Chapter 13
Fragmented Existence:
Living Alone with Dementia
and a Manifest Care Need

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ABSTRACT

Drawing on prior research by the author, this chapter presents the experience of persons with dementia who lived alone and had a manifest care need. By applying the life-world perspective and the theory of intentionality to the findings, the author broadens our understanding of how people with advanced dementia experience life. More specifically, life with dementia appeared to be characterized by a gradual loss of meaning due to impaired intentionality. Participants faced increasing difficulties in understanding the meaning of the everyday objects and chores, which ultimately affected the sense of space, time, language, and the body. Our findings suggest that persons with dementia fight disturbed intentionality and try to create meaningfulness, an effort that becomes extremely difficult and strenuous over time. Home care that takes everyday objects and chores as a point of departure has the potential to help persons with dementia anchor themselves in the concrete everyday world.

INTRODUCTION

In this chapter, the author focuses on the experience of dementia when the person is living alone with a manifest care need. The perception of what dementia means for those affected has evolved over time. During the 1990s, the concept of personhood emerged (Kitwood, 1997), broadening the understanding of dementia from the predominant biomedical perspective. Since the early 2000s, the voices of persons with dementia have begun to be heard. Both stories from persons with dementia and research present the image of a person well aware of the diagnosis and what it entails as well as the struggle to keep the self intact (Clare, 2003; Hedman, Hansebo, Ternestedt, Hellström, & Norberg, 2013; Sabat, 2002, 2006; Sabat, Fath, Moghaddam, & Harre, 1999).

A life-world phenomenological perspective, which takes the everyday world of persons with dementia as its reference point, could provide a supplementary perspective on their lived experience. A study of six

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persons with dementia who lived alone and had a manifest care need (Svanström & Johansson-Sundler, 2015 is the point of departure for this interpretation. The findings suggested that life with dementia for the participants meant a life with a broken identity as they gradually lost memories of themselves and their lives. It seemed as if the world of the participants was reduced to a quiet background which does not incite action. These participants had enormous difficulties relating to the surrounding world. Their existence was characterized by a strong sense of loneliness and a very vague understanding of the situation. They longed for other people and developed a state of existential boredom.

By applying a life-world perspective and using the theory of intentionality when interpreting these findings, and those from a study involving couples in which one partner had dementia and a manifest care need (Svanström & Dahlberg, 2004), the author is introducing a new understanding of life with advanced dementia in this chapter. More specifically, it is being proposed that life with dementia when having a manifest care need involves a gradual loss of meaning due to impaired intentionality. That is, persons with dementia face increasing difficulties in understanding the meaning of everyday objects and chores when intentional threads become slack. Intentional threads, according to Merleau-Ponty (2002), connect us to the world in a meaning-making manner when they are tight. In other words, when we perceive something, we simultaneously know what it is, how it relates to us, how it is used, and for what it is used. Through intentionality, objects urge us into action and movement. The intentional threads anchor us to objects, space, time, language, our bodies, and other people.

The incentive to use objects decreases for persons with dementia and affects their sense of space and time, and eventually also of language and the body. The afflicted person fights this and tries to tighten the intentional threads in order to create meaningfulness in existence. This effort becomes extremely difficult and strenuous over time, with even the easiest everyday chores requiring thought to accomplish.

The life-world perspective and theory of intentionality can aid professionals caring for persons with dementia. By helping the person with dementia tighten the intentional threads, caregivers can support the individual’s sense of being anchored in the world. Home care that supports intentionality and identity, as recommended at the end of this chapter, has the potential to lessen suffering and increase well-being by engaging the person in everyday chores that promote meaning. Such care could enhance the ability of the person with dementia to be anchored in language, time, and space.

BACKGROUND

About 25 years ago, I worked as a staff nurse in a group home for persons with dementia. The home was on the ground floor of a typical apartment building. There lived ten people, mostly women, who had moderate-to-severe dementia. The kitchen was the gathering point of the home. One woman who, along with her husband, had run a farmhouse never hesitated to participate in household chores. Sometimes it was necessary to make her slow her pace so that she would not become agitated or aggressive. On one occasion, during a trip in a minibus, we happened to pass within a couple of miles of her former home. Suddenly, she began to describe who lived in the houses we passed. She continued this for about two miles, and just as suddenly as she had started, she stopped. It was evident that she felt at home in herself on this short section of road. Normally, she could not state where she was or name the caregivers or the other residents in the group home.