Mapping a Participatory Culture Change Process in Dementia Care

Handout for GSA 2012 Poster Presentation

Authors: Sherry Dupuis, Carrie McAiney, Jennifer Carson, Lorna de Witt, Darla Fortune, Sacha Geer, Jennifer Gillies, Jessica Luh Kim, Lisa Meschino, Jenny Ploeg, Zara Rafferty

Purpose: Partnerships in Dementia Care (PiDC) Alliance researchers have been working with Culture Change Coalitions (CCC), made up of persons with dementia, family members, and staff across a range of positions, in four different LTC settings and systematically documenting the culture change process within those settings. This poster provides a detailed accounting of our culture change process thus far, by identifying the “Speedbumps” (i.e., situations, issues or experiences that remind us to slow down and critically reflect on the process) and “Ramps to Opportunities” (i.e., experiences, supports, and occasions that nurture relationships and open up new possibilities).

About the PiDC Alliance
The Partnerships in Dementia Care (PiDC) Alliance is a collaborative research initiative in Canada that brings together over 50 partners working in dementia and long-term care (LTC) to improve the dementia care experience by: 1) Implementing and evaluating the Culture Change (CC) process; 2) Supporting partnerships that foster involvement of all key stakeholders; 3) Identifying factors necessary to enable and support CC in dementia care; 4) Identifying potential outcomes of CC; 5) Building capacity to implement and sustain CC; and 6) Translating learnings broadly.

Guiding Integrative Theoretical Framework
Using participatory action research, our iterative and flexible process integrates three theoretical/methodological frameworks: Appreciative Inquiry, an Authentic Partnership Approach, and the Alzheimer Disease and Related Dementias (ADRD) Planning Framework.

Mapping the Culture Change Process
Creating a range of spaces for open, honest reflection enabled us to construct a map of our journey in all four research sites so far. This included:

- Individual and group critical reflections shared by partners at coalition meetings
- Critical reflection and dialogue among researchers
- Active interviews with partners
- Reflective notes written by researchers
- Creating and revisiting visual representations of the journey at coalition meetings

Researchers worked with partners to identify common and unique experiences across the four CC processes. The emergent themes reflect experiences at the personal, social/relational, and organizational/systemic levels.

To learn more about the PiDC Alliance and our methods, scan the code or visit www.pidc.uwaterloo.ca
**Personal Level Speed Bumps**

One personal level speed bump we encountered was the assumptions about the abilities of persons with dementia to contribute to the process. Persons with dementia are often considered incapable of learning and as a result are often not included in decision-making. We found it helpful to reflect on these assumptions by incorporating exercises on the consequences of excluding persons with dementia, using art-based approaches to facilitate inclusion, and reflecting on whose voices were missing throughout the process. Another personal level speed bump was related to tensions experienced in moving away from traditional problem-solving approaches. While it can be challenging to move away from the traditional approaches that have dominated dementia care, Appreciative Inquiry holds promise and has reminded us to take the time to fully engage our partners in a process of re-imagining new possibilities.

**Social/Relational Level Speed Bumps**

Social/relational level speed bumps were also evident as we experienced fluctuations in CCC membership due to staff turnover within our partner organizations and communication barriers relating to the use of academic and healthcare jargon, different languages spoken at culturally diverse CCC sites, members not feeling comfortable enough to share thoughts honestly, perceived social hierarchies related to cultural norms, and determining how to best connect with the broader community and engage them in our work. By re-visiting the process to welcome and introduce new members to Appreciative Inquiry, using ice-breakers to get to know each other and reflect on the process in a fun way, and developing creative ways of sharing information we were able to work collaboratively to limit the use of jargon, develop exercises aimed at increasing trust, and find ways to share information with the broader community.

**Organisational/Systemic Level Speed Bumps**

By paying attention to organisational/systemic level speed bumps we acknowledged the hierarchies that exist between management and frontline staff and worked to minimize power dynamics within the CCCs by using strengths-based approaches that demonstrate the value of everyone’s insight and experience. Also, by recognizing the need to build support from internal leadership and align our work with organizations’ strategic directions, we encouraged open dialogue aimed at learning how to best work together to facilitate leadership support. Throughout this process we experienced competing demands relating to staff responsibilities as well as the realities of LTC such as union rules and facility closures. These experiences prompted us to find strategies that support participation in the process, such as paying staff for time they spend on the project and ensuring participation from union representatives on the CCCs.

**Implications for Future Research and Processes of Culture Change in Long Term Care**

- Effective culture change for dementia care requires negotiation between multi-level issues which are personal, social and systemic.
- Ramps to Opportunity emerge from Speedbumps when we integrate guiding principles from Appreciative Inquiry, Authentic Partnerships and the ADRD frameworks.
- Mapping the Culture Change process creates an accessible reference for members of diverse CCC groups who are working through similar ‘speedbumps’ at different phases of the Appreciative Inquiry process.

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