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The Journal's 10 year anniversary - looking back and moving forward

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The Journal's 10 year Anniversary – Looking back and moving forward

Dementia

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This issue marks the 10th year of the Journal, whose guiding mission has been, “To provide a major international forum for social-behavioral research and practice that has direct relevance on improving the quality of life (QOL) and quality of care for people with dementia and their families” (Keady & Harris, 2002). For where the main focus of biomedical research has been on the cause of dementia, the focus of social-behavioral research is on the consequences of living with dementia. On a daily basis, persons with dementia and their family members must face alone and together this “lived experience,” with its ever constant changes, surprises, challenges, disappointments, and sometimes rewards; and most of all they must learn to cope. Social-behavioral research can help.

Pearlin et al. (2001) identified five research domains essential for future social research on the consequences of dementia: 1) the person with dementia, 2) the family and household, 3) the physical and social environment, 4) effective services and interventions, and 5) directions for health policy. This schematic was presented as a heuristic device to stimulate thinking about future research. Over the years, this Journal has played an important role in publishing articles that further deepened our understanding in all five recommended research areas. Reviewing the Journal’s last 10 years of publications, below are just a few examples of articles that reflect research in each of the domains.

Articles in the Journal have increased our understanding of the “inner worlds” of both the person with dementia and their care partner. Articles that explored “the inner world” of people with dementia were ones such as: 1) the very first paper published by the Journal, Sterin’s (2002) eloquent personal essay on how being diagnosed with dementia and the stigma that entailed, forever changed one’s social interactions and self-concept; Krause’s and Moyer’s (2006) discussion on how her diagnosis spurred them into becoming advocates for people with AD, and the meaning such work has brought to their lives; and Fazio’s and Mitchell’s study (2009), which demonstrated through evidence from remaining language and visual recognition that the self of the person with Alzheimer’s disease persists along the journey, expanding the work of Steven Sabat (2001). Each article and many others deepened our understanding of the lived experience.

A few notable articles about the “inner world” of carer experience were: 1) Weyl’s (2009) description of her journey with her husband Peter diagnosed with AD, as she loves and cares for him, and copes, recorded in a memoir, entitled, “Love song at the end of the day”; 2) Aubeeluck’s and Buchanan’s (2006) article that captured the Huntington’s disease spousal carer experience, a group that is often forgotten, using the methodology of photovoice. This study visually presented the carers’ quality of life, encompassing loss, loneliness, neglected needs and desire for escape; and 3) one of the most unique articles published over the years,

an article (and accompanying Editorial) by Parker, Young and Rogers (2010) in which a Deaf daughter described her Deaf mother's experiences with dementia, focusing on the problematic nature of recognizing dementia amongst Deaf people and the lack of appropriate diagnostic, care and support services. For Jacqueline Parker's mother to die in an environment where she was not understood and where no specialist services existed to interpret her communication and language is a reality which should stop us all in our tracks and ask the most searching of questions. These articles plus so many of other published in the Journal expanded our understanding of the care partner's perspective and their varied service needs.

In the realm of physical and social environmental effects on people with dementia, there were published studies such as: 1) the research by Cloffi, Fleming, Wilkes, Sinfield, and Le Mlere (2007) where through conducting focus groups with families and staff, researchers were able to document positive changes in behavior and functioning of residents in a special care unit when smaller more home-like units were initiated; 2) Van Hoof's and Kort's (2009) concept paper on designing a dementia friendly home in terms of architectural features, interior design, the indoor environment, and technological assistive devices all to facilitate people with dementia to remain independent and in their own homes as long as possible; and 3) Davis, Byers, Nay, and Koch (2009), who in their article argued that it is the lived experience of people with dementia that should guide the building of residential facilities suggesting seven living experiences to be considered in architectural design: eating, bedroom, family and community connections, personal enjoyment, staff, and end-of-life experiences.

As relates to service and intervention studies to improve quality of life and quality of care, the Journal published research such as: 1) Tremont's, Davis', Bishop's, and Fortinsky's (2008) randomized control pilot study on a new accessible and low cost telephone psychosocial intervention to reduce caregiver burden, which showed much promise; 2) Hicks-Moore's and Robinson's (2008) randomized control study on the use of hand message and music to lessen agitation in nursing home residents, where the data demonstrated some significant results; and 3) Malone's and Camp's (2007) work on Montessori-based dementia programming with residents in various institutional settings that used individually designed every day type activities, based on a person's past interests, which positively reinforced remaining skills.

In the domain of health policy, articles such as: 1) Wilkinson's and Weaks' (2008) editorial on the collaboration between Scottish policy makers, researchers, practitioners, people with dementia, and their families demonstrated how meaningful policy that impacts quality of life can be co-created; 2) Iliffe's and Manthorpe's (2007) discussion of England's National Institute of Health and Clinical Excellence and the Social Care Institute for Excellence guidelines on providing quality dementia care provided a insightful review and critique of a national policy, one of the few national policies on dementia care; and 3) Cayton's (2004) use of narratives as a way to inform and question the choices and challenges societies must make as they struggle to care for and develop policy to protect the rights and dignity of people with dementia.

So, yes, over the last 10 years the Journal has published articles in the five major domains of social-behavioral research and pushed the knowledge base further, and yet the Journal has done more than that. The Journal has also focused on the needs of special groups within the dementia population, who get little attention. The Journal published special issues devoted to people with intellectual difficulties affected by dementia, issue 4(4), and people with dementia at the end-of-life, issue 8(3). In addition, the Journal has advocated for moving

beyond the person-centered paradigm of care to a relationship-based center of care (Adams & Gardiner, 2005; Harris & Keady, 2006; Nolan and Keady, 2007) and recognized the importance of having people with dementia and their families more involved in the co- construction of research (Keady, Williams, & Hughes-Roberts, 2007; Mckillop & Wilkinson, 2004), and programs and product development (Orpwood, Bjerneby, Hagen, Maki, Faulkner, & Topo, 2004). And the Journal gave a forum to researchers and health care practitioners who questioned from epistemological, ethical and semantic perspectives the wisdom of clinically using the widely accepted term, mild cognitive impairment (Whitehouse & Moody, 2006). Work undertaken by Jo Moriarty on the Innovative Practice section and Heather Wilkinson on the Book Reviews section (and prior to this Sue Hahn) have made significant contributions to the field and our thanks to them and all contributors over the years.

But where does the Journal go from here? Our role as social behavioral scientists is to continue asking critical questions that challenge strongly held assumptions and develop new conceptual models about how best to measure, treat, deliver service, and care for people with dementia and their families. The Journal needs to continue its role as being an open forum to discuss cutting edge ideas and an arena to present data that test and re-test accepted and proposed interventions that have the potential to improve the quality of life and quality of care for people with dementia and their families. For as one man with dementia once told one of the editors, "I'm dying with Alzheimer's disease. I know that...What you need to do –what they [researchers] need to do – is help me figure out how to live with it" (Harris, 2002, xiii).

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