PATIENTS' SATISFACTION WITH INFORMATION ON DISEASE AND MORBIDITY

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This descriptive-correlational study aimed to evaluate the relation between patients' satisfaction with information they have about their disease and its morbidity. A questionnaire was applied in two samples: 235 individuals with recent experience of illness (network sampling) and 254 hospitalized cancer patients post-surgery (consecutive sampling). The Escala de Conhecimentos sobre a Doença(12) [Patients' Satisfaction with Information Questionnaire - PSIQ] and the Rotterdam Symptom Checklist were used. Results show that participants were dissatisfied with information received and this dissatisfaction was more pronounced in hospitalized patients. An inverse statistically significant correlation (p<0.001) is observed between patients' satisfaction with information and physical, psychological and global morbidity. The conclusion is that obtained results appoint to the need for health professionals to invest more in patient information and reinforce the benefits of this area of nursing care.

DESCRIPTORS: consumer satisfaction; information; disease; morbidity

LA SATISFACCIÓN DEL PACIENTE CON LA INFORMACIÓN OFRECIDA SOBRE SU ENFERMEDAD Y MORBILIDAD

Objetivo: el objetivo del estudio fue evaluar la relación entre la satisfacción de los pacientes con la información sobre la enfermedad y su morbilidad. Metodología: se trata de un estudio descriptivo y de correlación resultante de la aplicación de un cuestionario a dos muestras; siendo una de 235 personas con experiencia reciente de enfermedad (muestra en redes) y la otra de 254 pacientes hospitalizados después de una cirugía de cáncer (muestra consecutiva). Fue utilizada la Escala de Conocimientos sobre la Enfermedad y el Rotterdam Symptom Checklist. Resultados: los encuestados se muestran insatisfechos con la información, y esta insatisfacción es más pronunciada en los pacientes hospitalizados. Existe una correlación inversa estadísticamente significativa (p<0,001) entre la satisfacción de los pacientes con la información y su morbilidad física, psicológica y global. Conclusión: los resultados sugieren la necesidad de contar con una mayor participación de los profesionales ofreciendo información a los pacientes, lo que reforzaría los aspectos positivos de esta área de atención de enfermería.

DESCRIPTORES: satisfacción de los consumidores; información; enfermedad; morbilidad

SATISFAÇÃO DO DOENTE COM A INFORMAÇÃO SOBRE A DOENÇA E MORBIDADE

O estudo teve como objetivo avaliar a relação entre a satisfação dos doentes com a informação sobre a doença e a sua morbidade. É um estudo descritivo-correlacional, resultante da aplicação de questionário a duas amostras: 235 indivíduos com experiência recente de doença (amostra em redes) e 254 doentes oncológicos, internados pós-cirurgia (amostra consecutiva). Utilizada a Escala de Conhecimentos sobre a Doença e a Rotterdam Symptom Checklist. Os resultados mostram que os indivíduos inquiridos se apresentam insatisfeitos com a informação, sendo essa insatisfação mais pronunciada nos doentes internados. Verifica-se correlação inversa estatisticamente significativa (p<0,001) entre a satisfação dos doentes com a informação e a morbidade física, psicológica e global. Conclui-se que os resultados obtidos apontam para a necessidade de maior investimento dos profissionais de saúde na informação aos doentes e reforçam o lado positivo dessa área dos cuidados de enfermagem.

DESCRITORES: satisfação do usuário; informação; doença; morbidade

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INTRODUCTION

Patients' rights are acknowledged in several European countries, aiming to protect their autonomy. The right to be informed about one's health condition is one of these and perhaps the most important right, about which much has been discussed and written in recent years. Several studies reveal patients' desire to be informed[1-2].

Although health professionals understand the patients' right to information, they assume it is not always respected[3]. If, on the one hand, we are living a moment when patients' autonomy is strongly valued, on the other hand, some professionals are still afraid that too much information might be harmful, especially in cases of severe diseases.

Patients certainly have the right to be informed about their health condition. We know, however, there are no defined standards on how much information should be provided to patients so they can seek and cope with it in diverse ways. Therefore, different levels of information are presented, which consequently lead to different levels of satisfaction. Thus, it seems that, if one wants to focus on the patient, more than providing information according to an impersonal and rigid protocol, information should be transmitted in a personalized way, taking into account each specific patient.

Objective

This study aimed to analyze patients' satisfaction with information they have about the disease and its relation with physical, psychological and overall morbidity.

Patients' right to be informed

The relationship between health professionals and patients has considerably changed in the last decades due to acknowledged great advancements, which provided medicine with new alternatives to intervene. This relationship has also changed due to considerable social and cultural changes that strongly emphasize human rights and individual freedom, which have showed that, in most situations, there are several values at stake that go beyond expectations of cure. Currently, the relationship between health professionals and patients should be assumed as a kind of social contract between moral strangers[4] where respect for patients' autonomy is essential. In this perspective, which recommends phasing out the statute of patients (which viewed health care as a gift) to an attitude that takes into account the perspective of clients (who are entitled to the health care they are paying or have paid for), more curious and demanding attitudes are expected and encouraged[5].

We currently know that information is a real need of patients, as it allows them to construct positive attitudes in relation to the disease, more adequate responses to the situation, and an effective participation in decision-making and future perspectives. Information also has a central role in health education programs[6]. It is also essential because it determines attitudes towards the disease itself, decisions and future actions of patients and families, which in turn influence their quality of life[7].

Thus, information is due to patients, not only because it is a requirement to respect their autonomy, but also because it is a real benefit[8]. Several authors have appointed the beneficial effects clear information has on clients, positively affecting prevention, treatment and recovery, behavior change, favoring participation in decisions, continuity of care and maximization of health results[9-11].

METHOD

This quantitative study with descriptive-correlational design is the result of a questionnaire applied to 489 individuals, originated from two different samples. A total of 254 post-surgery cancer patients hospitalized in General Surgery and Surgical Specialty Units of a Public Portuguese Cancer Center were included (day of discharge) through consecutive sampling between June and July 2007. Another 235 individuals with recent history of disease, needing resources for special care but not hospitalized at the moment of data collection, were included through network sampling from the Portuguese population between March and July 2007.

Inclusion criteria for both groups were: being older than 18 years, Portuguese, physically and psychologically able to read, interpret and provide written answers, and provide consent to participate in the study.

All participants were assured anonymity and confidentially of responses. The inexistence of compensation or damages arising from participating in the study was also assured.

The administration of the Cancer Center authorized the application of the questionnaire in hospitalized patients after approval by its respective Ethics Committee. Before applying the questionnaire, the author had an informal conversation with patients, asked their collaboration and guaranteed that all ethical principles would be followed. Written consent form was provided.

Students from two undergraduate courses in Coimbra, Portugal applied the questionnaire. These students distributed one thousand questionnaires and were oriented not to fill out any questionnaires themselves, but ask for the collaboration of family members, friends or neighbors with recent disease experience. Given the particularities of this kind of sampling, an independent report was asked to the Ethics Committee at the Health Center of *São João*, a health institution in the metropolitan region of Porto, Portugal. Receiving correctly completed questionnaires was a sign of agreement to participate in the study and the Ethics Committee validated this assumption.

A sociodemographic questionnaire, the *Escala de Conhecimentos sobre a Doença*[12] [Patients' Satisfaction with Information Questionnaire - PSIQ] and the Portuguese version of the Rotterdam Symptom Checklist (RSCL)[13] were used.

The PSIQ permits to identify patients' satisfaction with the information they have about the disease through 28 items, equally divided into two dimensions: a dimension related to *projective and self-control information* – which includes items related to the future impact of disease and to knowledge and strategies that develop autonomy - and a dimension related to *medical information*, which includes aspects related to the disease itself, to its diagnosis and treatment. It presents good validity and reliability criteria, with internal consistency values (Cronbach's alpha) of 0.93 for the global scale score and 0.93 and 0.92 for each of the dimensions mentioned above, respectively. The PSIQ uses average values in the global scale score and in both dimensions, which can vary from zero (corresponding to the answer "I do not know anything") to three (corresponding to the answer "I know enough").

The RSCL is an instrument that permits to study the interviewees' morbidity through an evaluation of the occurrence (and intensity) of 30 symptoms pre-established in a list. It is a comprehensive instrument with simple answers. These 30 symptoms were distributed according to two factors that originated the classification that distinguishes physical from psychological symptoms. The psychological symptoms (factor 1) are: irritability, worrying, depressed mood, nervousness, difficulty sleeping, despairing about the future, tension, anxiety and difficulty concentrating. Of the 21 remaining symptoms, 18 are classified as physical symptoms and three are excluded because of asymmetrical answers (constipation, nausea and vomiting). Some more recent studies using RSCL recommend its use because of its validity and reliability.

The distribution of items according to two factors, as proposed by authors, was used in this study. Symptom 16 was also eliminated – decreased sexual interest – because it was not pertinent to hospitalized patients and also because most (not hospitalized) patients with recent experience of disease did not answer it, especially the oldest ones.

The RSCL internal consistency analysis revealed alpha values of 0.92 on the global scale score and 0.90 and 0.83 on the dimensions related to psychological and physical morbidity, respectively.

Descriptive measures of central tendency and dispersion were used. Because the PSIQ distribution of the global scale score and of both dimensions were not normal, non-parametric tests (Mann-Whitney and Spearman's correlation) were used for inferential analysis.

RESULTS

The female gender represented two thirds (68%) of the interviewees. Average age was 51.01 years (standard deviation=16.50 years), varying from 18 to 93 years old. "Married" was the prevailing marital status (70.4%). Only 18.8% of the participants had a higher education degree (bachelor's degree or teaching diploma). Almost half of the participants lived in the rural area.

Some descriptive statistical values related to participants' satisfaction in relation to information they received on the disease can be observed in Table 1. The average of answers to the dimension "medical

information" is 1.82 points, whereas the dimension "projective and self-control information" presented a slightly higher average answer score (1.97 points). The average of the global scale score is 1.90 points.

Table 1 – Descriptive statistics related to PSIQ

Statistics		Projective and self-control information	Medical information	Total Score
Average		1.97	1.82	1.90
Standard Deviation		0.84	0.80	0.78
Percentile	25	1.36	1.25	1.36
	50	2.21	1.93	2.14
	75	2.57	2.43	2.46

When average satisfaction values are compared to information on the disease, these are lower in hospitalized than in non-hospitalized patients and these differences are statistically significant (p<0.001) for the PSIQ global score as well as for each of the dimensions according to Mann-Whitney's U test.

In relation to morbidity, the symptoms that present the highest occurrence/intensity are almost all included in the dimension related to psychological morbidity, whereas those with the lowest occurrence/intensity are included in the dimension related to physical morbidity.

When average morbidity values are compared between patients hospitalized at the moment of data collection and those with a history of recent disease (but not hospitalized at the moment of data collection), hospitalized patients presented slightly lower values, both in the dimensions and in the RSCL global score. These differences are statistically significant for the RSCL global score (p<0.001), which is not the case when dimensions are analyzed separately.

We thus formulated the working hypothesis that assumes there is a relation between patients' satisfaction with information they have about the disease and the occurrence/intensity of symptoms.

To test the formulated hypothesis, a series of Spearman's correlation tests was performed between the PSIQ dimensions and its global score and both RSCL dimensions, whose results are presented in Table 2. We can observe there is a negative, weak correlation between PSIQ several dimensions and its global score and RSCL dimensions, and also that all these relations are statistically significant (p<0.001).

Table 2 – Results of Spearman's correlation test between satisfaction with information about the disease and morbidity (n=428)

RSCL	PSIQ					
	Projective and self-control information		Medical Information		Total Score	
	r_s	p	r_s	p	r_s	p
Physical Morbidity	-0.28	0.000	-0.22	0.000	-0.27	0.000
Psychological Morbidity	-0.32	0.000	-0.28	0.000	-0.32	0.000
Global Morbidity	-0.32	0.000	-0.27	0.000	-0.32	0.000

When analyses are performed separately, based on the type of patient (hospitalized or with recent disease), negative correlations with strong statistical significance (p<0.001) are still found in all situations with r_s values close to 0.3 in individuals with recent experience of disease, and around to 0.5 in hospitalized patients.

DISCUSSION

We verified that the participants are dissatisfied with information they have about the disease. Considering the maximum value of three points, the average obtained in this sample was very low, not reaching two points, both for the PSIQ global score and for each of the dimensions. Other studies show that most patients report they receive less information than what they expect[2,14]. It seems that, in practice, patients are not satisfied with this essential right, nor are professionals complying with their duty, which is to provide clear and complete information to patients.

We observed that both for PSIQ dimensions and for its global score, the obtained average values are always lower in the sample of hospitalized patients when compared to the sample of individuals with recent history of disease but not hospitalized at the moment of data collection, and that these differences are strongly statistically significant (p<0.001). That is, based on collected data, we can affirm that individuals who already passed the acute disease phase are significantly more satisfied with information they have about the disease when compared to hospitalized ones. It is important to keep in mind that the sample of hospitalized individuals is exclusively composed of

patients with cancer who were submitted to surgery, whereas there is no control on the type of pathology in the other sample, which can determine some differences. However, it seems that the time passed since the acute disease phase permits individuals not only to recover their balance in terms of health, but also to satisfy their information need.

The occurrence/intensity of a set of symptoms was evaluated through the RSCL. The dimension related to physical morbidity presents proportionally lower average values (based on the number of items) than the dimension related to psychological morbidity. This is a common result in the majority of studies using RSCL.

As opposed to the expected, hospitalized patients presented slightly lower physical, psychological and global morbidity than individuals with recent experience of disease (but not hospitalized at the time of data collection). We have to bear in mind that hospitalized patients are recovering from recent surgery, mutilating surgeries in many cases. There are no studies in literature that can be used for comparison, which requires further research.

Through a set of Spearman's correlation tests between PSIQ dimensions and its global score and both RSCL dimensions, we observed that there is negative correlation of strong statistical significance (p<0.001) between PSIQ and RSCL several dimensions and global results. These correlations are maintained when separate analyses are performed based on the participants' health condition (hospitalized or with recent history of disease), which confirms, in this sample, the hypothesis that there is a relation between patients' satisfaction with information they have about the disease and its morbidity, in which more satisfied patients present lower physical, psychological and global morbidity indexes.

RSCL has been widely used in several studies, especially in research focusing on patients' quality of life and suffering. For instance, the association between patients' global, physical and psychological morbidity and their levels of suffering has been clearly demonstrated[15]. Studies demonstrating relations between patients' morbidities and their knowledge on the disease or their desire to be informed were not found.

There are some studies addressing some specific symptoms. In a recent systematic review[16], the association between information provided to pre-surgery patients and postoperative pain was demonstrated and pain was milder in better-informed patients. Several studies have shown the beneficial effect of interventions focused on improving the health professional/patient relation in areas like pain, quality of life, functional status and wellbeing and levels of anxiety and depression[17].

In practice, the majority of nurses have practical examples in this area, demonstrating how information and attention to patients are important painkillers, relaxing or antidepressant, among other effects. The author has experienced many of these examples during his several years of experience in the cancer area, which are now confirmed by abundant scientific evidence.

The evaluation of results has to take into account some of the study limitations, which impose caution on its interpretation and especially on its generalization, mainly on data related to individuals with recent history of disease (but not hospitalized), because of the sample size and also because of the sampling technique.

CONCLUSION

Information on health and disease is an individual's inalienable right and arguments on the contrary are increasingly weaker, even in cases of severe diseases. This study reveals the importance of patients' satisfaction with information they receive on the disease.

We observed some dissatisfaction of participants with information they have about the disease and, based on the results obtained in the studied sample, we can affirm that, the more patients are satisfied with information they have about the disease, the lower their morbidity, that is, the lower symptoms' occurrence and intensity, which is in agreement with several studies that affirm the beneficial effects of information for patients.

These results have strong implications for nursing practice because they contribute to legitimate an important component of care. At the same time, they suggest the need for health professionals to invest more in providing information to patients.

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