

DEMENTIA AND CARE: THINKING BEYOND PERSONHOOD?

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19 JUNE 2026

ABSTRACTS (IN ORDER OF PRESENTATION)

Federico Zilio

Which Person? Philosophical Paradigms of Personhood in Dementia Care

When we talk about personhood in dementia care, who are we referring to? And when we adopt a person-centred approach, who are we thinking of? These questions highlight the conceptual complexity of the term “person” and its significant clinical and ethical implications. Personhood is not merely descriptive but morally laden, intrinsically linked to dignity, rights, and obligations we recognize toward others. This presentation provides a philosophical framework highlighting how contemporary personhood concepts are rooted in two historical paradigms: the classical-substantialist paradigm (Thomistic) and the modern-functionalist paradigm (Lockean). The former considers the person as a substantial entity intrinsically linked to human being as such, distinguishing between disposition (natural endowment), ability (developed capacity), and exercise (actual performance): personhood depends on rational nature as disposition, not on the actual exercise or even the developed ability of rational faculties. The latter identifies personhood with psychological and cognitive properties that can emerge, develop, and deteriorate or disappear, focusing primarily on exercise and ability rather than disposition. Rather than opposing these paradigms, I argue for their integration: the Thomistic-substantialist approach provides the ontological foundation for inalienable dignity and continuous personal identity, while the Lockean-functionalist perspective offers valuable tools for phenomenologically describing real changes in cognitive capacities and orienting specific therapeutic interventions. However, this integration requires that the Lockean dimension be subordinated to and reinterpreted within the Thomistic framework: psychological capacities are manifestations of personhood, not its constitutive conditions. Thus, in dementia care, thinking “beyond personhood” means moving beyond the purely Lockean-functionalist paradigm, which risks depersonalising patients whose cognitive capacities have deteriorated, but who still deserve full dignity and care. Instead, this integrated approach recognizes that patients with advanced dementia remain persons ontologically while experiencing genuine deterioration of personal capacities, grounding care practices that respect intrinsic dignity while remaining sensitive to changing phenomenological conditions throughout cognitive decline.

Annette Leibing

Against Personhood in Dementia Care: Alienation as a Shift of Attention

In this talk, I do not argue against personhood itself. Rather, I contend that, especially in dementia care settings as described by social scientists and gerontologists, personhood can easily become a fallacy of care. Instead, I will propose a renewed reading of alienation that, when applied to dementia care, helps us rethink taken-for-granted ideas about care by shifting attention to ordinary and prosthetic lives. Based on fieldwork in an ‘alternative’ dementia care home in Quebec, I juxtapose examples of person-centred and alienation-centred care to make my argument. Alienation here has three elements: ordinariness, prosthetics, and a critical reflection on origins by noting “what is wrong” in care assemblages.

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Nik Brown, Daniel Robins (Presenting Authors), Sarah Nettleton, Karl Atkin, Luna Dolezal **Queering Care and Reimagining Personhood: A Possible Posthumanist Sociology of Healthcare Robots in Dementia Care Settings**

This paper reports on findings from the trial of a telemediated robot care platform in a Finnish hospital brain injury unit. Based on qualitative fieldwork, we propose a sociological and phenomenological approach to healthcare robots that moves beyond traditional human/non-human binaries to explore the evolving landscape of dementia care and personhood. By tentatively adopting a ('possibly') 'robocentric' approach, we want to 'queer' the relationship between human and machine, recognising care as a more-than-human non-rationality produced through hybrid assemblages of humans, materials, and algorithms.

Central to this framework is the phenomenology of recognition and mis-recognition, where robots function as a 'double body' that invites patients to attribute biography and agency to artificial forms. In dementia contexts, 'affective technotouch' and zoomorphic robots suggest that care is not necessarily species-specific but an embodied encounter where the human is already implicated in the machine. However, telepresence technologies reveal a critical 'struggle for recognition' - as fixed robot morphologies can homogenise and occlude a caregiver's racial, gendered, and cultural identity, risking the transformation of human care practitioners into 'interchangeable commodities'.

Care robotics introduces a techno-biopolitics characterised by 'infopower', where, rather than a one-way service, care is reconfigured as mutual labor through a 'mutuality of maintenance'. Here, unfinished robots require human repair and care just as they support human health. This 'mangling of agency' suggests that personhood is iteratively produced through the entanglement of biological and artificial subjects.

Ultimately, this challenges the anthropocentric 'gold standard' of face-to-face interaction, proposing a posthumanist ontology where care is a relational practice of perpetual becoming.

Martin Chevallier

Infusing an animal robot with personhood? Caregivers' contribution to bonding with a demanding creature

This contribution revisits insights drawn from a two-week fieldwork in the dementia ward of a French nursing care home, where the "social" and "emotional" character of a seal robot, Paro, was shown to arise, to a large extent, from the tactile and verbal guidance provided by caregivers to older adults suffering from cognitive impairment, the latter guidance including sophisticated forms of "ontological work" (Chevallier, 2023). This talk will attempt to go further into the investigation of plural forms of ontological work by comparing two ways by which care professionals managed (or at least tried) to find a suitable position for a robot found appealing by some users at first glance, but nonetheless fundamentally reactive. These two modes of "interfacing" (Lipp, 2022) could be distinguished as follows: on the one hand, tight physical couplings with minimal verbal guidance, aimed at alleviating anxiety and agitation and sometimes, incidentally, leading to unspoken and unfathomable attributions of personhood to the robot; on the other hand, dialogue-based attributions that caregivers negotiated with older citizens, by asking and answering questions, addressing their perplexity, setting the robot "journey" among different users to prevent it from being monopolized, and eventually, supporting and fuelling residents' explicit views on the nature, identity and/or role of the robot. Moreover, this presentation will scrutinize the management of "uneven encounters" – that is, the concomitance of affectionate reactions from a resident and dismissive behaviours of other(s) who show no intention to treat it with affection or even no interest in it – through which caregivers accommodate and legitimize conflicting ways of dealing with Paro.

Blanca Deusdad, Marija Djurdjevic, Fernando Vidal

Preliminary findings from the ethnographic study *MyRobot*

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The *MyRobot* project explores how various sociocultural factors modulate the perception of companion robots among older adults with dementia and their care teams. The ethnographic study was conducted in eight nursing homes and day-care centres across several Spanish regions (Catalonia, Extremadura, Valencia, and Castilla-León) exploring beliefs, attitudes and relational dynamics developed during the use of the companion robot PARO (known in Spain as Nuka). Techniques for qualitative research we used included participant observation of Human–Robot Interaction, in-depth interviews with residents, relatives, and care professionals, and pre- and post-interaction questionnaires to measure the impact. We seek to describe how relationships with robotic companions emerge within broader networks of care. This includes inquiring into personhood and personal identity as relational processes. Preliminary findings indicate that dementia is narrated differently across stakeholders: relatives often describe it as a biographical rupture, while professionals frame it as a clinical trajectory. Despite cognitive decline, the continuity of the person is frequently recognized through signals, such as gaze, smiles, touch and affective responses, which highlight the relational and embodied dimensions of personhood in dementia care.

We observed that Paro (Nuka) operates primarily as a relational mediator, facilitating social interaction, emotional activation, and shared attention between residents, caregivers, and family members. We shall examine what the data may also say about Nuka’s liminal ontological status in practice: while officially a “medical device,” engagement with it brings it close to the status of a living being. Findings up to now confirm what other studies have documented, namely that companion robots should not be understood merely as therapeutic devices but as sociotechnical actors embedded in complex care ecologies.

Mariam Nofiss

Autonomy and Authenticity in Persons with Alzheimer’s Disease: A Relational Caring Approach

The traditional bioethical framework, rooted in liberal ideals of rationality and autonomy, often fails to uphold the dignity of persons with Alzheimer’s disease (AD) as their cognitive capacities decline. In clinical practice, situations arise in which patients with AD, despite retaining some decision-making capacity, express preferences that appear inconsistent with their previously held values, life narrative, or sense of self. In such cases, respecting autonomy becomes ethically problematic: how is it possible to respect a patient’s choice when it seems to conflict with who they are – or who they have been – and with what clinicians know about their longstanding desires and values?

This paper argues that the concept of authenticity – the capacity to act in accordance with one’s own values, beliefs, and personal history – provides a critical lens for rethinking personhood in dementia. It proposes to reconceive autonomy as comprising two interrelated dimensions: agency (the capacity to make a choice) and authenticity (the identity-based nature of that choice). This reframing allows us to move beyond functionalist models that risk reducing personhood to cognitive performance.

Adopting a bioethical and phenomenologically informed approach, the paper argues that autonomy and authenticity should be understood as intertwined and dynamic capacities subjected to vulnerability. Such a perspective enables dementia care to take the patient’s present lived experience seriously, without reducing personhood either to a cognitively “intact self” or to previously expressed wishes. Within a relational framework, advance directives and shared care planning can be reinterpreted as mediating tools that illuminate the tension between past and present orientations, thereby fostering a more collaborative and authentic clinical relationship.

Ultimately, by centering authenticity, this paper argues for moving beyond narrow definitions of personhood to better account for evolving identities, while preserving and promoting the dignity and moral agency of those living with AD.

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Neurological Process versus Neurological Capacity: Two Problems for a Disability-Based Affective Bioethics

Matthew Wolf-Meyer

The brain is a consistently problematic object. For scientists and physicians who operate in biomedical contexts, the brain is both an originator and manager of specific processes and a set of resources that serve as limits to individual capacities. In the case of the former, this includes such things as the control of reactive behaviors (e.g., the impulses that govern how a person reacts in a particular situation), as well as the regulation of physiological systems, which include elements of living like breathing and heart beats. In the case of the latter, the brain is often accepted as serving as the basis for a set of capacities that are expressed through social interactions: intelligence, communication, interiority, empathy, etc. I focus on two ethnographic cases drawn from clinical ethnography that help to explicate the difference in how people conceptualize neurological processes and capacities and the social responses they motivate. I use “affective bioethics” as a framework for clinical and extra-clinical decision-making. Affective bioethics prioritizes affective capacities and connections between individuals, communities, and their environments in contradistinction to forms of bioethical principlism and virtue ethics that often stress the importance of professional and biomedical norms that often exclude disability experiences.

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SPEAKERS' BIOGRAPHIES (IN ALPHABETICAL ORDER)

Nik Brown is Professor in Science and Technology Studies (STS) and Head of the Department of Sociology at the University of York, UK. He has specialised in STS and the Sociology of Health and Illness, writing and researching on the biopolitics of immunity. He has led externally funded research projects on transplantation, xenotransplantation, stem cell biobanking and regenerative therapies, antimicrobial resistance, hospital architectural design and healthcare robotics.

Martin Chevallier received his PhD in Sociology at the École des Hautes Études en Sciences Sociales (2023) with an investigation on the use of social robots in various sectors, particularly care and retail. As a specialist of technological innovation and participatory design issues in geriatric care and disability, he has been involved since 2021 in INNOVCARE, a research project on “care-led” approaches to innovation in the care of older citizens. The project is based on cross-border research and collaborations between French and Japanese social and human scientists, epidemiologists, medical practitioners and engineers. Chevallier’s research is anchored in STS, sociogerontechnology and the anthropology of aging.

Blanca Deusdad is Associate Professor of Social Work in the Department of Anthropology at Rovira i Virgili University and coordinator of the doctoral program in Social Work. She was principal investigator for the European H2020 SoCaTel project, on the co-creation of care services with older adults, and is currently co-PI of MyRobot, a research project on the use of the social robot PARO (“Nuka” in Spain) with people living with dementia. She was member of the Board of the Catalan Society of Geriatrics and Gerontology, has received a 2025 ICREA Academia research distinction from the Catalan University and Research Grants Management Agency (AGAUR), and was appointed coordinator of the European network for gerontological social work at the European Social Work Research Association (ESWRA).

Marija Djurdjevic holds a PhD in Humanities (Philosophy) from Pompeu Fabra University. In addition to her research trajectory in the social sciences – including cultural studies, social anthropology, and medical anthropology – she has worked as an advisor and manager of European R&D&I projects focused on healthcare innovation, particularly the redesign of services for vulnerable populations. Her current research examines the transformation of health systems toward integrated, person- and community-centred health and social care. She works primarily with qualitative and action research methodologies. She is currently a postdoctoral researcher in the MyRobot project, where she investigates healthcare professionals’ perceptions and uses of the therapeutic companion robot PARO in interventions involving older adults living with and without dementia.

Annette Leibing is full professor at the Nursing faculty at Université de Montréal. Her research concerns Alzheimer’s and Parkinson’s disease, aging and psychiatry, pharmaceuticals, elder care, futurities, and stem cells for the body in decline. After extensive research on the critical aspects of dementia prevention in Brazil, Canada, Germany, and Switzerland, she initiated, together with Mark Schweda, an international study group on “resisting the future.” In this framework, she is currently writing a book juxtaposing aging punks and former Jehovah’s Witnesses. She is also finishing, together with two authors and a composer, a book of short stories about forgetting.

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Mariam Nofiss is a PhD candidate in Food, Health, and Longevity Studies at the Department of Translational Medicine, University of Eastern Piedmont (Novara, Italy). Her research concerns the ethical challenges of population aging, particularly in the clinical context of neurodegenerative diseases such as Alzheimer's disease and ALS. She focuses on therapeutic-communicative strategies tailored to the unique needs of older adults. She also explores the intersection of ageism and epistemic injustice in clinical and social contexts, and collaborates with the neurology team at Novara's Ospedale Maggiore della Carità, participating in multidisciplinary ALS outpatient visits, providing bioethical consultation, and assisting in the development of a shared care planning protocol.

Dan Robins is a postdoctoral research associate in the Department of Sociology, University of York, working with Nik Brown on the biopolitics of the biosciences. He has published widely on Science and Technology Studies (STS) and its overlaps with death, health, data-led governance, and the environmental and technological management of the dead body.

Fernando Vidal is Research Professor of the Catalan Institution for Research and Advanced Studies (ICREA) at the Medical Anthropology Research Center (Rovira i Virgili University). He has long worked as intellectual historian of science, publishing, among others, *The Sciences of the Soul: The Early Modern Origins of Psychology*, and receiving in 2021 the Carlson Award "in recognition of extraordinary scholarship in the history of the human sciences." His two most recent academic books are *Being Brains: Making the Cerebral Subject* (with F. Ortega) and *Performing Brains on Screen*. His current works concerns the anthropology and phenomenology of the locked-in syndrome, the disorders of consciousness and the dementias, and ethics in the biomedical and human sciences.

Matthew Wolf-Meyer is Professor of Science and Technology Studies at Rensselaer Polytechnic Institute. He is the author of *The Slumbering Masses: Sleep, Medicine and Modern American Life* (2012), *Theory for the World to Come: Speculative Fiction and Apocalyptic Anthropology* (2019), *Unraveling: Remaking Personhood in a Neurodiverse Age* (2020), and *American Disgust: Racism, Microbial Medicine, and the Colony Within* (2024). He is the editor of *Proposals for a Caring Economy* (2025), *Mapping Medical Anthropology for the 21st Century* (with Junko Kitanaka and Eugene Raikhel, 2025), and *Naked Fieldnotes: A Rough Guide to Ethnographic Writing* (with Denielle Elliott, 2023). His research focuses on the biology of everyday life, affective approaches to subjectivity, and posthuman bioethics.

Federico Zilio is Assistant Professor in Moral Philosophy at the Department of Philosophy, Sociology, Education and Applied Psychology of the University of Padova. He was a visiting scholar at the Mind, Brain, Imaging and Neuroethics Research Unit of the Royal's Institute of Mental Health Research at the University of Ottawa (Canada), under the supervision of Prof. Northoff, with whom he has collaborated since 2018. His research focuses on the neuroethics of consciousness and neurotechnology. His books include *Persone oltre la mente. Neuroetica dei disordini della coscienza* (2024), and *Consciousness and World. A Neurophilosophical and Neuroethical Account* (2020).

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