

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.

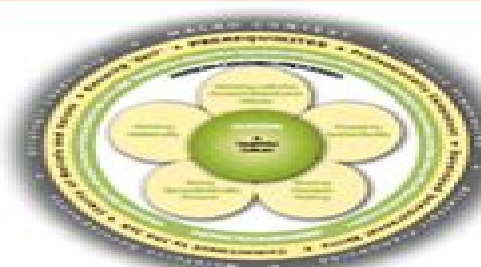


Figure 1: The Person-centred Practice Framework¹

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.

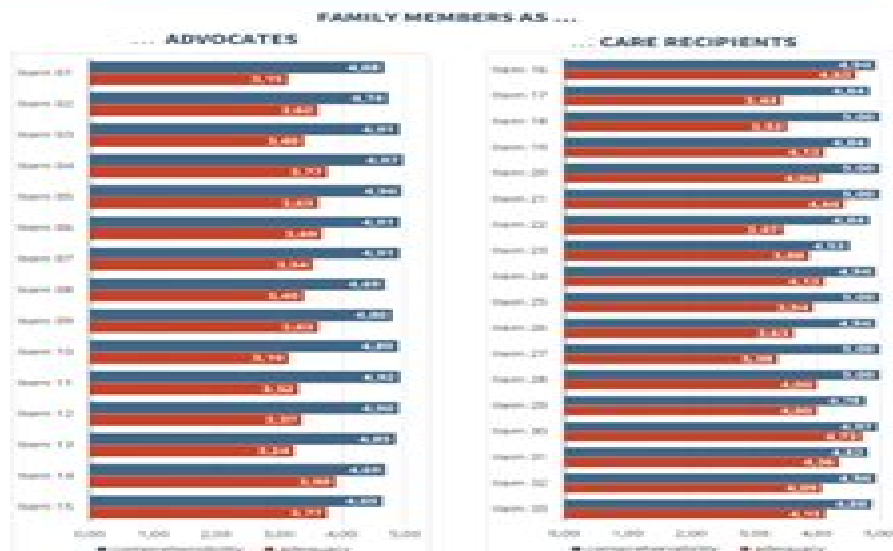


Figure 2: Mean scores for items representing advocate and care recipient roles (n=63)

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LONG-TERM CARE RONALD J. VOGEL , **Long Term Care** ,1983 *Long-term Care* ,1983 Handbook of Gerontological Services Abraham Monk,1990-06-29 Social Work Long-Term Care: Economic Issues and Policy Solutions Roland Eisen, Frank A. Sloan, 2012-12-06 Ensuring long term care LTC is one of the most urgent problems in health care today Demographic trends are expected to lead to a higher proportion of old and very old people in the global population As a result an increased proportion of global income will be devoted to LTC services With this in mind Long term Care Economic Issues and Policy Solutions aims to address the following important objectives to provide a detailed analysis of the arrangements and institutions designed to protect the disabled and dependent elderly people in various countries and to try to evaluate their respective merits to discuss the projections of future costs of protection for dependent elderly and to assess the impact of improvements in disability free life expectancy on the future cost of care and choices between informal and formal care to present empirical research on these decisions with special consideration of primary caregivers and on the substitution between in kind and cash benefits as well as between institutional or formal care and home or informal care to analyze different theoretical approaches in modeling decisions referring to LTC services to be provided both within and between generations With its mix of empirical theoretical and policy related contributions Long term Care Economic Issues and Policy Solutions will be of interest not only to health economists but also to social scientists health insurers and public policy advocates *Handbook of Clinical Nursing Research* Ada Sue Hinshaw, Suzanne L. Feetham, Joan Shaver, 1999-06-18 This ambitious and long awaited volume brings together foremost nursing scholars researchers and educators to review and critique the state of research across areas most relevant to clinical practice The contributorship appears as a veritable who's who of nursing research and the contents comprise primary areas in the vanguard of nursing science In the first section the authors explore theoretical issues the variety of philosophical approaches to scientific inquiry in nursing factors shaping nursing research and the relationship of the philosophical perspectives to research methodologies In later sections the scientists review and analyze the state of nursing science in relation to community health practice strategies family care health promotion biobehavioral investigations women's health gerontologic nursing and health system perspectives and outcomes For physiological as well as psychological research the most relevant theories driving the research are presented along with the review of multiple diverse instruments and measurement issues Comprehensive in scope cogent and truly thought provoking a book such as the Handbook of Clinical Nursing Research arrives only once or twice in a career It is a must have shelf reference for every nurse and for those who would teach them Current Catalog National Library of Medicine (U.S.), First multi year cumulation covers six years 1965 70 *National Library of Medicine Current Catalog* National Library of Medicine (U.S.), **Community Resources for Older Adults** Robbyn R. Wacker, Karen A. Roberto, 2018-06-13 Community Resources for Older Adults provides comprehensive up to date information on programs

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