Preface

The burgeoning literature on Alzheimer’s disease (AD) and the related dementias focuses predominantly on the process of cognitive decline and its negative impact on the individual, family, and society as a whole. In this volume, we challenge this negative orientation to AD, the related dementias, and mild cognitive impairment (MCI), a high-risk pre-dementia state. The biomedicalization of AD, starting in the 1970s, has resulted in a narrow understanding of dementia that stigmatizes and diminishes affected individuals and, consequently, their families. In this collection of essays, our authors broaden this limited biomedical conceptualization, bringing to light the continued personhood of individuals with dementia, evident in a myriad of ways throughout the course of the illness.

What the literature lacks to a great extent and we seek to rectify in this collection of essays is an understanding of the persistent and transformative levels of meaning in the inner life of persons affected by MCI, or AD or another dementia. The premise of our work is that the contents of the affected person’s interior world persist even as they become increasingly fragmented. This book is one of the few works the reader will find that strives to provide a balanced and realistic view of the essentially human dimensions of dementia.

We, the editors, assert that this book makes an important contribution to the field by providing a single convenient source of studies that seek to penetrate the human experience of MCI and dementia. In fact, the lack of effective medications to prevent or slow MCI as well as AD and the related dementias makes the effort to better understand how people experience these conditions critical. An in-depth understanding of how the individual experiences cognitive impairment is central to effective person-centered care that empowers the individual to function at his or her best and minimizes reliance on psychotropic medications. Out of a deep appreciation of the person arise personalized and compassionate responses that can reduce distress and enhance quality of life, thereby helping mitigate some of the negative consequences of dementia.

The book is designed to invite a range of readers to engage its messages and evaluate how the materials presented may be useful in generating future research, more informed practice, and more enlightened care. Specialists in biomedical aspects of AD will gain an appreciation of the subjective experience of affected individuals and the multiple ways they adapt to the threats that cognitive impairment poses, particularly to the integrity of the self. Psychologically oriented researchers and practitioners will be reaffirmed in their commitment to humanize and tailor their interventions. And, care providers will be supported in their efforts to improve quality of life in those they care for through innovative approaches such as “playful” communication.

Additionally, perhaps those moving along the path of MCI and dementia will gain hope, feel solidarity with the affected individuals who share their experiences throughout the essays in this collection, and
find self-affirming ways to adapt to daily challenges. As well, we hope that caregivers will find some measure of comfort and even much-needed encouragement through the knowledge and skills they gain from this volume. Many chapters in this book offer practices that can be implemented by professionals and/or family caregivers. In particular, the authors explore ways to facilitate interactions between caregivers and persons with dementia that are self-affirming and as such lead to positive outcomes (e.g., reduced distress and increased self-esteem).

A HUMAN DISEASE

AD and other dementias, as well as their precursor, MCI, affect most deeply what defines us as human: our consciousness, our selves, our identities, our connection to our past and contemporary experiences, our social actions, and our affiliations with others. Unless we struggle to adequately comprehend what is going on inside cognitively impaired individuals, they become increasingly lost to us and separated from our concept of the human person. The pathos that fills the lives of close caregivers as they watch cognitive decline progress can generate growing distance, deepening feelings of loss and frustration, and utter exhaustion. As dementia advances, the affected individual is increasingly estranged from the former inner being, from the changing self, and from the social surround. Our work suggests that this alienating process between the caregiver and the care recipient can best be remediated by efforts to rehumanize the cognitively impaired individual.

There is no doubt that AD is a shattering experience for those affected and their caregivers. Andrew, an individual with AD who participated in one of the lead editor’s panel presentations on the experience of living with dementia, described the impact of receiving the diagnosis as follows:

[The] doctor told me you have AD; that fractured me. It was traumatic. . . . It's still shocking. [I] haven't overcome the shock of the diagnosis yet even though it's been three years.

Exacerbating the familiar cognitive, behavioral, and physical challenges of AD is the diminishing capacity of affected individuals and caregivers to communicate their experiences, needs, and intentions to each other. The dimming of the self as previously known may be perceived by the caregiver as a barrier that is both imputed and existential. Caregivers who knew the affected individual prior to the diagnosis, even intimately, do not necessarily know who that individual is becoming, and the person may not fully comprehend what’s happening inside. Yet in order to meet needs, each must at least approximate knowledge of the self and the other as best as possible under ever-changing conditions. We submit that the most constructive approach for all concerned is to recognize the meaning world of the person with dementia as a subject of study and a tool for enhancing care.

PSYCHOSOCIAL STUDIES

Specialists in the cognitive disorders of interest (i.e., MCI, AD, and other dementias) write the chapters in this book from a particular perspective (e.g., psychosocial, philosophical, and biomedical). As the editors, we take a psychosocial approach, viewing the process of dementia in terms of the inner changes experienced by the person in the context of a lived existence. We see the individual’s experience as
influenced by (a) neurophysiological alterations, and (b) the social-psychological environment, which in combination affect all aspects of the inner person and external connections.

Our goal is to help refute the widespread stigmatizing perception of dementia as a tragic condition characterized solely by decline, deterioration, and loss. Psychosocial perspectives on dementia offered in this book challenge readers to balance this negative model of dementia with alternative conceptualizations that integrate the lived experience of affected individuals. Holistic, person-centered conceptualizations offered by the contributing authors reveal that life with dementia is much more complex and varied than popular stereotypes (e.g., “living death”) suggest. As well, our studies emphasize that the behaviors of people with dementia are most usefully interpreted as adaptations that sentient humans make in the face of neurocognitive changes and an interpersonal environment that is either self-diminishing or self-affirming.

Importantly, even emotional outbursts, apparent expressions of confusion, silences, and withdrawals can be seen as adaptive and reasonable responses to the illness and the interpersonal environment in which it is experienced. Caregivers who learn to compassionately interpret confused communication or behavior and respond accordingly, as encouraged by our authors, can help loved ones manage life tasks not only more appropriately and competently, but also in a self-affirming manner. Thus, our collection seeks to provide some insights and strategies to support caregivers in managing the daily challenges of care.

The central purpose of this collected work, however, is to search for retained and transformed elements of personhood. We ask the reader to momentarily suspend the conventional predisposition toward negativity, as difficult as this is, and focus on the contents of the waning intentional mind of the person with dementia. What are we specifically looking for? We are trying to bring to the fore levels and modes of consciousness in persons with dementia and dissect what is happening to the individual, the social self, and personal identity as the cognitive impairment progresses. Hence, our contributors seek to map out the interactions of persons affected by dementia with the world around them and analyze how these individuals struggle to make their way in their daily life contexts. It is these psychosocial aspects of dementia that constitute the focus and substance of this book.

PHENOMENOLOGY OF DEMENTIA

In scholarly terms, the chapters in this book take an essentially phenomenological approach to investigating the meaning structures of cognitively impaired persons during the course of MCI, or AD or another dementia. Phenomenological investigation asks the analyst to study states of consciousness in relation to social engagement. This orientation substantively focuses on how the intentions of actors and reciprocal interpretations of meanings produce social relationships. The particular challenges in a phenomenology of dementia are the apparently dimming consciousness and fading cognitive capacity of affected individuals plus the distanciation of their caregivers, making it difficult for the dyad to access each other’s meaning structures. The diverging constructive process is mutual: To the caregiver the cognitively impaired loved one is receding into an unknowable state, while to the care recipient the caregiver becomes increasingly incomprehensible.

Perhaps a phenomenological approach can support the task of constructive re-engagement. Presumably, caregivers reading these chapters will gain insights into the thoughts, feelings, and coping strategies of people with dementia. Such insights might make it possible for caregivers to empathize more fully with the experience of dementia. Concretely, subjective insights could empower caregivers to provide emotional and practical support that both enhances well-being and enables cognitively impaired
Preface

individuals to function maximally in daily life. Moreover, it would not be impossible, depending on individual capacity, for persons with MCI or early dementia to grasp some of the essentials conveyed in these chapters and, therewith, better anticipate and even prepare for cognitive decline. Toward the end of sustaining an ongoing if continually transforming constructive rapprochement between caregivers and affected individuals, such an undertaking as this book is surely a worthy one.

RESEARCH METHODS

The investigational tools used by the chapter authors are varied but essentially qualitative in nature. While huge and well-supported quantitative and biomedical databases on AD are being developed nationally and internationally, few forums exist for a systematic focus on purely subjective, experiential dimensions. Statistical data are provided in many chapters to support qualitative modes of empirical study, but the emphasis in this book is on humanistic means rather than on surveys, systematic questionnaires, and natural science methods. The methods of qualitative research applied by our authors include ethnography, case study, interviewing, observations, and clinical/counseling interventions.

By demonstrating the utility of these methods in the study of dementia, we hope to encourage their use in future research directed at further deepening our understanding of what it means to live with cognitive impairment. Potentially, such research could empower affected individuals and care providers to cope effectively with cognitive impairment and balance, perhaps even correct, the current excessive reliance on purely biomedical and quantitative conventional science in the field.

In this book, we seek to provide a human picture of AD and related disorders for the public, the scientific community, practitioners, clinicians, professional and family caregivers, and affected individuals themselves. By analyzing the alterations of meaning structures in dementia, the contents of this book can help care providers better serve the affected. By improving our approximate interpretations of states of consciousness in AD, we hope that our methods of intervention and treatment will yield more beneficial outcomes. If the chapters offered in the following simply advance shared meanings between caregivers and affected individuals, then this collection can be considered a significant achievement.

CHAPTER ORGANIZATION

We have decided to organize the chapters in four sections as follows: Foundations, Awareness and Identity, Practice, and Daily Life. First, the chapters in “Foundations” establish a framework for the book and provide elemental knowledge about the impact of one’s social context on the experience of dementia, what it means to live with cognitive impairment, cultural differences in the perception and experience of dementia, and biomedical advances in our understanding of AD and related conditions. To wet the reader’s appetite, we also introduce one of many innovative interventions offered by authors throughout the book.

Secondly, the “Awareness and Identity” section draws special attention to the complexity of these concepts in relationship to dementia through four chapters. In addition to a comprehensive review of the awareness literature in dementia, this section offers explorations of (a) identity via language, (b) the self-concept and coping strategies as revealed by self-help group participants, and (c) what art and reminiscence reveal about cognitive decline and identity.
Preface

Thirdly, the three chapters in the “Practice” section advance theoretically and research-based practices designed to help people with dementia adapt to constantly changing circumstances. Innovative practices presented by the authors address spirituality in dementia, the need for meaningful activity in MCI, and misperceptions of people with dementia and their behaviors that limit the ability of carers to provide effective support. Innovative practices addressing each of these, in order, are spiritual reminiscence, the Daily Enhancement of Meaningful Activity program, and an “experiential view” of dementia that emphasizes “expression,” preserved abilities, and opportunities for continued growth despite cognitive decline.

And, finally, the Daily Life section highlights progressive challenges in living that people with dementia face continuously and ways carers can respond to support adaptation. More specifically, the three chapters in this section address the impact of living alone, functional decline, and sleep-wake disruptions on the experience of dementia.

Foundations

Opening our initial section is “Listening to Alzheimer’s: The Role of Social Location in Illness Narratives.” In this chapter, O’Conner and Beard reveal the significance of social location to the experience of dementia. Rather than being universal, the experience of dementia is defined by the social contexts in which affected individuals live. As discussed by the authors, a variety of contextual factors, such as age, race/ethnicity, marital status, and mass media, directly and indirectly influence the person’s distinctive response to dementia. Finally, the authors recommend specific areas of research to clarify how people with dementia interpret and experience their illness.

Our second chapter, “Steve’s Story: Living with Mild Cognitive Impairment,” written jointly by the Heins and Dick-Muehlke, shows, in very personal terms, the uniqueness with which individuals respond to cognitive impairment. We see how Steve perceives and understands his own personal process, and, in line with Beard and O’Connor’s chapter, how contextual factors impact his coping strategies. Finally, through a review of the literature by Dick-Muehlke, we realize the many commonalities of his experience with others affected by MCI or early dementia.

In the third chapter, “Cognitive Decline and the Changing Self in Relationship,” Morhardt and Spira build on the Heins and Dick-Muehlke chapter by looking beyond the individual’s to the family system’s experience of dementia. In another intimate chapter, Peter and his family share their varying experiences of dementia. Dementia, as these authors posit, is not a singular experience. Not only is the person’s self-definition shaped by the history, structure, conversations, and expectations of family members, but the entire constellation of the family is deeply impacted. Dementia reflexively interacts within the family network, certainly testing the resiliency of all involved and inevitably changing the family’s way of seeing and organizing itself.

Moving from the individual to the family system, and then on to culture, the chapter by Card and Wang, “Taking Care to Play: Meaningful Communication in Dementia Care in Chinese Culture” opens the reader’s eyes to the cultural variations in how dementia is perceived and understood, and, therefore, experienced. Through their ethnographic research, these authors creatively translate play therapy concepts to dementia care. More specifically, the authors illustrate and promote “playful” communication strategies as an innovative way of facilitating interactions between caregivers and individuals with dementia.

While this book is directed at the lived experience of dementia, we recognize the importance of readers also having a solid biomedical understanding of MCI, AD, and related conditions. Hence, we
conclude the first section with Galvin and Kelleher’s “Dementia and Other Neurocognitive Disorders: An Overview,” which summarizes the latest biomedical information. The authors broadly review how AD, in particular, and its precursor, MCI, are currently understood, diagnosed, and treated. By including this chapter in the book, we affirm that the best care for people with dementia incorporates psychological, social, spiritual, and biological perspectives.

**Awareness and Identity**

Long-term leaders in this area of interest, Toms, Lawrence, and Clare lead off this section of the book with their chapter, “Awareness, Self and the Experience of Dementia: Foundations of a Psychologically Minded Approach.” In this comprehensive review of their own long-term research on awareness and the self in dementia as well as that of others, these authors overturn negative assumptions of what it means to live with cognitive impairment. Drawing on their current and past work, the authors demonstrate retained awareness as well as a sense of self and identity across the dementia trajectory.

In concert with Toms et al., von Kutzleben and Panke-Kochinke report that the experience of dementia does not constitute a biographical rupture in “Stable Self-Concepts and Flexible Coping Strategies of People with Dementia Attending Dementia Self-Help Groups in Germany: Results from the Qualitative Longitudinal SEIN Study.” Results of their phenomenological and longitudinal study suggest that the self-concept of people with early- to mid-stage dementia remains stable over time although coping strategies vary and include both defensive and protective approaches.

Fazio and Mitchell provide more evidence for the persistence of the self in their chapter, “Self-Preservation in Individuals with Alzheimer’s Disease: Empirical Evidence and the Role of the Social Environment.” These authors (a) discuss their past research, which demonstrated self-persistence in persons with mild-to-severe dementia through pronoun and attribute usage as well as visual self-recognition, (b) explore how care settings (i.e., adult day care and residential care) affect linguistic self-expressions, and (c) review current literature on the self in dementia. Taking these findings together, the authors affirm self-persistence throughout dementia. Importantly, the authors note the impact that malignant social positioning can have on both identity and care.

Closing this section, the chapter by Navarro-Prados, Díaz-Orueta, Martin-Niño, and Sánchez-Sánchez, “Art, Drawing Task Processes, and Identity Awareness: A Case Study on the Retro-genesis Phenomenon as an Indicator of the Progress of Dementia,” explores what a joint drawing and reminiscence program in Spain reveals about both cognitive decline and identity in a pilot sample of four people with dementia. Interestingly, although drawings reflect a cognitive regression, material from the reminiscence sessions demonstrates retained identity.

**Practice**

Here we focus in on the practices that promote intersubjective connections in dementia. Across the three chapters in this section, the authors offer qualitative material that testifies to the continued personhood of individuals with dementia and describe interventions that merit replication. To open this section, we chose a chapter which explores an under-addressed area in dementia, spirituality. In “Spiritual Factors in the Experience of Alzheimer’s Disease and Other Dementias,” MacKinley and Trevitt demonstrate how retrospective and prospective spiritual explorations promote interactions with moderately impaired individuals and reveal their ongoing concern with meaning, connection, and transcendence. Notably, in
their spiritual reminiscence program, the authors generate meaningful interactions that are frequently assumed not to be possible as dementia advances.

Next, Lu and Austrom’s chapter, “Disease Awareness, Cognitive Decline, & Communication in Persons with Mild Cognitive Impairment & Caregivers,” introduces the Daily Enhancement of Daily Activity (DEMA) program, designed specifically for people with MCI and their care partners based on the findings of focus groups and interviews. Utilizing a strength-based, positive health approach that builds on the skills and values of the person with MCI and care partner, DEMA is designed to enhance communication between the dyad and strengthen the ability of the affected individual to self-manage everyday challenges and engage in meaningful activity. Qualitative findings, specific to the experience of MCI, program guidelines, and encouraging outcomes from this pilot study can prove instructive for clinicians and care professionals.

Concluding the third section, Power’s chapter, “Changing Perception in Alzheimer’s: An Experiential View,” proposes a shift in dementia care from the predominant biomedical paradigm to an experiential one which recognizes the changing perceptions of people with dementia and emphasizes preserved abilities and continued growth. Rather than interpreting behaviors pathologically, Power urges the reader to view them in the larger context of expression, which might include, for example, curiosity, empathy, or caregiving. Operating from an experiential paradigm empowers carers to enhance the seven components of well-being – identity, connectedness, security, autonomy, meaning, growth, and joy – among people with dementia. Practitioners will find the suggestions Power makes for responding to behaviors positively, based on the experiential paradigm, particularly helpful.

**Daily Life**

Cognitive disorders such as MCI, AD, and other dementias can make even the simplest daily tasks a challenge to accomplish for the affected individually or even in tandem with a supportive caregiver. Recognizing the widespread impact of dementia on daily life, the last three chapters explore how affected individuals experience functional losses, strategies to maintain independence, and the impact of sleep-wake changes on behavior.

Exploring dementia from the philosophical perspectives of the life-world and intentionality, Svanström begins this section by connecting the reader to the existential plight of people with dementia who live alone in “A Fragmented Existence: Living Alone with Dementia and a Manifest Care Need.” As described in the chapter, six individuals with dementia who lived alone at the time they were observed by the author faced numerous difficulties making sense of everyday objects and routines, and accomplishing daily chores, suggesting a weakening of the intentional threads. Svanström identifies a key role for home care providers in (a) helping situate people with dementia who live alone in the everyday world, and (b) providing the support these individuals need to tighten the intentional threads and, thereby, accomplish everyday tasks more easily.

Next, Park and Busson’s chapter, “The Impact of Decline on Everyday Life in AD,” discusses the importance of identifying early changes in everyday functioning from a diagnostic perspective, but more importantly, for developing personalized interventions that facilitate adaptation and, thereby, improve the experience of everyday life. The authors provide recommendations that support dementia-affected individuals in the successful conduct of daily affairs as their ability to function independently is threatened.

Finally, we close our book with “The Sleep-Wake System and Alzheimer’s Disease” by Sharon. In this chapter, the author describes the impact of aging and AD on the sleep-wake system, with special
attention given to the detrimental effects of sleep disturbances on the daily life of people with dementia. In addition to describing both the sleep disturbances resulting from AD and sleep disorders that can co-exist with dementia, the author reviews treatments and identifies the important role that a sleep specialist can play in the care team.

Our Message

We, the editors of this collection, are proud to present the essays contained in this work. We feel that the reader will be informed, provoked, and encouraged, in particular, by the stories and experiences people with dementia share throughout the chapters. As a result, we hope that the reader will accept our challenge to view MCI, AD, and other dementias holistically, as (a) encompassing the social, psychological, and spiritual as well as biological, and (b) offering opportunities for growth even in the midst of decline.

Again and again, our authors found that the self persists in dementia. We urge our readers to let go of any assumptions about the “loss of self” in dementia and recognize how identity persists and is expressed, given an affirming interpersonal environment. Not only do we urge recognition, we hope that practitioners reading this book will implement practices, such as self-help groups and spiritual reminiscence, which foster expression of the self.

By exploring the subjective experience of dementia, our authors have uncovered the complex ways that affected individuals respond to cognitive impairment within their social contexts. Recognizing that it is natural for people with dementia to fluctuate between acknowledging and resisting the realities of their illness, we encourage our readers to respond with compassion and empathy. Throughout the course of dementia, whether expressed verbally or behaviorally, the reactions of people with dementia to their illness ought not to be pathologized but appreciated as unique, interpreted within the larger context, and responded to from a bio-psycho-social-spiritual perspective that enhances well-being.

We are grateful to our contributing authors and know that they, with us, hope that ultimately our readers will expand their views on MCI, AD, and other dementias, and, as a result, adopt person-centered practices that enhance well-being.

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