





Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper

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Abstract

The aim of this discussion paper is to explore factors and contexts that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. While a biomedical framing is founded upon a dichotomy between the body and self, such that the body can be subjected to a medical and objectifying gaze, relational theories of self, multiculturalism and technological advances for life-sustaining interventions present new dilemmas which necessitate discussion about what constitutes personhood. The concept of personhood is dynamic and evolving: where historical constructs of rationality, agency, autonomy and a conscious mind once formed the basis for personhood, these ideas have been challenged to encompass embodied, relational, social and cultural paradigms of selfhood. Themes in this discussion include: the right to personhood, mind–body dualism versus the embodied self; personhood as consciousness, rationality and narratives of self; social relational contexts of personhood and cultural contexts of personhood. Patricia Benner's and Christine Tanner's clinical judgement model is then applied to consider the implications for nursing care that seeks to reflexively incorporate personhood. Nurse clinicians are able to move between conceptions of personhood and act to support the body, as well as presumed autonomy and relational, social and cultural personhood. In doing so, they use analytical, intuitive and narrative reasoning which prioritises autonomous constructions of self. They also incorporate relational and social contexts of the person receiving care within the possibilities of technological advances and constraints of contextual resources.

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behaviours, cognition, conceptualisation, conscious disorders, nursing, personhood

1 | INTRODUCTION

Definitions and constructs of personhood in healthcare are contextual, and often depend on culture, beliefs and the medical conditions that affect a person, including impacts on their rationality, self-determination and capacity to interact with their social world (Garthoff, 2019; Penner & Hull, 2008; Scharmer, 2018; Walker & Lovat, 2015). Consequently, what encompasses nursing care for people with altered consciousness, cognition and behaviours is bound to be influenced by the value and understandings that nurses assign to personhood (Blain-Moraes et al., 2018). In many healthcare settings, and in health literature, notions of personhood are founded upon the existence of a biological being with unique personal attributes, who possesses autonomy (which may be either personal or relational), with most constructs of personhood incorporating both the body and society (Berenbaum et al., 2017; Kong et al., 2017; Playford & Playford, 2018; Walker & Lovat, 2015). This discussion paper draws on literature addressing both personhood and its relationship to care for people with altered consciousness, cognition and behaviours, including people with dementia (Berenbaum et al., 2017; Higgs & Gilleard, 2016; Milte et al., 2016; Palmer, 2013; Smebye & Kirkevold, 2013; Vukov, 2017), people in intensive care units (ICU) (Koksvik, 2016; Walker & Lovat, 2015) and older adults in residential care homes at end-of-life (Kong et al., 2017). It also examines research on the personhood of people with lived experience of mental health challenges (McTighe, 2015) and people in a neurologically nonresponsive state following severe traumatic brain injury (TBI) (Playford & Playford, 2018; Young, 2019).

2 | THE RIGHT TO PERSONHOOD, MIND-BODY DUALISM VERSUS THE EMBODIED SELF

There are complex and ethically, legally and politically fraught debates about what it means to be a person, including whether a person with diminished capacity or a nonresponsive patient is conceived of as a full person (Blain-Moraes et al., 2018; Koksvik, 2016; Penner & Hull, 2008; Playford & Playford, 2018). For example, in relation to the acknowledgement of humanness, the American philosopher Jeff McMahan argued:

How a being ought to be treated depends, to some significant extent, on its [sic] intrinsic properties—in particular, its psychological properties and capacities. With respect to this dimension of morality, there is nothing to distinguish the cognitively impaired from comparably endowed nonhuman animals. (1996, as cited in Playford & Playford, 2018, p. 1409)

Tristram Engelhardt also questioned the automatic right to personhood among people with significant impairment: 'If the significantly neurologically or physically damaged human being no longer has the attributes necessary to 'rationality', then that human being no longer enjoys a claim to personhood' (1996, as cited in Walker & Lovat, 2015, p. 311). Furthermore, James Walter proposed that a lack of particular capacities not only has implications for personhood, but also for access to clinical care: 'When the properties that define humanhood are absent, the patient is not considered a moral subject who possesses any rights to healthcare' (2004, as cited in Walker & Lovat, 2015, p. 311). While these ideas are quoted from the 1990s and early 2000s, even recent literature referred to people who are unresponsive as being in a 'vegetative state' (Playford & Playford, 2018); language that suggests that the unresponsive person becomes a nonperson when they are unable to interact with or respond to their world.

In medicine, the dichotomous construct of mind-body dualism has been central to conceptions of personhood, where the physical body as a vessel for life is seen as distinctly separate to the nonphysical, subjective and rational self (Descartes, 1641/1996). This Cartesian dualism reduces human beings to body organs or parts, separate from mind, emotions and sense of identity (White, 2013). Historically, as the care of living bodies moved from the home to hospitals, further study, comparison, classification and statistical evaluation of the physical body was made possible and has been referred to as a *medical gaze* over a *machine-body* (Foucault, 2003). The dehumanising impacts of this separation of the body from the person's identity, and the material and intellectual frameworks that maintain the *medical gaze*, have been described as 'infused' with power (Foucault, 2003). This is, particularly, relevant to the power of medicine to name, describe and control. The dehumanising impact of the Cartesian view of the body, and its consequence (the *medical gaze*) in objectifying the body, sees nothing in it that is intrinsic to personhood (White, 2013).

In contrast, personhood has been understood through the idea of the *lived body*, which has emerged to theorise a unified and embodied human existence (Koksvik, 2016). There is an intertwining of the physical (habitual, biological, organic) body with the existential (personal, spontaneous, individual) body that is constantly transformed by the situations people find themselves in, as they perceive their world and express themselves through their body (Merleau-Ponty, 1962, 1968).

3 | PERSONHOOD AS CONSCIOUSNESS, RATIONALITY AND NARRATIVES OF SELF

Central to the historical and philosophical positioning described, most definitions of personhood encompass the notion that a range of psychological and intellectual capacities impact on a person's

perception of the world, such as self-consciousness, rationality, cognition, moral agency, autonomy, linguistic ability and the ability to have goals and make plans (Penner & Hull, 2008; Playford & Playford, 2018; Walker & Lovat, 2015). This is, however, challenged by stages of human development and comparisons with nonhuman beings; for example, the notion that newborn babies have lesser cognitive abilities than adult chimpanzees (Premack 2007, in Playford & Playford, 2018).

While rationality and intellect develop over a lifetime, when they become a focus for perceived personhood, this can lead to the denial of the recognition of the human rights of individuals where intellectual capacity is lost due to disability, illness, injury or age-related degeneration (Lefebvre & Levert, 2012; Playford & Playford, 2018). In response to this denial, personhood has been reconceptualised in some settings. A study exploring how personhood was perceived by carers of people living in the community with dementia described personhood as having three dimensions that were not contingent on cognition, including: biologic, individual and sociologic (Berenbaum et al., 2017). For example, *biologic personhood* considers an individual as a biological being where the focus of care is on fulfilling biological needs, such as relief from pain; *individual personhood* encompasses lived experiences, values and past roles (which may be understood vicariously via other significant persons) and *sociologic personhood* includes how society perceives and interacts with the person (Berenbaum et al., 2017).

Personhood has also been reconceptualised in relation to stigma. Mental health challenges, and, particularly, those involving altered states of mind (e.g., psychosis) are an example of a state where a person's sense of reality can be altered (Matthews, 2016). In such a state, the person's behaviours may be deemed socially unacceptable or uninterpretable and respect for personhood may be diminished as behaviour is stigmatised: examples may include a person hearing voices or expressing ideas that are outside of consensus reality or a person threatening harm to self or others. In such cases, medical interventions are often instituted irrespective of the person's will, as capacity is determined to be diminished. While involuntary treatments may be perceived (by some) as appropriate for relieving the person's distress, they have come under heavy criticism from people with lived experience of mental health challenges, and those who advocate for their rights. Criticisms include clinicians overriding people's rights and engaging in care and interactions that are dehumanising and undermine personhood (Matthews, 2016). In such circumstances, recognition of the capacity of a person receiving care to create a meaningful narrative, intelligible to others, is not the basis of personhood (McTighe, 2015). Rather, the impacts of the social and political environment are taken seriously, given they are implicated in traumatising individuals and disrupting personal narratives. Consequently, the person with mental health challenges, who is experiencing distress and altered states, is understood as seeking to make sense of self within this disordered sociological context (McTighe, 2015).

4 | SOCIAL RELATIONAL CONTEXTS OF PERSONHOOD

Literature further examines the social and relational contexts of personhood. In relational personhood, the possibility of exercising autonomy in the world is viewed as essential (Walker & Lovat, 2015). While autonomy is usually viewed as the individual's capacity for self-determination, it is also intimately linked to the relationships individuals have with others, who may respond to requests or act as advocates based on their knowing of the person (Sofronas et al., 2018; White, 2013; Young, 2019). As embodied cultural creatures, we are dependent upon intersubjective bonds that are derived from our understanding as *beings-in-the-world* (Svenaesus, 2014). For example, in a discussion paper exploring withdrawal of life-sustaining treatment decisions in the ICU, the concept of personhood and autonomy was revised to incorporate social relationships with relatives, ICU staff and salient others in the community. These people were presumed to perceive the person's best interests and act as an advocate for them, and thereby bring into reality the idea, that 'our identities exist within the context of relationships' (Walker & Lovat, 2015, p. 311). However, one dilemma lies in the example of a hypothetical patient who might have valued unlimited medical intervention. In such a case, ongoing technical support would be considered justified without consideration of cost, resource availability or indeed, if that intervention was futile in sustaining meaningful life. However, this egoistic approach, which gives the individual primacy, not only requires positioning 'in the world of others, but rather in the world as it actually is' (Walker & Lovat, 2015, p. 312). An authentic account of autonomy necessarily connects with the person's real-world and temporal situation with others, including their future quality of life in that world, as 'the lived body is not a thing, it is a situation' (Beauvoir, 2011, as cited in Walker & Lovat, 2015, p. 312). As such, while personhood may persist through lived relationships despite serious neurological damage, this does not negate a decision to withdraw life-sustaining treatment (Walker & Lovat, 2015). Rather, the responsibility of upholding relational personhood within the world of a new future would be taken up by nurses, doctors, family and significant others to act, serve and advocate for the unresponsive person, with ongoing discussions about treatment at multiple time points, and with multiple viewpoints, based on evolving status and contexts (Playford & Playford, 2018).

Relational personhood was described in a Norwegian study as enacted, being both done and undone for ICU patients who were unresponsive, unconscious or with impaired lucidity (Koksvik, 2016). Relational personhood was undone where an ICU patient was unable to speak, and their words were replaced by the sounds of their monitored organs which conversed with the outside environment (e.g., cardiac rhythm alarms and the sound of the mechanical ventilator). In this way, machinery becomes an integral part of the person who is the patient, and part of a network between the person and their clinicians. However, in this work, only when the nurse turns from the machine to the person who is the patient, are relational

faculties taken into account and relational personhood enacted. While treatment in the ICU is founded on 'doing what has to be done', possibly without regard for the person who is the patient, relational personhood is negotiated between several factors that emerge as vital when the person's capacities for expression are inhibited (Koksvik, 2016, p. 140). Examples of 'doing personhood' in this context included covering the body to respect modesty and speaking to the person, whether or not they were perceived to hear and understand. 'Undoing personhood' was exemplified by speaking over the patient as if they were not present, or speaking for the patient, ignoring signs of distress or signs of care preferences (Koksvik, 2016). Furthermore, this study found that what a clinician viewed and valued also influenced how relational personhood was supported, or negated, in the doing and undoing of personhood. Some behaviours of the person who is the patient, even involuntary behaviours (like convulsions), could be labelled as deviant and therefore attributed a moral value, even when unrelated to a person's intentions, rationality, agency, autonomy or awareness (Koksvik, 2016). Such an approach to behavioural evaluation, contributes to the undoing of personhood. This supports Kitwood's notion that personhood is a 'standing or status bestowed upon one person by others, and in the context of social being' (Kitwood, 1997, p. 8).

5 | CULTURAL CONTEXTS OF PERSONHOOD

The meaning of personhood in healthcare has also been discussed from the perspective of culture with divergent meanings described between some Western and non-Western cultures (Koksvik, 2016; Kong et al., 2017; Playford & Playford, 2018). While in some Western cultures, personhood is promoted as dependent on a conscious and self-aware individual with agency and a right to individual choice, some non-Western cultures have prioritised relational personhood which may be denied, attenuated, withdrawn by others or lost (Conklin & Morgan, 1996; Koksvik, 2016; Playford & Playford, 2018).

These diverse cultural interpretations have also been found to shape nursing practice and patient experiences. For example, among the Tallensi ethnic group of Ghana, personhood has been described as being earned and is bestowed only upon those members of the community who demonstrate long periods of service to the community (Koksvik, 2016). In Botswana, aspects of personhood following unfavourable life events such as TBI, are traditionally understood as enhanced or diminished in the context of mystical powers, misfortune or interaction with ancestors (Mbakile-Mahlanza et al., 2015). In Hong Kong, a Western model of dignity was determined as overly individualistic and culturally irrelevant to Chinese people where consideration of collective family and community groups was more highly valued and where the interdependent self and familial connectedness took precedence in understanding personhood (Kong et al., 2017). However, it is an important consideration that in low-income countries, with severe resource constraints, access to highly technical life-saving

interventions may depend more upon access to resources and care, than on cultural considerations about life, death and personhood.

6 | DISCUSSION

This discussion paper aimed to explore conditions and factors that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. As the paper puts forward, not all elements of current definitions of personhood, are applicable to people who have diminished intellectual or psychological capacity. Indeed, there is an appreciation of the experiences and values of a person before their altered state, and the relationships with significant others, clinicians and the social world that sustain personhood. For example, autonomy does not merely reside within the individual, rather, relational autonomy exists and is supported by persons of significance, including strangers in the clinical context who engage with and interact with machines that 'speak' for the person. Within this discussion, recognition of the inequity and stigma and the tendency to withdraw personhood on this basis, is paramount. This discussion also suggests that personhood has a cultural context, informed by cultural expectations, beliefs, traditions and resources, which impact on notions and options to recognise personhood. These elements combined become part of a nurses' clinical assessment to inform nursing clinical judgement. However, it also requires the nurse to understand and challenge their own ideas about personhood, and how that may inform appropriate care.

In a reflection on practice within biomedical settings, dualistic perspectives of personhood and separation of mind and body may dominate, with a resulting impact on decision-making about a person's body that may be misaligned with the person's sense of self. Attribution of personhood also has a basis in morality. Ethical dilemmas may arise from how people and healthcare workers view life and death, and how diverse religious or spiritual beliefs may complicate decision-making in life-threatening situations. It also seems that society places great value on intellectual capacity, self-determination and intelligible narratives of self, meaning we are challenged to value people with cognitive impairment, reduced capacity or altered states of mind when providing medical intervention and person-centred care. Alterations in consciousness may also make it hard for people receiving care to express preferences, putting the emphasis on clinicians, including nurses, to promote personhood by understanding what they may have wanted or may wish to communicate. Finally, altered perceptions of reality and unusual behaviours, in, for example, those with mental health challenges, can make it challenging to connect with people. This is, particularly, so in highly controlled hospital environments where rights are withdrawn, and it is harder to manage behaviours in a way that does not dehumanise and reduce dignity (Cutler et al., 2021).

In wrestling with the ramifications of reflections on personhood, nurses might consider the seminal works of Patricia Benner and Christine Tanner. Tanner (2006) proposes that nurses interpret the

person's needs through three patterns of reasoning: *analytic reasoning*, which draws on the systematic use of objective clinical data to breakdown a situation and generate a range of possible responses. This type of reasoning may utilise observation charts and trends, care plans and pathways, guidelines and algorithms and speaks mainly to biologic personhood or the body of the person. *Intuitive reasoning* informs an immediate grasp of a situation based on experience of similar previous situations and pattern recognition, including past interactions with a patient, or with people from similar backgrounds or illness states (Benner, 1984; Benner & Tanner, 1987; Benner et al., 1996). *Narrative reasoning* involves clinicians making sense of a person's illness experience and explaining what one sees through having knowledge of their biopsychosocial lives, including relational aspects (Tanner, 2006). This may provide insight into the illness experience and meanings, ways of coping and both the patient's history and sense of future possibilities as well as relational knowledge of the person (Barkwell, 1991). These insights may not, however, be directly accessible from the person at the centre of care. Detailed nursing assessments in relation to these three types of reasoning support biologic, relational and cultural personhood for people receiving nursing care.

Before a nurse can pursue this reasoning pattern, they must notice phenomena that will set up their expectations about a person's situation. These phenomena occur within the *context* of care, the *background* to the current situation, and the existing *relationships* that underpin care (Tanner, 2006). When Tanner's clinical judgement model was used in a study of pain assessment for severely burned ICU patients (Taggart et al., 2021), *context* incorporated the severity of injury and phase of recovery, patient responsiveness and cognition, the presence of emotional trauma, medical devices that inhibit communication, relevant language proficiency and context of the unit culture. The *background* incorporated the culture, beliefs, values and experience of the ICU clinicians. Professional and therapeutic *relationships* were shaped by concepts drawn from Benner et al. (2009): the nurses' intentions to humanise and personalise care, knowing the patient as a person, knowing the patient's usual pattern of responses and the relationships between patients and clinicians (Taggart et al., 2021). These elements contribute to nurses' noticing salient phenomena that set up expectations and an initial grasp of the situation. What a nurse notices may determine their attention to personhood, which reasoning patterns they select and how they prioritise subsequent nursing interventions.

In contemporary clinical practice, the concept of personhood remains dynamic and continues to challenge and move away from the historical constructs of the possession of rationality, agency, autonomy and a conscious and intelligible mind. Technological advances for life-sustaining interventions, along with growing multiculturalism, present new dilemmas which necessitate an evolving discussion about the constitution of personhood (Koksvik, 2016). The insights provided seem to argue for the promotion of care that supports people to maximise their existing capacities, to limit the harm that could occur to them due to their limited abilities, and to

value personhood as an inherent quality sustained through lived relationships (Higgs & Gilleard, 2016; Vukov, 2017). Nursing strategies with positive impacts on personhood can promote comfort and dignity, provide access to meaningful activities, promote independence, communicate a person's value and support connections with family and friends (Kong et al., 2017; Milte et al., 2016; Palmer, 2013; Smebye & Kirkevold, 2013). For people with mental health challenges, research suggests that sociologic personhood and sense of psychological safety are enhanced when nurses actively seek ways to promote personhood through empowering the individual, collaborating with them and respecting equality and personal choice (Cutler et al., 2021). Such care demonstrates respect for the person's beliefs, emotions, values and lived experiences (Palmer, 2013). On the other hand, nursing approaches that construct personhood-inhibiting experiences can lead to a sense of losing oneself (Cutler et al., 2021). This is when people are unable to express their personal qualities and interests, where they are uprooted from environments that support personal expression, or where their voices and choices are marginalised, and when priority is placed on task-centred over person-centred interventions (Cutler et al., 2021; Kong et al., 2017; Smebye & Kirkevold, 2013).

7 | CONCLUSION

The purpose of this discussion paper was to explore conditions and factors that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. The primacy and inherency of rationality and individual autonomy to personhood when assessing and providing person-centred care for some populations has been questioned. The importance of sociorelational and cultural elements may be of greater importance. What nurses bring to a situation, the context of care and important interpersonal relationships may influence what they notice about a clinical situation and how that may support their assessment, clinical judgement and enactment of personhood. A clinical judgement model by Patricia Benner and Christine Tanner was used to highlight how nurses may use analytical, intuitive and narrative reasoning to support consideration of personhood, including biologic, sociological, relational and cultural personhood. Nurses might also consider individual, social and cultural contexts of care and how these impact on their considerations. These differences render challenges for nurse clinicians in promoting personhood and require reflexivity, understanding both one's own position towards people in one's care and the will to explore the person's lived relationships with significant others.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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