Chapter 3

Cognitive Decline and the Changing Self in Relationship

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ABSTRACT

When a member of a family is diagnosed with Alzheimer’s disease, the impact of the disease reverberates throughout the relationships within the family. This paper explores the challenges and strengths within one family as members manage and cope with Alzheimer’s disease. The person with dementia and his family members are individually interviewed and each person explores the consequences of the disease on personal well-being as well as the relationships within the family. The family demonstrates how dementia in one family member demands flexibility in family roles as they navigate life through the challenges of living with dementia.

INTRODUCTION

Alzheimer’s disease and other dementias impact everyone in the family. There are noticeable shifts in the perceptions members have of one another, themselves, and their relationships. Life experiences are progressively challenged as family members adapt to a new set of circumstances. The struggle to assimilate the diagnosis may push members into reconceptualizing their understanding of the past, present, and future. The consequences of the disease reverberate throughout the family as life decisions are organized around the illness. However, the strength of family relationships seems to be a factor in the ways members meet the challenges created by the disease.

An understanding of relational dynamics is important in order to effectively support the person with dementia and the family. While there has been extensive research on family caregiving and caregiver stress, as well as a focus on the diagnosed person’s needs (i.e., personhood), relatively little attention has been given to the complex family context and the historical perspectives of intertwining familial relationships, inclusive of all identified members of the family.

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In this paper, we explore the responses of members in one family living with dementia. Analysis of individual interviews with family members focuses on changes in the perceptions that each has of themselves and their family relationships.

THEORETICAL PERSPECTIVES

Several frameworks provide an understanding of family responses to dementia. Social constructionist theory proposes that (a) a person’s identity arises out of social interaction, and (b) the role of others’ perceptions is critical in the construction of a person’s social self (Gergen, 1971). While personal identity remains an internal process, the continuity of a person’s identity is dependent on the social relationships within which the person lives.

In the 1970s and 80s, Carl Rogers, a humanistic psychologist, founded the “person-centered” approach to care (Rogers, 1961). Rogers proposed that a person-centered approach, based on acceptance, caring, empathy, sensitivity, and active listening, promotes optimal human growth. In order to actualize human growth in late life, individuals should, according to Rogers (1980), have access to, and opportunities for, ongoing learning, personal challenges, and close and intimate relationships. He argued that human capacity for growth does not diminish with age, nor does the need for growth become less relevant as we age. The emphasis of person-centered care is on well-being and quality of life as defined by the individual (Crandell, et al., 2007).

In the late 1980s, the notion of “personhood” was introduced into the dementia literature as a critical component of the dementia experience and reconceptualized as socially constructed by and within one’s interactional environment. Kitwood (1997), most recognized for pioneering this approach, provided (a) a model of dementia which highlights the interaction between neurological impairment, the psychology of the person with dementia, and the social environment, and (b) strongly advocated for the respect of personhood.

Galazer-Levy and Cohler (1993) attested to the importance of available self objects – relationships – throughout the life course as a means of fulfilling essential needs for validation and emotional nurturance. The authors argued that the strong bonds between parents and children are particularly meaningful over the course of development and throughout later life. This includes the connections between adult children and parents in the context of life experiences and changing needs.

A diagnosis of dementia changes relationships for the diagnosed person and family as social roles and interactions of the affected member are diminished (Ryan, Bannister, & Anas, 2009). These consequences of dementia raise difficult issues that must be resolved for continued emotional well-being. How does the person with dementia continue to assert and explore his/her social identity under these circumstances? How do the partner and family contribute to or threaten the self of the person with dementia in their interactions? How are the couple and family relationships affected by the person’s dementia symptoms and changing self?

The life course perspective takes into consideration how age, relationships, developmental stage, and social issues impact people’s lives over time. This perspective allows us to understand that, for a person with a partner or parent who has dementia, the relationship is foreshadowed by a history of many years. There is interdependence within these lives that are inextricably linked. The experience of dementia in a family is also unique to the developmental stage of the person with dementia and the caregiving