PERSON-CENTERED MEMORY *and* COMMUNICATION INTERVENTIONS *for* DEMENTIA

A Case Study Approach

Medical Speech-Language Pathology

Series Editors

Kristie A. Spencer, PhD, CCC-SLP

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Person-Centered Memory and Communication Interventions for Dementia:
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Contents

Series Introduction

The Medical Speech-Language Pathology book series provides graduate students, clinicians, and clinical researchers with functional, comprehensive material to enhance practice in a medical setting. The books are designed to bolster transdisciplinary knowledge through infusion of information from neurology, pharmacology, radiology, otolaryngology, and other related disciplines. They capture our current understanding of complex clinical populations, often encountered in medical settings, and offer information to guide evaluation and management strategies. For each clinical population, case studies are used to promote application and integration of the material. Moreover, the handbooks are richly supplemented with figures, tables, and patient samples to enhance accessibility of the information. Each book in the series is authored by experienced professionals and content experts who are able to transform the research literature into clinically applicable and digestible information. The authors integrate theory and practice in a succinct manner, allowing immediate application to everyday practice. This book series advances the medical speech-language pathology community by merging fundamental concepts, clinical strategies, and current theories with research evidence, with the goal of fostering outstanding clinical practice and clinical research.

The first book of the series set the stage regarding the environment of the medical SLP as an interprofessional team member, the clinical populations encountered by the SLP, and the foundational knowledge needed to understand and interpret neuroimaging, medication influences, and infection control precautions.

The second book of the series is an invaluable resource on the frontotemporal dementias (FTDs) and primary progressive apraxia of speech (PPAOS). It is a cutting-edge tutorial that encompasses differential diagnosis, clinical examinations, speech/language/cognitive assessments, neuroimaging findings, and treatment recommendations.

In this outstanding third book of the Medical Speech-Language Pathology Series, the authors have brilliantly harnessed their extensive clinical and research experience with people with dementia, and created a novel, compelling, and practical resource. Their case-based approach puts the life of the person with dementia at the forefront. Through this personalized lens, the authors walk the readers through the clinical journey, sharing distinctive information about the background, disease presentation, approach to assessment, environmental influences, and treatment goals for each individual case. They contextualize the case information with rich details, highlighting the challenges and complexities of a diverse series of clinical scenarios. Assessment and treatment approaches are anchored in evidence-based and theoretically sound practice, while the importance of culturally responsive care and meaningful engagement is elevated. A wealth of treatment guidance is provided, with first-hand examples of how to effectively implement low-tech and high-tech memory/communication aids, spaced retrieval training, Montesorri-based organizational level interventions, caregiver trainings, and so forth. The practicality of the clinical guidance is effectively enhanced by materials on the PluralPlus companion website, including photos, forms, and screening tools. Centering their practices on the dignity and empowerment of individuals with dementia, the authors reframe and reconceptualize the traditional clinical approach. The result is an invaluable resource for clinical and scientific practice to best serve individuals with varied dementia syndromes.

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Acknowledgments

This book represents our deep passion for the personhood and individual identities and differences of each person we have met with dementia. It also illustrates our hope for people with dementia to live their remaining life with quality and dignity. We acknowledge the many resources available to support both speech-language pathologists and families of people with dementia, and we hope this book contributes to that literature. Our goal was to incorporate the work of pioneers and mentors (e.g., Michelle Bourgeois, Jennifer Brush, Cameron Camp) with our own clinical and research experiences in a framework of person-centered care. We also aim to provide hard-working clinicians with relatable examples and usable tools.

We are exceedingly grateful for each reviewer who provided such rich, constructive comments about the manuscript. We are so appreciative for your contributions!

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This book is dedicated to all people with dementia whom we have served and will serve, to every direct care worker tirelessly supporting people with dementia, and to every family member wrestling with what it looks like to see a loved one live with this syndrome. We see you and we honor your journeys.

CHAPTER 1

Introduction

PURPOSE AND KEY CONCEPTS

The purpose of this book is to bring to life ideas for evidence-based, person-centered interventions for persons with dementia and their care partners. Implementation of evidence-based practice is a challenge in healthcare in general. Based on our own clinical and research experiences, we recognize the challenges in dementia care. This chapter introduces a variety of key concepts that will be applied throughout the eight cases presented in this book. The eight chapters on cases emphasize each person and how person-centered assessments were completed to prepare person-centered interventions that capitalize on preserved skills, ability to learn, and prepared environments. Specific examples of cognitive and communication strategies are provided both in the chapters and in the accompanying PluralPlus companion website.

Throughout the book, we present diverse cases in terms of racial, cultural, and linguistic backgrounds, as well as various etiologies of dementia syndromes and contexts. We wish to emphasize that this is not a book about diversity, per se, but rather a book about people, and people are diverse. By embracing personal backgrounds, we demonstrate how person-centered interventions can be used to promote functioning, participation, quality of life, and ultimately personhood in people with dementia. We understand that there are implementation barriers in every context, so we address those barriers with hopes of inspiring clinicians to be creative in working through those problems. The solutions we describe might not exactly fit the context in which other clinicians work, but the aim is to see possibilities in the challenges. The final chapter provides a summary of key issues across the cases, a look at equity and inclusion through the lens of the cases, and a message of empowerment.

Personhood and Person-Centered Care

Over the past several decades, there have been many calls for culture change in long-term care and in dementia care. The rise of person-centered care for persons with dementia stems from the work of Kitwood (1997; Kitwood & Bredin, 1992), a psychogerontologist. He defined human beings as social beings who bestow personhood upon each other in the context of relationships. Person-centered care requires that we recognize the personhood of people with dementia, despite their difficulties in communicating their self-concept and identity. When people stop acknowledging the personhood of those with dementia, the consequences can be harsh, such as loss of social roles, social isolation, and objectification (Alsawy et al., 2020). In contrast, Kitwood urged care partners to recognize the personhood of those with dementia and to provide care that promotes dignity, respect, choice, self-determination, and purposeful living. We believe that such care would emphasize the person's strengths, promote purposeful living, and support the person in participating in decisions about their own life.

Calls for culture change have continued across the decades since Kitwood's work and have led to the development of more "home-like" long-term care models, such as the Eden Alternative, Wellspring, Pioneer Network (Robinson & Gallagher, 2008), and Montessori for Ageing and Dementia (Bourgeois et al., 2019). These models aim to increase engagement and interaction and decrease the behavioral and psychological symptoms of dementia (BPSDs) by providing a prepared environment, recognizing strengths, and encouraging meaningful engagement (e.g., Bourgeois et al., 2015; Robinson & Gallagher, 2008). Yet, there are still challenges in providing care that promotes personhood, so champions for people with dementia continue to shout the call for better care that promotes human rights and quality of life (e.g., Camp, 2019; Young et al., 2019). Throughout this book, we will advocate for person-centered care, as illustrated through the cases (for more extensive detail, see Hickey & Bourgeois, 2018).

Increasing Diversity of the Aging Population

Researchers, clinicians, and policymakers have been discussing the aging of the population for years and with it the significant rise in prevalence of dementia, calling these phenomena the "aging tsunami" or "gray tsunami" or "dementia tsunami," terms that may actually continue to perpetuate ageism and negative attitudes toward aging (Calasanti, 2020). Here we provide some information about the aging populations in the United States and then Canada, but note that these trends are happening in many other countries as well. According to the U.S. Census Bureau, 16% of the population were seniors in 2018; by 2030, the Baby Boomer generation (currently ~73 million people) will be at least 65 years old, a turning point in demographics of the United States (Vespa et al., 2020). Furthermore, by 2034, seniors are expected to outnumber children under 18 years for the first time in U.S. history, and by 2060, seniors are expected to grow to about 25% of the population.

Not only is the aging population increasing, but cultural and linguistic diversity is increasing. According to the U.S. Census Bureau, all non-white racial groups have grown faster than the white population between 2010 and 2019; further, the non-Hispanic white population is expected to decrease over time, while all other racial groups are expected to increase (Vespa et al., 2020). The rate of immigration is expected to grow faster than the birth rate so that by 2030, immigration is expected to be a more significant driver of population growth than births in the United States (Vespa et al., 2020). By 2044, people who are of races other than white are projected to comprise more than half of the population (Colby & Ortman, 2015).

In terms of linguistic diversity, hundreds of languages are spoken in the United States, with more linguistic diversity in major cities (Colby & Ortman, 2015). Although there is no official language in the United States, most people speak English. In the top 15 largest metro areas of the United States, around 150 to nearly 200 languages are spoken. The most common languages other than English include Spanish, Chinese, French, Tagalog, and Vietnamese. We must also consider at what age and how people learned the languages they use (e.g., home, community, and/or school), but a review of simultaneous versus sequential bilingualism is beyond the scope of this book.

In Canada, there were more seniors than children beginning in 2016. Seniors accounted for 17% of the population in 2018 and are estimated to account for between 21% and 30% of the population by 2068 (Statistics Canada, 2019). Racial diversity in Canada is growing from both births and immigration, with projections showing continued growth (Morency et al., 2017; Statistics Canada, 2016). In comparing population demographics from 2016 to projections of the demographics in 2036, the population of people who self-identified as visible minorities was 22.3% and is projected to grow to around 32% to 36%. Indigenous Canadians (First Nations, Métis, and Inuit) comprised 4.9% of the population, and that number is projected to rise to between 5.5% and 6.8%. Immigrants and second-generation Canadians accounted for nearly 40% of the population and are expected to grow to 50%.

In Canada, about 20% of the population speaks a language other than the official languages of English or French. Those whose mother tongue is neither English nor French are projected to be around 30% by 2036 (Morency et al., 2017; Statistics Canada, 2016). As in the United States, there is more linguistic diversity in major Canadian cities (Statistics Canada, 2011). The top other languages spoken include Mandarin, Cantonese, Punjabi, Spanish, Tagalog, and Arabic (Statistics Canada, 2011). In both the United States and Canada, there are also many Indigenous languages spoken.

Culturally Responsive Practice

Given the increasingly diverse aging population, we must attend to cultural and linguistic variations of our clients and consider the relevance of various assessment and intervention procedures. Culture is often explained using a metaphor of an iceberg, which has a small part above the surface that is observable and a much larger part that is invisible under the surface (Ting-Toomey & Chung, 2012). Many people think about or are aware of the parts that are observable above the surface when they think about culture, for example, food, dress, arts, dances, rituals/traditions, spirituality/religious practices, symbols, and language. The larger parts under the surface are the more important parts that comprise cultures, for instance, attitudes, beliefs, values, and assumptions. These invisible parts of culture are central to an individual's or a group's identity, for example, attitudes and beliefs toward aging, social status, and child-rearing; concepts of fairness; approaches to problem solving; and notions of beauty, modesty, time, and etiquette.

We learn culture implicitly and do not always reflect on our cultural identities and beliefs or values unless prompted to do so. Our cultural and religious beliefs, values, and assumptions that are under the surface lead to unconscious (or implicit) bias, which can be a barrier to culturally responsive practice (Hyter & Salas-Provance, 2019). Implicit bias is the way that we use assumptions and stereotypes to automatically make judgments or evaluations of a person or situation without being aware that we are doing so. Implicit bias affects our understanding of others who come from cultural and/or linguistic backgrounds different from our own. Thus, critical reflection of our own culture is a necessary first step before examining our awareness and understanding of other cultures and how our clients interact with our assessment and intervention procedures.

Culturally responsive assessment and intervention procedures use procedures that are fair and unbiased. Assessment should include a variety of procedures, including ethnographic observations and interviews (discussed more below) and dynamic assessment to supplement more standard assessment procedures, particularly when the norms for the test do not apply to the client (Hyter

& Salas-Provance, 2019; Nelson et al., 2014). These procedures allow us to understand the client in context and to determine strengths and facilitators that can be capitalized upon in intervention. Culturally responsive interventions use culturally and linguistically relevant stimuli when necessary, as well as honor cultural norms (e.g., for male-female and child-adult interactions) and monitor the client's and family's acceptance of the intervention and make modifications where necessary (Hyter & Salas-Provance, 2019). Bilingual and multilingual clients present additional considerations for the design of treatment plans, including questions around whether to treat in one or more languages. Additionally, translators and/or interpreters may be necessary for translating written materials or interpreting conversations with the client and family.

When we strive for culturally responsive practice, we seek to defeat the forces of institutional and structural racism as well as linguicism that are prevalent in healthcare and lead to health inequities. Racism results from the combination of racial prejudice plus power. Linguicism is a related concept but applies to language prejudice and power (Hyter & Salas-Provance, 2019; Phillipson, 1992). Since McKenzie (2003) argued that countering racism is a public health issue, research has advanced to demonstrate the true public health threat of racism, which can be due to psychological and physiological responses (Williams et al., 2019) and avoidance of healthcare services (e.g., Hyter & Salas-Provance, 2019). Elders who have lived with racism or linguicism for many decades may have impacts on their health, access to healthcare services, or response to intervention procedures. Clinicians must be mindful of how our implicit biases influence our evaluation of their performance and our relationships with clients and families. There is a long way to go in removing structural racism from healthcare (Bailey et al., 2017). Box 1–1 lists a few examples of resources for those who wish

Box 1–1. Examples of Web Resources for Aging and Diversity

- American Society on Aging
    - The Role of Early Life Trauma in Social Isolation: https://generations.asaging.org/adverse-childhood-experiences-trauma-isolation
- U.S. Administration on Aging: A Toolkit for Serving Diverse Communities: https://acl.gov/sites/default/files/programs/2017-03/AoA_DiversityToolkit_Full.pdf
- National Resource Center on LGBT Aging: https://www.lgbtagingcenter.org
- Diverse Elders Coalition: https://www.diverseelders.org
- American Psychological Association
    - Multicultural Aging Resource Guide (includes links to many other resources): https://www.apa.org/pi/aging/resources/guides/multicultural
    - Black Aging Matters—How to better address racism-related stress in African American older adults (webinar): https://www.youtube.com/watch?v=DqvF_7O0lSY
- The Aging and Health Report—Disparities and resilience among lesbian, gay, bisexual, and transgender older adults: http://depts.washington.edu/agepride/wordpress/wp-content/uploads/2012/10/Full-report10-25-12.pdf
- Rainbows of Aging: http://www.rainbowsofaging.org/
- Center for Cultural Diversity in Ageing: http://www.culturaldiversity.com.au

to further explore aging and diversity. Please also see the PluralPlus companion website for examples of resources for general anti-racism practices.

Flip the Rehab Model

The Flip the Rehab model, conceptualized by Bourgeois (2014a; Bourgeois, Brush et al., 2016; Hickey & Bourgeois, 2018), is one approach to person-centered care for persons with dementia; this is the approach that is illustrated through the eight cases in this book. This model derives from the Living with Aphasia: Framework for Outcomes Measurement (A-FROM) approach for people with aphasia, which encourages speech-language pathologists to begin treatment planning by identifying the desired outcomes with an intervention focus on life participation (A-FROM; Kagan & Simmons-Mackie, 2007; Kagan et al., 2008). The A-FROM was informed by the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001). The Flip the Rehab model adapts the A-FROM to promote life participation for persons living with dementia (Figure 1–1) and keeps the person living with dementia at the center of our thinking and care processes. This framework considers the severity of cognitive and related impairments, participation in life situations, the communication environment (social and physical),

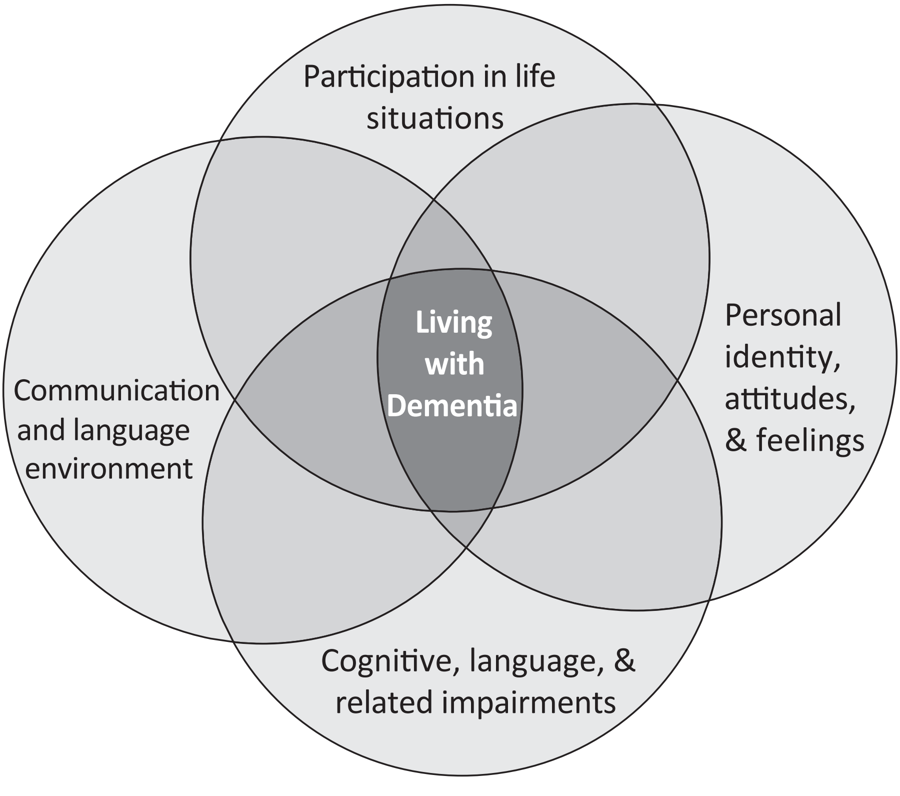

Figure 1–1. Living with Aphasia: Framework for Outcomes Measurement (A-FROM; Aphasia Institute, 2008; Kagan & Simmons-Mackie, 2007; Kagan et al., 2008) adapted for the Flip the Rehab model. Graphic used with permission from the Aphasia Institute.