Adapting the CARE Profiles to the Canadian Dementia Context

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Background

The Partnerships in Dementia Care (PIDD) 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 PIDD 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, family members, and staff work together to identify existing strengths and aspirations and use those strengths to achieve desired goals.
- To enhance the care experience and quality of life for residents, clients, and family members and the work life of staff in working long-term care settings.

The PIDD Alliance Integrated Theoretical Framework

<table>
<thead>
<tr>
<th>Group</th>
<th>Items in Scale</th>
<th>Original</th>
<th>Modified</th>
<th>New</th>
<th>TOTAL</th>
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</thead>
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<tr>
<td>Residents</td>
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<td>17</td>
<td>23</td>
<td>47</td>
<td></td>
</tr>
<tr>
<td>Family</td>
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<td>8</td>
<td>20</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Staff</td>
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<td>8</td>
<td>24</td>
<td>40</td>
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</table>

Purpose

- To share our participatory process in exploring and testing an adapted version of the CARE profiles in long-term care 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 residents, family members, and long-term care staff. 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) to ensure relationship-centered philosophy and the Senses framework.
- Examine the accessibility, understandability, and relevance of the items for persons with dementia, family members, and staff, 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.
- Determine the best way to present the items and the response categories most appropriate to the specific group.

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

Methods

- 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.

Family members and staff reported the items along a 5-point, Likert-type scale ranging 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 “no know”. If those scaled response options still represented a challenge for the resident, then an entire open-ended process was used. Some overall impressions of life at the LTC homes was also gathered from each, along with additional background information.

An Analytic Iterative Process

Once all of the data had been gathered and entered into SPSS v20, an iterative process was followed guided by a principle of refining the scales to establish internal consistency and independence of each of the Senses for each of the group respondents. Repeated application of factor analysis 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 (67.6%) and the average age was 81.6 years (SD=12.2). Most lived alone (44.1%) or were working full-time outside the home (38.1%). Daughters (48.4%), spouses (19.4%), and sons (17.6%) reported that they were either the sole primary caregiver (21.6%) or shared with some assistance with others (14.7%).

The vast majority of staff were women (90.4%), working predominately as nurses (25.5%) or personal support workers (25.5%) in the LTC home. Their average age was 44.0 years (SD=11.2). Most 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 (68.0%) and were 62.1 years of age on average (SD=13.2). Most were either retired (44.6%) or working full-time outside the home (31.8%). Daughters (44.6%), spouses (19.4%), and sons (17.0%) reported that they were either the sole primary caregiver (32.4%) or shared with some assistance with others (14.7%).

Overall, when the composite measures of the six Senses were assessed for the CARE profile, 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 (r=.95), family on, and staff (r=.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 indicates 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
