Experiences of Nurse Participation in Educational Programmes for Accompanying Relatives in the Hospital-Home Environment

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Health care requires special continuity at the hospital-home discharge interface. The family caregiver is involved due to their intrinsic capacity to accompany the patient. For Institutions Providers of Health Services, it is essential to evaluate the participation of the nurse in the Accompanying Family Program. The objective is to describe the scientific evidence on the experiences of participation of the patient in the Accompanying Family Program. A descriptive analysis of 40 articles of a quantitative and qualitative nature, was carried out using databases: Pubmed, Scielo, Scopus, Medline and EBSCO; Selecting for analysis, articles published no more than 5 years ago. The transcendent aspects highlight that the nurse initiates the accompaniment of the family caregiver during the patient's hospitalization, through education prior to discharge, strengthens the caregiver's capacities for the patient's recovery, the personal growth of the caregiver and the professional nurse. The experience visualizes cost-effective nuances and projects opportunities, based on concrete mechanisms of articulation of education for care in hospitalization and at home.

Keywords: growing in care, nurse, Family Caregiver Programme, sustainability, family caregiver

INTRODUCTION

The family continues to be valued as the unit of life of its members. Any transformation that occurs in the social-historical context profoundly affects health-illness processes and therefore modifies the relationships, decision-making, and behavior of health organizations and the attitudes of family members (da Silva, Santos, Pereira & Gonçalves, 2016). Throughout the human life cycle, there are crucial moments in the loss of health, which make the accompaniment of a family member in the hospital environment necessary, not only to streamline administrative procedures, but also because of the need for security, companionship, and affection is increased. Universally, professional nursing care responds to the existential condition of human vulnerability, with greater visibility in the early and extreme stages of life; also in the face of the effect of accidents or serious clinical complications of a physical or mental nature, documented over several decades in various countries (Boff, 2012).

In this context, Solan et al. (2015) agree that both the experience of being hospitalized and the transition from this setting to the home are stressful experiences, which awaken the need to improve the climate of proximity and trust between the family caregiver and with the patient. To this end, the experiences of nursing professionals converge in the need to progressively educate patients and carers so that the hospital stay constitutes a space for learning and growth for all, as well as increasing the capacity to care in basic aspects, providing the emotional support that every person deserves when their health is compromised for considerable periods and even more so when dealing with morbid processes with no alternative of frank recovery.

On the one hand, the teaching provided to the family caregiver represents an investment of human potential and material resources, which are part of the regular programming of health services, which allocate man hours with the express purpose of optimizing the operational and support processes to also benefit the caregiver, favoring the early identification of signs of exhaustion or caregiver burden, for preventive purposes (Díaz, 2015). In this sense, the initiative to support the primary caregiver or accompanying family member is part of the Patient- and Family-Centred Care Model in countries such as Colombia and Mexico. In Peru, it has been extended both in pediatric areas and in adult patients, and even in emergency services, in which the nurse has played and continues to play an outstanding role accompanied by a permanent concern for the improvement and productive sense of the initiative, always linked to the humanizing sphere (Aguilar, 2018).

In the Social Health Insurance-EsSalud, the Family Companion Caregiver initiative has evolved since the 1990s until, in 2015, it was made official by General Management Resolution No. 990, a document that broadly specifies the objectives, scope, purpose, methodology, and registration systems of this strategy, thus allowing the nurse to be more operational in the processes of recruitment, training, and monitoring of patient care and the role and/or difficulties experienced by the family caregiver, incorporating greater unity of criteria and evaluation indicators for the Family Companion Care initiative (EsSalud, 2015).

In light of the existing literature and thanks to the interest of different health researchers, it is widely known in the development of this initiative that the greatest needs of the family are information, flexible hours for visits, the minimum comfort they need during their stay in prolonged care situations and the relevance of the initiative in the socioemotional support perceived by children, hospitalized adults and the family caregiver him/herself. It has also been reported on the persistence of disinterest and lack of approach to the solution of the problems that pertain to the aforementioned elements (Andrade, Oliva, da Silva, 2017).

However, even though the initiative has been in place for almost two decades, little is known about the extent to which it has made concrete learning effective for primary caregivers, preventive support, and its effectiveness concerning the burden of caring for people with chronic problems, how nursing promotes better transitions from hospital to home for patients and families, and the transition to self-care according to resources and socio-cultural characteristics. It is of interest to know contributions in the administrative-economic order and regarding the role of the Family Companion initiative in the corporate image of the Health Service Provider Institutions, which try to respond to the efforts to achieve visibility in the context of the Humanisation of Health Care. Hence the interest in answering the question: Are there new pieces of evidence regarding potential benefits and solutions addressed by the nursing professional in the development of the Family Companion Care initiative in the hospitalization-home interface? In these experiences, is it possible to grow sustainably in the care provided by the nurse to patients and family caregivers? is the article aims to describe the potential of the Family Companion Care initiative for patients,

family caregivers, and health sector entities concerning the role of nursing professionals, based on a literature review of the available evidence.

METHODOLOGY

A descriptive analysis was made of 38 original articles and two review articles, of a quantitative and qualitative nature, in English, Portuguese, and Spanish. The electronic databases searched were: Pubmed, Scielo, Scopus, Medline, and EBSCO. The most commonly used descriptors were: accompanying relative, experience, and hospitals and the Boolean operators used were: AND, OR, NOT; combined AND OR. Articles were selected by verifying relevance to the object of study. Inclusion and exclusion criteria included articles up to 10 years old for the first phase, and for the final analysis, articles no older than 5 years, whose content was related to the potential of the accompanying family strategy, as long as the metric properties of quantitative studies and the quality criteria of qualitative research were included. Relevant aspects were analyzed utilizing deductive-inductive processes, leaving 10 articles for the final analysis of the information, from which relevant contributions were obtained.

RESULTS AND DISCUSSION

Brief Historical Perspective

Within the framework of the transformations of the Hospital Care Model and the Nursing Care Quality Model, the presence of the Accompanying Family Member has been identified since 1960, particularly in pediatric care settings. The objective revolved around reducing the impact of hospitalization on minors and controlling parental anxiety, as well as making their right to participate in the life and health of their children viable (Torres, Vanegas & Yepes, 2016). The family has been and will be one of the most connoted pillars in terms of its spontaneous and immediate response when one of its members loses their health. No matter the severity or duration of the ailments, family members will always be close to the patient, particularly in the face of the ever-increasing explosion of chronic conditions.

The World Health Organisation (2017) states that, with the boom in the implementation of quality standards in care, promoted worldwide in the last four decades by various entities responsible for the Accreditation processes of health institutions, the commitment of Member States and the increase in patients with chronic degenerative diseases, proposals for the implementation of Family Companion programs in adult hospitalization services, both in acute and chronic situations, are gaining momentum. Thanks to the progress of the Social Sciences and pastoral initiatives in the care of hospitalized patients, it is recognised that accompanying someone entails the idea of sharing difficulties and resources, of helping without invalidating others, of going together in search of goals, facing ups and downs, enjoying pleasant moments and facing adversities when they come (Reis, Cedraz, Franca & Oliveira, 2018).

Support is necessary at all moments of life and becomes essential when vulnerability increases due to the limitations of the disease or its consequences (Ortiz, Beca, Salas, Browne & Salas, 2018). On the one hand, from a legal perspective, the Senate of the Republic of Mexico (2016) states that in Latin America important steps have been taken in the management of patient accompaniment by relatives; Mexico included a reform of the law, while Chile and Brazil made progress based on the Humanization Policy that guarantees the permanence of the family and social networks in hospitals. Similarly, Cuba permanently includes two key points in its General Hospital Regulations: a) declaring that all patients admitted to the hospital have the right to receive quality care: dignified, humane, and supportive care by all the staff of the institution, and in point n) they have the right to participate in educational activities that raise their knowledge and contribute to adopting behaviors favorable to their health and that of their family, by all the staff (Ramos & Martínez, 2012).

On the other hand, greater social sensitivity in some spheres of life has led certain nations under the Crusades modality, such as in Mexico, to provide family members with comfort through the Chair-bed Programme, as some accompanying caregivers remain with their loved ones for more than 24 hours at a time, depending on the severity of the hospitalized relative's illness (IMSS, 2018). The strategies described imply that comfort is not only synonymous with convenience, but comprises a broader form of re-evaluating human needs and how the energy of the family member who spends a prolonged time with the sick person is compromised, deserving special understanding and facilitating their healthy rest and basic hygiene, to preserve balance and immunity in the face of the biological stress of caring for others day and night (Reyes & Leiton, 2014).

Potential for Socio-Emotional Benefit

In a very pleasing sense, it has been identified that 73.1% of patients enjoy accompaniment during their hospital stay, the motive of family caregivers being the recognition of the responsibility and affection that their loved ones deserve, as well as the knowledge of the anxiety and fear produced by the idea of the occurrence of some adverse event in hospitals, in the absence of family members or linked to factors related to the patient's socio-demographic profile. It is illustrative in this regard that Yeniocak and Topacogen (2018) in a research conducted in Turkey, the number of companions decreases as the patient's educational level increases. Despite identifying as an unfavorable element, the increased pressure for reports and demands for details on schedules and methods of care or other hospital procedures from family caregivers to health care staff, it is more acceptable for the patient to be accompanied by relatives and/or Friends

Another noteworthy aspect is that, on occasions, the nursing staff themselves experience the need for change and improvement in the development of the Family Companion strategy, observing delays in dialogue and in meeting the demands of their loved ones, attitudes of lack of diligence and timeliness in care, which leads to feelings of ambiguity in reconciling roles between the professional role and the role of family companion, making it necessary to strengthen the dialogue between companions and professionals for the well-being of the caregiver and the quality of care. It is then a matter of recognizing attributes of care that can certainly be improved (Beuter, Gomes, Tambara, Venturini, Geiss & Bruinsma, 2018).

It is interesting to understand how the potential socio-emotional benefit, is located from a sociological perspective, explained by da Silva, Pereira, & Gonçalves (2016) regarding how each family accompanying the patient, describes a person who comes from various groups or tribes; according to the metaphor of life in tribes and around the totem; in these groups of patients, professionals, and accompanying caregivers, they share emotions, affection, sympathy, mutual help, physical contact, communion, and religiosity, in a series of links with collective identity. Understanding this dynamic for health professionals is vital because the accompanying family member is increasingly part of a social group with greater presence and a growing sense of belonging, so reflection involves reformulating the relationships between caregivers, the cared-for being or patient and the members of the health team who permanently exchange knowledge and experiences, and it is desirable to perceive the elements of humanized care: listening attitude, empathy, understanding, specific help according to needs, affection, among others (Andrade, Oliva, da Silva, 2017).

Potential for Support in the Patient's Recovery

The experiences of the accompanying family member, from a phenomenological approach, move between the visible and the invisible, with the clinical care shared by family carers and nursing staff being the visible aspect of their work. In this care, which includes basic aspects of feeding the patient, support in ambulation, postural changes, support in dressing, and meeting elimination needs, they not only provide comfort, pain relief, and safety, but also allow the patient to feel well, calm and be oriented to what is going on in their environment. When it comes to hospitalized older people, they may be invisible to staff as they are not cared for holistically, always bearing in mind that there is a risk of remaining in basic activities or routines assisted by care technology (Andrade, Oliva & da Silva, 2017: 709–711).

This reality of care mobilizes a critical reflection on the initial and permanent assessment by nursing professionals: What does the patient's look, silence, or cry tell us? What has the accompanying caregiver picked up? How is it possible to plan the care of the elderly in this case, including experiences for the caregiver and the nursing staff, which means resignifying the presence of the nurse and the role of the caregiver himself/herself? This is the path to be made visible through the conscious exercise of the caring profession (Waldow, 2015). Following the aspects described Beuter et al. (2018:764-766) points out that to make this benefit effective in the recovery process, the accompanying family member needs teaching

and support from the nurse so that while the patient remains hospitalized, he is strengthened constructively and enjoying each stage without losing sight of his value as a person, his self-esteem. The daily life of a primary caregiver changes, losing sight of what is happening in their home, with their loved ones, and their assets and silently expressing the need to be welcomed and understood to fully comply with their work in the basic care of the patient; guiding the family caregiver is a task that the nursing professional sees not only as a function of their vocational choice but also as part of one of their substantive functions: to educate to promote behavioural changes that influence a better level of health and that of the family itself, so it demands planning, execution of operational and support processes to promote the ability of family members to care for the patient effectively and with love (Arpasi, 2016).

In this direction, Goldberg, Jeff, Troup, Kubba & Okrainec (2018) point out that the appropriately trained and trained accompanying family member supports the patient by helping them to understand, and comply with the pharmacological indications and care to be followed in the post-discharge phase. For the authors, these experiences constitute new opportunities for the well-being of the patient, and the family and also facilitate greater adherence to the patient's comprehensive treatment, promoting recovery, an aspect that represents a constant challenge for health professionals.

In particular, these benefits are tangible in patients with chronic diseases such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and community-acquired pneumonia (CAP). The role of the caregiver is critical, including one-off activities such as administering oxygen therapy which has a particular impact on the life of the patient and family, as well as assisting with activities of daily living: cooking, driving, and advocating for the patient with the doctor and other professionals so that they receive the necessary and understandable information to enable them to make decisions and avoid complications. In some contexts, the caregiver can act as a translator when language barriers exist (Cléries, Monserrat, Chiner & Escabarril, 2015). In this sense, it is necessary to bear in mind that receiving oxygen in a hospital or at home is culturally associated with the proximity of the end of life, so that understanding and clear, simple, and well-structured explanation by health professionals is indispensable in the opportunities for caregivers and nurses to grow in care.

Casildo (2016) argues that bearing in mind that the disease involves all spheres of human life and not only the physical aspect, but the role played by the accompanying family member is also linked to the guidance and advice provided by the nurse. He or she participates in the care of non-visible aspects including the relief of suffering and the teaching of holistic care measures for the patient, which the family caregiver needs to learn from the model developed by the nursing profession. In practice, in various services, even in emergencies, the accompanying family members perceive the nurse's commitment, responsibility and professional skill in their interaction and teachings to the family member who accompanies the patient and is integrated as part of the required care actions. To facilitate the recovery process, it is essential that the nurse promotes a harmonious and permanent interaction between the environment, interpersonal communication, and administrative facilities, to achieve the involvement of the family as the protagonist of their care under the guidance of the nurse who knows their needs and abilities to be strengthened (Vega, Luna Victoria, Gómez & Bustamante, 2017).

Potential for Supporting Administrative Processes

On the other hand, one of the least addressed topics is developed by Wittenberg, Kwekkeboom, Staaks, Verhoeff, and Boer (2017), Verhoeff and Boer (2017) who after reviewing 13 mostly qualitative articles, identified that health professionals do not take into account the opinion of companions regarding the division of responsibilities in patient care between professionals and companion caregivers, suggesting the need to address the issue openly and proactively to foster cooperation, respect and quality outcomes that benefit patients and staff of care facilities.

This contribution reveals how the role of the family caregiver in the administrative procedures required by the patient during their stay and before discharge has been viewed in different spaces; however, experience shows that despite the limitations in the conditions in which they remain accompanying the patient, their role is significant: they provide great support in providing information on countless aspects that develop around the patient and their care, they explain activities that are sometimes omitted being relevant because only they were present, in addition to the daily activities required by the patient's condition itself and the limitations in the provision of human resources that characterizes much of the care centers (Díaz and Bustamente, 2012).

Potential for Cost-Effectiveness and Other Evidenced Needs

Carlin & Guy (2019) are authors who describe aspects overlooked in other studies. Thus, it is recognized that, in different contexts, ages, and specialties, the presence of the accompanying family member contributes to the reduction of costs due to the reduced use of non-professional human potential in support of the nurse's work. For the authors, when assessing the effect of the participation of caregivers in the care and recovery of acute conditions, it contributes to a reduction in the length of hospitalization and also in the rate of post-discharge readmissions.

In this sense, while other studies emphasize the relational aspect of the Family Companion Strategy, the authors mentioned above specify the impact of having caregivers in the admission of patients who are hospitalized; it has been measured in terms of a lower probability of readmission equivalent to 3.6 percentage points less and a decrease of -0.10 days of hospitalization (p<0.001). In the experience of the Seguro Social de Salud (EsSalud, 2015), family members who live at home with the patient and accompany them during the hospital stay are recruited by the nurse and integrated into small individualized learning groups on basic care and simple emotional support measures that they put into practice for the patient; this is a way of replacing the work of technical nursing staff, especially in pediatric services, older adults or patients with highly dependent chronic conditions.

The evidence also argues in favor of achieving short-stay discharge processes and a marked decrease in adverse events for the patient through the presence of the companion. This situation is understandable insofar as the accompanying caregiver participates in hygiene, postural changes, ambulation, and feeding of the patient and his or her company allows immediate communication of any signs of alarm in the patient's well-being. However, this achievement requires enormous efforts in the training process of future health professionals, as it means systematizing learning experiences about family problems and the need to teach the family caregiver. Likewise, forging the professional's interest in acquiring indispensable resources for this work means ensuring that teachers and students positively take on the challenge of caring for people with chronic and complex conditions, which represent more than 45% of morbidity (da Silveira, da Silva and Luíz, 2016).

Considering that, among the articles reviewed, the predominant approach is qualitative, it is relevant to analyze that, among the relevant categories, the existence of barriers to process and using the information received by family caregivers are identified; in some cases, this experience is linked to mental exhaustion and difficulties in managing uncertainty.

Solan et al. (2015), after analyzing transcripts of individual interviews with caregivers of children discharged from the hospital in the previous 30 days, point out that listening to the family caregiver's requests provides insights for improving the existing care system; The disarticulation between the hospital world and the home persists and is not easily overcome so that a comprehensive understanding of the needs that arise in the transitions from hospital to home should be a permanent issue for the nursing professional; she is the one who is closest to the actions of the primary caregiver and the effects of her interventions or lack of them on the patients.

Among other aspects closely linked to the involvement of the nurse in the Family Companion Strategy and the options for development and improvement, Dos Santos, Crepaldi, & Ojeda. (2016) found the almost non-existence of intervention programmes in the hospital environment so that the caregiver can access more operational methods or techniques to solve problems related to the care needs of their patients. It is essential to look beyond the family caregiver's contribution to health and nursing staff; it implies looking in depth at their own needs as individuals, including focusing on the health of the Family Companion in a holistic perspective to promote and protect and healthy environments.

Pei-Chun, Ping-Keung, Jen Tai & Fan Lou. (2010) mentions that there are other groups of patients' companions; among them, those who care for patients with sequelae of cerebrovascular accidents (CVA), evidencing the needs for more health information, professional support to solve more complex problems and the formation of community networks, given the length of hospital stay, disability, and physical dependence that accompanies these patients; points out how nursing and rehabilitation professionals combine efforts for specific and accessible teaching to the accompanying family. It is very worrying for the relatives close to the patient's discharge to know how they will cope with the patient's safety and emotional changes, so the role of professionals needs to address particular sets of needs that change from admission to the patient's arrival home.

Reiteratively, Navas (2012) explains how the family, during hospitalization, begins to learn how to care for the dependent family member; however, intuitive knowledge predominates in their efforts, which gradually acquires aspects of greater security when the educational role of the nurse comes into play.

The last two references allude to situations typical of the everyday life of the hospital nurse. More than 60% of discharged patients leave with multiple care demands that extend for months at home, the primary caregiver feels relieved when they participate in spaces where they not only express fears and doubts but where they find organized knowledge that is dosed according to their needs to progressively strengthen their abilities to care for their loved ones (MINSA, 2017).

Another group with particular educational needs for the family caregiver is patients suffering from Amyotrophic Lateral Sclerosis (ALS). Al respecto, Cipolletta, Gammino, Francescon & Palmieri, (2018) specify that, in the experiences of these carers, new needs are discovered to live a daily life different from the one characterized by isolation, poor communication in the face of their difficulties, in which differences are evident depending on whether the person being cared for is a child, sibling or companion of the patient.

The new needs to be assumed by the team of nursing professionals in a multidisciplinary context are greater sources of support to help the family caregiver to face the illness, and to facilitate the satisfaction of needs expressed by the caregiver of a dependent person and incorporate them into networks where they can activate their personal and social resources to promote the well-being of patients, family, caregivers and health professionals (Fernández, & Angelo 2016).

CONCLUSION

The experiences reported in the articles reviewed allow us to identify that in addition to the beneficial aspects achieved in the Family Companion Strategy in the relational field and its contribution to patient recovery, significant progress has been made in the facilitating process carried out by the nursing professional, capturing and promoting learning spaces between health personnel and the family caregiver, a way of empowering the family in basic care that preserves the offer of affection that only the family can give. The evidence reviewed is a suggestive source of the contribution in terms of the cost-effectiveness of the strategy in question, which merits continuity and full support from health authorities.

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