

# Theoretical foundations guiding culture change: The work of the Partnerships in Dementia Care Alliance



Dementia  
2016, Vol. 15(1) 85–105

© The Author(s) 2014

Reprints and permissions:

[sagepub.co.uk/journalsPermissions.nav](http://sagepub.co.uk/journalsPermissions.nav)

DOI: 10.1177/1471301213518935

[dem.sagepub.com](http://dem.sagepub.com)



**Sherry Dupuis**

Department of Recreation and Leisure Studies, University of Waterloo, ON, Canada

**Carrie A McAiney**

Department of Psychiatry and Neurosciences, McMaster University, Hamilton, ON, Canada

**Darla Fortune**

Department of Recreation and Leisure Studies, University of Waterloo, ON, Canada

**Jenny Ploeg**

School of Nursing, McMaster University, Hamilton, ON, Canada

**Lorna de Witt**

Faculty of Nursing, University of Windsor, ON, Canada

## Abstract

Longstanding concerns about quality care provision, specifically in the area of long-term care, have prompted calls for changing the culture of care to reflect more client-driven and relationship-centred models. Despite an increase in culture change initiatives in both Canada and the United States, there is insufficient information about the theories and approaches that guide culture change. The purpose of this paper is to describe a culture change initiative currently underway in Canada, the Partnerships in Dementia Care Alliance, and the theoretical foundations informing our work. More specifically, we describe how the theoretical and philosophical underpinnings of the Alzheimer Disease and Related Dementias framework, the authentic partnership approach, participatory action research and Appreciative Inquiry have been integrated to guide a culture change process that encourages *working collaboratively, thinking and doing differently* and *re-imagining new possibilities* for changing the culture of dementia care.

## Keywords

culture change, dementia, long-term care, authentic partnership, participatory action research, Appreciative Inquiry

---

## Corresponding author:

Darla Fortune, University of Waterloo, 200 University Avenue, Waterloo, ON N2L 3G1 Canada.

Email: [dbfortune@uwaterloo.ca](mailto:dbfortune@uwaterloo.ca)

## Introduction

In 2009, half a million Canadians were living with Alzheimer's disease or a related dementia (ADRD) (Alzheimer Society of Canada, 2009). Projected prevalence rates in Canada suggest dramatic increases over the coming decades as the population ages. It is estimated that by 2034, over one million Canadians will have an illness causing dementia (ASC, 2009). These increases have significant implications both for persons diagnosed with dementia and their families, and also for the provision of care in both long-term and community care settings (Sachs, Shega, & Cox-Hayley, 2004). In 2010, approximately 20% of people receiving care in the community and 57% of people living in a long-term care (LTC) home had a diagnosis of ADRD (Canadian Institute for Health Information [CIHI], 2010). Recognizing the growing number of persons requiring care and support, Alzheimer's and other seniors and health associations around the world, including Canada and the United States, have identified dementia as an international health and social priority (World Health Organization [WHO], 2012). These organizations have been advocating for governments to take direct steps to understand the broad implications of the changing demographic landscape and to begin planning to address the needs of persons with ADRD, their families and support staff working in dementia care (National Advisory Council on Aging, 2004; Smale & Dupuis, 2004; WHO, 2012).

At the same time, the LTC sector in Canada is facing dramatic changes and is under pressure from aging-in-place initiatives, rising service expectations of families, and calls for alternative social models of care that allow for increased citizen choice and more humanistic approaches to care (Gibson & Barsade, 2003; Stevens, 2001). Difficulties in responding to these pressures affects both the quality of care and support provided to Canadians and the quality of work life for staff working in LTC settings (Bowers, Nolet, Roberts, & Esmond, n.d.; Gibson & Barsade, 2003). A report prepared for the Ontario Long-Term Care Association, for example, made it clear that Ontario's capacity to provide affordable, accessible, and high quality care in LTC settings is in jeopardy and will not meet future needs without significant innovation and transformation (The Conference Board of Canada, 2011). Increasing case loads, documented inter-professional conflicts and tensions between front-line and supervisory staff, and a focus on bed-and-body (Gubrium, 1975) task-based approaches to care have contributed to low staff morale, low job satisfaction, high staff turnover rates and absenteeism, and difficulty in recruiting and retaining skilled professionals and strong leaders in LTC (Bowers et al., n.d.; Jervis, 2002; McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001; McWilliam et al., 2003). These issues, which directly impact the provision of quality care, are exacerbated in the context of dementia care because of the misunderstandings and stigma associated with the disease. Further, a lack of staff education and training often leave staff ill-equipped to manage the complexity of issues associated with dementia care (Smale & Dupuis, 2004).

There is a growing consensus that the way care is currently delivered, regulated and financed is inadequate to meet the care needs and ensure a high quality of life for the growing numbers of older adults over the next several decades, particularly those living with dementia (Miller, Booth, & Mor, 2008). Initiatives in both Canada (McWilliam et al., 2001, 2003; Smale & Dupuis, 2004) and the United States (Bowers et al., n.d.; Deutschman, 2005) have identified the organizational culture within LTC as a factor that often detracts from quality care and quality of life. More specifically, challenges within the

current LTC culture include: (1) a hierarchical organizational structure that provides little support and few opportunities for participation in decision-making by those directly involved in care (Bowers et al., n.d.; McWilliam et al., 2003); (2) the domination of an acute, medical model of care despite significant increases in complex, dementia-related chronic health issues and providers' lack of preparedness to deal with these complex health issues (Deutschman, 2005; Diamond, 1992; Foner, 1995) (3) a focus on a unidirectional, provider-as-expert model of care that produces significant barriers to active and meaningful client participation in planning and decision-making around their own care (Bowers et al., n.d.; Dannefer, Stein, Siders, & Patterson, 2008; Jervis, 2002; McWilliam et al., 2003); and (4) a reliance on clinical outcome measures (e.g. Minimum Data Set scores) that inadequately reflect client experiences, thereby failing to use these experiences to inform effective care decisions (Bowers et al., n.d.; McWilliam et al., 2003). In dementia care more specifically, we still have not moved beyond a narrow focus on the 'condition' of dementia where the common notion is that a loss of self is inextricably linked to the deterioration associated with dementia (Davis, Byers, Nay, & Koch, 2009). Thus, current approaches continue to exclude persons with dementia from decision-making, fuelled by misunderstanding and stigma when persons with dementia are viewed as incapable of communicating their experiences, and thus presumed unable to make meaningful contributions to their own lives and the lives of others (Jolley & Benbow, 2000; Sterin, 2002). When such misconceptions perpetuate the exclusion of persons with dementia from decision-making they significantly limit possibilities in dementia care.

Longstanding concerns about quality care provision, specifically in the area of LTC, have prompted calls for culture change that move us away from the current top-down, provider-driven approaches to more client-driven approaches and relationship-centred models of care (McWilliam et al., 2001; Nolan, Davies, Brown, Keady, & Nolan, 2004; Smale & Dupuis, 2004). What is needed is a LTC culture that: (1) has strong bidirectional relationships at its core that are premised on an ethic where each participant is viewed as equal (Dannefer et al., 2008; Dupuis, Gillies, et al., 2012; Holstein, Parks, & Waymack, 2011); (2) ensures direct, active and meaningful involvement in planning and decision-making of all key participants including clients, family members, staff, administrators, other community members and partners, and policy makers (Dupuis, Gillies, Mantle, Loiselle, & Sadler, 2008; McWilliam et al., 2003; Nolan, Lundh, Grant, & Keady, 2003; Ronch, 2003); (3) provides empowering, life-affirming and humanistic approaches to care by focusing on the experiences and needs of all involved in the care context, including clients, family members and staff (Gibson & Barsade, 2003; Holstein et al., 2011; Nolan et al., 2004); and (4) values on-going education and learning for all staff and ensures that processes and strategies are in place so all staff are well-equipped in their jobs and better able to translate research into practice (McWilliam et al., 2009; Smale & Dupuis, 2004). The evidence is clear. When the multiple voices and experiences of everyone involved in the care context are recognised, valued, and incorporated in decision-making; health policies, programs, and services are more relevant to client and staff needs. Quality outcomes are subsequently improved for clients, family members, and staff. (Anderson et al., 1995; Sommers, Marton, Barbaccia, & Randolph, 2000).

Culture change initiatives have become increasingly popular in the United States in recent years (e.g. Pioneer Network, 2013; Thomas, 2003), and there is a similar recognized need for culture change in Canada. However, since research on culture change has not kept pace with the culture change movement (Rahman & Schnelle, 2008), there is insufficient information

about the theories and approaches that guide culture change initiatives. In fact, most culture change initiatives in LTC often lack theoretical grounding.

The purpose of this paper is to describe a culture change initiative currently underway in Canada, the Partnerships in Dementia Care (PiDC) Alliance and the theoretical foundations informing our work. More specifically, we describe the theoretical and philosophical underpinnings of the ADRD framework, the authentic partnership approach, participatory action research (PAR) and Appreciative Inquiry (AI) and share how these complementary theories and methodologies have been integrated and are being used to guide our work. Our hope is that by sharing this information we will be helping others as they embark on culture change work in the area of dementia care. We first briefly describe the PiDC Alliance and situate it within the larger culture change movement. We then introduce each of the theoretical frameworks guiding our research, integrating specific examples from our process thus far to illustrate how the frameworks are integrated within our work. Finally, we show how our integrated frameworks are guiding a culture change process that involves working collaboratively, thinking and doing differently, and re-imagining new possibilities for dementia care.

### **The PiDC Alliance: Changing the culture of dementia care**

The PiDC Alliance is a collaborative research network and culture change initiative based in Ontario, Canada. Our work is focused on improving the dementia care experience within both LTC home and community care settings. The PiDC Alliance brings together diverse members of the dementia care community, including individuals living with dementia, family partners in care, a wide range of professionals working in dementia care, an interdisciplinary team of researchers and over 50 community partners and organizations at the regional, provincial and national levels.

The ultimate goal of the PiDC Alliance is to facilitate sustainable culture change reflective of a relationship-centred, partnership approach in order to enhance the care experience for all those involved in dementia care. Our objectives include:

- (1) to systematically document and understand the culture change process and the factors that support and limit partnership approaches within different LTC home and community care settings;
- (2) to support the development of empowering partnerships that foster meaningful involvement of all key participants;
- (3) to build the capacity necessary to facilitate culture change in dementia care by strengthening the skills and knowledge bases of all those working in dementia care; and
- (4) to develop a multimodal and dynamic knowledge translation platform in which to share newly created tools and resources that might help others facilitate their own participatory culture change processes.

We are working to achieve these goals by implementing and evaluating the process of culture change within four diverse dementia care settings (three LTC homes and one community care setting). Culture Change Coalitions (CCCs), made up of persons living with dementia/residents, family partners in care, staff working in various disciplines and levels of healthcare, and researchers, have formed in each of these settings and are responsible for championing and facilitating the culture change process within their

specific settings. Our Knowledge Translation Specialist attends all culture change meetings to ensure that information is shared among the CCCs and also works with a Knowledge Mobilization Community of Practice to ensure learnings from the program are shared more broadly. To provide context for the culture change work being done by the PiDC Alliance, we discuss what it means to change the culture of dementia care.

## **What does it mean to change the culture of dementia care?**

Culture change within the LTC home sector has received considerable attention in recent years. Since over 50% of people living in a LTC home have a diagnosis of AD/DR (CIHI, 2010), initiatives directed toward changing the culture of LTC will inevitably have important implications for dementia care.

Culture change is an on-going and evolving process that involves the difficult work of critically re-examining the language, values, assumptions, attitudes, practices, approaches and policies embedded within an organization (Fagan, 2003; Misiorski & Rader, 2010; Pioneer Network, 2013). It works towards the development and implementation of a comprehensive set of fundamental reforms in order 'to create caring communities where both empowered front-line staff and [LTC residents and families] can flourish' (Rahman & Schnelle, 2008, pp. 142–143). Culture change in LTC homes is often described as the movement away from the medical institutional model of care toward a relational/community model of care that is grounded in the values of choice and self-determination; dignity and respect; the nurturance of mind, body and spirit; personhood; close interdependent relationships; collaborative decision-making; purposeful living; and enabling, normalizing environments (Fagan, 2003; Hill, Kolanowski, Milone-Nuzzo, & Yevchuk, 2011). As an example, the Pioneer Network (2013), a coalition formed in the United States consisting of people who are dedicated to changing the culture of aging and LTC, advocated for LTC to move away from institutional, provider-driven models of care to more humane, client-driven models of care that embrace flexibility and self-determination. This movement has commonly come to be known as the LTC culture change movement and is based on person-directed values and practices where the voices and narratives of people living in LTC and those working with them are considered and respected (Baker, 2007; Fagan, 2003; Hill et al., 2011; Misiorski & Rader, 2010).

Kitwood (1997) once explained that a change in the culture of care is a complex process that involves seeing things in a new way. It is commonly acknowledged that for culture change in LTC to occur, organizational practices, physical environments, relationships at all levels and workforce models must be transformed (Pioneer Network, 2013). Since language, activity and social relationships become institutionalized within a culture (Kemmis & McTaggart, 1988), transformation happens when we open up, challenge and change institutionalized forms of language, activity and established practices, as well as our ways of relating to one another. Transformation within the context of aging begins by troubling individual and societal attitudes toward aging that shape the language we use, our care relationships, government policy and regulation (Fagan, 2003; Holstein et al., 2011).

While the culture change movement is primarily focused on the LTC home sector, there is recognition that culture change is also needed in community care settings. McWilliam et al. (2001), for example, explored the experience of empowerment and disempowerment of in-home care among clients, family care partners and providers within a home care delivery system and discovered that the traditional expert model often dominated care

provision. The authors advocated for moving toward a culture of empowerment by creating more equitable care partnerships.

Since culture change is an organic and on-going process (Fagan, 2003), most models of culture change are accompanied by a warning to resist the temptation of a 'quick fix'. The clear message is that when change efforts are done in a way that does not involve everyone affected by them they are likely to be counterproductive. Scott, Mannion, Davies and Marshall (2003) reviewed some of the key debates surrounding the nature of culture change in healthcare organizations and strongly argued that top-down approaches that attempt to instill new values, beliefs and working relationships simply do not work. As they state, 'professional values, affirmed over centuries and woven into the fabric of healthcare organizations, are resilient enough to frustrate many attempts to "engineer" change from above' (Scott et al., 2003, p. 117). Yet, without leadership to help translate ideas into practice and to help provide encouragement and direction, the culture change process can lose momentum and its implementation will be short-lived (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009).

Further, when staff feel unsupported in their efforts to provide quality care or when they feel limited to do so by regimented and standardized practices, they are likely to be skeptical of culture change initiatives (Misiorski & Rader, 2010). Research conducted by DeForge, van Wyk, Hall and Salmoni (2011) showed how standardized care practices can impede efforts to provide individualized care and may result in staff feeling either unable or afraid to care. These feelings were related to a culture based on compliance within which common sense and authentic approaches to care and relating adopted by experienced staff were at odds with legislated approaches to care provision that emphasized a focus on completing tasks. Whenever tasks come before relationships in a LTC environment the culture devalues both persons providing care and persons receiving care (Ronch, 2004).

Though models guiding culture change may differ, relationships are considered to be at the heart of most culture change initiatives (Baker, 2007; Misiorski & Rader, 2010). In calling for relational ethics in aging and LTC, Holstein et al. (2011) highlight how relationships are critical to 'authentic caring', which differs from meeting needs and providing services. 'Care is created in and through relationships. It is not done *for* someone. It is done *with* someone' (Holstein et al., 2011, p. 128). Baker (2007) found clear evidence for this when visiting more than two dozen care homes in the United States. Many of those homes were aligned with culture change models. She determined that culture change is fundamentally about relationships and community and the strands of culture change – honouring choice, empowering staff, making a homey environment – come together to create community. Culture change in LTC is closely tied to the belief that residents and staff will thrive when institutions can be transformed into communities of bounded, interdependent relationships (Hill et al., 2011). For a culture change initiative to be effective, it must be grounded in what is real for people who live and work in LTC:

When people have solid relationships they can have true exchanges about what is working and what is not working. The process depends on these real conversations to allow people to work toward common goals. The change process needs strong relationships in place in order to go forward. Change activities should be designed so they strengthen and build upon these relationships (Quality Partners of Rhode Island, 2005–2006, p. 42).



As the quote above reflects, relationships are critical to the culture change process since they are the heart of work environments (Baker, 2007) and individuals are best understood within the contexts of their relationships (Holstein et al., 2011; Nolan et al., 2004). The PiDC Alliance recognizes that changing the culture of dementia care involves giving consideration to the many relationships that exist for persons living with dementia.

### An integrated theoretical framework for guiding culture change

Recognizing the need for culture change initiatives to be grounded in strong theoretical foundations and yet the paucity of theoretically informed examples within the LTC culture change literature, the PiDC Alliance set out to identify key frameworks and models that had interdependent, collaborative relationships at their core. This process led to the integration of the principles and tenets of four key theoretical and methodological frameworks – the ADRD Planning Framework, the Authentic Partnership Approach, PAR and AI – which then served to guide all of the work within the Alliance (see Figure 1 for the integrated framework). In this section, we describe each of these frameworks and how each framework has informed the work of the Alliance.

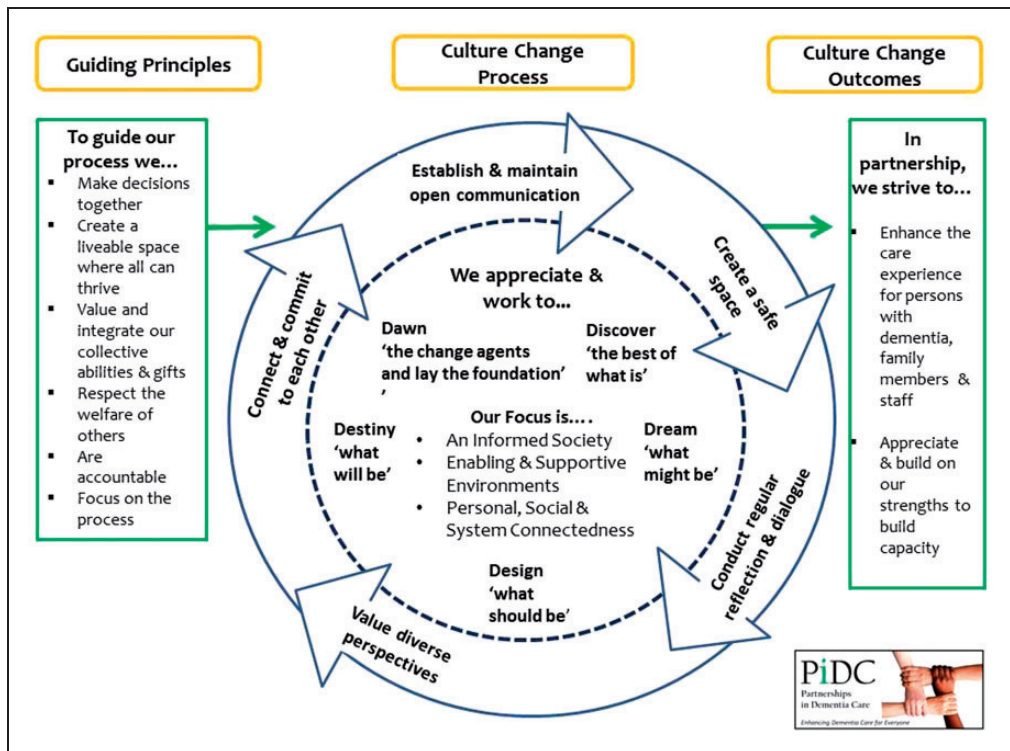


Figure 1. Integrated Theoretical Framework.

## Nurturing supportive dementia care through an ADRD framework

A detailed description of the ADRD Framework was outlined by Dupuis (2010) and later, working with community members, expanded to an age-friendly community platform (see [www.afc.uwaterloo.ca](http://www.afc.uwaterloo.ca)). Here we provide a synopsis of the framework. In 2004, the province of Ontario concluded a five-year comprehensive Alzheimer Strategy (1999–2004) that focused on service, education and research. As part of the Ontario Alzheimer Strategy Transition Project, the Roundtable on Future Planning for People Affected by ADRD was convened to develop a planning framework and tool-kit that would address the impact of dementia on government programs, communities and the province as a whole. The Roundtable included persons living with dementia, family partners in care, health care and social support service professionals, policy makers and researchers. All Roundtable members worked together to determine what was needed to enhance the quality of life for persons living with dementia and their families. A values-based and research-informed dementia framework was developed based on work completed during the Alzheimer Strategy, a survey of Roundtable members, consultations with other key stakeholders, and a review of research, policy planning documents and social models of care and support.

The resulting framework is informed by six guiding principles (see Dupuis, 2010). The first principle, *a relationship-based approach to care*, responds to the charge that focusing solely on the person living with dementia ignores the fact that the family, care staff, community and larger society are also affected by and shape others' illness experiences. This principle encourages the development of meaningful relationships among persons living with dementia, their family partners in care and the formal helping system. The second principle, *the ethical principle of 'do no harm'*, recognizes the need to be informed about the potential for harm and to identify the vulnerability associated with dementia. The third principle, *citizenry rights*, acknowledges that everyone has the right to meaningful choice and self-determination, to experience interdependence with other members of the community, to be fully engaged in life, and to be treated with respect and dignity. The fourth principle, *respect for diversity and inclusiveness*, urges various dimensions of diversity to be recognized and considered with sensitivity in policy and planning decisions. The fifth principle, *fairness in eligibility and accessibility*, encourages the provision of programs and services that are flexible enough to respond to the changing needs of persons living with dementia and their families. The sixth principle, *accountability*, stresses the need for shared responsibility by the citizens of Ontario, the government, health care professionals, and individuals living with dementia and their families to ensure the principles get translated into practice.

Three planning pillars that capture the essential life experiences affecting the well-being of persons living with dementia are grounded in the six guiding principles. These pillars consist of *an informed society* in which all citizens have adequate and reliable information about dementia; *enabling and supportive environments* that ensure continued engagement and connections with community throughout the dementia journey; and *personal, social and system connectedness* which dictates a thoughtful planning approach that supports meaningful relationships and partnerships and involvement in decision-making at the individual, community and service levels. Collectively, these planning pillars highlight the conditions necessary to move toward the realization of a vision of Ontario in relation to persons and families experiencing dementia. The vision sees Ontario as a place where all persons with dementia live meaningful lives through active personal and community



engagement. As Dupuis (2010) has argued, achieving this vision will require significant culture change that involves individuals and communities thinking differently about how to support persons with dementia.

Thinking differently about supporting persons with dementia opens up new possibilities for dementia care that are grounded in humanistic and social engagement. McIntyre (2003), for example, has urged us to view dementia as a social issue to be addressed and supported through human interaction. She observed that the positive aspects of dementia care experiences are virtually unknown and argued that more research is needed to explore relationships involving persons with dementia so we can better understand the unique potential of dementia for advancing our capacity for being in relationship with others. After recounting the 'spa days' that her mother enjoyed in the comfort of her own home, the spontaneous outings during which her mother shared her love of live music with a health care provider, and the heartfelt exchanges between her mother and a caring neighbour, McIntyre argued that relationships between persons living with dementia and others in one's community can be reciprocal social opportunities that increase our capacity to see the humanity in each other. McIntyre also suggested that re-imagining the experience of carers, and celebrating carers as people, offers an alternative to the image of 'caregiver as victim' and creates a chance to explore the learning and growth that can occur through the dementia care process.

The goals of the ADRD framework align well with the possibilities for dementia care described by McIntyre (2003). The first goal is to help those involved in dementia care enhance their ability to support persons with dementia and their families in humanistic ways. The second goal is to promote strong linkages across sectors in the creation of supportive dementia communities. The third goal is to mobilize authentic dementia care partnerships. Authentic partnerships describe partnerships with persons living with dementia, their families and others that promote equality and social justice (Dupuis, Gillies, et al., 2012; Dupuis et al., 2008). The principles embedded in the ADRD framework integrated with those of the authentic partnership approach (described next) created a moral compass for the PiDC Alliance's work and a means to regularly check that we were remaining true to the principles. The planning pillars served to highlight for us the complexity of relational care and the need to consider and challenge broader social contexts that support and more often impede, relational care.

### **Developing authentic partnerships within the context of dementia care**

Building on the work of Adams and Clarke (1999) and Nolan et al. (2004) and informed by research conducted in collaboration with persons with dementia, family care partners and a range of professionals working in dementia care, Dupuis and her team at the Murray Alzheimer Research and Education Program (MAREP) further developed the partnership approach in dementia care by identifying a number of principles and enabling factors necessary to fully support persons with dementia in decision-making with others (Dupuis, Gillies, et al., 2012; Dupuis et al., 2008). The authentic partnership approach recognizes how persons with dementia have traditionally been silenced and excluded from dementia care practices. It is grounded in the view that persons living with dementia and others involved in their care have a collective capacity for social action and change (Foley, 2001; Freire, 1972). This approach challenges the supremacy of expert knowledge by valuing and incorporating

the lived or experiential knowledge of all partners (Thomas, 1982). It also incorporates a systematic process of critical reflection and dialogue with others in community, as partners work collectively towards the realization of new possibilities (Freire, 1972).

Informed by analysis from several dementia care partnership projects and working closely with partners, including persons living with dementia, Dupuis, Gillies, et al. (2012) identified three principles that help to guide authentic partnerships. These guiding principles include developing a genuine regard for self and others, recognizing the power of synergistic relationships and focusing on the process. They also identified five enabling factors that need to be in place in order to sustain authentic partnerships over the long term. The first enabler, *connecting and committing*, promotes the inclusion of a diverse group of individuals who are involved in dementia care and involves identifying and supporting the strengths, talents, gifts and resources each individual brings to the partnership. The second enabler, *creating a safe space*, involves the creation of a space where all partners feel a sense of emotional and physical comfort and there is a common feeling of trust. A safe space is one in which partners feel comfortable expressing their views openly without fear of being judged or dismissed.

The third enabler to sustain authentic partnerships, *valuing diverse perspectives*, includes finding ways to demonstrate that all voices count by ensuring that each partner's perspective is heard, understood and included. The fourth enabler, *establishing and maintaining open communication*, recognizes that communication is a dynamic two-way process involving verbal and non-verbal forms, as well as active listening and engagement in dialogue. Facilitating open communication involves providing a range of alternatives for communicating contributions and remaining connected in a way that meets individual abilities and more effectively and creatively expresses a wide range of emotions and valued aspects of the self. The fifth enabler, *conducting regular critical reflection and dialogue*, means providing opportunities for all in the partnership to step back and reflect on the process by giving consideration to language, assumptions, attitudes, practices and implications of decisions. These five enablers are complementary to the principles guiding the ADRD framework in that they offer an alternative approach to dementia care by changing the way decisions are made, challenging notions of who is involved in the decision-making process, and identifying specific strategies for sustaining partnerships and collaborations.

Facilitating culture change in dementia care that is reflective of an authentic partnership approach using the ADRD framework necessitates the active engagement of all members of the community that are affected by dementia, including persons living with dementia. Dannefer et al. (2008) view such active engagement as a foundational element of care. They argued: 'If [clients] are deprived of the opportunity to practice engagement in the daily reproduction of life and in their caring for others, they are not being cared-for. This is especially true for those who have experienced so much loss – of home, of control over routine, of functional abilities' (Dannefer et al., 2008, p. 106). Dannefer et al. also described PAR as being conducive with active engagement in care since PAR approaches also ensure that research is purposeful, relevant and useful to the everyday lives of those within a specific community. The authentic partnership approach provided the PiDC Alliance with a set of reflective questions (see Dupuis, Gillies, et al., 2012) that members of the research management team and each CCC could regularly critically reflect on to ensure that the PiDC Alliance was creating and nurturing the elements necessary for sustained and meaningful collaborative decision-making.

## Using PAR to facilitate active engagement in changing the culture of dementia care

PAR involves a collaborative approach wherein partnerships are formed between individuals with firsthand knowledge of the issue under investigation and those who possess technical skills and formal knowledge with the issue (Lykes & Coquillon, 2006; Reason & Bradbury, 2006). A participatory approach to research is intended to enhance the relevance of the findings by improving the lives of those who participate in the research process (McTaggart, 1991). With an emphasis on education, collaborative learning and transformative action, PAR is as much about the processes as it is about the outcomes of research (Ristock & Pennell, 1996). Since PAR is context-specific and fluid, when issues arise and relationships develop, the methods and activities conducted are often adapted and revised. At its most participatory, researchers and project participants collaborate to inform project design, select methods, facilitate the project activities and review and evaluate the process as a whole.

Arguing that the expertise of residents living in LTC homes is often overlooked within culture change efforts, Shura, Siders and Dannefer (2010) observed that changes made are usually made 'on behalf' of residents with the intent of promoting their interests and quality of life. PAR provides an opportunity for residents to take an active role and contribute to culture change directly. An added benefit of PAR is that it enables residents to demonstrate their capabilities and dispel myths and misunderstandings related to their perceived helplessness.

In the participatory culture change project described by Shura et al. (2010) residents who became engaged in the process not only outnumbered staff and family members, they also participated in the project with greater regularity. PAR was found to be a viable method for residents to contribute to ideas being generated in relation to overall facility improvement. Shura et al. also deemed PAR to be an effective way to nurture and affirm residents' competence. Others have also used and described the possibilities of PAR approaches that are inclusive of residents and persons living with dementia in both LTC and community care settings (e.g. Dupuis, Whyte, et al., 2012; Lopez, 2012).

Members of the PiDC Alliance have found participatory approaches to research to be complementary to a culture change process guided by the ADRD framework and the authentic partnership approach. Thus, PAR serves as our primary methodology for all the work within the PiDC Alliance where persons with dementia work alongside family members and staff ranging from front-line to management and have opportunities to share their experiences in creative ways. PAR, however, has a tendency to be problem focused and we found that too much attention on problems can be constraining to culture change initiatives. Despite this, a problem orientation has guided many culture change initiatives to date (Murray, Higuchi, Edwards, Greenough, & Hoogeveen, 2011).

An emphasis on problems can be found in the description of PAR provided by Nelson, Ochocka, Griffin and Lord (1998) who defined PAR as an approach consisting of maximum participation of individuals whose lives are affected by the *problem* under study. Similarly, Frisby, Reid, Millar and Hoeber (2005) explained that the term 'participatory' in research refers to partnerships among people with *problems* to solve. Work with staff in the LTC sector and a review of the literature made it clear to us that such problem-focused methods would not be conducive for facilitating active engagement in a culture change process. Problem-focused approaches often lead to feelings of surplus powerlessness (Lerner,

1986). Further, a problem orientation diminishes the capacity of research to produce innovative theory that can inspire the imagination, commitment and dialogue needed to challenge guiding assumptions and open up new possibilities (Ludema, Cooperrider, & Barrett, 2006).

Recognizing that common approaches to improving care involving problem identification and solving have not served us well when it comes to enhancing dementia care, members of the PiDC Alliance identified the need for an alternative approach to culture change that would help LTC homes and communities identify and build on the strengths, gifts and assets that bring them to life. This realization prompted us to seek out more appreciative methodologies, which led to the use of AI. According to Elliott (1999), an appreciative approach to culture change seeks to achieve a transformation of a culture from one that is seen in negative terms to one that unleashes a collective capacity to imagine and build a better future. The aim of the PiDC Alliance is to develop appreciative knowledge of the current state of dementia care and identify positive aspects of the care experience from which we can build.

### **Adopting an appreciative approach to culture change**

As a departure from problem solving approaches that encourage us to look at what is not working well and develop an action plan to fix it, AI offers a framework for generative change that inspires synergism of an organization's best practices (Branson, 2004). When using AI, participants are encouraged to think creatively and radically and to move beyond the restrictions of current practice and constraints in order to articulate ideal states (Hammond, 1998). Problem solving often focuses closely on deficits, which contributes to the erosion of 'people power' and undermines collaborative processes (Cooperrider & Whitney, 2005). AI replaces deficit discourse with 'vocabularies of hope' (Grant & Humphries, 2006) and encourages wide participation whereby people have both voice and responsibility for creating new possibilities.

AI begins with the assumption that all organizations have significant life forces and these forces can be found in stories and imaginations (Cooperrider & Whitney, 2005; Ludema et al., 2006). The appreciative approach starts with three principles (Elliott, 1999). First, it involves a participative process that turns our appreciation toward the good and the life-giving. Second, it is a collaboration that involves a broad spectrum of participants. Third, it uncovers provocative propositions that are designed to stretch people's minds and energize everyone involved in the change process.

Cooperrider and Whitney (2005) have described AI as an invitation to a 'positive revolution' which involves a cooperative search for the 'best of people, their organizations, and the world around them' (p. 10). It creates space for new voices and new discoveries through expanding circles of dialogue (Ludema et al., 2006). Cooperrider and Whitney consider affirmative topics that elicit positive information to be the most important part of any AI endeavour since the seeds of change begin with the first questions we ask. For example, asking questions that get to the heart of positive care experiences is an important first step in creating positive change in dementia care. Memories, perceptions and hopes are shaped in the midst of appreciative questions and move us closer to understanding what a positive care experience looks like. This understanding is essential if good dementia care is going to find a voice (Kitwood, 1997).

The topics we choose and the questions we ask are considered to be fateful since they set the stage for what we discover (Ludema et al., 2006).

Since it is conceived as more of a philosophy than a method, there is no one way of *doing* AI (Finegold, Holland, & Lingham, 2002). However, most AI researchers and practitioners base their methods on an initial set of four principles which suggest that inquiry into the potential of a social system should begin with appreciation, should be collaborative, should be provocative and should be applicable (Bushe, 2011). The 4-D model developed from these principles is now almost universally described as the AI method.

The phases most often described in the 4-D model include: discovery, dream, design and destiny (Ludema et al., 2006). Since members of the PiDC Alliance adopted a PAR approach to AI, we found there was a need to incorporate an additional initial phase in order to lay the foundation and prepare for engaging in an appreciative process. This initial phase, which we refer to as *dawn*, provided members of the PiDC Alliance with the time to get to know one another and to build strong, trusting, authentic relationships before embarking on discovery. The purpose of the *discovery* phase is to identify the factors that give life to an organization. These factors reveal the 'best of what is' in a given situation. The next phase involves *dreaming* about what could be. Words, phrases and stories collected during the discovery phase offer positive guiding images of the future. The fourth phase involves *designing* the future through dialogue. People seek to find common ground through the sharing of discoveries and possibilities and work together to develop realistic plans of actions and steps necessary to realize the dream. *Destiny* is an invitation to create the future through innovation and action. This phase often involves widening the circle so more participants can join the conversation and work together to put the collaborative plan for change into action. Participatory in approach, AI is designed to include an 'ever-increasing number of voices in conversations that highlight strengths, assets, hopes and dreams' (Ludema et al., 2006, p. 163). Therefore it is important to include as many people throughout the process as possible.

There are clear commonalities between AI and other strengths-based change models such as asset-based community development (Kretzmann & McKnight, 1993). Lind and Smith (2008) for example, acknowledged how AI can facilitate ethical community health nursing by promoting action that is consistent with strengths-based community values. Bushe (2011), however, argued that many strengths-based approaches focus on the engagement of individual competencies and ignore relational realities. Conversely, Bushe explained that AI not only focuses on the best of what is, but engages all participants in a processes of re-imagining what could be and taking ownership for what will be. The generative momentum of the change process is fuelled by this combination of strengths and collective energy.

Strengths-based thinking and collective energy were the key components identified in a strategy for helping people to live well with dementia in the United Kingdom. Barnes and Guild (2011) described an AI process whereby people with dementia, their care partners and care providers from non-profit organizations came together to have conversations about what living well with dementia meant to them. As Barnes and Guild explained, bringing a mix of people together to tell their stories helped to generate energy and creativity needed to construct powerful visions of an alternate future.

AI has also been identified as a powerful tool for improving work life and nurturing working relationships in the healthcare sector. Wood (2004), for example, recounted two separate case studies involving AI, where nurses were invited to recall positive images and



emotions. This approach was considered to be effective for strengthening the connection that nurses have to their organization and profession. Wood explained that in both cases AI enabled the creation of new relationships with colleagues that were built on positive interaction and mutual successes. Engaging in AI helped to emphasize the positive aspects of nursing and the sense of accomplishment nurses felt when they were caring for others.

As the above examples suggest, the appreciative approach has shown promise in terms of what it can offer to the development of relationships within the healthcare sector and the creation of an alternate future that supports living well with dementia. As we describe in the next section, when this approach is integrated with PAR and the principles informing the ADRD framework and the authentic partnership approach, it can guide a culture change process that encourages *working collaboratively, thinking and doing differently, and re-imagining new possibilities* that will ultimately lead to a more enriching dementia care experience.

### **Integrating theoretical approaches: Working collaboratively, thinking and doing differently, and re-imagining new possibilities**

As the PiDC Alliance seeks to improve the dementia care experience for persons living with dementia, their family and other partners in care, volunteers and staff working in care settings, we continuously strive to ensure that all persons involved in the care context play a role in shaping the future within that care setting. As the integrated framework shown earlier in Figure 1 depicts, each CCC is embarking on an AI journey to improve dementia care using an iterative process. This iterative process involves beginning culture change work in one CCC setting, learning from the work being done and using these new learnings to make changes as well as to inform the work being done in other CCC settings. Using a PAR approach ensures that the direction taken by each CCC is determined by its members rather than dictated by the research team. Guided by the authentic partnership approach and ADRD framework, members of each CCC work to ensure the perspectives of all participants are included in decision-making while considering the broader social structures within which care is embedded. This involves CCC members critically reflecting on current discourses, practices and policies, ways of organizing and power structures, while integrating the collective abilities and gifts of the group to guide positive changes.

#### *Working collaboratively*

In the spirit of authentic partnerships, working collaboratively necessitates connecting and committing to each other, creating a safe space that is conducive to open and honest communication and having diverse perspectives heard and valued, as well as engaging in regular critical reflection and dialogue. This approach entails CCC members engaging in relationship building with one another and continuing to strengthen these relationships throughout the process. One of the CCCs works within a community care setting and is comprised of members of various community healthcare organizations, some of whom had no previous affiliations with other members of the coalition. In this case, various exercises were developed to help facilitate an authentic partnership approach where members could engage in dialogue, get to know each other, develop trust and establish a common ground for working together. For example, during the *dawn* phase, the group worked together to



understand what each member would need to feel safe in order to participate in the group in a meaningful way.

The other three CCCs are situated in three diverse LTC homes – one where only individuals with dementia reside, one that reflects a particular cultural community and one that is engaged in a corporate-wide culture change initiative. At these sites working collaboratively involves finding ways to ensure people feel safe to participate in decision-making and their participation is not limited by norms of relating determined by hierarchical organizational structures and the fear to speak out engendered by those structures. The authentic partnership approach integrated with PAR and AI is useful in this regard because it emphasizes the value of collective capacity and is designed to include an ever expanding number of voices in conversations where the primary focus is on strengths and assets (Ludema et al., 2006). We have also found that social events (e.g. eating meals together and celebrating accomplishments that have been made along the way) have been critical to fostering and nurturing the trusting relationships necessary for working collaboratively in meaningful ways.

### *Thinking and doing differently*

Thinking differently about the way we engage, and with whom we engage, in a culture change initiative can lead to changes in the way decisions are made and who is involved in the decision-making process. Ensuring the inclusion of all key participants means opening up space for persons living with dementia, who are often silenced and excluded from dementia care practices, to not only participate but also have their participation valued and incorporated. To facilitate this process, CCC members have engaged in reflexive exercises, guided by both the authentic partnership approach and PAR, which challenge their assumptions about the abilities of persons living with dementia. An example of such an exercise involves using quotes from persons living with dementia as a basis for reflecting on the impact of inclusion and exclusion and exploring ways to facilitate greater support and inclusion.

Facilitating inclusion has also meant doing things differently by finding creative ways to gather the experiences and perspectives of persons living with dementia, particularly persons who communicate primarily through non-verbal means. For example, the site of one CCC is a dementia-specific LTC home and coalition members at this site identified arts-based focus groups as an effective way for residents with varied abilities to share their perspectives and generate ideas relating to culture change. In these groups, persons with dementia were supported in sharing their experiences using collage and other art mediums. While previous PAR studies in LTC homes (e.g. Shura et al., 2010) have shown this to be a methodology that can engage residents as leaders, our experience illuminated some challenges to having residents with advanced dementia participate in the process with the same intensity and regularity as our other partners. However, our commitment to ensuring that the experience and knowledge of persons with dementia is not overlooked in culture change efforts led us to more closely examine what meaningful engagement in PAR can look like for persons with dementia across the dementia journey. Arts-based focused groups encouraged the active participation of residents with dementia and at times stimulated lively discussion about their ideas relating to culture change. For those later in the dementia journey, arts-based activities provided an alternative way for persons with dementia to share their experiences, but these reflections could sometimes be difficult to interpret. Acknowledging that more thought and innovation

is needed to find ways to support *all* persons living with dementia to meaningfully participate in PAR processes, we are continuously seeking to identify imaginative approaches to creating safe spaces that are so vital to their self-expression and communication.

Another aspect of thinking and doing differently involves considering alternatives to traditional ways of initiating culture change. Traditionally, the need for change in LTC homes arises from the recognition of a problem and then initiating quality improvement initiatives to address the problem (Murray et al., 2011). Murray et al. (2011) asked staff working in LTC homes in Ontario to consider how data currently being collected could be used to support change. They found that few front-line healthcare staff or managers could provide examples of change resulting from their data. This example speaks to the need to collect *new* data that will guide positive change, which is a foundational aspect of AI. Collecting positive stories of dementia care in a range of ways is a logical first step to identifying strengths and exemplary examples of quality care experiences and then using these as a foundation in creating change that can lead to enhanced care experiences for all. This approach is also guided by an understanding that the greater the involvement of key participants in the data collection process (including persons with dementia, family members, front-line staff and managers from all disciplines), the greater the likelihood that the findings will be meaningful and actually used to guide culture change.

### *Re-imagining new possibilities*

Thinking differently about culture change that is guided by an AI approach is intended to move the PiDC Alliance beyond the restrictions of current practice and toward a process that involves re-imagining new possibilities. As the PiDC Alliance engages participants in a process of re-imagining an alternate future for dementia care, it begins to move closer to creating a vision of what ideal dementia care could look like. In keeping with the theoretical underpinnings of AI, we recognize that our greatest resource is a collective imagination and discourse about the future (Finegold et al., 2002) as well as a willingness to challenge and change the status quo.

The work we have done thus far suggests that when people share positive stories and experiences and engage in dialogue about their meaning, themes will emerge that inspire new hope and possibility. One example of a new possibility was identified and put into practice by a CCC that formed within a LTC home involved in a corporate-wide culture change process. Members of this CCC used the positive stories they collected to create aspiration statements during the dream phase that depict a desirable future towards which to plan, educate and effect change. These statements reflected a shared desire within the home to offer flexible living, flexible dining and opportunities for meaningful and shared activities. A photo contest took place to encourage individuals involved in the life of the home to photograph these aspirations in action. In other words, whenever they saw something being done in the home to promote flexible living or flexible dining or whenever they saw individuals and groups engaged in meaningful and shared activities, they were asked to take a picture to capture it. Photos helped to spread the word about culture change, encourage on-going dialogue and reinforce a shared commitment to making these aspirations a reality. As our work progresses, members of the PiDC Alliance anticipate that this example will be one of many that will demonstrate how new possibilities emerge through a process that encourages us to identify and build on strengths and generate the collective capacity required to enhance the dementia care experience.

## Concluding remarks

Since culture change is a holistic and generative process, it will take time to tell what impact the work of the PiDC Alliance is having on transforming dementia care. Early indications are that the integration of the ADRD framework, the authentic partnership approach, PAR and AI can merge to create a unique framework for guiding a culture change process that has real potential for transforming individuals, practices and organizations. Other research has demonstrated the value of partnership approaches guided by AI and relationship-centred care to improving the quality of life for people in LTC settings. For example, *My Home Life* (MHL), a UK initiative aimed at promoting quality of life for individuals 'living, dying, visiting and working in care homes' (Owen, Meyer, Bentley, Heath, & Goodman, 2008, p. 96) found optimizing relationships between residents, family, staff and the wider community as well as facilitating shared decision-making concerning all aspects of home life to be crucial to promoting a positive culture within LTC (Meyer & Owen, 2008). While MHL offers an exemplar of a culture change initiative within care settings, it has not focused on changing the culture of dementia care specifically. In this paper, we have shown that the theories and philosophical underpinnings of the ADRD framework, the authentic partnership approach, PAR and AI offer different but complementary constructs for changing the culture of dementia care. Our purpose was to explain how these constructs can be integrated to guide a process of *working collaboratively, thinking and doing differently*, and *re-imagining new possibilities* – three ingredients that are integral to changing the culture of care.

## Acknowledgements

The authors gratefully acknowledge support from the Social Sciences and Humanities Research Council of Canada Community – University Research Alliances Program. We also acknowledge our fellow members of the PiDC Alliance for their heartfelt dedication to working collaboratively to change the culture of dementia care.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors gratefully acknowledge support from the Social Sciences and Humanities Research Council of Canada Community – University Research Alliances Program.

## References

- Adams, T., & Clarke, C. (1999). *Dementia care: Developing partnerships in practice*. London, UK: Baillière Tindall.
- Alzheimer Society of Canada. (2009). *Rising tide: The impact of dementia on Canadian society*. Toronto, Canada: Author.
- Anderson, R., Funnell, M., Butler, P., Arnold, M., Fitzgerald, J., & Feste, C. (1995). Patient empowerment. Results of a randomized controlled trial. *Diabetes Care*, *18*, 943–949.

- Baker, B. (2007). *Old age in a new age: The promise of transformative nursing homes*. Nashville, TN: Vanderbilt University Press.
- Barnes, J., & Guild, J. (2011). Living well with dementia: Creating a regional strategy for the East Midlands. In J. M. Watkins, B. Mohr, & R. Kelly (Eds.), *Appreciative inquiry: Change at the speed of imagination* (pp. 50–66). San Francisco, CA: Pfeiffer.
- Bowers, B., Nolet, K., Roberts, T., & Esmond, S. (n.d.). Implementing change in long-term care: A practical guide to transformation. Retrieved from [http://www.pioneernetwork.net/Data/Documents/Implementation\\_Manual\\_ChangeInLongTermCare%5B1%5D.pdf](http://www.pioneernetwork.net/Data/Documents/Implementation_Manual_ChangeInLongTermCare%5B1%5D.pdf).
- Branson, M. L. (2004). *Memories, hopes, and conversations: Appreciative inquiry and congregational change*. Herndon, VA: The Alban Institute.
- Bushe, G. R. (2011). Appreciative inquiry: Theory and critique. In D. Boje, B. Burnes, & J. Hassard (Eds.), *The Routledge companion to organizational change* (pp. 87–103). Oxford, UK: Routledge.
- Canadian Institute for Health Information (CIHI). (2010). *Caring for seniors with Alzheimer's disease and other forms of dementia*. Ottawa, ON: Author. Retrieved from [https://secure.cihi.ca/free\\_products/Dementia\\_AIB\\_2010\\_EN.pdf](https://secure.cihi.ca/free_products/Dementia_AIB_2010_EN.pdf).
- Cooperrider, D. L., & Whitney, D. (2005). *Appreciative inquiry: A positive revolution in change*. San Francisco, CA: Berrett-Koehler.
- Dannefer, D., Stein, P., Siders, R., & Patterson, R. (2008). Is that all there is? The concept of care and the dialectic of critique. *Journal of Aging Studies*, 22, 101–108.
- Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, 8(2), 185–203.
- DeForge, R., van Wyk, P., Hall, J., & Salmoni, A. (2011). Afraid to care; unable to care: A critical ethnography within a long-term care home. *Journal of Aging Studies*, 25(4), 415–426.
- Deutschman, M. T. (2005). An ethnographic study of nursing home culture to define organizational realities of culture change. *Journal of Health and Human Services Administration*, 28(1/2), 246–282.
- Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago, IL: The University of Chicago Press.
- Dupuis, S. L. (2010). A planning framework for improving the lives of persons with Alzheimer's disease and related dementias and their families: Implications for social policy, leisure policy and practice. In H. Mair, S. M. Arai, & D. G. Reid (Eds.), *Decentering work: Critical perspectives on leisure, social policy and human development* (pp. 91–117). Calgary, AB: Calgary University Press.
- Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., . . . Sadler, L. (2012). Moving beyond 'patient' and 'client' approaches: Mobilising authentic partnerships in dementia care. *Dementia*, 11(4), 428–450.
- Dupuis, S. L., Gillies, J., Mantle, A., Loiselle, L., & Sadler, L. (2008). *Creating partnerships in dementia: A changing melody tool-kit*. Waterloo, ON: Murray Alzheimer Research and Education Program.
- Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meschino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach in understanding leisure in the dementia context [Special issue on Leisure, Health and Disability]. *World Leisure Journal*, 54(3), 240–254.
- Elliott, C. (1999). *Locating the energy for change: An introduction to appreciative inquiry*. Winnipeg, MB: International Institute for Sustainable Development.
- Fagan, R. M. (2003). Pioneer network: Changing the culture of aging in America. *Journal of Social Work in Long-Term Care*, 2(1/2), 125–140.
- Finegold, M., Holland, B. M., & Lingham, T. (2002). Appreciative inquiry and public dialogue: An approach to community change. *Public Organization Review*, 2, 235–252.
- Foley, G. (2001). Radical adult education and learning. *International Journal of Lifelong Education*, 20(1/2), 71–88.
- Foner, N. (1995). *The caregiving dilemma: Work in an American nursing home*. Berkeley, CA: University of California Press.
- Freire, P. (1972). *Pedagogy of the oppressed*. Harmondsworth, UK: Penguin.

- Frisby, W., Reid, C., Millar, S., & Hoeber, L. (2005). Putting “participatory” into participatory forms of action research. *Journal of Sport Management, 19*(1), 367–396.
- Gibson, D. E., & Barsade, S. G. (2003). Managing organizational culture change: The case of long-term care. *Journal of Social Work in Long-Term Care, 2*(1/2), 11–34.
- Grant, S., & Humphries, M. (2006). Critical evaluation of appreciative inquiry: Bridging an apparent paradox. *Action Research, 4*(4), 401–418.
- Gubrium, J. F. (1975). *Living and dying at Murray Manor*. New York, NY: St. Martin’s Press.
- Hammond, S. A. (1998). *The thin book of appreciative inquiry*, 2nd ed. Bend, OR: Thin Book Publishing.
- Hill, N. L., Kolanowski, A. M., Milone-Nuzzo, P., & Yevchuk, A. (2011). Culture change models and resident health outcomes in long-term care. *Journal of Nursing Scholarship, 43*(1), 30–40.
- Holstein, M., Parks, J. A., & Waymack, M. H. (2011). *Ethics, aging, and society: The critical turn*. New York, NY: Springer.
- Jervis, L. L. (2002). Working in and around the ‘chain of command’: Power relations among nursing staff in an urban nursing home. *Nursing Inquiry, 9*(1), 12–23.
- Jolley, D., & Benbow, S. (2000). Stigma and Alzheimer’s disease: Causes, consequences and a constructive approach. *International Journal of Clinical Practice, 54*, 117–119.
- Kemmis, S., & McTaggart, R. (1988). *The action research planner*, 3rd ed. Victoria, AU: Deakin University.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.
- Kretzmann, J., & McKnight, J. (1993). *Building communities from the inside out*. Chicago, IL: ACTA.
- Lerner, M. (1986). *Surplus powerlessness*. Oakland, CA: Institute for Labor & Mental Health.
- Lind, C., & Smith, D. (2008). Analyzing the state of community health nursing: Advancing from deficit to strengths-based practice using appreciative inquiry. *Advances in Nursing Science, 31*(1), 28–41.
- Lopez, K. (2012). *Expanding understandings: Meanings and experiences of wellness from the perspectives of residents living in Long-Term Care (LTC) homes* (Unpublished doctoral dissertation). University of Waterloo, ON.
- Ludema, J. D., Cooperider, D. L., & Barrett, F. J. (2006). Appreciative inquiry: The power of the unconditional positive question. In P. Reason, & H. Bradbury (Eds.), *Handbook of action research* (pp. 155–165). London, UK: Sage.
- Lykes, M. B., & Coquillon, E. (2006). Participatory and action research and feminisms: Towards transformative praxis. In S. Hesse-Biber (Ed.), *Handbook of feminist research: Theory and praxis* (pp. 297–326). Thousand Oaks, CA: Sage.
- McIntyre, M. (2003). Dignity in dementia: Person-centered care in community. *Journal of Aging Studies, 17*, 473–484.
- McTaggart, R. (1991). Principles for participatory action research. *Adult Education Quarterly, 41*, 168–187.
- McWilliam, C., Colemm, S., Melito, C., Sweetland, D., Saidak, J., Smit, J., ... Milak, G. (2003). Building empowering partnerships for interprofessional care. *Journal of Interprofessional Care, 17*, 363–376.
- McWilliam, C., Kothari, A., Ward-Griffin, C., Forbes, D., Leipert, B., & South West Community Care Access Centre Home Care Collaboration. (2009). Evolving the theory and praxis of knowledge translation through social interaction: A social phenomenological study. *Implementation Science, 4*(26), 1–14.
- McWilliam, C., Ward-Griffin, C., Sweetland, D., Sutherland, C., & O’Halloran, L. (2001). The experience of empowerment in in-home services delivery. *Home Health Care Services Quarterly, 20*(4), 49–71.
- Meyer, J., & Owen, T. (2008). Calling for an international dialogue on quality of life in care homes. *International Journal of Older People Nursing, 3*, 291–294.
- Miller, E. A., Booth, M., & Mor, V. (2008). Assessing experts’ views of the future of long-term care. *Research on Aging, 30*, 450–473.



- Misiorski, S., & Rader, J. (2010). Selecting and prioritizing changes. *Getting started: Pioneering approaches to culture change in long-term care* (pp. 5.1–5.13). Retrieved from <http://phinational.org/sites/phinational.org/files/training/wp-content/uploads/GettingStartedCh5v3online.pdf> on 1/02/14.
- Murray, M. A., Higuchi, K. A. S., Edwards, N., Greenough, M., & Hoogeveen, K. (2011). Practice change in long-term care facilities in Ontario: Views of managers and staff. *Geriatric Nursing, 32*(6), 418–428.
- National Advisory Council on Aging. (2004). *The NACA position on Alzheimer disease and related dementias*. Ottawa, ON: Minister of Public Works and Government Services Canada.
- Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). Nothing about me, without me: Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Community Psychology Journal, 26*, 881–912.
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centered' care: A new vision for gerontological nursing. *International Journal of Older People Nursing, 13*, 45–53.
- Nolan, M. R., Lundh, U., Grant, G., & Keady, J. (2003). *Partnerships in family care*. Buckingham, UK: Open University Press.
- Owen, T., Meyer, J., Bentley, J., Heath, H., & Goodman, C. (2008). Better partnership between care homes and the NHS: Findings from the my home life programme. *Journal of Care Services Management, 3*(1), 96–106.
- Pioneer Network. (2013). About us. Retrieved from <http://www.pioneernetwork.net/AboutUs/About/QualityPartnersofRhodeIsland>.
- Quality Partners of Rhode Island. (2005–2006). *8th Scope of work task 1a: Individualized care training curriculum: The Holistic Approach to Transformational Change (HATCh)*. Providence, RI: Author.
- Rahman, A. N., & Schnelle, J. F. (2008). The nursing home culture-change movement: Recent past, present and future directions for research. *The Gerontologist, 48*(2), 142–148.
- Reason, P., & Bradbury, H. (2006). Introduction: Inquiry and participation in search of a world worthy of human aspiration. In P. Reason, & H. Bradbury (Eds.), *Handbook of action research* (pp. 1–14). Thousand Oaks, CA: Sage.
- Ristock, J., & Pennell, J. (1996). *Community research as empowerment: Feminist links, postmodern interruptions*. Toronto, Canada: Oxford University Press.
- Ronch, J. L. (2003). Leading culture change in long-term care: A map for the road ahead. *Journal of Social Work in Long-Term Care, 2*(1/2), 65–80.
- Ronch, J. L. (2004). Changing institutional culture: Can we re-value the nursing home? *Journal of Gerontological Social Work, 43*(1), 61–82.
- Sachs, G. A., Shega, J. W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of Nursing Scholarship, 32*, 251–258.
- Scott, T., Mannion, R., Davies, H. T. O., & Marshall, M. N. (2003). Implementing culture change in health care: Theory and practice. *International Journal for Quality in Health Care, 15*(2), 111–118.
- Shura, R., Siders, R. A., & Dannefer, D. (2010). Culture change in long-term care: Participatory action research and the role of the resident. *The Gerontologist, 51*(2), 212–225.
- Smale, B. J. A., & Dupuis, S. L. (2004). *In their own voices: A portrait of dementia caregivers in Ontario*. Final report prepared for the Ministry of Health and Long-Term Care and the Ontario Senior's Secretariat as part of Initiative #6 of the Ontario Alzheimer Strategy, Murray Alzheimer Research and Education Program, Waterloo, ON.
- Sommers, L. S., Marton, K. L., Barbaccia, J. C., & Randolph, J. (2000). Physician, nurse and social worker collaboration in primary care for chronically ill seniors. *Archives of Internal Medicine, 160*, 1825–1833.
- Sterin, G. J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia, 1*(1), 7–10.
- Stevens, C. H. (2001). A timeless dream. *Balance, 7*, 7–18.
- The Conference Board of Canada. (2011). *Elements of an effective innovation strategy for long term care in Ontario*. Ottawa, ON: Author.



- Thomas, J. E. (1982). *Radical adult education: Theory and practice*. Nottingham, UK: Department of Continuing Education, University of Nottingham.
- Thomas, W. H. (2003). Evolution of Eden. In A. S. Weiner, & J. L. Ronch (Eds.), *Culture change in long-term care* (pp. 141–158). Binghamton, NY: Haworth Social Work Practice Press.
- White-Chu, E., Graves, W. J., Godfrey, S. M., Bonner, A., & Sloane, P. (2009). Beyond the medical model: The culture change revolution in long-term care. *Journal of American Medical Directors Association, 10*, 370–378.
- Wood, S. (2004). Creating a positive future for nursing using appreciative inquiry. *AI Practitioner, 13*–18.
- World Health Organization (WHO). (2012). *Dementia: A public health priority*. Geneva, Switzerland: WHO Press.

### Author Biographies

**Sherry Dupuis**, PhD, is currently the co-PI on the Partnerships in Dementia Care Alliance, a large culture change in dementia care initiative in Canada, and a Professor in the Department of Recreation and Leisure Studies at the University of Waterloo. Address: Department of Recreation and Leisure Studies, Applied Health Sciences, University of Waterloo, Waterloo, ON, Canada N2L 3G1 [email: sldupuis@uwaterloo.ca].

**Carrie A McAiney**, PhD, is a Co-PI on the Partnerships in Dementia Care Alliance and an Associate Professor in the Department of Psychiatry and Behavioural Neurosciences, McMaster University and Director of Research and Evaluation for Seniors Mental Health at St. Joseph's Healthcare Hamilton. She has strong interests in health services research that aims to improve the care experience for persons living with dementia, their families and care partners. Address: 100 West 5th Street, Hamilton, ON, Canada [email: mcaineyc@mcmaster.ca].

**Darla Fortune**, PhD, is a Postdoctoral Fellow with the Partnerships in Dementia Care Alliance and a lecturer in the Department of Recreation and Leisure Studies at the University of Waterloo. She is interested in the use of participatory action research (PAR) to bring about social change. Address: Department of Recreation and Leisure Studies, Applied Health Sciences, University of Waterloo, Waterloo, ON, Canada N2L 3G1 [email: dbfortune@uwaterloo.ca].

**Jenny Ploeg**, RN, PhD, is a Professor in the School of Nursing, McMaster University, Hamilton, ON, Canada. She is also Scientific Director of the Aging, Community and Health Research Unit. She has extensive experience in health services research, particularly related to supporting older adults and their family caregivers. Address: School of Nursing, McMaster University, 1280 Main Street West, Hamilton, ON, Canada L8S 4K1 [email: ploegj@mcmaster.ca].

**Lorna de Witt**, RN, PhD, is an Assistant Professor, Faculty of Nursing, at the University of Windsor. In addition to involvement in projects examining cancer screening in vulnerable populations, she has an established program of research with people living alone with dementia. She also has a strong interest in culture change related to the care of people living with dementia. Address: 401 Sunset Avenue, Windsor, ON, Canada N9B 3P4 [email: ladewitt@uwindsor.ca].