*Original Article*

# Difficulties Perceived by ICU Nurses Providing End-of-Life Care: A Qualitative Study

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## Abstract

**Background:** With advances in medicine and technology, intensive care units (ICUs) have the capacity to treat patients who would have previously not been expected to survive and would therefore not have been managed in ICUs. When an individual is not expected to survive, doctors and nurses face the modern ethical dilemma of death associated with withdrawal of life-supporting strategies. The aim of this study was to identify difficulties perceived by ICU nurses providing end-of-life care (EOLC) in Poland.

**Methods:** The qualitative study was designed to investigate the difficulties, and the related barriers, to EOLC provided in ICUs in Poland. We conducted individual telephone interviews with ICU nurses from across Poland.

**Results:** The main issues raised during the interviews included (1) barriers attributable to the hospital, (2) barriers related to the patient's family, and (3) barriers related to the ICU personnel providing direct EOLC. The interviewed nurses considered the lack of support from managers to be the main barrier. We found that ICU nurses in Poland dealt with end-of-life aspects that were emotionally and psychologically taxing. In addition, they lacked specialized training in this area, especially with regard to family care and care provision.

**Conclusions:** A pressing need exists to improve facilities and make equipment ensuring a desirable standard of care more available. Specialized palliative care training programs should be incorporated into compulsory nursing curricula for ICU nurses.

## Keywords

critical care, end-of-life care, intensive care, nursing

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## Background

The main task of intensive care units (ICUs) is to stabilize patients who are in serious conditions. Technology plays a significant role in this process. However, despite scientific and technological advancements in this area, ICU death rates continue to be high. For instance, the mortality rate in Colombia is 32%; in Mexico, 25%; in the United Kingdom, it ranges from 15% to 36%; in Europe, from 6% to 27%; and in the United States, from 10% to 29%.[1–3] According to Baker et al., a change in the profile of a patient in serious condition is one of the underlying factors.[4] This makes it necessary to apply mortality analysis to both patient treatment and end-of-life care (EOLC), representing a challenge for professionals tasked with ensuring a good death in critical care.[1,5] Both end-of-life patients and their families are in need of appropriate care and support. At ICU, it is the nursing personnel's responsibility to provide such care.[1,6,7] International literature on EOLC in ICUs supports the use of "protocol bundles."[8] Extensive research exists to suggest that the approach

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to end-of-life patients should change toward a greater focus on the patients and their families.[6] The provision of EOLC comprises a significant component of work for critical care nurses, and EOLC has been identified as a research priority area in an international Delphi study.[9] Despite the frequency with which critical care nurses provide EOLC, evidence indicates that nurses are not adequately prepared to provide this care to patients and their families.[10]

Polish norms and procedures as well as laws applicable to ICU operation do not specify the options which should be available to EOLC nurses with regard to facilities, personnel, and standards. Article 22 of the Healthcare Provision Act of November 9, 2018, stipulates that the rooms and facilities of a health-care provider should meet the requirements applicable to the type and scope of health-care services provided.[11] The Act does not envisage private rooms (and waiting rooms for families) intended to provide end-of-life patients with a desirable setting to ensure their peace, intimacy, and dignity. Under Article 20.2 of the Act on the Patients' Rights and Commissioner of Patients' Rights, dated November 6, 2008, patients have the right to intimacy and dignity and to die in a peaceful setting.[12] The Regulation of the Minister of Health of December 12, 2018, on the organizational health-care standards in anaesthesiology and intensive care, one of the essential legislative instruments governing ICU operation in Poland, does not specify in what way EOLC should be provided to ICU patients.[13]

Futile medical-care guidelines relating to ICU patients, who are unable to make informed declarations of will, also fail to define the EOLC procedures to be followed by the nursing personnel. Once the decision is made to withdraw from sustaining bodily functions, both the therapeutic team and the nurses should proceed according to a specific protocol, which may be modified where reasonable, in order to provide end-of-life patients with desirable care while recognizing the needs of their families.[14] These guidelines emphasize that care should be provided in adherence to the principles of palliative care to relieve patients' suffering and provide them with the greatest comfort possible by prioritizing care.

Hence, ICUs should have rooms enabling patient and family care to be provided in a dignified setting. ICU employees often fail to recognize the needs of the families to ICU patients, who are often tired, and even physically and mentally exhausted.[15] Increasing frustration and upset leads to conflicts with, and stress among, the personnel, and their resulting reluctance to contact with patients' families. ICU personnel is responsible for maintaining regular contact with the patient's family, especially if he or she is dying. The relatives may be reluctant to talk about their emotions, feel lost, or afraid to bother the personnel taking care of the end-of-life patient. The nurses themselves tend to avoid talking to patients' relatives since they believe that information on the patient's condition should be given by the physician. Grief and dejection caused by the realization that all therapeutic options have been exhausted also hinders communication. However, even if there are no updates on the patient's condition, families look forward to communicating with, and receiving feedback from, the personnel.[15]

In view of the issues referred to above, we conducted a qualitative study to gain insight into specific experiences of nurses related to the provision of EOLC at ICU. Hence, we aimed to identify difficulties to EOLC provided in Polish ICUs, as they are perceived by nurses. This is the first study of this type in Poland, and we believe its findings will provide practical information to be used in further research and possibly to be applied in measures designed to remove the existing barriers to EOLC.

## Methods

### Design

To understand barriers to EOLC in ICUs, we applied a qualitative method of interview. This technique provides insight into social phenomena and their meanings, as well as the related experiences and opinions represented by the inteviewees,[16] in this case ICU nurses.

### Participants

The participants of the study included nurses from various ICUs from across Poland. The inclusion criteria were registered nurses (RN) with at least 2-year experience working at an ICU and a prior consent to participate. A total of 31 individuals participated, including 28 women and 3 men. We explained the interview methodology to the participants who gave their informed consents. Participation in the study was voluntary. We wanted the nurses to remain fully anonymous in their opinions related to the difficulties experienced when performing their daily EOLC duties. Their privacy and confidentiality of the information they provided were protected through a specially designed numbering system to identify each interview without using specific names. The interviews were conducted between February and June 2019.

### Procedure

To collect the data, we conducted partially structured telephone interviews with the nurses, starting with the main question: *Do you meet the respective inclusion criteria?; What barriers are you experiencing in your daily EOLC duties at your ICU?* The conversation time ranged

from 5 to 15 minutes. Each conversation was transcribed, and the respondents were assigned individual numbers. The interviewers knew who they were talking to, in order to avoid false respondents. They were provided with the following information: the Region (Figure 1) in which the nurse worked, age, gender, years of overall professional and ICU experience, and had to confirm that the invitation was sent via www.ptpaio.pl. The platform www.ptpaio.pl is an official website of the Polish Anesthesiology and Critical Care Nursing Association. Information about our research project was posted on the platform, along with an invitation for nurses to participate. Generally, the nurses were willing to engage in the conversation, enabling us to perform an accurate and reliable analysis.[17]

## Data Analysis

Each telephone interview was literally transcribed immediately after the conversation without omitting anything that the participant had said. The transcription was then saved on an electronic data carrier. Subsequently, we compiled the data and read the interviews line by line. First, we made a preliminary interpretation to identify the general aspects of the subject. Then, these aspects were encoded, analyzed and converted into data, and assigned with the interview and page number to help us locate the interview. These data were then processed within the conceptual framework underlying the phenomena described by the participants. The interpretation of these phenomena reflects the participant's views and the depth assigned to each result to give an accurate representation of the reality and to respect the feelings expressed by the participants. To make sure that the interview was valid and reliable, we had conducted a preliminary interview to assess the interviewers' communication and interaction abilities and to evaluate validity and clarity of the questions. Furthermore, we had our findings looked through by experts and each participant, helping us to estimate the extent to which our procedures were aligned with the realities of the interviewee and thereby to establish whether the interview could be replicated in the future.[17] Reporting of the study findings adheres to the SRQR checklist; see Supplemental Material.

## Ethical Considerations

The university's ethics committees approved this study (approval number: UR/KB/2018). All participants gave their written consent.


**Figure 1.** Administrative Regions of Poland (https://stat.gov.pl/statystyka-regionalna/jednostki-terytorialne/podzial-administracyjny-polski/).

**Table 1.** Sociodemographic Data of the Interviewed Nursing Staff.

| No. | Gender | Age | Nursing Experience | Years of Experience Working in the ICU |
|---|---|---|---|---|
| E1 | K | 44 | 24 | 24 |
| E2 | K | 55 | 35 | 27 |
| E3 | K | 59 | 39 | 15 |
| E4 | M | 25 | 3 | 3 |
| E5 | K | 43 | 19 | 10 |
| E6 | K | 51 | 30 | 16 |
| E7 | K | 59 | 39 | 21 |
| E8 | K | 45 | 20 | 18 |
| E9 | K | 38 | 14 | 12 |
| E10 | K | 27 | 2 | 2 |
| E11 | K | 26 | 2 | 2 |
| E12 | K | 25 | 2 | 2 |
| E13 | K | 25 | 3 | 3 |
| E14 | K | 26 | 2 | 2 |
| E15 | K | 37 | 10 | 6 |
| E16 | K | 27 | 4 | 2 |
| E17 | K | 45 | 20 | 15 |
| E18 | M | 27 | 5 | 5 |
| E19 | K | 24 | 2 | 2 |
| E20 | K | 27 | 3 | 2 |
| E21 | K | 27 | 3 | 2 |
| E22 | K | 33 | 10 | 7 |
| E23 | K | 45 | 24 | 22 |
| E24 | K | 48 | 25 | 25 |
| E25 | K | 28 | 4 | 2 |
| E26 | M | 31 | 9 | 9 |
| E27 | K | 55 | 36 | 32 |
| E28 | K | 32 | 8 | 8 |
| E29 | K | 40 | 15 | 15 |
| E30 | K | 50 | 30 | 20 |
| E31 | K | 55 | 34 | 32 |

## Findings

The mean age of the participants was 38.03 years, within the range of 24 to 59 years. Their professional nursing experience on average amounted to 15.35 years, ranging from 2 to 39 years. ICU experience averaged 11.70 years and ranged from 2 to 32 years. The characteristics of the participants are provided in Table 1.

### *Barriers to Providing EOLC in the ICU Setting*

Based on the content analysis, we grouped potential barriers into 3 categories. The first related to the hospital as the entity responsible for providing care to patients. Another category was related to patients' families, which, although indicated as a barrier relatively rarely, involved a number of relevant issues. The key group of barriers as perceived by the ICU nurses was related to the personnel, that is, the interdisciplinary ICU team that provides patients and their families with holistic care.

### *The Main Hospital-Related Barriers*

Below is a grouped list of structural hospital-related barriers identified by the interviewed nurses.

> Lack of end-of-life procedures in place at the hospital [E1]. Noncompliance with the ICU employment standards [E2, E8, E9, E17, E13, E14, E16, E17, E18, E19, E20, E23, E24], multiple-patient rooms (lack of intimacy), disturbances at the ICU such as noise, bright light [E2].

> Lack of hospital rooms prepared for end-of-life care [E7, E13, E14, E16, E17, E23, E24]. Hospital does not provide training in end-of-life care and psychological counseling [E20, E21]. Hospital does not provide private patient rooms or waiting rooms for families to wait for updates on the condition of their hospitalized relatives [E20]. A patient dies in close proximity of another patient's bed, there is no personnel to take care of the family, there are no hospital procedures, the hospital does not provide any training, generally the nurses have to cope with heavy stress and a lack of support from ICU managers [E25]. Lack of preparation to provide end-of-life care, lack of equipment to make sure families can take care of their hospitalized relatives in comfortable conditions [E23]

### *Barriers Related to Patients' Families*

We analyzed each interview and grouped the findings. Below is a detailed analysis of each barrier found in relation to patients' families.

> Lack of privacy for families and patients [E8] and frequent conflicts between families and the ICU personnel [E8]. Patients may not be given an opportunity to decide about their lives, the personnel receives no training in professional end-of-life care [E9]. Lack of psychological counseling services for families and patients [E11, E16, E26, E27]. We often have to ask the family of a dying patient to leave the room so we can move another patient in [E24].

### *Personnel-Related Barriers as Perceived by the Nurses*

We analyzed each interview and grouped the findings. Below is a detailed analysis of each barrier found in relation to personnel-related barriers to EOLC.

> Everyday practice is tough, no procedures, no personalised care plans for end-of-life patients. So many conferences on the issue and still nothing … TISS scores for cost reimbursement … I have a sad feeling that you don't let these people die humanely [E3].

> The biggest problem right now is that there are no procedures in place to make any decisions on end-of-life care [E4]. Heavy pressure from patients' families, lack of psychological support for the personnel [E5, E6, E27, E31] and personnel shortages are the main barrier [E5]. The stress experienced by nurses is also an important issue [E5, E13, E15, E31]. I have seen many cases of desensitization, burnout, and PTSD among the personnel [E9, E31]. We need training courses and workshops preparing nurses to provide professional end-of-life care [E2, E4, E10, E12, E13, E14]. Lack of communication between doctors and nurses [E15, E18, E31]. At my ICU there is no cooperation within the therapeutic team [E21], ... training in communication is needed ... [E21, E23,E24]. For many years we have not had enough nurses, 1 nurse has to take care of a dying patient while attending to 2 others, ... nurses are unable to pay enough attention to families (eg, to answer their questions, create an appropriate atmosphere). Patients staying in the same room, one of them dying, and another one being moved in. [E22]. Things are wrong with the employment standards, 1:3—you can't work like that [E24].

## Discussion

Our findings show that the barriers/difficulties perceived by the nursing personnel at ICUs are related to the hospital infrastructure, management, and environment, as well as patients' families, and they involve a lack of both psychological support and patient-friendly infrastructure. The barriers listed by the participants in relation to the ICU personnel focused on noncompliance with the employment standards, the lack of communication between nurses, doctors and families, professional burnout, fatigue, stress, and the lack of EOLC procedures and plans.

High-quality health care is one in which the medical, human, infrastructural, and financial resources are organized in the most efficient way possible to satisfy the needs of the public related to prevention, health promotion, diagnostics, treatment and rehabilitation, and to make sure that such care is as safe, effective, and efficient as required by the relevant standards. The hospital infrastructure is an extremely important factor in ensuring the desirable quality of health-care services; in fact, it is one of the objective indicators of health-care quality. Ranse et al. also found that the nursing personnel complained about structural and architectural barriers associated with infrastructural deficiencies and the lack of space and intimacy, making it difficult to implement the right procedures. The physical and organizational structure of ICUs has an adverse impact on EOLC.[18] Cramped spaces, inappropriate arrangement of patients' rooms, high bed occupancy rates, and shortage of funds to ensure comfortable and intimate conditions are among the major factors directly affecting EOLC patients and their families.[4,18–20]

This study provides evidence that critical care nursing support for patient and family-centered care during the provision of EOLC can influence their engagement in practices that promote control and inclusion of families.[10] Approximately 40% of families of adult end-of-life patients did not receive any spiritual and emotional support. Emotional/spiritual support was not offered to families (39.1%) and to the ICU personnel (0%).[8] As far as care provided to patients' families at ICUs is concerned, nurses recognized the need for satisfying the basic needs such as company, intimacy, education, and psychological and social support for families while also claiming that this is not enough.[1,6,8,21] There is extensive literature on issues related to this subject, but even though family's needs are recognized, its importance is not explicitly emphasized, and family-centered care involves primarily informing relatives about the treatment, procedures, and prognosis.[1,6,8,21] Contrary to expectations, studies have shown that some families consider communication from nurses to be vague and evasive, as they pay most of their attention to patients.[22] This might be attributable to the lack of training, guidelines, and/or procedures related to EOLC patients, as well as to the emotional burden nurses have to cope with on a daily basis.[20,22] Families might be a source of information on the quality of EOLC provided at ICUs. Their perception of communication, decision-making, nursing care, the ICU environment, and spiritual support has a strong impact on whether or not they are satisfied with EOLC at ICUs. Personalized and regular communication, support in decision-making, compassionate nursing care, a warm and family-friendly environment and spiritual support could be useful in helping families cope with their loss and increase their satisfaction with EOLC at ICUs.

Our study has shown that EOLC provided by nurses entails academically and culturally determined difficulties stemming from the treatment orientation of ICUs and the lack of training in EOLC. According to some studies, nurse training at ICUs focuses on patients' treatment and survival and does not include terminal patients and their families.[20,23] However, as shown by a number of studies, EOLC training is crucial for the development of relevant communication skills.[24] There are no training courses in care provided to patients' families in the end-of-life phase and in the ability to communicate with the families to know how they feel about the care provided by nurses. Researchers report that this may be due to the fact that the specificity of the nurses' role in EOLC is not clearly understood, and the related evidence is scarce,[6,7,25] ranging from specific to standardized strategies, and the ability to effectively cope with stress.[6,7,25]

Care is understood as a continuous and dynamic process, and death is a part of it.[20,26] It was found that nurses providing care to end-of-life patients and their families are likely to experience emotional and psychological distress, and this finding was consistent with other studies.[1,25] Existing research emphasizes that positive communication and cooperation, as well as impeccable manners, are necessary to provide a safe and high-quality EOLC. Discussions with patients and their families can be helpful in preparing them for the transition from active treatment to EOLC. Another important recommendation involves training and encouraging EOLC leaders from nursing and medical communities, as well as patient support coordinators, to communicate with each other and with patients' families on EOLC plans.[27]

Nurses who had actively acquired knowledge through education and access to literature showed stronger commitment to providing emotional support in interpersonal relations and making patient- and family-focused decisions.[10] Providing EOLC remains an important part of the clinicians' work in critical care facilities. According to critical care nurses, insufficient attention is devoted to education and training in this area of clinical practice.

Hence, education providers offering postgraduate programs in nursing care should be encouraged to place more emphasis on this aspect. Studies by Ranse et al. showed that EOLC contents were explicitly included in Australian postgraduate programs in nursing, although the actual contents clearly did not overlap with these programs. Most programs concerned organ donation (92%) and legal and ethical issues (77%). Conversely, the least popular contents included in postgraduate programs for nurses were related to the provision of direct clinical care to end-of-life patients and their families, including the physical changes experienced by dying patients (31%), withdrawal of ventilatory support and management of symptoms (23%), emotional support to families (23%), body care after death (23%), and withdrawal of life-support treatment (15%). EOLC contents constitute an important part of ICU care and should be included in postgraduate critical nursing programs. In the case of the Polish system of postgraduate education, these contents should form a module in a specialty program in anaesthesiology and intensive care nursing. ICU nurses postulate that more time should be devoted to EOLC. The author claims that urgent measures should be taken to fill the gaps in EOLC contents in formal education, including with regard to clinical EOLC. The study provides preliminary evidence that Australian critical nursing care programs vary in terms of EOLC contents. To solve the problems associated with the complexity of this phase in care, which largely takes place in ICUs, gaps in formal education contents should urgently be filled with emphasis to EOLC.[28]

In summary, we would like to highlight some very interesting results published in 2019 by Dobrowolska et al. from a survey involving Polish university students and investigating (a) the primary difficulties participants expected to encounter while working with dying patients, (b) their interest in developing competencies in caring for dying patients, and (c) their interest in working in palliative/hospice settings or with dying patients in the future. The surveyed students also anticipated that they would have difficulties while providing care to dying patients, related to psychosocial aspects of EOLC, communication with dying patients, cooperation and interaction with patients' families, and coping with the emotions experienced when seeing a dying person.[29]

We believe that more attention should be paid to these issues at the undergraduate and, even more so, at the graduate level. The Polish education system should be given clear guidelines for developing and improving the education standards for the professions of physician, nurse, midwife, and paramedic, amended in 2019. Dobrowolska et al. rightly argues that greater emphasis should be placed on self-reflection and teaching of stress-coping strategies, and that graduate programs in nursing and medical education should be redesigned to shift their focus from treatment more toward care. She is also correct in her observation that this is not only a matter of teaching materials but also of teaching strategies and methods. Cross-field education should be promoted, in particular addressing the psychosocial aspects of EOLC.[29]

Our findings can have the following implications for clinical practice: (a) filling in gaps in the curricula of postgraduate programs for ICU nurses, (b) revised mission and objectives of ICUs, (c) organizational changes to facilitate the arrangement of ICU beds to EOLC patients, (d) increased support for and psychological monitoring of EOLC nurses, and (e) availability of guidelines on how to handle communication with families and how to consult within interdisciplinary ICU teams.

## Limitation

This study has certain limitations. First, its findings are limited to the context of nursing care, without taking into consideration the perspectives of other professionals (physicians, physical therapists, dieticians, people offering spiritual support, and psychologists). More comprehensive research should be undertaken among larger focus groups comprising nurses from across Poland offering the participants' time for more comprehensive responses.

## Conclusions

Barriers to EOLC with regard to families concern lack of private patient rooms or waiting rooms where families could spend the time required by nurses to complete their nursing and care routines or to move in other ICU patients. Asking patients' relatives to leave the room when other patients are being attended to, or new patients are being moved ingenerates additional stress, and tensions between both the personnel and the families. Allowing the family to stay in the room separated by privacy curtains not only fails to provide intimacy but also exposes families to stressful situations, especially when the dying patient is a child. Some nurses tend to remain detached from patients and their relatives in EOLC. The interviewed nurses provided family care based on their personal experience and experienced lack of theoretical training to make their care more consistent. Both families and patients as well as ICU personnel appear to require assistance from in-house counselors. Postgraduate RN education should be expanded to include EOLC contents. Nurses need to be provided with well-designed, uniform national guidelines and protocols based on Evidence-based Nursing Practice (EBNP). Future studies should take into account the perspectives of other professionals involved in EOLC at ICUs.

### Authors' Contributions

DO and KW conceived and designed the study. DO and KW developed the study protocol. DO designed and tested the study instruments. DO and PJG supervised data collection. KW and PJG analyzed the data. DO and KW prepared and approved the manuscript.

### Declaration of Conflicting Interests

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### Supplemental Material

Supplemental material for this article is available online.

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