Received: 24 January 2023 | Revised: 8 June 2023 | Accepted: 7 July 2023

DOI: 10.1002/nop2.1944

EMPIRICAL RESEARCH QUALITATIVE

NursingOpen Open Access WILEY

Critically ill patients' experiences of nursing care and the effect on their personhood: A retrospective study

Ariné Kuyler[1] | Ensa Johnson[2]

[1]Centre of AAC, University of Pretoria, Hatfield, South Africa

[2]University of South Africa, Pretoria, South Africa

Correspondence
Ariné Kuyler, Centre of AAC, University of Pretoria, Cnr of Lynwood Road and Roper Street, Hatfield, South Africa 0028.
Email: arinekuyler@gmail.com

Abstract

Aim: This study aims to report patients' experiences of nursing care in the critical care unit and the resulting effect of such care on the personhood of patients.

Design and Method: The study adopted a qualitative design and aimed to include both descriptive and exploratory information. It involved a single participant group comprising ten previously critically ill patients with whom retrospective, semi-structured interviews were conducted in a natural setting during 2018. Private hospitals in Gauteng, South Africa, were targeted for data collection.

Results: The findings of this study were categorised and described according to Kitwood's conceptualisation of person-centred care. Five categories were identified by patients as impacting their personhood and perceived person-centred care.

Conclusion: Nurses ability to support perceived personhood of patients during person-centred care is integral to the betterment of the patient. Patient's experiences of nursing care can often be affected if they perceive their personhood as not being valued by nurses. This study creates increased awareness of these components to ensure that patient-nurse relationships are established adequately to meet both the patients' and the nurses' needs.

KEYWORDS
care, communication, experience, nurse, patient, personhood

1 | INTRODUCTION

Patients within the critical care unit may be psychologically vulnerable due to their cognitive, motor and sensory difficulties and environmental factors (Kwame & Petrucka, 2021; Umbrello et al., 2019). Additionally, the patient may experience communication difficulties which may impact their perceived personhood. To establish an individual's personhood, communication within interpersonal relationships is required (Fazio et al., 2018; Wolf-Meyer, 2020). Communication difficulties may cause the patient to report less autobiographical narratives to establish a sense of self, changing relationships with others and decrease expression of values (Chapman et al., 2022).

Personhood is defined as the social position that is assigned to a person based on interpersonal relationships through personal recognition, mutual respect and trust (Fazio et al., 2018; Hunter et al., 2013; Wolf-Meyer, 2020). Due to the impact of the patients' communication difficulties and reduced patient–nurse communication, the critical care nurse may play an integral part to support communication by increasing patients' communication experiences through

The first author of this manuscript contributed to the planning of the research and manuscript, conducting of research procedures and reporting of work described in the manuscript.

The second author contributed by assisting in planning of the work and reporting of work described in the manuscript.

person-centred care. Clissett et al. (2013) and Tieu et al. (2022) suggest that the main objective of person-centred care is to respect the personhood of the patient despite their communication difficulties.

Kitwood's conceptualises person-centred care for persons with dementia to include the following (i) comfort—the ability of the person to be resilient; (ii) attachment to others—supporting the functionality of the person; (iii) inclusion by others—feeling accepted and being supported in their social participation; (iv) occupation—the person's involvement in activities of daily living such as work, leisure; and (v) identity—the individual's ability to maintain continuity between the past and present (Kaufmann & Engel, 2016). Even though Kitwood's conceptualisation was originally intended for persons with dementia, it may have specific relevance to critically ill patients. This could be as both populations experience significant communication difficulties that may impact their perceived personhood and experiences.

Kitwood's idea of person-centred care assists healthcare practitioners in identifying areas of support to acknowledge patient personhood as critically ill patients often rely on healthcare practitioners to meet such needs. The support provided by the healthcare practitioner as well communication opportunities offered in the environment therefore determine whether patients' personhood is acknowledged (Mitchell & Agnelli, 2015).

The concept of personhood is multifaceted, but the key consideration for person-centred care is the relational aspect influenced by communication (Chapman et al., 2022). As both personhood and person-centred care require a patient–nurse relationship to establish the social position of the patient, these concepts can be seen as having a symbiotic relationship. Trust (personhood) can only be established between a patient and nurse when both the communication partners experience comfort and a sense of attachment (person-centred care). Additionally, mutual respect (personhood) requires the patient's understanding of the nurse's occupation and requires mutual inclusion during communication (person-centred care). Lastly, the patient's personal recognition (personhood) can be obtained when the nurse allows the patient to express their identity or sense of self (person-centred care).

Healthcare practitioners, especially nurses, play an integral part in providing communication support, meeting the biomedical needs of the patient and creating a positive environment to improve patient personhood (Terkelsen et al., 2019). However, at times nurses may have personal assumptions or may not fully understand the unique needs of critically ill patients (Mitchell & Agnelli, 2015). Components such as workload, non-nursing-related responsibilities, degree of job satisfaction or burnout and years of experience can hamper nurses' ability to provide person-centred care (Hajalizadeh et al., 2021; Hunter et al., 2013; Tan et al., 2015).

Additionally, these components may lead to misunderstandings between nurses and patients. These misunderstandings may cause patients to perceive that their personhood needs are not acknowledged affecting person-centred care. The aim of this article is to report how patients' experiences of nursing care in the critical care unit can affect personhood of patients and person-centred care.

2 | METHOD

A qualitative research design was used to conduct this study as it allowed the authors to subjectively and systematically describe and explore rich data sources from participants (McMillan & Schumacher, 2014). The data was collected through retrospective, semi-structured interviews in a natural setting (in the hospital or at the home of the patient) with a single participant group comprising 10 previously critically ill patients.

2.1 | Setting

Hospital managers at four private hospitals from a specific hospital group in Gauteng, South Africa, were targeted to obtain permission for data collection. These hospitals were targeted as they had various critical care units, including trauma and surgical critical care units. The critically ill patients had been referred by healthcare practitioners such as critical care nurses, doctors and speech-language pathologists working in these wards. The participants were interviewed at least 72 h after the communication difficulty experienced within the hospital or upon discharge at their home settings. This ensured that the participants were alert and aware of their surroundings to be able to sign and understand a consent form and participate in the interview. These skills should be intact for the participant to understand the requirements and to participate in the interview, which did not exceed 60–80 min.

2.2 | Ethics approval

Ethics approval was obtained from the research ethics committee of the relevant institution, and written permission was given by the research board of the hospital group and hospital managers of the four hospitals. No data collection procedures were initiated prior to obtaining written informed consent from all participants.

2.3 | Participants

Purposive convenient sampling was used to select participants who met selection criteria based on the following: their age (18 years and older); English proficiency; cognitive, motor, and linguistic ability to comprehend and answer interview questions; sensory capabilities (corrected vision and/or hearing with glasses or hearing aids); and communication difficulties experienced for at least 12 h. The Montreal Cognitive Assessment (MoCA) was used to screen participants' suitability for this study, and a score of 25 and higher was used to include patients (Nasreddine et al., 2005). Two of the 12 participants ($n = 12$) were excluded based on their MoCA scores of less than 25, resulting in a study group of 10 participants. Table 1 provides detailed biographical information of the selected patient participants ($n = 10$).

TABLE 1 Patients' demographic information.

Participant	Gender	Age	Initial ward admission	Reason for admission to the ward	Reason for communication difficulty	Duration of communication difficulty	MoCA score
P1	Female	25	ICU	MVA	Weakness and confusion	3 weeks	30
P2	Female	73	General ward	Colon cancer	Weakness and confusion	12 h	30
P3	Male	62	General ward	Assault	Intubation	1 month	29
P4	Female	65	Surgical ICU	2 Hernias	Intubation	2.5 days	27
P5	Male	64	ICU	Laryngeal cancer	Laryngectomy	7 days	30
P6	Male	71	General ward	Laryngeal cancer	Laryngectomy	1 month	30
P7	Female	60	ICU	Thrombosis, anxiety	Weakness and anxiety	2 days	30
P8	Female	59	ICU	Attempted suicide	Intubation	8 days	29
P9	Male	64	ICU	Laryngeal cancer	Laryngectomy	7 days	30
P10	Male	33	General ward	Burst vein	Intubation	12 h	30

Table 1 provides details of patient characteristics. The ages of the patient participants ($n = 10$) ranged from 25 to 73 years, with an average age of 57.6 years. There were no patients in the group of 40 to 49-year-olds. Fifty per cent of patients ($n = 5$) were in the second-oldest group, with ages ranging from 60 to 69 years. The geriatric population in this study had more hospital admissions than any of the other age groups.

Afrikaans was the most prominent language spoken by 60% of the participants, with 70% of patients being able to speak one additional language (English), 20% being able to speak no other language and 10% being able to speak more than two languages. Most of the participants had at least a Matric Certificate ($n = 8$) and two had a Grade 8 qualification. The participants from this study came from various backgrounds and their demographics differed.

Intubation was the main cause of communication difficulties ($n = 4$). Most participants (80%) were admitted to the critical care unit in 2018, while the remaining 20% were admitted to the critical care unit in 2016 due to laryngeal cancer. The participants had different reasons for admission to the critical care unit, e.g., a motor vehicle accident, colon cancer and complications during hernia operations. All participants (100%) experienced communication difficulties ranging in duration from 12 h to 1 month; 60% had a medical history of hypertension and 10% suffered from diabetes. All these factors influenced the patients' experience in the critical care unit.

2.4 | Data collection

Healthcare practitioners contacted patients with a history of admittance to the critical care unit to gain informed consent for participation during the period of 2018. Upon collection of the informed consent, the healthcare practitioners forwarded the contact information of the patient participants to the researchers. Subsequently, participants were contacted via email to arrange a date, time, and location that would be convenient for them to take part in a retrospective, semi-structured interview. Interviews were conducted at least 72 h after discharge, depending on when the referral was received, and the psychological and physiological status of the participant. Each interview consisted of a reminder of ethical considerations, open- and close-ended questions on personhood in the critical care unit, and patient–nurse communication and concluded with the first author providing thanks to the participants for sharing their experiences. The first author conducted all the interviews with participants and made field notes to increase personal reflexivity. Each interview was conducted in a natural setting—either at the hospital or at the patient's home. A procedural checklist was used to prepare the environment for the interview, and an interview script was used to guide the interviews. This ensured that the same procedure was followed with all participants which increases trustworthiness of results. The interviews were approximately 60–80 min and were audio- and video-recorded.

2.5 | Data analysis

The audio recordings of the interviews were transcribed verbatim by a research assistant and checked by the first author for correctness. These transcriptions were sent to the participants via email a week after the interview as part of member checking to ensure that their perceptions were correctly transcribed. Upon feedback from participants, qualitative content analysis was used to analyse the content obtained through the interviews (Elo et al., 2014). This type of analysis aided in the holistic comprehension of the data through the creation of categories for semantic data (DeFranco & Laplante, 2017).

During data analysis, a deductive approach was followed by both authors to ensure trustworthiness of findings and mutual agreement (Elo et al., 2014). Qualitative content analysis consists of a preparation phase (reviewing the data collection method, sampling strategy and selecting a unit of analysis), organisation phase (categorisation and abstraction, interpretation and representativeness of data) and reporting phase (reporting results and analysis process) (Elo et al., 2014). As a deductive approach was utilised, Kitwood's person-centred care approach was used to categorise data. The last step of this process entailed producing reports on how the data

obtained can be utilised to answer the research question (Roberts et al., 2019).

2.6 | Trustworthiness

In this study, the four components of trustworthiness were targeted, specifically credibility, transferability, conformability, and researcher bias, which will be discussed individually. Credibility refers to data that truthfully represent the population of this study (Roberts et al., 2019). Credibility was increased through member checking to ensure that the findings were accurate and reflective of the patient's experiences (Harper & Cole, 2012). The second author also provided peer debriefing to the first author to provide an external review of the research process and to increase referential adequacy (Sarvimaki, 2018). Transferability refers to the applicability of information representative of a larger population (Roberts et al., 2019). Thick and rich descriptions were provided in different settings. This assisted in increasing transferability, as it may be more representative of a larger population. Conformability refers to the clarity of data collection procedures and documentation (Roberts et al., 2019). The first author made field notes and made use of peer debriefing to ensure that personal bias and possible assumptions were addressed so as to not influence the findings.

3 | RESULTS

Kitwood's conceptualisation of person-centred care was utilised to report the findings of the interviews (Kitwood, 1997; Kitwood & Bredin, 1992). This conceptualisation assisted in understanding the connection between the person and their social environment (Fazio et al., 2018). To understand the said connection, the subjective experiences and needs of the person should be emphasised (Kaufmann & Engel, 2016).

Table 2 provides a summary of the findings of the study. The first concept of personhood addressed in the findings focused on trust by including comfort and attachment in person-centred care. Emphathy was classified as comfort according to Kitwood's conceptualisation (Kitwood, 1997; Kitwood & Bredin, 1992). Providing empathy and kindness to participants improved their social participation and reduced feelings of discomfort and loneliness (Hajalizadeh et al., 2021). More than half of participants ($n=7$; 70%) mentioned that nurses had not treated them with emphathy and that this contributed to their negative experience of the critical care unit. In contrast, the three remaining participants mentioned that nurses had been caring and kind during their stay in the critical care unit.

In the second category, namely attachment, nurses had to be physically present for adequate attachment and social participation to be established (Kitwood, 1997; Kitwood & Bredin, 1992). Half of the participants ($n=5$; 50%) indicated that the nurses were physically present during their stay in the critical care unit, while the other half mentioned that they searched for nurses but could not locate them ($n=5$; 50%).

The second aspect of personhood namely, mutual respect was addressed in the findings through inclusion and occupation in person-centred care. For patient participants to perceive that they received person-centred care relating to inclusion, nurses had to conduct themselves in a professional manner and provide care in a language that the patients understood (Kitwood, 1997; Kitwood & Bredin, 1992). Two participants (20%) mentioned that nurses did not provide care in a language that they understood or that nurses pretended to not understand them. However, eight of the participants were satisfied to receive care in English despite the fact that they had a different first language. Seven of the participants (70%) perceived that the nurses did not provide person-centred care in a professional manner, whereas the other three participants (30%) were satisfied with the level of professionalism displayed by the nurses.

The fourth category (i.e., occupation) included assistance, as this refers to the person's ability to independently perform the activities of daily living (Kitwood, 1997; Kitwood & Bredin, 1992). Most patients in a critical care unit have difficulty performing tasks independently and require assistance from the nurses. More than half of participants ($n=7$; 70%) in the current study mentioned that they had difficulty obtaining assistance from nurses to perform the activities of daily living such as walking and bathing.

Lastly, the concept of personhood including personal recognition was addressed through the identity category. Identity emphasised that information and knowledge were regarded as cardinal components of patients' perceived identity (Kitwood, 1997; Kitwood & Bredin, 1992). Having adequate knowledge and information allows patients to interpret their own condition and sense of self (i.e., identity) (Gao & Riley, 2010). Seven (70%) of the participants thought that the information they received was adequate, while three complained that nurses had not provided them adequate information about their health. Furthermore, one participant (10%) said that nurses did not have enough knowledge on laryngectomies and stoma care, which was in contrast to 90% of the participants ($n=9$) who thought that nurses were having adequate knoweldge about general healthcare-related problems.

4 | DISCUSSION

The aim of this article is to report how patients' experiences of nursing care in the critical care unit can affect personhood of patients and person-centred care. The study findings are discussed according to Kitwood's conceptualisation of the components of person-centred care and their relation to personhood. The components include comfort, attachment, inclusion, occupation and identity (Fazio et al., 2018; Kaufmann & Engel, 2016; Mitchell & Agnelli, 2015).

Maintaining patient personhood is an important component of person-centred care as it impacts patients' health outcomes (Fazio et al., 2018; Mitchell & Agnelli, 2015; Terkelsen et al., 2019).

TABLE 2 Findings of qualitative interviews.

Concept of personhood	Category relating to Kitwood's conceptualisation	Category	Definition	Patient quotes	Mentioned by participant
Trust	1. *Comfort*	Empathy	Patients' perceptions of nurses' empathy towards them in the critical care unit.	*Communication* • If you respond in a way they do not like, they shout at you and tell you to stop with your attitude. • They do not understand my emotional state or psychological state and have no sympathy with me. • Only one person understood me and told the others to move me slowly. • I just wanted to know that they understand what I am going through. • Nurses should reassure me that everything will be ok. • They do not understand me or my needs. • They were not interested in what I had to say. • I understand that they have a lot of work, but I just needed them to comfort me. *Care* • They do not care about me. • The way they treated me was traumatising and I requested the assistance from a psychologist in the ward. • They only care about the machines attached to me, but they do not care about me. • It is important that nurses are friendly and polite. • If nurses are nice to you and attend to you, you feel a lot better. • There was a nice nurse who helped me and saw my need before I even asked. • When the nurse helped me, she treated me well and I enjoyed working with her. • I thought I might die, but the nurse and doctor told me not to worry.	P1, P4, P5, P6, P7, P8, P9
	2. *Attachment*	Physically present	Patients' perceptions of nurses being physically present.	• In the ward there was one nurse for every two beds, but she was sitting in the corner away from me. • During lunch and visiting hour they were not there. • Nurses should say I am sitting next to you, just call me when you need me. • I was very sick and was placed in a single room and I struggled to get help from the nurses as they were never in the room.	P1, P6, P7, P8, P10

(Continues)

TABLE 2 (Continued)

Concept of personhood	Category relating to Kitwood's conceptualisation	Category	Definition	Patient quotes	Mentioned by participant
Mutual respect	3. *Inclusion*	Language	Patients' perceptions of nurses' giving care in a language that they understand.	• Nurses could understand my home language but acted like they do not understand. • If nurses spoke in their home language—a language that I did not understand—it made me feel excluded and alone.	P5, P8
		Conduct	Patients' perceptions of nurses' professional conduct in the critical care unit.	• They were lazy and did not want to help me. • They shouted at me and argued with me regarding the medication I was on before I was admitted to the critical care unit. • The nurses were making a lot of noise; they talked loudly to each other in the ward. • The nurse made me feel uncomfortable as she was staring at me the whole time. • The nurse was yawning the whole time and walked very slowly when I was there. • When I tried to get the nurses' assistance, they were always sleeping somewhere.	P1, P2, P3, P4, P5, P8, P9
	4. *Occupation*	Assistance	Patients' perceptions of nurses' assistance during their stay in the critical care unit.	• If you ask them to help you, they do it in a way they think best and do not consider your opinion. • They do not respond when you call them. • I was nauseous and they took long to call the doctor. • You want to request assistance, but you have no method to call the nurses as you cannot communicate. • The doctor instructed them to help me as I had to walk, but they did not want to do it and left me in my bed. • I need a bell to call the nurse due to my communication difficulties. • When I rang the bell, they responded. • I tried to scream for a nurse but could not get their attention. • The nurse helped me and provided physical support for me when I had to walk.	P1, P2, P5, P6, P7, P9, P10
Personal recognition	5. *Identity*	Information	Patients' perceptions of nurses' providing information regarding procedures, care, medication and families.	• When they moved me, they did not explain to me that I was being moved and this traumatised me as I did not know what to expect and they handled me without care. • They did not explain why they gave me a full body wash one day and the next only washed my hair. • The nurses kept asking me if I had a port, but I did not know what they were asking me.	P1, P5, P8
		Knowledge	Patient perceptions of nurses' knowledge about their specific needs.	• Nurses are not very smart. • The nurses had no knowledge of my laryngectomy and how to care for my stoma. • The nurses did not know that due to my laryngectomy I could not speak. • Nurses require training to care for stomas and to provide communication options for patients who cannot communicate.	P6

However, this study proves that even though this concept should be central to nursing care, various hindrances still exist within the critical care unit that affect the patient's perceived personhood. These obstacles include both characteristics related to the patient, such as communication difficulties and certain components of nursing care. Communication is of cardinal importance not only to establish a patient's personhood but also to nurture a relationship with nurses (Buckley et al., 2020). Nurses often have trouble establishing a relationship with patients who experience communication difficulties. These difficulties may cause frustration for nurses and can result in their nursing care being more task-orientated and in the duration of nurse–patient contact time being decreased (Bayog et al., 2020; Dithole et al., 2016).

Reduced nurse–patient contact time affects patients' experience of nurses and the latter's ability to offer the patients comfort through empathy. These brief experiences are often negative and remembered by patients (Topçu et al., 2017). This study confirmed that patients require physical care and psychological comfort. Participants recall their physical experiences of discomfort, noise and pain, and their psychological experiences of feeling isolated, depressed and anxious (Hajalizadeh et al., 2021). These experiences are often influenced by the nurse's ability to provide comfort to the patient. Most patients in this study experienced the nurses' ability to comfort them as negative, and this had a great impact on their perceived personhood. For example, one patient recalled: 'If you respond in a way they don't like, they shout at you and tell you to stop with your attitude'. This resulted in patients having reduced feelings of dignity, as dignity is situation dependent (Pringle et al., 2015).

Attachment between patients and nurses is also achieved by nurses being physically present. This study confirmed that patients require 'human presence' when they are vulnerable or find themselves in unknown circumstances. Nurses' caring behaviour provides 'human presence' that can enhance patients' mental and physical well-being and lead to physical, psychological and spiritual healing (Papastavrou et al., 2012). When patients have positive experiences of such human presence through interpersonal relationships with nurses, they will feel supported and this may have a positive effect on their perceived personhood (Nizzi et al., 2020).

In addition to patients' feeling supported in nurse–patient relationships, they also feel included through nurses' conduct and the language used during communication. The current study confirms that patients want to be included in all aspects of their care. If patients are involved in their own care, they tend to play a more active role and show increased accountability (Bear & Stockie, 2014). However, their attitude may be influenced by nurses conducting care in a professional manner. The professionalism of nurses is defined by the amount of dedication that they display in respect of person-centred care. In this study, patients may have sensed nurses to be not fully dedicated to their care, and therefore they experienced the nurses' professionalism in a negative manner (Dikmen et al., 2016). This affected the patients' perceived personhood as it made them feel unacknowledged and as mere objects that are given physical care (Zilio, 2020).

A further component that affected the personhood of critically ill patients was whether the nurses communicated with them in a manner and language that they as patients could understand. Nurses often have to provide care to patients from ethnic minority groups in the critical care unit (Van Keer et al., 2015). This may be difficult due to the latter's cultural and linguistic diversity, and because nurses may have different conceptualisations of the cause and treatment of ilnesses or hold different spiritual beliefs than their patients. Patients and nurses may also have divergent views on gender roles, which have an impact on care provision (Van Keer et al., 2015). These differences may result in conflict between nurses and patients and ultimately limits nurses understanding of the core values that make up personhood (Høye & Severinsson, 2010).

The second last component that may affect personhood is occupation (i.e., functioning in daily life) through assistance from nurses. Patients in the critical care unit often have multiple and complex disorders and therefore have difficulty performing the activities of daily living independently (Høye & Severinsson, 2010). This may increase the demands made on the nurses' time and assistance, thus intensifying the stresses of the work environment and the workload of the nurse. If multiple patients with complex disorders depend on their care, this reduces the nurses' ability to spend adequate time with each patient to try and communicate (Kieft et al., 2014). Eventually this may result in reduced quality of care perceived by patients and less patient satisfaction (Høye & Severinsson, 2010). Being dependent on others to perform tasks, coupled with experiencing reduced satisfaction with the care received, may seriously influence the individual's personhood as it negatively affects their sense of self (Nizzi et al., 2020).

This sense of self can refer to the patient's subjective perception of being able to take ownership of their own body and control their own actions (Nizzi et al., 2020). Patients' subjective sense of self determines how they identify themselves as a person. Due to the fluid nature of personhood, patient identity can be influenced by their knowledge about their personal state of health (Radha Krishna & Alsuwaigh, 2015). However, patients' knowledge often depends on the nurses' ability to provide them with accurate and adequate information and on the nurses' level of medical knowledge. If nurses provide adequate information, and the patients perceive nurses to be knowledgeable about their specific conditions, this may improve the patients' knowledge of their own rights and enhance their personal autonomy (Sofronas et al., 2018). It will ultimately increase their sense of personhood and self-determination, as the patients may perceive themselves as being capable and having the capacity to exercise their rights (Sofronas et al., 2018).

From the findings in this study, it was clear that patients' experience of nursing care can affect their sense of self and their perceived personhood. If patients' personhood is acknowledged and have positive experiences of nursing care, their level of satisfaction with the nursing staff and with the quality of care provided to them in the critical care unit may also improve (Høye & Severinsson, 2010).

4.1 | Limitations of the study

One of the limitations of this study was that the data collection procedures only included private hospitals from a specific hospital group in one of the nine provinces of South Africa. Another limitation was the small sample size. However, data saturation was obtained with the small sample size, and the qualitative nature of study provided rich and thick descriptions of the data.

5 | CONCLUSION

This study found that despite greater emphasis on the inclusion of personhood in the concept of person-centred care, various variables still exist that hamper the implementation of this concept. Furthermore, the study emphasised the importance of providing positive nursing experiences for patients, as this serves to improve patients' sense of self and their level of self-determination and health outcomes. Additionally, this study explained the detrimental impact that poor perceived person-centred care can have on patient's personhood. Future studies could perhaps include comparative research on patient experiences in both public and private institutions, ethnographic studies that observe the impact of different cultures on patient personhood or person-centred care and involve a larger sample, so as to increase the generalisation potential of the data.

ACKNOWLEDGEMENTS

We would like to thank prof. Tanya Heyns, prof. Isabel Coetzee and all the participants for their valuable input during the data collection procedures. We would also like to acknowledge Isabel Claasen who provided language editing.

FUNDING INFORMATION

The authors have no sources of funding to declare.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data is not shared.

ORCID

Ariné Kuyler https://orcid.org/0000-0003-2784-4601
Ensa Johnson https://orcid.org/0000-0001-6203-1433

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How to cite this article: Kuyler, A., & Johnson, E. (2023). Critically ill patients' experiences of nursing care and the effect on their personhood: A retrospective study. *Nursing Open*, *10*, 6903–6911. https://doi.org/10.1002/nop2.1944