

Manuscript Title: The Relational Care Framework: Promoting Continuity or Maintenance of Selfhood in Person-Centred Care

Authors: Matthew Tieu & Stephen Matthews

This article has been accepted for publication in the *Journal of Medicine and Philosophy* Published by Oxford University Press.

Abstract:

We argue that contemporary conceptualizations of “persons” have failed to achieve the moral goals of “person-centred care” (PCC, a model of dementia care developed by Tom Kitwood) and that they are detrimental to those receiving care, their families, and practitioners of care. We draw a distinction between personhood and selfhood, pointing out that continuity or maintenance of the latter is what is really at stake in dementia care. We then demonstrate how our conceptualization, which is one that privileges the lived experiences of people with dementia, and understands selfhood as formed relationally in connection with carers and the care environment, best captures Kitwood’s original idea. This conceptualization is also flexible enough to be applicable to the practice of caring for people at different stages of their dementia. Application of this conceptualization into PCC will best promote the well-being of people with dementia, while also encouraging respect and dignity in the care environment.

Key Words: *Dementia, Person-centred care (PCC), Tom Kitwood, Personhood, Selfhood, Identity*

Introduction

Person-Centred Care (PCC) was a welcome change from the medically and behaviourally oriented approach to dementia care associated with the old institutional or warehousing model. The phrase “person-centred” reminds us of the ethical obligation we have to treat those with dementia as persons, rather than mere patients. However, in recent years, the idea of PCC has been obscured by a tendency to characterize personhood in isolation from families, carers, the social environment and the broader community. As a result, contemporary understanding of PCC focuses primarily on promoting individualism and autonomy, and this is problematic theoretically, ethically, and practically. PCC ought to (and did in fact) conceive of people in care as embedded in the social environment, which in turn requires a conception of them as selves in relation to both the aged care setting, and (more importantly), those who care for them. Hence, our contention is that dementia in its various stages is better understood as a condition affecting the closely related concept of selfhood, which we define as essentially intersubjective, socially embedded, and depending on continuity of lived experience.

A key implication arising from this re-conceptualization relates to the stance that carers should take towards people with dementia. Such a stance requires viewing those in care as morally significant participants in social life, as having social presence or visibility, and as retaining a role, or position, or at the very least a set of interests, that (ideally) connects with their life pre-dementia. Therefore, in this paper we argue that PCC must focus on promoting continuity or maintenance of selfhood at the relevant stage of dementia, and this requires strategies that enable a person with dementia to retain an overarching sense of themselves based on their understanding of who they are, who they were and how they are received by others.

While this conceptualization has general applications, it is most relevant during the middle stages of dementia. For during this period, the ethical stance we take to those in care, like Peter Strawson’s *participant* stance (Strawson, 1974) in which it is considered appropriate to react to others as social

beings rather than as patients we manage, becomes tenuous. This is particularly so when cognitive impairment, especially in language and memory, damages one's capacity for normal social exchange, which often compels us to take the kind of ethical stance (as per Strawson's *objective* stance) where those in care are viewed merely as patients to be managed rather than participants in genuine intersubjective exchange and social life.¹

However, we contend that the decline during the middle stages of dementia is not sufficient to justify a move to an *objective* stance, where care risks devolving into the "institutional" or "warehousing" approach it had been designed to overcome. We maintain that it is important to retain elements of social participation and for carers to therefore maintain a stance that preserves a relationship based on such participation (i.e., a *participant* stance). However, in very late or advanced stages of dementia, occupying this stance may be impractical and may yield limited utility. Nevertheless, we argue that moving to an *objective* stance, purely understood, may not be best. For even during these stages, echoes of a past self are present, and often manifest as a style of behavioural and emotional expression demonstrating that a residual form of identity is still present.

In these cases, we think respectful care and the duty of providing ethical treatment requires attention to the dignity that is signified latently by this form of remaining selfhood. What does this mean? Michael Rosen (2012) identifies three strands of meaning for the rich and contested concept of dignity – dignity as a status borne out of hierarchy, dignity as intrinsic value (the Kantian notion that human beings have a dignity, and not a price), and lastly the idea of exhibiting a dignified manner when under duress. It is the last of these conceptualisations that comes closest to what may be applied in the care of a person with advanced dementia, someone who has presumably lost that which might undergird the familiar application of the term (such as a rational self-consciousness). Rosen suggests that in these kinds of cases it is a matter of symbolic respect and that the absence of receptivity by the other (and associated benefits of receptivity) would miss the point of this dignified approach to the caring relationship. Our duties here, he says, "...are so deep a part of us that we

could not be the people that we are without having them” (Rosen, 2012, 157). This, it seems to us, gets even greater purchase in the case of carers for whom an historical relationship exists with the one they care for.

The paper proceeds in two sections. In Section 1 we unpack the notion of PCC as defined by Tom Kitwood, including its historical connections to other clinical frameworks of care. We then diagnose what has gone wrong within extant applications of Kitwood’s framework, tracing the problem to the lack of clarity around conceptualizations of personhood, in particular a conceptualisation of persons as *objects* as opposed to *subjects*. We then argue for a different conceptualization underpinned by the related concept of selfhood, especially as supported by the possession of what we describe as an overarching sense of selfhood. The concept of selfhood we have in mind primarily serves as a pragmatic guiding model, but it is one that is compatible with, and supported by, a significant range of well-known models and definitions from cognitive psychology, social psychology, and philosophy.

In Section 2, we show how our conceptualization of selfhood may be applied in practice in what we call the “Relational Care Framework”. Importantly, our claim is that individualist notions of personhood (which Kitwood rejected) cannot be made to fit with the clinical realities of declining cognitive capacity. In dementia, progressive decline is often characterized by three stages corresponding to the mild, moderate, and severe effects on cognition and physical ability. We describe three scenarios of care that acknowledge these variations, showing how our framework has the flexibility to provide the correct conceptualization of selfhood and appropriate care stance within each of the scenarios.

Section 1 – Person-Centred Care (PCC)

1.1. What is PCC?

The idea of person-centred care (PCC) originated with Tom Kitwood, who adopted the term from Carl Rogers' "client-centred psychotherapy" and "person centred counselling" (also known as "Rogerian psychotherapy") and then applied it to the care of people with dementia (Rogers, 1957; Kitwood, 1997; Brooker, 2003). PCC is fundamentally based on what Kitwood referred to as an "enriched model of dementia" and is ethically grounded in a notion of personhood that he defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, 8). The "enriched model of dementia" refers to the idea that dementia is not just a biological or neurological condition but also a psychological and social condition. Kitwood pointed out that the symptoms of dementia are not just caused by structural failures of the brain but are caused by a multiplicity of factors (including physical health, biography, personality, and social environment) affecting the lived experience and quality of life of people with dementia. The ethical grounding for PCC comes from recognizing that we ought to treat people with dementia as "persons" (as defined above by Kitwood).

Drawing from those ideas, Kitwood argued that the traditional "institutional" or "warehousing" approach to dementia care, which focused primarily on medical and behavioral management of dementia as disease, ought to be replaced with a new culture of care that focused on promoting well-being and human dignity.

The new culture brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasizes the fact that our existence is essentially social. (Kitwood, 1997, 135)

Importantly, Kitwood placed much emphasis on promoting positive social interactions, authentic communication, and genuine relationships. For example, an important aspect of Kitwood's framework for PCC is avoiding what he calls "malignant social psychologies", which refer to

communications that constitute various forms of invalidation, ignoring, infantilizing, intimidation, mockery, and disparagement.

One of the most widely cited frameworks for understanding Kitwood's ideas about PCC is Dawn Brooker's VIPS framework. VIPS is an acronym that describes how people with dementia and their carers must be "valued", treated as "individuals", how we must incorporate their "perspective", and how we must attend to their "social environment" (Brooker, 2003, 2007). According to Brooker, providing a supportive social environment is the key to maintaining personhood on a day-to-day basis. It requires that we recognize that all human life is grounded in relationships and that people with dementia need an enriched social environment, one that both compensates for their impairment and fosters opportunities for personal growth. As Brooker states, "personhood can only be maintained in the context of relationships" (Brooker, 2007, 83).

While PCC is nowadays widely regarded as synonymous with "best practice" and "evidence-based practice" in aged care (Ekman et al., 2001; Kim and Park, 2017), researchers have bemoaned the lack of consensus on what the precise definition of PCC is (Slater, 2006; Edvardsson, Winbald and Sandman, 2008; Edvardsson, Fetherstonhaugh and Nay, 2010; McCormack and McCance, 2010). We believe that this is fundamentally due to the lack of conceptual clarity around what it means to be a person and thus what it means to promote personhood in the context of PCC. As a consequence, PCC has been understood and practiced in ways that place too much emphasis on the individual aspect of PCC at the expense of the social or relational aspects.

1.2. The Problem with Promoting Personhood

The notion of personhood functions as a foundational concept in ethics because having personhood is typically understood to imply a certain kind of moral status or moral value, evidenced by, for example, the ethical debates around ends of life, or human embryonic stem cell research. Hence, it

is reasonable to assume that personhood can provide an ethical foundation for PCC. Indeed, in addition to Kitwood's original definition, much of the current literature in nursing and aged care does define PCC in this way (Dewing, 1999; Penrod et al., 2007; De Bellis et al., 2009; Manthorpe and Samsi, 2016).

Unfortunately, personhood is a notoriously problematic concept in moral philosophy because there is no consensus on what constitutes personhood and what the necessary and sufficient conditions for personhood are (Farah and Heberlein, 2007; Higgs and Gilleard, 2016).² It is beyond the scope of our paper to go into any detail about these issues, but suffice it to say that PCC assumes an anthropocentric definition of personhood given that it is exclusively concerned with human beings with dementia.³ Furthermore, as part of our folk understanding of persons, we generally assume that persons refer only to human beings, and in particular, human beings as individual entities that can exist independently of their social and political environment.

Indeed, in the context of the current political economy (particularly in the West and emerging in other places) we see that there has been a tendency to operationalize PCC in accordance with this folk idea of personhood, whereby people with dementia are primarily viewed and treated in a way that assumes their personhood and agency exists independently of their social environment. For example, consider the recent trend in the way aged care policy is developed and implemented, which is primarily based on promoting independence, self-determination, self-management, and consumer choice (Manthorpe and Samsi, 2016). The political and economic ideology (neoliberalism) underpinning such a trend is one that redirects public resources to aged care recipients who are then primarily responsible for managing their care as consumers within the free market.⁴ Such policies are typically promoted as being person-centred, demonstrating that the operative definition of PCC is primarily concerned with promoting individualism, autonomy, and consumerism. It is interesting to note that a recent review on the understanding of PCC by Morgan and Yoder (2012) indicated that the term "individualised" (referring to the particular care needs of a client) is the most

frequently acknowledged attribute of PCC, while an equally important attribute is “empowerment” (referring to autonomy and self-confidence).

Critics have pointed out that such an understanding of PCC is misguided, arguing that there ought to be greater value placed on interdependence, carer-client relationships, shared decision making, and promoting connections with broader social networks (Tresolini and Pew-Fetzer Task Force 1994; Nolan et al., 2004; Beach and Inui, 2006; Nundy and Oswald, 2014). They also argue that the promotion of autonomy requires an appreciation of the interconnectedness of the carer-client relationship where decision making takes place within a framework of negotiation and mutual understanding (McCormack, 2001; McCormack, 2004; Munthe, Sandman and Cutas, 2011). Such views are well-founded and well supported by research demonstrating how adequate relationships with family and other people are important dimensions of quality of life measures for people with dementia (Moyle et al., 2001; Ettema et al., 2005). They are also a lot more consistent with the original ideals of PCC as formulated by Kitwood, who recognized that human beings were not only individual beings but also social beings.

Yet, the current direction of aged care policy takes PCC and the idea of promoting personhood to consist of facilitating a simplistic notion of autonomy and self-determination within the context of individualism and consumerism. It neglects the vital role that relationships and support networks play in facilitating care, shared decision making, and relational autonomy. The ethical implications of this should not be underestimated, especially when aged care services are becoming increasingly market-driven, in which issues concerning resourcing, equity, accessibility of services, choice of service providers and informed decision making inevitably arise. It is our view that the current understanding of personhood, in the context of PCC and the broader political economy, is not only conceptually problematic but also has the potential to be fraught with practical and ethical problems. We argue that dementia, in its various stages, is better understood as a condition that

affects selfhood, and that PCC is better understood conceptually and ethically as promoting continuity or maintenance of selfhood.⁵

1.3. PCC as Promoting Continuity of Selfhood

Recent studies have helped to reveal how people with dementia, their families and their care providers understand and operationalize PCC. They indicate that what all relevant parties are primarily concerned with is to help a person with dementia continue to be who they are, which relates to their past, present, and future achievements, activities, preferences, goals, relationships, and potential for well-being. Those are among some of the most relevant aspects of a person's quality of life and indeed, their sense of self. There is now a growing body of literature on dementia that focuses specifically on how dementia affects selfhood (Surr, 2006; Fazio, 2008; Caddell and Clare, 2010, 2011, 2013; Millett, 2011; Brown, 2017). Based on those studies, a definition of PCC as promoting or maintaining continuity of selfhood has started to emerge (Surr, 2006; Edvardsson, Fetherstonhaugh and Nay, 2010; Kelly, 2010; Cedervall, Torres and Aberg, 2015; Reed, Carson and Gibb, 2017). However, given that personhood is often considered as synonymous with selfhood, the idea of promoting continuity of selfhood might still be understood as a proxy for promoting personhood, so it is important to first clarify the distinction between personhood and selfhood.

The assumption of synonymy between personhood and selfhood is not entirely ill-founded. It might be traced back to John Locke who stated that "where-ever a man finds what he calls himself there, I think, another may say is the same Person" (Lock, 1689/2000, 112). Here the terms "himself" and "Person" have the same referent and in this regard they are synonymous. However, what is different is the perspectives from which the referent is described. The former refers to someone describing themselves from a first-person perspective, which requires an exercise of their capacity for subjectivity or reflexivity (self-referentiality). The latter refers to someone else describing them from

a third-person perspective, which does not necessarily denote their capacity for subjectivity, reflexivity, or intersubjectivity. Given that the referent in the former is the self, and the referent in the latter is another person, it points to a way in which we can draw a conceptual distinction between selfhood and personhood, respectively, from which emerges the kind of definition of selfhood that Catriona Mackenzie (2014) describes as follows.

...to be a self is to have a reflexive first-person perspective; it is to be able to conceive of oneself as a self, as having a subjective point of view that is distinct from other points of view and as the bearer of first-personal thoughts. (Mackenzie, 2014, 155)

Consider also another important (and orthogonally related) distinction described by Marya Schechtman (1990). It also captures the same kind of distinction between selfhood and personhood described above.

It is a philosophical commonplace that we have a dual perspective on persons. On the one hand, we view persons as one of the types of objects in the world, but, on the other, we view them as subjects and agents, creatures with a way of experiencing the world and with affect and volition". (Schechtman, 1990, 87)

Viewing persons as objects in the world entails a broad view of their personhood, which may include the capacity for subjectivity or reflexivity (among many other attributes associated with personhood). However, viewing persons in the narrower intersubjective sense gives focus to, and enables a more nuanced understanding of, a person's capacity for reflexivity and self-understanding. Thus, to view an individual human being in the widest sense, as an object, is to view their personhood, whereas to view a person as a subject, quite specifically, requires inclusion and integration of their first-person point of view and their intersubjective nature or, as we will use it here, their selfhood.

Of course, there are different kinds of subjectivity and reflexivity that form the basis of the many different concepts of selfhood in the literature (Gallagher, 2011). In the context of understanding dementia and PCC, the appropriate notion of selfhood must capture the relevant psychological and social dimensions of human subjective experience. Such a selfhood is one that emerges from the integration of various self-concepts or self-images that we acquire over time, into autobiographical narratives, yielding an overarching sense of identity (a sense derivable in answer to the question “who am I?”). There is also a hermeneutical dimension to this notion of selfhood, associated with interpretation and evaluation of those self-concepts, self-images and lived experiences, in particular, interpretation and evaluation of one’s place within relationships and the social world. Such a process is analogous to what psychologists and psychotherapists refer to as “narrative meaning making” (Singer, 2004; Fivush, Booker and Graci, 2017).

In the following section we offer a fuller analysis of this notion of selfhood and address a possible objection to it. For now, our claim is that in the context of PCC, selfhood is a better concept than personhood because it captures and integrates both the social or relational dimension of personhood (as highlighted by Kitwood) and the subjective dimension that is pertinent to understanding lived experience. Personhood can only achieve this by reference to selfhood.

1.4. An Overarching Sense of Selfhood

The right concept of self at stake in PCC is one involving continuity of selfhood, where continuity is best achieved psychologically when someone experiences what we call an “overarching sense of selfhood”, that is, a sense of *who* they are that depends on interpretations and evaluations they make about themselves derived from the relationships they have with their carer. First, it must be noted that our concept of self obtains under conditions that differ from the metaphysical conditions underwriting personhood, that is, what *makes* me the person I am over time. The way we posit

“self” is akin to the social psychology notion of self in which, as Velleman (2006) points out, “the word ‘self’ denotes a person’s self-conception rather than the entity, real or imagined, that this conception represents”, and therefore lacks the metaphysical baggage often associated with personhood (Velleman, 2006, 214). We also agree that “...the word ‘self’ does not denote any one entity but rather expresses a reflexive guise under which parts or aspects of a person are presented to his own mind” (Velleman, 2006, 1). On our conception, what is required for selfhood is that someone explicitly or implicitly presents to the world, or to their own mind, self-related descriptions of who they are, what their purpose is, their ends, or at the most general level a description enabling the person to make sense of themselves in the context they find themselves in.⁶

Second, a key element of our concept of selfhood is the presence of a retained sense of self-awareness, or reflexivity, wherein the self becomes an object in a thought addressed to itself. Reflexivity is required for those moral emotions like shame or pride in which a person reflects on their thoughts, motives, deeds, or roles. Reflexivity is central to PCC because without it a person loses insight into their condition, and so they lose the capacity to regard themselves as the addressees in relational care. Moreover, the malignant social psychologies Kitwood referred to depend on the person seeing themselves as the target of invalidation, intimidation, mockery and so on. At a more general level, those malignancies have the potential to be internalized by the person in a process of self-stigmatization, a process in which public stigma is accepted by the person who receives this negative label (Matthews, Dwyer and Snoek, 2017).

Third, that selfhood is overarching means that the self reflects on descriptions with temporal width, for example, having a certain role, or being engaged in a project over time, and in particular, being involved in a relationship with a certain history. We believe this overarching aspect is closely connected with the central proposition in our paper, which is that selfhood is essentially *relational*. This means that the self is developed along with others, particularly our intimates over time. A model for understanding this idea comes from the work on friendship by Cocking and Kennett (1998)

who argue that the relational self results from two processes: *direction* and *interpretation*. In direction it is a noteworthy feature of close friendship that we find ourselves readily agreeing to participate in activities that sit outside our ordinary habits and interests. We might, for instance, readily agree to attend the ballet even though we have little interest in the activity. It is the friendship that gets us over the line here, and so we find ourselves in expanded social worlds that differentiate our interests, and so our identities. More importantly, though, in the present context, is interpretation. Friends self-disclose in ways that intimately connect them. We disclose content that is often very private, and moreover we offer evaluations of each other that shine a light on our characters. I might, for example, point out to my friend that she is more sensitive to rational criticism than she herself believes. As my friend, she will take up this interpretation into her self-understanding over time, perhaps even take it up to the point of making changes to it.

Direction and interpretation feature in non-friendship relationships as well, including care relationships, where the co-creative effect we have spoken of may also play a role in who we are. Close others in care may influence behaviour, or provide a value-laden description of it, and in this way give shape to who we are. People in care regularly need the cooperation of others who have the potential to contribute significantly to how they see themselves. This process of relational self-construction is especially strong in long-lasting relationships (certainly with family or friends, and we would submit also in care relationships that endure) and is especially apt when thinking about the overarching sense of self we have posited. The sense of self we defend here, as relational and scaffolded over time, has implications for PCC practice of course, as we will discuss later.⁷

Fourth, the overarching sense of self comes in degrees. It is not the case that one either has it, or that one lacks it, but rather it fluctuates in fidelity, informational completeness, or temporal extension. In other words, one's sense of self can get some details wrong, there can be gaps in self-understanding, or one's sense of an extended self can be limited by cognitive impairment. For example, there can be selves that are "petrified" in time, that is, selves that are out of date due to

impairments (particularly associated with anosognosia) in the way the person is able to revise what psychologists refer to as *trait self-knowledge* (Mograbi, Brown and Morris, 2009; Sacks, 2019). We discuss a key example of this in more detail later.

It is beyond the scope of our paper to provide a thorough defense of the above account of selfhood against various differing accounts, particularly when there is a distinctive difficulty in dealing with the literature on selfhood. Roy Baumeister (1998) describes the literature on the self as making the issue “more elusive rather than clearer” (Baumeister, 1998, 680), and Stanley Klein says that “there is perhaps no term in psychology that is more widely used, yet less well-understood, than ‘self’” (Klein, 2012, 253). Difficulties notwithstanding, we point out that several prominent theories of selfhood in psychology and philosophy also emphasize the psychological, reflexive, temporal, and relational elements discussed above. For example, Rom Harre’s tripartite model of the self, describes the temporal unity of subjective experience and the totality of social self-knowledge (Harre, 1991, 1998). Roy Baumeister’s model of selfhood, describes the reflexive, interpersonal and unifying dimensions of selfhood (Baumeister, 1998). Ulrich Neisser’s model describes the unified sense of self that comes from conceptual forms of self-awareness (Neisser, 1988). There are also a number of narrative theories of selfhood discussed within literary and analytic philosophy, which emphasize the importance of autobiographical narratives (to have “a story”) as a mechanism by which self-knowledge and lived-experience is integrated into a unified whole so as to yield an overarching self that is hermeneutical in nature (MacIntyre, 1985; Ricoeur, 1985; Taylor, 1989; Schechtman, 1996; Bruner, 2003, 2006).

In summary, the conception of self we think ought to be at stake in PCC is one involving reflexivity, and descriptions of who a person is that relate to their context, or role, or relationships. These descriptions can be more or less detailed and can fade over time. Indeed, a sense of self can be out of date (or “petrified”) as often occurs in the later stages of Alzheimer’s dementia. Nevertheless, the ethical requirements of PCC in such cases can and should remain just as strong. We will discuss those

requirements in more detail later, but first we want to address a possible objection to our concept, the answer to which further explicates what is at stake here.

1.5. Applicability of an Overarching Self

It might be objected that if one's sense of being a continuous self derives from the integration of experiences, and those experiences cease to be remembered as dementia progresses, then the kind of selfhood we are positing (one that consists of an *overarching* sense of identity) is no longer applicable. We reply by pointing out that the sense of self we have in mind is sourced from two distinct cognitive pathways. It derives from one's experiences (and episodic memories), certainly, but also from trait self-knowledge. Trait self-knowledge is our awareness and understanding of who we are, which includes an evaluative dimension, that is, a self-assessment of the value of our characters. The psychology literature has established that despite impairments in episodic memory, trait self-knowledge can be preserved, and indeed updated. On the preservation point, Klein and Lax (2010) explore the question of what the self is:

...by reviewing research conducted with both normal and neuropsychological [including dementia] participants. Findings converge on the idea that the self may be more complex and differentiated than some previous treatments of the topic have suggested. Although some aspects of self-knowledge such as episodic recollection may be compromised in individuals, other aspects – for instance, semantic trait summaries – appear largely intact.
(Klein and Lax, 2010, 918)

In Alzheimer's dementia, episodic remembering is progressively impaired, but semantic memories (including of one's traits) are preserved, and indeed there are cases in the advanced range where preservation of trait self-knowledge is quite complete, leading to a sense of self that is locked in the past or "petrified". The concept of an out-of-date or "petrified" self points to a difficulty with the

third element we identified above, that is, temporality and relational history, which we specifically address later when we discuss cases of people whose out-of-date selves require care that upholds and re-energizes such selves.

In contrast, with regard to Semantic dementia, episodic remembering is preserved, while semantic memories are lost, such that the person with dementia has a sense of themselves primarily informed by recent experiences alone (Strikwerda-Brown et al., 2019). For example, episodic memories provide a source of pride or shame when an individual, during an instance of episodic remembering, brings credit or discredit to themselves. The individual doing the remembering *identifies* with that self, as someone (now) proud or ashamed. In this way the contents of an episodic memory inform the overarching sense of identity. Klein, Cosmides, and Costabile (2003) point out that there are also cases in which (with emphasis added) “individuals can acquire and update their fund of personality knowledge *despite* impairments to semantic and episodic memory” (Klein, Cosmides, and Costabile, 2003, 157-8). We thus have the following complexity: one’s overarching sense of identity is sourced via past experiences (episodic memories), as well as being sourced via trait self-knowledge. In the different dementias, and stages of those dementias, these sources and capacities degrade resulting in variation in the quality and accuracy of self-understanding.

With our conception of selfhood in mind, we can now offer a more pertinent way of understanding of how dementia affects our lives and how we can best deliver PCC. What we think is central to PCC, given this concept, is that a relatively robust sense of self persists through the changes wrought by dementia, but as time progresses and the symptoms of dementia become more apparent to carers, false assumptions are then made, one of the most common being around the idea of “loss of the self”. The individual with dementia at this point is particularly vulnerable, not only to disorientation in space and time, but also to an emotional or normative disorientation when carers do not recognize that their selfhood persists despite their behavioral presentation. When carers assume a loss of self (based on behavioral presentation) this unfortunately can be self-fulfilling. But even at

these later stages, the evidence indicates that the self (as we are defining it) remains sufficiently intact for patterns of respect, appreciation, and recognition by others to be taken up, understood, and interpreted in the right way. Given this vulnerability, the imperative to provide a care environment in which selfhood may be sustained, even enriched, commensurate with the progression of the dementia, becomes more paramount.

Our goal in the remainder of this paper is to elaborate on the importance of the social or interpersonal dimension of selfhood, how it contributes to an overarching selfhood, and how this bears on our understanding of PCC. This dimension is foremost based on viewing those in care as morally significant social agents, socially visible, and where possible as maintaining an accustomed role. This may be a role they once had professionally, or perhaps even resurrection of a guiding interest that was of great value, such as a musical or cultural interest.⁸ It requires understanding how the various stages of dementia affect selfhood and how carers should adapt their approach to promoting continuity or maintenance of selfhood in a way that is commensurate with those stages of dementia.

Section 2 – The Relational Care Framework

2.1. The Decline of Selfhood in Dementia

We have rejected the notion of personhood that has come to be associated with PCC as being too individualistic, where persons are seen as essentially independent and autonomous. The very term “person-centred” has been taken to indicate a certain kind of independent authority, an individual who can self-regulate, an individual who can negotiate the social realm independently, a self-manager, and, of particular alarm, a market consumer. By contrast we think a better conception of PCC holds that the standing of an individual with dementia in care depends on a particularized acceptance within the social environment based on who a person is, where interpersonal

interactions based on this can provide a stable platform for living, for continuing in some role, or more generally as a social agent. Our thesis prescribes a re-cast of PCC (as it is currently understood and operationalized), in different ethical terms, that is, as promoting continuity or maintenance of selfhood, which more aptly captures Kitwood's original understanding of dementia in terms of the iatrogenic psycho-social effects he identified.

The impact of relationships and social interactions on lived experience profoundly shapes selfhood and our overarching sense of identity. Indeed, promoting continuity of selfhood cannot be achieved independently of promoting relationships, social interaction, and psychosocial well-being, which in turn ideally requires continuity of the kind of social environment that people with dementia have been accustomed to throughout their life. Kitwood, with Kathleen Bredin, had explicitly described the social environment as important for maintaining selfhood, particularly when it begins to break down due to dementia, arguing that people with dementia are often still able to engage in meaningful interpersonal interactions (Kitwood and Bredin 1992).

While much of the research on how dementia affects selfhood reveals that certain functions associated with selfhood remain, even during later stages of dementia (Caddell and Clare, 2010; Strikwerda-Brown et al., 2019), it is important to understand how selfhood is affected during the progression of dementia and how the level of this effect may bear on the approach in PCC. There are three potential scenarios that capture the degree to which selfhood may decline during the progression of dementia, which have specific implications for how practitioners may approach PCC.⁹ First, dementia may affect selfhood without diminishing it to a point where there is no longer autobiographical unity. Studies have shown that people with mild (even moderate) forms of Alzheimer's disease display reduced temporal coherence in their autobiographical narratives and have a weaker, vague, and more abstract sense of self, but they still retain an overall sense of autobiographical unity over time (Addis and Tippett, 2004; Fazio and Mitchell, 2009; Tippett, Prebble and Addis, 2018).

Second, dementia may affect selfhood in such a way that autobiographical unity is lost. For example, in Alzheimer's disease the decline in autobiographical memory can lead to retrograde amnesia, which prevents a person having access to important memories and information. As a result, there is a loss of correspondence and coherence between past memories, present knowledge, goals and beliefs (El Haj et al., 2016). This can give rise to a propensity for confabulation and even delusions (Lee et al., 2007; Noel et al., 2018). Such a person cannot be said to lack selfhood entirely, but their selfhood does lack temporal continuity or unity. Their autobiographical narratives, and thus their sense of self, is primarily constrained to the present (Eustache et al., 2013; Strikwerda-Brown et al., 2019).

Third, as dementia progresses into advanced stages, there is a steep trajectory of decline, with high mortality rate, significant disability and an inevitable requirement of palliative care and end of life measures. During this advanced stage, dementia may affect selfhood to the point where there is no substantive or discernible autobiographical narrative underpinning experience. Symptoms may include an inability to recognize familiar faces, verbal abilities that are limited to less than 5 words, incontinence, total functional dependence, and difficulties in gait or an inability to walk (Reisberg et al., 1982; Mitchell et al., 2012). Symptoms are so severe that some media representations, very unfortunately, have described it as a "living death" (Woods, 1989; Peel, 2014).¹⁰ Some studies have also indicated that people with advanced stage dementia are less likely to recognize themselves in the mirror (Biringier and Anderson, 1992; Caddell and Clare, 2010; Chandra and Issac, 2014), and have difficulty using first-person and second-person pronouns like "I" and "you", respectively (Small et al., 1998). The loss of those abilities affects reflexivity and insight, and so constitutes the loss of the most fundamental capacities necessary for having a self-concept or self-image from which to construct autobiographical narratives that constitute our overarching selfhood. Hence, in this scenario, some may argue that it is apt to attribute a loss of selfhood to a person with very advanced dementia. However, we caution that within these stages there can be quite radical fluctuations, and

as Astrid Norberg points out, persons with advanced dementia can exhibit “moments of lucidity”, that is, moments in which they suddenly “understand, remember, and care” (Norberg, 2019, 208-9).

Because of the disunified and unstable nature of these expressions, the choice of which stance carers must take (e.g., Strawson’s *participant* stance or *objective* stance) becomes bewildering.

Clearly then, PCC understood as promoting continuity of selfhood, must be tailored to the degree of selfhood that exists commensurate with the stages of the progression of dementia. In the following sections we propose and unpack the Relational Care Framework, which describes how promoting continuity or maintenance of selfhood can be understood in terms of the ethical stances we take towards people with dementia, each reflecting the three scenarios of decline in selfhood introduced above.

2.2. Scenario 1

In the early stages of Alzheimer’s dementia, symptoms include short term memory loss (leading to, for example, misplacement of items), some occasional disorientation in space and time, difficulties completing familiar complex tasks, difficulties in planning and decision-making, and some minor aphasic disruptions. These symptoms, though, are compatible with the syndrome *mild cognitive impairment* (MCI), which is distinct from dementia (Burns and Zaudig, 2002). Crucially, they do not diminish selfhood to the point where continuity has become fragmented. The individual retains a sense of who they are largely with the overarching coherence we have identified. People in this condition continue to function well enough without a (formal) carer, and they may carry on life relatively unscathed by their symptoms. Casual care arrangements can be made that provide a supportive environment to compensate for loss of memory, but such ordinary common-sense responses in the domestic sphere fall short of professional or clinical realignments that are tailored to substantive changes in selfhood.

Moreover, at this point it is an open question whether a diagnosis should be sought for someone experiencing these relatively mild symptoms. Although early diagnosis bestows the advantages of early intervention, to receive a diagnosis (of say Alzheimer's, or even MCI), for some people at least, is highly stigmatizing. It also raises the potential problems of exacerbation of the condition through processes of self-stigmatization (Garand et al., 2009). People who experience such symptoms and changes want to retain their position (in family, work, education, etc.,) and not suffer discrimination. A diagnosis of a pathology-induced dementia can solidify such changes into an identity, the identity of someone who now sees themselves through the reductive prism of a publicly feared illness. Such fear and rejection can then turn inwards resulting in a feedback loop where the diagnosed person sees themselves as a certain kind of person, that is, a person contaminated by dementia. But this occurs only when the culture of care, and more broadly the public conception of dementia, contains negative labels and stereotypes as sources for the feedback of self-stigma (Matthews, Dwyer and Snoek, 2017). For this first scenario then, using our concept of selfhood requires close and empathic attention to the perspective of someone with dementia. It more carefully imports this perspective into care decisions resulting in a nuanced and accurate fit between lived experience and the care environment.

2.3. Scenario 2

Operationalizing PCC according to our framework gets most purchase in the middle stages of dementia when autobiographical unity begins to degrade.¹¹ Here we outline two key points helping to frame its application. The first key point, then, relates to a fundamental *phenomenological* dimension of the overarching sense of selfhood outlined earlier. This sense, we argue, remains throughout scenario 2. We capture the idea this way:

SD: Everyday life is such that there is something it is like for people with dementia to have thoughts and experiences, a feeling they (potentially) recognize as not qualitatively distinct from what it is like for themselves pre-dementia.

Emphasizing a continuity of phenomenological feel, pre and post diagnosis of dementia, is intended to forestall a view that underlies the temptation on the part of carers to infer that the person with dementia has an inner life unrecognizable from the way it once was. We agree with Steven Sabat that to make such an assumption is damaging to care relations especially when made indiscriminately (Sabat, 2018). SD relates to a moral point about the attitudes that carers ought to make in their attributions of selfhood to a person with dementia. The thought is that if we accept SD, we ought to assume that people with dementia (in this scenario) retain a sense of who they were before dementia and that they are now trying to make sense of themselves and the world as that person, now with dementia. Lynne Rudder Baker's characterization of first-person phenomena comes close to the idea we have in mind (Rudder Baker, 2000). A person who experiences (strong) first-person phenomena, she says:

...is able to attribute to himself first-person thoughts...Not only can he think of himself, but also he can think of himself as himself. He can consciously entertain thoughts and conceive of his thoughts as his own. (Rudder Baker, 2000, 67)

Regarding this connection Sabat describes the case of Dr. B, a scientist with moderate to advanced Alzheimer's Disease. Dr. B had deficits in episodic memory, aphasia, difficulties with simple tasks such as dressing, and frequently lost track of his thoughts. He was aware of the disruption to his thinking but despite this, he retained a sense of the disunification his dementia was causing. That is, he had a grasp of what it was like, and was insightful about the disruption to his ability to connect his experiences into some kind of coherent narrative trajectory. Dr. B said of his disease that it was something "constantly on my mind" (Sabat, 2018, 58), which makes sense only if Baker's first-person perspective remains in place, as per our SD assumption.

There is evidence for SD sourced from what people with dementia say and from careful observations from carers and clinicians. Take again Sabat's work referred to above. He describes two important phenomena regarding this connection – (1) that of *conversational repair*, and (2) *rational adaptation*. If we engage in *conversational repair* in dialogue with a person with dementia, we may supply words or phrases they meant to use but could not find, or complete a sentence they could not complete, or carefully imagine what was meant by this person given the context. The notion of *rational adaptation* refers to the interpretation of symptoms of dementia as in fact a rational response to what is happening to a person resulting from the brain damage wrought by pathology. A person with dementia may appear to behave strangely by suddenly crying, unpredictably wandering around, or failing to attend any social events. However, this behavior is likely *not* a symptom *per se* of dementia, but an understandable reaction (crying) to overwhelming sensory overload and confusion. It may be a reasonable response (taking a walk) to boredom or a lack of outside exercise facilities, or it may be a rational response to, and recognition of, one's lost ability to converse socially (self-exclusion).

In each of these cases we can see what dementia might be like *for us* (and so for the person pre-dementia) and then see that this apparent odd behavior would be normal for us, were we in a similar position. Essentially, SD asks us to extend an empathic response to those with dementia and invites us to imagine how we would respond in that condition where memory loss, word-finding problems, and other difficulties would have an effect on our rational selves. Those symptoms would leave us, understandably, bewildered. There is something it is like to have dementia symptoms, and there is something it is like not to have them, and there exists a point of view (or perspective) present in either condition.

We now turn to the second key point relating to how care may be framed using our concept of selfhood. When dementia is a threat to autobiographical unity the presence of selfhood is not automatically apparent but may be latent, awaiting the right cues for its elicitation. So understood,

carers are in best position to draw out the self via specific practices and interventions. Consider for example music therapy in cases where the individual is seemingly restored to himself (Matthews, 2015). In many such cases the individual may seem utterly distant and lost until they “remember who they are” as Oliver Sacks (2014) once put it.¹²

Especially towards the later periods within Scenario 2, fragmenting of memory and discontinuity within autobiographical narratives can render someone with dementia unable to make sense of their situation. This can be because of the inability to keep track of what is currently happening in the environment, particularly the social environment, given their current conception of their own position, role, or self-understanding. Nevertheless, such a person retains the resources for making sense of their situation so long as they are given the right tools, and this typically depends on providing care that is familiar, stable, and accepting of who they are. In other words, it depends on the quality of the relational care environment they are in. To bring the point out we mention two cases we think show that it is selfhood (one’s subjective experience of having an overarching identity that remains) and not (the more abstract) personhood, that matters in PCC.

Consider the case of Mr. Q as discussed by Oliver Sacks (2019). Mr. Q was a former janitor who continued in this “role” while in his nursing home run by the Little Sisters of the Poor. He would go about checking windows and doors so that they were locked, inspecting laundry and boiler rooms to see that all was functioning well, and so on, but this role was manufactured by the Sisters as a way of supporting Mr. Q’s agency. Mr. Q’s remaining self was out of date (“petrified”). He believed he was still a janitor, and that his place of residence was a place in which this role could be carried out. Should the Sisters treat him as an autonomous and temporally de-centred *person* and insist on the truth – “you are no longer a janitor, you ceased that role a decade ago, you have Alzheimer’s disease; this is an aged care facility”? Or should they enable his Janitorial *selfhood* to play out? Sacks puts the point this way:

The sisters...though perceiving his confusion and delusion, respected and even reinforced [his remaining] identity...they assisted him in his janitorial role, giving him keys to certain closets and encouraging him to lock up at night before he retired...And, though he slowly became more and more demented over the years, he seemed to be organized and held together in a remarkable way by his role...Should we have told Mr. Q. that he was no longer a janitor but a declining and demented patient in a nursing home? Should we have taken away his accustomed and well-rehearsed identity and replaced it with a “reality” that, though real to us, would have been meaningless to him? It seemed not only pointless but cruel to do so—and might well have hastened his decline. (Sacks, 2019, Feb 25)

Consider now the case of Martha as described by Orulv and Lars-Christer (2006). Martha has Alzheimer’s dementia and is attending the dayroom with several residents in a dementia care facility. It is the afternoon, and coffee has been served by the staff, who now have returned to the kitchen. Earlier, when Martha and another resident Catherine were sitting in the corridor, some uncertainty had arisen as to who would take care of the arrangements for the coffee. They wonder if perhaps they ought to assume some control. As things unfold in the day room, with sociability, and chitchat about the weather, TV, and childhood memories, a change occurs that is problematic. Martha’s understanding of the situation, as implicitly prompted by the earlier uncertainty, changes.

Somewhere along the way [Martha] assumes the status of gracious hostess – a part that has been hers innumerable times throughout her life. Equally innumerable are her stories about how she, like her mother before her, has taken pride in welcoming everyone to her home and in sharing her food and hospitality with other people...These narrative plots occur frequently in the body of material that can be described as variants of one overall storyline that binds together many of Martha’s stories. This storyline is of her being a generous and sharing person throughout her life... (Orulv and Lars-Christer, 2006, 655-6)

Continuity or maintenance of selfhood in both these cases (of Mr. Q and of Martha) is a matter of retaining an overarching sense of an identity where the identity in play involves role-based agency, and a role that is available to fit the circumstances. It is dependent on the quality of the relational care environment they are in, one that positively enables such roles. Furthermore, enabling such roles shows the need to revise or clarify one particular item in Kitwood's list of malignancies, what he called "treachery", the idea that it is wrong to deceive someone as a distraction or manipulation or trick to ensure compliance. Not all forms of deception have this pernicious element, and indeed, following Sacks's lead, we can see that there is a competing norm in play here, which is to provide the tools, reassurance, and guidance that elicit or affirm the selfhood available (or which remains) so as to enable a person with dementia to make sense of themselves and the world. This norm can be understood as a modified form of Strawson's *participant* stance. It is to treat them as a social being within the limited circumstances of the institution by providing them with the means to express their agency and thus enact their social being. It is to respect, even encourage, their remaining selfhood.

We do not suggest a full blown *participant* stance be adopted. Obviously attitudes that would amount to holding the person responsible would have to be modified. The main reason for this is that the attitudes taken up in these scenarios tend to support, or deflate, the self-image, falling short of blaming a person in the case where their dementia has affected their understanding of a situation. The evaluative responsiveness here is a matter separate from the proneness to attitudes that assume full (or near full) membership in the moral community, especially attitudes which demand that we account for our past actions, and answer to a charge that those actions have wronged us. In the cases we have looked at, this proneness is largely absent.

2.4. Scenario 3

At the start of this section, we described a scenario in which a person's dementia may be so severe that they may no longer possess the dimensions of selfhood we described previously (reflexivity, temporal unity, and relational history). Promotion of even a modified or attenuated participant stance (as described above) in this scenario will not be possible or appropriate. What is possible and permissible is to instead adopt a modified form of Strawson's *objective* stance or what we might term a *quasi-participant* stance. The claim that we should move to the *objective* stance requires a different kind of argument (Kennett, 2007). The stance we have in mind here need not imply only beneficently motivated care in the form of medical treatment of disease and the provision of basic human needs such as food, safety, shelter, toileting, and bathing, but offers scope for specific kinds of activities and social interaction. For example, consider the idea mentioned previously, that certain aspects of selfhood have been found to persist in advanced stages of dementia. While this is sometimes assumed to indicate that selfhood still persists, it refers more precisely to a person's capacity to retain a tacit embodied memory of certain individual preferences and affective tendencies. Such a capacity might explain why basic forms of social interaction with family and friends (Taylor, 2008; Walmsley and McCormack, 2014; Ellis and Astell, 2017; Lee et al., 2017; Fuchs, 2020) and simple leisure activities such as listening to music (Garrido et al., 2018, 2019) can evoke seemingly positive responses and experiences in people with advanced dementia. Therefore, even if a person with advanced dementia shows no sign of a remnant or "petrified" self, our view is that it is appropriate to enable them to continue to be exposed to an environment in which, for example, a lifelong hobby or interest is encouraged. This is not because it helps them to uphold their overarching sense of identity, but because it enables them to experience residual joy or pleasure from such activities.

Obviously, people in advanced stages of dementia who have lost their selfhood entirely (as we have defined it here) continue experiencing synchronically. They are capable of experiencing residual joy or pleasure from basic activities and interpersonal interactions. Therefore, the goal of PCC in this

context ought to be concerned with promoting the quality of those experiences derived from information sourced from within the *objective* stance but which also has the form of a *quasi-participant* stance (in virtue of the residual capacity to experience synchronically and in virtue of the carer's unique role). This contrasts significantly from the idea of PCC in scenario 2 as promoting continuity or maintenance of selfhood from a *participant* stance (proper). It is primarily concerned with promoting quality of life and well-being, but in a manner that can still acknowledge and accommodate a person's uniqueness, individual history, relational being, and humanity (key elements of a participant stance).

A person with advanced dementia may not be able to (conceptually) understand or identify with the kinds of expressions, reactions, or attitudes of others, that are central to the *participant* stance. We acknowledge that this is precisely what compels the move towards an *objective* stance in which Strawson claims that our expressions, reactions or attitudes (or "reactive attitudes" to use Strawson's phrase) towards others may remain "emotionally toned in many ways, but not in all ways", that is, they may include fear, pity, and love, but not resentment, gratitude, forgiveness or anger, which "belong to involvement or participation with others in inter-personal human relationships" (Strawson, 1974, 10). However, we argue that in virtue of a person's uniqueness, individual history, relational being and humanity, and in virtue of the unique role that carers and family members occupy, the reactive attitudes of gratitude and forgiveness remain relevant and ought to be expressed even though such reactive attitudes exist in surface form and not in substance (because for those attitudes to obtain requires full *participation* from both sides). Those reactive attitudes express and confer on another person the form of dignity we outlined earlier, as described by Rosen (2012), in which a duty to respect humanity does not depend on religion, or humanism (that someone must benefit), or Platonism, but that "in failing to respect the humanity of others [in the case where selfhood is gone] we actually undermine humanity in ourselves" (Rosen, 2012, 157). Carers who treat those with dementia at this time, gently addressing them by name, washing them,

reading to them, playing their favorite music and so on, uphold the dignity of the person, and their family and friends, by expressing a respectfulness that acknowledges their presence and of who they are.

Conclusion

We think that, largely, dementia symptoms mask the way a person was prior to diagnosis, and that interacting with them on this assumption, where possible, provides the best chance to promote and enrich the continuity of selfhood we have discussed. When this stance is taken, they become fellow social actors with an equivalent moral status, they become socially visible and they are not just treated but engaged with and addressed. In contrast, relegation to mere patient or consumer status, where people are treated as objects or clients to be managed presupposes the opposite, that they are socially invisible as moral persons. Often, of course, we may oscillate in our interactions, for especially during the middle stages of dementia, there is no clean distinction between a person and their symptoms. Furthermore, the selfhood of a person with dementia (in pre-advanced stages) is significantly shaped by the people they are in contact with, so who they are is partly up to *us* and *our* attitudes towards them.

Human agents do not really oscillate between two discrete states – one, the autonomous responsible individual, and the other, the wholly dependent individual, lacking in the capacity for voluntariness or autonomy. Since agents grow and develop dynamically in conjunction with social others, they do not write their own story to the exclusion of others. They are participants in a story where co-authorship is the norm. Carers and others who interact with people who have a pre-advanced dementia, particularly close others, are in a position to in fact orchestrate the social visibility of self, both publicly and inwardly when a person is given the space and time to make sense of their environment and their role within it (as in the example of Mr. Q). An appropriately

structured relational environment makes possible the overarching sense of self we have described, and PCC practices and policies that eschew such an understanding, we think, will miss much of what is morally at stake in the conception of dementia care Kitwood originally envisaged. Adapting our understanding of PCC accordingly will not only recover its original intent, but in promoting selfhood based on social relationships, it will also attend to what is acknowledged as a shared social responsibility in the context of aged care.

The effects of dementia on agency and the self (with all of the odd and seemingly confronting behaviors) can lead to social withdrawal and loss of personal contact, in a word, a loss of social visibility. Nevertheless, with the exception of certain situations where dementia has progressed to a highly advanced level, people with dementia remain socially sensitive participants with normal psychological needs for interaction and intimacy. They retain the capacity, surely, for co-authorship, and the ability to make sense of their life stories as best they can under the circumstances. As Kennett (2007) writes:

...if we accept the claim that in our relations with others we can become, invited, welcomed, or not, part authors of that person's self-conception and life story, we need carefully to consider the responsibility that is thus placed on us, particularly in our dealings with those whose identity and agency is already fragile. (Kennett, 2007, 104)

Notes

1. We use the term “intersubjective” broadly so as to capture those features that are relevant in typical social exchange. Of particular importance, however, is the role that empathy plays in constituting the kind of intersubjectivity we have in mind and discuss, that which also shapes the subjectivity of a person with dementia. We find Edith Stein’s phenomenological account of the relationship between empathy and intersubjectivity particularly germane and useful for our purposes (Stein, 1964).

2. The argument here is that the concept of “persons” does not correspond to any real category or entity that exists in the world and therefore should be abandoned.

3. For an objection to such a definition see Singer (2009).

4. Examples include the UK’s system of personal health budgets referred to as “Self-directed Support”, Sweden’s “Act on Free Choice System” reforms, and Australia’s recent implementation of “consumer directed care” (CDC).

5. We acknowledge a difficulty in continuing to use “PCC” having distinguished selfhood from personhood. However, “PCC” is deeply embedded in dementia care discourse and there appears no obvious solution to this problem other than to continue using the phrase “PCC”.

6. Our view is that such presentations take the form of autobiographical narratives that are self constituting. For further elaboration of this idea see Schechtman (1996).

7. It is important to notice on this relational point that it largely concerns how the self is maintained, and this is a point about a mechanism for ongoing self formation. It leaves open several questions we cannot address here including whether we are advocating an account of the self that is constitutively social, and what implications our view has for the concept of relational autonomy. We do not take a stand on those questions here. Many of these issues are discussed in Mackenzie and Stoljar (2000).

8. Agnieszka Jaworska claims that those with relatively late-stage Alzheimer's dementia have the capacity to value, and that this capacity persists over time (Jaworska, 1999). This is compatible with retaining an overarching sense of identity, especially where that identity is informed by a normative role.

9. This is based on the generalised three-stage trajectory of dementia, but we acknowledge that this is idealised, and that the trajectory in practice for some individual may vary based on the biopsychosocial specifics of that person and the type of pathology. The literature on the trajectory of dementia has registered a more accurate seven-stage categorisation. See Rose and Lopez (2012).

10. For a critique see Aquilina and Hughes (2005).

11. To be clear, we don't put forward a first-order prescriptive model. Our purpose is to clarify how such models would best work given our revisionary concept of selfhood.

12. These comments are made by Sacks in considering the case of Henry in the documentary *Alive Inside*. <https://www.youtube.com/watch?v=8HLEr-zP3fc> (accessed May 16, 2021).

References

Addis, D. R. and L. J. Tippett. 2004. Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory* 12(1):56–74.

Aquilina, C. and J. C. Hughes. 2005. The Return of the Living Dead: agency lost and found. In *Dementia: mind, meaning, and the person*, eds. J. C. Hughes, S. J. Louw, and S. R. Sabat, 143-61. Oxford, United Kingdom: Oxford University Press.

Baumeister, R. F. 1998. The self. In *Handbook of social psychology 4th ed*, eds. D. T. Gilbert, S. T. Fiske, and G. Lindzey, 680-740. New York: McGraw-Hill.

Beach, M. C and T. Inui. 2006. Relationship- centred Care: A Constructive Reframing. *Journal of General Internal Medicine* 21(S1):S3-8.

Biringer, F. and J. R. Anderson. 1992. Self-recognition in Alzheimer's disease: a mirror and video study. *Journal of Gerontology* 47(6):385–8.

Brooker, D. 2003. What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13(3):215-22.

Brooker, D. 2007. *Person-Centred Dementia Care: Making services better*. London, United Kingdom: Jessica Kingsley Publishers.

Brown, J. 2017. Self and identity over time: dementia. *Journal of evaluation in clinical practice* 23(5):1006-12.

Bruner, J. 2003. Self-Making Narratives. In *Autobiographical Memory and the Construction of a Narrative Self: Developmental and Cultural Perspectives*, eds. R. Fivush, and C. A. Haden, 209-25. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

Bruner, J. 2006. A Narrative Model of Self-Construction. *Annals of the New York Academy of Sciences* 818(1):145-61.

Burns, A. and M. Zaudig. 2002. Mild Cognitive Impairment in Older People. *The Lancet* 360:1963-65.

Caddell, L. S. and L. Clare. 2010. The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review* 30(1):113-26.

Caddell, L. S. and L. Clare. 2011. Interventions supporting self and identity in people with dementia: A systematic review. *Aging and Mental Health* 15(7):797-810.

Caddell, L. S. and L. Clare. 2013. Studying the self in people with dementia: How might we proceed? *Dementia* 12(2):192-209.

Cedervall, Y., S. Torres, and A. C. Aberg. 2015. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging & Mental Health* 19(8):679-88.

Chandra, S. R. and T. G. Issac. 2014. Neurodegeneration and Mirror Image Agnosia. *North American Journal of Medical Sciences* 6(9):472-7.

Cocking, D. and J. Kennett. 1998. Friendship and the self. *Ethics* 108(3):502-27.

Dewing, J. 1999. Dementia. Part 1: Person-centred care. *Professional Nurse* 14(8):585-8.

De Bellis, A. M., S. Bradley, A. J. Wotherspoon, B. Walter, P. Guerin, M. Cecchin, and J. Paterson. 2009. *Come into my world: How to interact with a person who has dementia*. Flinders University, South Australia: Hyde Park Press.

Edvardsson, D., B. Winblad, and P. O. Sandman. 2008. Person-centred care for people with severe Alzheimer's disease – current status and ways forward. *Lancet Neurology* 7(4):362–7.

Edvardsson, D., D. Fetherstonhaugh, and R. Nay. 2010. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing* 19(17-18):2611–8.

Ekman, I., K. Swedberg, C. Taft, A. Lindseth, A. Norberg, E. Brink, J. Carlsson, et al. 2011. Person-centred care - ready for prime time. *European Journal of Cardiovascular Nursing* 10(4):248-51.

El Haj, M., P. Antoine, P. Amouyel, J-C. Lambert, F. Pasquier, and D. Kapogiannis. 2016. Autobiographical memory decline in Alzheimer's disease, a theoretical and clinical overview. *Aging Research Reviews* 23(PtB):183-92.

Ellis, M. and A. Astell. 2017. Communicating with people living with dementia who are nonverbal: The creation of Adaptive Interaction. *PLoS One* 12(8):e0180395.

Ettema, T. P., R-M Droes, J. de Lange, M. E. Ooms, G. J. Mellenbergh, and M. W. Ribbe. 2005. The concept of quality of life in dementia in the different stages of the disease. *International Psychogeriatrics* 17(3):353-70.

Eustache, M-L., M. Laisney, A. Juskenaite, O. Letortu, H. Platel, F. Eustache, and B. Desgranges. 2013. Sense of identity in advanced Alzheimer's dementia: a cognitive dissociation between sameness and selfhood? *Consciousness and Cognition* 22(4):1456-67.

Farah, M. J. and A. S. Heberlein. 2007. Personhood and neuroscience: Naturalizing or nihilating? *The American Journal of Bioethics* 7(1):37-48.

Fazio, S. 2008. *The enduring self in people with Alzheimer's: Getting to the heart of individualized care*. Baltimore, MD: Health Professions Press.

Fazio, S. and D. B. Mitchell. 2009. Persistence of self in individuals with Alzheimer's disease: Evidence from language and visual recognition. *Dementia* 8(1):39-59.

Fivush, R., J. A. Booker, and M. E. Graci. 2017. Ongoing Narrative Meaning-Making Within Events and Across the Life Span. *Imagination, Cognition and Personality* 37(2):127-52.

Fuchs, T. 2020. Embodiment and personal identity in dementia. *Medicine, Health Care and Philosophy* 23(4):665-76.

Garand, L., J. H. Lingler, K. O. Conner, and M. A. Dew. 2009. Diagnostic Labels, Stigma, and Participation in Research Related to Dementia and Mild Cognitive Impairment. *Research in Gerontological Nursing* 2(2):112-21.

Garrido, S., C. J. Stevens, E. Chang, L. Dunne, and J. Perz. 2018. Music and Dementia: Individual Differences in Response to Personalized Playlists. *Journal of Alzheimer's Disease* 64(3):933-41.

Garrido, S., C. J. Stevens, E. Chang, L. Dunne, and J. Perz. 2019. Musical Features and Affective Responses to Personalized Playlists in People With Probable Dementia. *American Journal of Alzheimer's Disease and other Dementias* 34(4):247-53.

Gallagher, S. 2011. *The Oxford Handbook of Self*. Oxford, United Kingdom: Oxford University Press.

Harre, R. 1991. The Discursive Production of Selves. *Theory and Psychology* 1(1):51-63.

Harre, R. 1998. *The Singular Self: An Introduction to the Psychology of Personhood*. London, United Kingdom: Sage.

Higgs, P. and C. Gilleard. 2016. Interrogating personhood and dementia. *Aging and Mental Health* 20(8):773-80.

Jaworska, A. 1999. Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy and Public Affairs* 28(2):105-38.

Kelly, F. 2010. Recognising and supporting self in dementia: A new way to facilitate a person-centred approach to dementia care. *Ageing and Society* 30(1):103–24.

Kennett, J. 2007. Mental disorder, moral agency, and the self. In *The Oxford Handbook of Bioethics*, ed. B. Steinbock, 90-113. New York: Oxford University Press.

Kim, S. K. and M. Park. 2017. Effectiveness of person-centred care on people with dementia: a systematic review and meta-analysis. *Clinical Interventions in Aging* 12:381–39.

Kitwood, T. and Bredin, K. 1992. *Person to Person: A Guide to the Care of Those with Failing Mental Powers*. Essex, United Kingdom: Gale Centre Publications.

Kitwood, T. 1997. *Dementia reconsidered: The person comes first*. Buckingham, United Kingdom: Open University Press.

Klein, S. B. 2012. The self and science: Is it time for a new approach to the study of human experience? *Current Directions in Psychological Science* 21(4):253-57

Klein, S. B., L. Cosmides, and K. A. Costabile. 2003. Preserved knowledge of self in a case of Alzheimer's dementia. *Social Cognition* 21(2):157-65.

Klein S. B. and M. L. Lax. 2010. The unanticipated resilience of trait self-knowledge in the face of neural damage. *Memory* 18(8):918–48.

Lee, E., K. Meguro, R. Hashimoto, M. Meguro, H. Ishii, S. Yamaguchi, and E. Mori. 2007. Confabulations in episodic memory are associated with delusions in Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology* 20(1):34-40.

Lee, K. H., M. Boltz, H. Lee., and D. L. Algase. 2017. Does Social Interaction Matter Psychological Well-Being in Persons With Dementia? *American Journal of Alzheimer's Disease and other Dementias* 32(4):207-12.

Locke, J. 1689/2000. An Essay Concerning Human Understanding. In *John Locke: An Essay concerning Human Understanding in focus (1st ed)*, eds. G. Fuller, R. Stecker, and J. P. Wright, 67-122. London, United Kingdom: Routledge.

MacIntyre, A. 1985. *After Virtue: A Study in Moral Theory*. London, United Kingdom: Duckworth.

Mackenzie, C. 2014. Embodied agents, narrative selves. *Philosophical Explorations* 17(2):154-71.

Mackenzie, C. and Stoljar, N. 2000. *Relational autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press.

Manthorpe, J. and K. Samsi. 2016. Person-centred dementia care: current perspectives. *Clinical Interventions in Aging* 11:1733-40.

Matthews, S. 2015. Dementia and the Power of Music Therapy. *Bioethics* 29(8):573-79.

Matthews, S., R. Dwyer, and A. Snoek. 2017. Stigma and self-stigma in addiction. *Journal of Bioethical Inquiry* 14(2):275-86.

McCormack, B. 2001. Autonomy and the relationship between nurses and older people. *Ageing and Society* 21(4):417-46.

McCormack, B. 2004. Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing* 13(3a):31-8.

McCormack, B. and McCance, T. 2010. *Person-centred Nursing: Theory and Practice*. Oxford, United Kingdom: Wiley Blackwell.

Millett, S. 2011. Self and embodiment: A bio-phenomenological approach to dementia. *Dementia*. 10(4):509-22.

Mitchell, S. L., B. S. Black, M. Ersek, L. C. Hanson, S. C. Miller, G. A. Sachs, J. M. Teno, and R. S. Morrison. 2012. Advanced Dementia: State of the Art and Priorities for the Next Decade. *Annals of Internal Medicine* 156(1-1):45-51.

Mograbi, D. C., R. G. Brown., and R. G. Morris. 2009. Anosognosia in Alzheimer's disease – the petrified self. *Consciousness and Cognition* 18(4):989–1003.

Morgan, S., and L. H. Yoder. 2012. A Concept Analysis of Person-Centred Care. *Journal of Holistic Nursing* 30(1):6-15.

Moyle, W., L. Venturto, S. Griffiths, P. Grimbeek, M. McAllister, D. Oxlade, and J. Murfield. 2011.

Factors influencing quality of life for people with dementia: a qualitative perspective. *Aging and Mental Health* 15(8):970-7.

Munthe, C., L. Sandman, and D. Cutas. 2011. Person Centred Care and Shared Decision Making:

Implications for Ethics, Public Health and Research. *Journal of Health Philosophy and Policy* 20(3):231-49.

Neisser, U. 1988. Five kinds of self-knowledge. *Philosophical Psychology* 1(1):35–59.

Noel, M., F. Larøi, K. Gallouj, and M. El Haj. 2018. Relationships Between Confabulations and Mental

Time Travel in Alzheimer's Disease. *The Journal of Neuropsychiatry and Clinical Neurosciences* 30(4):302-9.

Nolan, M. R., S. Davies, J. Brown, J. Keady, and J. Nolan. 2004. Beyond 'person-centred' care: a new

vision for gerontological nursing. *International Journal of Older People Nursing* 13(3a):45-53.

Norberg, A. 2019. Sense of Self among Persons with Advanced Dementia. In *Alzheimer's Disease*, ed.

T. Wisniewski, 205-21. Brisbane, Australia: Codon Publications.

Nundy, S. and J. Oswald. 2014. Relationship-centred care: A new paradigm for population health management. *Healthcare* 2(4):216-19.

Orulv, L. and H. Lars-Christer. 2006. Confabulation: sense-making, self-making and world-making in dementia. *Discourse Studies* 8(5):647-73.

Peel, E. 2014. 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': representations of dementia in print media and carer discourse. *Sociology of Health & Illness* 36(6):885-901.

Penrod, J., F. Yu, A. Kolanowski, D. M. Fick, S. J. Loeb, and J. E. Hupcey. 2007. Reframing Person-Centred Nursing Care for Persons with Dementia. *Research and Theory for Nursing Practice* 21(1):57-72.

Reed, P., J. Carson, and Z. Gibb. 2017. Transcending the Tragedy Discourse of Dementia: An Ethical Imperative for Promoting Selfhood, Meaningful Relationships, and Well-Being. *AMA Journal of Ethics* 19(7):693-703.

Reisberg, B., S. H. Ferris, M. J. de Leon, and T. Crook. 1982. The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry* 139(9):1136-9.

Ricoeur, P. 1985. "History as Narrative and Practice", interview with Paul Ricoeur by Peter Kemp.

Philosophy Today 29(3):213-22.

Rogers, C. R. 1957. The necessary and sufficient conditions of therapeutic personality change.

Journal of Consulting Psychology 21(2):95–103.

Rose, K., and R. P. Lopez. 2012. Transitions in dementia care: theoretical support for nursing roles.

American Journal of Alzheimer's Disease and Other Dementias 26(3):212-7.

Rosen, M. 2012. *Dignity: its history and meaning*. Cambridge MA: Harvard University Press.

Rudder Baker, L. 2000. *Persons and Bodies: A Constitution View*. Cambridge, United Kingdom:

Cambridge University Press.

Sabat, S. R. 2018. *Alzheimer's Disease and Dementia: What everyone needs to know*. New York:

Oxford University Press.

Sacks, O. 2014. *Alive Inside*. Available: <https://www.youtube.com/watch?v=8HLEr-zP3fc> (accessed

May 16, 2021).

Sacks, O. 2019, Feb 25. How much a dementia patient needs to know: should a doctor replace an accustomed identity with a meaningless “reality”? *The New Yorker*.

<https://www.newyorker.com/magazine/2019/03/04/how-much-a-dementia-patient-needs-to-know> (accessed May 16, 2021).

Schechtman, M. 1990. Personhood and Personal Identity. *The Journal of Philosophy* 87(2):71-92.

Schechtman, M. 1996. *The Constitution of Selves*. Ithaca, N.Y.: Cornell University Press.

Singer, J. A. 2004. Narrative identity and meaning-making across the adult lifespan: An introduction. *Journal of Personality* 72(3):437–60.

Singer, P. 2009. Speciesism and Moral Status. *Metaphilosophy* 40(3-4):567-81.

Slater, L. 2006. Person-centredness: a concept analysis. *Contemporary Nurse* 23(1):135-44.

Small, J. A., K. Geldhart, G. Gutman, and M. A. C. Scott. 1998. The discourse of self in dementia. *Ageing and Society* 18(3):291-316.

Stein, W. J., trans. 1964. *On the Problem of Empathy*. Dordrecht, Netherlands: Springer Science+Business Media.

Strawson, P. F. 1974. *Freedom and resentment, in Freedom and Resentment and Other Essays*.

London, United Kingdom: Methuen.

Strikwerda-Brown, C., D. M. Grilli, J. Andrews-Hanna, and M. Irish. 2019. "All is not lost" – Rethinking the nature of the self in dementia. *Aging Research Reviews* 54:100932.

Surr, C. A. 2006. Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science and Medicine* 62(7):1720-30.

Taylor, C. 1989. *Sources of the Self: The Making of the Modern Identity*. Cambridge, MA: Harvard University Press.

Taylor, J. S. 2008. On recognition, caring, and dementia. *Medical Anthropology Quarterly* 22(4):313-35.

Tippett, L. J., S. C. Prebble, and D. R. Addis. 2018. The Persistence of the Self over Time in Mild Cognitive Impairment and Alzheimer's Disease. *Frontiers in Psychology* 9:94.

Tresolini, C. P. and The Pew-Fetzer Task Force. 1994. *Health Professions Education and Relationships-centred Care: A Report of the Pew-Fetzer Task Force on Advancing Psychosocial Education*. San Francisco: Pew Health Professions Commission.

Velleman, D. J. 2006. *Self to Self: Selected Essays*. New York: Cambridge University Press.

Walmsley, B. D., and L. McCormack. 2014. The dance of communication: retaining family membership despite severe non-speech dementia. *Dementia* 13(5):626-41.

Woods, R. T. 1989. *Alzheimer's Disease: Coping With a Living Death*. London, United Kingdom: Souvenir Press.