HEALTH EDUCATION: A STRATEGY OF CARE FOR THE LAY CAREGIVER

Luccas Melo de Souza[1]
Wiliam Wegner[2]
Maria Isabel Pinto Coelho Gorini[3]

Souza LM, Wegner W, Gorini MIPC. Health education: a strategy of care for the lay caregiver. Rev Latino-am Enfermagem 2007 março-abril; 15(2):337-43.

This article aimed to reflect about the importance of the role nurses perform in strategies of health education to lay caregivers, who are important actors in the health/disease process. It is a thematic reflection, built through bibliographic review, which discusses the role of lay caregivers in different stages of the life cycle. Considering the participation of lay caregivers in the Brazilian reality, strategies have been sought to include them in the health care, given the little attention Public Policies have given to them. Therefore, the nurses as health educators, must offer support to the lay caregivers helping them to choose among available alternatives, while delivering care, to not harm their own health. Concluding, health education can be an alternative to offer attention to the lay caregivers, while the nurse has important role in the development of alternatives.

DESCRIPTORS: nursing; health education; caregivers; patient escort service

EDUCACIÓN EN SALUD: UNA ESTRATEGIA DE CUIDADO AL CUIDADOR LEGO

Este artículo tiene por objetivo reflexionar acerca de la importancia de la intervención de enfermería a través de estrategias de educación en salud, para los cuidadores legos, actores fundamentales en el proceso salud/enfermedad. Se trata de una reflexión temática, construida por medio de la búsqueda bibliográfica, a través de la cual se discute el rol de los cuidadores en las diferentes etapas del ciclo vital. Tomando como base la actual participación de los cuidadores legos en el escenario brasileño, se buscan estrategias para incluirlos en la asistencia de salud teniendo en vista la poca relevancia que las Políticas Públicas les han demostrado. Así, el enfermero, como educador en salud, debe ofrecer subsidios a los cuidadores legos para que sean capaces de escoger entre las alternativas disponibles para el cuidado de los enfermos, de forma tal que esta función no perjudique la salud del paciente. Se concluye que la educación en salud puede ser una forma alternativa para ofrecer atención de salud a los cuidadores legos, siendo el rol del enfermero indispensable para el desarrollo de estrategias.

DESCRIPTORES: enfermería; educación en salud; cuidadores; acompañantes de pacientes

EDUCAÇÃO EM SAÚDE: UMA ESTRATÉGIA DE CUIDADO AO CUIDADOR LEIGO

Objetiva-se, com este artigo, tecer reflexões acerca da importância da atuação do enfermeiro por meio de estratégias de educação em saúde aos cuidadores leigos, atores fundamentais no processo saúde/doença. Trata-se de reflexão temática, construída a partir de busca bibliográfica, através da qual se discute o papel desses cuidadores nas diferentes etapas do ciclo vital. Tomando como base sua atual participação no cenário brasileiro, buscam-se estratégias para incluí-los na assistência de saúde, tendo em vista a pouca relevância que as Políticas Públicas têm demonstrado a eles. Assim, o enfermeiro, como educador em saúde, deve buscar oferecer subsídios aos cuidadores leigos para que escolham as alternativas disponíveis, durante a fase em que cuidam dos doentes, sem que essa função acarrete prejuízo à sua saúde. Conclui-se que a educação em saúde pode ser alternativa para oferecer atenção aos cuidadores leigos, tendo o enfermeiro papel indispensável no desenvolvimento de suas estratégias.

DESCRITORES: enfermagem; educação em saúde; cuidadores; acompanhantes de pacientes

[1] RN, Nursing Master student, e-mail: luccasm@ibestvip.com.br; [2] RN, Children Hospital Santo Antônio, Nursing Master student, e-mail: wiliamwegner@yahoo.com.br; [3] RN, PhD in Education, Adjunct Professor, e-mail: gorini@terra.com.br. Federal University of Rio Grande do Sul College of Nursing

Disponible en castellano/Disponível em língua portuguesa
SciELO Brasil www.scielo.br/rlae

INTRODUCTION

Nursing is a knowledge area that covers activities like care, management and education, among others. In the different scenarios where its professional practice is exercised – hospitals, health units, outpatient clinics, schools, kindergartens, companies and homes –, the horizon of nursing does not remain restricted to people in disease situations[1]. Among nurses' different activity forms in modern society, education practice appears as the main health promotion strategy.

According to literature, health education is a teaching-learning process aimed at health promotion, and professionals in this area are the main mediators for this to occur. These professionals are educators prepared to propose strategies, with a view to offering ways that make possible transformations in people/communities[2]. With respect to care strategies, it should be highlighted that nursing, as an art, allows nurses to perform their functions creatively and with multiple alternatives, not generalizing their actions to a common group, but maintaining each human being's inherent peculiarities.

There are two ways of focusing on health education: the first refers to the 'old' Public Health, in which education practices are particularly directed at disease prevention. The second, 'new' health education hopes to move beyond the biomedical model and expand to broad objectives that aim for a healthy life[3]. In this study, the perspective of radical health education is emphasized, a newly proposed model – based on the 'new' Public Health – that attempts to promote a social transformation by fighting against emerging social inequalities in health systems[3-5].

Radical health education works with groups and highlights that this is the way to exchange experiences and conceptions in a certain group/reality. This would make it possible to construct a critical collective conscience and then surpass it to the participants' individual level: thus, each person's autonomy would be promoted through education[4].

Nowadays, it is empirically observed that education practice focuses on sick people or people susceptible to changes in their health state, as professionals direct their actions at persons who attend health services because of a possible disease. However, there is little concern about people who take care of the ill but do not perform any paid and/or professional work in this sense: lay caregivers. Sometimes, it is forgotten that these can also present health unbalance. One explanation for this lack of attention to lay caregivers can be attributed to the historical roots of the profession.

As a job, nursing appeared with an emphasis on care for sick people, and it was through this practice that its consolidation as a profession occurred. However, over time and as a result of scientific progress, new spaces have been conquered and this paradigm – centered on the ill only – was gradually changed. Due to different reasons, the family and lay caregivers became significant in the nursing team's daily reality, when accompanying the patient in hospital, as well as when they participate (in)directly in care in hospital and/or at home. Thus, the element of the lay caregiver emerged in nurse/patient interaction.

Despite this significance, scientific literature and professional practice reveal the need for research and reflections on lay caregivers, mainly in terms of health education for this public. These persons' physical, emotional and social health tends to be strained, mainly due to the burden imposed by the care task, which can transform them into a new demand for health services[6]. It is highlighted that, besides care delivery to sick/hospitalized persons, support to informal (lay) caregivers represents a new challenge to the Brazilian health system, which also justifies the need for studies about this theme[7].

This reflection is also justified by the relevance of lay caregivers as, in many cases, they stay with the patient full-time and can provide the health team with fundamental information about their relative's situation. These caregivers receive attention and are researched on abroad, but are often ignored in Brazil: by the government (due to the lack of resources and political structure to help caregivers); by families and communities (due to the low valuation of this function, generally centered in one single person, in view of difficulties to diversify caregivers) and also by researchers, partially due to the lack or absence of resources to conduct studies or due to difficulties to make out perspectives for using the results[8]. Thus, a macro-structural problem is identified, which involves different social segments and actors and remains static towards the presented difficulties.

This article aims to reflect on the importance of nurses' actions, through health education strategies, for lay caregivers, given the relevance of their participation in the health/disease process[9].

To carry out this reflection, we sought theoretical foundations from books, theses, dissertations and journal articles, through a review in the database LILACS, in the SCIELO electronic library and in the Library Automation System at Rio Grande do Sul Federal University. The descriptors used were '*cuidadores* (patient caregivers) or *acompanhantes de pacientes* (patient companions) or *educação em saúde* (health education), associated with the word *enfermagem* (nursing)'. The results were selected by reading the abstracts and, if they dealt with the study object, the texts were analyzed for possible application. On the whole, 25 references were used to support this article. These were organized according to the interests of the intended arguments, in combination with questions from the authors' professional practice and experience, thus allowing for reflections about the theme.

LAY CAREGIVERS IN THE BRAZILIAN SCENARIO

Care is a science especially performed by nursing professionals in hospitals and health units. However, it is known that, historically and culturally, care is also delivered by people without professional training, in the family/community context and in health institutions(10). The expression 'lay caregivers' is used to indicate these persons. In view of difficulties to find a definition of the term in scientific literature, the authors of this study consider it as that person who delivers care to the patient – in the institutional and family environments -, without payment and/or specialized professional training.

According to literature, lay caregivers have always existed. Care practice traditionally started in the private home sphere, as the family structure included multiple generations, thus making this practice possible. Relatives were acknowledged as the source of care for dependent persons, and the female figure was chosen to be responsible for this care(10).

However, the Industrial Revolution entailed the population's urbanization, increased demands for workforce and women's entry into the job market. This was reflected in changes in the family structure, which became predominantly one-generational. Thus, the State, in order to keep up social production, started to deliver care to the working population. Hospitals, asylums, mental hospitals and care homes were created. These places were aimed at concentrating human and technological resources to deliver care to the sick population. Hence, the State assumes the role of care delivery to its citizens, moving the burden of care from the family to the State(10).

Nowadays, professional practice allows us to affirm that, often, the ill faces this phase in life with the presence of a relative who, out of need and even without specialized training, becomes a caregiver. On the counterpart, established health programs in Brazil ignore lay caregivers, who are fundamental components for sick persons' rehabilitation and recovery.

This 'disregard' of lay caregivers is a source of concern as, nowadays, established health systems in Brazil tend to indicate that people should stay at their homes – both patients whose disease is under control (especially chronic-degenerative diseases) and those in palliative care situations – under the care of their family. This is partially due to institutions' and the State's concern to reduce hospital care costs, as well as to the importance of stimulating bonds between patients and relatives in the home environment(10). Thus, the State divides the responsibility to take care of the ill with the family, making the family and community spaces be revalued as care environments.

In Brazil, like in the rest of the world, in most situations, women with some degree of relationship and physically and/or affectively close to the patient deliver lay care. More specifically, it can be inferred that wives, mothers or daughters reflect the lay caregiver's profile(7,11-16), as it is commonly affirmed that women are responsible to take care of the house, children or elderly, since they are destined by common sense to be mothers and take care of the family(17). Moreover, as women live longer, they are responsible to take care of their husbands, as men theoretically get ill and die earlier(7).

Besides being delivered mainly by people with some degree of relationship with the patient, lay care also centers in one single family caregiver, who is often overloaded with this responsibility(15,18-19).

In professional practice, parents take care of their ill children/adolescents, while adults/elderly are mainly attended by their husband/wife or son/daughter(11-14). In most situations, caregivers accompany their relatives for several days in hospital and await hospital discharge. It should be mentioned

that, during the lay caregiver's stay with the patient, it is not uncommon for changes in the former's health state to occur[6]. However, most health institutions are not structured to attend them. This disregard and lack of planning can affect the care they deliver to the patient. This characterizes the hegemonic model (traditional, only directed at individualism and the established disease), which has not been overcome yet, to be replaced by the holistic model, which considers the integrality of the human being and the accompanying family[20], thus including the lay caregiver as a person who needs care.

The family receives the responsibility to take care of its members. This task is related to each person's social responsibility towards his/her relatives[21]. However, this relative should be in healthy conditions to deliver care actions to people they are close with. From the radical health education perspective[3-5], lay caregivers are expected to have acquired sufficient autonomy to take care of themselves and the person they are accompanying. However, for this to occur, a mediator is needed. It is believed that nurses can play this facilitating role, as these professionals deliver care close to the patient/ lay caregiver dyad and are directly involved with educational issues related to health care.

It should be highlighted that the family is not only the care unit, but should also be considered as the unit that needs care[22]. The maintenance of families' and overloaded, stressed or exhausted caregivers' health or quality of life is threatened due to their care responsibility. In many situations, they present feelings of impotence, concern, tiredness and irritability[15,19].

However, health professionals do not yet give due emphasis to the care the relatives deliver, in view of the little relevance public policies have demonstrated towards the theme, as mentioned before. Moreover, health professionals are especially prepared for care delivery to sick persons, with a disease-oriented focus. Thus, they forget about the people related with the patients, who need information and support in their difficulties, which often affect or will affect their own health[23].

To accomplish this approach, which considers the integrality of groups, the focus should be expanded to multiple sectors, involving not only the persons responsible for changes, but including public policies, economy and culture as essential variants to achieve modification in the macro-structure that influences the health area[20].

HEALTH EDUCATION FOR LAY CAREGIVERS

Nowadays, their are different approaches to health education. However, in view of their similarities, they can be grouped in two proposals: traditional health education and radical health education, which have recently been discussed in Brazil[3-5,24].

The traditional approach is based on disease prevention, expressing the hegemonic model of biomedical care. In this approach, action focuses on the disease and on changing individual behavior, and is generated and imposed by health professionals[3-4].

In another perspective, the radical health education model intends to work with a modern education perspective, arousing people's and social groups' critical awareness and involving them in health-related aspects. This proposal aims to achieve its goals through group work, with a view to arousing collective awareness, which will support social transformation[3-4,24].

In the radical model, the role of the health educator is that of facilitating the subjects' discoveries and reflections about reality, and individuals are empowered and autonomous to choose alternatives[3-4].

In line with radical health education[3-5], it is expected that critical awareness will be aroused in lay caregivers, which will allow them a better life, based on their preparation to choose possible ways, with a view to expanding their own capacity to take care of people as well.

Professional experience confirms that lay caregivers are important actors in care delivery from childhood to old age, independently of the ill person's health state. It is emphasized that, to deliver care expressively, it is fundamental to create conditions for the lay caregivers to feel prepared to perform these functions, giving them a critical view of what they are doing. This awareness is needed to expand the care action beyond the sick person, extending care to the caregivers themselves.

Literature highlights that health professionals active in education should expand their praxis beyond the simple transference of information, working to stimulate people's/groups' senses, that is: to perceive the user, to establish relations and to solve common problems[25]. In this sense, radical health education foresees the construction of collective awareness by arousing each social agent's potentialities related to his/her actual health-related needs[3-5].

The lay caregiver is a new actor to be taken into account in discussions on health education. It is through health education, in combination with other measures, that one can make out tools to partially transform the health area. In many situations, people affected by some change in their health state have someone to take care of them during this period. Thus, it should be asked: is this person taking care of the patient also taking care of him-/herself? It is known that all human beings have fragile points, which can come to the surface any time. Hence, when support from lay caregivers is required, these may be equally incapable of delivering care to the patient, because they need health care themselves.

Thus, health education emerges as a way to implant health care programs for lay caregivers. Even if initially based on disease prevention, they can then move on to the radical model, which adapts to the reality of groups. It is believe that these programs can evolve to the holistic paradigm, which considers the human being as a whole and highlights that, in this whole, the lay caregivers will also have their space, as they are inserted in this care context.

An analysis of the hospital environment reveals that relatives who take care of and accompany people who are considered ill sometimes are in no appropriate living and health conditions to perform this activity. This represents a severe and alarming Public Health problem which, at the moment, is not being included in health professionals' and especially nurses' care planning. Moreover, nurses need to prepare lay caregivers to carry out integral instead of fragmented care actions, which normally happen. Literature highlights that the multiple aspects of the health-disease process should be integrated, considering prevention and promotion together with strictly curative care[20].

Care is not restricted to the act of delivering some action to somebody, but happens based on the existence itself as a human being, and it is based on this awareness that one has the opportunity to get to know one's own possibilities, within the life context[25].

It is reaffirmed that health education to lay caregivers is an appropriate strategy to achieve the holistic health care paradigm. In this article, nurses are indicated as key pieces to develop this process with lay caregivers as, during their professional training, they have accumulated (even if partially), elements that can allow them to emerge in this context, besides the fact that they work near the caregiver/ patient groups. In this sense, the authors agree with other researchers' assertion[24] that nurses, as well as other health professionals, can promote individuals' awareness of aspects in their reality that can be transformed to facilitate healthy choices, using group work.

Based on this acknowledgement of lay caregivers' significance, it is important to create contextualized methods for learning and direct care to this part of the population, encouraging work and research as early as in health professionals' academic education.

FINAL CONSIDERATIONS

It is vital that public policies and care strategies do not exclusively concentrate on sick persons while ignoring the importance of lay caregivers.

From the perspective of the holistic health care paradigm, the importance of lay caregivers cannot be disregarded. These persons are believed to (in)directly influence the patient's health care, whether by delivering direct care (such as personal hygiene care) or indirect support (simply by serving as a companion). It is highlighted that 'taking care of the caregiver' reflects the concern to expressively watch over the human being as a whole, considering a multi-axis and holistic approach.

Health education practice is an important tool to stimulate the principles guiding the notion of self-care, that is, it is through health education that a healthy life is aimed for. Besides proposing alternative ways to lay caregivers, health education also deserves emphasis because it prepares them to acquire a critical self-awareness to reconsider concepts and values.

Moreover, through radical health education, human groups are 'empowered' by means of the autonomy they receive to choose the best way to follow, but it is known that the alternatives found to live better are problematized collectively.

Thus, nurses are important for lay caregivers, in the hospital or domestic environment, even if their practice primarily focuses on disease prevention and then expands. In this sense, nurses can start directing their action to the prevention of complications and the promotion of lay caregivers' health, and this practice improves the care the latter deliver.

In preventing complications, nurses can work in activities directed at all lay caregivers, advising them to deliver care to the patient and equally strengthening self-care. One of these care strategies can be developed through lay caregiver groups, allowing for joint experience exchange and stimulating them to take responsibility for their health, in accordance with their possibilities.

Nursing professionals should also identify lay caregivers who are vulnerable to suffering some health problem, with a view to decreasing the chance that acute or chronic diseases will occur. In this perspective, their attention should individually focus on each lay caregiver, with a view to discussing alternative and specific ways for each situation. The relevance of health services' support programs is emphasized, which should provide lay caregivers with mechanisms that facilitate multiprofessional support, including medical, physiotherapeutic and psychological care, among others. Thus, 'practicing health' is considered as the opportunity to offer people access to health services.

In situations when the lay caregivers present some disease, nurses act when the health problem has already occurred. Therefore, besides adequate treatment, one of the objectives should be the prevention of relapse. When the problem is identified, nurses need to instruct the lay caregivers about the importance of seeking specialized care. Moreover, they should inform or refer them to some health institution to seek treatment. Hence, the need is reaffirmed to create facilitating mechanisms for lay caregivers to achieve care for their own health.

It is believed that nurses' praxis actually depends on health education as a way of achieving the independence and autonomy of the person who receives care. The lay caregiver is a part that is not attended by the established health system, which does not adequately visualize its importance in the recovery and rehabilitation of sick persons' health. However, to avoid this from happening, first, there is a need to take care of the caregivers and prepare them for this activity. Health education offers ways for lay caregivers to take care of themselves and, from this point onwards, take care of other people, in accordance with each culture and values. However, in most cases, the lay caregivers only prioritize care for the persons needing their help, ignoring themselves as beings and solely dedicating themselves to the persons receiving care.

Therefore, health education is important for care to lay caregivers, as it prepares them to preserve their health and live a healthy life, with a view to taking expressive care of persons they are close with. It is also highlighted that public policies should present proposals to help this part of the population, which current health programs still ignore. Thus, it is emphasized that care delivery does not only involve the patient, but also the whole surrounding context, in which the lay caregiver emerges as a care instrument. As health professionals, nurses are responsible for inserting these subjects as a focus in their daily praxis and for involving them as a part of their care activities, using health education for this goal.

REFERENCES

1. Caldas CP. Cuidando do idoso que vivencia uma síndrome demencial: a família como cliente da enfermagem. Rev Texto e Contexto Enfermagem 2001 maio; 10(2): 68-93.
2. Pedro ENR. Vivências e (con)vivências de crianças portadoras de HIV/AIDS e seus familiares: implicações educacionais. [tese]. Porto Alegre (RS): Faculdade de Educação/PUC-RS; 2000.
3. Oliveira DLLC. A 'nova' saúde pública e a promoção da saúde via educação: entre a tradição e a inovação. Rev Latino-am Enfermagem 2005 maio; 13(3): 423-31.
4. Oliveira DLLC. Brazilian adolescent women talk about HIV/AIDS risk: reconceptualizing risk sex - what implications for health promotion? [thesis]. London (UK): University of London; 2001.
5. Gastaldo D. É a educação em saúde "saudável"? repensando a educação em saúde através do conceito de bio-poder. Rev Educação e Realidade 1997 janeiro-julho; 22(1): 147-68.
6. Benjumea CC. Cuidado familiar en condiciones crónicas: una aproximación a la literatura. Rev Texto e Contexto Enfermagem 2004 janeiro-março; 13(1): 137-46.
7. Karsch UMS. Idosos dependentes: famílias cuidadoras. Cad Saúde Pública 2003 maio; 19(3): 861-6.
8. Karsch UMS, Leal MGS. Pesquisando cuidadores: visita a uma prática metodológica. In: Karsch UMS, organizadora. Envelhecimento com dependência: revelando cuidadores. São Paulo (SP): EDUC; 1998. p. 21-45.
9. Karsch UMS. Introdução. In: Karsch UMS, organizadora. Envelhecimento com dependência: revelando cuidadores. São Paulo (SP): EDUC; 1998. p. 13-9.
10. Watanabe HAW, Dernil AM. Cuidadores de idosos: uma experiência em uma unidade básica de saúde - projeto CapacIDADE. O Mundo da Saúde 2005 dezembro-outubro; 29(4): 639-44.
11. Paula MG, Marcon SS. Percepção de cuidadores domiciliares sobre a atuação da equipe de saúde da família no atendimento a indivíduos dependentes. Fam Saúde Desenvolv 2001 julho; 3(2): 135-45.

12. Garrido R, Menezes PR. Impacto em cuidadores de idosos com demência atendidos em um serviço psicogeriátrico. Rev Saúde Pública 2004 dezembro; 38(6): 835-41.

13. Rodrigues MR, Almeida RT. Papel do responsável pelos cuidados à saúde do paciente no domicílio - um estudo de caso. Acta Paul Enfermagem 2005 janeiro; 18(1): 20-4.

14. Pazinatto MC. Características clínicas e funcionais do paciente idoso que recebe alta hospitalar e suas necessidades de cuidados após alta. [dissertação]. Porto Alegre (RS) PUC-RS; 2003.

15. Garcia MAM, Frigerio RM, Miyamoto DA, Merlin SS. Idosos e cuidadores fragilizados? O Mundo da Saúde 2005 dezembro-outubro; 29(4): 645-52.

16. Tobias MA, Lemos NFD. A percepção do envelhecimento do cuidador idoso diante do cuidado. O Mundo da Saúde 2005 dezembro-outubro; 29(4): 653-61.

17. Silva IP. As relações de poder no cotidiano das mulheres cuidadoras [dissertação]. São Paulo (SP): PUC-SP; 1995

18. Cerqueira ATAR, Oliveira NIL. Programa de apoio a cuidadores: uma noção terapêutica e preventiva na atenção à saúde dos idosos. Psicol USP 2002 janeiro; 13(1): 133-50.

19. Gonçalves LHT, Alvarez AM, Santos SMA. Os cuidadores leigos de pessoas idosas. In: Duarte YAO, Diogo MJD. Atendimento domiciliar: um enfoque gerontológico. São Paulo (SP): Atheneu; 2000. p. 101-10.

20. Briceño-León R. Bienestar, salud pública y cambio social. In: Briceño-Leon R, Minayo MCS, Coimbra Jr. CEA. Salud y equidad: una mirada desde las ciencias socieales. Rio de Janeiro (RJ): Fiocruz; 2000. p. 15-24.

21. Marcon SS, Andrade OG, Silva DMP. Percepção de cuidadores-familiares sobre o cuidado no domicílio. Rev Texto e Contexto Enfermagem 1998 maio; 7(2): 289-307.

22. Souza AIJ. Cuidando de famílias: identificando ações de cuidado e não cuidado nos familiares. In: Elsen I, Marcon SS, Santos MR, organizadoras. O viver em família e sua interface com a saúde e a doença. Maringá (PR): Eduem; 2002. p. 363-80.

23. Henckemaier L. Dificuldades ao cuidar da família no hospital. In: Elsen I, Marcon SS, Santos MR, organizadoras. O viver em família e sua interface com a saúde e a doença. Maringá (PR): Eduem; 2002. p. 403-19.

24. Souza ACS, Colomé ICS, Costa LED, Olliveira DLLC. A educação em saúde na comunidade: uma estratégia facilitadora da promoção da saúde. Rev Gaúch Enfermagem 2005 agosto; 26(2): 147-3.

25. Pedroso M. O significado do cuidar de si mesmo para os educadores em saúde. [dissertação]. Porto Alegre (RS): Escola de Enfermagem/UFRGS; 2000.

Recebido em: 28.9.2005
Aprovado em: 25.9.2006