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Cancer patients' knowledge about their legal rights

O CONHECIMENTO DOS PACIENTES COM CÂNCER SOBRE SEUS DIREITOS LEGAIS

EL CONOCIMIENTO DE LOS PACIENTES CON CÁNCER SOBRE SUS DERECHOS LEGALES

Helena Megumi Sonobe¹, Luciana Scatralhe Buetto², Márcia Maria Fontão Zago³

ABSTRACT

The study objectives were: to survey the knowledge that oncology patients have about their legal rights, to identify the most known rights, and verify their knowledge about the procedure for requesting it. A survey was performed applying a checklist instrument during an interview. Participants were 42 oncology patients who were undergoing chemotherapy and their relatives. Of all participants, 57% were female; 28% were between 61 and 70 years old; 62% had completed only primary education; 72% were married; 50% had a family income of 2.6 minimum salaries. 45% were unaware of the benefits; among the existing benefits, retirement was recognized by 23%; 33% stated the medical record as the most important document; 38% had access to the information through the media; 23% had not requested any benefits and 31% reported obtaining some kind of benefit. In conclusion, nurses should work effectively to disseminate the patients' rights, so that benefits are guaranteed and their condition as citizens is respected.

DESCRIPTORS

Patient rights
Knowledge
Neoplasms
Nursing

RESUMO

Os objetivos do estudo foram: levantar o conhecimento dos pacientes oncológicos sobre seus direitos, identificar os mais conhecidos e verificar o conhecimento dos procedimentos para sua solicitação. Foi realizado um levantamento, aplicando um instrumento tipo check-list numa entrevista. Participaram 42 pacientes oncológicos que realizavam quimioterapia e seus familiares. 57% eram do sexo feminino; 28% tinham idade entre 61 e 70 anos; 62% cursaram apenas o 1º grau; 72% eram casados; 50% tinham renda familiar de 2,6 salários mínimos. 45% desconheciam os benefícios; dentre os benefícios existentes, a aposentadoria foi reconhecida por 23%; 33% citaram o laudo médico como o documento mais importante; 38% tiveram acesso às informações pela mídia; 23% não haviam solicitado nenhum benefício e 31% relataram obtenção de algum benefício. Concluímos que o enfermeiro precisa atuar com efetividade na divulgação dos direitos dos pacientes, para que os benefícios sejam assegurados e sua condição de cidadão seja respeitada.

DESCRIPTORES

Direitos do paciente
Conhecimento
Neoplasias
Enfermagem

RESUMEN

El estudio objetivó: investigar el conocimiento de los pacientes oncológicos respecto de sus derechos, identificar los más conocidos y verificar el conocimiento de los procedimientos para su solicitud. Se realizó una colecta, aplicando un instrumento tipo check-list en una entrevista. Participaron 42 pacientes oncológicos que realizaban quimioterapia y sus familiares. 57% eran mujeres; 28% con edad entre 61 y 70 años; 62% cursaron apenas primer grado; 72% era casado; 50% tenía renta familiar de 2,6 salarios mínimos; 45% desconocía los beneficios; entre los existentes, la jubilación fue reconocida por el 23%; 33% citó el laudo médico como documento más importante; 38% tuvo acceso a informaciones por los medios; 23% no había solicitado ningún beneficio y 31% refirió obtención de algún beneficio. Concluimos que el enfermero precisa actuar efectivamente en la divulgación de derechos de los pacientes, para que los mismos sean asegurados y la condición de ciudadanía sea respetada.

DESCRIPTORES

Derechos del paciente
Conocimiento
Neoplasias
Enfermería

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INTRODUCTION

A cancer diagnosis can have unpredictable consequences for patients and their families. In the Western culture, cancer is associated with pain, suffering, physical limitations, dependency and fear of death; it represents a rupture in one's life plans. On the other hand, disclosing the diagnosis to patients enables them and their families to trigger their coping strategies to deal with the effects of the disease and its treatment in the best way they can⁽¹⁾.

The trajectory of patients with cancer has drawn the attention of health professionals in various fields and concern with the emotional aspects has been a theme much explored through various theoretical and methodological frameworks⁽²⁾.

The technological progress of diagnostic means and therapeutic procedures has extended patients' survival. Even though Brazilian data for 2006 were not available, the USA reported there are more than 10 million cancer survivors⁽¹⁾. In this context, concerns over patient rehabilitation, survival, and quality of life emerge.

It is acknowledged that morbidity is a striking aspect during the survival period, especially during treatment, and impedes patients from performing occupational activities. We know that most of the cancer patients who seek care in the Brazilian Unified Health System (SUS) are from the working class. Many of them are not formally employed, which may affect the dynamics and functioning of their families during treatment, especially when there are unpredictable extra expenses⁽³⁾.

The rights of patients are ensured by various documents, among them, the Charter for the Rights of Health Users⁽⁴⁾. Brazilian law ensures some special rights to individuals with cancer and other severe diseases⁽⁵⁻⁶⁾.

The financial problems of cancer patients could be minimized if everyone had access to rights and benefits, granted and ensured by federal, state and city laws. The law should reach all individuals, without prejudice or privileges, the application of which is a duty of the government through its representatives. However, it is known that even though individuals have constitutional guarantees, there is a gap between written law and the practice of health services⁽⁴⁾.

Given the context experienced by patients during the cancer treatment, the work of health professionals in providing information on the rights of cancer patients is essential to intervene in the social context in which these patients are inserted, ensuring they are welcomed and adhere to the proposed treatment.

Hence, this study sought to answer the following questions: what do cancer patients know about their legal rights?

Which rights have they secured? What are the difficulties to obtain these rights and what facilitates obtainment?

OBJECTIVES

Given the preceding discussion, this study was performed with the following objectives: 1) identify the knowledge of cancer patients concerning their rights; 2) identify the most commonly known rights; 3) verify the knowledge they have concerning the procedures needed to ask for such rights to be honored.

LITERATURE REVIEW

Individuals undergoing cancer treatment incur considerable financial burden characterized as direct and indirect expenses. Direct expenses include items such as prescribed medications, diagnostic or therapeutic procedures and hospitalization. Indirect expenses are those not directly applied to medical care; these are lower but important costs. These expenses are a responsibility of the patient, regardless of whether they have a health plan or insurance, or are covered by the SUS. Patients often need to reduce work hours or leave their jobs, either because of the time spent for treatment or because of complications from the disease. Fatigue and other adverse effects of treatment sometimes hinder patients from working with the same intensity as they had before the disease. This situation is particularly devastating for single individuals and families from the working class⁽⁷⁾.

Even though there are legal protections, difficulties maintaining a job remain after the treatment. It is important to keep in mind that some of these patients experience discrimination from their employers and co-workers once they go back to work because some believe that cancer patients are incapable of performing their activities in the way they did prior to the disease. Hence, the difficulty in keeping one's job can be financially and emotionally devastating for survivors, even if they are physically fit. Difficulties faced in the employment sphere certainly affect the entire economic and emotional dynamics of the family⁽⁷⁾.

Problems with transportation and accommodation are the primary indirect expenses. The specialized cancer centers are not always located in the city of origin of the cancer patients, which forces them and their caregivers to travel to other cities. Even if they stay in hospitality houses, they still have to buy food and personal hygiene items, among others⁽⁷⁾.

Indirect expenses seem trivial when compared to direct expenses, however, they represent a cruel reality for families from working classes and can be an important barrier for them to receive care, which affects the treatment results⁽⁷⁾.

A study carried out in Ontario, Canada with 282 cancer patients under treatment for breast, colorectal, lung or prostate cancer between 2001 and 2003 revealed that indirect personal expenses not covered by the official health system were related to material resources for care, medication, accommodation, alternative and complementary therapies, vitamins and others. According to the authors, most of the patients were well served by the national health care programs and the variables that influenced indirect expenses were related to the tumor site, hospitalization, age and number of trips necessary to receive treatment. Trips were considered the most problematic, especially among patients younger than 65 years of age and without health plans or insurance. They added that educational and social level are not predictive factors for high indirect expenses; these costs affect all individuals without making distinctions⁽⁸⁾.

No studies addressing the knowledge of cancer patients concerning their legal rights were found in the indexed national periodicals. Only one descriptive study addressed the social implications, among other aspects, faced by 25 families of patients with osteosarcoma in the lower limbs. The following results were presented by the authors: 92% reported that expenses increased after their diagnosis, which reduced family income; 43% did not have financial resources and transportation to attend the consultations, in addition to other difficulties. The results indicate that even when patients are treated by the SUS, they have increased expenses since cancer requires prolonged treatment, different types of exams and frequent medical return visits, causing the family to spend time and resources for trips to the hospital and other needs that derive from the new routine imposed by the disease⁽⁹⁾.

Coupled with this scenario, the small number of national studies addressing this subject after 2000 justifies this study.

METHOD

This survey study investigates the knowledge and attitudes of people concerning the legal rights of cancer patients⁽¹⁰⁾. The study was carried out in the Cancer Center of the Benevolent Society and Hospital *Santa Casa da Misericórdia de Ribeirão Preto*, SP, Brazil after authorization was obtained from the Technical Director responsible for the unit and the Research Ethics Committee at the University of São Paulo at Ribeirão Preto, College of Nursing (protocol no. 0833/2007).

The sample was composed of patients undergoing outpatient chemotherapy and their adult companions, who agreed to participate in the study and sign free and informed consent forms. Data were collected through individual interviews from December 2007 to January 2008. The patients, who for some reason were unaware of the diagnosis, or were younger than 18 years old and did not have a companion, were excluded from the sample.

A data collection instrument was used. It addressed socio-demographic data, knowledge concerning the rights of cancer patients, and ways to demand such rights through a checklist that included the main ensured rights: special funding for disabled individuals, CPMF* exemption, right to withdraw FGTS, PIS/PASEP**, income tax exemption, income tax exemption in retirement, discharge from home financing, reconstructive breast surgery, expedited lawsuits, imported medication, social assistance to the elderly and the disabled, retirement due to disability, permanent assistance, financial aid due to disease, private social security, life insurance, professional rehabilitation of disabled workers, right to buy adapted or special vehicles, tax exemption for the purchase of adapted vehicles, inter-state free pass, city and inter-city free public transportation⁽⁵⁾. The last item of the instrument consisted of an open question for the individuals to express their needs concerning their rights.

After each interview, all the patients were informed of their rights and received an informational leaflet. Data analysis used descriptive statistics and content analysis was used for the comments of patients in the last item.

RESULTS

A total of 42 (100%) patients were interviewed; 24 (57%) were women and 18 (43%) were men. In relation to age, five (12%) were between 30 and 40 years old, seven (17%) between 41 and 50 years old, eight (19%) between 51 and 60 years old, 12 (28%) were between 61 and 70 years old, eight (19%) between 71 and 80 years old and two (5%) were older than 81 years old.

Data related to education revealed that 26 (62%) only attended primary school, nine (21%) attended secondary school, five (12%) had a bachelor's degree and two (5%) were illiterate. In relation to marital status, 30 (72%) were married, only one (2%) was single, two (5%) were divorced and nine (21%) were categorized as *other* according to the used instrument.

The family income of 21 (50%) patients was up to 2.6 times the minimum wage (MW); 13 (31%) up to 5.2 times MW; one (2%) up to 7.8 MW; two (5%) with income above 7.8 MW and five (12%) patients did not answer this question.

A total of 39 (93%) patients were in a condition to participate in the study. Of these, two (9%) patients did not know the diagnosis and one (4%) was too weak, which impeded his participation. Of the total, 22 (52%) were accompanied by relatives who completed the requested information.

In relation to the types of rights, 19 (45%) patients were unaware of such benefits, 23 (55%) had some knowledge concerning the existence of these benefits, and only one (4%) reported he had a book addressing the related law. The rights reported by patients are described in Table 1.

*CPMF: tax on financial transactions. ** FGTS, PIS/PASEP: These are somewhat similar to Individual Retirement Accounts.

Table 1 - Benefits known by the interviewed patients and number of citations - Ribeirão Preto, SP, Brazil - 2008

Benefits	Number of citations
Retirement	10
Financial aid due to disease	07
Tax exemption in retirement	07
FGTS withdrawal	05
Tax exemption in the purchase of vehicles	05
Free public transportation	04
Transportation of imported medication	04
Discharge from home financing	04
PIS/PASEP withdrawal	03
Income tax exemption	03
Automobile tax exemption	02
Property tax exemption	01
Permanent assistance	01
Sales tax exemption	01
CPMF exemption	01
Refund of life insurance	01

Four (9.5%) patients reported that the treatment offered by SUS included one of these benefits. In relation to the papers necessary to obtain such rights, the answers are presented in Table 2.

Table 2 - Documents reported by the interviewees as necessary to obtain the rights and the number of citations - Ribeirão Preto, SP, Brazil - 2008

Type of document	Number of citations
Medical report	14
National ID	07
Anatomo-pathological examination	06
Tax ID number	06
Proof of residence	02
Employee ID	02
Proof of income	01
Social Security Card	01
Birth or marriage certificate	01

One (2%) of the participants reported the SUS National Card was necessary but this document was not listed in the instrument used in the interviews.

In relation to access to information, two (5%) patients received orientations from physicians, one (2%) from nurses, four (9.5%) received information from other cancer patients and 16 (38%) were informed by other means.

Even being aware of their rights, 10 (23%) patients had not asked for any benefit and 13 (31%) reported they had already received some of the benefits. Seven (17%) partici-

pants noted some elements that facilitate the submission of the request for the benefits: completion of the forms, the employees and physicians of the oncology service were cooperative, the employees of the agencies responsible for the benefits were quick and provided the correct information. Six (14%) patients listed the following difficulties: lack of knowledge or obsolete knowledge of employees of the agencies responsible for the benefits, high demand of patients in these agencies, lack of organization, insufficient number of employees to meet the demand of patients, few appointments available in the agencies' schedule.

DISCUSSION

The number of interviewees, 42 (100%), who were undergoing chemotherapy, was below that of the previous months. Some patients, with medical authorization, postponed chemotherapy due to the holiday season, expecting to be physically better to celebrate the holidays with their families.

Despite all the clarification provided to patients about the study, some patients were initially apprehensive in relation to the interview, but such feelings were overcome and all of them showed interest in the subject throughout the course of the interviews.

These emotional responses are expected and evidence the apprehensiveness of patients in the face of the rights issue, which is something that is not part of routine discussions in Brazilian culture. Hence, the feeling of loss of autonomy is a consequence of a lack of knowledge on the subject.

The therapeutic relationship between the health professional and the patient should complement knowledge and the need of information so that individuals participate in the solution of their care needs through the acquisition of knowledge. Acknowledging the patient's autonomy encourages them to push their limits, helps them develop their own opinions about the meaning and respect for human dignity⁽¹¹⁾.

The 18 (43%) male patients participating were uneasier than the women in answering questions about the subject, and even apologized for not being informed about the benefits to which they were entitled. The 24 (57%) female patients considered the interview an informal conversation and showed more understanding of the theme.

When asked about their knowledge concerning their rights ensured by law, 19 (45%) interviewees did not know about the existence of such benefits and four (9.5%) considered the treatment they received from SUS one of the ensured rights.

None of the individuals displayed knowledge of all the rights to which cancer patients are entitled. Of the 24 (55%) patients who reported knowledge about their rights, the most cited benefits were: retirement, financial aid due to disease, income tax exemption in retirement, FGTS with-

drawals, tax exemption in the purchase of automobiles, free public transportation, transportation of imported medication, and discharge from home financing. It is noteworthy that one (2%) of the interviewees had received a book addressing the subject and displayed knowledge about it.

In regard to the patients' profile, 52% were older than 61 years old, which corresponds to the estimates indicating an increase of the disease for this age range between 2008 and 2009⁽¹²⁾. The individuals' age and other socio-demographic characteristics are in agreement with the economic context of the Brazilian population. The income that support the interviewees' families can be compromised with the emergency of unforeseen situations such as becoming sick with cancer, a fact mentioned by one interviewee, who reported he was experiencing hardships due to the disease. Patients with family income above 2.8 times the MW did not report financial difficulties after the disease, a facet that deserves investigation in the future.

Access to information concerning the rights of cancer patients for 20 (48%) of the interviewees occurred through other means and not through guidance provided by the health team. Oftentimes the health professionals who deliver care to this clientele are not familiar with this specific law. It shows the need to include this subject in the education of health professionals who work with these patients, especially in specialized facilities⁽¹³⁻¹⁴⁾.

The country's socio-political-legal structure has not favored integration and the range of action of benefits, while the centers of research development should disseminate knowledge and information to the community through professionals from the health field and other fields as well. Constant updating is needed, because information is complex and advancements occur all the time in all sectors, including the legal field.

Information is either transmitted verbally or through leaflets, a resource not always available because it depends on financing and incentive for its development and supply and also requires intellectual ability for individuals to understand it.

The media also disseminates information but usually does not provide all the necessary information and clarifications due to the type of language used and can lead to misinterpretation or even fail to reach the population as expected.

The right to retirement was a benefit mentioned by 23% of the interviewees, which may indicate that family finances are compromised when one faces the disease and incapacity to maintain a paid job. This benefit is ensured in many other situations, which makes the population hold the incorrect idea that retirement is always a citizen's right in all severe situations experienced by people.

The concept of disability in patients with cancer is a source of disagreement among medical experts and patients depend on decisions based on clinical experiences, not necessarily in the oncologic field. A situation related to the consultation

of a medical expert, who did not acknowledge the validity of documents that proved the presence of oncologic disease, is shown in the report of one of the interviewees:

...he (the physician) says he doesn't believe in the exams because my physical appearance is 'great'... he doesn't perceive my pain, says I'm fine, that I'm strong and that I'm good to work... (patient 2).

This disease oftentimes develops insidiously, suddenly, with nonspecific signs and symptoms, which may result in a delayed diagnosis. Other times, it may progress rapidly and severely, though not immediately physically visible. Hence, evaluation and follow-up by specialized professionals is essential.

Patients with cancer have their roles within the family structure changed and become vulnerable to the actions of other people who assume their responsibility and the maintenance of their basic needs through daily care. This vulnerability leads to feelings of helplessness, disability. In addition to the physical aspect, this incapacity also reflects on the psychological, social, emotional, moral and financial dimensions^(3,15).

An evaluation performed by an expert can intensify a patient's already compromised psychosocial situation because it can generate conflicts with the oncologist's evaluation, exacerbate a search for information concerning the pathology and its development, and trigger social isolation, rupture of family routine, and longing for dying and loneliness⁽¹⁶⁾. This change process also affects the caregiver who ends up enduring an excess of responsibilities, which is a stressful factor in the relationship with the patient⁽¹⁶⁾.

The financial aid and income tax exemption due to disease were mentioned by seven interviewees (17%), but they did not relate them to labor rights. These benefits are for individuals with physical disabilities and the elderly in general; cancer patients are included as one of the groups that receive such benefits.

As shown in Table 1, the other benefits were less frequently mentioned, which indicates the lack of knowledge of the population in relation to the Federal Constitution. One of the greatest difficulties reported by the participants refers to the application of law: each agency responsible for the benefit has a distinct interpretation.

In relation to the required documentation, the most commonly mentioned was the medical report, cited by 14 (33.4%) patients, even more frequently cited than personal documents and the anatomic-pathological examination, which actually proves the existence of the disease.

Even though the Brazilian Health System National Card is not required, one interviewee reported this would be one of the required documents. The purpose of this card is to build a database aiming to organize the health services, through the reception, storing and transmission of updated information concerning care delivery in order to qualify the access of individuals to the health services. This registra-

tion enables the health system to facilitate care delivery to the population, to enlarge access to medication, and to maintain a reliable follow-up of care flow.

At the end of each interview, patients were asked to report their experiences in the search for their rights. A discrepancy of opinions was observed, though the number of patients who reported difficulties is statistically equal to the number of patients who did not report any problem in obtaining their rights.

The patients who experienced no difficulties obtaining the benefits associated it with the oncologic team at the unit, who sent all the necessary documentation and sped up the process in the social security department.

In turn, the patients who had difficulties highlighted the existent bureaucracy and lack of organization of government agencies responsible for the benefit, describing situations in which the individuals cannot schedule an appointment in advance, that is, they have to follow the order of arrival of those applying for the benefit, while there is a limited number of possible appointments per day. This fact forces many patients, almost always already debilitated and who do not have a priority to schedule appointments, to return to the agency other times, which results in extra financial expense, physical fatigue, and may even lead them to give up the benefit.

The professionals' lack of hospitality was also reported. It is noticeable how the absence of integration and humanization in the reception of patients deprives care of quality. The rights of cancer patients will only be concretized when the relationship among patients, health professionals and government services manage to concomitantly fill in gaps and achieve their goals.

There is total lack of information in these agencies, in which some even question the existence of the benefit, evidencing the need to train and prepare professionals to assist individuals who are in situations of physical and emotional fragility. The inefficient access to public agencies deprives patients of energy due to the stress it causes. It may also aggravate the disease to the extent individuals are excluded, a condition imposed by neglect⁽¹⁷⁾.

The promotion of educational campaigns addressing legal subjects, including rights ensured to the population in certain situations of disease, interconnecting universities, professionals, non-government organizations and community, can remedy this problem.

All the professionals working with care provided to cancer patients need to recognize and respect the rights of patients. Health professionals and specifically those in the nursing field, should in addition to respecting the ethical and legal rights of patients, demonstrate attention, respect and understanding of the situation they experience and provide information and guidance concerning the rights patients are entitled to. The quantity and quality of information available to patients can help them to make decisions and deal with difficulties⁽¹³⁻¹⁴⁾.

The literature acknowledges that even though there are resources available to assist cancer patients dealing with direct and indirect expenses during treatments, their economic needs remain a critical and growing problem due to medical follow-up. The specificity of information on the indirect costs of treatment and legal rights can help patients and their families to plan for the future and increase their self-confidence during decision-making, improving treatment results^(7,18).

CONCLUSION

Aiming to investigate the knowledge of cancer patients concerning their rights, identify the rights of which patients are most aware and verify the knowledge of patients concerning the procedures required from them to have access to these rights, interviews were held with 42 cancer patients who were receiving chemotherapy, employing an instrument especially developed for this study.

A total of 24 (57%) individuals were women and 18 (43%) were men; 12 (28%) interviewees were between 61 and 70 years old, 26 (62%) had only primary school education, 30 (72%) were married, and the family income of 21 (50%) was up to 2.6 times the minimum wage.

In relation to knowledge on the rights of cancer patients, 45% (19) were not familiar with the benefits they were entitled to; among the existent benefits, retirement was the most acknowledged by 10 (23%) of the interviewees; and among the required documentation, 14 (33%) mentioned the medical report.

The acquisition of information concerning rights was mainly obtained through the media (38%) and from other cancer patients (9.5%), which shows the low participation of nurses in the process.

Patients were from diverse socio-cultural levels and the benefits met different needs of each. While some applied for retirement, others asked for tax exemptions as legal entities related to their employment status. The context of cancer patients includes diverse needs, given the need to guarantee support for the family for greater financial stability.

The lack of knowledge and dissemination of patients' rights means that these benefits are not in fact ensured as citizens' rights. It is difficult to expect that a society that excludes an expressive part of its members from access to social and economic benefits it produces will treat them more appropriately when they become ill or need special care. Talking about the right to health means right to life, physical, psychological, social and emotional wellbeing.

Even acknowledging this study's limitations in relation to the sample and restricted focus, the results encourage further investigation of the theme in order to acquire a broader view of the financial hardships and knowledge of rights among cancer patients and families.

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