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Sense of security of home-dwelling people with an early stage memory disorder: a qualitative study

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Progressive memory disorder affects people's independent functioning in life, thus threatening their safe living at home. A key goal in Finnish social and health policy is to promote older people's possibilities for accessible and safe living at home for as long as possible by improving home care for older people and enhancing support for informal caregivers. A wider range of adequate home care services are needed to help people with a memory disorder to continue living in their own homes safely. The purpose of this qualitative study is to describe, what creates the sense of security for home-dwelling people diagnosed with an early stage memory disorder.



Background

The prevalence of memory disorders is increasing worldwide due to the aging of the population. Progressive memory disorder affects patients' cognitive functions, thus impairing their independent functioning in life [1]. This in turn threatens their safe living at home [2]. The majority of those living with a memory disorder live in their own home in the community and would wish to remain living there for as long as possible. Although caring for a person with a memory disorder is not the responsibility solely of the family members, they have a crucial supportive role for the person diagnosed [1]. Meeting the needs for care, services and support of both people with the diagnosis and their family caregivers is necessary in order to promote safe living and good quality of life with a memory disorder [3].

There is a need for new models of health care services that are continuous, holistic and integrated [3], rehabilitative, tailored, timely and coordinated [4], and support the quality of life of people with the memory disorder and their families [1]. A key goal in Finnish social and health policy is to promote older people's possibilities for accessible and safe living at home for as long as possible by improving home care for older people and enhancing support for informal caregivers [5] [6]. In Finland, there is an urgent need to reform care services towards supportive home care [7]. A wider range of adequate home care services are needed to help people with a memory disorder to continue living in their own homes safely [4] [7].

Different contextual, emotional and individual factors contribute to a sense of security for older people [8] [9]. The concept of the sense of security has a long historical background. According to Maslow's [10] hierarchy of needs theory, security is the state of being secure, specifically the freedom from fear, danger, risk, care, poverty, and anxiety. There are earlier studies concerning the sense of security for older people in general. Feeling a sense of security is a key issue in ensuring older people's independence, social inclusion, and social participation [5]. Older people's sense of security is strongly related to secure relationships [8] [11], perceived health, sense of control and knowledge about their everyday life situations [8], and economic security [11]. The sense of security is a subjective feeling adapted to one's own needs, self-confidence, and sense of belonging and being liked [12]. Meaningfulness in life and the ability to master crises indicate an older person's subjective feeling of security [11]. The sense of security in older people is associated with satisfaction with the home and living environment [13], physical activity [14], and quality of life [15]. An environment supporting the well-being of the home-dwelling older person is formed of physical, social, and symbolic attributes that relate to the experienced sense of security [16] [17]. However, the sense of security has also been connected to suffering in older people's lives, such as a fear of the unknown, physical pain, and anxiety [18], and fear of crime [19]. The concept of security has been evaluated from the risk perspective, such as the risk of falling [20], the problems of medical treatment [21], and the risk of injuries and accidents [22].

Research strategy

Study participants were home-dwelling people with a diagnosed early stage memory disorder (n=10). They were from 43 to 78 years of age. Participants were selected by purposeful sampling through the Memory Association of the Oulu Region. Family members (n=3) and nurses (n=2) were included in the study, as we wanted to have a supplementary understanding from their viewpoints.

Data were collected using individual semi-structured interviews in the homes of the study participants between April and May 2016 by the first author. Nurses were interviewed at their workplace. The attributes of the physical, social, and symbolical environment [16] formed the broad themes for the interviews. All interviews were digitally recorded and transcribed verbatim. Interviews lasted 40-60 minutes. The data were analyzed using inductive content analysis by the first author [23] [24]. The analysis process included open coding, creating categories, and abstraction [24].

Ethical considerations

The first author ensured that the study participants were able to decide on the participation and had the capacity to give their consent. The study participants were informed about the study, both verbally and with a written information sheet. As this study focused on both the emotional and sensitive experiences of vulnerable individuals, special attention was given to protecting the well-being and autonomy of the study participants [25] [26].

Results

Three factors affecting the sense of security of home-dwelling people with an early stage memory disorder were identified: health and daily functioning, the features of physical and social environment, and the psycho-social resources of an individual (Figure 1).

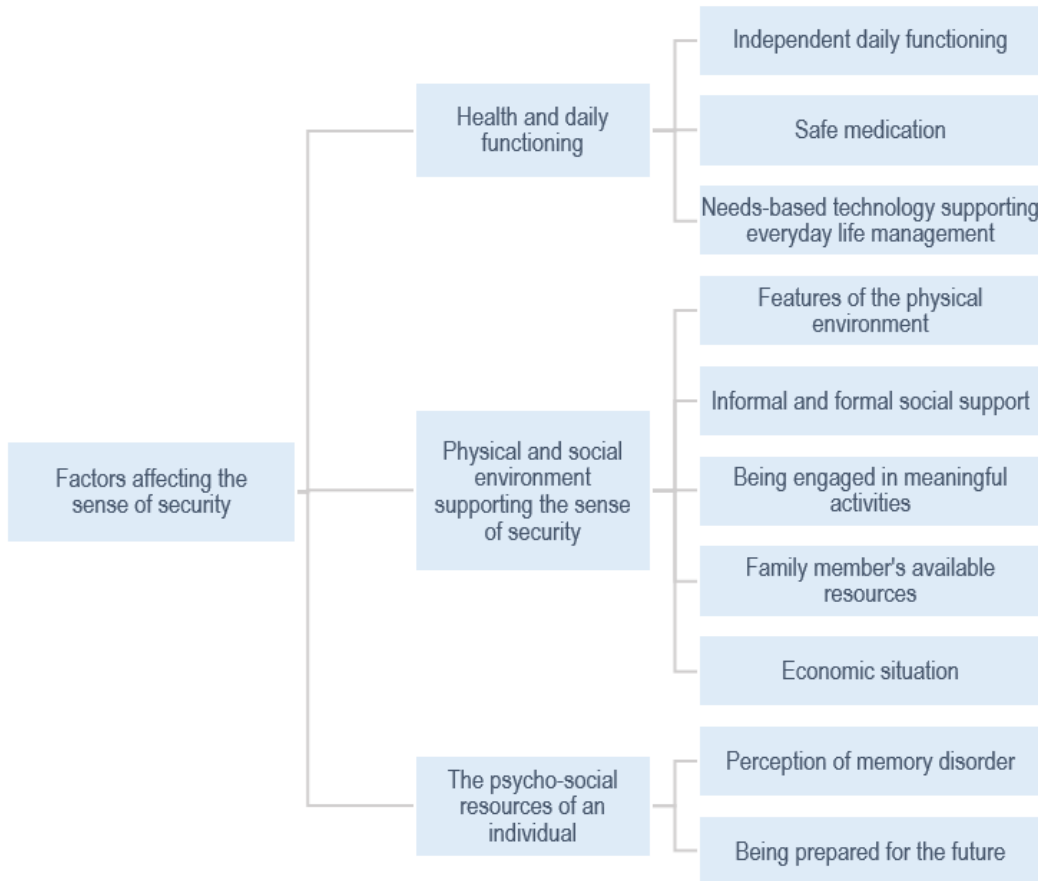


FIGURE 1. Factors affecting the sense of security of home-dwelling people with an early stage memory disorder

Health and daily functioning

Health and daily functioning includes an individual's independent daily functioning, safe medication, and needs-based technology supporting everyday life management. Study participants described that independent daily functioning was one of the most important things that supported their sense of security. Independent daily functioning consisted of daily routines, self-confidence, and living independently. Even if participants expressed feelings of insufficiency and dependence on another person, they also told that they would like to have control of their daily routines for as long as possible. Daily routines were related to their circadian rhythm, and they experienced a sense of security when things happened in the same way every day. A feeling of continuity was interconnected with self-confidence when people were able to make decisions independently.

Safe medication supported the sense of security. Study participants reported that although the loss of memory impeded remembering, all were still able to take medications themselves or with the help of family members. They also experienced pill dispensers, calendar alerts, and electronic applications as being useful for reminding them to take medications.

The study participants consistently pointed out that technology could support daily functioning and help them to manage everyday life. However, they had ambivalent feelings towards technology: on the other hand, they were satisfied about feeling independent and free, but at the same time they wanted to be secure even if it meant being monitored by technical security devices. Based on the participants' experiences, they responded positively to the technical security devices and safety technology, but they also felt that they did not yet need any technological systems for everyday life and activities. They also reported that they did not know how to use the technical security devices or where to get them.

The features of the physical and social environment

The sense of security was related to the features of the physical and social environment, which included features of the physical environment, informal and formal social support, being engaged in meaningful activities, family member's available resources, and economic situation. Familiar living environment, the absence of fears and threats, and the natural environment, were aspects that had supportive significance for the sense of security in people with a memory disorder. The living environment consisted of a peaceful and safe environment without fears and threats, such as a fear of falling. Some participants described that their own home where they have been living for a long time created their sense of security. The natural environment increased their happiness and well-being because the nature gave them strength and a feeling of safety.

Both the informal and formal social support were important for study participants' social life, resources to manage everyday life, and comprehensive health and well-being. The informal social support from family members, friends, and neighbors supported the sense of security. Furthermore, study participants reported that professional support, such as practical information and advice, were important for coping with the diagnosis. Having the opportunity to talk about the feelings and concerns was relieving and helped people to deal with their problems.

People with a memory disorder experienced that being engaged in meaningful activities was important for their social participation, independence, and well-being. Meaningful activities created a sense of well-being and self-esteem. They emphasized that by being in the same situation with peers, they were able to give emotional, social, and practical help to each other. This strengthened their sense of belonging and of being valued.

Family members stated that their available resources consisted of the ability to adapt to changing situations and the ability to manage everyday life. They also pointed out that it is important to take care of their own well-being and health and to focus on the positive things in life in the present. The family members' sense of security was related to their close ones' well-being and the received support from health care professionals.

Furthermore, economic situation affected the sense of security for study participants because it enabled them to get necessary services and medications.

The psycho-social resources of an individual

Study participants experienced that the sense of security is related to the perception of the memory disorder and being prepared for the future. Their perception of the diagnosis was twofold: they were relieved and wanted to focus on positive things in life, but they also experienced negative feelings such as anger, fear, and hopelessness.

People with a memory disorder were worried about the progress of the disease and its effects on family members. They were also concerned about their close one's condition and resources to take care of them. Their fears for the future were related to the fears of institutional care and loss of self-determination. The participants wanted to live at home as long as possible. They also wanted to be regarded as themselves, not according to their memory disorder. Living in the present and focusing on the positive things in life helped them in making plans for the future. After receiving a diagnosis of a memory disorder, some participants prepared for the future by discussing their wishes and future care with people close to them.

Discussion

The results showed that independent daily functioning is a part of the people's physical and social well-being [27], including daily routines, self-confidence, and living independently. According to previous studies, the sense of security has a relationship with the sense of control [8] and continuity [12], which are also significant findings in this study. Being dependent on another person's help may cause feelings of being a burden on others [28] [29], and this is the reason why people will actively try to maintain their independence and control over their own lives [30] [29].

Needs-based technology supporting everyday life management was related to the sense of security. People had ambivalent feelings towards technology. Although they expressed positive interest towards assistive technology, they also felt that they do not yet need any technological systems. They also wanted to have a sense of self-efficacy as long as possible. At the same time, they were worried about their security and managing at home. According to Boström et al. [31] and Hoof et al. [32], older persons generally had positive feelings and attitudes toward technology. Earlier studies [33] [32] [31] have confirmed that technology helps to create a barrier-free home environment, which enhances a person's daily functioning and safe living at home. However, it is important to make the technology individualized and to introduce it to users at a sensitive

time [31]. As this study indicated, the challenges for technology are in how technology can help home-dwelling people with a memory disorder and what kind of solutions are available.

An association between the sense of security and relationships such as family and friends has been found in earlier studies [8] [34]. Informal and formal social support, including social contacts and activities as well as resources to manage everyday life, were important for people with a memory disorder; this is in line with earlier studies [35] [11] [9] [8]. Furthermore, reciprocally helping each other was important for the study participants, as earlier studies have confirmed [29] [36].

Study participants had ambivalent feelings such as fear and uncertainty about the future along with relief and hope. According to Lawrence et al. [37], the threats that commonly accompany dementia depend on a person's understanding and attitude towards their own disease and their life values. As noted in earlier studies [38] [29] people with the diagnosis wanted to be recognized as individuals and they wanted to feel important and valuable.

In this study, an analysis was verified by other authors to increase the comprehensiveness of the data [39]. However, the study has some limitations. First, the sample was drawn from Northern Finland in one district area, which potentially limits the transferability of findings. Second, the study sample was small.

The results could be utilized to design tailored home health care services for home-dwelling people with a memory disorder. With adequate support, people with an early stage memory disorder could have accessible and safe living at home, which in turn could delay a move to long-term care. Further research is needed to generate a more comprehensive understanding of the sense of security for home-dwelling people with an early stage memory disorder and means to promote it.

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Metatiedot

Nimeke: Sense of security of home-dwelling people with an early stage memory disorder: a qualitative study

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Aihe, asiasanat: ikääntyneet, kotona asuminen, kvalitatiivinen tutkimus, muistisairaat, muistisairaudet, turvallisuus, turvattomuus, home-dwelling, memory disorders, security, qualitative research

Tiivistelmä: The sense of security in home-dwelling people with an early stage memory disorder substantially affects their well-being and quality of life and also threatens their management of everyday life and living at home. The aim of this study was to describe what creates a sense of security in home-dwelling people with an early stage memory disorder. This was a qualitative study: interviews (n=15) were conducted with people with a diagnosed early stage memory disorder (n=10), family members (n=3), and nurses (n=2). A qualitative content analysis was used to analyze the data. Three factors affecting the sense of security were identified: health and daily functioning, features of the physical and social environment, and the psycho-social resources of an individual. By recognizing the factors affecting the sense of security, this knowledge could be utilized by health care workers to support the sense of security and to design health care services individually for home-dwelling people with a memory disorder.

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