



“It was like reading a detective novel”: Using PAR to work together for culture change



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ABSTRACT

Participatory action research (PAR), with its focus on engagement and collaboration, is uniquely suited to enhancing culture change initiatives in dementia care. Yet, there is limited literature of its application to culture change approaches in care settings, and even less in dementia specific care contexts. To address these gaps in the literature, the purpose of this paper is to examine the complexities of a PAR project aimed at changing the culture of dementia care in two diverse dementia care settings, including a long term care (LTC) and community care setting. Drawing from data gathered throughout the PAR process, we unpack the challenges experienced by participants working together to guide culture change within their respective care settings. These challenges include: overextending selves through culture change participation; fluctuating group membership; feeling uncertainty, confusion and apprehension about the process; frustratingly slow process; and seeking diverse group representation in decision making. We also highlight the potential for appreciative inquiry (AI) to be integrated with PAR to guide a process whereby participants involved in culture change initiatives can develop strategies to mitigate challenges they experience. We view the challenges and strategies shared here as being constructive to would-be culture change agents and hope this paper will move others to consider the use of PAR when engaging in culture change initiatives.

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Introduction

There have been growing concerns regarding the inadequacy of the long-term care (LTC) sector to ensure quality care and quality of life for older adults (Jones, 2011; Miller, Booth, & Mor, 2008). Hierarchical structures and provider-as-expert models prevalent in LTC are criticized for excluding persons directly involved in care from the decision-making process (Jones, 2011). Exclusion from decision-making is even more pronounced in dementia care because it is often assumed that persons with dementia are unable to communicate their experiences or make meaningful contributions to their care (Jolley & Benbow, 2000; Sterin, 2002). Moreover, the dominant discourse surrounding dementia care contributes to common

perceptions that equate dementia with a decline of a person's humanity (Mitchell, Dupuis, & Kontos, 2013).

Calls for culture change in LTC as well as dementia care more generally have sparked a movement away from the medical, institutional model of care toward a relational, community model of living (Baker, 2007; Fagan, 2003; Hill, Kolanowski, Milone-Nuzzo, & Yevchuk, 2011; Misiorski & Rader, 2010; Pioneer Network, 2013; Thomas, 2003). Many of these culture change initiatives are guided by person-centered care and aim to place the person, rather than the disease or illness, at the center of all care decisions. When person-centered care is adopted, the focus is on valuing older adults as persons who have continued strengths and abilities (Kitwood, 1997; Koren, 2010) and incorporating their perspectives and personal preferences into decisions about care (Jones, 2011). Principles most often used to guide person-centered culture change initiatives include choice and self-determination; dignity and respect; the nurturance of mind,

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body and spirit; personhood; close interdependent relationships, collaborative decision-making; purposeful living; and enabling, normalizing environments (Fagan, 2003; Hill et al., 2011; Koren, 2010).

Person-centered care is considered a step in the right direction toward a better quality of life in LTC (Jones, 2011, Koren, 2010) and has been applauded for humanizing dementia care practices (Brooker, 2007; McIntyre, 2003). However, some researchers have argued that person-centered care focuses too closely on the individual and fails to consider the social and political contexts of care (e.g., Nolan et al., 2004). Relationship-centered care is offered as a way to look beyond the person at the center of care and more fully support the broader care relationship (Nolan, Davies, Ryan, & Keady, 2008). Applying this approach to dementia care advances the idea that quality care happens when there are strong reciprocal and interdependent relationships among everyone involved in care, including the person with dementia, family members, and healthcare staff.

Relationships are commonly identified in the literature as being at the heart of culture change initiatives (e.g., Baker, 2007; Misorski & Rader, 2010). Participatory action research (PAR) is considered uniquely suited to research aimed at culture change because of its ability to facilitate the participation of individuals most impacted by culture change efforts (Shura, Siders, & Dannefer, 2011). In PAR approaches, partnerships are formed among participants connected to the research topic who together guide a process of mutual learning to explore possibilities for transformation (Frisby, Reid, Millar, & Hoeber, 2005).

Despite the synergy between PAR and change initiatives, there is limited literature of its application to culture change in care settings, and even less in contexts specific to dementia care. When the intricacy of a PAR process is considered alongside the complexity associated with engaging in sustainable culture change (Kitwood, 1997; Pioneer Network, 2013; Scott, Mannion, Davies, & Marshall, 2003), it is likely the challenges encountered throughout the research process will be intensified. Yet, there is little literature exploring the challenges associated with a PAR approach to culture change. Also lacking is research that explores the ways research groups engaging in culture change collaboratively determine and implement strategies that help them negotiate and resolve challenges they encounter.

To address these gaps in the literature, the purpose of this paper is to examine the challenges experienced by participants engaged in PAR aimed at changing the culture of dementia care to reflect a more relationship-centered care approach. Our paper is focussed specifically on the experiences of people involved in culture change initiatives in two diverse dementia care settings: one LTC home and one community care setting. We explore how participants in each of these settings experienced challenges while engaging in PAR coupled with appreciative inquiry (AI). We also discuss how the PAR and AI processes enabled participants to establish specific strategies to address these challenges as they worked together to facilitate change.

Interspersing PAR with culture change

In PAR, researchers form partnerships with members of a community to identify issues of local importance, determine ways to study these issues, and take action on the newly

acquired knowledge (Lykes & Coquillon, 2006). PAR is a methodology that is principally concerned with social change (Reid & Frisby, 2008). Change also happens within the research context as power relations between researchers and other participants become reconceptualized in new ways that move away from traditional positivist/post-positivist views of researcher as “expert”. A PAR approach brings power in relationships to the forefront and works to balance power differentials by ensuring the wisdom and experiences of all participants are recognized and valued (Blair & Minkler, 2009; Boyes-Watson & Pranis, 2012).

While PAR appears to be an effective methodological choice to guide a culture change research process, negotiating power relationships within care settings is never simple or straightforward. Aveyard and Davies (2006) described how broad participation is often encouraged when it comes to identifying areas for change and development within LTC and other healthcare settings. However, responsibility for determining forms of action and enacting change often remains with staff at the management level and seldom involves the range of individuals directly involved in care and most impacted by the change. There are also often few opportunities for family members and residents, especially persons living with dementia, to meaningfully participate in the culture change process (Shura et al., 2011).

It has been shown that staff, family, persons with dementia/residents, and researchers working in authentic partnership to become actively involved in the knowledge production process enhance the relevance of the research (Dupuis et al., 2012a). Partnership approaches also increase the likelihood that data collected and analyzed collaboratively will lead to collective action (Bray, Lee, Smith, & Yorks, 2000) and help to ensure that research within care settings is purposeful, relevant, and useful to the everyday lives of all involved (Dannefer, Stein, Siders, & Patterson, 2008). When people are working together in true collaboration, rather than individually or in isolation, there is greater potential to create and sustain change (Aveyard & Davies, 2006).

While negotiating power dynamics and creating a space where people feel safe to fully participate are key considerations for PAR, there are other challenges inherent to PAR processes that also warrant consideration. Since research often takes place in complex social and political environments, PAR seldom follows a smooth or straightforward pathway (Cornwall & Jewkes, 1995). People may also enter a PAR project with preconceived ideas about desirable outcomes and develop unrealistic expectations about what can be achieved. Such challenges and expectations can be particularly complex when PAR is focused on culture change since culture change is an organic and on-going process rather than an end product or outcome (Fagan, 2003). In the next section, we discuss the research context and process of engaging in a PAR process with members of the dementia care community to facilitate sustainable culture change in two different care settings.

The research context and process

The Partnerships in Dementia Care (PiDC) Alliance

The Partnerships in Dementia Care (PiDC) Alliance is a collaborative research network and culture change initiative

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