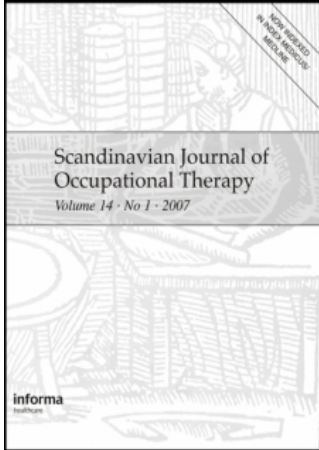


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Annika Öhman ^a; Staffan Josephsson ^a; Louise Nygård ^a

^a Division of Occupational Therapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden

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ORIGINAL ARTICLE

Awareness through interaction in everyday occupations: Experiences of people with Alzheimer's disease

ANNIKA ÖHMAN, STAFFAN JOSEPHSSON & LOUISE NYGÅRD

*Division of Occupational Therapy, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden***Abstract**

The aim of this study was to explore and describe the characteristics of awareness of the consequences of having Alzheimer's disease on everyday life occupations. Six community-dwelling participants with Alzheimer's disease were interviewed on repeated occasions about their lived experiences of everyday occupations. A phenomenological method was adopted for the analysis. The findings show that the participants discovered and explored the changes in how they performed everyday occupations in the context of their social relations and through immediate reflections on their forgetfulness. They attempted to handle the changes by adapting their behaviour. Awareness of the changes in their lives was evident in their reflections, as they tried to make sense of what was happening to them. This seemed to be related to an elusive perception of change in situations that they found impossible to influence. The participants reflected on the impact their condition had on other people near them. Their reflections also involved emotional reactions to the shortcomings they experienced. In conclusion, the findings show how these people with Alzheimer's disease were able to express awareness of the consequences of their illness through their reflections on their experiences of interaction with the occupations and the social environment.

Key words: *Activities of daily living, ADL, dementia, insight, phenomenology, qualitative methodology*

Introduction

During recent years a vivid interest has developed in the concept of awareness, especially in stroke rehabilitation (1) and dementia (2). These studies suggest that awareness is an important factor for successful rehabilitation, e.g. in the use of adaptive strategies. Awareness in people with dementia has been the subject of an extensive body of literature in medicine and neuropsychology, although it is mainly described as a cognitive dimension (3). Lack of awareness has been identified as one of many symptoms of dementia (4). In the literature, the assessment methods and measures of awareness available have been examined, but the nature of awareness and a clear definition of the concept remain to be determined (5). However, several authors have emphasized the importance of considering factors other than the disease that may influence a person's awareness, by adopting a social or psychological perspective (2,6). The present situation is that an early diagnosis (7) and the use

of new drug therapies (8) enable people with Alzheimer's disease (AD) to remain in their own homes for longer after a diagnosis has been made. From what is known, it is reasonable to assume that awareness of the consequences of AD has an influence on a person's ability to perform daily occupations, and hence to remain at home. Downs (9) stated that intervention strategies that will support community living should be developed to take into consideration certain aspects of awareness. However, if this is to be accomplished, empirical studies conducted from the clients' perspective are needed to gain a deeper understanding of the different aspects of awareness.

During the past decade, it has been recognized that people with dementia are important agents for an understanding of the subjective experience of living with the condition (10). The perspective of the person with dementia was first described in the early 1990s as a neglected field of research by Cotrell & Schulz (11), and subsequently others

have emphasized this (9,12,13). The absence of studies from the standpoint of people with dementia indicates a supposition that they would not be sufficiently reliable to provide objective knowledge about living with the condition owing to decreased insight or a lack of awareness (14). However, ways of gaining an insight into the subjective life-world of those with dementia have been suggested, such as using the voices of people with dementia in accounts and interviews (15). Previous research has also shown that people with AD, especially in its early stages, can describe their cognitive disabilities and their problems and talk about their experiences in performing everyday occupations (16,17). Some of the specific challenges of interviewing people with dementia have been analyzed (18,19), as a result of which, adapted interview techniques have been suggested and the combination of conducting interviews and making observations is recommended. The use of implicit memory, defined as a change in behavior that occurs as a result of previous experiences (20), as in acts and the performance of daily occupations, is also suggested as one way to provide access to the experiences of people with Alzheimer's disease, in contrast to the emphasis on explicit and verbally expressed awareness. For example, persons with AD may express their awareness through descriptions, and through their attitude, intentions and acts (19,21). In spite of the extensive literature on awareness in dementia, there are few empirical studies that consider its clinical significance. When people with AD are considered to have a high degree of awareness, they are considered to manage everyday life better, which includes, for instance, the use of technical aids and compensatory strategies (6,22). The level of awareness of people with dementia is also described as being important for interventions and for their ability to live independently in the community (12,23). It should be noted that the majority of studies of the subjective experience of persons with dementia are based on verbal tests and questionnaires (5) despite the fact that their ability to communicate and to describe memory problems and semantics is decreased.

The phenomenological approach is believed to be a valid way to study the experiences of living with dementia (6,14,16,24). In phenomenology, the person's life-world is the point of departure, which is subjective and also taken for granted (25). Through the examination of the lived experiences in the everyday world, in contrast to experimental experiences or attitudes and beliefs, phenomenology seeks to describe the essence or character of an experienced phenomenon, as it presents itself to someone (26,27). Hence, phenomenology offers a method for accessing experienced realities (28). When healthy,

people assume a natural attitude to subjective bodily experience and to their health, which is taken for granted. When ill, people's relationship with the world is disturbed and they are no longer able to participate in everyday occupations as they once did, which may also interrupt the "taken-for-grantedness" and their natural attitude to the subjective body and to the idea of health itself (26). This disruption in the "taken-for-grantedness" might be expressed in different ways. The emergence of Alzheimer's disease implies that the person begins to reflect on his or her experiences of a changing life-world (16). However, people with dementia are described as losing some of their ability to be aware of and to communicate their experiences (18). With the intention of gaining a deeper insight into this issue, the authors set out to explore how the awareness of people with Alzheimer's disease may show itself in the context of everyday life occupations. Consequently, the aim of this study was to explore and describe the characteristics of the phenomenon awareness of the consequences of having Alzheimer's disease on everyday occupations.

Material and methods

Selection of participants

The participants were six community-dwelling older adults, recruited from a geriatric outpatient memory investigation unit. The primary inclusion criterion was having a clinical diagnosis of a mild to moderate degree of Alzheimer's disease, according to criteria established by DSM-IV (29) and NINCDS-ADRDA (30). Participants also should be able to articulate their experiences of living with the disease, which did not imply having an explicit awareness of their occupational limitations and difficulties. The six persons selected had been diagnosed with AD about two years prior to the data collection. The participants have also been included in previous studies (17,21). Some characteristics of the participants are presented in Table I.

The local ethical committee approved the study. Both written and verbal informed consent was obtained from each participant. The participants also received repeated verbal information about the study at the beginning of each data-collection session.

Data collection

Data were collected primarily in the participants' homes, although the first interview for five of the participants was conducted in a clinical setting. Repeated informal interviews were conducted using an interview guide (32) that comprised open-ended

Table I. Characteristics of participants ($n=6$): Age, gender, marital status, diagnosis, main symptoms, symptom duration, and MMSE Score.

Age	Gender	Marital status	Diagnosis	Main symptoms ²	Symptom duration ²	MMSE ³
80	Male	Married	AD ¹	Memory impairment Disorientation	4–5 years	21/30
80	Male	Widower	AD	Memory impairment	6 years	28/30
65	Male	Married	AD	Memory impairment Visuospatial disability Psychomotor retardation	8 years	24/30
70	Female	Widow	AD	Memory impairment Dysphasia Cognitive decline	8 years	24/30
68	Female	Divorced	AD	Memory impairment Cognitive decline	6 years	18/30
73	Female	Married	AD	Memory impairment Dysphasia Cognitive decline	7 years	15/30

¹AD = Alzheimer's disease.

²Main symptoms and duration according to medical records at the time of the data collection.

³MMSE = Mini Mental State Examination (31). Higher score indicates better performance.

questions aiming at getting concrete descriptions of the participants' lived experiences of everyday life occupations, e.g. "Please tell me about the things you usually do on an ordinary day" and "Please describe a situation when you have experienced memory problems". Participants were also regularly encouraged to explain the meaning they attributed to these occupations and to describe their perceptions of their competence and of changes. All interviews were carried out in an informal and reflective manner with the intention of allowing the informants to take their time, and of enabling the interviewer to repeat the questions, covering the same ground in different ways. It also enabled the interviewer to use different approaches to the themes and to rephrase the questions to make them more understandable according to the needs of the individual participants, and to pose follow-up questions. All participants were interviewed on two or three occasions within two weeks, depending on each participant's personal circumstances. Only one participant was interviewed on four occasions. The interviews, which were tape-recorded and lasted between 19 minutes and 2 hours, were transcribed verbatim, making a total of about 650 pages.

Data analysis

First, all data were read through to get a good understanding of the content and of how awareness was expressed, as lived by the participants. In the next step the interviews were reread, one participant at a time, to identify all parts of the text indicating expressions of the lived experiences of awareness, e.g. relating to the participants' experiences of the disability, descriptions of their attempts to compensate for forgetfulness and manage daily occupations, and reflections on their present situation with regard to their disability. Data that were not consistent with the aim of the study, for instance, giving accounts of

family matters, were excluded from further analysis in this study.

A modified version of the Empirical, Phenomenological, Psychological (EPP) method (27) was used throughout the analysis. The EPP method is a qualitative and interpretative method aiming to describe both the structure and process of a phenomenon. The intention in adopting this method is to describe the meaning structure of a life-world phenomenon based on the research participants' accounts of their lived experiences, spontaneously and in detail. The psychological focus of this method was replaced with the perspective of occupational therapy, focusing on the experience and meaning of everyday occupations. The phenomenon in this exploration was formulated as *the awareness of the consequences of having Alzheimer's disease on everyday occupations*.

The analysis continued with a new open reading of all selected data, with the intention to be as open as possible to the lived phenomena. The aim was to obtain an empathic and overall understanding of the content, refraining from imposing any theoretical model or theory. The text was then divided into meaning units each time there was a shift in meaning in the data. Thereafter, the meaning units were analysed in the light of the whole, and transformed from their particular facts to their explicit and implicit meaning, i.e. *the eidetic reduction through interpretation*, using a language close to data. Preliminary themes were created as part of the procedure of identifying the main characteristics of the phenomena. Subsequently, the analysis included synthesizing the transformed meaning units into "situated structures of meanings", presented as a synopsis for each participant encompassing the characteristics of the phenomenon. This step also included returning to the original data to ensure that relevant characteristics were not overlooked. In the following, the situated structures from all participants were compared and synthesized into a "general

structure” that incorporated all the characteristics of the phenomenon based on all situated structures.

The researchers continually examined the horizontal consistency of all characteristics by discussing conflicting interpretations to ensure that the final interpretation was the most plausible and that it was valid as recommended by Karlsson (27). The interpretations were also continuously discussed in peer reviews with other researchers who were familiar with the phenomenological approach to research.

Results

The structure of the phenomenon *the awareness of the consequences of having Alzheimer's disease on everyday life occupations* is presented as two main characteristics, one having three sub-characteristics, the second having five (Table II).

Discovering and managing changes in occupational and social interactions

Awareness of the consequences of Alzheimer's disease was apparent in the participants' experiences of how “little by little” they discovered and explored occupational changes in their performance of everyday occupations and in their interaction with people, their social environment and in immediate reflections on forgetfulness. They compared these changes with how things used to be before, and they attempted to manage changes to their occupations by adopting a variety of adaptive approaches in both their performance and their social interactions.

Discovering and exploring changes

Changes related to the management of everyday occupations were gradually noticed and expressed by the participants with regard to their interactions with other people. The participants' first notions of things being different from how they had been before were in their retrospective experience, being linked to

Table II. Main characteristics and sub-characteristics of the phenomenon awareness of the consequences of having Alzheimer's disease on everyday life occupations.

Discovering and managing changes in occupational and social interactions:

Discovering and exploring changes

Immediate expressions of forgetfulness

Developing adaptive approaches

Reflecting on a changing life situation:

Making sense of what's going on

An elusive perception of change

Relating to a situation that seems to be “unaffected”

Reflecting on the consequences of their predicament for others

Reacting emotionally to the shortcomings experienced

changes in their occupational performance in everyday life, e.g. mislaying objects at home and having difficulty counting out money at the grocery store. When, little by little, they discovered that the accomplishment of some occupations had changed in comparison with how it had been before, they concluded that something had changed or was in the process of changing. As the participants experienced a growing gap between how things were before the disease and how things were at present, they had begun to realize that their expectations concerning what they were able to manage would not be met. One person told of repeated events of forgetfulness during the performance of morning routines as follows: “Little things happen every day. For instance, it might happen that I have forgotten to put the water on to boil for my tea when I'm already sitting with my sandwiches.”

Following the gradual discovery of their limitations, the participants sought to explore emerging changes in their occupations in everyday situations. To probe the limits of their capacity, they sometimes exposed themselves to challenging occupations, like one woman who was fond of baking, who said that she would keep on doing this to discover where her limits were. In the participants' minds, succeeding in an occupation seemed to contribute to an inner sense of still being competent, as before. For example, one participant explained with contentment that she could still manage all her gardening without the help offered by her children. On the other hand, the participants also expressed a mistrust of their ability to do things as well as they used to do.

Some of the participants had suspicions that certain changes were hard for them to see, and that other people would be more able to notice the changes. One participant even remarked that he had become aware of the consequences of the disease through reflections made by others, and this had made the changes visible to him. The experiences of competence were also influenced by the attitudes they encountered from others. If other people could appreciate what they did, the participants concluded that they probably still passed as being as competent as before. For example, one male participant drove his car, conducting various errands every day. Some days he picked up his grandchildren from school “They [the parents] must think I'm driving reasonably well, otherwise they would tell me and I would stop immediately”, he said. This participant's experience of not being able to do things as he had before onset of the disease seemed to be counterbalanced by his perception that others confirmed he was still competent. This seemed to have the meaning of “as long as other people trust me, things cannot be too bad.” Hence, both occupations

and social situations seemed to provide an avenue to explore his changing life situation and to examine his current occupational limits and capabilities.

Immediate expressions of forgetfulness

Awareness of the consequences of the illness was spontaneously expressed by the participants in relation to situations in which they experienced forgetfulness that was apparent immediately, for example when losing track in the middle of a conversation. "If I'm interrupted I slip out of the conversation and after that I don't know where I was", said one participant, who also remarked during the ongoing interview "Now I've lost it again, see! But it'll soon be back." Often their immediate reflections went together with a comment about "being stressed by the situation" and explanations like "it's a new environment". Immediate expressions of awareness also came to the fore when participants were talking aloud whilst performing occupations, in a self-guided procedure, commonly verbalized through expressions such as: "Where did I put it?" These immediate expressions of the experience of shortcomings and of trying to provide themselves with feedback on their performance showed their immediate awareness of their forgetfulness in occupational performance.

Developing adaptive approaches

The participants told of how they gradually tried to adapt their performance to incorporate new ways of doing their occupations. On their own initiative, they used a variety of adaptive approaches to compensate for their decreased memory, such as repeatedly checking what they had just done and always reserving extra time, allowing for time-consuming misadventures, or using memory supports such as written reminders. One participant explained "I keep a slip of paper in my wallet where I have telephone numbers and things like that. Among other things, I have my own number, because I can't remember that either." One frequently used adaptive approach was provided by visual clues. For example, one female participant explained how she had found a way to continue baking in spite of her difficulties: "I take out all the ingredients and put them on the table so I can see them. And when I have used a thing, I put it back again. So if it's not there, I know I've used it." Giving up occupations that were too challenging or entrusting certain occupations to a significant other, such as paying the bills, were also approaches commonly used by the participants. These seemed to be deliberate acts, with the purpose being to

provide relief from something that had become too burdensome.

Some participants also described attempts to facilitate their social life, to make them feel more at ease in their interactions with others by deliberately choosing between telling their friends about their illness and their changing abilities, or choosing not to tell. One participant said: "No ... my intimate friends possibly, but I don't talk that much about it ... This is my concern, and I will sort it out because it afflicts me, me and my family. But our neighbours know." He continued with a reflection: "I don't think it's obvious [to others] that I'm sick, and sometimes you would like to say that 'I'm actually not that well' ... without complaining about it." Referring to his uncertainty about whether to tell others about his condition, he continued: "I don't think I'm physically ill. It doesn't show, I mean, I'm not limping or anything." He perceived that his disability might not be obvious to an observer and, hence, he reflected on the dilemma that he might be considered to be strange or a bit odd if people did not know of his condition.

Reflecting on a changing life situation

The participants' reflections on the changes occurring in their everyday occupations also involved awareness of a changing life situation. This came to the fore when they tried to make sense of what was happening to them, and to relate this to the elusive perception of change. They described this as a life situation that was difficult to grasp and not possible to influence. They also reflected on the impact of their condition on people near to them, looking beyond the immediate meaning that the changes had for them. Their reflections also concerned various emotions as a reaction to the shortcomings they experienced and other changes.

Making sense of what's going on

All participants revealed how they were trying to make sense of and contextualize their changing life situation and the origin and course of the disease. Some of the participants associated their symptoms with previous traumatic incidents that they thought might have contributed to the development of the disease. For example, one participant had lost her husband in an accident some years earlier and said, "It's clear that this grief over my husband has contributed: I really think so". Some participants had seen a resemblance between their own memory problems and similar problems experienced by relatives known to have had dementia. One participant had a brother with dementia and acknowledged

his difficulties, "The worst thing is that I now compare myself with him, and that is . . . horrifying", he said. The comparison frightened him raising concerns about what might become of him in the near future, as he pondered the possible changes his disease might bring in its later stages.

While all participants stated that they knew that they had a disease called Alzheimer's disease, they also talked about their experiences of forgetfulness as a normal course of aging when life is drawing to an end and the demands of the environment decrease. For example one participant said, "I know this problem is common. I'm not alone. At my age you can almost count on it." Such thoughts regarding a shared experience of forgetfulness in old age seemed to comfort the participants, and confirmed their experiences. The perceptions of memory loss were also described by some of the participants as being just short-term memory problems, and hence not very serious. "On the whole, it's not serious. It's just this short-term memory. It annoys me that I can not manage to get around it" one male participant said. He continued "It's ridiculous to forget these things! It's so trivial!"

An elusive perception of change

The participants reflected on how they literally perceived that something felt different now, but it was difficult to grasp how, and to articulate this explicitly. Sometimes their observations were related to a physical experience, where sensations played a part. They linked this to the view that Alzheimer's disease is an illness, and an expectation that they would therefore feel ill. They all placed these changes as coming from the region of the head. One participant said: "I don't have a sane thought in my head any more". Another participant told of how he felt a strange sensation on the side of his head when he shook it, the same side he had hit just before the onset of the disease, and he reflected on this sensation as a possible manifestation of his disease.

Even though all participants talked about their illness by its name, the actual perception of it was described as being difficult to identify as a part of oneself. All participants elaborated on how ignorant they felt when it came to how they were supposed to feel when having this disease. "I don't know, I would like to hear about . . . How sick are you when you have this? It's so very difficult being well and yet being sick" said one participant. The participants strove to understand the situation, but their perceptions were elusive and seemed difficult to grasp. In contrast, most of them perceived a feeling of physical

well-being and considered that their overall life situation was satisfactory. One participant said: "I'm so happy that I am physically well [laughs]. So . . . so I make sure I'm out and about a lot." While all participants perceived these elusive changes, they all also underscored the importance and joy of still experiencing physical well-being.

Relating to a situation that seems to be "unaffected"

The participants' experiences of their predicament in everyday life were also evident in the attitude they adopted towards the disease itself, which they could not affect, and which created a life-changing situation they knew they had to live with and adapt to. Almost all of the participants considered that a progressive decrease in their memory was inevitable. Memory training would not affect the memory deficit, they said. Their memory would neither be improved nor would their deficits be prevented by engaging in such effort but, at best, they may be decreased. For example one participant said, "I don't think you can train and train and get it back, I don't believe that. Because I've tried to train a little bit, but it didn't have any effect." All participants emphasized the option of getting on with life and of accepting things as they were, focusing on making the best of their situation and being happy with what they had. This choice was not presented in terms of denying their problems; rather it was as an option that could make an "unaffected" life situation easier to manage.

Well aware of the disease, the participants also knew that its influence on everyday life would eventually increase. "You have to accept the life you have. But at the same time you know you might not be able to live at home that long, which is also difficult. So it is . . . You have to accept that too", one participant said. The participants pondered on what their condition might be in the future. One male participant said with regard to his possible future "I think I have a good life. I don't want to be a survivor in the sense of being completely senile or something, I'd rather die, I think." A female participant had a valued role as a grandmother and explained her worries about the Christmas dinner a few months ahead, wondering if she would be able to do all the dishes for her grandchildren that she used to do before the onset of the disease. Hence, awareness of the disease as expressed in relation to a changing life situation included both the present situation and concerns about eventual consequences such as being able to remain at home and manage everyday life in the future.

Reflecting on the consequences of their predicament for others

All participants reflected on what their illness and its impact on everyday life could bring about and mean to others near to them. Reflecting back on the onset of the disease to the present, they wondered about the impact of the illness on their future lives. They all implicitly and explicitly elaborated on these matters, recognizing the fact that their predicament had to be noticed by others and had to influence other people in one way or another. For example, one participant said: "Of course my wife worries about me. It's not fun to see a person change". Another participant said: "It's my husband that cries the most, not me. And I can't help him with this, only comfort him."

The participants reflected on the prospect that the illness might be an obstacle to other people—for instance, a spouse—preventing them from doing the things that they used to do. The participants also described how they increasingly experienced a dependence on others. A married participant said: "It would be terrible if something happened to my husband, because I'm totally dependent on him." Most participants expressed their intention to remain independent for as long as they could, suggesting that they knew that this was not self-evident.

The participants also pondered on people with dementia in general. A few of them reflected on how best to approach people with dementia and their families. "Everyone asks 'How is it with John?' when it's the wife and children who should be in focus, I think. Because they are carrying the burden. Everyone forgets the wife and the relatives", said one of the participants, referring to the general situation for the family of a person with dementia.

In conclusion, all participants reflected on the concrete and emotional consequences their predicament had for others and they elaborated on the influence that their illness must have on people close to them.

Reacting emotionally to the shortcomings experienced

Emotional reactions were aroused in the participants as they faced their shortcomings and talked about other consequences of their disease. The most common reaction of the participants was for them to be angry and annoyed with themselves in those situations where they thought they ought to remember something. For example one participant said, "The worst thing is my short-term memory, which irritates me so much. I get angry with myself". The spectrum of emotions they expressed also included feelings of insecurity regarding current abilities and of low self-esteem. The experience of feeling stupid and ashamed in situations of memory failure

was recounted and some participants shared their underlying fear of appearing to be a fool in the eyes of others.

In contrast, all participants also depicted situations when they viewed the shortcomings arising from their forgetfulness from a comic point of view. For instance, one participant said, "It's just small things that you forget. You can just laugh at it." The efforts to balance seriousness with jokes in complex situations by reducing difficult emotions through the use of humour showed an awareness of their perceived shortcomings. "You see, how can I remember a thing like that?" one participant said laughing, in answer to a tricky question. The ability to laugh and make jokes about their own forgetfulness seemed to be used at times by all participants as an approach to handling a rather difficult situation, and could be one way to reduce the emotional strain of the perceived shortcomings.

Discussion

The findings of this phenomenological study reveal that awareness of disability in an occupational context is a complex phenomenon. Most experience-based research has focused on how awareness is experienced in general, but at the time of writing no previous study specifically focusing on the everyday occupations of people with Alzheimer's disease had been found. With this focus, the findings of this study demonstrate how the participants expressed awareness of things being different, and of changes taking place in their everyday lives, which is in contrast to the biomedical perspective on people with dementia as being unaware and with very limited resources to communicate their experiences (14). The findings suggest that the participants were able to express awareness when they were encouraged to describe their everyday life and their experiences, as recommended by Nygård (19), and confirm the notion that the individual with Alzheimer's disease is an important contributor to dementia research, in accordance with recent literature (12,18).

Surprisingly, one characteristic of awareness that was evident among the participants in this study concerned their reflections on the consequences their predicament had on others. Such reflections were not expected, as they have not been found in other studies, apart from that of a publication by Pearce et al. (33), who described how men with Alzheimer's disease were concerned with how their memory problems affected their wives' health and lifestyles. This is similar to the findings of this study, in which participants dwelled on what their illness meant to their loved ones, explaining, for example,

that others must be worried about them because of their illness. This suggests that awareness should be understood in a larger context, including factors such as personal expectations, social norms and interactions with other people. Consistent with our findings, several other authors have suggested that an understanding of awareness in dementia should adopt a contextual and interactional perspective (12,34,35).

In occupational therapy research, the importance of social interaction has been identified and an emphasis has been placed on how this is an important dimension of healthy people's occupations (36). The possibility that people with dementia do reflect on their illness having repercussions for loved ones and other people around them is important, and should be taken into consideration in dementia care when occupational therapists often collaborate with a couple where one of the couple has Alzheimer's disease. This finding indicates that the person with dementia is an important contributor in planning for interventions, suggesting that the relationship between a person with AD and that person's carer is more complex than a one-way communication between carer and receiver of care. Further studies of the experiences of people with dementia that explore the development and construction of awareness are needed to deepen our understanding of the social construction of awareness.

Another finding of this study was the participants' perception that changes were difficult to grasp and to describe. The elusiveness of the experience could help us to understand why people with dementia have difficulties in formulating their experiences concretely. The participants in this study felt unsure of what they were supposed to feel. While they were all well aware of their diagnosis they seemed to be engaged in a tension between getting on with their day-to-day lives and knowing that Alzheimer's disease is a progressive and disabling illness leading to dependence and a need for constant support. Their reflections were possibly imbued with the shared societal view of dementia as a much feared and stigmatizing disease that depicts people with this diagnosis as "victims" or "sufferers" (12,14,37). This knowledge seemed to be in conflict with the difficulty of "feeling" the disease, of getting a grip on its extent, and incorporating the illness experience into daily living.

Several authors have noted that awareness can vary as settings change and fluctuate in the course of the disease (38,39). This is an important aspect in the care of people with AD that has implications for their care and treatment. However, the evidence of a fluctuating awareness was not apparent in the present findings. This could be explained by our

intention to tap into the experiences of the person, using interviews aimed at getting descriptions from the participants' life-world. In the sense intended here, if one is unaware of something, there is the implication that this something could not be experienced and described by the person. Hence, a participant with fluctuating awareness could not be expected to describe this experience. Thus, a fluctuation of awareness is only something that could be noticed by others.

There is no evidence that occupational therapy can influence the progression of dementia. However, by understanding more about how people experience the consequences of having Alzheimer's disease, occupational therapists can create an everyday context that will support people with dementia in social interactions, for instance, through supporting engagement in valued occupations by simplifying the tasks, and guiding spouses. Awareness is described as being important for successful rehabilitation and should be one aspect used to guide occupational therapy interventions (1). Hence, as a starting point for planning interventions, it would be important for clients to be supported in formulating their experiences, by giving them time and the opportunity to express their experiences. Ways of doing that as professionals could include reformulating questions and giving examples, and attending to expressions of awareness in everyday occupations (19). Gaining an understanding of how people perceive their situation and how awareness is expressed will also be significant for how we approach and interact with people with dementia diagnoses (40); this conclusion is perhaps the most important clinical implication of this study.

After careful consideration of the possible ways to gain access to expressions of awareness in people with dementia, we chose a phenomenological approach (27) as had been suggested by other researchers (5,39). This approach elicited an understanding of how people with Alzheimer's disease may express awareness. Since a phenomenological method requires in-depth studies on a limited number of participants, the findings could not be generalized to all people with Alzheimer's disease. However, our findings can be taken as a point of departure in practice and future studies.

This study agrees that awareness is a multifaceted construct as described in the research and literature. The findings demonstrate how awareness of the consequences of Alzheimer's disease in everyday occupations may be expressed through individual reflections on occupations within social environments. By acknowledging and supporting the voices of people with Alzheimer's disease we can enhance our understanding of how they experience their

everyday lives. This is one avenue that can be pursued to further improve the provision of care for people with Alzheimer's disease.

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