Situated Personhood:
Insights from Caregivers of Behaviorally Unresponsive Individuals

Johnny Brennan[1], Molly Kelleher[1], Stefanie Blain-Moraes[2] and Laura Specker Sullivan[1]

[1]Fordham University, [2]McGill University

Introduction

- **A growing number of individuals live with conditions that render them behaviorally unresponsive**, including persons with profound and multiple disabilities, persons with advanced dementia, and those in disorders of consciousness such as coma, minimally conscious state, and locked-in syndrome[1].
- Caring for behaviorally unresponsive individuals poses challenges:
  - Most (if not all) of the necessary communication surrounding care is up to the interpretation of the caregivers
  - The unresponsive state of the individual raises questions about personhood and moral status.
- The **Static View of personhood** has a strict view on the relationship between personhood and moral status.
- The **Situated View** opens conceptual space between personhood and moral status.

Goal: To argue for a different conception of personhood, what we will call situated personhood, representing the perspectives of personal caregivers as they attend to the needs of their behaviorally unresponsive loved ones.

Methods

- This project was **a secondary analysis of primary data** collected by Dr. Blain-Moraes and her McGill team.
- The co-authors utilized Atlas.ti to qualitatively analyze the **extant interviews and field notes from work with caregivers of individuals who are behaviorally unresponsive, including persons with advanced dementia and individuals in disorders of consciousness.**

- A series of thematic codes and sub-codes were developed through iterative engagement with the data.
- We coded passages with the most specific code applicable, often using multiple codes for the same passage. This was necessary to capture the nuanced experiences of the caregivers. When we were unsure about which sub-code(s) were most applicable, we coded passages with the more general parent code(s).

Evidence for Situated Personhood

Limitations and Uncertainty

Caregivers described an acute sense of their limitations in caring for behaviorally unresponsive persons, stemming primarily from the nature of taking care of all of another person's needs as well as uncertainty about how to interpret the individual's behaviors, reflexive actions, and sub-communicative vocalizations.

Drifting Personhood and Intentionality

Caregivers reflect a sense that the individual for whom they are caring drifts in and out of personhood. At times they care for the loved one they remember, at times they care for a different person, and yet at other times they care for a body without much in the way of recognizable personhood. The behaviors and vocalizations of the individual often lack an intentionality that is associated with personhood and their sense of their loved one's personhood waxes and wane in concert with the loved one's lucidity and expression of personhood-like behaviors such as recognition, recollection of significant individuals and events, desires, intentions, and the like.

Strategies for Holding in Personhood

In circumstances in which personhood is difficult to judge, caregivers "fill the gap" to reach the threshold through a repertoire of strategies: memories, shared cultural values, other family and friends, and technological interventions such as biomusic.

Hilde Lindemann calls this process "holding in personhood." It is "the practice of…constructing or maintaining an identity for her when she cannot, or can no longer, do it for herself."[2]

These efforts were hampered by structural forces in the healthcare system that impeded holding loved ones in personhood, and instead facilitated letting go of personhood, most often by viewing or treating the patient as a spectacle or as an object.
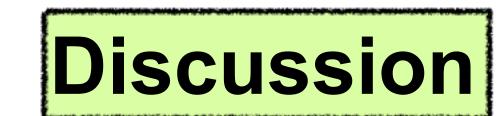
Letting Go of Personhood

Despite the obstacles posed by these structural forces, momentarily letting go of personhood was another strategy at the disposal of caregivers to help them in dealing with the stresses of such involved care. Caregivers sometimes took advantage of this strategy to facilitate efficient care of their loved ones aimed at maintaining their overall dignity.

Results

Factors Affecting Perception of Personhood
- Limitations and Uncertainty
- Drifting Personhood and Uncertain Intentionality
- Strategies for Holding in Personhood
- Letting go of Personhood

Discussion

Rather than comprising an absolute status, personhood is judged by caregivers to be a threshold concept that individuals who are behaviorally unresponsive reach in certain situations and in response to certain people.
- Recent work in feminist ethics and disability studies has questioned the primacy of rationality, offering care and other relational characteristics as alternatives[2,4,5,6,7].
- The Situated View of personhood expands the conditions of personhood with the result that personhood is both more relational and dynamic. This view is more forgiving than the static view of personhood.

Conclusions

- The **Situated View calls for a wide-ranging environment of care that is more supportive of recognizing personhood in individuals who are no longer capable of intentionally expressing their personhood.**
  - Overworked, underpaid, and under-resourced health care positions do not support this type of environment.
- The benefits of structural change for the maintenance of personhood in behaviorally unresponsive patients are robust enough that we ought to attempt such changes.

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