

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.

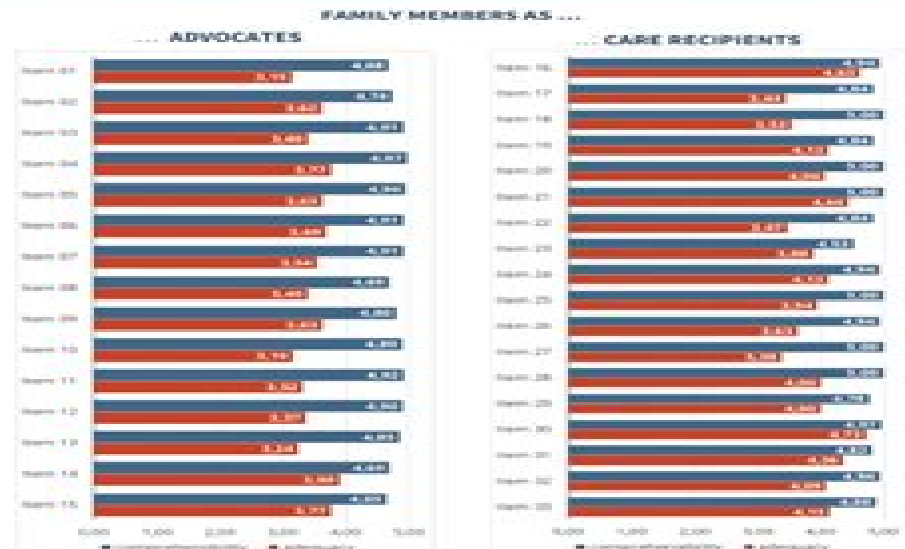


Figure 2: Mean scores for items representing advocate and care recipient roles (n=63)

Long Term Care Perspectives From Research And Demonstrations

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LONG-TERM CARE RONALD J. VOGEL , 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 *DHHS Publication No. (PHS). ,1989*

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 services and policies pertaining to

older adults Authors Robbyn 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 came 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

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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

For-Profit Enterprise in Health Care Institute of Medicine, Committee on Implications of For-Profit Enterprise in Health Care, 1986-01-01 This book is the most authoritative assessment of the

advantages and disadvantages of recent trends toward the commercialization of health care says Robert Pear of The New York Times This major study by the Institute of Medicine examines virtually all aspects of for profit health care in the United States including the quality and availability of health care the cost of medical care access to financial capital implications for education and research and the fiduciary role of the physician In addition to the report the book contains 15 papers by experts in the field of for profit health care covering a broad range of topics from trends in the growth of major investor owned hospital companies to the ethical issues in for profit health care The report makes a lasting contribution to the health policy literature Journal of Health Politics Policy and Law **Health Care Financing Review** ,1988 *New Perspectives on HIV-related Illnesses* William N. LeVee,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 **Annual Report on Medicare Covering Fiscal Year ...** United States. Health Care Financing Administration,1983 **Annual Report on Medicare** United States. Health Care Financing Administration,1981 *Medicare Annual Report to the Congress* , **Health Spending in the 1980's** Mark S. Freeland,Carol E. Schendler,1984 Caregiving Systems Steven H. Zarit,Leonard I. Pearlin,2019-02-21 Caregiving has emerged as a critical issue in the second half of the life cycle With the growth of the older population there have been dramatic increases in the number of people needing care and assistance The responsibility for care typically falls on families at a time when they have limited resources to meet these needs At a societal level the need for care for growing numbers of disabled elders poses a major challenge for how to organize supportive services in an efficient and responsive system Bringing together multiple perspectives on caregiving the authors explore informal and formal family caregiving and the pivotal issue of how these systems interface and interact An overview of this variation is provided by examining family caregiving from three perspectives the effects of culture on helping patterns and family responsibility how different disabilities affect patterns of family care and longitudinal perspectives on the impact that caregiving has on family members

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