fons.org/library/journal-ipdj-home

International Practice Development Journal

Online journal of FoNS in association with the IPDC and PcP-ICoP (ISSN 2046-9292)

ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Disrupting dehumanising and intersecting patterns of modernity with a relational ethic of caring

Gail Mitchell, Sherry L. Dupuis*, Pia Kontos, Christine Jonas-Simpson and Julia Gray

*Corresponding Author: University of Waterloo, Waterloo, Ontario, Canada
Email: sldupuis@uwaterloo.ca

Submitted for publication: 28th June 2019
Accepted for publication: 6th January 2020
Published: 13th May 2020
https://doi.org/10.19043/ipdj.101.002

Abstract

Background: This article describes two dehumanising patterns associated with modern culture and their consequences of stigma and suffering for persons living with dementia: the increasing division, judgment and exclusion of persons based on difference, disability, and undesirability; and the increasing attention to management and control, and their links with ageism, healthism and consumerism. These patterns have been established in media, policies, discourses and care practices, and have profound and harmful consequences for persons living with dementia.
Aim: Inspired by philosophers Foster and Foucault, we examine societal patterns that intensify stigma and suffering for persons living with dementia through a critical lens. We then turn to a relational model of citizenship in order to advance an alternative care ethic. Subsequently, we provide examples for relational practices and legacies that model a relational care ethic and thereby disrupt the harmful patterns of modern culture.
Conclusion: This article argues that relational practices that foster relational citizenship and relational caring create a more humane world for persons living with memory loss.
Implications for practice development: Longstanding concerns about stigmatising attitudes and inhumane care practices have prompted urgent calls for culture change in dementia and long-term care. Most recently, researchers and professionals have emphasised the relational nature of caring and advocate for the adoption of relational caring practices. This article critiques the harmful patterns of modern culture that threaten the quality of care and quality of life, and offers relational practice possibilities for enhancing care and life quality, and honouring the full citizenship of persons living with dementia.

Keywords: Stigma, dementia, discourse, critique, dehumanising patterns, relational caring

As Western societies moved away from using religious authorities to guide personal choice and community responsibility, the rational, self-actualising human was poised to play a major role in shaping modern culture (Foster, 2016). The promise of modernity, linked with the traditional ideal of autonomy, prioritised independence, self-sufficiency and separation from others (Braudo-Bahat, 2017). The internal, individualistic conceptualisation of the autonomous person is 'complicit with structures of domination and subordination, in particular with the suppression of others who are deemed incapable of achieving rational self-mastery' (Mackenzie and Stoljar, 2000, p 11). Indeed, the Enlightenment conception of autonomy, which places high value on cognition as an integral aspect of an individual's dignity, underpins the equating of loss of cognition in dementia with loss of dignity. The traditional ideal of autonomy has also provided the foundation for what has become a culture of therapeutics, with prescribed interventions aimed at managing, correcting and transcending what are perceived as personal and biological weaknesses and defects (Foster, 2016). The point of our critique of autonomy, in its traditional form, is not to reject the concept of autonomy altogether. Instead, we argue for the replacement of a notion of autonomy that presupposes an atomistic conception of the self (that is, individuals are self-sufficient and abstracted from the social relations in which they are embedded) with a relational view of autonomy (Mackenzie and Stoljar, 2000), centred on interdependence and reciprocity, and a commitment to our mutual flourishing as individuals and a society.

Our intent in this article is to describe two dehumanising patterns of modernity and their consequences for persons living with dementia. Consistent with Foucault (1988), we provide a critique in order to disrupt these dehumanising patterns. Foucault (1988, p 154) described critique as: 'Not a matter of saying that things are not right as they are. It is a matter of pointing out on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practices that we accept rest.' We expose accepted patterns in order to create space for conversations that might generate different practice possibilities. We are members of Collective Disruption (crackedondementia.ca), a group comprising researchers and scholar artists affiliated with the social and health sciences, and humanities. The dehumanising patterns as they have been established in the media, policies, discourses and care practices in relation to dementia command the group's attention. Two dehumanising and interconnecting patterns we are particularly concerned with are:

- The increasing division, judgement, and exclusion of persons based on difference, disability, and undesirability
- The increasing attention to management and control and their links with ageism, healthism, and consumerism

We wish to disrupt these complex patterns in order to call attention to what is increasingly seen as normal and ordinary – the taken for granted (Cheek, 2008) – and to emphasise the need for communities to create patterns of relating that are inclusive, non-judgmental, communal and compassionate. Ideas in this article have been informed by Foster's (2016) detailed look at the therapeutic culture, authenticity and neoliberalism. Foster describes the interconnections between 'the rise of the ethic of authenticity' (where individuals strive to realise their real and ideal selves), the 'entrenchment of a therapeutic ethos' and the movement from external social and moral authority to a new internalised social control (p 100). He argues:

> *'…the adaptation of the therapeutic sensibility to the new practices of management has generated a new type of control that works through the subjectivity of the subject. Rather than passivity, vulnerability and the loss of autonomy, the therapeutic ethos has become adapted to a very austere ideal of autonomy and self-fulfilment that takes shape as a form of managed self-care… The self, released from communal obligation, has been integrated in new circuits of power that normalise the behaviour and practices of self-provision. This transformation… has severed the notion of authenticity entirely from any sense of public and collective responsibility'* (Foster, 2016, p 113).

As Foster argues, the new 'neoliberal model of self-care' that emerges has profound social consequences, affecting how we understand and relate to one another, eroding relational and collective values, particularly in relation to the responsibilities we have to each other and to the common good (Foster, 2016, p 109). The purpose here is to build on Foster's ideas by extending his critical insights to disrupt the dehumanising patterns seen in dementia discourse and practices. After considering the harmful patterns of modern culture, this article turns to a relational model of citizenship in order to advance an alternative care ethic. We go on to provide examples of relational practices and legacies that model a relational care ethic, thereby disrupting these harmful patterns and offering new possibilities for practice development.

We begin this article with a caveat. Each of us has meaningful experiences in life, practice and research with persons and families living with dementia. We deeply appreciate the challenges and restrictions, and the losses and fears that a label of dementia can mean, and do not in any way intend to trivialise or romanticise the experiences of persons with dementia and their families. However, we have also learned that serious misrepresentations and harmful consequences can emerge from the words, images and portrayals of persons living with dementia. This work is intended to disrupt the discourses and the harmful care processes that can accompany the diagnosis of dementia.

Pattern #1: Division, judgment and exclusion based on difference, disability and undesirability

For more than two decades we, along with others, have been working to challenge the culture of dementia care in North American society, which is focused on the body and its various functions and deficits (Fagan, 2003; Deutschman, 2005; Bartlett and O'Connor, 2007; Dupuis et al., 2016a). We have critiqued the language, images and understandings that accompany a diagnosis of dementia (Jonas-Simpson et al., 2012; Mitchell et al., 2013; Gray et al., 2017). We have struggled with and challenged the predominant approach in dementia care that seeks to assess and manage people according to the labels assigned by outsiders who focus primarily on problematic behaviours and undesirable functions of the body (Dupuis et al., 2012a; Grigorovich et al., 2019). And we share concerns that the stigma associated with dementia fuels fear and loathing such that old age itself is now equated with the 'dreaded' diagnosis of dementia (Whitehouse and George, 2008).

Two dominant and inter-related discourses fuel the stigmatisation, judgement and social exclusion of persons living with dementia and their family carers. These are biomedical, and dementia as tragedy (Basting, 2009; Behuniak, 2010; Zeilig, 2014). Within the biomedical discourse, the person with dementia is reduced to their neuropathology – that is, their diagnosis (Downs, 2006; Behuniak, 2010). Care practices are restricted to attending to bodily needs (Twigg, 2000; Daly and Szebehely, 2012) within a unidirectional provider-as-expert model of care. With the adoption of the biomedical model, a therapy culture has come to define dementia care wherein persons with dementia and living in long-term care homes are subjected to multiple assessments by various professionals who populate a list of needs and functional deficits and assign interventions, therapies and modifications to meet them (Wiersma and Dupuis, 2010). The primary focus of therapeutic intervention is to manage 'challenging behaviours' with mechanical, environmental and/or pharmacological/chemical restraints (Schneider et al., 2006; Maust et al., 2015). In addition to the harm caused by such treatments in the dementia context (O'Keeffe, 2017), this approach to care sets up significant barriers to meaningful participation by persons living with dementia in planning and decision-making around their own care (Dannefer et al., 2008; Dupuis et al., 2012b) and to living in 'normalised' ways. Leisure activities such as gardening and music are used and valued primarily as non-pharmacological 'treatments' or 'therapies' to achieve a host of medicalised outcomes (Dupuis et al., 2012c; Genoe and Whyte, 2015; Kontos and Grigorovich, 2018), notably the control of misunderstood actions and expressions (Dupuis et al., 2012a; 2012b). In this way, valued aspects of daily life become medicalised (Foster, 2016). Persons living with dementia are also presumed to be unable to learn or develop new skills, or to make meaningful contributions to their own lives and the lives of others (Sterin, 2002; Kontos, 2005; Dupuis et al., 2012b). In a study conducted by Dupuis et al. (2013), a person living with dementia reflected on how she was underestimated and dismissed in long-term care:

> *'They think I can't do anything. Until they get used to me and what I can still do many try to take over. They also give meaningless activities like tip all the pens and pencils out on the table, mix them up and then ask us to sort them out. That made me angry. One care worker accused me of lying when I talked about being involved with a consumer committee because she said that if I had dementia I couldn't do it.'*

The dehumanising conditions of life and care in these settings have led to their being described as 'contemporary "gulags", sites of increasing use of chemical restraints, places of abuse and violence, and locations of tragedies that reveal high levels of neglect' (Chivers, 2015, pp 134-135).

The language embedded within the biomedical model, and what is used by formal care providers, reflects a broader cultural discourse of dementia as tragedy that is based on the assumption that the neuropathology associated with dementia 'eradicates the essence of the person' (Dalziel, 1994, p 1407; Behuniak, 2011; Kontos, 2012a; Peel, 2014; Zeilig, 2014). This is evident in the metaphors and images in policy and popular culture that represent dementia as 'the funeral without end', 'the loss of self', 'the zombie', and 'a living death' (Mitchell et al., 2013). This discourse has its roots in the 17th-century rise of the 'modern self', which brought with it the coupling of the self and the brain (Vidal, 2009) with memory coming to be understood as necessary for personhood (Katz, 2013). When the self is assumed 'lost' or 'eroded', loss of agency and citizenship status ensues (Dupuis et al., 2016b; Kontos et al., 2017a). As Kontos et al. (2017a, p 182) argue:

> *'An individual's status as citizen, which denotes entitlement to connection to a community and country, rights and responsibilities as a community member, and freedom from discrimination (Bartlett and O'Connor, 2007), is seen as irrevocably eroded by dementia because communicative competence and intellectual capacities are inextricably linked to the practice and status of citizenship.'*

Alzheimer's Research UK and its social medial campaign #sharetheorange (Alzheimer's Research UK, 2016) provides a powerful example of this tragedy discourse. The campaign includes a video created by the makers of the Wallace and Gromit stories (an animation comedy series) and features the actor Christopher Eccleston. The video uses an image of a slowly disintegrating orange to illustrate how dementia 'physically attacks your brain... until it strips away everything that makes you you, and then you die'. It compares dementia with diseases like cancer, saying it 'destroys' not only the brain but the person. And at the end, the last section of the orange falls over signaling death.

The intent of this campaign is to raise money to help find a cure for dementia and the strategy appears to involve fostering fear of dementia. The profound impact that stigma has on people labeled with a 'spoiled identity' has been convincingly demonstrated by Goffman (1963) and others (Falk, 2001; Aldridge et al., 2019). The images and words used to describe dementia impact, in profound ways, on how persons with dementia view themselves and their worth as human beings. Indeed, self-internalisation of stigma associated with dementia has been linked to avoidance of social interactions, isolation, feelings of shame and inadequacy, depression, anxiety and even suicide (Erlangsen et al., 2008; Benbow and Jolley, 2012; Koyama et al., 2015). Death is the most devastating consequence of stigma. Also, with the successful lobbying to have euthanasia an approved and accepted medical intervention to relieve pain and suffering (Johnstone, 2011), death may increasingly be embraced as the preferred choice, even among persons living with dementia, as government legislation and regulations are revised. Our arguments in favour of a relational ethic of care are by no means intended to imply that individuals should not have the right to choose the moment of death. Yet proponents of a radical democratisation of end-of-life autonomy do not consider that an individual's decision to die may be largely mediated by social factors, which, in the case of dementia, refers to the harm imposed by society privileging rationality and cognitive memory, and consequently excluding individuals with dementia from the sphere of human dignity and respect (Braswell, 2011). The fear potentially engendered by campaigns such as #sharetheorange also fuels the internalised need to self-manage in order to avoid developing dementia if possible. We turn to this point in the next section.

Pattern #2: Ageism, healthism and consumerism

Adults in today's society are expected to be in control and to exercise judgement and discretion to keep their personal matters in check, particularly with regard to health, which has moved from being a human right to a personal and moral duty (Galvin, 2002; Foster, 2016). The increasing emphasis on individual responsibility, control and autonomy has been linked to the rise of neoliberalism and economic rationalism – that is, the idea that the market should determine what is to be produced and how it is to be produced (Crawford, 2006; Cheek, 2008; Ayo, 2012). As Galvin (2002, p 117) points out:

> *At the heart of this shift in political posture is the neoliberal resurrection of the classical liberal concept of 'negative liberty' which seeks to minimise the intervention of political administration in the lives of citizens and, in the current context, casts them as 'consumers' and 'enterprising' individuals who make 'choices' and who, consequently, are responsible for the outcomes of these choices. As a result, circumstances which were once viewed as either resulting from the failure of the modern state or simply a matter of social responsibility, such as sickness, poverty, unemployment, homelessness, racism and exposure to crime, are now being redefined as matters of individual responsibility.*

Responsible and empowered citizens are to fulfil their moral obligations to monitor and manage all the risks that present themselves, to be the 'good self-manager' (Ellis et al., 2017). They are to do this by attending to the current and ever-evolving understanding of what constitute healthy lifestyle choices (for example, nutrition, exercise, stimulation) and avoiding risky health behaviours, such as smoking, alcohol intake or fat consumption (Galvin, 2002); what Foucault (1988) called 'technologies of the self'. A plethora of supports and products to assist individuals with this responsibility has emerged. These include regular screening services and devices, fitness centres, lifestyle coaches, nutrition and health food stores, self-help books, and even lifestyle prescriptions that general practitioners are mandated to offer (Cheek, 2008; Katz and Marshall, 2018). All these '[foster] an increasingly intimate connection between health and the market place' (Galvin, 2002, p 121) and encourage the 'consumerist frenzy' (p 127). As Ball emphasises, individuals have become an 'auditable commodity' (p 225).

Further, in a climate where ageism is rampant and societal pressures to look younger are pervasive, older adults experience even stronger pressures to do all that is possible 'to remedy or defy an aging body' and reduce the risks of getting certain diseases (Pond et al., 2010, p 742), especially Alzheimer's disease. Coupled with the predominant dementia-as-tragedy discourse discussed earlier, which engenders enormous fear and anxiety of getting an illness causing dementia (Higgs and Gilleard, 2017), and the rhetoric of the 'burden' of dementia and chronic illness on the carers and the healthcare system (Johnstone, 2011), older adults are being targeted more and more to self-manage their bodies and lifestyles in order to ward off the prospect of succumbing to dementia and other chronic diseases (George and Whitehouse, 2011; Katz and Marshall, 2018).

Emphasising the impending harm associated with the risk of developing chronic illnesses, most particularly illnesses causing dementia, '[stimulates] a sense of panic, a sense of urgency, and a sense that action must be taken now' (Ayo, 2012, p 103). In fact, a growing body of literature is exploring the notion of individual responsibility and self-management in the context of dementia (Mountain, 2006; Martin et al., 2013; Quinn et al., 2015). Examples of pressure to self-manage in this way are found in the push to sell software programs, brain health games and devices, and food supplements that help manage memory loss before it becomes a diagnosis of dementia (George and Whitehouse, 2011; Katz and Marshall, 2018). Drug companies have created food supplements to treat pre-dementia. The suggestion that a supplement significantly increases memory and helps sharpen a person's focus and attention compels all individuals with pre-dementia to purchase and consume the product. One such supplement made the parent drug company one of the fastest-growing companies in America, and now the Federal Drug Association is issuing warnings as class action suits get filed (Janet et al., 2012).

A powerful example of this pressure to self-manage is found in the documentary *Monster in the Mind: The Convenient Un-Truth about Alzheimer's* (Carper, 2016). The documentary was directed by Jean Carper, a former CNN senior medical correspondent and author of *Stop Aging Now* (1996) and *Food – Your Miracle Medicine (1994)*. When she became aware that she was a carrier of the APOE gene, the number one gene for Alzheimer's, she became, by her own admission, obsessed with finding out everything she could about the disease. This resulted in the book *100 Simple Things You Can Do to Prevent Alzheimer's and Age-Related Memory Loss* (Carper, 2010), just one of many books purporting to help readers ward off or delay dementia. In her 2016 documentary, Carper reaches out to 'industry experts' around the world from a range of disciplines and undergoes hi-tech testing, screening and surveillance to predict her chances of developing Alzheimer's. She also changes her eating patterns, starts taking supplements, exercises regularly for brain health and sees a psychic; all powerful indicators of the embodiment of the ideology of healthism – that is, viewing health-promoting activities as a moral obligation and an individual's responsibility (Crawford, 2006) and the therapeutic ethos described by Foster (2016). The documentary is successful in exposing some myths about dementia and raising awareness of the complexity of illnesses causing dementia, and the failures of the focus on a cure and current drug testing. However, it resorts to the dominant tragedy discourse in order to do so, and thus perpetuates the fear and loathing of dementia. This is aptly captured in the conclusion Carper reaches after having nightmares about dementia:

> *'Oh my God, Alzheimer's is a ghost story. It's not just a medical problem, or a conventional scientific quest for a cure. It's in essence a science fiction horror disaster movie. The disease is predicted to become an apocalypse by mid century… It survives on an irrational fear of mysterious forces that attack and slowly shrink our brains, turning us into victims who resemble that repulsive half-dead half-alive creature, the zombie – created by the dark imaginations of horror filmmakers in the 1930s and indelibly embedded in the public consciousness by* Night of the Living Dead.*'*

By the end of the documentary, the message is clear: it is up to individuals to take responsibility to change their lifestyles and self-manage the risks of getting dementia. Advertisements for the documentary call this an 'inspiring happy ending, showing us how to *save ourselves and the world from dementia*' (emphasis added).

As Katz and Marshall argue (2003, p 44): 'The marketing, pharmaceutical and consumerist industries… and the concurrent neoliberal political agendas that require people to adopt risk-aversive, active, self-reliant lifestyles' are dangerous and profound. At a minimum the intense focus on marketing to individuals to encourage consumption as a means to avoid ageing and chronic illness is alarming. But, when individual choice, freedom and responsibility are the focus, inequities in health are viewed as inevitable and acceptable, and the person who becomes ill is ultimately the one who is blamed for not being the 'good' citizen; this person is held 'morally culpable' (Galvin, 2002, p 117). Individuals who develop illnesses can be subsequently punished through policies and structures that can deny access to health resources and even the right to continued life. In 2009, an advisor to the UK government suggested persons with dementia may have a moral duty to die, especially because of wasting human and fiscal resources (Beckford, 2008; Malpas, 2009). The duty to die is communicated with what Kate Swaffer (2014) has termed Prescribed Disengagement™. Swaffer is a leading advocate for those living with dementia, who described how, when she was diagnosed with dementia, her healthcare professionals and service providers all told her to give up her studies, go home, put her end-of-life affairs in order and get acquainted with aged care, including selecting a respite day care and residential care facility, sooner rather than later. She coined the term to describe how many people with dementia are written off after a diagnosis and also speaks out about the profound consequences of prescribed disengagement:

> *'This sets up people with dementia to live a life without hope, without any sense of a future and destroys the notion of wellbeing. This Prescribed Disengagement™ sets up a chain reaction of*

> *hopelessness and terror which negatively impacts a person's ability to be positive, resilient and proactive, ultimately affecting their wellbeing and quality of life'* (Swaffer, 2014).

Despite such concerning patterns, we are inspired by Romesin and Verden-Zoller's (2009) alternative theory of human evolution, presented in their book, *Origin of Humanness in the Biology of Love*. Rather than supporting the 'survival of the fittest' construct, these authors clearly show how human evolution has been created through collaborative and loving communities, largely supported through the biology of women and familial structures extended over time. Romesin and Verden-Zoller propose that human beings shape the future through patterns being lived in the present moment. As we have argued, current predominant patterns of biomedical functional care, fuelled by the tragedy discourse of dementia, impose unnecessary suffering. We call for the ethical duty to promote, preserve and sustain the human flourishing of persons living with dementia by supporting their embodied and relational capabilities. We draw on a relational model of citizenship (Dupuis et al., 2016b; Miller and Kontos, 2016; Kontos et al., 2016a; 2017a; Grigorovich and Kontos, 2018; Kontos and Grigorovich, 2018; Grigorovich et al., 2019) to conceptualise and articulate what this relational care ethic entails.

Relational citizenship: An alternative commitment for community

An alternative to the deficit-based disease model of memory loss is the relational model of citizenship, which recognises relationality, and primordial and sociocultural dispositions of the body as fundamental sources of selfhood. This is termed 'embodied selfhood' (Kontos et al., 2016a; Grigorovich and Kontos, 2018; Miller and Kontos, 2016; Dupuis et al., 2016b; Kontos et al., 2017a). Embodied selfhood takes its theoretical bearings from Merleau-Ponty's reconceptualisation of perception (1962) and Bourdieu's concept of habitus (1977, 1990). Together, these theoretical bearings highlight the importance of a pre-reflective way of knowing that both sustains and animates self-expression, and that is always intertwined with a shared world. In so doing, it importantly challenges the Cartesian dualism that splits mind from body, positions the former as superior to the latter and holds cognition as the guarantor of selfhood. Granting agency to the pre-reflective body, separate and apart from cognition, importantly challenges assumptions of loss of agency with dementia by treating the body as itself having creative and intentional capacity. Thus, even in the face of cognitive impairment, agency persists.

The relational model of citizenship signals an important shift away from person-centred care (Kitwood, 1997) and relationship-centred care (Nolan et al., 2002). Person-centred care places the person – not the illness or disease – and their values, desires, preferences and patterns of living at the centre of care. Rather than pathologising behaviour, it focuses on understanding the meaningfulness of personal expressions (Dupuis et al., 2012a). While person-centred care is arguably the most important paradigm shift in dementia care practice since the 1990s (Bartlett and O'Connor, 2010), it has inspired new care models meant to address its limitations, such as the lack of attention to the relational nature of care (Nolan et al., 2002) and issues of agency and power inherent in care contexts (Bartlett and O'Connor, 2010; Dupuis et al., 2012b; Kontos et al., 2017a). Relationship-centred care has played a key role in shifting the focus from person-centred notions of autonomy and individuality to recognising 'the interdependencies and reciprocities that underpin caring relationships' (Nolan et al., 2002, p 203) and the status that people with dementia have as active partners in their own care (Adams and Clarke, 1999; Dupuis et al., 2012b). Despite these contributions, relationship-centred care focuses solely on care relationships, neglecting the broader political and cultural embeddedness of individuals and the profound ways in which broader structures can shape the experiences of people with dementia (Bartlett and O'Connor, 2007). A citizenship lens calls attention to the sociopolitical landscape and the misuses of power that can dis-able and oppress persons living with a dementia, and is a means of addressing social injustices and ultimately improving the quality of care and life for all people living with dementia (Bartlett and O'Connor, 2010; Bartlett, 2016; Kontos et al., 2017a).

The relational citizenship model is unique in that it brings together embodiment, selfhood, and relationality, in that selfhood is understood to be inherently embodied, intercorporeal (with/in the body), and relational (Kontos et al., 2016a; 2017a). The model further upholds that our body-self/body-world relations must be supported in and through a matrix of human rights (Kontos et al., 2016a; Grigorovich and Kontos, 2018) and interpersonal commitments. Relational citizenship is premised on a new kind of ethic that necessitates the reframing of dementia care from the narrow focus on body care and management, to the conservation of human flourishing in relationship (Jennings, 2009; Kontos and Grigorovich, 2018), which we have termed relational caring (Dupuis et al., 2016c; 2018). This requires the cultivation of a relational environment at a policy level and in clinical and wider public structures and practices, so that persons with dementia can 'experience freedom from discrimination' (Bartlett and O'Connor, 2010, p 37) and have their capabilities for creativity, imagination and other positive human potentialities fully supported (Kontos et al., 2016a). In addition to theorising relational caring and citizenship, we have developed and identified practices that support human flourishing and quality of life for persons living with dementia that have implications for practice development.

Flourishing in relational communities and practices

The Dotsa Bitove Wellness Academy (Dotsa Bitove Wellness Academy, n.d.) inspires and facilitates expressions of self in relationship through the arts and movement in an open, homelike environment (Mitchell et al., 2019). Relationships and intergenerational learning experiences disrupt the labels and categories that typically divide, segregate and stigmatise persons living with dementia (Jonas-Simpson et al., 2017a, 2017b). Artistic expression and practices hold the potential to support relationship-building and aesthetic ways of being in the world as embodied, imaginative, sensory, emotional and vulnerable (Gray et al., 2019). The Dotsa Bitove Wellness Academy is founded on three fundamental concepts: knowing otherwise (Olthius, 1997), embodied selfhood (Kontos, 2005, 2012a, 2012b), and relationality (Jordan et al., 2004; Nolan et al., 2006; Arai et al., 2015). The academy is an assessment- and therapy-free space that has an impact, not only on persons living with dementia, but on all who enter and engage within its community, including care partners, staff, students, artists and volunteers. Everyone within the community has an opportunity to thrive with dementia, and everyone in the space is viewed and valued as a teacher and a learner. Persons with dementia teach and show those of us without dementia how to feel free to be ourselves (Jonas-Simpson et al., 2017a). Joy is expressed and experienced individually and as a collective, especially while dancing, singing and making music and in creative play. A short film has been created to show how relational caring is experienced within a loving dementia-inclusive community (see Jonas-Simpson et al., 2017b).

Christakis and Fowler (2009, p 31) found that social networks 'magnify what they are seeded with' and can influence, for example, the 'spread of joy'. Those authors go on to propose that 'as part of a social network, we transcend ourselves, for good or ill, and become a part of something much larger. We are connected'. We see how being part of the collective at the academy opens all of us to something much larger. Persons living with dementia, who are often excluded, alone and isolated, are given opportunities to be in relationship with others; their relational citizenship is supported, for example, in their participation in the arts for life enrichment, in comforting someone having a bad day, in their expressions of joy and sadness, in asking someone to dance, or in advocacy work such as organising a food drive during the holidays, as one woman living with dementia did. In addition, opportunities to be in relationship with young people enhances community and joy for both (Jonas-Simpson, 2017b). In all of these ways the Dotsa Bitove Wellness Academy is not only supporting relational practice, it is creating a legacy of relational caring where an entire community living with dementia is flourishing.

The performance art of elder-clowning is another innovative relational arts-based practice that enriches the lives of individuals with dementia in long-term residential care. It offers a cultural/aesthetic approach to relational caring that, in many ways, uniquely recognises and supports relational citizenship in individuals living with dementia. Akin to circus and theatrical clowns, elder-clowns wear a red nose but they wear minimal make-up and tend to wear clothing reminiscent of earlier eras, such as 1950s swing dresses. In addition to drawing on artistic techniques such as music and slapstick, elder-clowns also rely on familial details to inform interactions with each individual resident.

Encounters might, for example, involve elder-clowns singing a resident's favourite song with them while strumming a miniature, colourful ukulele, or co-creating an improvised song with a resident about something personal (for fuller descriptions of elder-clowning see Kontos et al., 2016b, 2017b; Miller and Kontos, 2016).

The fundamental goal of all elder-clown training is to prepare the clowns to achieve an interactional state known as 'presence', which refers to being authentic, and is cultivated through attentive listening, and extraordinary focus and sensitivity (Kontos et al., 2017b). As part of their training, clown-practitioners learn to become 'completely attuned to the other,' and to be able to distinguish 'with increasing subtlety between differences in how the other person relates with the world, attentively, physically and sensorily' (Hendriks, 2012, p 469). This means they do not impose themselves or any medically oriented therapeutic goals in their interactions, including any demands for 'cheerfulness' (Gray et al., 2019), but rather they attend to subtle embodied expressions, including emotions, movements and body language as part of playful encounters. Thus, much of the intersubjective communication that takes place between the clown and individuals living with dementia is at the affect level. This has been termed 'affective relationality' (Kontos et al., 2017b) and encompasses both joyfulness and sadness. There is a relational intersection between the 'imaginative reality' of elder-clowns and that of the person living with dementia (Kontos et al., 2017b). In this relational play space, elder-clowns draw on the performative coherence (Hydén and Örulv, 2009; Kontos and Martin, 2013) of the storytelling of individuals living with dementia to co-construct imaginative scenarios. Imaginative possibility is particularly valuable in the context of dementia, where boundaries shift between time, place and person, and become more fluid and less defined (Mitchell et al., 2013). Elder-clowning is also characterised by 'reciprocal playfulness' (Kontos et al., 2017b) where elder-clowns build on the ways in which persons with dementia can be deliberately playful, offering moments of fantasy, availability and laughter. Elder-clowns' 'affective resonance' (Hartling and Littlefield, quoted in Freedberg, 2007, p 255), their offer of imaginative possibilities, and support of reciprocal playfulness form significant dimensions of relational citizenship in the context of the interpersonal mutuality of caring. Elder-clowning demonstrates, perhaps too clearly, the deep chasm between how life can be enriched in practice for persons living with dementia in long-term care homes and the predominance of managed care devoid of relational practice. This begs the following questions, however: how do we find ourselves so far away from supporting life enrichment and human flourishing in long-term care homes that we need to draw on the art of clown to help us to see the humanity of persons living with dementia and how to support relational caring? How can we support care providers/partners in adopting these same relational skills in their caring practices?

Shifting to the culture of relational caring practice

One of the most significant impediments to transforming the culture of care from behavioural management to relational caring practice, exemplified at the Dotsa Bitove Wellness Academy and in elder-clowning, has been the lack of understanding of what it means to be and act relational in practice. Relational caring practices require not only a change in taken-for-granted patterns of relating but also a radical philosophical shift in terms of how care and living are understood. To this end, formal carers need opportunities to challenge and critically reflect on their own language, assumptions and ways of being, and they need opportunities to learn about and practice being in new relational ways. Arts-based and dialogical education methods targeted at building understanding and skills regarding relational caring (for example: showing empathy and curiosity by being emotionally present; being aware of the consequences of our feelings and actions on others; experiencing vulnerability as inevitable; working as a team; empowering others; questioning inhumane practices; and advocating for change) are showing promise in expanding understandings and supporting relational practices in different aged care settings (Greenwood, 2015; Kontos et al., 2018; Dupuis et al., 2019). For example, we worked closely with team members in long-term care settings to develop the 'Relational Caring Learning Series' (Dupuis et al., 2018). We recognised that for personal transformation to happen, there was a need to create a non-traditional learning space, 'a different social environment' (Greenwood, 2015, p 230), deeply embedded within a relational caring ethic. Throughout the series, professionals share and learn together. They are provided with opportunities to critically reflect on taken-for-granted assumptions about persons living with dementia, older adults, their colleagues and current care practices. Reflections are facilitated with a critical immersion in relational concepts and ideas through, for example, art-making, theatrical exercises, sharing of stories, opportunities to try out new ways of relating in practice and other reflective exercises. Results from the pilot of the series demonstrate that when professionals have a safe space to critically reflect on and imagine new ways of being and relating, this new understanding nurtures relational caring (Dupuis et al., 2019). However, culture change that supports relational practices requires more than what we call relational literacies; it requires a strong structural foundation that provides space for relational practice, including the elimination of stigma, language and the inhumane care practices and policies that prevail in many dementia care settings. It also requires strong leadership committed to relational caring practices, including modeling, mentoring and supporting professionals as they try them out. Finally, a truly relational community focuses on nurturing relationships and friendships between all in the care context, including persons living with dementia, family members and professionals. This requires flattening traditional hierarchies, thinking about relationships within dementia care settings differently, and providing regular opportunities to come together as a community, such as in shared meals and social activities, community mourning and celebrations, and just to have fun.

Conclusion

In this article we have exposed two dehumanising and intersecting patterns that shape the experiences of persons and families living with dementia in profound and harmful ways: increasing division, judgement and exclusion of persons based on difference, disability and undesirability; and increasing attention to management and control and their links with ageism, healthism and consumerism. Situating taken-for-granted and often unchallenged discourses and practices within the broader sociocultural and political landscape opens a space for questioning what is, understanding the consequences and imagining how we might create new humanising ways of being and relating for a better future. We call on others who share our concerns to take up a relational caring ethic in order to create a more humane world for persons living with dementia.

References

Adams, T. and Clarke, C. (1999) *Dementia Care: Developing Partnerships in Practice*. London: Bailliere Tindall.

Aldridge, H., Fisher, P. and Laidlaw, K. (2019) Experiences of shame for people with dementia: an interpretative phenomenological analysis. *Dementia*. Vol. 18. No. 5. pp 1896-1911. https://doi.org/10.1177/1471301217732430.

Alzheimer's Research UK (2016) *#sharetheorange*. Retrieved from: youtube.com/watch?v=x9MvEZskR6o. (Last accessed 2nd December 2019).

Arai, S., Berbary, L. and Dupuis, S. (2015) Dialogues for re-imagined praxis: using theory in practice to transform structural, ideological, and discursive "realities" with/in communities. *Leisure/Loisir.* Vol. 39. No. 2. pp 299-321. https://doi.org/10.1080/14927713.2015.1086585.

Ayo, N. (2012) Understanding health promotion in a neoliberal climate and the making of health conscious citizens. *Critical Public Health.* Vol. 22. No. 1. pp 99-105. https://doi.org/10.1080/09581596.2010.520692.

Ball, S. (2003) The teacher's soul and the terrors of performativity. *Journal of Education Policy*. Vol. 18. No. 2. pp 215-228. https://doi.org/10.1080/0268093022000043065.

Bartlett, R. (2016) Scanning the concepetual horizons of citizenship. *Dementia*. Vol. 15. No. 3. pp 453-461. https://doi.org/10.1177/1471301216644114.

Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies*. Vol. 21. No. 2. pp 107-118. https://doi.org/10.1016/j.jaging.2006.09.002.

Bartlett, R. and O'Connor, D. (2010) *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: The Policy Press.

Basting, A. (2009) *Forget Memory*. Baltimore, US: Johns Hopkins University.

Beckford, M. (2008) Baroness Warnock: Dementia sufferers may have a 'duty to die'. *The Telegraph*. Retrieved from: tinyurl.com/telegraph-warnock. (Last accessed 2nd December 2019).

Behuniak, S. (2010) Toward a political model of dementia: power as compassionate care. *Journal of Aging Studies.* Vol. 24. No. 4. pp 231-240. https://doi.org/10.1016/j.jaging.2010.05.003.

Behuniak, S. (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society.* Vol. 31. No. 1. pp 70-92. https://doi.org/10.1017/S0144686X10000693.

Benbow, S. and Jolley, D. (2012) Dementia: stigma and its effects. *Neurodengenerative Disease Management*. Vol. 2. No. 2. pp 165-172. https://doi.org/*10.2217*/nmt.12.7.

Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Bourdieu, P. (1990) *The Logic of Practice*. Cambridge: Polity Press.

Braswell, H. (2011) Can there be a disability studies theory of 'end-of-life authonomy'? *Disability Studies Quarterly*. Vol. 31. No. 4. http://dx.doi.org/10.18061/dsq.v31i4.1704.

Braudo-Bahat, Y. (2017) Towards relational conceptualization of the right to personal autonomy. *American University Journal of Gender, Social Policy and the Law*. Vol. 25. No. 2. pp 111-154. Retrieved from: tinyurl.com/Braudo-autonomy. (Last accessed 10th March 2020).

Carper, J. (2010) *100 Simple Things You Can Do to Prevent Alzheimer's and Age-related Memory Loss.* New York: Little Brown and Company.

Carper, J. (2016) *Monster in the Mind. The Convenient Un-truth about Alzheimer's.* Retreived from: youtube.com/watch?v=yqdM5UzpvMQ. (Last accessed 26th March 2020).

Cheek, J. (2008) Healthism: A new conservativism? *Qualitative Health Research.* Vol. 18. No. 7. pp 974-982. https://doi.org/10.1177/1049732308320444.

Chivers, S. (2015) 'Blind people don't run': Escaping the 'nursing home specter' in *Children of Nature* and *Cloudburst*. *Journal Aging Studies*. Vol. 34. pp 134-141.

Christakis, N. and Fowler, J. (2009) *Connected: How your Friends' Friends' Friends Affect Everything you Feel, Think and Do*. New York: Little Brown and Co.

Crawford, R. (2006) Health as meaningful social practice. *Health.* Vol. 10. No. 4. pp 401-420. https://doi.org/10.1177/1363459306067310.

Daly, T. and Szebehely, M. (2012) Unheard voices, unmapped terrain: care work in long-term residential care for older people in Canada and Sweden. *International Journal of Social Welfare.* Vol. 21. No. 2. pp 139-148. https://doi.org/10.1111/j.1468-2397.2011.00806.x.

Dalziel, W. (1994) Dementia: no longer the silent epidemic. *Canadian Medical Association Journal*. Vol. 151. No. 10. pp 1407-1409. Retrieved from: https://tinyurl.com/dalziel-silent. (Last accessed 1st September 2018).

Dannefer, D., Stein, P., Siders, R. and Patterson, R. (2008) Is that all there is? The concept of care and the dialectic of critique. *Journal of Aging Studies.* Vol. 22. No. 2. pp 101-108. https://doi.org/10.1016/j.jaging.2007.12.017.

Deutschman, M. (2005) An enthnographic study of nursing home culture to define organization realities of culture change. *Journal of Health and Human Services Administration*. Vol. 28. No. 2. pp 246-282. Retrieved from: jstor.org/stable/41288066. (Last accessed 2nd December 2019).

Dotsa Bitove Wellness Academy (n.d.) *Dotsa Bitove*. Retrieved from: www.dotsabitove.com. (Last accessed 2nd December 2019).

Downs, M., Clare, L. and Mackenzie, J. (2006) Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort. Chp 15 *in* Hughes J., Louw, S. and Sabat, S. (Eds.) (2006) *Dementia: Mind, Meaning, and the Person*. Oxford: Oxford University Press. pp 235-258.

Dupuis, S., Wiersma, E. and Loiselle, L. (2012a) Pathologizing behavior: meanings of behaviors in dementia care. *Journal of Aging Studies*. Vol. 26. No. 2. pp 162-173. https://doi.org/10.1016/j.jaging.2011.12.001.

Dupuis, S., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L. and Sadler, L. (2012b) Moving beyond 'patient' and 'client' approaches: mobilising 'authentic partnerships' in dementia care. *Dementia*. Vol. 11. No. 4. pp 428-450. https://doi.org/10.1177/1471301211421063.

Dupuis, S., Whyte, C., Carson, J., Genoe, R., Meshino, L. and Sadler, L. (2012c) Just dance with me: an authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal.* Vol. 54. No. 3. pp 240-254. https://doi.org/10.1080/04419057.2012.702454.

Dupuis, S., Carson, J. and Whyte, C. (2013) Aligning TR practice in LTC homes with culture change values. *Canadian Therapeutic Recreation Association's (CTRA) 17th Annual Conference*. Montreal, May 2013.

Dupuis, S., McAiney, C., Fortune, D., Ploeg, J. and Witt, L. (2016a) Theoretical foundations guiding culture change: the work of the Partnerships in Dementia Care Alliance. *Dementia.* Vol. 15. No. 1. pp 85-105. https://doi.org/10.1177/1471301213518935.

Dupuis, S., Kontos, P., Mitchell, G., Jonas-Simpson, C. and Gray, J. (2016b) Re-claiming citizenship through the arts. *Dementia.* Vol. 15. No. 3. pp 358-380. https://doi.org/10.1177/1471301216637206.

Dupuis, S., Gray, J., Jonas-Simpson, C., Kontos, P. and Mitchell, G. (2016c) *Relational Caring*. Factsheet prepared for Toward Relational Care: A hands-on workshop exploring relationality through theatre. Presented at the Walk with Me: Changing the Culture of Aging in Canada conference. Retrieved from: tinyurl.com/relational-caring-factsheet. (Last accessed 26th March 2020).

Dupuis, S., McAiney, C., Hickman, K., Jonas-Simpson, C., Kontos, P., Mitchell, G. and Gray, J. with partners from Extendicare Canada and the Alzheimer Society of Canada (2018) *Relational Caring Learning Series*. Waterloo, Canada: Partnerships in Dementia Care Alliance.

Dupuis, S., McAiney, C., Engell, K. and Main, S. (2019) *Piloting the Relational Caring Learning Series: Final Report*. Waterloo, Canada: Partnerships in Dementia Care Alliance. (Submitted to Alzheimer Society of Canada 14th November 2019).

Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C. and Demain, S. (2017) Conceptualistion of the 'good' self-manager: a qualitative investigation of stakeholder views on the self-management of long-term health conditions. *Social Science and Medicine*. Vol. 176. pp 25-33. https://doi.org/10.1016/j.socscimed.2017.01.018.

Erlangsen, A., Zarit, S. and Conwell, Y. (2008) Hospital-diagnosed dementia and suicide: a longitudinal study using prospective, nationwide register data. *The American Journal of Geriatric Psychiatry*. Vol. 16. No. 3. pp 220-228. https://doi.org/10.1097/JGP.0b013e3181602a12.

Fagan, R. (2003) Pioneer Network: changing the culture of aging in America. *Journal of Social Work in Long-Term Care*. Vol. 2. Nos. 1-2. pp 125-140. https://doi.org/10.1300/J181v02n01_09.

Falk, G. (2001) *Stigma: How We Treat Outsiders*. Amherst, US: Prometheus Books.

Foster, R. (2016) Therapeutic culture, authenticity and neo-liberalism. *History of the Human Sciences*. Vol. 29. No. 1. pp 99-116. https://doi.org/10.1177/0952695115617384.

Foucault, M. (1988) Technologies of the self. Chp 2 *in* Martin, L., Gutman, H. and Hutton, P. (Eds.) (1988) *Technologies of the Self: A Seminar with Michel Foucault*. London: Penguin. pp 16-50.

Freedberg, S. (2007) Re-examining empathy: a relational-feminist point of view. *Social Work*. Vol. 52. No. 3. pp 251-259. https://doi.org/10.1093/sw/52.3.251.

Galvin, R. (2002) Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals. *Health: An interdisciplinary Journal of the Social Study of Health, Illness and Medicine*. Vol. 6. No. 2. pp 107-137. https://doi.org/10.1177/136345930200600201.

Genoe, R. and Whyte, C. (2015) Confronting ageism through therapeutic recreation practice. *Leisure/Loisir.* Vol. 39. No. 2. pp 235-252. https://doi.org/10.1080/14927713.2015.1086583.

George, D. and Whitehouse, P. (2011) Marketplace of memory: what the brain fitness technology industry says about us and how we can do better. *The Gerontologist.* Vol. 51. No. 5. pp 590-596. https://doi.org/10.1093/geront/gnr042.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliff, US: Prentice Hall.

Gray, J. (2019) Working within an aesthetic of relationality: theoretical considerations of embodiment, imagination and foolishness as part of theatre making about dementia. *Research in Drama Education: The Journal of Applied Theatre and Performance*. *Special Issue on Theatre, Dementia and Relationality.* Vol. 24. No. 1. pp 6-22. https://doi.org/10.1080/13569783.2018.1535270.

Gray, J., Kontos, P., Dupuis, S., Mitchell, G. and Jonas-Simpson, C. (2017) Dementia (re)performed: interrogating tensions between relational engagement and regulatory policies in care homes through theatre. Chp 9 *in* Chivers, S. and Kriebernegg, U. (Eds.) (2017) *Care Home Stories: Aging, Disability, and Long-term Residential Care*. Bielefeld, Germany: Transcript-Verlag. pp 105-120.

Gray, J., Donnelly, H. and Gibson, B. (2019) Seriously foolish and foolishly serious: the art and practice of clowning in children's rehabilitation. *Journal of Medical Humanities*. pp 1-17. https://doi.org/10.1007/s10912-019-09570-0.

Greenwood, D. (2015) Using a drama-based education programme to develop a 'relational' approach to care for those working with people living with dementia. *RIDE: The Journal of Applied Theatre and Performance*. Vol. 20. No. 2. pp 225-236. https://doi.org/10.1080/13569783.2015.1019444.

Grigorovich, A. and Kontos, P. (2018) Advancing an ethic of embodied relational sexuality to guide decision-making in dementia care. *The Gerontologist*. Vol. 58. No. 2. pp 219-225. https://doi.org/10.1093/geront/gnw137.

Grigorovich, A., Kontos, P. and Kontos, A.P. (2019) The 'violent resident': a critical exploration of the ethics of resident-to-resident aggression. *Journal of Bioethical Inquiry*. Vol. 16. No. 2. pp 173-183. https://doi.org/10.1007/s11673-019-09898-1.

Hendriks, R. (2012) Tackling indifference – clowning, dementia, and the articulation of a sensitive body. *Medical Anthropology.* Vol. 31. No. 6. pp 459-476. https://doi.org/10.1080/01459740.201.674991.

Higgs, P. and Gilleard, C. (2017) Ageing, dementia and the social mind: past, present and future perspectives. *Sociology of Health & Illness*. Vol. 39. No. 2. pp 175-181. https://doi.org/10.1111/1467-9566.12536.

Hydén, L. and Örulv, L. (2009) Narrative and identity in Alzheimer's disease: a case study. *Journal of Aging Studies*. Vol. 23. No. 4. pp 205-214. https://doi.org/10.1016/j.jaging.2008.01.001.

Janet, Janet and Suggs, LLC. (2012) *Consumer Alerts: Class-action Lawsuit Filed Against 'Memory Supplement' Marketers.* Retrieved from: https://www.jjsjustice.com/blog/prevagen-fda-investigation/. (Last accessed 2nd December 2019).

Jennings. B. (2009) Agency and moral relationship in dementia. *Metaphilosophy.* Vol. 40. Nos. 3-4. pp 425-437. https://doi.org/10.1111/j.1467-9973.2009.01591.x.

Johnstone, M. (2011) Metaphors, stigma and the 'Alzheimerization' of the euthanasia debate. *Dementia*. Vol. 12. No. 4. pp 377-393. https://doi.org/10.1177/1471301211429168.

Jonas-Simpson, C., Mitchell, G.J., Carson, J., Whyte, C., Dupuis, S. and Gillies, J. (2012) Phenomenological shifts for healthcare professionals after experiencing a research-based drama on living with dementia. *Journal of Advanced Nursing*. Vol. 68. No. 9. pp 1944-1955. https://doi.org/10.1111/j.1365-2648.2011.05877.x.

Jonas-Simpson, C. with research team: Mitchell, G., Dupuis, S., Kontos, P. and Cross, N. (2017a) *Free to Be: Experiences of Relational Caring at the Dotsa Bitove Wellness Academy.* (Research-based short film). Toronto: Dotsa Bitove Wellness Academy. Retrieved from: dotsabitove.com/research-based-art. (Last accessed 2nd December 2019).

Jonas-Simpson, C. with research team: Cross, N. and Meschino, L. (2017b) *Transgenerational Learning Through the Arts at the Dotsa Bitove Wellness Academy.* (Research-based Short Film). Toronto: Dotsa Bitove Wellness Academy. Retrieved from: dotsabitove.com/research-based-art. (Last accessed 2nd December 2019).

Jordan, J., Walker, M. and Hartling, L. (2004) *The Complexity of Connection: Writings from the Stone Center's Jean Baker Miller Training Institute*. New York: The Guilford Press.

Katz, S. (2013) Dementia, personhood and embodiment: what can we learn from the medieval history of memory? *Dementia*. Vol. 12. No. 3. pp 303-314. https://doi.org/10.1177/1471301213476505.

Katz, S. and Marshall, B. (2003) New sex for old: lifestyle, consumerism, and the ethics of ageing well. *Journal of Aging Studies.* Vol. 17. pp 3-16. https://doi.org/10.1016/S0890-4065(02)00086-5.

Katz, S. and Marshall, B. (2018) Tracked and fit: Fitbits, brain games, and the quantification of the aging body. *Journal of Aging Studies.* Vol. 45. pp 63-68. https://doi.org/10.1016/j.jaging.2018.01.009.

Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*. Buckingham, UK: Open University Press.

Kontos, P. (2005) Embodied selfhood in Alzheimer's disease: rethinking person-centred care. *Dementia:*

The International Journal of Social Research and Practice. Vol. 4. No. 4. pp 553-570. https://doi.org/10.1177/1471301205058311.

Kontos, P. (2012a) Alzheimer expressions or expressions despite Alzheimer's? *Occasion: Interdisciplinary Studies in the Humanities.* Vol. 4. pp 1-12. Retrieved from: https://tinyurl.com/Kontos-expressions. (Last accessed 29th August 2018).

Kontos, P. (2012b) Rethinking sociability in long-term care: an embodied dimension of selfhood. *Dementia.* Vol. 11. No. 3. pp 329-346. https://doi.org/10.1177/1471301211421073.

Kontos, P. and Martin, W. (2013) Embodiment and dementia: exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia.* Vol. 12. No. 3. pp 288-302. https://doi.org/10.1177/1471301213479787.

Kontos, P., Grigorovich, A., Kontos, A. and Miller, K.-L. (2016a) Citizenship, human rights, and dementia: towards a new embodied relational ethic of sexuality. *Dementia.* Vol. 15. No. 3. pp 315-329. https://doi.org/10.1177/1471301216636258.

Kontos, P., Miller, K.-L., Colobong, R., Palma Lazgare, L., Binns, M., Low, L-F., Surr, C. and Naglie, G. (2016b) Elder-clowning in long-term dementia care: results of a pilot study. *Journal of the American Geriatrics Society.* Vol. 64. No. 2. pp. 347-353. https://doi.org/10.1111/jgs.13941.

Kontos, P., Miller, K.-L. and Kontos, A.P. (2017a) Relational citizenship: supporting embodied selfhood and relationality in dementia care. *Sociology of Health and Illness.* Vol. 39. No. 2. pp 182-198 https://doi.org/10.1111/1467-9566.12453.

Kontos, P., Miller, K.-L., Mitchell, G. and Stirling-Twist, J. (2017b) Presence redefined: the reciprocal nature of engagement between elder-clowns and persons with dementia. *Dementia.* Vol. 16. No. 1. pp 46-66. https://doi.org/10.1177/1471301215580895.

Kontos, P. and Grigorovich, A. (2018) Rethinking musicality in dementia as embodied and relational. *Journal of Aging Studies*. Vol. 45. pp 39-48. https://doi.org/10.1016/j.jaging.2018.01.006.

Kontos, P., Grigorovich, A., Dupuis, S., Jonas-Simpson, C., Mitchell, G. and Gray, J. (2018) Raising the curtain on dementia stigma: fostering a new cultural imaginary for a more inclusive society. *Critical Public Health*. Vol. 30. No. 1. https://doi.org/10.1080/09581596.2018.1508822.

Koyama, A., Fujise, N., Matsushita, M., Ishikawa, T., Hashimoto, M. and Ikeda, M. (2015) Suicidal ideation and related factors among dementia patients. *Journal of Affective Disorders*. Vol. 178. No. 1. pp 66-70. https://doi.org/10.1016/j.jad.2015.02.019.

Machenzie, C. and Stoljar, N. (2000) Introduction. *In* Machenzie, C. and Stoljar, N. (Eds.) (2000) *Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford: Oxford University Press. pp 3-34.

Malpas, P. (2009) Do those afflicted with dementia have a moral duty to die? A response to Baroness Warnock. *Journal of the New Zealand Medical Association*. Vol. 122. No. 1,296. pp 53-60.

Martin, F., Turner, A., Wallace, L. and Bradbury, N. (2013) Conceptualisation of self-management intervention for people with early stage dementia. *European Journal of Ageing.* Vol. 10. No. 2. pp 75-87. https://doi.org/10.1007/s10433-012-0253-5.

Maust, D., Kim, H., Seyfried, L., Chiang, C., Kavanagh, J., Schneider, L. and Kales, H. (2015) Antipsychotics, other psychotropics, and the risk of death in patients with dementia: number needed to harm. *Journal of the American Medical Association Psychiatry.* Vol. 72. No. 5. pp 438-445. https://doi.org/10.1001/jamapsychiatry.2014.3018.

Merleau-Ponty, M. (1962) *Phenomenology of Perception*. London: Routledge.

Miller, K. and Kontos, P. (2016) The use of elder-clowning to foster relational citizenship in dementia care. Chp 8 *in* Andreassen, T., Gubrium, J. and Solvang, P. (Eds.) (2016) *Reimagining the Human Service Relationship*. New York: Columbia University Press. pp 158-177.

Mitchell, G., Dupuis, S. and Kontos, P. (2013) Dementia discourse: from imposed suffering to knowing other-wise. *Journal of Applied Hermeneutics*. Vol. 2013. Article 5. pp 1-19. https://doi.org/10.11575/jah.v0i2.53220.

Mitchell, G., Jonas-Simpson, C., Richards, J., Brown, S. and Bitove, V. (2019) Creating a wellness academy for persons living with dementia: An innovative practice in relational arts. *Dementia*. Online First. https://doi.org/10.1177/1471301219895647.

Mountain, G. (2006) Self-management for people with early dementia: an exploration of concepts and supporting evidence. *Dementia*. Vol. 5. No. 3. pp 429-446. https://doi.org/10.1177/1471301206067117.

Nolan, M., Davies, S. and Brown, J. (2006) Transitions in care homes: towards relationship-centred care using the 'Senses Framework'. *Quality in Ageing and Older Adults*. Vol. 7. No. 3. pp 5-14. https://doi.org/10.1108/14717794200600015.

Nolan, M., Ryan, T., Enderby, P. and Reid, D. (2002) Towards a more inclusive vision of dementia care practice and research. *Dementia*. Vol. 1 No. 2. pp 193-211. https://doi.org/10.1177/147130120200100206.

O'Keeffe, S. (2017) Physical restraints and nursing home residents: dying to be safe? *Age and Ageing*. Vol. 46. No. 4. pp 536-537. https://doi.org/10.1093/ageing/afx014.

Olthuis, J. (Ed.) (1997) *Knowing Other-Wise. Philosophy at the Threshold of Spirituality*. New York: Fordham University.

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 and Illness.* Vol. 36. No. 6. pp 885-901. https://doi.org/10.1111/1467-9566.12122.

Pond, R., Stephens, C. and Alpass, F. (2010) Virtuously watching one's health: older adults' regulation of self in the pursuit of health. *Journal of Health Psychology.* Vol. 15. No. 5. pp 734-743. https://doi.org/10.1177/1359105310368068.

Quinn, C., Toms, G., Anderson, D. and Clare, L. (2015) A review of self-management interventions for people with dementia and mild cognitive impairment. *Journal of Applied Gerontology.* Vol. 35. No. 11. pp 1154-1188. https://doi.org/10.1177/0733464814566852.

Romesin, H. and Verden-Zoller, G. (2009) *The Origins of Humanness in the Biology of Love*. Exeter: Imprint Academic.

Schneider, L., Dagerman, K. and Insel, P. (2006) Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *The American Journal of Geriatric Psychiatry.* Vol. 14. No. 3. pp 191-210. https://doi.org/10.1097/01.JGP.0000200589.01396.6d.

Sterin, G. (2002) Essay on a word: a lived experience of Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice.* Vol. 1. No. 1. pp 7-10. https://doi.org/10.1177/147130120200100103.

Swaffer, K. (2014) Reinvesting in life is the best prescription. *Australian Journal of Dementia Care*. Retrieved from: https://journalofdementiacare.com/reinvesting-in-life-is-the-best-prescription/. (Last accessed 29th August 2018).

Twigg, J. (2000) *Bathing: The Body and Community Care*. London: Routledge.

Vidal, F. (2009) Brainhood, anthropological figure of modernity. *History of the Human Sciences*. Vol. 22. No. 1. pp 5-36. https://doi.org/10.1177/0952695108099133.

Whitehouse, P. and George, D. (2008) *The Myth of Alzheimer's: What you Aren't Being Told about Today's Most Dreaded Diagnosis*. New York: Macmillan.

Wiersma, E. and Dupuis, S. (2010) Becoming institutional bodies: socialisation into a long-term care home. *Journal of Aging Studies*. Vol. 25. No. 4. pp 278-291. https://doi.org/10.1016/j.jaging.2010.08.003.

Zeilig, H. (2014) Dementia as a cultural metaphor. *The Gerontologist.* Vol. 54. No. 2. pp 258-267. https://doi.org/10.1093/geront/gns203.

Gail Mitchell (PhD, RN), Professor Emeritus, School of Nursing, Faculty of Health, York University, Toronto, Ontario, Canada.

Sherry L. Dupuis (PhD), Professor, Department of Recreation and Leisure Studies, University of Waterloo; Co-Director, Partnerships in Dementia Care Alliance, University of Waterloo, Ontario, Canada.

Pia Kontos (PhD), Senior Scientist, Toronto Rehabilitation Institute – University Health Network; Associate Professor, Dalla Lana School of Public Health, University of Toronto, Ontario, Canada.

Christine Jonas-Simpson (PhD, RN), Associate Professor, Faculty of Health, York University, Toronto, Ontario, Canada.

Julia Gray (PhD), Post-Doctoral Fellow, The Critical Disability and Rehabilitation Studies Lab, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada.