

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

Stefan Gschwentner, Martin Wallner, Hanna Mayer | stefan.gschwentner@klu.ac.at

Karl Landsteiner University of Health Sciences, Department of General Health Studies, Division Nursing Science with focus on Person-Centred Care Research, Krems, Austria

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.

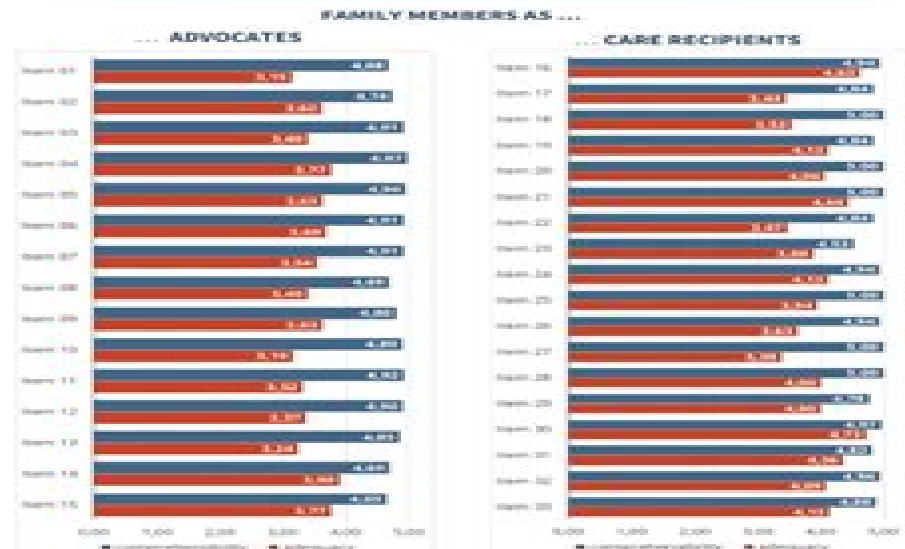


Figure 2: Mean scores for items representing advocate and care recipient roles (n=63)

Long Term Care Perspectives From Research And Demonstrations

Roland Eisen, Frank A. Sloan



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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 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 comes 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

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

New Perspectives on HIV-related Illnesses William N. LeVee,1989 *Robotics Technology and Its Varied Uses* United States. Congress. House. Committee on Science, Space, and Technology. Subcommittee on Science, Research, and Technology,1989

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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