

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.

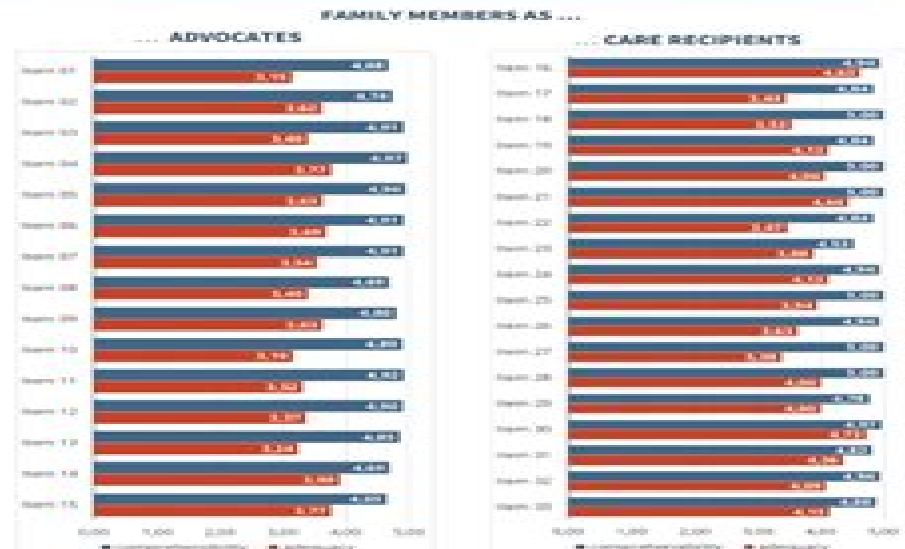
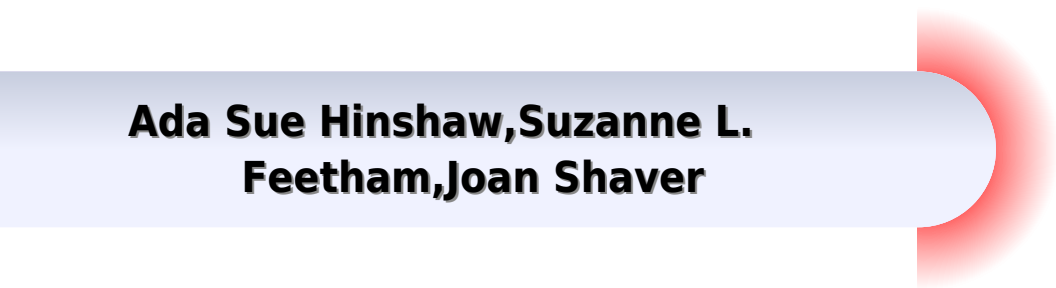


Figure 2: Mean scores for items representing advocate and care recipient roles (n=63)

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R Wacker and Karen A Roberto build reader awareness of programs and discuss how to better understand help seeking behavior as well as explain ways to take advantage of the resources available to older adults The substantially revised Fifth Edition includes new topics and updated research tables and figures to help answer key questions about the evolution and utilization of programs for older adults and the challenges that service providers face *Mental Health Consultation in Nursing Homes* Michael A. Smyer, Diane Brannon, Margaret D. Cohn, 1990-12 The most complete book to date concerning the institutionalized care of the mentally ill elderly A compassionate comprehensive portrayal of the problems of caring for older persons by family members and nursing home staff Essential reading for all those working with the elderly Bertram J Cohler Committee on Human Development University of Chicago The real strength of this book lies in its initial conceptualization of the nursing home as a community with a community's complexity of forces working both for and counter to the best interests of its members contrasting the traditional view that the institution is the enemy of its residents M Powell Lawton Director of Research Philadelphia Geriatric Center This eminently readable book meets a long standing need in the field of mental health reflected in the fact that many nursing home residents suffer mental and emotional problems not infrequently the cause of their placement Rooted solidly in theory research and clinical evidence yet with a clear eye to practical applications this excellent book will appeal to scholars educators students administrators consultants and practitioners Barbara Silverstone Executive Director The Lighthouse This book come out at the right time in our return to a national discussion of the mental health needs of older adults Scholarly in breadth and thoroughness the authors draw on their wealth of practical experience to edify topics on the nursing home industry and its community of caregivers families and residents and on strategies for mental health consultation assessment and intervention It is thoughtfully written Carrell Wendland Ph D President Beverly Foundation *Monthly Catalog of United States Government Publications* United States. Superintendent of Documents, 1985 February issue includes Appendix entitled Directory of United States Government periodicals and subscription publications September issue includes List of depository libraries June and December issues include semiannual index **The Coming Health Crisis** John R. Wolfe, 1993-04 Moreover other traditionally reliable sources of financial assistance Social Security Medicare and Medicaid have faced serious financial difficulties in recent years Who will the aged turn to for assistance The Coming Health Crisis suggests that as funds from all quarters dwindle older Americans will have to look to alternative programs for financial assistance Wolfe urges immediate action to develop new saving programs and increase existing transfer schemes to head off an imminent crisis Although tax increases might provide some resources he demonstrates that it is more important to accumulate capital to create solid reserves for the future Wolfe also explores two roles for government prefunding new or existing social insurance programs and promoting private insurance options **Health Care Financing Review**, 1988 **DHHS Publication No. (PHS).**, 1989 Improving the Quality of Care in Nursing Homes Institute of Medicine, Committee on Nursing Home Regulation, 1986-02-01 As more people live longer the

need for quality long term care for the elderly will increase dramatically This volume examines the current system of nursing home regulations and proposes an overhaul to better provide for those confined to such facilities It determines the need for regulations and concludes that the present regulatory system is inadequate stating that what is needed is not more regulation but better regulation This long anticipated study provides a wealth of useful background information in depth study and discussion for nursing home administrators students and teachers in the health care field professionals involved in caring for the elderly and geriatric specialists

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Aging Social Policies Robbyn R. Wacker,Karen A Roberto,2010-12-07 Our population is aging What will we do about it Due to population explosion and a global increase in average life expectancies an unprecedentedly high percentage of the world s population is aging By the middle of this century there will be up to 2 billion individuals over the age of 65 a demographic shift never before experienced in our human history In addition declining birth rates in industrialized countries means a decrease in the number of adults under 64 In **Aging Social Policies An International Perspective** the authors consider how policy domestic and international affects and will continue to affect the lives of our aging population

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