Nurses’ and stroke patients’ perceptions of Health Education

Perceções dos enfermeiros e doentes com AVC sobre a Educação para a Saúde
Percepções dos enfermeiros y los pacientes con accidente cerebrovascular en la Educación para la Salud

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Abstract

Theoretical framework: Stroke causes multiple changes in the daily lives of patients and their families, but rehabilitation emerges an opportunity. The RNCCI (National Network of Integrated Continuous Care; Rede Nacional de Cuidados Continuados Integrados) facilitates rehabilitation, and health education enables the necessary change of attitude for rehabilitation.

Objectives: To identify and disclose nurses’ and stroke patients’ perceptions of the Health Education practices in the RNCCI.

Methodology: A qualitative study was conducted. Semi-structured interviews were performed to 8 patients and 17 nurses. The technique used was the content analysis of interviews. Based on previously established categories, other categories emerged.

Results: Patients assigned nurses most of the responsibility for the rehabilitation process. Nurses associated the psychological aspects and the importance of family involvement with the patients’ adherence to the therapeutic regimen.

Conclusion: While patients seem to be in the biomedical model, nurses point to the biopsychosocial model as a guide to their health education practices in the network.

Keywords: nursing; rehabilitation; education; health.

Resumo

Enquadramento: O Acidente Vascular Cerebral (AVC) acarreta múltiplas alterações no quotidiano do doente e seus familiares mas a reabilitação é considerada uma oportunidade. A Rede Nacional de Cuidados Continuados Integrados (RNCCI) facilita a reabilitação e a educação para a saúde possibilita a mudança de atitude necessária para a reabilitação.

Objetivos: Conhecer e divulgar as perceções de doentes com AVC e enfermeiros relativamente às práticas de Educação para a Saúde na RNCCI.

Metodologia: Qualitativa, com entrevista semi-estruturada, a 8 doentes e a 17 enfermeiros. A técnica escolhida foi a análise de conteúdo das entrevistas. Partimos de categorias definidas a priori, e emergiram outras categorias.

Resultados: Os doentes atribuíram aos enfermeiros a maior parte da responsabilidade pela reabilitação. Os enfermeiros relacionaram os aspectos psicológicos e a importância do envolvimento da família com a adesão do doente ao regime terapêutico.

Conclusão: Os doentes demonstraram que se encontram no modelo biomédico, por outro lado os enfermeiros apontam o modelo biopsicosocial como orientador das suas práticas de Educação para a Saúde na rede.

Palavras-chave: enfermagem; reabilitação; educação; saúde.

Resumen

Marco contextual: El accidente cerebrovascular provoca múltiples cambios en la vida cotidiana de los pacientes y sus familias, pero la rehabilitación se considera una oportunidad. La Red Nacional de Atención Integral (RNCCI por sus siglas en portugués) facilita la rehabilitación y la educación para la salud permite el cambio de actitud necesario para la rehabilitación.

Objetivos: Conocer y divulgar las percepciones de los pacientes con accidente cerebrovascular y de los enfermeros con respecto a las prácticas de educación para la salud en la RNCCI.

Metodología: Cualitativa con entrevistas semiestructuradas a 8 pacientes y 17 enfermeros. La técnica elegida fue el análisis de contenido de las entrevistas. Partimos de categorías definidas a priori y surgieron otras categorías.

Resultados: Los pacientes atribuyeron a los enfermeros la mayor parte de la responsabilidad en el proceso de rehabilitación. Los enfermeros relacionaron los aspectos psicológicos y la importancia de la participación de la familia con la adhesión del paciente al régimen terapéutico.

Conclusión: Por un lado, los pacientes demuestran que se encuentran en el modelo biomédico. Por otro lado, los enfermeros señalan el modelo biopsicosocial como orientador de sus prácticas de educación para la salud en la red.

Palabras clave: enfermería; rehabilitación; educación; salud.
Introduction

In the more developed countries with public health and social support policies in Europe and abroad, the priority need emerges to find solutions for dependent people (Unidade de Missão para Cuidados Continuados Integrados, 2010). The increase in existing shortcomings results from an increase in the number of older people and in the incidence of chronic patients, and a reduction of informal support to these groups. Thus, health policies have changed and an intermediate level of care has emerged - the Portuguese National Network for Integrated Continuous (RNCCI). This network aims to meet the needs of the elderly or dependent people who require healthcare services. It is a place of excellence to implement Health Education practices, especially with patients undergoing rehabilitation. The objective of the study was to identify stroke patients’ and nurses’ perceptions of Health Education practices in the Portuguese National Network for Integrated Continuous Care.

Background

The Portuguese National Network for Integrated Continuous Care is one of the most innovative projects in Portugal within the scope of social policies and intersectoral collaboration. It emerged from a partnership between the Ministry of Health and the Ministry of Labour and Social Solidarity, in which this co-funding and partnership are recommendations of the World Health Organization. It was created to respond to the progressive demographic aging, the prevalence of disabling chronic diseases, a deficient coverage of continuous care services in Portugal, a health system based on acute disease or prevention paradigms, and a substantial reduction of the informal support network.

According to Decree-Law no. 101/06, of 6 June 2006, the Network is composed of continuous healthcare and social support units and teams, which also include palliative care. Its origin lies in the neighbourhood community services, including hospitals, healthcare centres, district and local social security centres, and local authorities. Integrated continuous care is provided by inpatient units, outpatient units, hospital teams, and home care teams. Inpatient units include convalescence units, medium-term and rehabilitation units, long-term and maintenance units, and palliative care units. The outpatient unit includes the day care and autonomy promotion unit. Hospital teams are composed of discharge management teams and intra-hospital teams for support in palliative care. Finally, there are home care teams, integrated continuous care teams, and community teams for support in palliative care.

For patients to access the Portuguese National Network for Integrated Continuous Care, the nurses responsible for providing differentiated or Primary Health Care must refer them to the most relevant units according to prognosis. After referral by the Discharge Management Team and with the approval of the Local Coordination Team, the patient must wait for a vacancy at the selected unit. Once admitted to the convalescence or rehabilitation unit, the patient and the multidisciplinary team begin the rehabilitation process.

According to Tones and Tilford (1994, p. 11),

Health education is any intentional activity which is designed to achieve health or illness related learning ... produce changes in knowledge and understanding or ways of thinking; it may influence or clarify values; it may bring about some shift in belief or attitude; it may facilitate the acquisition of skills; it may even effect changes in behaviour or lifestyle.

This study focused on stroke patients, given that stroke is characterised by a disruption in blood supply to a part of the brain. The blood carries essential nutrients and oxygen to the brain, so the lack of supply compromises brain cell function. Nurses were chosen to participate in this study due to the partnership that is established between nurse and patient and essential for the development of Health Education practices. Thus, all this potential inspires a more in-depth research within the scope of Health Education. As such, the objective of the study was to identify stroke patients’ and nurses’ perceptions of Health Education practices in the Portuguese National Network for Integrated Continuous Care.

Research question

What are stroke patients’ and nurses’ perceptions of Health Education practices in the Portuguese National Network for Integrated Continuous Care?
Methodology

Permission was initially requested to the institutions for data collection. Short- and medium-term continuous care units of the Minho region, Northern Portugal, were invited to participate. However, only three of the five invited units accepted to participate in the study. A total of eight patients (three from two units and two from one unit) and 17 nurses (six from one unit, six from another unit, and five from another unit) participated in the study. Taking into account their level of understanding, participants (both nurses and patients) were then explained the purpose of the study and guaranteed the anonymity of the information provided. An informed consent form was designed to formalise this commitment with the research participants. This form was completed in duplicate, thus confirming this contract.

An exploratory-descriptive study was conducted with a convenience sample. A semi-structured interview was used for data collection. Two different interviews were designed: one for patients and another one for nurses. The final data collection tools are the result of several changes during research development. A pre-test was designed to assess relevant issues related to Health Education in that context and with that target population. The pre-test was applied to two nurses and two patients admitted to a medium-term continuous care unit in the Northern region of Portugal.

The eight patients who participated in the study were selected as a result of a regular contact with the Nursing team of each one of the selected units to select patients who were in the same rehabilitation phase. Thus, the selected patients had a diagnosis of stroke and were at the same stage of the rehabilitation process, i.e., they were in similar physical and cognitive conditions to cooperate during the interview and accepted to participate.

On the other hand, the 17 nurses interviewed had the same probability of being selected, as the only indispensable condition was being healthcare providers in the units selected for the study and accepting to participate. The interviews were conducted between February and May 2009.

Interview data were classified based on previously defined categories that resulted from the five main areas that, according to Neves and Galvão (2003), should be covered by Health Education. The first area refers to health protection or disease prevention through the elimination of risk behaviours; the second area refers to the need for mechanisms of financial resources in situations of illness; the third area refers to the individual (psychological) preparation for awareness of human frailty; the fourth area is characterised by a genuine and active engagement in the therapeutic process, symmetrical in the relationship with the professional; and, finally, the importance of the perception of the finitude of human life. Despite the fact that the data obtained did not fit into two of the previously defined categories, it allowed for the construction of other categories: obstacles to Health Education practices; opportunities for improvement regarding Health Education practices; and quality indicators of Health Education practices. Each category is framed by multiple registration units, which, in turn, are fleshing by the respective context units. Context units are extracts of the text defined as being the result of the transcription of nurses’ and patients’ interviews.

Results

From the point of view of patients admitted to the Portuguese National Network for Integrated Continuous Care, Health Education practices cover the categories Disease prevention through diet care, travel to health services, practice of physical exercise, hygiene care, and absence of addictive habits; Individual Preparation by considering the disease as changing the family roles, as a learning process, and as focus of low self-esteem; Active Participation with a problematizing participation, i.e., the disease was seen as an educative process that allowed for the patient’s release of conscience and emancipation. On the contrary, there were reports of banking participation and also of lack of participation in the rehabilitation process (Freire, 2005). Finally, patients believe that the eating habits are a quality indicator for Health Education practices, as can be seen in Table 1.
From the perspective of the nurses who provide care in the Portuguese National Network for Integrated Continuous Care, Health Education practices are aimed at Disease prevention through the prevention of depression, promotion of self-care, and management of therapeutic regimen; Obstacles to Health Education practices include the lack of human resources, time, methodology, space, and family involvement, patient passivity, and the lack of community resources; Opportunities for improvement include the empathetic relationship, the monitoring of Health Education practices, the critical spirit, and family involvement; Active Participation involves patient motivation and accountability. Finally, the nurses suggest the patients’ readmission rate, the reduced level of dependence in self-care, and the patients’ change of behaviour are possible quality indicators of Health Education practices in the Portuguese National Network for Integrated Continuous Care, as can be seen in Table 2.

In general, patients suggested that hygiene and diet care, the absence of addictions, and the practice of physical exercise are the necessary care for disease prevention and health promotion. This is in line with Santos (2000) in considering that the first generation of Health Education models is essentially informative. They assume that the lack of information is responsible for unhealthy behaviours and attitudes. In addition, they are inspired by the biomedical model, which, in turn, is based on disease prevention and treatment in the form of prescriptions and recommendations. Thus, the sampled patients have limited the notion of health to the mere absence of disease.
From the nurses’ perspective, the prevention of depression contributed to disease prevention or health protection, “In patients who have a tendency to become depressed, we have to work on that in order to motivate them in their work and achieve a better outcome” (A2) (February 2009). The nurses reported that the stroke patient is more vulnerable and more prone to develop a depression, particularly during the rehabilitation period. Depression may be triggered by a variety of factors, but, according to Cassell (2004), the notion of being a burden on the lives of those who they love the most is profoundly self-destructive of their identities and a source of suffering. According to MacIntyre (1999), the human being is a rational species, thus being one of the most vulnerable species, especially due to the affective ability. In this way, nurses come closer to the concept of health by Tones and Tilford (2001) that covers a balance between the biological, psychological, sociological, and spiritual dimensions which, in turn, are associated with genetic influences, healthcare services, and lifestyles.

Moreover, the nurses mentioned that self-care is a highly promoted type of care. However, the merely practical notion of acquiring skills dates back to the biomedical model, which is purely instructive and authoritarian. Dias (2009) points out that, according to the UNESCO Nairobi Declaration (1976), the educational phenomena create the necessary conditions for the integral and harmonious development of the human being in all its dimensions. Thus, the patients’ physical and mental autonomy, especially mental autonomy, is essential for their harmonious development in all dimensions of their lives. By combining the need to prevent depression and promote self-care, the sampled nurses associate the biomedical model with the holistic model “Hygiene care, trying to understand a little bit of these people’s habits, their housing conditions, if they have a bath, if they have a shower, trying to understand this part” (A1) (February, 2009).

As regards the education/rehabilitation process, nurses pointed out the importance of the patients’ effective management of their therapeutic regimen. This is in line with Moreno, Garcia, and Campos (2000), who give priority to the behaviour-centred Health Education models of second generation, in which the goal is to achieve healthy behaviours using the information only as a link in the process chain. Thus, health is considered to be the result of the individual’s behaviour, which is determined by stimuli from the surrounding environment. However, the same authors added the need to develop third-generation Health Education models, i.e. critical models, given the lack of efficiency of previous approaches. These models propose social changes, associate morbidity and mortality with economic policies, and try to reduce inequalities and promote community participation. Based on this third-generation Health Education models, the need emerges for nurses to encourage the development of psychological empowerment, i.e. the ability for people to make their own decisions and to not allow others make the decision for them. This is essential for an effective management of the therapeutic regimen. Some nurses stated that many patients did not effectively develop this skill, which prevented the patient’s health stock from increasing. Finally, the nurses reported a lack of feedback on the patients’ management of the therapeutic regimen at home. They added that recovery may be jeopardised when patients do not follow the plan established during hospitalisation at the unit while in their homes.

Another previously established category was the individual preparation, starting with a reflection on the disease. This category has gained visibility among the patients given the description of different experiences. For some patients, the disease made the established family structure more complex and forced the other family members to readapt to new roles.

Sometimes I even say to my husband: this was a sign for you, it was not for me, it was to give you a lesson that you must work and appreciate your wife, because you don’t do that. You were used to having the old lady doing everything, you didn’t know when to pay the electricity, water or phone bills, I’m still the one paying the rent! If he has to make some calculations, I’m the one doing them, he expects me to do that too. And I say “you’re expecting me to do this? and he says, C’mon, you can do that. (A1) (April 2009)

In view of the above, the remaining family members had to reformulate each other’s roles within the family structure and dynamics. Since the person responsible for several tasks was not present, the other family members would be responsible for replacing him/her. In this sample, the experience of disease demonstrated the learning and adaptation capacity of the patient and the relatives involved. However, due to the
multiplicity of changes in the lives of these patients and their families, the disease may be self-destructive, leading to low self-esteem, particularly in terms of sexuality. More specifically, some patients questioned the strength of their marriage because they felt diminished in this dimension. On the other hand, the circumstances led to the emergence or bringing together of significant persons in the patient’s life, who become facilitators during the process. However, despite most sampled patients feeling supported by family and friends at an early stage, as time went by, the changes in the life of the chronically ill patient became normal for the family, which stopped caring so much for and worrying about the patient. Therefore, we believe that the patient must be prepared for this phenomenon.

In the last decade, Neves and Galvão (2003) argued that the concept of patient underwent a profound change, as the shift from passive patients to more active patients became an exercise of citizenship. This movement of awareness and accountability evolved from an individual level to a community level, through the creation of support groups and associations for patients with the same condition. That said we expected to substantiate the category of active participation with many examples of this. However, most patients participated in banking mode, i.e. they replied to the instructions provided. Others withdrew from participation, as they had no knowledge of their therapeutic regimen, nor expressed their dissatisfaction with this fact, which revealed their functional illiteracy (functional illiteracy is the lack of basic knowledge on the multiple communication codes existing in the different dimensions of people’s lives). A single patient was observed who was actively involved in the rehabilitation process, taking over the responsibility for her health and questioning its different dimensions. Most of the nurses mentioned that they encouraged patients, but only a minority used the term accountability to describe the action that was directed to the patient during the therapeutic process. A dichotomy was observed between the biomedical model (blaming the patient for his/her performance) and the empowerment model (the patient is unable to achieve positive outcomes if he/she is not motivated and aware of the importance of his/her role in the therapeutic process).

With regard to the obstacles to Health Education practices, the nurses considered that the patient’s family was responsible for the lack of efficiency of the Health Education process. As the reasons were being described, accusations were made regarding the non-attendance at scheduled training sessions, the lack of motivation and interest in the learning process (which is related to the patient’s therapeutic process). This point of view is particularly important if we think that the family or caregiver (relative or not) will be co-responsible for the patient’s therapeutic process until he/she becomes autonomous. In this way, the nurse has proved to be a professional who facilitates the family members’ understanding of the patient’s clinical situation and promotes their active involvement in the construction of new meanings for their life contexts. Focusing on the nurses’ academic training and based on the holistic paradigm, which gives priority to the family’s role in the health concept, Rodrigues, Pereira, and Barroso (2005) argue that it is possible to establish an alliance with the family with a view to improving the homeostatic balance mechanisms.

Other causes were identified by the nurses, including the patient’s passivity, lack of motivation, compromised level of understanding as a result of the stroke, and the emotional problems that affect disease acceptance. The nurses argued that patients must accept the disorder (the disease) and assign it a meaning, in order to facilitate the transition to different learning levels. Another obstacle identified was the lack of human resources, which, in turn, triggers the lack of time for the provision of quality care. According to Tavares and Silva (2010), the effectiveness of continuous care can only be improved if head nurses, administrators of Long-term Care Units, and Network managers reconsider the allocation of qualified human resources and material resources needed at the units, promote professional training, and create the conditions for a partnership with the family. The lack of community resources was also mentioned, which is in line with the report of the European Commission (2007) that shows that more than 80% of the respondents in Portugal prefer to receive care in their own homes (still a lower number than that found among respondents from other countries of the European Union). However, as highlighted by the nurses in this study, no adequate structures and means to provide quality home care
As for the previously established categories related to the availability of financial resources as a precautionary measure in case of an expected situation of illness and to the assumption of mortality, no evidence was found for keeping them as Health Education categories. This study informs the scientific community that only three of the previously established categories (Disease prevention, Individual preparation, and Active participation) by Neves and Galvão (2003) are covered by the Health Education practices in the RNCCI. On the other hand, other categories have emerged that had not yet been described (Obstacles, Opportunities for improvement, and Quality indicators of Health Education practices).

Conclusion

Taking into account such a complex situation as the rehabilitation process, the pathogenic paradigm was found to be the most prevalent one among the Network patients. The patients focused on disease prevention and treatment, and considered the healthcare professionals to be responsible for most of their rehabilitation process. We believe that the passive and submissive attitude of most patients reflects the biomedical model that permeates some institutions, professionals, citizens, and the community in general. On the other hand, the nurses emphasised the biopsychosocial model as a guide to their practices, considered that the psychological and social aspects are responsible for the development of diseases, and associated the patient’s psychological aspects with the adherence to the therapeutic regimen.

The Portuguese National Network for Integrated Continuous Care is characterised as a dynamic, integrated, and continuous model that offers different types of care aimed at achieving its objectives. However, based on this study, no conditions have yet been created to expand the assumptions of psychological empowerment. Most patients did not participate in the rehabilitation process, given that they had no knowledge of their health condition and no expectations regarding the future. Only few patients focused on the general resources of resistance (individual abilities to cope with the disorders). From the nurses’ perspective, the families need to improve functional literacy, since most of them have difficulty in mastering the various functions of their
surrounding environment. This happens mainly because the families cannot operationalise what they are taught regarding patient care or mobilise the community resources.

The study limitations are related to sample size and the number of units involved, since we believe that the involvement of more units, nurses and stroke patients would contribute to a more complete and comprehensive data collection. The period in which the study was carried out can also be considered a limitation, since the units only existed for three years and were still in a pioneer stage of project implementation. We concluded that there are obstacles to Health Education practices, opportunities for improvement, and potential quality indicators for Health Education practices in the Portuguese National Network for Integrated Continuous Care. Based on these findings, other projects may be developed to overcome these obstacles, as well as strategies to improve and monitor the potential quality indicators suggested here. As a result, we can develop a culture of measurement of Nursing care provision and validation of Nursing care. Based on these results, further studies should be developed on Health Education in the Portuguese National Network for Integrated Continuous Care, particularly with patients with other diseases, their families, and other professionals of the multidisciplinary team.

References


