



# Adapting the CARE Profiles to the Canadian Dementia Context

Sherry L. Dupuis<sup>1</sup>, Bryan Smale<sup>2</sup>, Jennifer Gillies<sup>1</sup>, Carrie McAiney<sup>3</sup>, and Michael Nolan<sup>4</sup>

<sup>1</sup> Murray Alzheimer Research and Education Program, University of Waterloo; <sup>2</sup> Canadian Index of Wellbeing, University of Waterloo;

<sup>3</sup> Psychiatry and Behavioural, McMaster University; <sup>4</sup> Sheffield Institute for Studies on Ageing, University of Sheffield

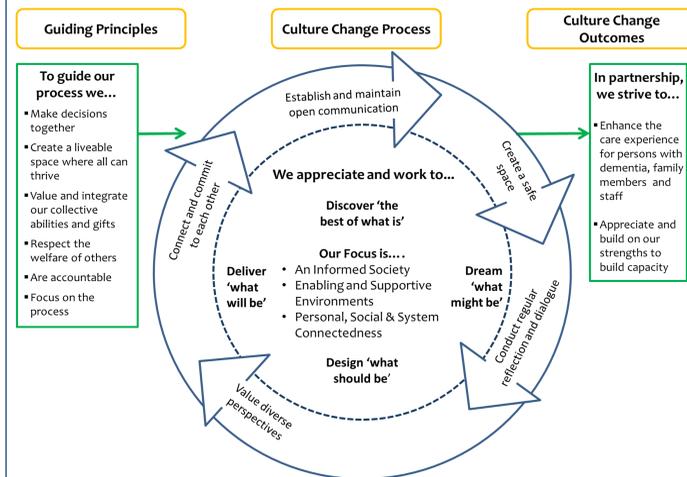


## Background

The Partnerships in Dementia Care (PiDC) Alliance is a collaborative research initiative in Canada that brings together over 50 individuals and organisations working in dementia and long-term care (LTC) to improve the dementia care experience for residents, family members, and staff in different long-term care settings. The purpose of the PiDC Alliance is:

- to facilitate sustainable long term care (LTC) culture change where all voices in long-term care settings, including residents/clients, family members and staff, are heard and included in decision-making;
- to use a participatory and appreciative approach where residents/clients, family members and staff work collectively to identify existing strengths and aspirations and use those strengths to achieve desired goals; and
- ultimately, to enhance the care experience and quality of life for residents/clients and family members and the work life of staff working in long-term care settings.

## The PiDC Alliance Integrated Theoretical Framework



The Alliance is drawing heavily on relationship-centred (Nolan et al., 2003) and authentic partnership (Dupuis et al., 2012) models of care, which have at their roots a belief that optimal care can only happen when persons with dementia, family members, and staff **all** experience caring relationships and positive care environments and have opportunities to participate in decision-making. Drawing on the *Senses Framework*, everyone involved in the care relationship – residents/clients, family members, and staff – should be engaged in relationships that promote the following:

- a sense of *security* – to feel safe
- a sense of *belonging* – to feel part of things
- a sense of *continuity* – to experience links and consistency
- a sense of *purpose* – to have a personally valuable goal or goals
- a sense of *achievement* – to make progress towards a desired goal or goals
- a sense of *significance* – to feel that “you” matter (Nolan et al., 2004, p. 49).

One of the first tasks of the Alliance was to examine the applicability of a relationship-centred tool, the Combined Assessment of Residential Environments (CARE) Profiles (Faulkner et al., 2006), to the Canadian LTC and dementia contexts.

## Purpose

- To share our participatory process in examining and pilot-testing an adapted version of the CARE profiles in long-term and dementia care.



## Process of Adapting the CARE Profiles

Using participatory action research and appreciative inquiry, a Culture Change Coalition (CCC) was created in a dementia-specific LTC home in Ontario, Canada. The CCC included persons with dementia, family members, front-line staff across a range of positions in LTC, managers and the administrator, researchers and students. The CCC is responsible for all decision-making related to the change process at the site. In adapting the CARE profiles, CCC members worked together to:

- critically reflect on the original items in the CARE Profile (30 items per key stakeholder group in the original profiles) in light of relationship-centred philosophy and the Senses Framework;
- examine the accessibility, understanding, and relevance of the items for persons with dementia, family members, and the range of staff working in long-term and dementia care in Canada;
- explore alternative ways to support the involvement of those living with dementia in sharing their care experiences; and
- determine the best way to present the items and the response categories most appropriate to the specific group.

The result of this process was adapted versions of the CARE profiles for residents, family members, and staff, each of which included some of the original items (and excluded others), some that were modified from their original wording to fit the Canadian context and the specific group, and primarily, several new items.

Group	Items in Scale			TOTAL
	Original	Modified	New	
Residents	7	17	23	47
Family	10	8	20	38
Staff	8	8	24	40

## Methods

### Sample:

Residents, family members, and staff at six long-term care homes in Ontario were invited to participate in the pilot study using the adapted CARE profiles. Overall, 177 family members and 148 staff members completed self-administered questionnaires, and 133 residents participated in face-to-face interviews conducted by trained research assistants using a structured, modified version of the CARE profile.

### Adapted CARE Profile Questionnaires:

Following the review and adaptation of the items in the three CARE profiles by the CCC, the items were randomly ordered on the questionnaires to be used with residents, family members, and staff. For residents, a total of 47 items were included for the six Senses in the CARE profile; for family members, a total of 38 items were used; and for staff, 40 items.

Family members and staff responded to the items along 5-point, Likert-type scales ranging from “strongly disagree” (value=1) to “strongly agree” (value =5). Residents, depending on the degree of cognitive impairment, responded to the items in the scale using two alternative formats: (1) a 5-point agreement scale from “strongly disagree” (value=1) to “strongly agree” (value=5), similar to that used by family members and staff, or (2) a 3-point scale with options of “mostly yes”, “mostly no”, and “do not know”. If these scaled response options still represented a challenge for the resident, then an entirely open-ended process was used. Some overall impressions of life at the LTC homes was also gathered from each group, along with additional background information.

### An iterative analysis process:

Once all of the data had been gathered and entered into SPSS V.20, an iterative process was followed guided by a principle of refining the scales to establish internal consistency and integrity of each of the Senses for each of the respondent groups. Repeated application of factor analysis (PCA) and reliability tests (Cronbach’s alpha) on each Sense enabled us to assess the internal consistency of the Sense for a particular group as well as identify items that best captured conceptually the meaning of the Sense. We also were able to identify those items that were inconsistent with that meaning or represented a challenge for each group’s participants.

## Results

### Sample Description:

**Residents:** Approximately two-thirds of the residents interviewed were women (67.0%) and the average age was 81.6 years ( $SD=11.2$ ). They had been living in the LTC home for about two years on average.

**Family members:** Slightly more than two-thirds of the family members were women (69.0%) and were 62.1 years of age on average ( $SD=12.3$ ). Most were either retired (44.8%) or working full-time outside the home (32.8%). Daughters (48.8%), spouses (19.4%), and sons (17.6%) reported that they were either the sole primary caregiver (32.9%) or shared that role with some assistance with others (34.7%).

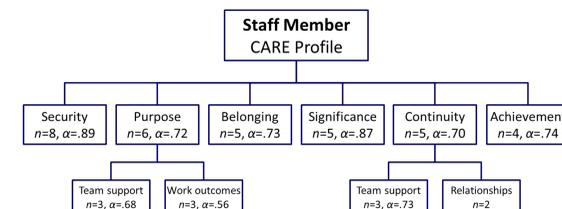
**Staff:** The vast majority of staff were women (90.4%), working predominately as nurses (40.4%) or personal support workers (25.5%) in the LTC home. Their average age was 44.0 years ( $SD=10.4$ ), and they had worked at the LTC home for just over nine years on average ( $M=9.2$ ,  $SD=8.3$ ).

### The Adapted CARE Profiles

Throughout these results, a consistent process of item-to-scale analysis and interpretation was used to assess the “fit” of items to the relevant Sense and overall Profile for each group. Conceptual fit was privileged over simple empirical adequacy (e.g., an item with greater face validity was retained when a more parsimonious solution was desired). Overall, for all three groups, most items were retained as they demonstrated good empirical fit and internal stability (i.e., uni-dimensionality).

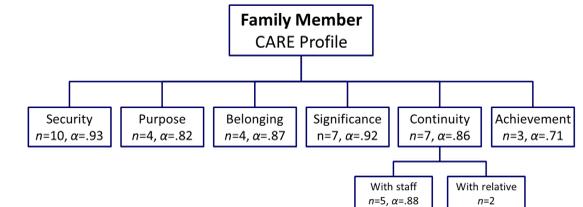
### Staff CARE Profile:

Each of the Senses in the staff CARE profile showed good to high internal consistency (Cronbach alphas ranging from .70 to .89) and four of six Senses showing good uni-dimensionality. The two Senses with sub-dimensions – Purpose and Continuity – revealed meaningful nuances to each Sense consistent with its intended meaning.



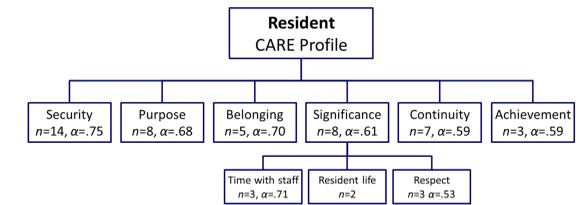
### Family Member CARE Profile:

The Senses in the family member CARE profile showed very high internal consistency with reliability scores ranging from .82 to .93 for five Senses, and .71 for Achievement. Five of the six Senses showed good uni-dimensionality and Continuity revealed how family members regarded the experience of this sense through interactions with the staff and with their relative.



### Resident CARE Profile:

Even though the internal consistency for each of the Senses for the residents’ CARE profile were not, overall, as high as staff and family members (Cronbach alphas from .59 to .75), they still demonstrated a high degree of uni-dimensionality. The Sense “Significance” revealed how residents regarded their experience of time with staff, of resident life, and of the respect they received from others.



Overall, when the composite measures of the six Senses were assessed for the CARE profiles, all three groups showed a very high degree of internal consistency in their overall profiles. In other words, the six Senses combined to reflect a highly reliable CARE profile for each group, including residents (Residents  $\alpha=.85$ , Family  $\alpha=.96$ , Staff  $\alpha=.91$ ).

## Discussion

The use of participatory action research and appreciative inquiry – involving residents, family members, and staff – to critique and generate items for the six Senses in the adapted CARE profiles proved to be highly effective in capturing the experiences of each group. The high internal consistency and principally uni-dimensional structure for each Sense across all three groups clearly indicate how a more participatory approach provided confidence in the ability of these scales to reflect the relevant experiences of these groups in the LTC and dementia context. These results for the adapted CARE profiles in the Canadian context compare favourably to those demonstrated by Faulkner et al. (2006).

Nevertheless, more work is needed to understand and strengthen the CARE profile for residents. The comparatively poorer performance of the CARE profile for residents appears to be rooted more in residents’ perceived differences in the dementia context than an issue with measurement. Scores on items and the Senses for residents tended to show higher variability, and along with the reflective notes of the RAs conducting interviews, suggested that differences were attributable more to the experiential contexts of residents than to comprehension.

### References

Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing ‘authentic partnerships’ in dementia care, support, and services. *Dementia* (available online).  
 Faulkner, M., Davies, S., Nolan, M.R., & Brown-Wilson, C. (2006). Development of the combined assessment or residential environments (CARE) profiles. *Journal of Advanced Nursing*, 55(6), 664-677.  
 Nolan, M.R., Davies, S., & Grant, G. (Eds.). (2001). *Working with older people and their families: Key issues in policy and practice*. Buckingham: Open University Press.  
 Nolan, M.R., Lunsh, L., Grant, G., & Keady, J. (2003). Partnership in family care: Understanding the caregiver career. Maidenhead: Open University Press.  
 Nolan, M.R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond ‘person-centred’ care: A new vision for gerontological nursing. *International Journal of Older People Nursing*, 13, 3a, 45-53.