Chapter 12
Changing Perception in Alzheimer’s: An Experiential View

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ABSTRACT

In this chapter, the author will explain how the predominant models for viewing Alzheimer’s and other forms of dementia fail to provide an adequate understanding of the changing perceptions of people who live with these conditions and consequently limit our ability to provide effective support. An alternative “experiential” model will be presented and used to reframe several concepts regarding the changing mind. New insights from this model inform an innovative approach to understanding and supporting people whose perceptual mechanisms and communication abilities differ from those of their care partners, and suggest a strength-based framework for enhancing several aspects of well-being, regardless of one’s diagnosis or cognitive ability.

INTRODUCTION

The dominant biomedical model for understanding dementia is a deficit-based view that focuses on disease and decline, characterizing individuals primarily in terms of losses and inabilities. As a result many of the individual’s personal expressions are viewed as manifestations of disease; this has contributed to the overuse of largely ineffective and potentially harmful psychotropic medications (Power, 2010).

An alternative view that has emerged is the need-driven dementia-compromised behavior model (Algase, et al., 1996), which sees many such expressions as attempts to communicate unmet needs, or as reactions to deleterious effects of the living environment. Applications of this model teach the practice of detecting such unmet needs and environmental influencers, and then suggest algorithms for responding to the person through nonpharmacological interventions (e.g., U. Iowa, 2009).

While the need-driven model represents a more holistic approach, and certainly has validity for many forms of distress, it is nevertheless a limited view of the person that has not completely liberated itself

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from the deficit-based biomedical view of dementia. This is partly because such a view continues to pathologize personal expressions and does not recognize the fact that some behaviors may not represent either disease or distress. It also falls short in the manner in which interventions are prescribed, often without truly understanding the experience of the individual in a historical context.

In this chapter, the author will challenge and deconstruct the dominant deficit-based paradigms for viewing dementia, and use an experiential model to show how many of the personal expressions we see reflect novel patterns of processing and communication by individuals who have experienced cognitive change. From these insights, a framework will be offered that provides an innovative approach to preserving well-being, regardless of one’s underlying diagnosis or abilities.

(In this chapter, the female pronoun is used as a referent, reflecting the higher incidence and prevalence of dementia in females.)

BACKGROUND

The dominant biomedical model of dementia that has emerged over the past several decades focuses heavily on dementia as a progressive, incurable, and ultimately fatal disease. We explore the various structural and chemical changes in the brain in exquisite detail and compile assessments that are primarily concerned with deficits—what the person has lost or can no longer do. While these deficits undoubtedly exist, our focus on them creates a one-dimensional view of the person, which explains why many of our responses to her personal expressions are also very one-dimensional.

There are many ways in which a narrow deficit-based view of dementia fails to provide a full picture. One fundamental example is the array of tests that are employed to evaluate cognition. Each assessment tool is comprised of a number of discrete tasks to be performed, relating to various aspects of cognition, such as orientation, short-term word retrieval, clock drawing, calculation, or sentence construction. Each tool reports a score based on the number of such tasks that are performed correctly.

Many such tests have good sensitivity for identifying discrete deficits in cognitive function. However, much of one’s daily actions and interactions involve more complex and integrative thinking than these tests can identify. While deficits in certain areas may lead to impairment in some complex tasks (e.g., memory loss or math impairment affecting timely and accurate bill paying), there are many other integrative skills that are not measured (or often cannot be measured in a quantitative manner), even though they may be well preserved far into one’s life with dementia. Examples of such skills include dispensing advice, teaching an activity (such as knitting or cooking), engaging in art or music, reading to a small child, or providing comfort and consolation to a person in distress. (Representative examples of these abilities can be found in Dijkstra, Bourgeois, Youmans, & Hancock, 2006; DuPuis, et al., 2012; Rosebrook, 2007; Sabat, 2001.)

In discussing our traditional approach to standardized testing, Sabat (2001) remarked, “The natural, spontaneous flow of interaction between people in rich social contexts allows room for the demonstration of abilities that are not assessed or measured in the context of formal testing and research” (p. 268). Earlier in the text, he critiqued language assessments, such as the Verbal Expression Test and the Boston Diagnostic Aphasia Examination, noting: “To infer anything about the Alzheimer’s sufferers’ conversational abilities from such approaches involves a daunting problem of validity, for there is nothing in the test situations that remotely resembles the definition of conversation” (p. 27).