Foreword

Public awareness of the silent epidemic of Alzheimer’s disease (AD) and related disorders has steadily grown over the past three decades. Ironically, however, the voice of the person with dementia has been one of the last to be heard. The shift in clinical and public interest to earlier stages of cognitive impairment (e.g., mild cognitive impairment) has opened public discourse to include a greater number of affected individuals in expressing themselves. All practitioners dedicated to a holistic approach to Alzheimer’s and related disorders recognize the paramount importance of listening to the individual at the heart of the matter.

In this book, the editors (Cordula Dick-Muehlke, Ruobing Li, & Myron Orleans) have assembled a collection of “Psychosocial Studies of the Individual’s Changing Perspectives in Alzheimer Disease” by a group of international experts from the United States, United Kingdom, China, Spain, Sweden, and Germany. This body of work is timely and much needed. The primary focus of this book is not on the pathophysiology of Alzheimer disease, its psychosocial impact on caregivers, or its economic impact on society.

Rather this book focuses on the perspective of individuals affected by dementia. To accurately represent the voice of persons whose ability to remember and communicate may be compromised requires a special level of dedication and expertise. Information is gathered from interviews and transcripts by professionals trained in rigorous phenomenological methods (see chapters by Heins & Dick-Muehlke; MacKinlay & Trevitt; Lu & Austrom; Toms, Lawrence, & Clare) to best ensure accuracy and authenticity.

From the viewpoint of a neurologist, the toll that AD takes upon specialized neuronal networks is selective. Memory, language, visual-spatial, and executive systems are affected in a progressive manner corresponding to the loss of synapses, spread of neurofibrillary tangles, and neurodegeneration. In AD, the primary motor/sensory and the social salience systems are relatively spared. At the present time, little is known, using objective methods (e.g., fMRI, qEEG, MRI, DTI), about deleterious effects on brain networks that govern awareness of the various aspects of self (e.g., identity, attributes and beliefs, social persona, autobiographical self, and internal visceral states).

Data from interviews using phenomenological methods, suggest that self-identify and concept are relatively preserved, at least until the later stages of dementia (Toms, Lawrence, & Clare). Quantitative analyses of pronouns and self-attributes in language have been used to assess degree of self-awareness across stages of cognitive impairment (Fazio & Mitchell). In the absence of knowledge otherwise, we must assume that some sense of self persists, still to be honored, upheld, and respected as personhood.

Biomedical models are oriented to finding a biological treatment (“eure”) for pathological processes (i.e., abnormal physical and physiological changes) in the brain (Galvin & Kelleher; Sharon). Importantly, these models shed limited insight on what is experienced at the individual or personal level (Power).
Alternative frameworks are needed to better understand and support (“care for”) the personhood of the individual, who is experiencing a multitude of biological, psychological, and social changes. Medical education programs typically use biomedical models of disease to train clinicians. As the number of persons with progressive cognitive impairment continues to grow, clinicians must also employ psychosocial models to better serve patient needs.

This book outlines several frameworks or models to better understand and support an individual’s perspective and experience. These include ethnographic (O’Connor & Beard), spiritually oriented (MacKinlay & Trevitt), processuality (von Kutzleben & Panke-Kochinke), and psychologically minded (Toms, Lawrence, & Clare) approaches, as well as an experiential model (Power), levels of awareness (Toms, Lawrence, & Clare), and the life-world perspective plus theory of intentionality (Svanström). Ideally, such frameworks will help clinicians and care partners better understand where an individual is “coming from existentially.” The act of understanding (i.e., being heard or known) is, in and of itself, a measure of validation. This type of understanding may also add an important dimension to interpersonal and social interaction, as well as to problem solving and intervention.

As social beings, our self-concept is influenced significantly by the attitudes others hold toward us. While it may be politically expedient to broadcast the tragic loss of memory, independence, and self associated with AD, these messages may unintentionally lead to increased stigma, anxiety, and under-valuation of persons so labeled (O’Connor & Beard; Svanström). Our attitudes, actions, and engagement can improve an individual’s experience and sense of well-being, even in the later stages of dementia. We are reminded not to overlook or forget the strengths, skills, wisdom, dedication, and love that remain.

Organized programs such as self-help groups (von Kutzleben & Panke-Kochinke), spiritual reminiscence (MacKinlay & Trevitt), dyads to enhance meaningful activities (Lu & Austrom), and art therapy (Navarro-Prados, Díaz-Orueta, Martin-Niño, & Sánchez-Sánchez) are designed to engage the individual as a participating partner. Strategies are more likely to be effective when they are customized to the individual’s ethnography, social location, and biography (O’Connor & Beard). This customization requires time and effort to discover the background and social circumstances of each individual.

New skills can be developed to improve the experience of persons with dementia. Care partners can be taught to overlook weaknesses in verbal semantics and inherent logic, and to focus instead on identifying emotional and personal concerns using other behavioral clues. When individual perspectives are unclear or discordant, Card and Wang suggest the use of “play” (in the sense of suspended judgment, imagination, and fun) to enhance the quality of interpersonal interaction. Promoting an individual’s sense of self-efficacy in tasks of daily living through compensatory strategies and use of technological aids may significantly improve sense of well-being (Park). In more advanced stages of dementia, training staff to observe awareness at the sensory and perceptual level may improve quality of care (Toms, Lawrence & Clare).

Findings from treatment studies, including Selbstbestimmung und Intervention (SEIN), Daily Enhancement of Meaningful Activity (DEMA), and the Memory Impairment and Dementia Awareness Study (MIDAS) are reviewed. Most of these studies use qualitative research methodologies, since many of the relevant outcomes are difficult or impossible to quantify at the present time. A few randomized controlled intervention trials are described (e.g., AwareCare, an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings). Demonstrating the effects of various treatment interventions on the experience and perspective of persons with dementia remains a challenging research arena.
It is a personal honor to be invited by Dr. Dick-Muehlke to offer my perspectives as a behavioral neuropsychologist, clinical investigator, and director of a federally funded Alzheimer Disease Research Center at the University of Southern California. As a recurring highlight of our biannual “Many Faces of Dementia” conference for health professionals, Dr. Dick-Muehlke has facilitated a panel discussion by persons with dementia and their care partners. As demonstrated in the chapter written with Steve and Gincy Heins, she upholds the voices of persons who courageously walk a journey not of their own choosing.

This collection of essays from internationally acclaimed psychosocial experts in dementia takes these individual perspectives to a much deeper level. Collectively, the authors provide a comprehensive review of the literature and ongoing research studies, outline a wealth of approaches/models to better assess and understand individual perspectives and experience, and offer therapeutic frameworks that are responsive to individual well-being and quality of life. We thank and congratulate the editors and authors for this compassionate, humanitarian, and scholarly contribution to the field.

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