*Article*

Nursing Ethics
2015, Vol. 22(7) 803–814

10.1177/0969733014547970
nej.sagepub.com

# Nurses' autonomy in end-of-life situations in intensive care units

**Maria Cristina Paganini**
Universidade Federal do Paraná, Brazil; University of Tuiuti do Paraná, Brazil

**Regina Szylit Bousso**
University of São Paulo, Brazil

## Abstract

**Background:** The intensive care unit environment focuses on interventions and support therapies that prolong life. The exercise by nurses of their autonomy impacts on perception of the role they assume in the multidisciplinary team and on their function in the intensive care unit context. There is much international research relating to nurses' involvement in end-of-life situations; however, there is a paucity of research in this area in Brazil. In the Brazilian medical scenario, life support limitation generated a certain reluctance of a legal nature, which has now become unjustifiable with the publication of a resolution by the Federal Medical Council. In Brazil, the lack of medical commitments to end-of-life care is evident.

**Objective:** To understand the process by which nurses exercise autonomy in making end-of-life decisions in intensive care units.

**Research design:** Symbolic Interactionism and Corbin and Strauss theory methodology were used for this study.

**Participants and research context:** Data were collected through single audio-recorded qualitative interviews with 14 critical care nurses. The comparative analysis of the data has permitted the understanding of the meaning of nurse's experience in exercising autonomy relating to end-of-life decision-making.

**Ethical considerations:** Institutional ethics approval was obtained for data collection. Participants gave informed consent. All data were anonymized.

**Findings:** The results revealed that nurses experience the need to exercise autonomy in intensive care units on a daily basis. Their experience expressed by the process of increase opportunities to exercise autonomy is conditioned by the pressure of the intensive care unit environment, in which nurses can grow, feel empowered, and exercise their autonomy or else can continuously depend on the decisions made by other professionals.

**Conclusion:** Nurses exercise their autonomy through care. They work to create new spaces at the same time that they acquire new knowledge and make decisions. Because of the complexity of the end-of-life situation, nurses must adopt a proactive attitude that inserts them into the decision-making process.

## Keywords

Decision-making, end-of-life care, grounded theory, intensive care, life support systems, nurse, professional autonomy, qualitative research

**Corresponding author:** Maria Cristina Paganini, Universidade Federal do Paraná, Manoel dos Santos Barreto, 5, 80530-250, Curitiba, Brazil.
Email: pagnine@brturbo.com.br

## Introduction

As patients approach the end of life (EOL), their disease process may create an immediate life-threatening emergency requiring admission to hospital.[1,2] Responses to such emergencies may result in ethical challenges regarding the helpfulness or futility of interventions.[2,3]

The EOL patient usually spends most of last year living at home, although 90% spend some time in hospital, where about 55% of all deaths occur. Half of them spend at least the last 3 days of their lives in intensive care units (ICUs).[4]

Since the 1970s, advances in pharmaceuticals and medical technology have created new options in terms of the treatment of patients with serious conditions, including illnesses that were previously incurable. Advances in support therapy, such as mechanical ventilation, inotropic and vasoactive medications, and dialysis, have permitted the management of various kinds of organ failure.[5–8]

As a result of the Brazilian cultural characteristics, the paternalistic approach has been used as the model for EOL decisions. Besides the cultural perspectives, legal fears, a lack of knowledge, and a lack of training on the ethical aspects of end-of-life care (EOLC), physicians frequently provide full curative treatment to terminally ill patients. As a consequence, patient's and family's participation and nurse's involvement in the Brazilian ICU EOL decision-making process are scarce.[9]

In the Brazilian context, critical care nurses frequently provide care to patients who fail to respond to treatments offered to support and prolong life.

Regarding decision-making, the main difference between countries is the degree of involvement of the patient and/or their families in the decision-making process. The question of who should be responsible for making decisions is difficult to answer.[10]

Indeed decisions in the ICU are provoked by sudden and unexpected events, generally arising from clinical changes in a patient's state of health. Various researchers throughout the world with different perspectives have studied nurse's involvement in EOL process decision-making.[7,8,11–14]

Previous research examining nurses' involvement in EOL decision-making suggests that there needs to be a "shared" understanding of each multiprofessional team members' roles, responsibilities, and aims[15] and that there needs to be more focus on transitions from curative treatment to EOLC.[16]

A study by Fumis and Deheinzelin[8] in 13 ICUs in São Paulo, involving 176 doctors, 204 nurses, and family members of patients with cancer, demonstrates that nurses adopted limited support for critically ill patients. The results show that 75% of nurses approve the attitude of doctors in openly discussing the case with the family of such patients as to the withdrawal of ventilatory support. Nurses recognize that in the Brazilian scenario, patients and families have little or no preparation to take the decision.

Understanding nurses in the process of exercising their autonomy in EOL situations means generating knowledge about a new phase of activity for ICU nurses relating to evidence that can clarify and strengthen the decision process. This challenge, as well as its implications on practice, teaching, and research, is well presented and discussed in professional and ethical debates abroad but not nearly as much in Brazil.

No known previous studies have examined nurses' professional autonomy of Brazilian intensive care nurses in EOL decisions and their practices with terminally ill patients. This study, which discusses decision-making in EOL situations, explores how nurses exercise autonomy in their practices.

## Review of the literature

### *EOLC and nurse autonomy*

In the United States, in 2004, the National Institutes of Health (NIH)[17] State of-the-Science Conference statement defined EOL as the care provided to a person during the final stages of life. In 2005, in England,

the National End of Life Care Programme, EOL was defined as "[ . . . ] a phase of life that ends in death" and "[ . . . ] as the combination of situations that involve clinical deterioration, lack of response to treatment, or the patient's desire to limit their treatment."[18] In this perspective, Izumi et al.[19] defined "EOLC" as "to assist persons who are facing imminent or distant death to have the best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages."

In Brazil, however, EOL or palliative care is not a compulsory component of health professional education, and few Brazilian intensive care residency and fellowship programs have a formal educational training in this area.[20–22] In a Brazilian study conducted by Fumis and Deheinzelin involving incompetent patients for EOL decisions, for example, physicians were less likely to propose withdrawal of patient from mechanical ventilation than nurses.

In this perspective, professional autonomy is an important feature of nurse professionalism.[23] It is particularly important in EOLC where nurses may need to assume the role of advocates for patients when they are at their most vulnerable and for their families.

Dworkin[24] in 1988 have used the concept of autonomy in the sense of defining and giving support to matters that involve principles of justice, the limits of freedom of expression, and the nature of the free state. "Autonomy is a human characteristic, and a desirable quality to have" and the autonomous practice is essential for safe and quality patient care.[25]

Other expressions of professional autonomy include the determination of conduct based on judgment and related to care and action as well as freedom of thought and choice. Research studies have reported that nurses experience a range of difficulties or shortcomings during the decision-making process. Such difficulties can be attributed to lack of legal/ethical education. To overcome these, it becomes necessary to create collaborative relationship between nurses and doctors; to intensify the confidence of nurses compared to physicians; and to strengthen approach and participation of patients and families in the decision-making process.[12,26]

## Method

### Design

The choice of Symbolic Interactionism (SI) as the theory of reference and Corbin and Strauss's Grounded Theory (GT) as the methodological reference point allowed us to recognize the interactions and experiences of ICU nurses in terms of how they make decisions in EOLC and to understand nurses' exercise of autonomy. GT is based on pragmatism and SI. These two theories here—pragmatism and SI—involve concurrent data collection and analysis done simultaneously. This framework allows exploring the interactions between the parties, but always under the perceived social point of view.

In this study, autonomy is an open definition; nurses define it by themselves in the interviews. In this study, the normative approach was used to find out not only how things were but above all how they should be.

The first author (M.C.P.) who did not belong to the ICUs team conducted all interviews of this study, thus ensuring a fairly consistent method of data collection. This researcher had previous experience in qualitative interviewing, professional knowledge of EOLC, and education in professional ethics. The second author (R.S.B.) helped in the analysis process.

### Participants and recruitment

Potential participants were identified after the researcher had the opportunity to present and explain the protocol to a group of 40 ICU nurses and the head nurse. If the nurses expressed interest in the study, the

**Table 1.** Participants' demographic data.

| Participant no. | Nurses caring for patient from | Delegated management | Time in nursing | Years of work in ICU | Nurse background/ education |
|---|---|---|---|---|---|
| 1 | Public health hospital | No | 04 | 03 | Specialist in ICU |
| 2 | Public health hospital | No | 24 | 17 | Specialist in ICU |
| 3 | Public health hospital | No | 08 | 06 | Specialist in ICU |
| 4 | Public health hospital | No | 15 | 13 | Specialist in ICU |
| 5 | Public health hospital | No | 07 | 06 | Specialist in ICU |
| 6 | Public health hospital | No | 03 | 03 | Specialist in ICU |
| 7 | Public health hospital | No | 01 | 01 | Not specialist in ICU |
| 8 | Public health hospital | No | 05 | 05 | Specialist in ICU |
| 9 | Private hospital | No | 06 | 06 | Cardiology |
| 10 | Private hospital | No | 02 | 02 | Not specialist in ICU |
| 11 | Private hospital | No | 02 | 02 | Not specialist in ICU |
| 12 | Private hospital | Yes | 06 | 06 | Not specialist in ICU |
| 13 | Private hospital | Yes | 08 | 07 | Not specialist in ICU |
| 14 | Private hospital | Yes | 05 | 05 | Specialist in ICU |

ICU: intensive care unit. ICU-A ICU-B ICU-C

researcher then contacted the nurse by telephone or in person to set up an appointment to meet with them, explain the study, answer their questions, and obtain their consent to participate.

Theoretical sampling was used to select participants from the three ICU settings in two different hospitals in Brazil. In GT, sampling is based not on a predetermined number of subjects but instead is based upon theoretical concerns such as saturation of data to enable theory development. This study does not intend to analyze, interpret, discuss, or make any conclusion related to the differences of the hospitals (public and private). Differences between sample groups are requested, once differentiated experiences help to understand the phenomenon.

Saturation of data was achieved with 14 participants, 7 nurses from the first institution and 7 nurses from the second (Table 1). This was the point at which no new information emerged from the interviews and data replicated.

## *Interview*

Data were collected between March and August 2010 through face-to-face in-depth semi-structured interviews. As is usual in GT, a guiding question was developed to commence interviews, with additional questions added to the sequence of interviewing as theoretical saturation was sought. The starting question was *Describe a situation in which you have used your autonomy here in the ICU in an EOL situation.*

The interviews lasted 40–60 min and were conducted in a reserved room in or next to the ICU, whichever was more convenient for the nurse. They were tape-recorded and transcribed verbatim, and the process of comparing and analyzing the data began. The data were anonymized and stored in secured files in a locked office. Field notes, both descriptive and reflective, memos of events, thoughts, and ideas were recorded by the interviewer.

## *Analysis*

The process was based on interaction and constant comparison between the empirical data and successive analyses. Analysis of memos combined with line-by-line analysis of interview data, from which key words

and phrases were identified, formed the basis of data analysis. The following sequence of analysis was adopted: open coding, axial coding, and selective coding.[27] While the categories were being formed, new questions were added to clarify ideas that came up, as the following:

- What is the nurses' role in the decision-making process in EOL situations?
- Is there any difference between the nurses' role in the decision-making process in EOL situation when the patient is from the private healthcare sector?

Nurses had varying degrees of years of experience in ICU, ranging from 2 to 24 years, and working time in ICU/high care unit (HCU) ranges from 1 year to 13 years. Nurse's education, gender, and age were also examined. Eight nurses are specialist in ICU area.

### *Ethical consideration*

All study procedures were completed in accordance with the study protocol approved by the hospital's Institutional Review Board, Federal University Paraná—Brazil, number CEP/SD: 20806247/2009-11 e o CAAE: 0382.0.208.000-09.

After receiving approval from the Institutional Review Board, the investigators conferred with hospitals' administration to identify nurses meeting the study criteria. To be eligible for participation, nurses required a minimum of 1 year's experience in the ICU and required experience of caring for patients at the EOL.

## Results

A brief synopsis of the core category of GT which emerged from the research is given here to set the discussion. Nurses experience the need to exercise autonomy in EOL decision-making in ICUs on a daily basis; their experience was expressed by the process of *increase opportunities to exercise autonomy*. The three phenomena are the steps that nurses experience when the process of change in the treatment and care of patients in EOL situations begins. They face causal conditions which allow them to act and decide on their behalf in relation to care, therefore leading to increased opportunities for the exercise of their autonomy. Three phenomena were apparent from the interactions experienced by nurses during this process.

### *Phenomenon 1: ICU nurses work in a high-pressure environment (cause)*

The ICU's context, *a high-pressure environment*, affects not only the work that a nurse performs in the unit, but also other clinical aspects related to the patient, the nurse's interactions with other professionals, and the role played by the family in new treatments.

Nurses see the rules of the ICU as possibilities or controls to help them care for patients. These rules, which are constructed over time, are tied to the interactions and decisions of a multidisciplinary team and are molded in a continuous way by health professionals, patients, and families. An environment with predetermined rules can facilitate or interfere with the decisions that a professional makes: the rules function as charms that help them feel strong enough to act:

> [ . . . ] in a shift, a nurse thinks she has to do [ . . . ] in some way, introduce a care [activity], do the things she understands are necessary but for whatever reason she cannot do it. So, I think that they decide to center everything on the doctor . . . only with authorization. (7.4—recruited from private hospital)

Issues surrounding advanced life support reflect one way in which nurses must understand a new form of care. Intensive care valorizes the benefits of medical behaviors and interventions for patients. Each patient

in the ICU is classified according to the seriousness of his or her condition, and the care team must follow a prognostic classification system to determine the conduct and care that should be adopted:

> Sometimes, they have already tried everything, and he (the patient) is suffering. There are many factors that tell you whether or not the patient is viable. Sometimes, they don't know the situation; it could be a "super" tumor, and they are still treating it. I ask myself how far they (the doctors) are going to go, how long are they going to keep treating (the patient)? (1.7—recruited from public hospital)

Nurses identify the changes to EOLC and recognize that decisions previously defined in a paternalistic and authoritarian manner by the doctors now require not only their positioning but also the desires and decisions of the patients and their families.

Nurses described themselves as evaluating the patient's clinical condition, i.e. seriousness and repercussions of their physiopathological condition, to adjust the care plan and to prepare for the decisions that need to be made:

> [ . . . ] you have to keep your eyes peeled, you need to know what care you need to give. I always examine all the patients, as well, so I can keep track of how they are, get to know them, make my own decisions. (10.12—recruited from private hospital)

When caring for a patient in a critical state, nurses establish a direct and intense relationship with the family. They identity with the suffering, apprehension, and perplexity of a family that has someone in the ICU. Nurses know that families can fall apart because they do not know how to deal with the EOL process or how they should behave. The statement presented below represents one nurse's view:

> We nurses still do not talk about the end-of-life. It seems like we give information about care, but we don't say anything that could lead to questions about the procedures or whether the patient is "dying." (2.8—recruited from public hospital)

### *Phenomenon 2: empower themselves to make decisions (strategies)*

Within the context of *high-pressure environment*, nurses *empower themselves to make decisions*, and it is directed at protecting the power that allows nurses to exercise their autonomy, in view of the changes they face in coping with EOL situations in the ICU. Nurses note the decrease or lack of space to exercise their autonomy in the face of changes in driving situations regarding EOL. Therefore, they should develop strategies that reduce their uncertainties and weaknesses and help them find alternatives. They evaluate the structure and philosophy of the institution and require support for decision-making.

They create strategies that help them to deal with the experience and discover new ways of making decisions. Above all, nurses utilize the instruments they have in their power: their knowledge base and experiences with intensive care.

Care knowledge is part of the structure of patterns and professional values that nurses accumulate; this knowledge helps them to perform their care role and empowers them to make decisions. Being prepared and having knowledge about intensive care give nurses the authority to identify and handle the patients' needs. It also gives them the ability to identify and plan their actions freely. As one of the nurses related:

> What is going to be done . . . the best thing I can do for him, what should be done . . . I think that it's my knowledge [ . . . ], that makes it easier and gives me the certainty . . . my knowledge supports and facilitates how I care for the patient's needs. (2.31—recruited from public hospital)

By enhancing visibility, nurses reinforce their direct participation in care; they put time into working cooperatively and planning their actions in conjunction with the nursing and healthcare teams. They direct their actions to be in line with how work is organized in the ICU, so as to be included and recognized by the team, and they consider the different elements that comprise the work of a multiprofessional team. One nurse stated,

> I think we should get involved in the discussion that leads to our position as a nurse in care. We need to be aware and contribute to what we know about the patient and family. We need to be heard by doctors because we care directly from the patient, he is in our hands. (5.16—recruited from public hospital)

Leading the nursing team concerns how nurses act to coordinate the care provided to the patient and to consolidate power. To lead, nurses motivate and influence other members of the team in an ethical and positive way. Below is a statement by one nurse:

> [ . . . ] I try to show my leadership, I try to demonstrate that I know everything or as much as I can about what is happening. (1.2—recruited from public hospital)

Nurses act and move to protect their power in the face of change. When empowered, they felt it is easier to find spaces to exercise their autonomy. Once nurses feel that they can participate fully in care-related discussions and negotiations, they begin to be more involved in decisions. Nurses act by making comments about practical situations to balance and take back power as related by one of the participants:

> I think we should get involved in the discussion that leads to our position as nurses in care. We need to be aware and contribute to what we know about patients and their families. We need to be heard by doctors because we care directly from the patients. They are in our hands. (9.15—recruited from private hospital)

### *Phenomenon 3: review the spaces where they can exercise autonomy (consequence)*

In the process of *increasing opportunities to exercise autonomy*, nurses move to *review the spaces where they can exercise autonomy*. This stage is expressed as the consequences of a process that is represented by different styles of decision-making on the part of nurses, which may or may not improve opportunities for exercising autonomy. For this reason, nurses review the spaces and reconsider who else can act in the EOL process with respect to planning patient care or interacting with team members and the institution. Autonomy is a competence that manifests itself as a form of power in the role that nurses assume in the ICU.

For nurses, self-government, freedom, and independence to define and plan the care being provided are linked to teamwork. By being more involved in discussions, nurses feel at ease to negotiate how to handle and care for the patients. They are also involved in the decisions, and thus, their opportunities to exercise autonomy expand, redirecting the flow of power.

In the process of finding spaces for autonomy, nurses identify that they can make various decisions with respect to the family's participation in the EOL. When they act in an autonomous way, they define, together with the family, how often they will be with the patient, considering what is most convenient for them and for the patient. Nurses can freely adjust their decisions to the needs of the situation:

> [ . . . ] Thus, for instance, I can define and allow the relatives to have contact with the patient at the end-of-life. [ . . . ], it is the last time the relatives are going to have with him. It is something that we have the freedom to do here [ . . . ] (4.16—recruited from public hospital)

As nurses become empowered to exercise autonomy, they apply their own judgment to give form to the action and to their decisions. By knowing the changes involved, nurses can rapidly take decisions and choose actions, as one of the nurses affirms:

> When I evaluate a patient or if I see that a patent is hypovolemic, or if he has a fever or is hypertensive, or even if he is using drugs, I always go talk to the doctor. I say: "The patient is like this ... with these parameters ..." I always go ask the doctor questions about how the patient is and saying what I think should be done. If there is a discrepancy between what is being planned and what I find, I must discuss it and whenever I evaluate the patient and find a discrepancy, I go there to talk about it, I never leave what I find alone. (5.4—recruited from public hospital)

On the other hand, there are times when nurses find no spaces for the exercise of autonomy. Interference by the medical team can make nurses limit themselves in terms of what they identify as possible:

> [...] well, when you see lots of things being done wrong and you don't have the freedom to even say what is wrong. You don't have the freedom to go see a patient and define the best way to care for him, and you can't do anything ... (1.4—recruited from public hospital)

In these circumstances, nurses come to sense that members of their team do not trust each other. When they are questioned about the decisions they make, nurses begin to feel insecure, and they recognize that this insecurity interferes with their relationship with the nursing team.

Being aware of the difficulty in guaranteeing their position and decisions about care, they do what the doctor tells them to do, despite feeling uncomfortable with it and belittled, as expressed below:

> [...] it is a situation related to my care [...], it isn't his role. So, I am very careful, I understand that caring for patients in such a critical state puts you in a very fragile position, and whoever is here has to remain calm, not exposed, and also has to make a series of necessary decisions, to feel free to choose. It's a very difficult situation and one I have to get around and will talk about [...] (10.37—recruited from private hospital)

Such experiences lead to feelings of frustration and the lack of power to perform or decide what is necessary. Some situations arise when nurses are not very involved in clinical discussions, despite being responsible for planning and giving care. For example, discussions of how a patient will be treated are performed in another space and by doctors:

> [...] the clinical side should be discussed together with the nurse, the characteristics and actions for the end-of-life, for death, but this doesn't happen. In reality, this discussion happens [...] during the rounds in 1% of the cases ... we are only informed. No, in reality, we *carry out* the decision that they have chosen. So, I ask myself in this case: "What is my autonomy in this role?" My autonomy comes second, after everything has already been decided. (3.2—recruited from public hospital)

## Discussion

This study offers a substantive theory about nurses' exercise of autonomy in the EOL processes in the ICU. The theory employed during the research stemmed from experience and from the reality that nurses develop and face in caring for patients in the ICU.

Moments of empowerment and weakening in exercising or not exercising autonomy in decisions over patient EOLC are evident in the results. The contradictions between power and weakness are related either to a large amount of experience in care or to a lack of recognition and a feeling of decisions not being shared.

In coping with changes in treatment and care involved in the EOL process, nurses see themselves as unable to act and perceive that their role must be different.

Their role requires not only a mastery of care but also their participation in the care-giving process: staying with the patient, the family, and the team, and using their knowledge to adjust and define the best way of conducting treatment and care.

In analyzing the trajectory of this study, we have maintained the idea of a process; it is obvious that the actions and interactions involved were the result of changes in responses to contingencies and reflect the consequences of the situations that nurses encounter in exercising their autonomy in caring for patients. Brazilian studies of this process mainly have discussed medical decisions about the need for or withdrawal of life support. Few of these studies have included the experiences of the nurse as a participant and researcher.[10,20,28–32] In these studies, the doctor is the one responsible for making decisions, although they suggest the need for multidisciplinary discussion. Only one of these studies investigated the position and participation of nurses.[8] At an international level, studies involving the participation and spread of nurses' knowledge have become more common and important.[4,33–35]

We did not directly investigate what significance nurses give to the EOL, but we gave them the chance to tell us how they experienced their ''professional autonomy'' during this phase. They reported when they did and did not feel autonomous, by way of the interactions they had with the patient, family, and team during care. Other questions also arise in the process of EOLC, such as the beliefs, concepts, and values applied to prolong the life of a critically ill person, to curtail it, or even to determine the moment of death. These causal elements lead nurses to self-question and to revisit their interactions in terms of discovering new meaning.

Miyashita et al. (2007)[36] conclude that nurses' professional autonomy is an important component of care at EOL. When nurses feel autonomous, they begin to think critically and independently, which facilitates the planning and delivery of nursing care. For the ICU nurses to feel autonomous, they must be able to find a place of action in the multidisciplinary team and must also be integrated into everyday discussion. ICU nurses provide more direct care to critical patients as well as maintain closer contact with the families. Another difference in nurses' exercising of autonomy in ICU is the central role they assume in relation to the remaining team members. In this role, they directly or indirectly participate in decision-making and contribute information/facts so that the right decisions can be defined.

The theoretical model used presents the limits and possibilities that nurses have in exercising their autonomy in the EOL process. For them, exercising autonomy depends on the relationships, truths, counterpositions, and negatives that they experience in caring for the patient. Nurses realize, however, that when the nursing organization is not structured to offer support for their decisions, there is a lack of the needed professional recognition by patients, families, and staff.

Nurses' professional autonomy is an important component in the care at EOL. When nurses feel autonomous, they begin to think critically and independently, which facilitates the planning and delivery of nursing care.

Exercising autonomy empowers them; if they feel unable to do so, they are weakened and feel vulnerable before the patient, their family, and the team. Fears remain in terms of legal questioning and legal actions against health professionals working in the ICU. Decisions become dilemmas because the results of offering adequate measures of care and conduct to EOL patients can be compromising.[32,37] However, Piva et al.[31] oppose this view, demonstrating that the Medical Ethics Code[38] makes it the doctor's duty to avoid therapeutic ''resistance'' and to offer palliative care to patients in the final stage of a serious illness.

The literature review performed shows that one view of care is the way that nurses recover their role and feel valued in the face of the EOL for the patient they are treating.[1,8,33] Critical care nurses and physicians identified similar barriers, supports, and changes needed to improve EOLC in the ICU.

There is evidence for the need to enhance health professionals' education and to reinforce the practice of EOLC.[39]

## Conclusion

Understanding how nurses exercise autonomy in EOL decision-making in the ICU is a challenging goal. This theme, which is inspiring and thought-provoking, has been less explored in the Brazilian context and raises many questions, such as decisions which include choices for introduction or withdrawal of support, among others, which allow the patient to be heard and to choose how the end of his or her life will be handled.

For nurses, power comes from applying personal and institutional resources. While exercising autonomy in making decisions about care in EOL situations, nurses develop the authority to determine new ways to handle care. They referred suffering interference from the medical team which made them step back or limit themselves in terms of performing what they thought possible.

Despite finding new spaces in which to exercise their autonomy, nurses still depend and have to deal with the medical team when taking decisions. Although most ICU doctors and nurses agree with the decisions taken, there is a clear lack of knowledge about how decision-making can be shared and how the actions and conducts of treatment and care can be jointly administered. This rubric raises questions about studies that treat the concepts of death and the value of life. It involves the issue of how to transform such complex and difficult decisions into moments that reinforce and sustain professionals working in the ICU. We recommend that new empirical studies about different aspects of the EOL be performed, and we especially encourage quantitative research to understand data on decision-making processes at EOL to support the reformulation of competences and skills expected to care for dying patients and their families.

In conclusion, nurses exercise their autonomy through care. They work to create new spaces at the same time that they acquire new knowledge and make decisions. Because of the complexity of the EOL situation, nurses must adopt a proactive attitude that inserts them into the decision-making process.

## Study limitations

Death and decision-making at the EOL are usually complex, and in Brazil, the challenge of conducting studies into these areas is made even more difficult because of the lack of objective data in the medical records. In addition, it is possible that the nurses would have been reluctant to openly express any criticism of medical decisions for fear of possible repercussions. Another limitation is that the study was carried out in just three ICUs in the south region of Brazil. However, the data obtained were consistent and did collect data on nurses' participation in the process by which nurses exercise autonomy in making EOL decisions in ICUs.

### Conflict of interest

The authors declare that there is no conflict of interest.

### Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### References

1. Emanuele L, Ferris FD, Von Gunten CF, et al. The last hours of living: practical advice for clinicians, http://www.medscape.org/viewprogram/5808 (2010, accessed 12 December 2012).

2. Forero R, McDonnell G, Gallego B, et al. A literature review on care at the end-of-life in the emergency department. *Emerg Med Int*, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3303563/ (2012, accessed 21 December 2012).
3. Damghi N, Belayachi J, Aggoug B, et al. Withholding and withdrawing life-sustaining therapy in a Moroccan Emergency Department: an observational study. *BMC Emerg Med*, http://www.biomedcentral.com/content/pdf/1471-227X-11-12.pdf (2011, accessed 12 August 2012).
4. Bach V. Nursing roles in end-of-life decision making in critical care settings. *West J Nurs Res* 2009; 31(4): 496–512.
5. Maza VTS, Lasaosa FJC, Rico AP, et al. End of life decision-making in critical care. *An Esp Pediatr* 2002; 57(6): 511–517.
6. Zawistowski CA and De Vita MA. A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life-sustaining treatment. *Pediatr Crit Care Med* 2004; 5(3): 216–223.
7. Luce JM. End-of-life decision making in the intensive care unit. *Am J Respir Crit Care Med* 2010; 182: 6–11.
8. Fumis RR and Deheinzelin D. Respiratory support withdrawal in intensive care units: families, physicians and nurses views on two hypothetical clinical scenarios. *Crit Care* 2010; 14(6): R235.
9. Piva JP and Soares M. End-of-life care in Brazilian ICUs is not just a legal issue: adequate training and knowledge are essential to improve care. *Rev Bras Ter Intensiva* 2011; 23(4): 388–390, http://www.scielo.br/pdf/rbti/v23n4/en_a02v23n4.pdf (accessed 4 November 2011).
10. Lago PM, Nilson C, Piva JP, et al. Nurses' participation in the end-of-life process in two paediatric intensive care units in Brazil. *Int J Palliat Nurs* 2011; 17(6): 264–270.
11. Westphal DM and McKee SA. End-of-life decision making in the intensive care unit: physician and nurse perspectives. *Am J Med Qual* 2009; 24(3): 222–228.
12. Gazarian PK, Henneman EA and Chandler GE. Nurse decision making in the prearrest period. *Clin Nurs Res* 2010; 19(1): 21–37.
13. Lind R, Lorem GF, Nortvedt P, et al. Intensive care nurses' involvement in end-of-life process—perspectives of relatives. *Nurs Ethics* 2012; 19(5): 666–676.
14. Tamayo-Velazquez MI, Simón-Lorda OS and Cruz-Piqueras M. Euthanasia and physician-assisted suicide: knowledge, attitudes and experiences of nurses in Andalusia (Spain). *Nurs Ethics* 2012; 19(5): 677–691.
15. Long-Sutehall T, Willis H, Palmer R, et al. Negotiating dying: a grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. *Int J Nurs Stud* 2011; 48: 1466–1474.
16. Coombs M, Long-Sutehall T and Shannon S. International dialogue on end-of-life: challenges in the UK and USA. *Nurs Crit Care* 2010; 15(5): 234–240.
17. National End of Life Care Programme—NSW Department of Health. *Guidelines for end of life care and decision-making*. London, http://www.cena.org.au/nsw/end_of_life_guidelines.pdf (2005, accessed 16 March 2011).
18. NIH State-of-the-Science Conference Statement on improving end-of-life care. *NIH Consens State Sci Statements* 2004; 21(3): 1–28.
19. Izumi S, Nagae H, Sakurai C, et al. Defining end-of-life care from perspectives of nursing ethics. *Nurs Ethics* 2012; 19(5): 608–618.
20. Lago PM, Piva JP, Kipper D, et al. Life support limitation at three pediatric intensive care units in southern Brazil. *J Pediatr* 2005; 81(2): 111–117.
21. Moritz R, Lago PM, Souza RP, et al. End-of-life and palliative care in intensive care units. *Rev Bras Ter Intensiva* 2008; 20(4): 422–428.
22. Kipper D, Piva J, Garcia PC, et al. Evolution of the medical practices and modes of death on pediatric intensive care in southern Brazil. *Pediatr Crit Care Med* 2005; 6(3): 258–263.
23. Ohnsorg K and Leller HRG, Widdershoven GAM, et al. "Ambivalence" at the end of life: how to understand patients' wishes ethically. *Nurs Ethics* 2012; 19(5): 629–641.

24. Dworkin G. *The theory and practice of autonomy*. Cambridge: Cambridge University Press, 1988, p. 188.
25. Kramer M and Schmalenberg C. The practice of clinical autonomy in hospitals: 20,000 nurses tell their story. *Crit Care Nurse* 2008; 28(6): 58–71, http://ccn.aacnjournals.org/content/28/6/58.full.pdf+html (accessed 5 August 2012).
26. Silén M, Svantesson M and Ahlström G. Nurse's conceptions of decision making concerning life-sustaining treatment. *Nurs Ethics* 2008; 15(2): 160–173.
27. Corbin J and Strauss AL. *Basics of qualitative research: grounded theory procedures and techniques*. 3rd ed. London: Sage, 2008, p. 379.
28. Moritz RD and Nassar SM. The attitude of health professionals concerning death. *Rev Bras Ter Intensiva* 2004; 16(1): 14–21.
29. Moritz RD. Health professional facing death and dying. *Bioetica* 2005; 13(2): 51–63.
30. Coombs M, Addington-Hall J and Long-Sutehall T. Challenges in transitions: from intervention to end-of-life care in intensive care: a qualitative study. *Int J Nurs Stud* 2011; 49: 519–527.
31. Piva JP, Garcia PCR and Lago PM. Dilemmas and difficulties involving end of life decisions and palliative care in children. *Rev Bras Ter Intensiva* 2011; 23(1): 78–86, http://www.scielo.br/scielo.php?script=sci_arttext&;pid=S0103-507X2011000100013 (accessed 5 August 2011).
32. Soares M. End-of-life in Brazil: the long and winding road. *Crit Care* 2011; 15: 110, http://ccforum.com/content/pdf/cc9962.pdf (accessed 3 June 2011).
33. Hopkinson JB, Hallet CE and Luker KA. Everyday death: how do nurses cope with caring for dying people in hospital? *Int J Nurs Stud* 2005; 42(2): 125–133.
34. Inghelbrecht E, Bilsen J, Mortier F, et al. Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, *Belgium*. *Palliat Med* 2009; 23(7): 649–658.
35. Peterson J, Johnson MA, Halvorsen B, et al. What is it so stressful about caring for a dying patient? A qualitative study of nurses' experiences. *Int J Palliat Nurs* 2010; 16(4): 181–187.
36. Miyashita M, Nakai Y, Sasahara T, et al. Nursing autonomy plays an important role in nurses' attitudes toward caring for dying patients. *Am J Hosp Palliat Care* 2007; 24(3): 202–210.
37. Ferrand E, Lemaire F, Regnier B, et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. *Am J Respir Crit Care Med* 2003; 167(10): 1310–1315.
38. Brazilian Federal Medical Council. Resolution CFM No. 1931/2009, http://www.portalmedico.org.br/novocodigo/integra.asp
39. Festic E, Grewal R, Rabatin JT, et al. End of life care in the intensive care unit: the perceived barriers, supports, and changes needed. *Acta Med Acad* 2010; 39: 150–158.