

ORIGINAL PAPER

Intensive care nurses' experiences with brain-dead patients – a phenomenological qualitative study

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Abstract

Aim: This study explores nurses' experiences of caring for (potentially) brain-dead patients. **Design:** A qualitative interpretative phenomenological design was chosen to describe the phenomenon in all its complexity and dimensions. **Methods:** In 2016, twelve episodic interviews were conducted with intensive care nurses from six wards. The interviews related to their experiences of caring for (potentially) brain-dead patients and were analyzed according to Benner's Interpretative Phenomenology. **Results:** Three key phenomena were generated: 1) The brain is dead; the body is alive; 2) Coping within high performance medicine and 3) Power(-lessness). The participants' experience was that caring for a (potentially) brain-dead patient and explaining brain death to the patient's relatives is very demanding. In the intensive care unit, nurses are required to diligently provide exemplary methodical and routine care, most of the time without an outlet to relieve their own work-related burdens. In some situations, the interviewees felt powerless. **Conclusion:** The data collected have provided a deeper insight into the situation intensive care nurses face when caring for (potentially) brain-dead patients. Nevertheless, the authors recommend further research on all phenomena, and also the design of appropriate training and support for nurses.

Keywords: brain-dead, experiences, intensive care nurse, phenomenology, qualitative.

Introduction

Patients are diagnosed with brain death in intensive care units (ICUs) all over the world (Flodén & Forsberg, 2009; Flodén et al., 2011; Guido et al., 2009; Lemes & Bastos, 2007). First the intensive care staff attempts to save life; when suspicion arises that the patient might be brain dead, this leads to an examination and possible diagnosis of brain-death. All intensive care nurses may, thus, spend time caring for patients with a diagnosis of "potential brain death". A diagnosis of "(potential) brain death", implies a change in focus from saving life to preserving organs, and ultimately, to organ donation.

International studies on nurses' experiences of organ donation (Flodén & Forsberg, 2009; Flodén et al., 2011; Guido et al., 2009; Lemes & Bastos, 2007;

Monforte-Royo & Roqué, 2012; Pearson et al., 2001) describe how nurses acknowledge the difference between brain death and death, feel responsible for the vital signs of the patients diagnosed as brain-dead, and want to advocate for their patients' wills (Flodén et al., 2011). The studies further identify that communication between the nurses and patients' families is complex and often difficult, and that the potential of organ donation is perceived as a burden to the families (Flodén et al., 2011; Guido et al., 2009). One study emphasized the balancing act between professional responsibilities and patients' rights, as nurses strive to keep organs alive, but nevertheless feel a sense of guilt toward the brain-dead patients. The study also highlighted the interconnected tasks that need to be addressed in a short period of time should organ donation be approved (Moghaddam et al., 2018).

There seems to be a cultural aspect to the situation, with nurses from different countries having different

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opinions on how to care for patients with brain death (Forsberg et al., 2014; Salehi et al., 2013; Yousefi et al., 2014), e.g., Iranian nurses describe caring for brain-dead donor patients as an “excruciating tasks” (Salehi et al., 2013), whereas Brazilian nurses feel well prepared to care for these patients (Guido et al., 2009), and in Sweden nurses emphasize extensive efforts to preserve and safeguard the dignity of a brain-dead patient (Forsberg et al., 2014). Therefore, an investigation into experiences of (potentially) brain-dead patients might pertain only to the particular cultural region analyzed.

Furthermore, there is a lack of standards or guidance on how tasks and workflows can be structured and organized until the brain-death diagnosis is confirmed (Moghaddam et al., 2018).

Most studies focus on organ donation and not on nursing care before or during diagnosis of a patient with brain death. It is unclear how intensive care nurses experience and care for the (potentially) brain-dead patients. There is also a lack of understanding on the process of changing the therapy goal from saving the patient’s life to organ preservation and, finally, to decisions regarding organ donation. To our knowledge, there has been no investigation into the lived experience of intensive care nurses caring for (potentially) brain-dead patients in Germany.

The German Medical Association provides physicians with procedural rules for determining final, irreversible loss of all functions of the cerebrum, cerebellum, and brainstem (Bundesärztekammer, 2015). As far as we are aware, there is no such guidance for nurses caring for (potentially) brain-dead patients.

In a survey, 82% of the German nurse participants stated that they sometimes (52%) or always (30%) had burdensome experiences when caring for a brain-dead patient (Bundeszentrale für gesundheitliche Aufklärung [BZgA], 2011). However, the cause of the nurses’ distress while caring for brain-dead patients, and how nurses view brain death remained unclear. It was therefore necessary to investigate these phenomena. To obtain initial insights into this area, a qualitative preliminary study of six nurses on their experiences of caring for (potentially) brain-dead patients was conducted in 2014 (Drexler, 2015). In the findings, the following recurring themes were identified: present care of (potentially) brain-dead patients; communication with all involved parties; interactions with patients’ families; standard operating procedures for brain-death determination and subsequent steps; and nurses’ approaches to the concept of brain death and the Lazarus

phenomenon (spinal reflexes in brain-dead patients [Josten, 2020]). As only a small sample was interviewed, it is likely that data saturation was not established and additional phenomena might have been identified (Drexler, 2015).

Aim

This study aimed to provide deeper insights into how intensive care nurses experience caring for (potentially) brain-dead patients.

This objective is part of a larger study, in which not only nurses but also physicians and families of (potentially) brain-dead patients were interviewed on their experiences (Drexler et al., 2019).

Methods

Design

A qualitative design (Creswell, 2007) with episodic interviews was chosen to collect data on the lived experience of intensive care nurses. The methodology follows the phenomenology of Martin Heidegger, who advocates using hermeneutics, based on the ontological view that lived experience is an interpretive process (Dowling, 2007; Spichiger & Pracke, 2003).

Inquiring and telling can access associations within experiences (Flick, 2012).

Sample

Nurse managers were contacted in six departments with ICUs at a German university medical center (Creswell, 2007). With the approval of nurse managers, the primary investigator introduced the overall study with its objectives and line of action. The ICU nurses who were willing to participate were asked to contact the study investigator to schedule an interview. The inclusion criteria were: informed consent, registered nurse, German-speaking, and having cared for a (potentially) brain-dead patient (ideally within the last twelve months).

The recruited nurses were from various departments, of mixed gender, with various qualifications and work experience. For phenomenological studies, Creswell suggests a sample size “from 3 to 4 individuals to 10 to 15” (Creswell, 2007), who have experienced the phenomenon of brain death (Creswell, 2007).

Data collection

The preexisting interview guide was extended according to the findings of the preliminary study (Drexler, 2015). The opening question was: “Tell me about a situation that you remember clearly in which

you cared for a (potentially) brain-dead patient. What was your experience of the situation?” The primary investigator had experience in qualitative research and intensive care nursing, including caring for (potentially) brain-dead patients. This background helped to establish a foundation of trust during the interviews with the nurses (Tong et al., 2007).

Seven interviews were conducted between April and December 2016. From the six existing interviews (conducted in 2014) from the preliminary study (Drexler, 2015), five could be included in the data analysis. One person was not available. The participants gave explicit consent for their interviews to be re-used for the analyses in this study. These previous interviews were included for further in-depth analysis. All interviews were conducted face-to-face by the primary investigator, in her office.

The interviews were digitally recorded, pseudonymized, and names processed using the program “Audacity” (Version 2.1.2) with its feature “Silent conversion”. The audio files were transcribed verbatim (without regional accents), five by the primary investigator, using the program f4 (Dresing & Pehl, 2015) and the others by a company.

Data analysis

The obtained data were analyzed according to Benner’s interpretive phenomenology (Benner, 1994), which generates a discussion between

practical insights and individual life experiences. Interpretive phenomenology helps to illustrate the participants’ experiences from their own points of view and, subsequently, to interpret natural events, opinions, concerns, worries, and anxieties. For this, Benner provides paradigm cases, thematic analysis, and exemplars as a strategy (Benner, 1994).

Two researchers analyzed and interpreted the raw data separately (the primary investigator and a BScN nurse) and defined themes for the thematic analysis (Benner, 1994). The data were organized using the program MAXQDA 12 (Verbi, Release 12.3.0). After the thematic analysis, we generated main themes based on topics and subtopics.

For the in-depth analysis, the primary investigator summarized each interview based on the research question (key aspects) (Christ & Tanner, 2003), condensing the data to generate further interpretations. At this stage, each case was given a title and keywords. Subsequently, the main themes from the first analysis and the in-depth analysis (Table 1) were compared in order to understand the major concerns and opinions of the nurses (Benner, 1994).

At all stages of the interpretation process, the primary investigator reflected on her own experiences. It can be assumed that her own experiences may have influenced the interpretation (Benner, 1994).

Table 1 Overview of themes identified in the in-depth analysis

Themes deep analysis	Understand the nurses experience
Brain death	Nurses themselves understand / do not understand brain death / nurses only consider the living body Death is when the heart stops beating Brain death is nothing ordinary
Insufficient communication in the care team	Non-communication
Resignation / Giving up	Helplessness / powerlessness
Responsibility	Knowledge – lack of knowledge
Nurses must perform in high performance medicine	No training for specific situations, everybody must know and do everything No professional support Ignoring burdens Difficulty: nurses know patients when alive, experience patients’ decline over time Difficulty: nurses know patients’ families and support them over a period of time
Maintaining professionalism versus personalization of experience	First experiences in this respect often completely change the nurses’ attitudes towards brain death and organ donation Nurses feel a need to treat the relatives just as they would treat their own next of kin in the same situation Reactive behavior Distance – closeness Unbearable identification with the situation Nurses taking leave from brain-dead patient Highly complex event

During analysis, e.g., of ambiguous cases, or in cases of differing interpretations between the two researchers, several research groups were contacted to enable critical reflection and to analyze particular sections of the interviews. Study advisors supported the entire process, discussing research steps in personal coaching sessions with the primary investigator (Christ & Tanner, 2003; Creswell, 2007). The COREQ criteria (Tong et al., 2007) were used to prepare this paper. The exemplars were translated into English with due diligence, and slightly adapted to maintain the original German meaning.

Results

Twelve ICU nurse interviews were included (four male, eight female). The work experience of the ICU nurses ranged from nine months to 18 years. Five participants had completed professional training for intensive care nursing. All participants had experience of caring for brain-dead patients. The interviews lasted, on average, 21 minutes (range six min 58 sec to 49 min 13 sec).

Three key phenomena emerged from the data supported by exemplars: 1) The brain is dead; the body is alive; 2) Coping within high performance medicine; 3) Power(-lessness). The labeling of the phenomena illustrates the meaning from the perspective of the participants. The results are shown in Table 2.

The brain is dead, the body is alive

Intensive care nursing does not differentiate between the care of a brain-dead patient and that of a living patient. The participants considered the brain-dead patient to be not completely dead, yet also not completely alive. In other words, the brain is dead, the body is still alive. “... to me it is a dying patient and brain death to me is not equivalent with death, which I realized in that situation” (P11).

Each interviewed ICU nurse differed in describing how she / he perceived brain death and death, dying, and when a patient was considered dead. Most of the participants continued to speak to a patient after a positive brain death diagnosis had been made. It helped them to feel better. Despite (potentially) brain-dead patients being described as a “shell” or “body” (P6), nurses rarely saw them as such. “At this stage to me he is still a patient under my care, even if he is **PRIMARILY** a dead person. Right? In that moment, he is not a dead person to me. He is a human being still on a path, still in need of care. (...) I think that in that moment the soul has not detached from the body yet, and that there is still

something there that deserves to be treated humanely” (P8).

Currently, there are no guidelines for the nursing care of (potentially) brain-dead patients. Medical standards for organ-preserving intensive care measures do exist and the nurses were familiar with them. However, the (physical) nursing care of these patients varied in how nurses experienced it and how they performed it. Some nurses cared for patients arbitrarily, according to how they felt they should be handled. This was also done, on a very conscious level, for the nurses’ own wellbeing. “... I care for him until the end, like I would for any other patient. And I think it makes it easier for me ... Or I think I’ll care for them the way I would want to be cared for” (P2).

The amount of nursing care a brain-dead patient required was discussed in several nursing teams. The state the patients were in when they were no longer alive, yet not quite dead, left nurses unclear as to how to provide them with care. The participants were insecure and sometimes found it difficult to describe how they felt about it. “... I don’t know, it’s really hard to describe, what’s going on inside and to keep on dealing with someone in that situation. It’s really (...) just about basic needs. Right, not basic needs actually, because the patient doesn’t even **HAVE** needs any longer. So, it’s really difficult. You just need to (...) talk to the patient, but there’s hardly any response – well, no response at all basically. The patient doesn’t respond, they can’t, neither talking nor gestures or eyes or whatever, just like with intubated patients – so you are left with the physical stuff, like excretions, sweating and (...) you are still busy monitoring fluid balance. Yeah, it’s difficult (...) on the outside. I mean just working with the body only” (P9).

Coping within high performance medicine

Stressful situations were not actively processed by the participants, either in the team or by nurses individually. Even in situations they were familiar with only theoretically (like the Lazarus phenomenon) and were experiencing firsthand for the first time, they had to perform professionally and did not have the opportunity to discuss the situation, except on a medical and technical level. One experienced ICU nurse witnessed how new co-workers were initially overwhelmed when caring for a brain-dead patient. They were given minimal instructions or none at all. However, some of the ICU nurses interviewed also described how, due to their own expert knowledge (i.e., knowing what the patient and family may be going through), they strongly

Table 2 Overview of identified key phenomenon

The construction of the key phenomenon	Key phenomenon
The brain-dead patient is not considered dead	The brain is dead, the body is alive
These nurses only consider a patient dead when the heart stops beating	
Ambiguity about the exact point in time when death occurs	
Nurses look at a living body	
The process of dying is different with organ donation	
Care for the brain-dead patient	
Nurses must know and do everything	
Stressful aspects must be ignored in the day-to-day professional routine	
Caring for brain-dead patients is challenging	
Supporting the family adds extra stress	
Applying expert knowledge	Coping within high performance medicine
Knowledge and lack of knowledge about brain death in novice nurses	
Caring for a brain-dead patient is a highly complex event	
Ideas exist to improve the situation	
Nurses' reactive behavior	
Personnel structure of an intensive care unit	
General conditions	
Responsibility	
(Non-)communication	
Hierarchy	Power(-lessness)
Length of time until patient dies	

identified with the brain-dead patient and could always care for such patients.

The participants had to cope with mental and emotional distress on their own and needed to find individual ways of coming to terms with the stress. Stress was not openly admitted and tended to be played down and considered taboo. Professional support for nurses was unheard of or was not discussed within the care team. “... *there is no time for that during the shift, it's really just – yeah, getting on with work, with or without a break. Sometimes when you, you can't, which actually happened to me once, (...) I'm at my limit. I started to tear up (...) which is unusual and for a moment, there I stood in the middle of the room and was at a loss how to cope. When a co-worker came in and told me: 'Now, wipe away the tears, take three deep breaths and back to work.' So that's what I did, and I stayed the course until the end of my shift. And then you're glad when it's over, you have to get OUT of there. You've got to get away from people because ICUs are very loud*” (P9).

The nurse said that no help was forthcoming within the team when needed and professional help was not available to her at the time. In general, it seems to be an expectation of professional nurses that they struggle on by themselves with the physical and emotional burden of caring for (potentially) brain-dead patients. In the extract below, a novice ICU nurse had to actively demand support from the ICU team so that she could work according to the rules of care. As brain-dead patients are not routine

patients, the initial training period for a novice ICU nurse does not always include caring for a (potentially) brain-dead patient. Thus, introduction to such patients occurs at a stage when the ICU nurse is working independently and must cope on his / her own. “*But of course, it was still new to me. And if I hadn't told them clearly 'Hey, I need some help here' or 'I have no experience and no idea what to do', well, I don't know, I would have stood there, kind of helpless*” (P10).

In contrast, one ICU nurse reported that she did not develop any emotional connection to the patients and their families. She strived to retain a professional equanimous attitude whether caring for people or caring for bodies with living organs. However, she also experienced exceptional cases: “*Yeah. Well, I seem to be one of the lucky ones who are able to cope rather well. (...) It's like, I leave the hospital, close the door behind me and forget about the patient. Almost always at least... The example I just told you about was a little bit different. That one I actually took home with me*” (P7).

In challenging situations that arise in the care of (potentially) brain-dead patients, the ICU nurses had to come to terms with their own feelings. In addition to their own feelings, they needed to attend to the families and their needs. It seemed to be especially challenging that once diagnosis was established, the ICU nurses had to explain to the family that, although the patient did not appear dead, (the heart was beating and the skin was still rosy), he or she was, in fact, brain dead and the machines

were keeping the body alive to preserve the organs. *“She [family member] came and pretty much almost lay down on him, crying. They didn’t – the father and mother – they didn’t understand, (...) I don’t know, but that was really difficult, telling them he was dead and they didn’t realize it”* (P2).

ICU nurses seem to regulate to what extent a patient’s family receives support. The participants themselves decided how much support they were able to provide, with regard to their own professional responsibility and personal emotional stability. As a consequence, the provision of support for families was highly dependent upon the individual ICU nurse caring for their loved ones, and on that nurse’s mental and emotional state. *“I definitely see co-workers, who, at least as far as my interpretation goes, have huge respect and are maybe also afraid of situations like these, and, therefore, allow very little contact with the family, but I also see co-workers, who have quite close contact, in that they invite the family to talk”* (P5).

Caring for a (potentially) brain-dead patient became even more challenging when nursing students, who also needed guidance and support from the ICU nurse in charge, assisted in providing care. In such situations, the ICU nurse had to consider her/his own emotional state, the family’s needs, and also the student’s nursing knowledge and emotions. *“I had a STUDENT with me. TO ME that was special, I’ve actually had nursing students with me on a more regular basis now, but to be in this different position all of a sudden – not just to be dealing with myself and how to get myself through this in one piece, but to ALSO be responsible for someone who is NEW to the situation, who therefore experiences an even higher stress level, to take them on board and support them – that was new to me, and I needed to try and see what works. And I hope that it was a POSITIVE experience for her”* (P9).

Caring for a (potentially) brain-dead patient is a complex situation requiring competency, professionalism, and responsibility from nurses. On the ICU ward, (potentially) brain-dead patients were often cared for next to “regular” patients, “regular” here meaning patients with a life-saving or curative treatment goal, suggesting that care teams were under the impression that patients not undergoing curative treatment required less intensive care, and that these patients were less demanding and required little time to be cared for. The ICU seemed to be regarded as a place where lives were saved, and not where palliative care should be provided. This common practice was critically questioned by one ICU nurse. *“That’s the WRONG attitude, in MY*

opinion. At times these patients actually need MORE TIME as such, not more CARE and not (...) a greater NUMBER of interventions. But without STRESS and STRAIN during the interventions, and that takes a lot of TIME (...) you really need to deliberately, consciously INVEST TIME in the patients, which doesn’t often happen” (P9).

Power(-lessness)

ICU nurses’ participation in physicians’ conversations with the patients’ families varied between departments. The interviewed ICU nurses understood the severity of a patient’s physical condition, due to acquired expertise, work experience, and information obtained from physicians. However, in Germany it is not in their responsibility to share that information with the family. Thus, the family does not always receive all of the information. *“... but because nurses are not allowed to provide information, on the medical clinical condition of the patient and that is definitely a difficult situation for me”* (P1).

The participants therefore often experienced an internal conflict in knowing more but not being able to share the information, and they felt disloyal to the family. This was a stressful experience since the ICU nurses saw themselves as the patients’ advocate.

Most of the participants were excluded from physician’s conversations with the family due to time or staff restrictions, or the physicians not inviting them, which diminished the exchange of information, either because they obtained limited information themselves about the current condition of the patient or because they were unaware how much and what information was being shared with the family.

At times, the course of continued treatment was decided upon in the physician/family meetings. If ICU nurses were not involved, they had no knowledge of the extent to which the course of action was explained to the family by the physician. A disrupted information flow concerning the treatment goal can also lead to the care team obtaining incomplete or inaccurate information, causing misinterpretations and distress. *“I felt ashamed with how the situation went. And with the co-worker who followed me on the next shift, who I had a long conversation with outside the door, and the two of us came to the conclusion that we were NOT going to go along with that and that we’d override the physician’s order. (...) and my co-worker later on also called in the ethics committee”* (P8).

ICU nurses taking part in the physician’s conversation with a patient’s family accounted

for the treatment decisions together with the physician. This process make them feel informed and involved. The participants had diverse experiences of the time period until the brain-death diagnosis was established. One ICU nurse felt certain about a patient's outcome, leaving her devoid of power or resources to help this patient: *"And since you know that it definitely WON'T get better, all you do timewise is WAIT until the brain-death diagnostics can start. And that's always a really stressful situation because you wait and do nothing and basically you know the outcome. The patient will pass away"* (P9).

Discussion

The identified phenomena (Table 2) provide a deeper insight into the ICU nurses' experiences of the process of preserving life, patient deterioration, the care of a (potentially) brain-dead patient, brain death diagnoses, and the corresponding decisions.

Caring for the living body of a brain-dead person is a worldwide phenomenon (Flodén et al., 2011; Moghaddam et al., 2018; Ronayne, 2009; Sadala & Mendes, 2000; Victorino et al., 2019). Sadala and Mendes (2000) reflect on ICU nurses' approaches when caring for a dead person with biological life. The authors found that the focus of care is on preserving the organs. In line with our study, the authors additionally point out that, to ICU nurses, the brain-dead patient is not fully dead. This state of being was described as "ambiguous and contradictory" by the participating ICU nurses (Sadala & Mendes, 2000).

Nurses understand the pathophysiological processes behind brain death yet still find it difficult to consider the patient as dead (Ronayne, 2009). As a consequence, ICU nurses care for brain-dead patients as if they were still alive, wanting to ensure the patient's well-being, as well as their own. Our interviewed ICU nurses did not know what the "needs" (P9) of (potentially) brain-dead patients really were. Caring for these patients and supporting their families was challenging regardless of subsequent organ donation.

Flodén et al. (2011) acknowledge that ICU nurses are supposed to assist patients back to health and are not trained for post-death care. Caring for an organ donor requires more personal commitment and emotional strength than caring for a regular ICU patient (Flodén et al., 2011). The required time investment, as well as the complexities of caring for a brain-dead patient, are also described as being demanding for caregivers (Victorino et al., 2019). In Germany, ICU nurses grant family access to a patient under intensive care,

and it is ultimately their decision how much contact is possible (Kuhlmann, 2004). The present study adds that it is also dependent on the emotional state of the ICU nurse whether the family receives the support it needs. Even if the patient does not have a life-threatening illness, relatives of ICU patients can experience "family intensive-care-unit syndrome", which includes stress, anxiety, depression, and post-traumatic stress disorder, as well as cognitive blunting and sleep deprivation in family members (Matt et al., 2017; Netzer & Sullivan, 2014).

Our study, like others, indicated that caring for a brain-dead patient is often experienced as stressful and burdensome (Flodén et al., 2011; Guido et al., 2009; Pearson et al., 2001). Common themes are supporting the family (including dignified support and concern for the family) (Flodén et al., 2011; Guido et al., 2009), communicating with the family (Flodén et al., 2011; Guido et al., 2009; Pearson et al., 2001), and asking about organ donation (Flodén et al., 2011; Guido et al., 2009). Our results broaden this knowledge in showing the difficulties experienced by ICU nurses in high performance medicine due to professional attitudes and lack of support. In addition, not being able to influence the course of action disrupted information flow, and feelings of disloyalty to the family when not able to communicate freely with them add to ICU nurses' stress.

The present study also adds to the understanding of the phenomenon power(-lessness), which is not explicitly described in other international research. The results in this paper suggest that interviewed nurses need support and recommendations on how to care for patients with (potential) brain death. This support involves fundamental changes to the corporate culture of the ICUs, for examples, increased support for ICU nurses in terms of stress management, education, and training in communication. Salehi et al. (2013), also describe the need for emotional support for ICU nurses caring for an organ donor. They also point out that ICU nurses are not prepared for families' emotional reactions and that they continue to think about their patients after the end of their shifts and during their time off work (Salehi et al., 2013).

The requirement to train new co-workers or instruct vocational nursing training students or academic nursing science students puts additional strain on nurses.

Limitation of study

The interviewed nurses were from different ICUs at a single German medical center and the primary investigator also worked in the same medical center.

It seems apparent that the majority of the interviewed ICU nurses described the stress they were under in the hope of encouraging changes in future protocols. It can be assumed that ICU nurses who do not experience such stress most likely did not volunteer to participate or that nurses who struggle with their circumstances were too affected to discuss their experiences.

Finally, the first part of the data analysis was interpreted by two researchers, while the second part was analyzed by the primary investigator.

Conclusion

The results show that caring for (potentially) brain-dead patients was demanding in the context of high-performance medicine, and sometimes left nurses feeling powerless. ICU nurses were required to provide the highest level of care but did not themselves have access to a professional support network. Despite emotionally challenging situations, feelings were not acknowledged within the healthcare teams. By developing concepts, further training, psychological support, or reflective team communication, a fundamental change within the healthcare system hierarchy and the attitude of ICU nurses could be promoted. What becomes apparent here is that training for nurses needs to be implemented regarding both technical knowledge and knowledge on how to nurture their own mental and emotional health.

Brain death is intangible to many, making it difficult for ICU nurses to define structured nursing interventions and/or to convey death and dying of (potentially) brain-dead patients to the family. The authors suggest that further research focusing on the phenomenon of brain death should be conducted with ICU nurses who care for this patient group. That research could deepen understanding of the described situations and, potentially, quantify the experiences and attitudes so that the phenomena could be statistically analyzed. It would be interesting to quantify how many nurses are affected by feelings of powerlessness, how many nurses believe that the brain is dead while the body is alive, and what it means to perform nursing in high-performance medicine in the context of potentially brain-dead patients.

Ethical aspects and conflict of interest

The responsible ethics committee (EK) provided approval for this study (EK 87/16). Clinical Trial registration number: German Clinical Trials Register DRKS-ID: DRKS00010420.

Participants voluntarily chose to take part in the interviews. Prior to providing informed consent, the study was explained to potential participants and they were encouraged to take their time when making their decision.

No conflict of interest has been declared by the authors.

Funding

The study was financed within the framework of the Academy for Young Researchers in Care Research, Baden-Württemberg, at the Ministry of Science, Research and the Arts in Baden-Württemberg. A sum of 50,000 Euro was awarded of which 10,000 Euro was allocated to the Section of Health Care Research and Rehabilitation Research, Medical Centre – University of Freiburg, Faculty of Medicine, University of Freiburg, Germany.

Acknowledgement

We would like to thank the participants who kindly shared their practical experiences with us. We also want to thank all those in the various clinics and departments for their support and for allowing us to introduce our research proposal into the department. Special thanks go to Matthias Windeisen the BScN nurse who co-analysed the interviews. Our co-workers and peer groups were very supportive in this. As the study is part of the first author's doctoral thesis, she would also like to thank her co-workers and fellow students for their encouragement and assistance throughout this time. In addition, we give special thanks to the linguist for the English translation, editing, and review and, finally, to the framework of the Academy for Young Researchers in Care Research, Baden-Württemberg, at the Ministry of Science, Research and the Arts in Baden-Württemberg for funding this study.

Author contributions

Conception and design (SD, EF-G), data analysis and interpretation (SD, AS), manuscript draft (SD), critical revision of the manuscript (SD, AS, EF-G), final approval of the manuscript (SD, AS, EF-G).

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