Objective: to understand how nurses deal with the elderly's autonomy at the end of life.

Method: qualitative, exploratory study, guided by the Grounded Theory. Ten nurses, eight doctors and 15 nursing technicians were interviewed between November 2016 and May 2017 at a university hospital in Rio de Janeiro/Brazil. Results: nurses deal with the elderly's autonomy in compliance with the code of ethics and exercise leadership in actions and interactions to defend this right, evaluating, guiding and listening to the preferences of the elderly; interacting with the family; and sharing information with the health team. Final considerations: the elderly's autonomy must be ensured in care planning, based on patient-centered communication and developed in the interaction among agents involved in care. The discussion on “Living Wills” Health Care Directives and principles of palliative care must be encouraged.

Descriptors: Nursing; Personal Autonomy; Hospice Care; Aged Rights; Chronic Disease; Hospitalization.

RESUMO
Objetivo: compreender a forma como os enfermeiros lidam com a autonomia do idoso na terminalidade da vida. Método: estudo qualitativo, exploratório, guiado pela Teoria Fundamentada nos Dados. Dez enfermeiros, oito médicos e 15 técnicos de enfermagem foram entrevistados entre novembro de 2016 e maio de 2017, em um hospital universitário, no Rio de Janeiro/Brasil. Resultados: os enfermeiros lidam com a autonomia do idoso em atendimento ao código de ética e exercem a liderança nas ações e interações para defender este direito, avaliando, orientando e ouvindo as preferências dos idosos; interagindo com a família; e compartilhando informações com o equipe de saúde. Considerações finais: a autonomia dos idosos deve ser assegurada no planejamento assistencial, tendo como base a comunicação centrada no paciente e desenvolvida no processo interacional entre os agentes envolvidos no cuidado. É preciso fomentar a discussão sobre as Diretivas Antecipadas de Vontades e sobre os princípios dos cuidados paliativos.

Descritores: Enfermagem; Autonomia Pessoal; Hospice Care; Aged Rights; Enfermedad Crónica; Hospitalizar.

RESUMEN
Objetivo: comprender la forma en que los enfermeros se ocupan de la autonomía del anciano en relación con el fin de la vida. Método: estudio cualitativo, exploratorio, guiado por la Teoría Fundamentada en los Datos. Diez enfermeros, ocho médicos y 15 técnicos de enfermería fueron entrevistados entre noviembre de 2016 y mayo de 2017, en un hospital universitario, en Río de Janeiro/Brasil. Resultados: los enfermeros lidian con la autonomía del anciano en atención al código de ética y ejercen el liderazgo en las acciones e interacciones para defender este derecho, evaluando, orientando y escuchando las preferencias de los ancianos; interactuando con la familia; y compartiendo información con el equipo de salud. Consideraciones finales: la autonomía de los ancianos debe ser asegurada en la planificación asistencial, teniendo como base la comunicación centrada en el paciente y desarrollada en el proceso interacional entre los agentes involucrados en el cuidado. Es necesario fomentar la discusión sobre las Directivas Anticipadas de Vontades (Directivas Anticipadas de Voluntades) y sobre los principios de los cuidados paliativos.

Descritores: Enfermería; Autonomía Personal; Cuidados Paliativos en la Terminalidad de la Vida; Derechos de los Ancianos; Enfermedad Crónica; Hospitalización.
INTRODUCTION

As the population ages, chronic noncommunicable diseases (CNCD) account for approximately 70% of the world’s deaths annually\(^1\). Such diseases are associated with the clinical syndrome in the elderly, which results in physiological impairment, with increased hospitalizations and length of stay in health institutions. It is worth noting that interventions to control CNCD require high financial resources, specialized health services, palliative care provision, and training of health professionals\(^2\).

This reality affects the knowledge area of Nursing, since, once hospitalized, the elderly with CNCD suffer impact on quality of life and self-care capacity. Thus, the elderly need assistance with a high degree of dependence on the nursing team, as well as advocates for the preservation of their autonomy\(^3\).

Autonomy can be understood as a very personal right expressed in the capacity to make decisions, that is, in the freedom that people have to act and make their own decisions, according to their values and, consequently, decide what they think is best for them. Although the elderly are dependent, the right to autonomy must be guaranteed, since there is no relation between the need for care and the person’s ability to take decisions about his own life\(^4-5\).

Although all have rights and duties according to the civil order, it is necessary to reflect on the right of autonomy under the bias of uncontested self-determination. Since people need to be understood in the context in which they are inserted, setting the precedent for shared decision-making, since there is no absolute right\(^6\).

Age is not a factor that incapacitates the person to personally perform the acts of civil life, such as deciding about life itself and death. However, frailties imposed by the disease and hospitalization, relations of power based on the scientific knowledge of Medicine and the domination of the biomedical curativist paradigm can generate situations in which the right to the elderly’s autonomy is violated. Thus, as a health team member, the nurse can gather elements that favor the creation of links and the development of actions and interactions in the scope of care management to defend the elderly’s autonomy\(^7-8\).

OBJECTIVE

To understand how nurses deal with the elderly’s autonomy at the end of life.

METHOD

Ethical aspects

The ethical aspects of research with human beings were respected, in compliance with Resolution 466/2012 of the National Health Council. Thus, the research project was approved by the proponent and co-participating institutions, respectively, Escola de Enfermagem Anna Nery and “Clementino Fraga Filho” University Hospital. All participants received information about the research and signed the Free and Informed Consent Term. Anonymity was ensured, with interview cut-outs identified by alphanumeric codes.

Methodological framework

The Grounded Theory (GT) was applied, based on the precepts from the Straussian School. With the GT, it is sought to unveil the understanding of the multiple phenomena of nursing team’s performance setting from elements such as meanings, opinions, values and perceptions, and thus to meet the requisites of the object of study\(^9\).

Type of study

This is a qualitative, exploratory study.

Study setting

Data were collected in medical clinic wards of a university hospital in the city of Rio de Janeiro, Brazil, between November 2016 and May 2017.

Collection and organization of data

The analytical process’ ability to target different sample groups is among the principles of GT development based on hypotheses that arise during data collection and analysis. When they arise, these new sample groups allow us to understand the rooting of the phenomenon investigated from other perceptions or meanings that directly influence the theorization of the research phenomenon. This possibility occurs because, in GT, data are collected and analyzed simultaneously. Thus, in addition to the group of nurses, two other sample groups were constructed, presented in Chart 1.

Chart 1 – Presentation of sample groups, Rio de Janeiro, Brazil, 2017

<table>
<thead>
<tr>
<th>Groups</th>
<th>Participants</th>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
<th>Generating question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Sample Group</td>
<td>Ten nurses</td>
<td>Having employment relationship with the institution and minimum experience of six months in medical clinic wards.</td>
<td>Being away from work for any reason during data collection. Acting in exclusively administrative positions.</td>
<td>What do you understand by the elderly’s autonomy at the end of life?</td>
</tr>
<tr>
<td>2nd Sample Group</td>
<td>Eight doctors, being a clinical responsible and seven medical residents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3rd Sample Group</td>
<td>15 nursing technicians</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Data saturation was discussed among researchers, whereas the categories were constructed with theoretical depth so as to be able, together, to explain the phenomenon investigated. In addition, the GT analytical process allows some resources to evaluate data theoretical density, in spite of even weighing saturation.

**Data analysis**

Data were analyzed by two researchers, independently. No divergences were identified and no analysis of a third researcher was necessary. Coding steps were followed by open coding, axial coding and integration. These steps highlight the analytical process of the information in the GT, which occurs from data division, conceptualization and correlation[46].

In open coding, transcribed interviews raw data are analyzed line by line in the microanalysis, generating preliminary codes. In axial coding, preliminary codes are grouped by similarity, forming conceptual codes. Such codes may form subcategories which will then be grouped into categories representing concepts. In the last stage of integration, the paradigmatic model is applied to reveal the central category or central phenomenon of the study[46].

The paradigmatic model is composed of the following elements: conditioning factors, action-interaction strategies and consequences. Conditioning factors aim to answer the questions about why, when and how things happen, and to evidence the consequences. Conditioning factors aim to answer the questions about why, when and how things happen, and to evidence the consequences. Action-interaction strategies comprise people’s responses to particular problems, challenges or objectives. These responses result from the meanings attributed to them after perceptions about certain situations. Consequences can be understood as the actual results or expectations of certain actions[46].

It should be noted that the coding generated three categories. However, considering the scope and importance of possible actions-interactions that can be implemented by the nurse to defend the elderly’s autonomy, it was detailed, in this section, only a category referring to the paradigmatic component actions-interactions strategies. This category gathers the ways individuals deal with certain situations, in this case, the elderly’s autonomy and what people do to solve certain problems that emerge in the social context in which they are inserted.

With regard to the results, it is emphasized that the constant return to data using the constant comparison method is in itself one of the possibilities of validation.

**RESULTS**

Regarding the professional profile of participants, among nurses, the mean age was 39 years. The mean time in the sector was four years and the experience in palliative care was seven years. Eight nurses have Post-Graduate Degree. Among doctors, the mean age was 31 years. The mean time of performance in the sector and experience in palliative care was four years. Among nursing technicians, the mean age was 45 years. The mean time in the sector and experience in palliative care was seven years.

Regarding coding and systematic analysis of data, the category entitled “Establishing actions and interactions to defend the elderly’s autonomy in palliative care at the end of life”. This category represents the element of action-interaction strategies of the paradigmatic model, which contributed to the definition of the following central phenomenon: articulating elements of nursing and profile developed in its exercise in hospital care to defend the elderly’s autonomy at the end of life.

This category consists of four subcategories presented in Chart 2.

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**Chart 2 – Presentation of raw data and main conceptual codes of subcategories, Rio de Janeiro, Brazil, 2017**

<table>
<thead>
<tr>
<th>Subcategory 1: Interacting with the family to defend the elderly’s autonomy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raw data</strong></td>
</tr>
<tr>
<td>The main thing is the family oriented, participatory, who understands what is happening. Sometimes you can promote the elderly’s autonomy, but come the children who do not agree and want you to do everything. (M8) In communication with the family, we try to call those who are closest to a very open conversation; we do not lie or omit things. (M5) You have to see how the family feels at the moment. If it is very hopeful, we have to slow down. (M2) Often, the family itself is a barrier because the elderly person is able to go to the bathroom, take the bath, but the family wants to bathe in the bed. (T5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subcategory 2: Interacting with the elderly autonomy to defend its autonomy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Raw data</strong></td>
</tr>
<tr>
<td>A good deed comes from caring, listening. Sometimes the patient does not want anything, but knowing how to listen to what he has to tell you is an essential care for him [...]. We have to respect the patient’s decision, speaking his true condition, listening to his complaints. Dialogue is essential, as it favors the elderly’s autonomy. (E4) I face the elderly’s autonomy as relative because it depends on the level of consciousness and the state it is. But, in my view, he who must decide what he wants. (E8) It is necessary to give the patient the option to participate in the decisions about his life, but if it is not clear to him what is happening and the options, he will not be able to express what he wants. (E3)</td>
</tr>
</tbody>
</table>

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*To be continued*
Challenges and resolve strategies for maintaining the elderly's autonomy

The study participants expressed concern that the information provided to the elderly was confusing and insufficient, which made it difficult to understand their decisions about end-of-life care. This lack of clarity and understanding often resulted in the elderly feeling overwhelmed and unable to participate in their own care. Nurses, as the primary caregivers, play a crucial role in facilitating the elderly’s autonomy by ensuring clear communication, respect, and sensitivity in their interactions. This involves being patient, understanding the elderly's physical and mental state, and engaging in dialogue to identify their preferences and needs. Effective communication also helps to clarify doubts about the elderly’s health and the implications of their decisions, ensuring that they understand the consequences of their choices.

Information sharing is emphasized as an essential tool for nurses to facilitate the elderly’s autonomy. This includes providing clear and accurate information about their health, treatment options, and outcomes, as well as involving family members in the decision-making process. The nurse’s role in communication is pivotal, as they often serve as mediators between the elderly and other healthcare professionals, ensuring that the elderly’s perspectives are heard and respected. This involves maintaining open lines of communication with the family, health team members, and the elderly themselves, to foster a shared understanding of the care plan and the elderly’s autonomy.

The nurse’s leadership is fundamental to the elderly’s autonomy, especially if there is cognitive deficit or other health impairments. The nurse, often the patient’s primary caregiver, has the opportunity to advocate for the elderly’s preferences and make decisions that align with their values and needs. Additionally, the nurse can play a significant role in supporting the family by facilitating communication and addressing their concerns, which can enhance the elderly’s sense of agency and control over their care.

Nurses play an important role in information sharing, as they are often the first point of contact for patients and their families. This role is crucial in facilitating the elderly’s autonomy, as it allows nurses to become familiar with the elderly’s unique needs and preferences. Effective communication involves being attentive to the elderly’s emotional state and their relatives, as this can significantly impact their decision-making process. Nurses can help in clarifying doubts about the elderly’s health and the implications of their decisions, ensuring that they understand the consequences of their choices.

The study participants also highlighted the importance of maintaining open lines of communication with the family, health team members, and the elderly themselves, to foster a shared understanding of the care plan and the elderly’s autonomy. This involves maintaining open lines of communication with the family, health team members, and the elderly themselves, to foster a shared understanding of the care plan and the elderly’s autonomy. This involves ensuring that the elderly and their family members are engaged in the decision-making process, which can be facilitated through family conferences or other participatory strategies. These strategies allow the elderly to voice their preferences and concerns, empowering them to make informed decisions about their care.

In conclusion, nurses play a crucial role in maintaining the elderly’s autonomy by ensuring clear communication, respect, and sensitivity in their interactions. This involves being patient, understanding the elderly’s physical and mental state, and engaging in dialogue to identify their preferences and needs. Effective communication also helps to clarify doubts about the elderly’s health and the implications of their decisions, ensuring that they understand the consequences of their choices. Encouraging the participation of the elderly in the decisions about their treatments is essential in promoting their autonomy and quality of life.
interdisciplinary care approach that values their preferences. In Brazil, respect for autonomy and provision of information about clinical condition and treatment options are ethical and legal pre-suppositions provided in codes of ethics for health professionals[18].

For nursing professionals, such prerogatives are contained in the Resolution of the Federal Nursing Council (Conselho Federal de Enfermagem) 564/2017, in articles 39 and 42 which include the professional duty to provide information on health treatment, respect and promote actions that promote the person’s participation in treatment decisions. In this way, it is confirmed that patient’s autonomy must be ensured in the care process, based on communication and developed in the interactional process among agents involved in care[16,18-19].

Although communication and proposition of shared decisions meet the philosophy of palliative care, it is necessary to emphasize that there are possible barriers in health institutions to promote the elderly’s autonomy. For example, we can find professional paternalism and unpreparedness to define diagnosis and prognosis, which contributes to generate false expectations and psychosocial commitments. Thus, unilateral and inadequate decision-making emerge from professional judgments that do not meet patients’ wishes and that can distract them from the exercise of their autonomy[18]. It is fundamental to work as a team and to involve the elderly and their family in the decision-making process to avoid concentration of decision-making in the doctor.

In addition to the aforementioned barriers, frailty and vulnerability of the hospitalized elderly person with possible impairment of lucidity also interferes with the exercise of their autonomy, since this right is no longer recognized, which refers to the need for legal representation and the overlapping of the power of medicine.

Faced with biotechnological advances and the progressive complexity of care process due to population aging, it is imperative to guarantee the right to the elderly’s autonomy so that they can decide what treatment they want according to their ethical, moral and religious values. As it is one of the principles of bioethics, autonomy aims to protect them against the misuse of futile therapeutic measures aimed at maintaining life, even if without quality.

Present in international treaties, such as the Universal Declaration on Bioethics and Human Rights of the United Nations Educational, Scientific and Cultural Organization, Science and Culture and in Brazilian legislation, such as the Estatuto do Idoso (Statute of the Elderly) and the Constitution of the Federal Republic of Brazil, principles of the elderly’s autonomy and best interests are intended to ensure the right to opt for the health treatment more favorable, safeguarding their dignity.

It is confirmed in some passages of statements that patient has the right to autonomy, including deciding whether or not to stay hospitalized, as he is aware of the evolutionary process of his illness. However, this autonomy seems to be conditioned to certain factors; among them, their health condition and their cognitive ability to make decisions. With this, there are data that affirm that the autonomy is not an absolute right, since it must be shared between patient, professionals and relatives. Regarding the shared decision, patients need to be encouraged by the health team to play an active role in the decision-making process. Thus, you can express your values, needs, preferences and what you want to achieve with the proposed treatment.

It is important to establish the incentive for shared decision-making in institutions, at the heart of the systematization of care, identifying the barriers that may prevent the defense of the elderly’s autonomy. In this context, nurses add fundamental importance since they have the possibility to promote communication in a clear way to identify circumstances threatening the elderly’s autonomy and act informing them in order to make them an active agent in their treatment, as well as mediate and facilitate the team care planning[5,21].

The elderly’s passivity in the relations with doctors can be analyzed from the perspective of the social and cultural representation that medicine exerts in society. Doctor is viewed by the majority of the population as the professional who has knowledge about the body and is fully empowered to make the best decisions for patients. However, it is necessary to consider this relationship, since the sociocultural pressure of the doctor’s role can hinder exchange of information, shared decision-making and exercise of the elderly’s autonomy[22].

Caring for patients at the end of life should be provided from an interdisciplinary perspective. Each professional category should offer its own knowledge and technologies, establish communication with each other and, in this way, exchange information about patients’ clinical condition, so that the best treatment can be offered that meet their expectations. Thus, the importance of interactive actions among caregivers is confirmed. Regarding the nurses’ performance, because they are closer to patients and their families, through clinical reasoning, the Nursing Process and communication as a work tool, they have mechanisms to promote interlock among health team, as well as contribute to patient-centered decision-making process[23].

The nurse when transmitting certain information and promotes the dialogue with medical staff, is validating teamwork as an assurance mechanism to defend the elderly’s autonomy. The dialogue in a team enlarges the possibilities of care, generating new care behaviors and the performance of professionals who, until then, were not included in the care planning, for example, through issuance of opinions. This is the case in the case of experts participation in several areas, such as oncology, geriatrics and palliative care.

Care planning is also qualified when any on-duty staff member has expertise in palliative care, which contributes to the design of goals to promote comfort and quality of life. Thus, given the difficulties and adversities already highlighted to share decisions, communicate bad news and defend principles, such as autonomy, the importance of specific knowledge in palliative care.

In Brazil, the nurse’s role in defense of patients’ rights, with emphasis on autonomy, is not adequately consolidated. However, due to the profession’s characteristics with philosophical and humanistic bases, as well as the professional profile that can be developed in the practice of care, nurses have many opportunities and methodological tools. For example, the Nursing Process, to evaluate patients in an individualized way, identify different responses and needs and safeguard their rights, providing support and information.

However, hospitalization of the elderly, given their even more potent fragilities, can trigger feelings of inability to make their own decisions. In this way, dependence on one’s own care and feelings of insecurity entails the de-personalization of the elderly.
But, nurses’ small attitudes, such as the exercise of listening, can raise the protagonist status of the elderly in their care.

Although not necessarily the nurse can be the representative figure of the defender of the elderly, in certain situations, in compliance with the ethical precepts in the professional exercise, must defend it, thus protecting their autonomy.[24-28]

The elderly’s autonomy defense by the nurse comprises a special and specific professional duty that is part of the moral presuppositions, capable of enhancing social visibility of the profession. But, on the other hand, it can be hampered in the realities where there is risk of functional overload due to the polarization of multiple tasks and the deficit of human resources.

Nurses need specific skills, motivation and professional commitment to defend the elderly’s autonomy. However, in promoting this defense, the nurse may have conflicts with other health professionals. Therefore, it is necessary to maintain an assertive behavior, to have diplomacy and ability to communicate and negotiate, since its actions in favor of the elderly can generate confrontation of opinions, interests and false interpretations.

Based on the professional profile developed in the care practice, it is understood that the defense action is interpersonal in nature and depends on the degree of the relationship established between nurse and patient. However, coping with barriers to this action can trigger a sense of impotence and moral outrage.[24-28] Among barriers, in addition to the clinical condition of the elderly, there is a lack of institutional support, lack of power, lack of training to perform such activity, lack of time due to multiple tasks and the threat of punishment and loss of employment.

The elderly’s autonomy defense by the nurse must also be discussed under the prism of the risk of paternalism, especially when the elderly present changes in the level of consciousness and can no longer express their desires. In this case, it is necessary to disseminate knowledge about the “Living Wills” Health Care Directives as a tool that can be used by the elderly to express their desires about the end of life in situations that can no longer respond for their actions.[26-27]

The defense exercised by the nurse represents an indicator of the quality of nursing services. In taking on this role, nurses regard patients as human endowed with their beliefs. This belief distances them from a merely technical position in the moments that need to elucidate some doubt or even in the approaches of hospital routine.[25,26]

**Study limitations**

It is recognized as a limitation of this study the fact that a single research setting was explored, although it is a large general hospital. Another limiting aspect refers to the sample groups composition, since they did not participate in the study: family members, other health professionals or even the elderly. With this, there is a need for new scientific productions on the theme including new participants.

Although not a limitation, since the method does not provide for the need to return data to participants, it is important to execute other forms of validation of results that can count on the group’s evaluation or part of the group of participants of the research. It seeks representativeness of the investigated reality and possible applicability to other realities.

**Contributions to the fields of Nursing, Health and Public Policy**

To provide greater visibility of the Brazilian nurse’s role in the field of health advocacy and contribute to the quality of the service provided; to defend the elderly’s autonomy, which is key element in palliative care; to encourage discussions to meet international guidelines and public policies regarding the need for palliative care, especially for the elderly with CNCD.

**FINAL CONSIDERATIONS**

The elderly’s autonomy at the end of life refers to their participation in decision-making on issues inherent in their care, in respect of dignity. However, several situations can violate it, such as disease and hospitalization fragility.

As they remain close to patient and their family, nurses can play an important role in defending the elderly’s autonomy by establishing effective communication and guidance on care. Its position in the institutional organization chart and professions characteristics confer privileges to establish actions and interactions within the scope of nursing and health team, elderly and their families, to carry out individualized care based on bioethical and humanistic principles.

Thus, in compliance with the professional code of ethics, nurses can intervene to protect the elderly’s autonomy in situations of vulnerability. In other words, when they unable to express their needs, beliefs and values, such as, for example, the situation of CNCD at an advanced stage and in care at the end of life. Autonomy is a fundamental element for the implementation of palliative care, requiring expanded discussions about this principle and the sharing of decision-making, since they imply in nursing practice.

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