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LONG-TERM CARE AND NURSING CARE:
THE ELDERLY PERSPECTIVE

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ABSTRACT

Objective: The aim of this work is to obtain a thorough understanding of nursing care in the context of long-term care, from the perspective of those who receive care. Considering the poor health care relatives because provided outside hospitals, long-term care is a comprehensive set of assistance to persons who need help from others for long periods of time, especially the elderly. In recent years, these contexts have required more attention because there is recognition of the specificity of these contexts, and the recognition that these are essential knowledge and specific competencies, which are configured with care. **Methods**: This mixed-design study integrated 113 seniors from 10 long-term care contexts which included nursing homes and integrated responses in the National Network of Integrated Continuous Care spread over 7 locations in the district of Castelo Branco. **Results**: The typological analysis of the speeches of the elderly showed that the perceptions related to the outcome of care are less present in the speeches of the expressions related to the developed care and how nurses behave in these contexts. **Conclusions**: In the analyzed contexts, nursing care is perceived as effective, is common to the way of being of nurses and their acting processes and has a significant expression in intervention outcomes.

Descriptors: Elderly, long-term care, nursing care

INTRODUCTION

Formal care systems were developed in recent decades to meet the needs of older and more vulnerable persons when they are unable to do so independently and their families are unable to provide them with the necessary support in their homes. This type of social and health responses, safeguarded in the European Union by the Social Protection Committee are referred to as long-term care (LTC) (Nogueira, 2009).

LTC thus represents a diverse group of health care and social support, of a formal and informal nature, provided for people with varying degrees of dependence especially the elderly as is stated by the World Health Organization (WHO) and the Organization for Economic Cooperation and Development (OECD). Considered as a political and crosscutting issue for several areas, these comprise a significant set of aids and services, and are intended for those who depend on others in daily life activities and who do not have the capacity for long-term self-care. LTC can be provided by informal and formal caregivers including health, social and other professionals (OECD, 2005; Simoens, Villeneuve & Hurst, 2005; WHO, 2002).

The assistance typology although separate, in most cases, from preventive care, rehabilitation care and chronic disease management, it is increasingly recognized as essential to the health and well-being of the elderly and it is desirable that the logic behind this division be re-examined (Kümpers et al, 2010) to ensure access to comprehensive long term care to anyone who needs them (WHO, 2006).

Considered as the poor relatives of health services, as they are provided outside hospitals, the LTC and their specificity have required more attention from researchers in recent years. In addition, the recurrent poor quality of care has been attributed to the inadequate skills of carers and the small number of nursing care hours provided (Spilsbury, Hewitt, Stirk & Bowman, 2011). The World Health Organization has recognized the specificity of these contexts and has stressed the need for these to require knowledge and skills that transcend the boundaries of specific disciplines (Dubois, Singh & Jiwani, 2008) and that are configured with care.

Understood as a way of being, or a way of acting, the caring and the care is imposed by the acknowledgment of the fragility and vulnerability of the human being that needs "to be the target of concern, of attentiveness or a worry and apprehension" (Carrilho, 2010, p.112). The view that the ability to care or to worry about things, about people, about the course of life and society, is essential and has been present in the reflection of thinkers such as Heidegger (1926), who considered the caring (cure) as an integral part of being and others (Mayeroff, 1971; Reich, 1995) that stressed their indispensability in relations between humans.

Mayeroff (1971) argues that only caring and being cared for can give meaning to life and help create order and stability. Furthermore, as a philosophical idea, caring can grow and develop in the exploration and discovery of its essential characteristics. Understood as a philosophy of action, the caring of the other or taking care of another reflects thoughts, emotions and actions which have implied ways of being and relating that encompasses the other's help always in the direction of their growth.

In a working review of the LTC and the quality of care in these settings submitted to the European Union, Nies et al. (2010) propose another perspective of care that completes the described perspective. Designed only as analogous to a service, the provision of care and their usage are two separate processes, and those who produce them and those who receive them do not need to know each other. Designed as a special service, a human service, this imposes other requirements specifically to the need of an interpersonal relationship and mutual emotions between those providing care and who receiving and which are integral parts of the economic exchange. In this perspective the production process and

usage cannot be separated and the duration of working time is an integral part of the outcome (Nies et al, 2010) because it is in the relationship that is established with the person that the therapeutic value of the intervention lies. These particular relationships, described as therapeutic (Basto, 2005; Lopes, 2005) are built on knowledge, mutual trust, understanding and knowledge sharing (McCormack, Dewing & McCance, 2011) and are an integral part of nursing care.

Such care or just "nursing care" as a practice that "is built on the nurse-client interaction with the intention of contributing to their well-being and or reduce their suffering" (Basto, 2009, p.12) refers to the professional intervention of nurses with people and its complexity to mean that it is understood as being health care (Basto, 2009).

Authors such as Watson (2009) and Swanson (2013) have stressed the influence that care environments have on care practices and as such maintain that, in environments where there is a culture of care there also exists better quality of care and improved user satisfaction.

METHODS

This interdependence and other findings lead us to question nursing care in the context of LTC and how the elderly and their close ones perceive it. The research was done through a mixed-design, integrated into the methodology of a case study in order to understand the holistically phenomenon (Coutinho, 2011) and get a deep insight into nursing care in these contexts. The recognition of the interdependence between subjects and contexts imposed a comprehensive approach recognizing that the identified dynamic could be both cause and effect (Guerra, 2010).

The study subjects were elderly and or family who received nursing care in the context of LTC and expressed desire to participate. Apart from these, other inclusion criteria were: to be aware of time, space and identity and to be able to read and write.

The contexts studied, 10 in total, included nursing homes and integrated responses in the National Network of Integrated Continuous Care (RNCCI) – mid and long term stay care facilities (UMDR and ULDM) and an integrated continuous care team (ECCI) spread over 7 locations in the district of Castelo Branco.

The vulnerability of this particular group required that there was a safeguard of the six ethical principles that should guide the investigation as recommended by the International Council of Nurses referred by Nunes (2013). The principle of beneficence and non-maleficence were guaranteed from the deep conviction that this research would benefit the

elderly and society and was not liable to cause them harm. The principle of loyalty was guaranteed by establishing a relationship on trust and the principle of justice was protected by not favouring any elderly person in detriment of another. The careful analysis of surveys and accurate transcription of interviews as well as the relationship of trust established with the elderly who were given all the information about the risks and benefits of the work, and who were further guaranteed that there was no risk to any participants ensured that the answers were truthful and real. The interviews were only identified with a number and the contexts with a letter guaranteeing each and every person anonymity and confidentiality.

There were 113 elderly participants and the qualitative study integrated information from 15 interviews from users from different contexts to ensure "characteristic diversity" (Guerra, 2010, p. 46) capable of varying the assessment of the phenomenon.

After obtaining consent to "dive into" the institutions and identify potential participants, as a first step a meeting was held with the technical directors and / or those responsible for the nursing services, who were explained the objectives and methodology adopted for the study. Then another meeting was scheduled with the elderly and the researcher. There, the elderly were informed and clarified in detail on the research objectives and methods of collecting information. They were guaranteed total anonymity of responses and the confidentiality of information that would be obtained and they were allowed to contact with the Caring Behaviours Inventory (ICC) of Ferreira and Cruz (2011) and explained how it should be filled in.

The quantitative information, as already mentioned, was obtained from the translated, adapted and validated ICC for the population of Portuguese patients by Ferreira and Cruz (2011) from the "Caring Behaviours Inventory" (Wolf et al., 1994, in Watson, 2009). Conceptually supported in literature on caring and the theory of transpersonal caring, this behaviour inventory takes nursing care as "an interactive and inter-subjective process that occurs in shared moments of vulnerability" (Watson, 2009, p. 53). It consists of 30 items or caring behaviours grouped into four dimensions: "disposition and positive attention to the user", "understanding and technical investment", "communication investment" and "ethical investment" rated on a Likert scale ranging from points 1 (never) to 6 (always). For each of the statements the elderly were asked to indicate the degree of agreement with the behaviours that nurses adopted in the relationship.

Subsequently, interviews were scheduled with the elderly who have expressed the desire to do. Some were from the 1st sample and others who, because they had difficulties in reading and writing, had only been integrated in this part of the study because they were

considered "key informants" (Guerra, 2010). Each one was clearly explained the purpose of the interview and were given knowledge of the script thus establishing a favourable partnership to generate "the possibility of reflexivity in the two elements of interaction" (Guerra, 2010, p. 51), authorization was obtained to release the contents of the interviews recorded on audio and which lasted on average 45 minutes. They were also given the opportunity to listen to your voices, defending and ensuring their freedom and dignity, but only three seniors expressed the desire to do so.

Data with measurable characteristics were organized and interpreted using descriptive statistics (SPSS version 15.0) and the care behaviours were subjected to factor analysis in principal components with orthogonal rotation (varimax) to promote behaviours that gathered more consensuses among elderly and their weight in each dimension. We retained, in each dimension, proposals with a weight of 0.40 thereby reducing the number of variables or "factors" to maximize the explanatory ability of the set of all the behaviours, which allowed for the identification of subgroups of questions that assessed the same behaviour (Yanai & Ichikawa, 2007).

The information gathered from the interviews was analysed and interpreted through content analysis technique, classifying the material collected according to relevant criteria that allowed for hidden variables to be found which were likely to explain the variations of the different dimensions (Guerra, 2010). We favoured the "types by similarity", regrouping through content proximity criteria the reviews on caring relationship "in exclusive groupings" (Guerra, 2010, p. 78) which was subsequently triangulated with quantitative data and theory.

RESULTS

Information obtained between May 2012 and March 2013 came from 113 elderly people from 70 (62.5%) were female and 42 (37.5%) were male. Predominantly elderly over 80 years old (58.0%) and the standard was 84 years old.

Most reported having only attended primary school (between 0 and 4 years of schooling) and female participants revealed higher levels of education, 13 said 10 or more years. In the group of males, only 5 reported similar levels of education.

Of the elderly studied, 66 (58.4%) had been receiving nursing care for less than 24 months and the average length of care was 30 months.

The context in which care was given to 75 elderly (66.4%) was in social sector facilities (nursing homes) and 28 RNCCI structures (24.8%) as inpatients or outpatients (8 informal caregivers) and 10 elderly (8.8%) received nursing care in mixed system of units (RNCCI and social sector).

Perceived Caring Behaviours in Long-Term Care

Statistical analysis of care behaviours perceived from the ICC, grouped in the 4 dimensions that it comprises revealed a mode of 6 in all of the behaviours and the disposition dimension and positive attention received had higher mean values (5:49) as opposed to the communicational investment dimension which had lower average values (table 1).

Table 1 - Descriptive statistics of care for dimensions perceived by users

		Inverted Ethical Investment	Communicational Investment	Comprehensive and technical Investment	Disposition and Positive Attention
N	Valid	113	113	113	113
	Lost	0	0	0	0
Average		5,38	4,66	5,04	5,49
Median		6,00	4,83	5,17	5,75
Mode		6	6	6	6
SD / σ		,967	1,212	1,014	,746
Variance		,934	1,468	1,028	,557
Range		5	5	5	5
Minimum		1	1	1	1
Maximum		6	6	6	6

The factor analysis of the Communicational Investment dimension was able to extract two factors with their own values being greater than one, which explained 69% of the variance. The rounded matrix reported that the variables "They help me grow as a person" and "They are my confidants" were the behaviors perceived, which had greater weight contribution in this dimension. In relation to the size Comprehensive and Technical Investment, only one factor was extracted with its own value higher than one and that explains 48% of the variance. In this dimension the behaviors, "They ensure a comforting presence" and "They listen to the opinion on the care they will give me", were those that contributed most weight. In the Ethical Investment dimension two factors were extracted with their own values greater than one which explained 64% of the variance. The rounded matrix reported that the behaviors, "They choose less appropriate times to talk about

my situation" and "They transmit confidential information about me in front of other users" (presented with a reversed score) which never or almost never happened, were those which contributed to this dimension.

As regards to the care dimension, Disposition and Positive Attention drew out three factors with their own values greater than one, which explains 60% of the variance. According to the rounded matrix the behaviours "They help to ease my pain," "They respect my privacy," "They are friendly" "They use a soft, friendly voice" and "They take care of me as a human being" that contributed, namely with more weight in the perception of the users.

Caring in Long-Term Care: The perception of the elderly

The perceptions of care were obtained from 15 in-depth interviews with the elderly and with the reflection on their interaction with nurses in different contexts. From the expressions of this interaction it was possible to extract opinions and perceptions likely to be grouped into three types of care by similarity (Guerra, 2010), namely "care as a way of being of nurses" which added the perceptions related to the mode of being of nurses in these contexts; "care as a way to intervene" which includes perceptions related to the care or activities developed and "care as a result of intervention" that grouped the perceptions and expressions related to the concrete result of the intervention e.g. nursing care (table 2).

Table 2 - Caring typologies by similarity (Guerra, 2010). The perception of the elderly

Typology	Principal opinions of the elderly	Frequency
1st TYPE: Caring as a way of being of nurses	Perceptions related to the way of being of nurses	E1(B); E2(B); E3(B); E4(C);E5(C); E6(D); E7(D); E9(A); E11(H); E13(H); E14(J); E15(J)
2nd TYPE: caring as a way to intervene	Perceptions related to the types of care developed	E1(B); E2(B); E4(C); E6 (D); E7(D); E8(D); E9(A); E10(G); E11(H); E12(H); E13(H); E15(J)
3rd TYPE: Caring as a result of intervention	Perceptions related to the result of care	E3(B); E4(C); E6(D); E7(D); E8(D); E10(G); E11(H); E12(H); E13(H); E14(J)

The typological analysis of the discourse and its interpretation also revealed that the perceptions related to the outcome of care are less often present in the discourse regarding the expressions related to the care developed or how nurses behaved in these contexts. This means that caring as a way of being of nurses and care as a way to intervene are better understood and better defined by the elderly than care as a result of the intervention.

DISCUSSION

When analysed from the perceptions of the elderly in the context of long-term care and based on the caring behaviours inventory grouped into four dimensions (Ferreira & Cruz, 2011) nursing care was expressed as effective, effectiveness, which was confirmed by the high values of all the dimensions suggesting a philosophy of action, that is a way of being and acting of nurses in these specific contexts. The practical orientation of caring and its ethical demand requires the carer to have knowledge and skills and awareness to preserve the dignity of the other, which can be compromised if that other, rather than a subject becomes an object for the caregiver (Gadow, 1984 reported by Swanson, 2013). However, in the analysed contexts, ethical care and the realization that the dignity of the elderly is protected and preserved by nurses it was perceived as present in the relationship and expressed as a right and a requirement of nursing care as an elderly lady said. *"I'm still around but it is only based on pills and injections ... but I'm still around until one day I'll stop ... but the nurses treat us as they should do, they don't abandon us, they treat us as they should do, otherwise I wouldn't be here (...) but that is their duty"* [E5 (C)].

The ethical investment (Ferreira & Cruz, 2011) that was placed on the relationship also found expression in behaviour perceived by the elderly since, some of these behaviours such as, choosing less appropriate times to talk about the situation of the elderly person or transmit sensitive information in front of other elderly persons were behaviours that have never or almost never been perceived.

Unlike these, the behaviours "be friendly", "use a soft, friendly voice," respect the user's privacy and taking care of the user as a person, integrating the dimension disposition and positive attention (Ferreira & Cruz, 2011) were perceived as almost always or always present in the interaction and found similarities in the discourse of the elderly when they spoke of their relationship with the nurses: *"There is one around here who has a beard, he is very friendly (...). This tall one ... pinches my nose and says I look like a 20 year old girl. I don't like being old"* [E1(B)].

In the interaction, described by the elderly, particular importance was given to feeling good, knowing the problems of the users, being available and showing good will, showing respect and being kind and friendly, being a good listener, having moral and being good tempered, having patience and consideration be essential or very important and being friendly and cheerful, being treated like family and being called by your name, perceptions related to the way of being of nurses and which are also forms of caring as outlined. *"They are very affectionate (...) and my friends. One pats me on the back another kisses me, they are all really my friends (....) And it is very important that they [the nurses] are loving"* [E8 (C)].

This way of being is of fundamental importance because, unlike what happens with cognitive and functional domains, emotional well-being and emotional stability can be present at high levels in the elderly as a result of tried *coping* strategies focused on emotions (Afonso, 2012) and that have been expressed from the caring relationship.

Although the affectionate behaviour has not been explored very much in nursing research, the elderly considered it fundamental emphasising that being caring and paying attention as ways to focus on the user because it has an implicit way of being which appreciates the person in detail and which involves the care giver and the receiver (Swanson, 2013). Patience and listening skills were also highlighted and suggest the centrality of care on the elderly and on another significant person as referred a care receiver *"Nurse L. shows a lot of patience ... and she is a good listener ... she always calls him by his name, she is careful in this"* [E7(D)].

Patience here identified more than a passive waiting is rather a kind of participation with another (Mayeroff, 1971) and it is an important element of care because it allows the other to grow at their own pace and in their own way.

Recognized as fundamental in long-term care significant others (Lage, 2005) require the same attention that is given to the elderly themselves and that attention was also perceived in the relationship just as trust. *"They come to treat my husband [the nurses] but they also look after me. And they give me lots of good advice and are always supporting me, when I need to know something I ask them anything and they are always in my favour and encourage me a lot"* [E6 (D)].

Perceived as an attitude, caring as a fundamental condition or ability to understand each other's needs, can focus on both the general and on the specific (Mayeroff, 1971) and it requires time and knowledge that elderly people also understood. *"They show no hurry and when they see that there are problems for the doctor to solve they send me straight to the doctor. And they always treat me with good will"* [E3 (B].

Other behaviours such as ensuring reassuring/comforting presence, listening to the opinion of the elderly about the care that will be provided and knowing their main problems and needs, were also perceived as common. Apart from these, gestures and attitudes such as calm, nurturing, helping, encouraging, defending, clarifying, cherishing, doing treatments, giving medications and giving time which the doctor does not give, were perceived as developed care and provide in these contexts modes of intervening or *caring as a way of nurses intervening* elucidating on the comprehensive and technical investment (Ferreira & Cruz, 2011) that is placed in the relationship.

Caring as a way to intervene, therefore integrated a set of actions by and for the other (Swanson, 2013) perceived as care of a more instrumental nature or by other supervisory and protective as mentioned by another elderly lady. *"They put a plaster on me twice a week but are always saying that I don't need to be in pain, I can take other medication so that I am to not in pain"* [E4 (C)]. And these interventions, deliberate and pre-planned result in therapies because they intended to provide health and wellness to the user and to be considered as ways of providing nursing care (Watson, 2009) and what other care receivers perceive: *"And even the jokes she does the playing around that is does with him make him more active"* [E7 (D)].

Caring is also helping the other to grow (Mayeroff, 1971) and in *the way nurses intervene* in these contexts nursing care was understood by the elderly as capable of enabling their growth by supporting emotionally, providing information and validating the information provided, fundamental behaviours in terms of health and management of self care (Swanson, 2013) which were also highlighted in the communication investment dimension (Ferreira & Cruz, 2011) with the behaviours helping the elderly to grow as a person and being their confidant.

As a result of the intervention, the caring was identified in these contexts and from the perceptions of users, as a beneficial complicity, relevant interventions that sustain life, rewarding presence, contribution in problem solving, clinical improvements, sense of tranquillity and security, feeling cherished, feeling accompanied and feeling good about the care. Furthermore, although in the literature there is no absolute consensus on the importance of care in treating the disease, there is recognition of its value for health, well being and quality of life of the elderly (Nies et al., 2010; Watson, 2009). This recognition is linked to the World Health Organization definition of LTC as a system that combines activities undertaken by informal or formal caregivers, family, or health professionals and social services who should ensure the best quality of life for the person according to their individual preferences, preserving as much as possible their autonomy, independence and personal participation (WHO, 2006).

Measuring the results of caring in the elderly may seem complex, however, the results of the care interventions are materialized by the resolution of the physical and emotional needs of users and are expressed in feelings of self-care, autonomy, comfort, security, peace and relaxation (Sherwood, 2013) also expressed by the elderly in these particular contexts of the sense of security. *"I feel much more calm when I know that the nurses are here are more often ... I feel much better close to them because if anything happens to us we can call them straight away, and they come"* [E4 (C)].

For others, the outcome of care was the comfort provided by pain control. *"Nurses know that I have osteoarthritis in the knees. From time to time they put some ointment here and give me a massage ... the swelling doesn't all leave but it does a little and the pain gets better ... relieves"* [E11 (D)].

Pain is one of the causes of illness and malaise that the elderly reported in this study. This symptom accompanying transversely acute situations of illness and chronic health problems and its effective control is a personal right and a duty of health professionals. Considered since 2003 as the fifth vital sign (Direção Geral da Saúde, 2003), pain is often undervalued, in that in many care contexts, its assessment is not carried out in a systematic way neither is the result of the intervention developed to reduce or minimize it, monitored.

Therefore, these and other challenges are those that elderly people offer, because the presence of pain, while reducing the quality of life and makes the person susceptible to the onset of other clinical conditions, such as depression, sleep disorders, anxiety and eventually, aggressive behaviour, it is also a threat to the identity of the person, to their dignity and respect, and contributes to increased vulnerability and the erosion of their autonomy and independence (Brown & McCormack, 2011) and so it is important to delay and minimize it.

In addition to the resolution of physical and emotional needs improving "empowerment" is also considered an important outcome of care (Swanson, 2013) as said by another elderly lady *"They give me information and teach me a lot. I was taught to do many things because I was not prepared. The best thing they could have done was arrange long-term care and nurses come to my house ... because we feel more assisted"* [E6 (D)].

The effective management and the "empowerment" of the elderly and their families, also identified by other researchers, help the elderly and families to be competent in the care and they should be the objective of health professionals at the interface between formal and informal care (Lage, 2005). This "information management" already referred to and identified by Lopes (2005), enables informal carers to make proper use of their resources because the formal and informal care systems are not independent processes (Lage, 2005).

In addition efficient teaching and education are also important ways of caring because they allow the user and or family to learn to live with the situation of dependence, to manage it and develop behaviours to adapt. It begins with the assessment of educational and information needs and the results are measured using the ability that one has to incorporate new behaviours of "empowerment" or health in the preferred lifestyle (Habel, 2011).

The convergence between clinical objectives and the objectives of the person being cared for, developed in accordance with their capabilities and the enhancement of their role is transported into practice by the partnership between nurses and the user / family and is part of the professional intervention process or nursing therapy (Ordem dos Enfermeiros, 2001), implemented and evaluated in a systematic way, it also allows for the identification of the results of care as a therapeutic intervention.

CONCLUSIONS

The ability of societies to provide good quality in long-term care to everyone who needs it, must be protected and preserved as advocated by the European Commission, because the normal changes through aging are joined by the chronic diseases that require an interdisciplinary approach identified as critical to delay the decline and maintain health, and not less importantly is the knowledge of the challenges that are posed to different professionals.

This study had as its principle objective obtaining a thorough understanding of how the elderly perceive and interpret these challenges, particularly those which are put to nurses in long-term care, that is to say about nursing care in these specific contexts. The scarce information concerning the care for the elderly as nursing therapy, which recognized as complex because the elderly carry with them vulnerability, risks and dependencies, was improved and enriched with this study. From data of a quantitative and qualitative nature to be triangulated with the theory, the information concluded that in the analysed contexts nursing caring is effective and transversal to the way of being of nurses and to the way they act which reflects in the outcome of interventions and significantly contributes to the health and well being of the elderly in these care contexts.

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