Chapter 42

A Method for Eliciting the Support Needs from People with Early-Stage Dementia for Maintaining Social Living

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ABSTRACT

In the area of welfare engineering, various technological research and developmental efforts have been made to support people with dementia. However, it is not clear if these efforts are based on the real needs of these people. When providing support to people with dementia, it is essential to know exactly what their needs are. Nevertheless, it is not easy to obtain appropriate answers from these people by simply asking “How can we help you?” In addition, it is unlikely that answers from those people will cover all of their support needs. In this chapter, a new method based on the “Person-Centered Care” concept is proposed for eliciting the support needs from, and determining their priorities for people with early-stage dementia.
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dementia who are eager to maintain their social living despite coping with various difficulties. First, all of the actual and potential tasks of social living in their daily life are determined. Support needs are then extracted systematically from those tasks by paying attention to what factors are bothering these people or are confusing to them rather than directly asking the individuals what type of support they want or need. Finally, the support needs are prioritized by taking the degree of the individuals’ confusion and task frequency into consideration. When interviewing people with dementia, special care must be taken to ensure that the individuals who have memory impairment are not overburdened. In the proposed method, visual materials such as cards and boards with illustrations are utilized so that people with dementia can answer questions more easily. Some interviews were conducted based on the proposed method to confirm that support needs can be determined systematically from people with early-stage dementia.

INTRODUCTION

People with early-stage dementia are reported to be eager to maintain their social living by actively contributing to society or continuing to work (Alzheimer’s Association, 2008). Over the past five to ten years, many of those people have started to speak out about how deeply they are suffering from dementia (Boden, 1998; Bryden, 2004). Consequently, the support environment for people with dementia is changing, with a new focus on the concept of “Person-Centered Care” (Benson & Kitwood, 2000). In other words, care must be administered with the aim of meeting more of the individuals’ expectations than the caregivers’ wishes. Of course, holistic support from society at large, including the efforts of government to address dementia care as well as various technological research and developmental efforts, is indispensable. However, it is not clear if the activities in the technological field (Lee & Dey 2008; Hamada, et al. 2008) are aimed at solving the real needs of people with dementia based on the “Person-Centered Care” concept.

How can we determine the real needs of people with early-stage dementia? Generally speaking, it is not easy to obtain appropriate answers from anyone, regardless of whether they are suffering from dementia or not, by simply asking “How can we help you?” People with dementia are even less likely to state their needs because they tend to reduce their wants and needs due to feelings of restraint and/or resignation or the lack of self-awareness of impairment. It is also possible that verbal communication would not be effective for interviewing people with dementia because of their impairment in short term memory. Furthermore, even if these people reply to questions, it is unlikely that the obtained answers will include all of their support needs. Therefore, a solution to these problems must be found to effectively identify the support needs of people with early-stage dementia.

The aim of this research was, first, to identify what kinds of difficulties people with dementia are facing in their social living situations and what kinds of support needs they desire. We then sought to identify which support requirements could be realized effectively by technology. To accomplish these goals, a new interviewing method is proposed for identifying the support needs of people with early-stage dementia. With the proposed method, support needs can be determined by respecting the individuals’ needs and wants based on the Person-Centered Care concept along with caregivers’ cooperation. This method was carefully designed by considering not only what the individuals cannot do but also what the individuals wish to do, so that their support needs are systematically identified and prioritized from the individuals’ point of view. Several interviews of people with dementia were conducted, and the effectiveness as well as the limitations of the proposed method are discussed.
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