Assessment of hope in patients with chronic illness and their family or caregivers*

Avaliação da esperança em pacientes com doença crônica e em familiares ou cuidadores

Evaluación de la esperanza en pacientes con enfermedad crónica y en familiares o cuidadores

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ABSTRACT

Objectives: To evaluate the level of hope among the three different groups and correlate their levels with demographic and clinical variables. **Methods:** Descriptive study with a sample of 131 individuals (including 47 cancer patients, 40 diabetic patients and 44 caregivers/ family / caregivers) responding to Hertha's Scale of Hope, Rosenberg's Self-esteem Scale, the Beck Depression Inventory, and an instrument including personal data. **Results:** There was no difference in hope scores between groups. Hope was positively correlated with self-esteem and negatively correlated with depression. For cancer patients, the hope score was not related to any clinical variable. For diabetic patients, different forms of treatment and other comorbidities were not found to influence hope. **Conclusion:** Patients with chronic disease and their families had high hope scores. The measurement of hope can improve nursing care.
Keywords: Life expectancy; Chronic disease; Caregivers; Family

RESUMO

Objetivos: Avaliar o escore de esperança entre os três diferentes grupos e suas variáveis sociodemográficas e clínicas e correlacionar esperança com essas variáveis. **Métodos:** Estudo descritivo com amostra constituída por 131 indivíduos – 47 pacientes oncológicos, 40 pacientes diabéticos e 44 acompanhantes/ familiares/cuidadores - que responderam às Escalas de Esperança de Herth e de Autoestima de Rosenberg, o Inventário de Depressão de Beck, e um instrumento com dados pessoais. **Resultados:** Não houve diferença nos escores de esperança entre os grupos. A esperança correlacionou-se positivamente com autoestima e negativamente com a depressão. Para pacientes oncológicos, o escore de esperança não se relacionou a nenhuma variável clínica. Para os pacientes diabéticos, as diferentes formas de tratamento e outras comorbidades não influenciaram na esperança. **Conclusão**: Os pacientes com doença crônica e seus familiares apresentaram escores altos de esperança. A mensuração da esperança pode melhorar o cuidado de enfermagem.
Descritores: Esperança de vida; Doença crônica; Cuidadores; Família

RESUMEN

Objetivos: Evaluar el escore de esperanza entre los tres diferentes grupos y sus variables sociodemográficas y clínicas y correlacionar la esperanza con esas variables. **Métodos:** Estudio descriptivo con una muestra constituida por 131 individuos – 47 pacientes oncológicos, 40 pacientes diabéticos y 44 acompañantes/ familiares/cuidadores - que respondieron a las Escalas de Esperanza de Herth y de Autoestima de Rosenberg, el Inventario de Depresión de Beck, y un instrumento con datos personales. **Resultados:** No hubo diferencia en los escores de esperanza entre los grupos. La esperanza se correlacionó positivamente con la autoestima y negativamente con la depresión. Para pacientes oncológicos, el escore de esperanza no se relacionó a ninguna variable clínica. Para los pacientes diabéticos, las diferentes formas de tratamiento y otras co-morbidades no influyeron en la esperanza. **Conclusión**: Los pacientes con enfermedad crónica y sus familiares presentaron escores altos de esperanza. La mensuración de la esperanza puede mejorar el cuidado de enfermería.
Descriptores: Esperanza de vida; Enfermedad crônica; Cuidadores; Familia

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INTRODUCTION

Human beings always live waiting for something. They wait for better days, good working conditions, a pay raise, rain or sun, the birth of a child, good health conditions and education, among other things. In brief, hope is what drives men forward in their daily life.

Hope is a state associated with a positive perspective of the future[1]; an effective coping strategy[2-3]; the expectation of achieving an objective, something necessary for life[4]; "…a fantastic dimension of life…"[5]; an inner power that enriches the being[6]; something that enables one to overcome the current situation and to have a new awareness of the being[7]; that which originates from one's faith in God, giving meaning and joy to life[8].

Hope is what drives individuals to act, move and achieve something. Lack of hope makes them dull and purposeless, waiting for death[4]. Hope is associated with well-being, quality of life and remaining time of life. It provides strength to resolve problems and to face difficulties, such as losses, tragedies, solitude and suffering[9].

Authors[10] conceptualized hope into two spheres and six dimensions. The spheres are characterized as general hope, i.e. a certain future benefit, although with an uncertain development; and specific hope, i.e. that associated with a particular object. The dimensions are as follows: affective – refers to emotions associated with hope; cognitive – thoughts and desires associated with hope; behavioral – actions performed to achieve hope; affiliating – consists in the relationship one has with oneself, with others and with God; temporal – the relationship between the past, present and future and hope; and contextual – includes personal experiences of life as a whole, as these are influenced by the experience of hope. In the process of chronicity, there are serious conditions when patients and their family members lose hope. Nurses can also lose hope, when the death of a patient becomes imminent. However, hope must not focus exclusively on the desire of cure or more years of life. A person can wait for something in the short term, which can be achieved, such as an extra week without suffering, a phone call to a person whom they love, another sight of spring, or the hope for a good death, worthy of this person and including those they love close by[5].

The beginning of a chronic disease in an adult individual implies behavioral changes that must be integrated with their life pattern. Personal needs change, routine tasks become difficult, finances become limited and losses accumulate[11].

Nurses have technical and human abilities to care for cancer patients, who frequently return to the hospital environment to continue their treatment[12]. The measurement of hope in these patients, as well as in diabetics, can provide the means to improve nursing care, as it is directed towards the patients' individual needs.

In recent years, interest in the concept, measurement and importance of hope has increased[1,13-15]. There are many instruments used to measure hope, such as the Herth Hope Index[9], an instrument abbreviated from the Herth Hope Scale (HHS)[15], the Nowotny Hope Scale[13], and the Miller Hope Scale[1], among others.

In Brazil, there are no studies that measure hope in patients with chronic diseases, which justifies the need for the present study, with the purpose of comparing hope between two chronic diseases, cancer and diabetes, including a group of family members and caregivers without chronic diseases.

Thus, the present study aimed to assess the hope score among these three different groups and to correlate hope with clinical variables.

METHODS

A descriptive study was conducted in the *Ambulatório de Quimioterapia de Adultos do Hospital São Paulo* (São Paulo Hospital Adult Chemotherapy Oupatient Clinic), university hospital of the *Universidade Federal de São Paulo*, *Liga de Controle de Diabetes* (Diabetes Control League) of the Discipline of Endocrinology of the *Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo* and *Associação Nacional de Assistência ao Diabético* (Brazilian Association of Diabetes Care). Data were collected between March and August 2006.

The sample was comprised of 131 individuals, who agreed to participate in the study and met the following inclusion criteria: to be a cancer patient with initial or metastatic disease, under chemotherapeutic treatment in the outpatient clinic, with or without complications resulting from cancer or its treatment, and to be aware of their diagnosis; or to have type 2 diabetes mellitus, with or without complications, and under outpatient treatment; or to be a companion, family member or caregiver of patients, as they are in the same socio-demographic context as these sample patients. The following criteria were adopted for the three groups: to be aged 18 years or older; to have cognitive ability to respond to the instrument questions, and to have at least six years of education.

The sample number represented in the data of the tables corresponded to 115 patients with complete information about the three scores (hope, self-esteem and depression), thus enabling the statistical analysis.

Socio-demographic and clinical data collection was made possible using three different instruments of characterization, one of which is for diabetic patients, another for cancer patients, and the last one for companions. They contain information about socio-

demographic and clinical characteristics, such as sex, age, marital status, religion, level of education, profession, current work status, monthly household income and information about the disease and treatment. These variables were selected due to their importance for chronic patients.

The clinical variables investigated for diabetic patients were time of diagnosis, glycated hemoglobin, type of treatment (oral hypoglycemic drug, insulin or both), physical activity, Body Mass Index (BMI), hypertension, dyslipidemia and microangiopathic complications. For cancer patients, the clinical variables were time of diagnosis, localized or metastatic disease, complications of treatment and pain.

The Brazilian version of the Herth Hope Index[16] was used to assess hope in the sample. It is a scale comprised of ten items, with a total score ranging from 12 to 48. The higher the score, the greater the level of hope. Items three and six have an inverted score.

The Rosenberg Self-Esteem Scale[17] (RSES) was used to assess self-esteem. It is a scale with ten sentences, with a score from zero to three each, where the higher the score, the lower the level of self-esteem.

The Beck Depression Inventory (BDI) was used to assess depression in the sample. It is a self-assessment instrument, frequently used in research or clinical practice to measure depression. It is a scale comprised of 21 items, including symptoms and attitudes. The score of each item varies from zero to three. The cut-off point depends on the sample. Scores higher than 15 indicated dysphoria among non-depressive patients. The term "depression" should be used for scores higher than 20, preferably with the clinical diagnosis[18].

Data collection was performed in the waiting room of the above mentioned services, before, during and after routine outpatient treatment, and after explanations about the study, clarification of questions and signing of the Informed Consent Form.

Self-administered instruments of assessment of hope, self-esteem and depression were distributed to patients or read to them, in a reserved space that guaranteed their privacy to give individual responses.

Descriptive statistics were used to describe the characteristics of socio-demographic and clinical variables of the sample. Chi-square test or Fisher's exact test was used to evaluate the relationship of qualitative variables of the hope scale among the three groups. Pearson's correlation test was used to explore the relationship among hope, depression and self-esteem in these three groups.

The present research project was approved by the Research Ethics Committee of the School of Nursing of the *Universidade de São Paulo* (Process 508/2005).

RESULTS

With regard to the clinical characteristics, of the three types of cancer most frequently found in the sample of 47 patients, 19 (40.4%) were diagnosed cases of breast cancer (women); 11 (23.4%), hematological diseases (leukemia, lymphoma and myeloma); and 3 (6.3%), gastrointestinal cancer (colon and stomach). In the numerical pain scale, zero being without pain and ten being intense pain, 48.9% of patients with cancer reported pain with a mean score of 6.23 in the previous week. The majority of patients with cancer (51.1%) considered this to be a restrictive disease. Mean time since diagnosis was 1.01 years.

Among the 40 diabetic patients, 27 (67.5%) had hypertension as a comorbidity; 16 (40%) used oral hypoglycemic drugs exclusively, 12 (30%) used insulin only, 9 (22.5%) used both oral hypoglycemic drugs and insulin, and 3 (7.5%) controlled their glycemia through the diet only. Among sample patients, 14 (35%) considered diabetes to be a restrictive disease. Participants had a mean BMI of 28.11 ± 5.37, indicating overweight. Mean time of diagnosis was 13.15 years.

In the sample, assessment of hope is shown in the data of Table 1. The application of the HHS achieved high scores, considering the variation between 12 and 48, where a value of 48 is the highest HHS score.

The correlation among hope, self-esteem and depression is shown in the data of Table 2.

The correlation between HHS and BDI is negative, i.e. the higher the hope score, the lower the depression score. In addition, the correlation between HHS and the RSES is negative, in other words, the higher the hope score, the lower the self-esteem score. It should be

Table 1 - Hope scores, according to groups of cancer patients, diabetics and family members/caregivers, São Paulo, SP, Brazil, from March to August 2006.

	Group	Lowest score	Median	Highest score	Mean	Standard-deviation	Total	*P* value
	Oncology	33	42.5	48	41.57	4.60	42	
HHS	Diabetes	31	40.0	48	40.46	4.88	39	0.348
	Family members or caregivers	32	41.5	47	40.88	3.77	34	

Table 2. Correlation among HHS, BDI and RSES scores in the groups of cancer patients, diabetics and family members or caregivers*, São Paulo, SP, Brazil, from March to August 2006.

		Herth Hope Scale			
		General	Oncology	Diabetes	Family members or caregivers
BDI	Pearson's correlation	-0.39	-0.37	-0.45	-0.45
	P value	<0.001**	0.016**	0.004**	0.008**
	N	115	42*	39*	34*
RSES	Pearson's correlation	-0.50	-0.55	-0.59	-0.38
	P value	<0.001**	<0.001**	<0.001**	0.028**
	N	115	42*	39*	34*

*sample with compete information for the three scores;
**statistically significant

emphasized that the RSES score is inverted, i.e. the higher the numerical value of RSES, the lower the self-esteem. However, the higher the hope, the higher the self-esteem.

The level of hope was not associated with the diagnosis of cancer. Among the most frequent diagnoses, breast cancer and hematological diseases, there was no significant difference (p=0.216) in the level of hope. For the clinical variable "pain", there was no statistical difference (p=0.109), as patients with and without pain had similar hope scores.

Among diabetic patients, despite the different forms of treatment provided, there was no difference in the hope score among patients who only used oral hypoglycemic drugs, those who only used insulin and others who used both (p=0.794). The presence of the diagnosis of arterial hypertension did not have an influence on the level of hope in diabetic patients (p=0.512).

DISCUSSION

The studies describe the important role of hope in chronic diseases and the meaningful role of nursing in proposing interventions in health care for patients and their caregivers to maintain and raise their hopes[5,10,15].

With regard to the clinical variables of patients with cancer, type of tumor and presence of pain were not associated with hope. Another study that used the Herth Hope Index did not find a difference in the hope score between patients with and without pain[19]. In the same study, the stage of disease did not influence the level of hope[19]. A study conducted in Taiwan showed that patients with cancer and pain had lower levels of performance and hope, and high levels of mood disorders, such as confusion, fatigue and depression, when compared to patients with cancer and without pain[20]. After data were controlled for sex, stage of disease and location of disease, because patients had significant differences, the levels of hope, tension and depression were not different between patients with pain and those without it[20].

The presence of hypertension and type of treatment in diabetic patients did not show a significant association with hope.

The groups of this study did not show differences in the total hope score. The groups of patients with cancer, diabetics and the group of family members or caregivers had a high total hope score.

Pearson's correlation between HHS and BDI score and RSES is negative and significant, i.e. the higher the level of hope, the lower the depression score, and the higher the hope score, the lower the self-esteem score, because the latter score is inverted. An Italian study that assessed hope and associated variables, during and after hospitalization, showed that hope was positively correlated to self-esteem and negatively to depression[21]. An American study conducted with 100 elderly individuals diagnosed with cancer showed a positive correlation among intrinsic religiosity, spiritual well-being, hope and other positive mood states. The same study showed a negative correlation among intrinsic religiosity, depression and other existing negative mood states[22].

In a study with terminally ill patients, the desire of anticipating death was significantly associated with the clinical diagnosis of depression, measures of severity of depressive symptoms and lack of hope[23].

New studies that measure hope in different samples of patients with chronic diseases, after a certain nursing intervention, need to be conducted in Brazil.

CONCLUSION

The present study enabled the measurement of hope in a sample comprised of chronically ill patients and their family members and caregivers. The sample showed a high hope score and no differences among patients with cancer, diabetes and their family members and caregivers.

With regard to the clinical variables of patients with cancer, the type of tumor and presence of pain did not influence hope. Among diabetic patients, despite the different forms of treatment performed, there were

no significant differences in the hope score.

The correlation between hope and depression is negative, i.e. the higher the hope score, the lower the depression score. In contrast, the correlation between hope and self-esteem is positive, in other words, the higher the hope, the higher the self-esteem.

The measurement of hope enables an improvement in nursing care, in addition to allowing interventions to be proposed to patients and their caregivers, so they can maintain and raise their hopes.

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