

Experiences of Active Everyday Life Among Persons with Prodromal Alzheimer's Disease: A Qualitative Study

Mandana Fallahpour^{1,2}, Heather Fritz³, Charlotta Thunborg^{2,4}, Ulrika Akenine², Miia Kivipelto^{2,5,6}

¹Department of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Stockholm, Sweden; ²Department of Neurobiology, Care Sciences and Society, Division of Clinical Geriatrics, Karolinska Institutet, Stockholm, Sweden; ³School of Occupational Therapy, Pacific Northwest University of Health Sciences, Yakima, WA, USA; ⁴School of Health, Care and Social Welfare, Department of Physiotherapy, Mälardalen University, Västerås, Sweden; ⁵Institute of Public Health and Clinical Nutrition, University of Eastern Finland, Kuopio, Finland; ⁶Stockholms Sjukhem, Research & Development Unit, Stockholm, Sweden

Correspondence: Mandana Fallahpour, Department of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Stockholm, Sweden, Email mandana.fallahpour@ki.se

Introduction: Identifying strategies to prevent or delay cognitive decline among the rising numbers of elderly is acknowledged as a global public health priority. Research suggests that an active lifestyle in terms of participation in activities has the potential to reduce the risk of later-life cognitive decline. The concept of “active everyday life”, however, needs to be further explored.

Aim: The study aimed to explore and describe the active everyday lives of persons with prodromal Alzheimer's disease (AD) in terms of quality of participation in activities and perceived restrictions.

Methods: This qualitative study was part of a larger project, the MIND-AD_{MINI} trial. Nine in-depth interviews were conducted with seven participants (2 males, 5 females; mean age of 72.3) at baseline before the intervention. The data were collected from January to October 2018 and analyzed using the grounded theory approach.

Results: Four categories emerged from the analysis: (i) active body and mind; (ii) doing desired meaningful activities to feel engaged, contented, and satisfied; (iii) doing in the context of being connected to others; (iv) ability in making decisions and taking actions. From these categories, which presented the key elements of an active everyday life, a core category was identified: Living a complete life in flow.

Conclusion: The findings suggest key elements of participation quality that contribute to an active life. The identified elements are important to be considered in rehabilitation to provide opportunities and possibilities for participation to enable and improve the quality of participation among persons with cognitive impairments.

Keywords: Alzheimer's disease, everyday life, activity, participation, prevention, qualitative method

Background

Identifying strategies to prevent or delay cognitive decline and promote quality of life among the rising numbers of elderly has been recognized as a global public health priority.¹ Research suggests that an active lifestyle, and specifically, participation in cognitive, physical, and social activities has the potential to reduce the risk of cognitive decline and dementia in later life^{2–4} and to promote health and well-being as recommended by World Health Organization^{5,6} and contributes to the prevention of cognitive decline in later life. Though existing research suggests an active lifestyle overall has health-promoting effects, many questions remain. For example, a recent systematic review examined the role of participation in activities in preventing later-life cognitive decline and showed that existing studies have ignored participation quality (eg, an individual's subjective experience) and focused instead only on the quantity of participation (eg, frequency, intensity, duration).⁷

Previous literature^{7–9} stresses the importance of considering the subjective experiences of individuals (eg, interest, motivation, beliefs, and meaning) in applying a client-centered approach and enabling participation in activities,

increasing the quality of individuals' participation. Focusing on the quality of participation in activities necessitates attending to why individuals do what they do, the meaning of participation, and the dimensions of participation (eg, the way that they do it) that contribute to the overall quality of the experience.⁸ Focusing on quantity of participation only (versus quality) limits our ability to generate useful strategies for maintaining cognitive function and well-being in later life.⁷ For example, many individuals encounter age-related functional and contextual changes in later life that reduce their overall quantity of participation. In the face of such activity restrictions, studies that focus only on participation quantity fall short in explaining why many older adults remain cognitively intact and experience high levels of well-being, despite the reduced quantity of participation. Thus, the quality of participation may be an equally important factor influencing the relationship between participation, cognitive preservation, and well-being.⁷ Indeed, the Covid-19 pandemic has shed light on the myriad of ways changes to activity quality impact well-being and quality of life as important as the participation quantity.^{10–12}

The aim of this study was to explore and describe the active everyday lives of persons with prodromal Alzheimer's disease (AD) in terms of quality of participation in activities and perceived restrictions. We drew on the World Health Organization's Active Ageing Policy to conceptualize "active lifestyle" as synonymous with active aging, which refers to "the process of optimizing opportunities for health, participation, and security in order to enhance the quality of life as people age".⁵ As such, we were not concerned with the quantity and frequency of participation. Instead, we aimed to understand how opportunities and possibilities for participation emerge as well as the quality of those forms of participation.

Prodromal AD, defined as a pre-dementia phase, is characterized clinically as mild cognitive impairment (MCI).¹³ Persons with prodromal AD (PAD) are cognitively intact with biomarker evidence of brain amyloid deposition representing a group at high risk for cognitive decline and dementia.¹⁴ The emergence of the first clinical symptoms of PAD can occur as early as 12 years before a dementia diagnosis,¹⁵ which suggests some individuals may experience a long and progressive prodromal phase of AD, inclusive of successive emergence of cognitive deficits, depressive symptoms, and functional impairments. Thus, while concerns over cognitive preservation may be particularly high among this group, few studies have examined persons with AD's subjective experiences regarding being active or having an active everyday life.

This study was a qualitative sub-study of the Multimodal Preventive Trials for Alzheimer's Disease (MIND-AD_{MINI}) project (ClinicalTrials.gov NCT03249688), which targeted persons with PAD.¹⁶ The MIND-AD_{MINI} project¹⁶ sought to establish the feasibility of an adapted FINGER-based multimodal lifestyle intervention² for persons with PAD. More about the intervention program is found elsewhere.^{16,17} This study explores the experience of active everyday life among a sample of persons with PAD who took part in the trial. We chose to focus on persons with PAD because they are at risk for further cognitive decline and activity restrictions while also often being especially concerned with how their everyday life activities could serve to preserve their cognitive function over time. Data collection for this study was conducted with participants at baseline before they started the intervention. This qualitative study aimed to develop knowledge regarding the meaning of the concept of active participation in everyday life, or active everyday life for those with PAD.

Methods

Design

A qualitative, interview-based study was conducted to explore the experiences of active everyday life among persons with PAD, who were recruited from an ongoing trial, Mind-AD_{MINI}.¹⁶ All interviews were conducted in Swedish (the participants' native language). A grounded theory approach was used to analyze the data as interpreted by Charmaz.¹⁸ We chose to use a grounded theory approach because it is an optimal choice when the study goal is to generate a theoretical understanding of the experiences of active everyday life after AD, from the perspective of persons with AD.

Participants

We recruited a purposive sample of Swedish individuals ages 60–85 diagnosed with PAD, (verified through a physician's report or self-report) who were participating in the MIND-AD_{MINI} trial. Inclusion criteria for the MIND-AD_{MINI} trial are

presented in a previous publication describing the protocol.¹⁶ Participants were invited to participate in this qualitative sub-study if they were (i) interested in participation, and (ii) able to speak in Swedish and share their experiences. Participants in the MIND-AD_{MINI} trial who gave their consent to participate in the qualitative sub-study were contacted by the third author. Participants were provided with both oral and written information about the study. Of eight participants who agreed to take part in this qualitative study, seven gave their informed consent and were interviewed. One participant decided not to take part in the study and dropped out due to lack of time. The characteristics of the participants are presented in Table 1.

Ethical Approval

The ethical approval for the MIND-AD_{MINI} trial and this sub-study was granted by the Regional Ethical Review Board (Regionala Etikprövningsnämnden) in Stockholm, Sweden (Registration number: 2016/2605-31/1). All participants signed a separate consent form for this interview study in accordance with the Declaration of Helsinki (World Medical Association of Helsinki, 2013).¹⁹ Furthermore, the participants' informed consent included the publication of anonymized responses.

Data Collection

The MIND-AD_{MINI} trial was conducted between October 2017 and December 2019. In this qualitative sub-study, the data were collected from January to October 2018 using individually, face-to-face in-depth interviews with seven participants at the baseline phase before the participants start the MIND-AD_{MINI} intervention trial. Five participants (2 males and 3 females) were interviewed once, and two female participants were interviewed twice to capture the area of exploration and saturation of the data, resulting in nine interviews. Two female participants were interviewed with their partners. The first author conducted the interviews with prior experience conducting in-depth qualitative interviews. An interview guide was created based on the guidelines for qualitative interviews²⁰ that corresponded to the aim of the study. The participants were specifically asked questions regarding their experiences of active participation in different areas of everyday life considered as having an active everyday life (i) through their life span and before any symptoms of cognitive impairment, and (ii) during the prodromal AD phase. The topic areas of inquiry in the interviews are presented in Box 1. Semi-structured questions allowed the participants to freely reflect on the areas of inquiry and to make examples of concrete situations in which they experienced themselves as active.²¹ Following the principles of theoretical

Table 1 Demographic Characteristics of the Participants (n = 7)

Characteristics	n
Age Mean (Range)	72.3 (62–79)
Gender Male Female	2 5
Marital status Married Single/widow/divorced	5 2
Living status With others Alone	6 1
Education High school University	2 5

Box I Topic Areas of Inquiry in the Interviews**Using Open Questions, the Participants Were Asked to Describe the Following:**

Experiences of active participation in different areas of everyday life through the life span and before having any symptoms of cognitive impairment
 Experiences of active participation in different areas of everyday life during the prodromal AD phase
 Description of concrete examples of different areas of everyday life in which they experienced themselves as active in their participation
 Experiences of restrictions in active participation in different areas of everyday life

sampling and constant comparison,^{18,22} theoretically important ideas introduced in earlier interviews were added to the interview guide as probes and those ideas were queried in subsequent interviews. All the interviews were audio-taped and transcribed verbatim with participant permission. During the interview, notes were taken by the interviewer. The interviews took between 60 to 90 minutes. Interviews were conducted in close connection to a MIND-AD_{MINI} trial activity in a university hospital facility in Stockholm.

Data Analysis

A grounded theory approach was utilized to analyze data.¹⁸ Grounded theory analysis is an optimal choice when the study goal is to generate a theoretical understanding of the experiences of active everyday life after PAD, from the perspective of persons with PAD. Analysis began with initial line-by-line reading and coding of the text. This initial coding led to two additional interviews to query some experiences in more depth. The initial coding was followed by focused coding, which involved searching for the most frequent or significant codes and aggregating codes based on thematic or conceptual similarity. Finally, axial coding refined the dimensions of categories by relating them to sub-categories. The interrelationships between categories emerging from the data during the initial, focused, and axial coding, served as the basis for the core category. To increase credibility, we used peer debriefing and discussed the analysis for each participant with the research group until agreement was reached on the key dimensions and sub-dimensions of experience. The analysis was based on the constant comparative method- and back and forth process between data and the ongoing analysis to ensure that the analysis was grounded in the data. As saturation was achieved after the addition of the ninth interview, no further participants were enrolled in the study.

Results

Nine interviews were conducted among $n = 7$ participants with PAD. The participants' mean age was 72.3 years and five participants were female. The demographic characteristics of the participants were previously presented in Table 1.

Four categories emerged from the analysis: (i) active body and mind; (ii) doing desired meaningful activities to feel engaged, contented, and satisfied; (iii) doing in the context of being connected to others; (iv) ability in making decisions and taking actions. From these categories, which presented the key elements of an active everyday life, a core category was identified: *Living a complete life in flow* (Figure 1).

Core Category: Living a Complete Life in Flow

This core category denotes the key elements of an active everyday life, referred to here as an active life, that are important to an individuals' sense of fulfillment, well-being, completeness, and satisfaction with life (See Figure 1). Participants' descriptions of an active life emphasized the importance of having a body that functioned properly and doing desired activities together with family, friends, and colleagues in the context of "togetherness". Specifically, participants in this study expressed "doing" with persons with whom they felt a connection to, contributed to life continuity and provided opportunities to experience flow and feel satisfaction. Though participants still experienced an active life, they described variations of passive to active engagement as well as how the quality of "active" had changed for them. Those variations were driven, in part, by the cognitive and physical changes that participants experienced after developing PAD symptoms. In response to those changes, some participants modified their participation. For example, some participants described that they might increasingly participate in activities that were less challenging and demanding while reducing participation in those they experienced as more challenging, such as social activities, volunteer and

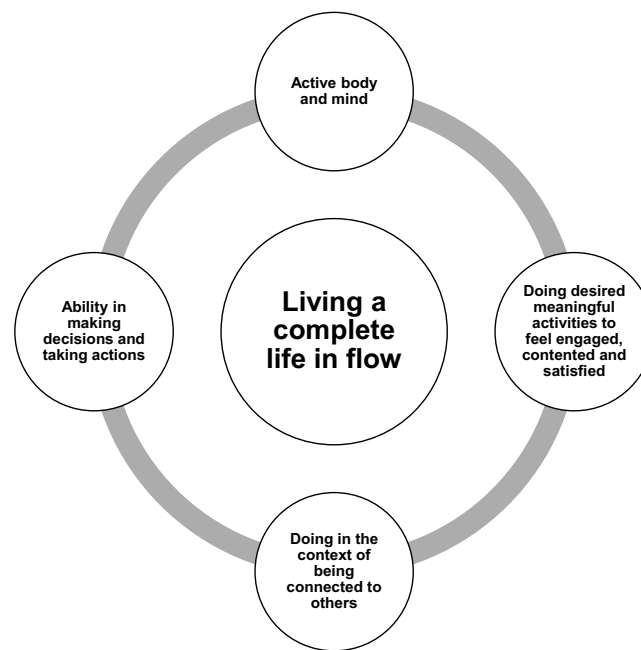


Figure 1 Key elements of an active everyday life.

paid work or activities outside the home. Other participants still participated in activities because they were desired but did so less frequently. The following categories further characterize how participants experienced different elements of an active life and how participation in activities changed for them after the onset of PAD symptoms.

Active Body and Mind

An active life included physical and cognitive dimensions. Reductions in physical and cognitive capacities contributed to changes in the meaning and experience of participation, as well as the types of activities the individual chose to do. Specifically, though participants reported experiencing limitations in their ability to participate in certain activities after diagnosis, they still saw themselves as active beings. For example, one participant frequently played games for leisure and described how prior to his diagnosis he was mentally “quick” and good at playing games. Though he now regarded himself as slower in both thinking and acting, he continued playing games daily and viewed game-playing as a tool to improve his cognitive function/performance. Though the participant still enjoyed playing games, the meaning now was less about reinforcing feelings of competence and more about maintaining cognitive capacities.

I played Bridge two, or three times a week. [I] played volleyball, I met friends. Met family. I [was] very much [social] And physical too. ... Yes, I was ... quite successful in [Bridge]. [It has been] the most important activity for me to play indeed ... and it is still ... I am still active, indeed. Therefore, I do not just sit and nag about [everything] ... I am a very positive person. (Participant 4, Male, 73 years old)

In addition to feeling mentally “slower”, mental fatigue was a common experience reported among participants. Mental fatigue was especially challenging at night and was one reason why some participants altered participation in certain activities. For example, after a cognitively demanding day, some participants preferred to participate in less cognitively challenging activities, such as watching TV.

In the evening, I am tired and... and most often, I watch TV. But I am not proud of myself that I can't ... I think that I am a bit... I am probably a bit, I don't know if I should if I use the right words, but a little depressed and low energy, I think. I think I have a hard time grasping things [especially in the evenings]. (Participant 1, female, 62 years old)

Social situations and group activities posed the most challenges and contributed the most to mental fatigue because they were more cognitively demanding. Participants needed to pay attention, remember, and recall names, and engage in reciprocal discussion. Though many participants still enjoyed social activities, and therefore still participated in them, they experienced activities differently compared to before the diagnosis.

... If I am going to meet a lot of people, and like, yes, hang out as usual. I get ..., today I get very much tired of going to parties, for example, because I do not know. Somehow it feels like I must sharpen up more to be able to handle the situations. (Participant 2, female, 71 years old)

Participants also stressed being active meant being able to physically do something and have a daily plan to fulfill. Their descriptions stress the importance of physicality as part of experiencing an active life. For instance, one participant described how it was meaningful for her to be physically active and remain interested in making things with her hands (eg gardening, weaving, swimming).

Yes, I have always been interested in flower care ... what is it called, now I lose the word here ... help me with the word (says to her partner and he says flowers) ... flowers. Yes, agriculture, or whatever you want to call it then. (Her partner says garden) I do not know ... garden. And I am interested in sewing. I have sewn, crocheted, knitted, and woven. I have gone through it, and it was something new for me to weave and I learned that here on (names a place). And yes, what's more? Yes, I have been involved in building one, two, and three houses. Yes, I have nailed and wallpapered. I've done everything [physical with hands] possible, and yes, and [I have made] jam and juices, because it is fun when it is your own berries and fruits. (Participant 5, female, 79 years old)

Participants also stressed the importance of other body systems in achieving an active life. For example, one participant discussed how she had previously been very active and felt connected to her body. Changes in her hearing, visual abilities, and the need to use glasses and auditory assistive devices had led her to change the nature of her participation in certain activities. The participant was clear, however, that she had decided by herself to change her participation due to her memory problems and her diminished visual and auditory abilities.

Doing Desired Meaningful Activities to Feel Engaged, Contented, and Satisfied

Participants expressed that despite PAD symptoms, they could still experience being active and feel engaged and satisfied when participating in desired activities. Thus, the “meaning” of the activity was central to the perception of being active. However, while certain activities were still meaningful, individuals participated in them less frequently due to physical and cognitive changes experienced after PAD onset.

For instance, one participant shared that he had gambled throughout his life. Though he still enjoyed gambling, he could not do this activity as before because of changes in his cognitive function. He described that he had become slower in thinking, memorizing, remembering, and acting (taking action). Moreover, he experienced mental fatigue, which prevented him from gambling at night. Despite his limitations, he still described himself as active because he could still participate in gambling, though less frequently and via a different modality (playing on a computer).

I play bridge normally. At a very high level. [I] Play in the largest Swedish club. And then I have noticed now because I only play there now once a week. Previously, it was several times but now it is only once a week. However, I play on a computer. There is a worldwide one called ‘Bridge Base Online’. (Participant 4, male, 73 years old)

Another participant stated she could not really describe herself as active anymore because she had given up participation in the activities she was interested in (eg, gardening, weaving, traveling, meeting her friends) due to the restrictions she experienced. She noted her interest in doing some activities had changed, such as activities involving meeting other people. Her partner attributed the changes in her participation to her participant being slower and clumsier than before and to her having less motivation to enact plans. Though she had intentions to act, she struggled to initiate and follow through. Because of those challenges, her partner noted she had less interest in doing activities she had previously enjoyed and was less active.

Yes, everything slows down. It does actually ... and a little clumsier. (Participant 5, female, 79 years old)

Doing in the Context of Being Connected to Others

When describing their experiences of an active life, participants emphasized the importance of meaningful others. Specifically, they described how being active was not only about participating in desired activities, but also about participating with others personally connected to them. In addition, participant narratives emphasized two life situations that provided the opportunity to be connected with others, spending time with family and work.

Family and Friends as a Meaningful Context for an Active Life

Participants described that before, when they worked and had family around, they experienced their lives as active, ongoing, and full of possibilities for getting engaged in a variety of activities and that having the entire family together made them feel this way again. Engaging in activities with family and friends created opportunities to have more contact with others and for engaging in more numerous and varied activities, resulting in more varied activity choices.

Yes, but then it was a lot at work, yes it was. And then of course ... Now they are my sons, I have two sons Then there were a lot of activities they had to go to. It was football and it was handball, and it was anything. So that, like life just spun around with everything. So that it was always very much. Mm. But it ... (Participant 1, female, 62 years old)

Participants also described that while social connections mattered, being with those with whom there was a sense of shared history and “togetherness” was especially important to an active life. Togetherness could be felt when the elements of companionship, love, connectedness, and support were present in the experience. For example, one participant described how meaningful it was for her to be with friends with whom she shared a long history and did many activities together. Though she could not remember how she was as a kid, she had close friends that were still in touch with her and who had done different activities with her throughout her life. She described that they even retired at the same time.

My friends, they stopped working [got retired] at about the same time as me then. One of my friends worked as a dentist down in Switzerland, so we were there and visited her several times a year in Switzerland. So that we have been [there] and traveled a lot [together]. ... we have done a lot together ... And we are ..., we are three, sometimes three or four in that group, and we travel a lot together. We do a lot of things together ... I am very active with them. So there, so that I think of myself as very active. (Participant 7, female, 71 years old)

In our sample, spouses/partners, children, and close friends contributed the most to feelings of shared history and togetherness. For example, three participants described their life partners as significant supports, one participant identified her daughter and three close friends as having the same role and critical to an active life.

While participants described an active life as one in which an individual has things to do with meaningful others, they also noted that a lack of family, friends, and meaningful others led to feelings of loneliness. For example, one participant described her loneliness and isolation as disturbing and as restricting an active life. She emphasized her need to have others in her life for companionship and connectedness as a motivating context for her active engagement in activities.

Usually, I take a long walk. I walk about between one and one and a half miles a day. So, I am out a lot. I do not like being at home alone so much, but I like to go out among people and above all move around. Sometimes I meet friends who have stopped working [are retired], but there are many of my former friends who are still working, so that, it can be a little lonely sometimes. (Participant 1, female, 62 years old)

Having family and friends did not guarantee feelings of an active life, however. For example, two participants experienced loneliness despite having significant others in their lives (one had a partner and the other her child). They described a lack of connectedness in their relationships. They described how the feeling of loneliness experienced as a lack of connectedness with their significant others influenced their perception of an active life. One participant described how his relationship with his partner had changed. Previously, he had a routine of doing different activities with his partner (walking, being outdoors, playing golf). Because of PAD symptoms, he no longer had the same capacities as his partner. Thus, while his partner maintained the same activities and routines as before (eg, golf), he found himself alone and having to find his own things to do.

And then so, before we were always out and went together ... but since I now have this [diagnosis], I have a hard time keeping up with her, and then it is better that we go separately. So, then we usually go out and walk. I by myself, and she by herself. And then, in normal cases, we usually, yes 2–4 times a week, I usually play golf during this summer period. And eeh, she has, continued to play golf. So that she still does it, which means that she is away 2–4 days a week for such a round when she is out, it takes between 4 and 6 hours before she gets home, and then, during that period so I usually go out and do different things. Yes, sitting and solving sudoku [puzzle] and listening to the radio and..... (Participant 6, Male 78 years old)

Having meaningful others was described as important as (i) meeting the human need for togetherness, (ii) providing a context of connectedness and companionship for participation in desired activities, and (iii) fulfilling the human need for supporting each other.

Work: An Important Activity to Make Life Active

Participants described work as previously being their main everyday activity and how it was meaningful and contributed to their sense of an active life. Through work, participants identified as active individuals in different dimensions eg, socially, physically, and cognitively. Participants also described work in general as an opportunity to (i) get actively engaged in life, (ii) get connected with others and do things together (social networks and social activities), and (iii) develop their identity. Participants' narratives illustrate the difference between having a busy and active life prior to the PAD diagnosis where at times it was difficult to even find some free time and the lack of active life experienced after ceasing paid work. For example, one participant was forced to leave her job due to her cognitive deficits after working a lifetime. She experienced a quick, undesired transition from an active to a passive life. She described that afterward she was confused about what to do and had difficulty facing the challenge of "empty" days. She described how she had always seen herself as competent, busy, and hardworking and how, now, her view of herself had changed since her diagnosis and leaving her work.

... While I was working, then I always had a lot to do. As I said, I worked as a project manager and also as... had responsibilities for the staff. So that it was, it was pretty hectic. [I had] a lot to do all the time. Yes, right up until I started getting sick. So, I worked one hundred percent. I was probably a... [she was sad and didn't finish the sentence] What should I say? Yes, I worked very hard. Very much. And I was appreciated for that. And that was what was so sad about it when I got sick, then I was not worth anything. (Participant 1, female, 62 years old)

Work was also experienced as an opportunity for social connections and activities. Getting retired or leaving a job could therefore affect the experience of being connected with others and restrict opportunities to participate in activities. One participant described that leaving her job led her to have a less active social life. She experienced a mismatch with her previous friends at work due to the different patterns of everyday life (working and free time). The gap restricted her from socializing with them and she expressed feelings of loneliness and missing her working social life.

Yes, I really miss it [my work], even though it could be a lot at work and so on, but I miss that life and [my]colleagues and, I think it is a bit hard namely to be [by] myself and... I need some company from others. ... and because there are still many persons out of my circle of acquaintances, that still works. I have a few [persons] who are a little older like... I am used to meeting them sometimes and we do some activities. But I think it is surely too little social life. (Participant 1, female, 62 years old)

Though some participants lamented the transition from everyday working life, others found that work was difficult to manage due to its complexity. For example, one participant who participated in volunteer work described how the social situations at her volunteer work were too challenging and stressful to manage by herself, which led her to quit her long-held volunteer work.

I can handle when I must do things that I may not do every day, and if I have to meet a lot of people, and like, yes, hang out as usual. ... today I get very much tired of going to parties, for example, because, I do not know, somehow it feels like I must sharpen up more to be able to handle the situations. And I have received tablets like this, sedative tablets that I can take if I feel anxious. ... So, I think, right now it is probably almost the most difficult situation, and to know how to handle this, my situation towards others. (Participant 2, female, 72 years old)

Ability in Making Decisions and Taking Actions

Participants in the study described that their experience of an active life was not only defined by their “doing/ performance” but also by how they made the decisions, plans, and took actions to make things happen. They described difficulties with making choices and decisions, planning, and taking action when needed. Participants who expressed the most issues with such cognitive capacities also reported less feelings of having an active life. These participants found it most difficult to decide which activities to take part in the first place as well as how to plan the different steps necessary to make participation possible. One participant described that she needed to be “pushed” by someone to do things and take action. She described that she wanted and wished to do things, but she experienced a significant problem with starting/ initiating them and making them happen which made her dissatisfied with her passive life.

I have not really taken up any activity that is concrete. I have been thinking a lot, to..., in some ways, to pass the time, one can say that I should do something, but I have not really been able to make it happen. I think I've had a bit of a hard time getting myself to really accomplish anything, that now I'm going to do this, now I'm going to do this, but it gets a little bit [delayed], yeah, I'll do that later, I'll do that later. Yes, so I... I'm not so proud of myself in that way, that I have not really been able to deal with things, but... Yes, I just let it [the time] go, the days. (Participant 1, female, 62 years old)

Similarly, another participant's partner shared that his partner had ideas about activities she wanted to do but was unable to initiate action or take the steps forward to follow through on activities. He expressed that this was quite different from how she used to be and that the change caused restrictions in her having an active life.

Yes, there are restrictions. It is slower and the interest is not as great, the interest in the ideas [is not as significant as before], but the ideas exist, and it is possible to see the difference in her interest in activities [for example] meeting people, yes, and [her interest in] taking care of things. The ideas exist but not the activity itself. The activity does not really exist. (Partner to participant 5, female, 79 years old)

Discussion

We conducted a qualitative study to examine the experience of active life among persons with PAD in terms of quality of participation in activities and perceived restrictions. The study findings suggest individuals experienced PAD symptoms that changed the nature of and opportunities for participation in desired activities and such changes had implications for one's sense of having an active life. As the quality of participation changed, meaning derived from participation (and whether one still experienced an active life) was connected to personal histories and occupational identities. Being able to find ways to still have an active life contributed to one's continued sense of “mastery” or competence in everyday life.⁸ The findings also suggest key elements of participation quality that contribute to an active life. Specifically, the findings illustrate how being able to choose and execute desired activities that make use of the body and that can be done with meaningful others and in a way that reinforced one's sense of competence were essential to one's sense of active life. These results are in line with the previous research describing the essential meaning of participation in everyday activities.²³

In this study, participants' descriptions of being active in life emphasized the importance of the context in which doing meaningful and desired activities happened, the role of meaningful others, and the context of togetherness which provided opportunities to experience flow, life satisfaction, and continuity in one's life. Previous empirical research²⁴ has described togetherness as an acted relation, stressing how the act of doing activities with someone could create togetherness and belonging and is a way for individuals to negotiate and construct meaning. Previous research²⁴ also found that participation in activities together with others (i) could create hope and expectations of future actions, and (ii) is experienced as a social process including change over time. The study findings complement existing literature as they highlight the need to consider and create opportunities for individuals with PAD and related cognitive impairments to become part of an enacted togetherness. Doing so could enable an active life and improve the quality of their participation in activities and promote health and well-being.

Findings in this study are supported by Phinney²⁵ who found that participation in desired activities was meaningful for persons with AD since through their engagement, they experienced feelings of pleasure and enjoyment, felt a sense of connection and belonging, and retained a sense of autonomy and personal identity. The findings also reflect how the

process of meaning-making is ongoing throughout life.²⁶ An active life was associated with doing activities with whom there were shared histories and connections. A sense of belonging and togetherness (even after PAD diagnosis) was continually negotiated and built through shared participation. Togetherness was defined as “being part of something in which the persons involved were contributing to each other in various ways” (p. 371).²⁷ Previous research emphasized how a sense of belonging could connect individuals and places through shared stories, culture, and experiences.²⁷ Our findings align with the work of Nyman et al²⁷ suggest that while a sense of togetherness might be challenged due to life situations (eg, disease), it could be created and maintained through an ongoing process of nurturing established relationships as well as creating new ones.

The study findings also align with prior work on agency and control²³ by stressing the importance of subjective experiences of choice, control, and agency vis-à-vis experiencing an active life. Agency, defined as making things happen by individuals’ own actions, involves choice, action, and the ability to influence the outcomes of one’s actions,²⁸ which was experienced as challenging in the context of PAD. Research also stressed the importance of agency among persons with AD to preserve a sense of self since they are at risk of diminished agency.²⁹

The findings in this study expand our knowledge regarding the dimensions of an active everyday life, which present the quality dimensions of active participation in everyday life, among persons with PAD, as a group at risk of developing cognitive impairment. To our knowledge, this is the first study to explore the concept of “active everyday life” among persons with late-life cognitive impairment in general and persons with PAD in particular. The findings suggest a role for rehabilitation professionals in assisting individuals with PAD and related cognitive impairments to ensure they can participate in desired activities with meaningful others in ways that match but do not overwhelm their changing capacities. The findings are clinically important to promote the quality of active participation in every life among persons at risk of developing later-life cognitive impairment, which together with increasing the quantity of participation can contribute to prevent or delay further development of cognitive decline.⁷ Future research is needed to understand how individuals with PAD experience participation in everyday activities and their active everyday life after the multimodal lifestyle intervention program such as the MIND-AD_{MINI} prevention trial.

Methodological Limitations

Our study has several limitations. We chose to recruit a sample of only Swedish older adults. A different sample of older adults from other countries with different social and healthcare systems may yield different experiences. Our study also included a small sample of seven participants and resulted in nine interviews. However, the sample reflects a variety of demographic characteristics, providing the opportunity for a more heterogeneous sample to capture different experiences among the participants and rich data to fulfill the study aim. One might reflect that the unequal gender distribution of the sample might have impacted the findings in the study. The recruitment process included 8 participants at the beginning (3 males and 5 females), of whom one male participant dropped out due to lack of time. Even if the number of female participants was higher than the male participants, the questions were formulated regarding different areas of everyday life covering human experiences on a general level and not specifically targeting the gender-specific activities. Two female participants were interviewed twice, whereas five other participants (2 males and 3 females) were interviewed once, which resulted in a total of nine interviews. These two participants were interviewed twice to fully capture the area of exploration and saturation of the data, and it has not influenced the findings.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis, and interpretation, or in all these areas: took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

Disclosure

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