

Measuring Person-Centredness from the Perspectives of Families of Long-Term Care Residents: Development of a Questionnaire

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Background and Purpose

Contemporary person-centred care theory advocates to include not only patients but also staff and families of patients as persons when striving to develop person-centred practice.

While family involvement is considered a cornerstone of good care, instrument development for practice development and evaluation purposes lags behind. Moreover, **conceptual ambiguity remains regarding the role(s)** of families in long-term care.

The purpose of this study was to develop a standardized questionnaire to measure person-centredness from the perspective of families of long-term care residents.

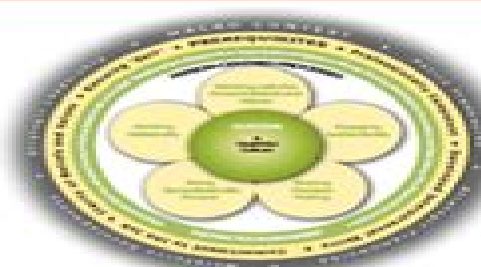


Figure 1: The Person-centred Practice Framework¹

Person-centred practice is defined as:

"... an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development." (p. 20)

Results

Phase 1 (n=63) indicated good comprehensibility of the questionnaire with a mean agreement of 4.87 for both roles. On the other hand, adequacy ratings displayed lower mean scores for items pertaining to the advocate role (3.51), compared to 4.00 of the care recipient role (Figure 2). These findings indicate a certain degree of misalignment between theoretically ascribed roles and self-perceived roles of families, as was also evident in the feedback received through open ended commentary (Figure 3).

This discrepancy particularly came to bear regarding their involvement in particular care processes, in which some respondents articulated having no insight into. Furthermore, results indicated that family preferences regarding their involvement will likely need to be negotiated individually.



Figure 3: Open-ended quotes from participants' feedback

Conclusions and Implications

Findings demonstrate the importance of thorough theoretical work regarding the clarification of roles and expectations of, as well as expectations towards, families of residents in long-term care in the development of person-centred theory and practice. Phase 2 will show if these aspects also occur on a larger scale and will also provide the opportunity to revise the questionnaire.

Methods

A multi-phase research design was conceived to design the questionnaire. Existing instruments for patients and staff based on a recognised theoretical framework, the Person-centred Practice Framework (Figure 1), were rephrased and combined to form a self-report questionnaire for families. Based on the "person-centred processes" of person-centred practice inventory², the questionnaire contains 33 items regarding care processes and reflects families' roles both as **care recipients** as well as **advocates of their loved ones in care**.

Phase 1 involved a developmental pretest and aimed at testing the **comprehensibility** and **adequacy** of the questionnaire. Participants were asked to rate each item on a scale from 0 (lowest) – 5 (highest) for both aspects and were invited to provide feedback in text form. Mean values for each item were calculated.

Phase 2 is scheduled to begin in fall of 2023 and involves a survey to assess response behavior with an estimated sample size of n=500. Following phase 2, the questionnaire will be further revised and psychometrically tested.

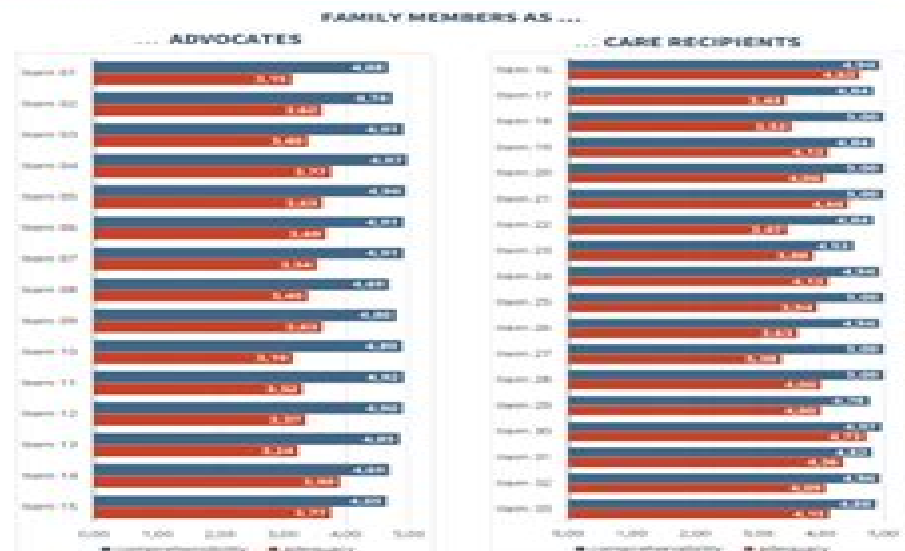


Figure 2: Mean scores for items representing advocate and care recipient roles (n=63)

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