

interview transcripts, memos, and interviewer discussions to identify methodological and ethical challenges that arose during the interviewing process. Challenges were identified across all phases of research, and included relational concerns with PLWD and family members due to disclosure of sensitive information, risk of re-traumatization in discussing past experiences, multiple roles of caregivers with conflicting perspectives, variable recall capacity, limited prior appraisal of caregiving, and request of interviewers for medical advice or selecting services. We outline events evidencing these challenges and proposed strategies (i.e. use of research consults, interview debriefing) to strengthen research capacity to anticipate and respond to them.

PREDICTORS OF PARTICIPATION RESTRICTION IN MIDLIFE CAREGIVERS: AN EXPLORATORY STUDY

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Mid-life family caregivers (CGs) are at risk for participation restrictions (reduced engagement in valued roles and activities) due to competing demands of work, parenting, and family caregiving responsibilities. When CGs experience participation restrictions, quality of care for care recipients (CR) decreases, yet CG burden and risk for poor health increases. The purpose of this study was to identify the factors contributing to decreased participation in mid-life CGs. Participants were CGs aged 45-64 years (n = 677) from the National Study of Caregiving/National Health and Aging Trends Study. We used multivariate logistic regression to determine attributes of CGs, CRs, and the care situation that independently contribute to participation restrictions. We found that negative aspects of caregiving (OR = 1.51, 95% CI = 1.33, 1.71) and CR depression and anxiety (OR = 0.90, 95% CI = 0.83, 0.99) significantly predicted participation restrictions (p < 0.05). Positive aspects of care (OR = 0.87, 95% CI = 0.74, 1.01), frequency of helping with chores (OR = 1.30, 95% CI = 0.98, 1.70), frequency of providing personal care (OR = 1.24, 95% CI = 0.97, 1.59), and frequency of providing help getting around the home (OR = 1.30, 95% CI = 0.97, 1.75) showed trends for association with participation restrictions (p < 0.10). We identified factors that are related to participation restriction in mid-life CGs. Some of these factors (e.g., positive and negative aspects of caregiving, frequency of assistance provided) are potentially modifiable intervention targets that could bolster participation in this at-risk group.

Session 3540 (Symposium)

FRIENDSHIP AND LONELINESS AMONG PEOPLE LIVING WITH DEMENTIA: TOWARD COMMUNITY AND SHARED HUMANITY

Chair: Daniel R. Y. Gan

Co-Chair: Habib Chaudhury

Discussant: Jim Mann

An increasing number of people living with dementia (PLWD) age in community. In North America, this number ranges from 61-81% of the total number of PLWD. As many

as one in three PLWD do not live with a care partner. Since most PLWD do not drive, many may spend a significant proportion of time within half a mile of their homes. Yet, the neighbourhood may or may not provide “ways of being in the world that are more accepting and embracing of the kinds of disruptions that dementia can produce” (Hillman & Latimer, 2017). To support continued social participation, meaningful everyday networks are required. PLWD and care partners may identify more or less strongly with a community depending on their position in the network, its spaces, and activities. According to Nancy (1991), “community” has been conjured as an antidote to the loneliness of the human condition, which explains its allure. In response, Costello (2014) argued that “community” requires one to constantly try and “fall short” in caring for another’s changing experiences. The value of a community thus depends on the quality of its friendships – the ability of otherwise lonely individuals to empathize – which may be threatened by challenges to PLWD’s personhood. This symposium brings together expertise in community gerontology, philosophy, and neuropsychology to advance current conceptualizations of personhood in community amid cognitive decline. These will be discussed in relation to lived experiences, with the aim to inform future research and practice of dementia care and prevention in community.

AT-HOMENESS: RETHINKING PERSONHOOD-IN-COMMUNITY THROUGH THE LENS OF SOCIAL IDENTITY

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Since Chaudhury’s seminal work (2008), spatial ethnographies of the everyday lives of people living with dementia (PLWD) have proliferated. From an experiential perspective, geographies of home (Blunt & Varley, 2004) and geographies of dementia may overlap significantly. We conducted a meta-ethnographic synthesis of n=28 articles to identify points of convergence and divergence in these literatures using comparative thematic analysis with NVivo 12. Whereas geographies of home highlight at-homeness (e.g., ontological safety and daily activities), geographies of dementia underscore communal and civic participation (e.g., social relationships). These themes converge around “social identity” which may be an important construct that helps PLWD feel at home. The quality of life of PLWD in the community may be influenced by prior (and present) experiences of at-homeness. These become more pertinent as older adults shelter in place. We discuss the implications of these findings in relation to relational models of personhood-in-community (Swinton, 2020) and community gerontology.

MUTUAL RECOGNITION: EMPATHY AS THE FOUNDATION OF COMMUNITY IN DEMENTIA

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This paper explores the challenges of developing a healthy, genuine community as some of its members experience cognitive decline or dementia. I draw upon philosophical discussions on community (Stein, 2000) and Husserlian empathy