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ORIGINAL ARTICLE

HEALTH EDUCATION PRACTICE IN THE VIEW OF INFORMAL CAREGIVERS IN INTEGRATED CONTINUING CARE

PRÁTICA DE EDUCAÇÃO EM SAÚDE NA VISÃO DOS CUIDADORES INFORMAIS EM CUIDADOS CONTINUADOS INTEGRADOS

PRÁCTICA DE EDUCACIÓN EN SALUD EN LA VISIÓN DE LOS CUIDADORES INFORMALES EN CUIDADOS CONTINUADOS INTEGRADOS

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ABSTRACT

Objective: to describe the importance of health education in the view of informal caregivers in integrated continuing care. **Method:** this is a cross-sectional, descriptive and exploratory study, carried out with 60 informal caregivers (IC) in a hospital service. The data were collected through a structured instrument and analyzed by descriptive statistics, presented in tables. **Results:** the ICs consider that health education is an important factor in contributing to patients' learning and solving doubts; they also considered the meeting time to be satisfactory and the environment to be optimal. Most ICs had no experience with health education. **Conclusion:** health education was considered an important factor for the practice of ICs since they learned and doubted and the space offered is the only one available for the improvement of CI. **Descriptors:** Perception; Comprehensive Health Care; Education; Health Promotion.

RESUMO

Objetivo: descrever a importância da educação em saúde na visão dos cuidadores informais em cuidados continuados integrados. **Método:** estudo de corte transversal, descritivo e exploratório, realizado com 60 cuidadores informais (CI) em um serviço hospitalar. Os dados foram coletados por meio de instrumento estruturado, analisados pela estatística descritiva e apresentados em tabelas. **Resultados:** os CI consideram que a educação em saúde constitui fator importante por contribuir com a aprendizagem dos pacientes e solucionar dúvidas; consideraram o tempo das reuniões satisfatório e o ambiente ótimo. A maioria dos CI não tinha nenhuma experiência com educação em saúde. **Conclusão:** a educação em saúde foi considerada um importante fator para a prática dos CI, pois aprenderam e tiraram dúvidas e o espaço oferecido constitui o único disponível para o aprimoramento do CI. **Descritores:** Percepção; Atenção Integral à Saúde; Educação; Promoção da Saúde.

RESUMEN

Objetivo: describir la importancia de la educación en salud en la visión de los cuidadores informales en cuidados continuados integrados. **Método:** estudio de cohorte transversal, descriptivo y exploratorio, realizado con 60 cuidadores informales (CI) en un servicio hospitalario. Los datos fueron recogidos por medio de instrumento estructurado y analizados por la estadística descriptiva, presentados en cuadros. **Resultados:** los CI consideran que la educación en salud constituye un factor importante por contribuir con el aprendizaje de los pacientes y solucionar dudas; consideraron el tiempo de las reuniones satisfactorio y el ambiente óptimo. La mayoría de los CI no tenían ninguna experiencia con educación en salud. **Conclusión:** la educación en salud fue considerada un importante factor para la práctica de los CI, pues aprendieron y se sacaron dudas y el espacio ofrecido constituye el único disponible para el mejoramiento del CI. **Descriptor:** Percepción; Atención Integral de Salud; Educación; Promoción de la Salud.

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INTRODUCTION

Health education practices are a health promotion strategy guaranteeing people's autonomy and quality of life, who should have the opportunity to know and control the determinants of their health and promote a healthier life, besides reducing diseases.¹

It is essential to differentiate "health education" from "education in health". The first one is the practice of popular education in health, which values knowledge, prior knowledge of the population and not only scientific knowledge, while the second one refers to permanent health education in order to search in the gaps of the knowledge of professionals directed to the quality of work processes in health.²

Regarding the health education, it is necessary to understand it as a potential for social and cultural changes. Thus, the method for its performance is discussed by thinkers such as Paulo Freire, as a strategy to educate mainly adults. The adult needs for their learning to be observed their practice and experience and in this way create a space for dialogue to build knowledge together from their experiences³

Another reflection to be made is the population segment increases the most in Brazil, the elderly population.⁴ Thus, it is inherent to reflect on the epidemiological and demographic changes, where it is observed that with the increase of the aging also the number of Non-Transmissible Chronic Diseases (NTCD), which have a long period of latency and prolonged course as characteristics. Among the complications of NTCD, there is the Stroke that often leading to incapacities and dependence.⁵

In this context, the caregiver figure, defined according to the GM/MS Ordinance number 963, dated May 27, 2013, as "a person with or without a family bond with the user, able to assist him with his needs and activities of daily life."⁶ However, it is worth noting that the empowerment of these caregivers depends on a number of factors, including several aspects of educational practice.

In the meantime, the need for health education for the informal caregiver (IC) is important, who represents those who provide health care both institutionally and in the family environment, who sometimes work without remuneration and/or specialized professional training.⁷ Caring involves actions, behaviors, and attitudes whose actions taken in care vary according to the conditions in

which each situation occurs and the type of relationship established between individuals.⁸

Integrated Continuing Care (ICC) was established in Brazil based on Portuguese experience, which, through Decree-Law 101/2006, dated June 6, established the National Network of Integrated Continuing Care in that country and emphasized the participation and co-responsibility of the family and the main caregivers in the provision of care and also considered the need for health education for family members and caregivers.⁹

Based on the experiences of Portugal, the GM/MS Ordinance Number 2.809 of December 07, 2012, regulates the ICC in Brazil as the long-term care of clients who no longer need highly complex services, but rather an intermediate care between the acute or chronic hospital, and primary health and home care, with the use of IC training to perform care after hospital discharge.¹⁰

A study carried out in Brazil with nursing professionals from the state of Mato Grosso do Sul on ICC pointed out the importance of ICs when they mention that they are responsible for emotional support to the individual, as well as physical and post-discharge rehabilitation aid because they are able to take the necessary care.¹¹ Thus, the purpose of this study is to:

- Describe the importance of health education practice in the view of informal caregivers in integrated continuing care.

METHOD

This is a cross-sectional, descriptive and exploratory study of a quantitative approach performed at an Integrated Continuing Care Unit in the state of Mato Grosso do Sul (MS), center-west of Brazil, linked to a general, philanthropic, medium complexity hospital of the Unified Health System (SUS).

The hospital's characteristic is to approach patients' self-care and autonomy for their daily living activities, as well as to include caregivers/family members in the care of the patient through the health education process to prepare them for continued care.¹¹

The ICC unit of the referred hospital on average assists about twenty-two patients in the process of biopsychosocial rehabilitation per month, when the presence of a person to become a caregiver constitutes one of the criteria for admission to the service, being 18 years old or over. Usually, the caregiver presented to this role was a family member or friend of the patient who assumed the status of "informal caregiver" (IC).

One of the functions of the IC in the ICC service was to attend meetings called “meeting for caregivers”, a term used by professionals of the hospital institution, held once a week, lasting between 60 and 90 minutes in the afternoon. The participation of the IC should be at all weekly meetings until the discharge of the ICC service.

These meetings aim to discuss topics related to the experiences of the patients' health care and their self-care. They are a space for ICs to expose their desires, ask questions and socialize among members who perform the same type of function. They are conducted by a health professional (Nursing, Physiotherapy, Social Work, Pharmacy, Psychology or Nutrition), whose dialogic practice constitutes the dynamics adopted for the meetings.

An instrument for data collection was elaborated in the form of a structured form for the accomplishment of this study, to be applied by the researchers directly to the IC. The instrument is made up of two parts, the first one for sociodemographic characterization (gender, age, color, and education level) and the second one to record the importance of health education practice through the IC meetings in integrated continuing care.

The data collection was carried out from March to June of 2016, in a total of 16 meetings for caregivers, being moments of the collection. Data were collected after each meeting on topics related to health education. The ICs were individually addressed and invited to participate in the study after explaining the research objectives. Those who agreed to participate were asked to sign the Free and Informed Consent Form and forwarded individually to a reserved room for a maximum period of up to two hours after the meeting. It is worth mentioning that each IC was interviewed only once.

The information collected in the interviews was transcribed and then read to the ICs, in search of a reliable record and approval by the participants. The subject identification data was organized into a database through the Microsoft Excel 2010® program. The analysis was performed by descriptive statistics.

The protocol of this research was approved in its ethical and methodological aspects by the Research Ethics Committee of the Federal University of Mato Grosso do Sul, under opinion 1,432,742 and CAAE 52903915.0.0000.0021, in compliance with resolution CNS/MS number 466/2012 which deals with research involving human beings.

RESULTS

There were 60 ICs interviewed, with a mean age of 43.2 years old (+14.9, 19-72) and most were females (80.0%). Regarding the years of study, there was a predominance of complete secondary education (35.0%), followed by complete and incomplete primary education (23.3%) and five (8.3%) ICs had completed higher education.

Among the 60 IC subjects in the study, 42 of them (70.0%) participated for the first time at the time of data collection and only nine (15.0%) reported having received health care orientations of the patient and/or the self-care in other settings such as hospital institutions, Basic Family Health Units (UBSF), clinic-school of a university and lectures during the school life.

Regarding the importance of the themes of the meetings, most of them (93.3%) considered it extremely important, due to the fact that they provide greater security to care. Regarding the relevance of the themes discussed, four individuals (6.7%) classified it as little relevant because “they did not have people in the family with the disease discussed”, another because they “already had enough knowledge” about the subject and one (1.7%) reported no importance and justified that “did not perform the activity discussed at the meeting”.

As to the continuity of care at home, almost all of ICs (93.3%) said that the themes “will help in the care of the patient”. Those who answered that “they will not help in the care” (6.7%) the justifications were because of the following reasons, “not being smokers”; “the patient does not listen to the caregiver”, “the caregiver will not continue in the care” or “because the patient does not use enteral diet”.

It was verified that 45 ICs (75.0%) referred to the need for the health education meeting to guide the care required for comfort and quality of life, both the caregiver and patient. Also, 15 (25.0%) reported that although they need to discuss these preventive health-care practices, they would also like to discuss the medical diagnoses of the subjects who are about their care.

Regarding the active participation in the caregivers meeting, 24 (40.0%) reported not having contributed in this sense, attributed to the shyness factor. Another 32 (53.3%) stated that they did not present their experiences with the topic because they did not think it would be necessary/important to cooperate in the meeting. It should be noted that since the

participants were interviewed only once, it was not possible to verify if the dialogic participation would increase in successive meetings.

Regarding the perception about learning from the caregiver meetings, most ICs (63.3%) reported that they learned a lot from the other caregivers. However, 55 ICs (91.7%) reported learning more from the professionals who conducted the meetings.

According to Table 1, a large part (66.6%) of the ICs informed that they already had

knowledge of the subject. However, they mentioned contributions to their learning both by the professional that conducted the meeting and the other ICs. Also, 39 ICs (65.0%) felt more prepared to take care of patients after the meetings, because many doubts were healed. Most of the ICs (76.6%) considered that the meeting time was satisfactory; nine (15.0%) reported apprehension/anxiety, as they did not “want to leave” the patient alone during the time they attended the meeting.

Table 1. Informal caregivers' perception about learning at the health education meeting on integrated continuing care. Campo Grande/MS, 2017 (n=60).

Characteristics of the meetings	n	%
Learning about the subjects covered*		
Learning with professionals and IC, despite knowing the subject	40	66.6
More prepared after doubts in meetings with professionals and ICs	39	65.0
They had no doubt that they already knew the subject.	08	13.3
They felt comfortable and helped with the learning of the others.	05	8.3
Duration of the meeting*		
The time was satisfactory to approach the subject	46	76.6
The time was long because they left the patient without their care	09	15.0
The weather was unsatisfactory to fully address the subject	09	15.0

* More than one IC answer was considered.

In Table 2, the IC assessed the available environment for the meetings and found it adequate for health education activities. The optimal perception, which constituted the best level of judgment, was the most predominant in all environmental characteristics.

However, those who attributed a poor evaluation to temperature (5.0%) pointed to the use of air conditioning as responsible for

the very cold environment. Others (1.7%) indicated the organization of the chairs in a negative way because they did not allow visualization of all caregivers. Regarding the discomfort of the chairs (5.0%), they considered them to be inadequate, especially for obese people.

Table 2. Informal caregivers' perception of the environment of health education meetings on integrated continuing care. Campo Grande - MS, 2017 (n=60).

Characteristics of the meetings	I did not notice n (%)	Bad n (%)	Good n (%)	Very good n (%)	Great n (%)
Room size	00 (0.0)	00 (0.0)	19 (31.7)	11 (18.3)	30 (50.0)
Lighting	03 (5.0)	00 (0.0)	13 (21.7)	11 (18.3)	33 (55.0)
Temperature	03 (5.0)	03 (5.0)	23 (38.3)	06 (10)	26 (43.3)
Organization of chairs	01 (1.7)	01 (1.7)	19 (31.7)	06 (10)	33 (43.3)
Comfortable chairs	01 (1.7)	03 (5.0)	19 (31.7)	07 (11.7)	30 (50.0)
Cleaning	03 (5.0)	00 (0.0)	04 (6.7)	07 (11.7)	46 (76.7)

DISCUSSION

Most CIs in this study are female (80.0%), with a mean age of 43.2 years old and a high school education (35.0%). A study conducted in the state of Pará corroborates these findings, when 96.8% of the caregivers were informal and 80.7% were female, besides the predominance of the same level of schooling found (35.0%).¹²

The representation of the woman as the main caregiver is constantly found in literature, related to the fact that the task of caring is associated with the female figure,

usually daughters, coming from historical, cultural, social and affective roots.¹³

In this study, most ICs (85.0%) reported never having received guidelines for prevention of health problems and improvement of the quality of life before health education meetings conducted by the service under study. This finding is a concern with this population due to the lack of experience with health education practices. However, to develop popular education in health, it is necessary to consider that it is essential to take the prior knowledge of the learner as a starting point of the pedagogical

process because by valuing his knowledge and values he allows him to feel at ease and to maintain his initiative.¹⁴

It is worth mentioning that only two ICs reported that they experienced health education practices in UBSF, when the Family Health Strategy constitutes a space for health education, since its central role is the educational practice aimed at health promotion, in a way to assist the community with the practices necessary to improve the quality of life, as well as being the main "gateway" to SUS.¹⁵

However, education in health can be done within the family, at school, at work, or in any other community space. It is a component of the Ottawa Charter, which rescues the dimension of Health Education and advancing with the idea of empowerment, the training process as knowledge acquisition and community political awareness.¹⁶

With regard to the school environment, an IC has reported experience in this space. In a study of 11 countries that involved 20 health education experts at the school, it was identified that skills for the professional to deal with health education in schools are knowledge, skills, and attitudes. However, thematic and greater efforts to train these professionals that meet these skills are needed.¹⁷

Regarding the hospital environment, only two ICs reported having experienced education in health, even considering educational practices as a tool in the hospital for the continuity of care at home.¹⁸ Thus, the guidelines should not only be assimilated but also understood and incorporated, where skills development and knowledge acquisition will be achieved through stimulating strategies, by broadening the interrelation between the various professions, specialties, services, patients, families, neighbors and local social organizations to strengthen and reorient their practices, knowledge and struggles.¹⁴

A study conducted in Itaúna do Sul, State of Paraná, southern Brazil, with 18 ICs in the hospital environment, reported that they did not receive care guidelines for patients and felt the need for greater communication from the multidisciplinary team. This fact evidences the need of the work in the hospital environment with the reception and practice of health education to provide the caregiver with greater autonomy and capacity for continued care after hospital discharge.¹⁹

Educational practices need attention to their planning, instigating social participation. Concerning the participation of ICs in the

meetings, 40% did not participate actively and 53.3% did not discuss their experiences. In the justifications, it was verified that there was less interaction of the subjects due to unfamiliarity with the dynamics.

In an analysis of 33 health education practices, 38.0% of the practices promoted the active participation of the subjects, 6.0% provided the construction of knowledge, and 40.0% used different methods when those that were not related to the active participation of the subject are characterized by the predominance of managerial aspects, by the lack of interaction and involvement of the participants and in some cases by the targeting of very specific themes.²⁰

When considering participation in the meetings, more than half of the caregivers (53.3%) reported that they did not have their experiences. It stands out in the model of health education that within practices in groups one of the fundamental objectives is the exchange of experience when it is up to the facilitator to consider the relationship between the subjects and the society for the construction of a critical conscience by the participants.²¹

It was also verified that ICs referred to learning with health professionals more expressively than with other ICs. It is possible to attribute to the fact of the non-expressive participation of ICs and also the perception that the health professional is considered as the holder of the knowledge for the training received.²²

In a study carried out in the State of Ceará, it was observed that during the educational activities implemented in the waiting room, it was possible to perceive that the users felt more comfortable to participate spontaneously and to expose their opinions from the formation of bonds. In that situation, the participatory strategies used were the talk circles and plays with the use of puppets.²³

When planning health education activities in an expanded way, public policies should be included in the discussion, the use of appropriate environments and reorientation of health services to overcome clinical and curative treatments and to propose a liberating pedagogy committed to the development of solidarity and citizenship.²⁴⁻⁵

When ICs were questioned about the environment used in the meetings, they attributed the optimum concept to most of the mentioned situations. This is possibly explained by the fact that the ICC is located in a relatively new physical space, adapted for accessibility, with light colors, adequate

lighting, climate control by air conditioners, chairs suitable for the comfort of most ICs, besides the conditions of hygiene and conservation of the environment.

The hospital environment carries aspects that are distant from the proposal of health promotion in its historical context, since the physical dimension and structure of the hospital is a factor that hinders the process of changes in these spaces more than in smaller organizations.^{26, 27}

Regarding the time of health education activities, there is no static pattern, but it is necessary to think that it should not be exhaustive and in this study, most ICs considered it satisfactory (76.6%). It should also be considered that at the time of the meetings, the patients receiving care were left without their ICs, thus they could generate concern about the care practice for them, but to minimize the anxiety of the ICs was directed that there was a nursing team to perform necessary care during their absence for the meetings.

Regarding the duration of health education activities, a study conducted with 151 people in the state of Minas Gerais found that the greater the time spent in educational activities, the greater the knowledge and the better the practice of self-care.²⁸

The main limitations of this study are the fact that the assessment with ICs was carried out in a single moment, a fact that limits a more detailed description to analyze the weight of the approach of dialogical practice as a method to promote health education. Another limitation is not to have been evaluated the vision of the professionals that promote the educational practices, as well as the quality in the moment of the implementation of the IC care. Therefore, it is necessary to do more studies with different approaches and methodological designs to elucidate these items.

CONCLUSION

Through this study, it was possible to perceive that the continued care in the described service is carried out by informal caregivers, as in much of the country. Many correspond to caregivers without any specific training for health promotion and rehabilitation or even without a minimum required a degree of education for the actions inherent to a caregiver or accompanying a person who requires ongoing care in their treatment.

The space created by the service is a unique place to acquire knowledge, either

through health professionals able to provide health education to ICs, or by more experienced ICs to exchange experiences. In this way, more services of this nature should be created through public policies that foster their creation and maintenance of attention to a group exponent in the population, mainly due to the aging population that requires adjustments in the current society for this growing demand.

In general, the service described significantly contributes to the quality of life of its clients by promoting health education activities to ICs ensuring the continuity of hospital care and improving the levels of recovery and quality of life of its clients and reduction of costs and length of hospital stay.

It is fundamental that there is training for health professionals to provide practices that meet popular health education, which should be strengthened in the hospital environment, as well as the exchange of knowledge between the agents involved in the care process and modify the image of the professional as the only holder of knowledge.

It is suggested that the professionals carry out the health education practices to consider the knowledge and the vision of the ICs and from this, they carry out the planning of the process for the execution of the educational activities.

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