

A PROGRAM FOR HOMELESS PERSONS

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A large community health care organisation expanded their community-based assertive outreach Homeless Persons Program (HPP) to address a significant level of unmet health care need among people experiencing homelessness in a south-eastern region of Victoria despite the presence of well established homeless and healthcare services.

Evaluation of HPP program showed that the majority of assisted clients were successfully referred to at least three services. Key to clients accessing the services was the strong advocacy provided by the HPP nurse. This program has also helped establish various initiatives to improve clients' social inclusion. The HPP model has positively impacted on clients' lives and improved their capacity to engage with health and welfare services. This engagement has led to an increased sense of self-belief, resilience and improved social connections which have helped in reclaiming aspects of their lives.

SESSION 3390 (SYMPOSIUM)**ENHANCING THE INFORMED CONSENT PROCESS IN CLINICAL DEMENTIA RESEARCH**

Chair: J. Haberstroh, *Goethe University Frankfurt, Frankfurt am Main, DEUTSCHLAND, Germany*

Co-Chair: J. Vollmann, *Ruhr University Bochum, Bochum, Germany*

Discussant: J. Moye, *VA Medical Center, Jamaica Plain, Massachusetts*

The high number of people suffering from dementia will significantly increase in European countries and elsewhere in the coming decades. No treatments are currently available that can reverse or even halt the neurodegenerative process, and dementia is a considerable burden on patients and caregivers, as well as on societies as a whole. For this reason, there is a substantial need for further medical dementia research. People with dementia have the right to decide whether or not they want to participate in clinical research and to give their free, prior and informed consent. However, as dementia progresses, they can lose their ability to give informed consent to complex medical research because of an increasing loss of cognitive functions. At first sight, it seems ethically problematic to involve dementia patients in research, as people with impaired mental capacity must be protected against the risks of research participation. Furthermore, in contrast to informed consent to medical treatment, an individual benefit from participation in research can rarely be taken for granted. However, people with dementia also have a right to benefit from medical research in particular, so their categorical exclusion would appear to be ethically problematic too. High standards for the informed consent process and a thorough assessment of mental capacity are therefore important for the protection of research participants. In this Symposium, the international, interdisciplinary ENSURE project will be presented. This project aims to contribute towards achieving an adequate balance between autonomy and the protection of dementia patients in clinical research.

ENSURE PROJECT: SUPPORTED DECISION-MAKING AND CAPACITY ASSESSMENT IN CLINICAL DEMENTIA RESEARCH

J. Haberstroh, F. Oswald, J. Pantel, *Frankfurt Forum for Interdisciplinary Ageing Research, Goethe University Frankfurt, Frankfurt am Main, DEUTSCHLAND, Germany*

This talk opens the symposium "Enhancing the Informed Consent Process in Clinical Dementia Research" and gives an overview of the project "Enhancing the Informed Consent Process: Supported decision-making and capacity assessment in clinical dementia research" (ENSURE). ENSURE aims to provide interdisciplinary recommendations to support the development of an action model of an informed consent process in clinical dementia research that a) enhances the capacity to consent of people with dementia, b) improves the assessment of decision-making capacity, c) protects those who do not have the capacity to consent, and d) guarantees the ethically justified inclusion of research subjects in clinical dementia research. To achieve this, four international project partners cooperate on four interdisciplinary interlinked subprojects to be conducted in three successive phases. The disciplines involved are gerontology, ethics and law. In the symposium, the project partners will present the results of the first project phase of three of the subprojects.

OPPORTUNITIES AND RISKS OF SUPPORTED DECISION-MAKING IN DEMENTIA RESEARCH. AN ETHICAL ANALYSIS

J. Vollmann, J. Gather, M. Scholten, *Ruhr University Bochum, Bochum, Germany*

According to the interpretation of the Committee on the Rights of People with Disabilities (the Committee), article 12 of the United Nations Convention on the Rights of People with Disabilities (CRPD) represents a radical departure from the widely accepted functional approach to assessing competence, along with acknowledged procedures of substitute decision-making, in favor of a new paradigm of supported decision-making (SDM). Although sharing the Committee's concerns about the discrimination of mentally disabled people and welcoming the development of new measures for the enhancement of decision-making capacity, we have several reservations regarding the Committee's interpretation. Our main worry is that the SDM model runs the risk of failing to distinguish between substitute and supported decision-making. We therefore recommend a more limited and case-specific application of SDM with a clear and transparent idea of the individual competence of patients involved in clinical dementia research.

ETHICAL FRAMEWORK OF INFORMED CONSENT AND DECISION-MAKING IN DEMENTIA RESEARCH

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Impaired decision-making capacity is a symptomatic feature in a number of neurodegenerative diseases, but the nature of these decision-making deficits depends on the particular disease. The level of impairment that renders a patient unable to make valid decisions should ideally reflect a societal judgment about the appropriate balance between respecting the patient's autonomy and protecting the patient from the potentially negative consequences of such a decision.

Although many types of decision-making exist, studies of decision-making in patients with neurodegenerative diseases generally use two decision-making paradigms; decision-making under ambiguity and decision-making under risk. The main objective of this study is to determine the issues that should be taken into account during the informed consent process. This study encompasses two intertwined phases. The results will be integrated into an in-depth normative analysis of the conceptual and ethical issues raised by the informed consent process in clinical dementia research.

GERONTOLOGICAL DEMANDS AND ACTUAL CONDITIONS OF INFORMED CONSENT PROCEDURES IN DEMENTIA RESEARCH

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In phase 1, the subproject Gerontology aims to identify the country-specific demands and actual conditions governing informed consent procedures in clinical dementia research in the participating countries. About 90 people with early stage dementia, and 90 caregivers/legal guardians (all involved in clinical dementia research) will be included. For the recruitment of potential subjects, we contact dementia researchers in Germany, Spain, and Portugal and ask them to share our online-study with their study participants. Semi-structured online-interviews are conducted over a period of 6 months. Participants are interviewed in order to gather information on existing informed consent conditions in clinical dementia research. Furthermore, participants are asked to formulate and rate their needs, whereby the emphasis lays on the assessment of p-e fit indices in the domains of spatial and social needs versus existing conditions. Phase 1 will be finished in June 2017. The results of phase 1 will be presented.

SESSION 3340 (SYMPOSIUM)

TOWARD THE DEVELOPMENT OF A PERSON-CENTERED INDEX OF AGING WELL IN CANADA AND MEXICO

Chair: E. Belanger, *Brown University, Providence, Rhode Island*

Co-Chair: U. Perez-Zepeda, *Instituto Nacional de Geriatria*

Discussant: M. Zunzunegui, *Universite de Montreal, Montreal, Quebec, Canada*

Despite a growing interest in successful aging among gerontologists, there remains a lack of consensus about the definition of this concept. The most common definition was proposed by Rowe & Kahn (1997): “a low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life” (p. 433). This appears unrealistic for the majority of older adults with no more than 11.9% percent of Americans, and a mean of 8.5% of older adults across European countries being free from major chronic diseases, physical disability, cognitive impairment, and participating in social and productive activities. When asked, the perspective of older adults themselves is broader, less medical, and more positive than those of the aforementioned researchers, and not dependent upon absence of disability or chronic illness. Literature reviews of lay perspectives confirm the importance of psychosocial components such as life satisfaction and

self-mastery. This symposium includes three presentations as well as a thorough introduction about different models of successful and positive aging, and their prevalence and limitations. The first presentation is a qualitative description of older adults’ perceptions of aging well in Canada. The second concerns the development of a person-centered index of aging well and description of its distribution in Canada and Mexico, while the last addresses the individual and structural determinants of aging well from the perspective of older adults. Developing comprehensive measures of positive aging processes is important for health promotion if we are to tackle outcomes that truly matter to older adults.

OLDER ADULTS’ LAY PERCEPTIONS OF AGING WELL: A QUALITATIVE STUDY IN CANADA

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Literature reviews about lay perspectives on successful aging suggest additional psychosocial components to the biomedical definition proposed by Rowe and Khan (1997). The research question guiding this study was: What is the perspective of older adults on aging well in Canada? A descriptive study was carried out, using inductive qualitative content analysis to explore the domains of aging well that Canadian older adults report on, as compared with existing literature on lay perspectives. A random sub-sample of 40 older adults was selected from the ongoing International Mobility in Aging Study at two Canadian sites (Saint-Hyacinthe and Kingston), using a stratified selection process to ensure a diversity of ages, genders and education levels. Forty semi-structured qualitative interviews were carried out with participants to explore their perspectives on aging well. The results confirm the importance of symptomatic health conditions including pain, as well as psychosocial components, such as attitude toward aging.

DEVELOPMENT OF A PERSON-CENTERED INDEX OF AGING WELL IN CANADA AND MEXICO

R.C. Castrejon-Perez², E. Belanger^{1,3}, U. Perez-Zepeda², M. Zunzunegui^{1,3}, *1. University of Montreal, Montreal, Quebec, Canada, 2. Instituto Nacional de Geriatria, Mexico City, Mexico, 3. Public Health Research Institute (IRSPUM), Montreal, Quebec, Canada*

Starting from the results of a qualitative study in Canada and existing literature in different contexts, an index capturing most of the domains used in definitions of successful aging was constructed, with a particular focus on lay perspectives. The index was developed using data gathered in 2014 from 663 Canadian participants in the International Mobility in Aging Study (IMIAS) and 15,698 Mexican participants in the Mexican Healthy Aging Study (MHAS). It was computed as a continuous score (0 to 100) containing health-related components (ADL disability, mobility disability, pain, self-rated health, and cognitive function), and psychosocial components (mood, productive activities, social relations, life satisfaction, and self-mastery). Mean scores on aging well were 80 among Canadian older adults and 59 among Mexican participants. The detailed scores indicate aspects of