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Measuring the 'dose' of person-centred care in aged care: Development of staff and family questionnaires

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ABSTRACT

Aims

To develop a theoretically and psychometrically sound instrument to measure the ‘dose’ of person-centred care practice in long-term care.

Background

Although person-centred care has been adopted for long-term care across the world, there is a lack of theory-based instruments to measure its impact. Two questionnaires were developed to measure person-centred care from the perspectives of staff and family based on current person-centred care frameworks: Kitwood, Nolan, and Eden Alternative.

Methods

Phase I: literature review and focus groups identified potential items for the questionnaires. Phase II: academic experts, local staff and family members of residents assessed content validity. Phase III: psychometric testing.

Results

A 34-item staff questionnaire (Cronbach’s Alpha =0.942) with two factors “Making person-centredness real” and “Making the environment meaningful for life and work”. A 30-item family questionnaire (Cronbach’s Alpha =0.947), with three factors “Staff care about what is meaningful to my family member”, “Staff know and respect my family member”, and “We are all part of a family”. The factors did not directly reflect the theoretical constructs from Kitwood’s and Nolan’s work.

Conclusion

Two instruments, capturing the ‘dose’ or active practice of delivering person-centred care, have demonstrated sound psychometric properties. The study contributes to understanding the theoretical components of person-centred care.

What problem did the study address?

The study addressed the lack of robust tools to measure how much person-centred care is taking place in aged care facilities.

What were the main findings?

Staff and family questionnaires were produced based on strong theoretical foundations combining concepts of prominent person-centred theories and rigorous psychometric testing.

Where and on whom with the research have an impact?

The instruments can be used to determine if person-centred care makes a difference, to compare if person-centred care changes or develops over time or between facilities. Ultimately residents, families and staff will benefit from the ability to measure how much person-centred care residents receive.

Key words: person-centered care; aged care; long-term care; instrument development; psychometrics, staff, family, nursing

1. INTRODUCTION

The call for long-term care (LTC) services for older adults to provide person-centred care (PCC) has become part of policy in a number of countries globally (Alzheimer's Disease International, 2012) including the USA (Centers for Medicare and Medicaid Services [CMS], 2009), the United Kingdom (UK) (Department of Health, 2011; National Institute for Health and Clinical Excellence, 2006), and Australia (Department of Social Services Australia, 2015) among others. Despite the frequent use of the term, there has been little progress on its measurement. Until this happens it is not easy to determine if PCC is occurring or making a difference to the quality of care for residents in LTC (Fazio, Pace et al. 2018). This paper reports the development of staff and family questionnaires; two of three complementary questionnaires designed to measure PCC in LTC settings. The questionnaires were developed with and for the Western New York Alliance for PCC (the Alliance), a group of seven LTC facilities who received funding from a local philanthropic foundation to train their staff on person-centred practices using the Eden Alternative™ program (Thomas, 1996).

For this study we defined PCC as a dynamic process that facilitates individualized emotional, social, physical, and spiritual support with the person based on their needs, values, aspirations, and preferences. Person-centered care promotes well-being through continuation of self and normality and the experience of living a life of enjoyment, comfort, belonging, purpose, and meaning. It is based on humanistic values and the fundamental premise that every person has a unique history, strengths, interests, and needs and has the right to self-determination in how to go about living their life (Dementia Action Alliance Research Group, 2013).

2. BACKGROUND

The “Artifacts of Culture Change” evaluation tool developed by the CMS and hosted by the Pioneer Network was being used by the Alliance members. It was designed to help administrators, collaborating with facility stakeholders, monitor the progress of culture change within their facility

and store data (CMS, 2006). This 79-item survey is completed as a comprehensive checklist of focusing largely on environmental changes indicating the facility's adoption of and commitment to culture change processes. The importance of the issues being monitored is not questioned, but it is clear that PCC is more than just the improvement of the environment. Our brief from the Alliance was to create a way to measure the practice of PCC, not just the environment, thus overall progress of working toward PCC could be assessed. To develop this measure, we first reviewed the published literature to see if existing tools were suitable.

Edvardsson and Innes (2010) conducted a comparative review of 12 published tools designed to measure person-centeredness for persons with dementia across different care settings. One of these tools, Dementia Care Mapping (DCM), which is a highly structured, quantifiable observation of mood and engagement of older adults with dementia and the quality of interactions between staff and residents, was dementia specific. (Brooker & Surr, 2005; Brooker & Surr, 2006). As Edvardsson and Innes commented, common limitations among these tools is that they have not been validated beyond the development period; therefore, their psychometric properties need further exploration. Our systematic search of the literature to locate other existing tools was not successful (BLINDED FOR PEER REVIEW), as other available tools included specific policies which limited their use at other facilities or for evidence-building through evaluation. Furthermore, they lacked a firm theoretical grounding to support the inclusion of the items, either directly or implicitly. Therefore, the purpose of this study was to develop a theory-based instrument measuring PCC in LTC settings that could be used across facilities for comparison and to aid research and practice development.

Over recent years there has been considerable effort in developing standard and agreed domains and measures for research in LTC. Significantly, the WE-THRIVE (The Worldwide Elements to Harmonize Research in LTC Living Environments) collaborative identified four measurement domains on which to base suitable common data elements for comparative LTC research. These are reported as: organizational context (external and internal to the LTC setting);

workforce; PCC; and care outcomes (Corazzini et al., 2019). The work reported here closely aligns to the domain of PCC. Edvardsson et al (2019) focused their work on finding measures for well-being, quality of life, and personhood for the WE-THRIVE collaborative. The results of their extensive review found no existing measures focused on the quantification of PCC actions, or in other words how much PCC was happening. Thus, this new instrument contributes another perspective to the much needed area of measuring PCC.

2.1 Theoretical foundation

There are several models of PCC; some focus on the environment such as green or small houses (Robinson & Gallagher, 2008; Rabig, Thomas, Kane, Culter, & McAilly, 2006), some on leadership and organizational issues such as Eden Alternative (Thomas, 1996), and others on resident activities such as Spark of Life™ (Verity, 2009) and Eden Alternative® (Thomas, 1996). These models form around moral principles of valuing the person first, acknowledging and using their personal biography, and incorporating personal choices, preferences, and aspirations. There has been no single definition of PCC embraced by all, but these principles have guided the culture change movement (BLINDED FOR PEER REVIEW). We reviewed these models to identify domains of PCC.

Tom Kitwood, referred to by many scholars as the Father of PCC, developed the Enriched Model of Dementia Care following extensive ethnographic study of residents and staff in LTC settings in the UK (Kitwood, 1997). As noted in Edvardsson and Innes (2010) review, except for DCM, there were no tools measuring PCC for residents with dementia. Therefore, we chose to use Kitwood's model (as we intended to use DCM in other research), and this model provided the schema that identity, attachment, inclusion, comfort, and occupation were essential to maintain personhood in elders with dementia.

Two additional domains of PCC (Relationships and Environment) were identified from Nolan's Senses Framework and Eden Alternative Model, which has been the basis for the promotion of relationship-centered care, an important development of PCC (Nolan, Brown, Davies,

Nolan, & Keady, 2006). It posits that having a sense of security, continuity, belonging, purpose, fulfillment, and significance contribute to an older adult's well-being. Though it overlaps somewhat, Nolan's relationship domain was not clearly addressed by Kitwood's model, therefore we added it to our model.

One important principle of the Eden Alternative model (Thomas, 1996) is the creation of a more natural environment: plants; outside space; companionship of pets; along with intergenerational activities are a signature of Eden. Additionally, Eden recognized the importance of leadership support as key to the culture change process along with relationship building with all stakeholders (Williams, et al. 2015).

After reviewing all PCC models, we decided on Kitwood's model of the concepts on personhood as the basis, adding environment and relationships for completeness. Thus the theoretical constructs for measuring the practice of PCC of the new instruments was based on seven broad domains (identity, inclusion, attachment, comfort, occupation, environment, and relationship); the conceptual definitions for which are shown in Table 1.

3. THE STUDY

3.1 Aim

The purpose of the study was to develop a theoretically and psychometrically sound instrument to quantify the practice ("the dose") of PCC in LTC settings as rated by staff and family.

3.2 Setting

Six Alliance facilities provided access to staff and family members for all phases of the instrument development. The participating Alliance members represented a wide range of LTC including for profit, not-for-profit, unionized, non-unionized, larger religious-affiliated, and small family run facilities. At the time of the study each site had introduced PCC practices through staff education utilizing Eden Alternative training. They were all measuring progress with the CMS "Artifacts of Culture Change" tool.

4. METHODS

We used a three-phased process to develop and test the instruments: item identification; content validity; and psychometric testing (Figure 1 and 2). Each phase will be described separately including the design process, testing, results, and theoretical issues.

4.1 Sample/Participants

For the staff questionnaire, we recruited CNAs and other assistants, Licensed Practical Nurses, Registered Nurses, housekeepers, maintenance, activities workers, and coordinators from three assisted living and skilled nursing facilities. For the family questionnaire, we recruited individuals who self-identified as family members, relatives, or friends of a resident who lived in those facilities.

4.2 Phase I – Item development – staff and family items

All the published tools were developed following reviews of the literature and included many important elements. We wanted to build on these, utilizing the data generated from the Alliance members, thus we combined all items from the 12 published tools into a list. Using a local expert panel of authors and clinical partners, we allocated each item as staff-related or family-related. Through discussion and consensus building, we further allocated items into the seven domains of our theoretical framework. From this process we realized that not all seven domains were represented. Thus, we utilized focus groups to further gather information from staff and family members on what they believed best demonstrated PCC.

Following consenting procedures, we recorded each group, ensuring verbatim transcription. We combined the narrative to identify ideas that captured the participants' perspectives of PCC and how they knew when it happened. This included their attitudes to residents, as well as staff and family actions and any outcomes they noted.

4.2.1 Staff questionnaire

We conducted three focus groups plus an individual interview which included 20 direct care staff. Two manuscript authors reviewed and independently coded the transcripts using a content analysis method. They developed initial codes based on the occurrence and frequency of

participants' words and concepts describing PCC, listing and clustering those codes into categories based on similarity and overlap. They met to discuss their findings until a consensus regarding the final categories was reached.

4.2.2 Family questionnaire

The same process was used for the development of the family questionnaire. Flyers about the focus group interviews were posted at each facility and family interested in participating contacted our staff. Two family focus groups were conducted at one assisted living and one skilled nursing facility, with a total of seven participants.

4.3 Phase II – Content validity by expert panel

For content validity for the staff questionnaire, we recruited 28 experts consisting of seven academic experts from the UK, USA, and Australia representing geriatric medicine and nursing, social sciences, and methodologists, and 21 staff from four facilities to complete a content validity form. For the family questionnaire we recruited 22 experts; 16 family members from four facilities and six academics from the same pool as the staff questionnaire.

Items for each questionnaire were placed in a table. Experts were given our definition of each domain and asked to rate each item for its relevance to PCC, the allocation to each domain, and the clarity of language on a scale from 1-4, with 4 being most relevant and clearest. Finally, they were asked to suggest any addition or deletion of items. We calculated a Content Validity Index (CVI) for each item based on the agreement of content experts on item relevance and clarity and used $CVI = 0.80$ as the cut point to represent acceptable agreement on the relevance of each item to the construct of each category (Lynn, 1986).

4.4 Phase III – Psychometric testing

4.4.1 Psychometric testing of staff questionnaire

Based on the estimated total number of direct care staff and potential loss of the questionnaires, 500 questionnaires were sent out to seven sites with 70 to 100 questionnaires distributed to each site. The research team did not receive any unused questionnaires. Based

on a denominator of 500, the initial response rate looked promising with a 50.6% response rate (n=253). Unfortunately, only about half of these were direct care staff and our final sample for psychometric testing was 121 which resulted in a response rate of 24.2%. Of these 121 we had 34 participants repeat the questionnaire one week later.

4.4.2 Psychometric testing of family questionnaire

A total of 480 questionnaires were sent out to 7 sites. A letter of invitation was sent to next of kin by the facility. Based on a denominator of 480, we had a response rate of 25.6 % (n=171). Of these 171, 13 participants repeated the questionnaire one week later.

4.5 Ethical Considerations

Each phase of the development process was approved separately by the University Institutional Review Board. The participating facilities did not have their own research ethics boards, however, each management board reviewed the protocols and accepted the University's formal review and approval.

5. RESULTS

5.1 Phase I – Item development

5.1.1 Staff questionnaire

A total of 232 potential staff items; 132 from the focus groups and 100 from the existing tools were identified. Our expert panel met on several occasions to reduce the number of items. Our rationale for this was as follows: 1) removal of duplicate and similar meaning items to reduce the burden for respondents and to minimize the impact on psychometric properties; and 2) if the duplicate was an item from an existing tool then the focus group item was retained to closer resemble the voice of our participants. The theoretical and psychometric properties of published items were not known, so the expert panel decided to use our participants' expressions over duplicate published items with the aim of making the language more accessible for participants. The process ended with 103 items, 17 items from the literature and 86 from focus groups.

5.1.2 Family questionnaire

As described previously, two family focus groups with a total of seven participants were conducted. Using the same procedure, a total of 119 items were identified consisting of 72 from the focus groups and 47 from the existing tools. After the same procedure was followed to reduce items, a total of 100 were generated.

5.1.3 Theoretical issues in phase I

Using our expert panel over a series of meetings, we attributed each item to one of the seven domains, establishing the framework of the new instrument. For both questionnaires we had considerable difficulty deciding item allocation to the identity, inclusion, and attachment domains, in particular where there seemed to be substantial overlap. We used Brooker's (2004) definitions of each domain and extended these with the "themes" from the focus groups. We ultimately provided a simplified version of these defining characteristics to our expert panel as we moved onto Phase II. The difficulty we had in differentiating these concepts heralded our later findings in Phase III, an issue to which we will return. We also found that neither staff nor family members had provided us with much for the domain of 'comfort'. It was apparent that in the USA, the term comfort was used by staff as a euphemism for end-of-life care, so comfort issues like pain or social discomfort did not arise from the focus group. Nor were these issues adequately covered in the existing tools. For the family focus groups, end-of-life issues were exceptionally difficult to discuss even hypothetically. Discussion regarding 'occupation' also was limited in its scope for both groups and focused on opportunities for organized activities rather than activities with meaning for individuals. To round out the items in these difficult domains, our team added items from their theoretical knowledge and clinical experience to more fully examine the concepts of 'comfort' and 'occupation'. Items relating to the 'environment' were fairly straight forward to allocate. However, the 'relationships' domain also overlapped with 'identity', 'inclusion' and 'attachment'. Finally, 'relationships' became the domain to categorize those of family members, such as between residents and family or staff and family.

5.2 Phase II – Content validity

The initial step in refining the instrument was to remove any item that had achieved expert agreement of relevance of $<.80$. Some retained items required clarification, leading us to reword them. After scrutiny of the remaining items the need for a frequency scale became obvious in order to represent dose or quantity of PCC. This focused our attention onto action or quantifiable behaviors such as “I take care of each resident in different ways according to their individual needs and preferences.” Items related to attitudes, such as, “people with dementia are just like children,” or simply valuing knowledge, such as, “knowing the resident’s history is important,” were removed. We concentrated on actions demonstrating PCC for the staff questionnaire, and for the family questionnaire we included actions of staff that were seen or experienced by family members. Although attitudes and knowledge are important, it is possible for staff to have measurable knowledge and positive attitudes but not actually put them into action on a routine basis due to personal and organizational constraints. Our decision therefore was to focus on action statements which also helped with the parsimony of the instruments. After undertaking this process, the staff version was reduced to 75 items and the family version to 68 items.

5.2.1 Theoretical and measurement issues in phase II

One problem that arose during content validity testing was the difficulty posed, particularly by staff, of rating a concept opposed to person-centered values as relevant to PCC. For example: “I follow the family's decision about resident's care even if it conflicts with the resident’s choices.” The response to such an item was often “not relevant” as participants disagreed with the meaning. There was minimal disagreement on the allocation of items to the seven domains and these were resolved through discussion with the expert panel until consensus was achieved.

5.3 Phase III - Psychometric Properties

5.3.1 Staff questionnaire

5.3.1.1 Characteristics of staff

The staff (n=121) responding to the Phase III study questionnaire were predominantly female (88%), with a mean age of 42 years (± 12.5 , range 19-68 years), who had worked in LTC for

a mean of 14.5 years (± 10.4 , range 3 months – 40 years). Respondents were 77% White, 16% Black, 4% Asian, and 3% other. All respondents had completed at least high school, with 45% having a college education and 32% having a baccalaureate degree or higher, 14% were Registered Nurses, 37% Licensed Practical Nurses, and 49% CNA.

5.3.1.2 Factorial structure and theoretical constructs

Because the theoretical constructs of PCC are distinctive, we considered that the underlying factors of the PCC tools are conceptually different. We used principal components analysis (PCA) with orthogonal Varimax-rotation with Kaiser Normalization to determine the underlying factorial structure of the instrument. All of the retained factors should have unrotated eigenvalues greater than 1 (Tinsley & Tinsley, 1987). The screen plot and percentage of variance of each factor were considered to decide on the factor solution. Furthermore, rotated factors were interpreted by examining the items with a minimum loading of 0.4. If items loaded high on more than one factor (> 0.5) or loaded low on all of the factors (< 0.4), they would be considered problematic and removed from analysis (Nunnally & Bernstein, 1994). We also reviewed the conceptual relevance to the PCC philosophy of each item. Using this process, we eliminated 41 items from the questionnaire.

Our analysis resulted in a 2-factor solution accounting for 46.6% of the variance with the 34-item model. Many items loaded heavily on the same factor which conceptually reflected Kitwood's 4 domains of personhood including identity, inclusion, attachment, and comfort. This factor was labeled as "making person-centeredness real" (26 items). The absolute value of factor loadings of these 26 items ranged from .823 to .434 (Table 2). Occupation, the fifth domain of Kitwood's model did not load with "making person-centeredness real". This could represent a less passive interaction from the perspective of the resident. Items related to meaningful occupation for residents loaded onto a second factor along with items relating to the staff perspective of their own work and how they are valued in a workplace/facility with person-centered culture. Thus, the second factor was labeled

“making the environment meaningful for life and work” (8 items) to capture the meaning that was important for both the resident and staff. The absolute value of factor loadings of these 8 items ranged from .722 to .459 (Table 2).

5.3.1.3 Reliability

Internal consistency using Cronbach’s Alpha was calculated for the whole questionnaire and the two subscales. The total Cronbach’s was 0.942; the “making person-centeredness real” subscale was 0.947; and 0.758 for the “making meaning in life and work subscale”. Test retest reliability was calculated for the whole questionnaire (n=34) using Intraclass Correlation Coefficient (ICC): 0.819, $p < 0.000$ (CI = 0.670-0.904).

5.3.1.4 Results of staff questionnaire

Overall the staff rated themselves fairly high on the PCC staff questionnaire. Table 3 displays the mean and range for the total score and two subscales.

5.3.2 Psychometric Properties of family questionnaire

5.3.2.1 Characteristics of family

The family member respondents were predominantly female (77%) and White (98%) with only 1.2% reporting being Black and 0.8% Asian. Of family respondents, 7% reported attending high school without a diploma, 20% a high school diploma, 14% attending some college, and 59% having a baccalaureate degree or higher.

5.3.2.2 Factorial structure and theoretical constructs

We used the same statistical approaches to examine the underlying structure of the family questionnaire and the same criteria to determine the number of retained factors and the inclusion and exclusion of items. The result of the PCA indicated a 3-factor solution accounting for 54% of the variance with the 30 items. The absolute value of factor loadings of the 30 items ranged from .791 to .419 (Table 4). The three factors were named to reflect the item content: Factor 1 was “staff care about what is meaningful/important to my family member” (13 items); factor 2 was “staff

know and respect my family member” (9 items); and factor 3 was “we are all (staff, family and resident) part of a family/team” (8 items).

Factor 1 included mostly items that had been attributed to occupation and focused on meaningful activity. Other items, although originally related to comfort and identity, were actually meaningful as they related to comforting when another resident was ill or dying, or knowing what upsets the resident. These related to staff understanding and recognizing meaningful events. The relationship item that remained in this factor addressed the staff assisting the family member with changes in the resident; the staff recognizing the importance of this to the family member clearly places it with the other items related to staff caring about meaning.

Factor 2 included mostly items that conceptually reflected the three remaining domains of Kitwood’s model: identity, inclusion, and comfort. Knowing the resident and the family seeing evidence of this seems to fit conceptually as the fundamental element of PCC. When staff know (identity) and respect the resident, inclusion and comfort naturally follow but these appear to be indistinguishable as separate domains in our questionnaire.

Factor 3 included mostly items originally attributed to environment with the remainder consisting of relationship items. The sense of team or family is evident in the items in this factor. Comfort in dealing with staff, and the family member themselves feeling included are elements that fit within this grouping.

5.3.2.3 Reliability

The Cronbach’s for the total scale was 0.947; for the staff care about what is meaningful to my family member subscale Cronbach’s was 0.916; for the staff know and respect my family member the Cronbach’s was 0.860; and for the we are all part of a family/team subscale Cronbach’s was 0.836. Test retest reliability was calculated for the whole questionnaire (n=17) using Intraclass Correlation Coefficient (ICC): 0.904, $p < 0.000$ (CI = 0.867-0.989).

5.3.2.4 Results of family questionnaire

Overall the family rated the facility fairly high on the PCC questionnaire except for the third subscale. Table 5 displays the mean and range for the total score and three subscales. Although the mean scores were on the high end, the full range was used suggesting the instrument can detect differences.

5.4 Instrument

5.4.1 Scoring the questionnaires

The scoring process assumes that each item carries equal weight in representing PCC action and equal contribution to an overall assessment of how much PCC (dose) is occurring in the facility. Each item response is a frequency indicating how often/much a particular item occurs. The scoring is a Likert-type scale with 5 points: Almost never (1-point), Seldom (2-points), Sometimes (3-points), Often (4-points), and Almost Always (5-points). A total score as well as the sub-scores can be calculated (one for each factor) with a high score representing a higher dose of PCC.

The family questionnaire items are all worded positively to avoid confusion noted in the content validity phase. The staff questionnaire has five items that are worded negatively including item 9, 16, 19, 24, and 31. The wording reflects the problems that were identified by staff in the focus groups. Wording these concepts positively would seem unnatural or awkward; staff may be able to relate better to these items as negative statements and respond honestly.

Conceptually, we envisage that the total and sub-scores can be analyzed as continuous variables. Individual items should be analyzed as ordinal variables. For the staff questionnaire, after reversing the five negative items, the possible range for the total scale is 34 – 170; for “making person-centeredness real” sub-scale the range is 26 – 130; and for the “making meaning in life and work” sub-scale the range is 8 – 40. For the family questionnaire the possible range for the total scale is 30 – 150; for the “staff care about what is meaningful to my family member” subscale the range is 14 – 70; for “the staff know and respect my family member” subscale the range is 8 – 40; and for the “we are all part of a family/team” subscale the range is also 8 – 40. For all the scores a higher score represents more person-centered actions.

6. DISCUSSION

We have reported the development of staff and family questionnaires measuring the frequency of PCC as represented by key actions. The questionnaires have a strong theoretical framework drawing on the major theorists in PCC (Kitwood 1997) and relationship-centered care (Nolan et. al., 2006) and a common model for implementing person-centered principles into practice in LTC facilities, the Eden Alternative®. The expression of PCC in the items drew mainly from the verbatim quotes from staff and family members, endorsed and supplemented by published literature. We set about the task in a systematic way to produce as rigorous a product as possible.

Most striking about the results of the study is that the data did not support the proposed seven theoretical domains. Our interpretation of that finding focuses on the difficulty of differentiating between concepts such as inclusion and relationship. From a theoretical, abstract point of view, these concepts may be distinct, but in practice it is not so easy to distinguish the differences. This was particularly clear with the staff questionnaire where we must question whether there is an operational difference between four of the five domains of Kitwood's concepts of personhood. It would seem that identity, inclusiveness, attachment, and comfort, although defined differently, are expressed simultaneously, at least from the staff perspective. In human interaction these four domains are rarely mutually exclusive. Therefore, in promoting a resident's personhood, these domains are carried out concurrently even in one action.

Meaningful occupation from Kitwood's model was the only concept that stood alone. Furthermore, the items related to work and physical environment also loaded on this factor. It seems from this combination of items that the meaningfulness of the staff's work is intertwined with the meaningful occupation of the residents. This is something that may be corrected or confirmed in future studies with larger samples.

The factor structure for the family questionnaire is different. The first of the three subscales suggest the importance of meaningful occupation as a primary concern. This, along with the staff being able to help family members make meaning out of what was happening to the resident, in

terms of interpreting behavior, aiding communication, or recognizing deterioration, show the importance of meaning-making for residents, staff, and families. The second subscale focuses on family members being able to see staff recognizing who the resident is and knowing them as a person. This is very much how Kitwood envisioned the importance of identity as central to personhood. The third subscale of the family questionnaire shows the idea of family and team. The essence of this factor is inclusion and attachment and the ease with which the family can come and go in the facility and speak freely with staff.

It would seem then that the family questionnaire has more of a sense of Kitwood's domains as identifiable components than the staff questionnaire. Possibly, because the family are not actually providing much care, they are more evaluative and abstract about what the staff are doing. This may make the domains more distinguishable behaviorally from their perspective.

6. LIMITATIONS

Although we utilized a systemic approach to develop the items of the questionnaires, there are several limitations to be addressed. The facilities in the study were already working towards developing person-centered cultures, thus we do not know if staff and families from more traditional LTC facilities will respond to the language of the items in terms of person-centered jargon. Greater diversity of organizational culture, type of facility, background, and education of staff and family members may reveal different factor structures and interpretation. Although we tested content validity, test-retest reliability, and internal consistency, the fact remains that the samples were relatively small with all the attending implications for generalizability. Such small sample sizes in our study were not sufficient to provide more desirable factor solutions of our PPC tools. Further examination for their psychometric properties in a large sample is warranted. Furthermore, the one-week interval between test-retest might have a memory effect on reliability.

7. CONCLUSION

We developed a psychometrically sound instrument to measure PCC in LTC settings utilizing a foundation of established theories augmented with the voices of experienced LTC

caregivers and family members. The measure will provide the means to assess progress in an organizations transformation to PCC, and to establish if interventions and outcomes can be attributed to PCC. Both of these functions should contribute to understanding and applying person-centered principles into everyday practice. Further research to test and validate the questionnaires in other countries with larger samples is needed.

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Conflict of Interest Statement

No conflict of interest has been declared by the author(s).