was not statistically associated with the performing of preventive exams. These findings highlight the need for intervention by health professionals, especially nurses, who may conduct health education activities for this population, which is an essential component of nursing care in oncogenetics.

## DESCRIPTORS

Risk factors  
Neoplasms  
Genetic predisposition to disease  
Oncologic nursing

## RESUMO

O presente estudo teve como objetivo descrever a percepção de causas e risco para neoplasias, bem como associar comportamentos adotados para prevenção de tumores e história familiar dessa patologia em indivíduos com suspeita de síndromes neoplásicas hereditárias. A amostra de conveniência foi constituída por 51 usuários atendidos em um ambulatório de aconselhamento oncogenético de um hospital-escola do interior paulista. Utilizou-se um instrumento previamente traduzido e adaptado para a cultura brasileira. Os respondentes consideraram seu risco de câncer como sendo igual ao da população em geral e a história familiar de malignidades não foi estatisticamente associada à realização de exames preventivos. Os resultados deste estudo evidenciam a necessidade de intervenção dos profissionais de saúde, em especial do enfermeiro, o qual pode desenvolver atividades de educação em saúde junto a essa clientela, como um dos componentes essenciais para o cuidado de enfermagem em oncogenética.

## DESCRITORES

Fatores de risco  
Neoplasias  
Predisposição genética para doença  
Enfermagem oncológica

## RESUMEN

El estudio objetivó describir la percepción de causas y riesgo de padecer neoplasias, así como asociar comportamientos adoptados para la prevención de tumores e historia familiar de la patología en individuos con sospecha de síndromes neoplásicos hereditarios. La muestra de conveniencia se constituyó de 51 pacientes atendidos en ambulatorio de asesoramiento oncogenético de un hospital escuela del interior paulista. Se utilizó un instrumento traducido y adaptado a la cultura brasileña. Los consultados consideraron su riesgo de cáncer como equiparable al de la población en general, la historia familiar de enfermedades malignas no fue estadísticamente asociada a la realización de estudios preventivos. Los resultados del estudio demuestran la necesidad de intervención de los profesionales de salud, en especial del enfermero, el cual puede desarrollar actividades de educación en salud conjuntamente con estos sujetos, como uno de los componentes esenciales para el cuidado de enfermería en oncogenética.

## DESCRIPTORES

Factores de riesgo  
Neoplasias  
Predisposición genética a la enfermedad  
Enfermería oncológica

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## INTRODUCTION

Around the world, the public demand for oncogenetic counseling is increasing<sup>(1)</sup>. In Brazil, various oncogenetics services emerged and established themselves in the first decade of the 21<sup>st</sup> century<sup>(2)</sup>. These services have aided families at risk for hereditary neoplastic syndromes (HNS), offered genetic tests, provided pretest and posttest counseling, and delivered personalized health care, in line with the implications of the human genome project. These syndromes derive from inherited mutations in germline genes, which predispose their carriers to an increased risk of malignant tumors<sup>(3)</sup>. For oncologic genetic counseling services, a huge challenge is to provide individualized and nondirective counseling, providing relevant information to users in response to the users' requests and health needs<sup>(4)</sup>. However, little is known about these clients and about whether these actions actually respond to the clients' needs, promoting health and preventing cancer.

Oncologic genetic counseling is a process based on nondirectivity and unbiasedness<sup>(1)</sup>, with the aim of improving knowledge and understanding of the genetic bases of cancer and estimating both the subjective and objective as well as the personal and familial risks of developing that disease, beyond addressing the possible consequences of taking genetic tests<sup>(1,4,5)</sup>. It is also important to supply information about the condition in question, the possibility of minimizing exposure to risk factors, the disease prognosis and treatment options<sup>(1)</sup>. The intent is to help families develop realistic viewpoints on their personal risk and to become familiar with the possible medical, psychological and familial implications of counseling<sup>(1)</sup>. Risk information is often based on a family history of malignant tumors and on the probability of inheriting cancer. Family history relates to the occurrence of more than one case of cancer in close relatives, observed more frequently among these subjects than in the general population, potentially due to genetic susceptibility to tumors inherited from relatives<sup>(1)</sup>. The literature confirms that nondirective genetic counseling can effectively enhance people's awareness of the risk of developing malignant tumors and knowledge about genetic tests<sup>(1,4,5)</sup>.

Studies have shown that, in general, people have little or no knowledge of their risk for developing cancer. Even people who have already become victims of this disease are not aware of the increased risk of recurrence in comparison with the general population<sup>(6-7)</sup>. However, the precision of risk estimates has varied across publications<sup>(1,8)</sup>. Concerning hereditary cancer syndromes, many patients surprisingly overestimate their risk of cancer and experi-

ence anxiety over the course of the disease. Questions related to risk perception and the effect of genetics and genetic counseling on the understanding of this risk are particularly relevant<sup>(1)</sup>.

Healthcare team members active in cancer genetics counseling need to be aware of how families perceive and assess their risk of malignant tumors and of the families' attitudes and preventive behaviors<sup>(5,9)</sup>. The families using counseling services seem to be increasingly concerned with their family members' risk. Therefore, it is important to know how these individuals understand their own cancer risk, whether this risk is perceived differently in the case of a family history of neoplasia and what the implications of this perception are for adherence to cancer surveillance practices, and particularly preventive tests<sup>(9)</sup>. From this perspective, the present study aimed to describe neoplasia risk perception and to associate tumor prevention behaviors with a family history of cancer in individuals with suspected hereditary neoplastic syndromes.

## METHOD

A descriptive, cross-sectional quantitative study was conducted at an oncologic genetic counseling (OGC) outpatient clinic in a university hospital in São Paulo state between May and October 2009. This service offers counseling and follow-up to users with a diagnosis or suspected diagnosis of HNS and with a personal and/or family history of cancer, so as to permit the identification and the follow up of those individuals. Here, a family history of malignant tumors was defined as the existence of two or more first and/or second-degree relatives with tumors across three generations, including the proband.

Male and female individuals were invited to participate in a convenience sample. All of the participants were aged 18 years or older and able to voluntarily consent to join the study and had scheduled an appointment at the outpatient clinic with a diagnosis or suspected diagnosis of hereditary neoplastic syndrome. The exclusion criteria were nonattendance at previously scheduled consultations and the existence of any physical condition that would prevent the individual from answering the data-collection instrument. During care, family members who accompanied the abovementioned subjects were also offered the opportunity to participate in the research. Thus, the final study sample consisted of 51 participants.

For data collection, the Cancer Awareness and Needs Survey (CANS) was used, which had been previously translated into Portuguese and adapted to the Brazilian cul-

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ture. This survey was originally developed by researchers at the City Of Hope Comprehensive Cancer Center (COH) and adapted according to the cognitive level of the fourth to fifth year of North American primary education, as well as for use in a Latino population, including people from Spain, Mexico, and Central and South America who live in the United States<sup>(10)</sup>. The instrument was then submitted for content validation by an expert panel and tested before definitive use<sup>(11)</sup>. The CANS consists of questions related to sociodemographic data (age, gender, education, ethnicity, and number of children); personal and family history of malignant tumors; access to information and resources related to preventative tests for cancer; and interest in genetics services. In addition to these questions, the instrument also includes two scales related to categorical variables with Likert-type answer options.

The first scale refers to the participants' risk perception of the main tumors present in HNS, as follows: *none/very low (1); less than other people (2); equal to other people (3); higher than other people (4); and much higher than other people (5)*. For this scale, the arithmetic mean of the item scores was used to obtain the overall scores for each participant.

The second scale was aimed at characterizing the respondents' opinions about established cancer risk factors, such as alcohol and tobacco use; eating habits; and environmental, emotional, genetic and hereditary factors. The answer options ranged between zero (no effect on cancer risk) and 5 (very strong effect on cancer risk). No specific meanings were attributed to scores of 1, 2, 3 and 4, which served as mere gradations between the extreme ends. On that scale, the five Likert options were dichotomized *a posteriori* in two categories, one of which affirmed that the risk factors *had no effect or some effect on the cancer risk*, with score options ranging between 0 and 4, whereas the other category indicated that a certain factor *strongly affects the risk of cancer*<sup>(7)</sup>, corresponding to a score of 5. For this scale, instead of determining the total mean or median scores, the researchers decided to obtain the frequency distribution for the answers in each of the categories described above.

COH researchers authorized the use and adaptation of the CANS to the Brazilian context and provided the orientation needed for data analysis. To guarantee the quality of the cultural adaptation, a method recommended by experts was used<sup>(12)</sup>. Three bilingual researchers, whose native language was Brazilian Portuguese, translated the original instrument into Portuguese. The three translated versions were compared, and a consensus version was generated, which a foreign, bilingual translator back-translated into English before approval from the authors of the original instrument. The result was the final Portuguese version of the survey. To assess the instrument's applicability to Brazilian culture, as well as the answer time needed and possible difficulties that the respondents could face while completing the instrument, a pilot study

was performed. This preliminary study involved 20 OGC users who were not included in the final research sample, as small changes were made to the terminology used in the original version of the instrument.

The data collection was completed through individual interviews conducted by the primary author and research assistants, all of whom had received training and were supervised by the research advisor. Each interview took an average of thirty minutes. The collected data were submitted to double entry for the sake of qualitative validation and then analyzed using Statistical Package for the Social Sciences, version 17.0. Descriptive statistics were calculated, and the data were explored using contingency tables and analyzed by applying the chi-square test to examine the association between family cancer history and the completion of preventive tests (significance level of  $\alpha=0.05$ ).

To compare the personal and/or family history of cancer and perceived risk of malignant tumors, Kruskal-Wallis' nonparametric test was used, after previously applying the Kolmogorov-Smirnov test to verify the normal distribution of the sample means, given the small sample size. Additionally, to test whether the participants' gender was associated with their opinion on risk factors and whether a family history of cancer was associated with preventive behaviors, the nonparametric chi-square test was used.

Out of respect and ethical care for the study participants, study approval was sought from an institutional review board (Protocol 1020/2009). Eligible subjects could read the Informed Consent Form (ICF) to clarify the research objectives and methods. The participants then signed two copies of the ICF and kept one copy for contacting the researcher. The participants' anonymity and information privacy were respected.

## RESULTS

### Participant characteristics

Fifty-one participants fit the inclusion criteria, 35 (68.6%) of whom were female. The respondents' ages ranged between 19 and 70 years, with a mean age of 40 years (SD=13.0) and a median age of 39.4 years. However, most of the sample (52.9%) was between 18 and 39 years of age. The subjects reported between zero and five children, with an average of one child per participant. Regarding education, 35.3% of the participants had concluded secondary education, one was illiterate and two held a specialized degree.

The sample consisted of 32 (62.7%) individuals who had appointments scheduled at the OGC, as well as 19 (37.3%) of their family members. Twenty-eight (87.5%) of the 32 individuals with scheduled appointments had previously visited the clinic and were considered returning cases, whereas the other four participants were new cases.

Concerning cancer history, 41 individuals had a personal and/or family history. Among the participants with a personal history of cancer, 18 (35.3%) also had a family history. The other 23 (45.1%) individuals reported only a family history of tumors, whereas only two participants had a personal history alone. Eight (15.7%) participants denied having a personal or family history of cancer, as these individuals were relatives, but without a biological relationship, of others with cancer.

Among the subjects who had a personal history of malignant tumors, the most prevalent types of tumors were breast and colorectal cancer (CRC), which six and five users reported, respectively. Other types of tumors cited included head and neck (three cases), stomach (three), liver (two), lung, prostate, kidney, pancreas and uterus, with the latter five tumor types corresponding to one case each. Moreover, three among the 20 subjects with malignant tumors reported more than one type of cancer.

The mean age when the disease appeared was 38 years (SD=14.6).

### Perceived risk

The participants were asked about their perceived risk of developing the main tumors related to hereditary cancer syndromes, including breast, ovarian, prostate and CRC tumors, beyond any others that the individuals wanted to list (table 1). For each cancer type, most subjects affirmed risks equal to or smaller than the risk in the general population. Among the cancer types indicated under "Other", head and neck (N=6), lung (N=4), skin (N=3), liver (N=1) and stomach (N=1) cancers were cited. Certain individuals marked this item and identified more than once cancer type, whereas other participants marked the item without indicating a specific tumor type. In those cases in which this question was left unanswered (2), the subjects could not or did not want to describe their perceived risk.

**Table 1** – Distribution of study subjects according to perceived risk of different cancer types. Ribeirão Preto, SP, 2009

	None/very low N (%)	Less than that of other people N (%)	Equal to that of other people N (%)	Greater than that of other people N (%)	Much greater than that of other people N (%)	Total subjects who answered the question N (%)
<b>Male and female</b>						
Intestine	4 (8.0)	8 (16.0)	25 (50.0)	8 (16.0)	5 (10.0)	50
Breast	7 (14.3)	4 (8.2)	28 (57.1)	6 (12.2)	4 (8.2)	49
<b>Women only</b>						
Ovarian	5 (14.7)	2 (5.9)	23 (67.6)	2 (5.9)	2 (5.9)	34
<b>Men only</b>						
Prostate	1 (7.1)	2 (14.3)	7 (50.0)	4 (28.6)	0 (0)	14
Other	2 (8.7)	1 (4.3)	11 (47.8)	8 (34.8)	1 (4.3)	23

To investigate whether answers to the question about perceived risk was influenced by each subject's personal or family history, users with a personal history of cancer, family history of cancer or both were categorized into three groups: a) subjects with a personal and a family history of cancer (HP+/HF+); b) subjects with a family history of cancer only (HP-/HF+); and c) subjects with a personal history of cancer only, independent of having or not having a family history of the disease (HP+). After this division, for each group, the means, standard deviations and medians were calculated per item, pertaining to breast, ovarian, intestine and prostate cancer risk. Next, the normal distribution of the means in each of these groups was verified. As normality was not observed in certain groups, and as other groups yielded a very small N, Kruskal-Wallis' nonparametric test was applied. When comparing the median risk scores for all of the cancer types listed above, no statistically significant difference was found, with three as the median in the three groups.

### Risk factors for cancer

Regarding the risk factors for malignant tumors, 39 (76.5%) subjects listed one or more factors that somehow affected cancer development, whereas 12 (23.5%)

individuals were unable to answer this question. Among the factors mentioned in the "strongly affect cancer risk" category, 28 participants cited emotional and psychological factors, 25 mentioned hereditary and genetic aspects, 20 attributed the disease to tobacco use, 18 cited eating habits, nine referenced environmental factors, and three attributed cancer to alcohol consumption. Regarding the "other risk factors", four subjects answered that cancer can emerge from the worsening of preexisting conditions, two associated cancer with lifestyle and one linked cancer to drugs use. No statistically significant association was found between the participants' gender and the risk factors for cancer that the individuals cited. A significant association was found, however, between the female gender and the perception that genetics strongly affect the risk of developing malignant tumors ( $\chi^2_{1}=5.38, p=0.02$ ).

### Preventive behaviors

Concerning preventive tests, nine male subjects reported that they did not take any type of test because they are too young. Of these individuals, six were younger than 30 and had no family history of prostate cancer. One man claimed to have no money or health insurance for testing, and another man stated that he had not been advised



about testing. Among the women, one individual reported that she was not interested in any type of screening.

The study found no statistically significant association between a family history of cancer and preventive behav-

iors. For the women, these behaviors included the breast self-exam, mammography and pap smear. For the men, preventive measures included the Prostate-Specific Antigen (PSA) test and rectal examination, and for both genders, colonoscopy (Table 2).

**Table 2** – Distribution of subjects according to family history of cancer and completion of preventive exams. Ribeirão Preto, SP, 2009

Family history	Preventive behaviors									
	Self-exam		Mammography		Pap smear		Prostate exam <sup>(a)</sup>		Colonoscopy	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Presence of family history	25	6	22	9	27	4	5	5	16	25
Absence of family history	3	1	3	1	4	0	1	5	3	7
$\chi^2_1$	0.07		0.03		0.58		1.78		0.28	
p-value	0.83		0.68		0.60		0.26		0.44	

(a) Rectal examination or prostate-specific antigen (PSA) dosage.

In total, 38 (74.5%) subjects mentioned not having health insurance and thus being dependent on public services for cancer screening.

### Access to information about and services for preventive exams and genetic tests

Approximately 75% of the sample (38 subjects) believed that they did not have the necessary information about preventive exams for avoiding cancer. The majority of these individuals (22 cases) were up to 39 years of age. The most mentioned information sources through which the respondents learned about cancer risks and preventive tests were physicians (86.3% of subjects), television (82.4%), nurses (78.4%), books (52.9%), magazines (47.1%), the internet (47.1%), family or friends (45.1%), the news (37.3%) and the radio (31.4%). Other sources (3.9%) were also cited.

Among the 42 subjects who had undergone screening, at least 16 took exams at more than one place, 32 used the hospital and, among the latter, 21 were screened exclusively at the hospital. Among the 18 participants who took tumor prevention tests at community health centers, 17 individuals were women.

The study subjects expressed an interest in participating in educational activities, counseling and genetic tests for HNS risk assessment. All of the participants also indicated that they would like to learn more about their own cancer risk. Moreover, 50 (98%) subjects were willing to talk to a specialist to discover whether they are at high risk, and 49 (96.1%) individuals were willing to take a blood test to learn about their risk of hereditary tumors.

## DISCUSSION

The establishment of oncogenetic services poses new challenges to health professionals as well as to the families whom these professionals aid<sup>(13)</sup>. To minimize the impact of cancer on the population, the prevalence of be-

havioral and environmental factors that enhance cancer risk first need to be reduced<sup>(14)</sup>. Therefore, people's knowledge, attitudes and practices regarding tumors must be assessed, considering that prevention and early detection are basic strategies to control this disease<sup>(15)</sup>. In the literature, few studies have focused on oncogenetic counseling in the Brazilian population or the profile of clients using these services across the Brazilian territory, which could help to highlight risk perception issues, the measures taken during screening exams and subjects' adherence to those measures. Thus, in the present study, attempts were made to address the current reality in Brazil.

The study sample comprised clients from an oncogenetic counseling clinic with ages ranging between 19 and 70 years, with a mean of 40 years and a predominant age range between 18 and 39 years. Similar data were described in a prior study<sup>(10)</sup> in which the sample's age ranged between 18 and 81 years, with a mean age of 43 years. It has been reported that early age is an important factor in diagnosing an inherited predisposition to cancer<sup>(16-17)</sup>. Hence, health-related efforts to prevent tumors should be encouraged among individuals at an early age, and especially in those people with a family history of malignant tumors<sup>(18)</sup>.

In the present study, most study participants had been referred to oncogenetic counseling because of a personal and/or family history of cancer (N=41). However, several people visiting the genetic risk-assessment services for hereditary cancer were unaware of why they had been referred to those services. Physicians and other health professionals involved in the referral and counter-referral processes need to prepare patients for the service that these individuals will receive. It is essential to offer information to this population about how the genetic counseling process for cancer proceeds, emphasizing the collection of the family history and the importance of its validation. This preparation would allow patients to develop realistic expectations of what is involved in the risk assessment of tumor development. Thus, difficulties in coping with the genetic-risk information received could be mitigated and

a greater adherence to cancer screening and surveillance pathways could be underscored<sup>(13)</sup>.

The cancer types most often mentioned by subjects with a personal cancer history were breast and intestinal tumors, which were also the most prevalent in family members. These data are in line with the findings of previous Brazilian population-based studies and records<sup>(19)</sup>. Regarding age at diagnosis, patients were diagnosed with cancer at a mean age of 38 years. Tumors diagnosed at an early age (that is, younger than 50 years) indicate a high probability of hereditary genetic predisposition. The initial age of diagnosis of malignant tumors is an important criterion to be considered in the assessment of hereditary neoplastic syndrome risks, in accordance with international guidelines<sup>(18)</sup>.

In the current study, although the participants were referred to and visited the oncogenetic counseling service, the large majority of the interviewed subjects considered their oncologic risk to be the same or smaller than the risk in the general population. This finding differs from the results of earlier studies, in which most participants estimated their own risk as higher than the risk in the overall population<sup>(20,21)</sup>. Certain reports have affirmed that approximately 25% of patients have a precise risk perception, whereas 50% of patients tend to overestimate their cancer risk<sup>(1,4)</sup>. That difference may be partially justified by disparities in genetic-service referrals and demands in the North American and European contexts, in addition to considerable existing sociodemographic differences<sup>(21)</sup>, hampering possible comparisons. As observed, many clients arrive at genetic counseling services with incorrect perceptions of their own tumor development risks, which can frequently make these individuals less receptive to obtaining the appropriate information<sup>(1,4)</sup>. Certain authors have highlighted that cultural factors represent the main influence on users' perceived risk of malignant tumors<sup>(1,4)</sup>. Culture even affects these individuals' trust in oncologic-care professionals and institutions. Patients' searches for standardized or experimental treatments can be strongly influenced by cultural issues, which are consequently a critical variable in research, affecting relationships between minority groups, health professionals and care institutions<sup>(1,4)</sup>. It should be highlighted that the risk of cancer development attributed to genetics and heredity, as cited by the research subjects in the current study, could be strongly affected by research bias, given that 55% of the sample consisted of patients who had returned to the service and only 8% of the sample consisted of new cases. Moreover, this research was not aimed at assessing the subjects' actual understanding of the concepts and meanings of the terms *genetics* and *heredity*, which participants may have defined subjectively and even intuitively.

Regarding cancer screening and prevention behaviors, most of the interviewed women reported periodical breast self-exams (80%), mammography (71.4%) and Pap smears (88.6%). That behavior was independent of having

a personal and/or family history of neoplasia. According to important organizations that report cancer estimates and propose surveillance and screening protocols, early detection is one of the most important factors in the reduction of breast cancer-associated morbidity and mortality<sup>(13,18)</sup>. In particular, breast self-exams and clinical exams, mammography and Pap smears are the most appropriate and effective measures to guarantee the early detection of breast and cervical cancer<sup>(18)</sup>. In the group studied, those preventive exams were accomplished at an appropriate frequency. The quality of the exams should be questioned, though, particularly for the breast self-exams. Due to the limited sample, these study results may not represent the general population, and again, the fact that these women visited an oncogenetic counseling service could explain their higher adherence to preventive practices, although even greater adherence would be expected based on this logic. In that sense, further research is needed to confirm adherence to those preventive practices as a consequence of genetic counseling consultations.

Among the male participants, six (37.5%) had undergone preventive exams for prostate cancer, and those individuals who had not done so alleged that they were not in the correct age range for this test. In particular, those subjects were younger than 50 years of age. Prostate cancer is a disease that can be detected early through diagnostic screening methods. For the early detection of cancer in individuals without symptoms, annual rectal examinations and serum PSA tests are recommended from the age of 50. Those exams are low in cost, and the tests' sensitivities and specificities levels are also suitable. Studies even suggest that screening men using these exams beginning at an age of 50 has reduced the incidence of late disease and influenced mortality rates<sup>(15)</sup>.

Concerning screening for CRC, 37.2% of participants underwent a colonoscopy. Screening exams for relatives should start at the age of 40, or ten years before the age of the youngest victim in the family<sup>(18)</sup>.

Furthermore, many subjects referred to taking cancer prevention tests at the same hospital. Although this choice could be partially for convenience's sake, as most patients were already pursuing a follow-up at highly complex services and thus underwent testing at a single location, it is questionable whether professionals truly know how to integrate care. Except for exams such as colonoscopies, professionals could refer their patients to other sites for less complex services, thus reducing the service burden at a large hospital<sup>(2,4)</sup>.

When asked whether they had the necessary information about cancer and tumor prevention, most subjects (75%) believed they did not. This finding may guide the establishment of information strategies to permit a better understanding of prevention issues in this population, which is fundamental to successful health-promoting efforts<sup>(1,4,5)</sup>. Those strategies, despite being a priority, cannot exist without a previous understanding of prior stud-

ies that reveal patients' actual information needs<sup>(5,8)</sup>. A further understanding of those needs will permit the development of materials and strategies to prepare and support individuals at different cancer risk levels, with the aim of making informed decisions in the assessment of genetic risks<sup>(21)</sup>.

In the present study, despite citing a lack of knowledge about cancer prevention, the study subjects cited physicians as their main information source (86.3%). Similar data were reported in a systematic literature review covering the period between 1980 and 2003, which showed that health professionals are the information source most frequently cited by patients, with physicians in first place, followed by nurses<sup>(8)</sup>. It is essential for nursing professionals to establish an effective communication channel for patients and patients' relatives, with the goal of putting the therapeutic process into practice and providing emotional support<sup>(22)</sup>. This study did not aim to assess the type, quality or effectiveness of the information that the research participants were offered, although the positive effect of this information on the study sample can be inferred, as most patients frequently underwent screening exams. Understanding what users need to know and where these individuals receive information during treatment is essential to guarantee high-quality care<sup>(8,21,22)</sup>.

The study subjects' interest in cancer risk assessment was indicated by their answers to the questions about their intent to participate in neoplasia risk-assessment services. All of the subjects mentioned their interest in talking to a specialist to discover whether they were at high risk of cancer and to undergo blood tests to find out about the probability of developing cancer. These findings were similar to other results found in the literature<sup>(1,4,5)</sup>. In a research study involving a North American population of Latin origin, it was observed that most interviewees (85%) expressed interest in obtaining information on their personal cancer risk and motivation to participate in genetic services related to the disease<sup>(10)</sup>.

Certain limitations may have affected the present research, possibly related to the clinic's reduced clientele, which was still growing at the time of the study. Another fact that may have biased the survey of certain study variables is that the study addressed subjects at an oncologic genetic-counseling clinic at which a proportion of the individuals were already receiving care.

One important potential outcome of this research was the unveiling of the reality of families experiencing the assessment process for hereditary cancer risks. Future possibilities include further research to broaden the analysis of the aspects investigated here and a consideration of other qualitative and quantitative methods.

## CONCLUSION

This study sought to investigate cancer risk perception and preventive behaviors related to cancer in a sample of individuals with suspected hereditary neoplastic syndromes. These individuals were visiting an oncologic genetic-counseling service in a hospital in São Paulo State. The participants considered their risk of developing malignant tumors similar to the risk in the general population, independent of their personal and/or family history of cancer. These participants followed cancer prevention recommendations similarly to the general population, without a statistically significant relationship between taking preventive exams and a family history of malignant tumors. Most families reported not having the necessary information about tumor screening, and all of the participants expressed interest in receiving further orientation about their personal risk of developing cancer and the possibility of taking genetic tests. Hence, this study indicated the need for knowledge about how individuals perceive their risk of neoplasia and the causes of the disease. This knowledge may help health professionals to propose individualized interventions in response to the demands of families who are receiving genetic counseling for hereditary cancer syndromes.

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