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Participation in Everyday Life Before and After a Housing Adaptation

Björg Thordardottir, Agneta Malmgren Fänge, Carlos Chiatti, and Lisa Ekstam

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ABSTRACT

Housing adaptation aims to enable clients to live independently in their own homes. Studies focusing on participation in everyday life following a housing adaptation are lacking and needed. This study aimed to explore housing adaptation clients’ experiences of participation in everyday life before and after a housing adaptation, through the lens of a housing adaptation, using a qualitative follow-up design, with 11 participants. It was found that when the housing adaptation met the participants’ needs, performance of activities improved and the housing adaptation opened doors to engagement and participation in everyday life. Thus, focus on performance and engagement in everyday life at the onset of the housing adaptation process, combined with regular follow-ups, may enhance participation.

KEYWORDS
Content analysis; engagement; occupational therapy; performance; semistructured interviews

Introduction

At a time when the world’s population is aging, more people with chronic health conditions and disabilities are living in their own homes, at risk of facing restricted participation in everyday life (World Health Organization [WHO] & World Bank, 2011). The aging-in-place policy applied in many countries (Socialstyrelsen, 2015; WHO, 2015) demands that society allocate resources to targeted interventions that enable participation for all, and thereby promote health and well-being (WHO & World Bank, 2011). Key components for participation are activity performance, subjective experience, and interpersonal connection, all of which are affected by both internal and external conditions (Cogan & Carlson, 2017). Performance is the actual doing of an observable task that can be described in terms of qualities such as efficiency, independence, physical effort, and safety (Fischer, 1997). The broader concept “participation” also involves a person’s engagement—a subjective experience, which thus cannot be observed. Both performing and engaging in
activities are considered important for health and well-being (Kielhofner, 2008; Wilcock & Hocking, 2015; Yerxa, 1998). This study focuses on participation in everyday life, and in particular on housing adaptation clients’ subjective experiences of both performance of and engagement in activities with a temporal dimension (Larsson-Lund & Nyman, 2017; Townsend & Polatajko, 2013).

While housing adaptation (HA) is a common intervention provided by municipality services in Sweden, there is wide variation globally. The aim of the Swedish HA legislation is to enable independent living in one’s own home and is defined as the removal of physical environmental barriers and/or alteration of the housing (Svensk författningssamling [SFS], 1992). Sweden is a Western developed nation with a total population of approximately 10 million, with 20% of the population aged 65 years and over (Eurostat Statistics, 2017). Of the total population, 65.2% own their dwelling and 34.8 are tenants (Eurostat Statistics, 2017). In southern Sweden, where this study was undertaken, the majority (89%) of the population live in urban areas (i.e., localities), and this is close to the corresponding proportion (87%) of the total population in Sweden (Statistics Sweden, 2017).

People applying for an HA have different ages and levels of cognitive and physical function (Kim, Ahn, Steinhoff, & Lee, 2014; Thordardottir, Chiatti, Ekstam, & Malmgren Fänge, 2016). They often have a reduced ability to perform activities (Johansson, Lilja, Petersson, & Borell, 2007; Petersson, Kottorp, Bergstrom, & Lilja, 2009; Petersson, Lilja, & Borell, 2012; Peterssson, Lilja, Hammel, & Kottorp, 2008); their functional capacity is too low to overcome the environmental barriers in their own home, and thus they become dependent on others.

Earlier studies on HA have focused on aspects related to independence in everyday life (Fänge & Iwarsson, 2005b; Niva & Skär, 2006; Petersson et al., 2009; Petersson et al., 2008; Stark, Landsbaum, Palmer, Somerville, & Morris, 2009) and outcomes such as cost-effectiveness (Jutkowitz, Gitlin, Pizzi, Lee, & Dennis, 2012), decision making (Aplin, de Jonge, & Gustafsson, 2013), and safety in relation to falls (Chase, Mann, Wasek, & Arbesman, 2012; Keall et al., 2015; Pynoos, Steinman, Do Nguyen, & Bressette, 2012). Only a few studies have considered alterations of housing as a means of maintaining valuable relationships and roles and remaining active with the opportunity to socialize outside the home (Pettersson, Löfqvist, & Fänge, 2012; Tanner, Tilse, & De Jonge, 2008). A recent systematic review of the effects of HA found no studies that had focused on engagement in activities outside the home as an outcome (Stark, Keglovits, Arbesman, & Lieberman, 2017). Clients who have high expectations of the outcomes of the HA more easily come to a decision to apply, compared with those whose expectations are lower (Ekstam, Fänge, & Carlsson, 2016). Clients with high expectations expected that the HA would enable them to regain or increase their physical activities, gain more independence, freedom, and integrity, and remain living safely at home (Ekstam et al., 2016). In order to explore whether the expectations and influences of the HA on the clients’ performance and engagement in everyday life are sustainable over time, both a short- and long-term perspective is
The short-term perspective is especially vital since it can capture possible improvements in performance and engagement during the first months after HA (Petersson et al., 2009). A more long-term perspective is needed to capture eventual changes in performance and engagement further down the line—for example, to explore whether or not the HA matched the initial expectations the clients had when they applied (Ekstam et al., 2016; Fänge & Iwarsson, 2005a).

Performance and engagement are highly context dependent (Townsend & Polatajko, 2013). Therefore, it is important to elaborate on contextual aspects when developing knowledge concerning how an HA influences everyday life. This calls for further exploration of activity performance, as well as engagement in meaningful activities, that is, occupations, both in the home and outside it (Law, 2002; Townsend & Polatajko, 2013). This knowledge is valuable for professionals engaged in the process of HA, as well as for the clients themselves, in order to enable client-centered interventions in the home, tailored to the client’s needs and preferences. Therefore, the aim of this study was to explore HA clients’ experiences of participation in everyday life before and after an HA, through the lens of an HA.

Material and methods

Study design and context

This study has a qualitative longitudinal design, with data collected in the homes of the participants through semistructured interviews before and three and twelve months after an HA.

Sampling procedure and participants

The study is a part of a larger longitudinal study of HA clients, the Research Strategy for Housing Adaptation (ResHA) study (Ekstam, Carlsson, Chiatti, Nilsson, & Malmgren Fänge, 2014). Inclusion criteria for people for the parent study were living independently in the community in apartments with shared entrances or houses with own entrances; being more than 20 years of age; applying for an HA via an occupational therapist employed by the municipality; and being able to communicate and follow instructions in Swedish. Excluded were those living in sheltered housing and those who could not speak or understand the Swedish language.

In this specific study, the participants were sampled purposefully, to ensure diversity (Creswell, 2014) in terms of gender, age, living arrangements, type of housing, type of HA applied for, and use of mobility devices. Seventeen participants were enrolled in the study when they had applied for an HA, and participated in an interview before the HA. At a second interview 3 months after the HA, 15 participants were interviewed—one of the initial 17 had been declined the adaptation, and one was deceased. At a third interview, 12 months after the HA, 11 participants were interviewed—four additional participants had dropped out due to disease. The participants’ characteristics are presented in Table 1.
Data collection

Data were collected by means of semistructured interviews conducted by the last author (LE). Data collection took place in the participants’ homes on three different occasions: before, and then 3 months and 12 months after the HA. The first interview was undertaken in close connection to the time of the HA application. Seven participants received their adaptations within 2 months, three had to wait 4 to 5 months, and for one participant, who had a larger adaptation made, it took 9 months before the HA was finalized. The interviews were semistructured, following an interview guide. Probes and follow-up questions were participant specific, as they addressed their own experiences of everyday life and the HA process in the context of their homes. The initial interview focused on experiences of performance and engagement in everyday life in the light of the HA application, and the participants’ expectations of how the HA would influence everyday life and their health. Both interviews conducted after the HA focused on the participants’ experiences of their health, performance and engagement in everyday life, and whether or not their expectations of the HA had been met. Each interview took about 60–90 minutes. All interviews were transcribed verbatim.

Data analysis

Structured content analysis (Graneheim & Lundman, 2004) was used in order to allow for comparison between the participants, with a focus on performance and engagement before and after the HA. Only those participating in all three interviews were included in the analysis. The data analysis began with the first (BT) and last (LE) authors reading through and listening to the interviews several times.

Table 1. Participant characteristics, n = 11.

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<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Age, years: range, mean</td>
<td>45–95, 71</td>
</tr>
<tr>
<td>Gender: male/female</td>
<td>5/6</td>
</tr>
<tr>
<td>Single living/cohabiting</td>
<td>6/5</td>
</tr>
<tr>
<td>Use of mobility devices indoors, n</td>
<td>8</td>
</tr>
<tr>
<td>Use of mobility devices outdoors, n</td>
<td>9</td>
</tr>
<tr>
<td>Type of dwelling</td>
<td></td>
</tr>
<tr>
<td>– One-family house/own entrance</td>
<td>5</td>
</tr>
<tr>
<td>– Apartment/shared entrance</td>
<td>6</td>
</tr>
<tr>
<td>Urban/rural</td>
<td></td>
</tr>
<tr>
<td>– One-family house/own entrance</td>
<td>5</td>
</tr>
<tr>
<td>– Apartment/shared entrance</td>
<td>6</td>
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<tr>
<td>Type of HA applied for</td>
<td></td>
</tr>
<tr>
<td>– Ramp at the entrance</td>
<td>2</td>
</tr>
<tr>
<td>– Grab bar at the entrance</td>
<td>1</td>
</tr>
<tr>
<td>– Stair lift in the hallway</td>
<td>1</td>
</tr>
<tr>
<td>– Automatic door opener at lift/garage</td>
<td>2</td>
</tr>
<tr>
<td>– Bathroom extension</td>
<td>1</td>
</tr>
<tr>
<td>– Replace bathtub with shower stall</td>
<td>2</td>
</tr>
<tr>
<td>– Grab bars</td>
<td>3</td>
</tr>
<tr>
<td>– Longer tap in kitchen</td>
<td>1</td>
</tr>
<tr>
<td>– Widen door opening</td>
<td>1</td>
</tr>
<tr>
<td>– Removal of thresholds indoors</td>
<td>4</td>
</tr>
<tr>
<td>– Oven guard</td>
<td>1</td>
</tr>
</tbody>
</table>

aSome participants applied for more than one HA.
in order to get an overview of the content and the general tone. The two authors separately coded all interviews for one participant, and discussed their findings. BT then systematically coded all remaining interviews. The codes for all participants were compared at each interview point (before and at 3 and 12 months after HA), and were sorted into tentative categories reflecting the specific content at each interview point. In the last step, the participants’ narratives of their experiences from each interview point resulted in two categories capturing changes over time (Esterberg, 2002). In order to establish rigor in the findings, the second author (AMF) critically examined the findings as they emerged. The findings were thereafter discussed by all authors, supported by BT’s reflective notes taken throughout the analysis process, and revised until all data related to the aim fitted into a single category in an acceptable way. One main theme emerged from all the data and categories.

**Ethics**

After the client had contacted an occupational therapist regarding the need for an HA, the client was invited to participate in the study. Participation was completely voluntary and after oral and written information about the study, participants gave their written informed consent. Withdrawal or declined participation in the study did not affect further services. All data were stored in an encrypted format accessible only by the researchers in the study. The study was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr. 2013/592).

**Findings**

**Ongoing struggle to perform and engage in everyday life**

A main theme, “Ongoing struggle to perform and engage in everyday life,” emerged from the findings. The theme describes how the participants struggle to perform and engage in activities, not only before but also after the HA, and that the performance of activities was experienced as a moving target over time. Before the HA, the participants described how they, for a longer or shorter time, had experienced increased difficulties or increased dependency when performing and engaging in activities both in and outside the home. Many expected the HA to be a straightforward intervention that would help them overcome activity-related problems. When receiving the HA, performance and engagement in everyday life were still a struggle and the HA had not solved all the problems the clients had expected it to when they applied.

Three months after HA, participants reported improvements as well as failures to improve performance, for example, in self-care or walking around in the home with a mobility device. As the health status for some participants declined over time, they described how additional measures had to be taken to make everyday life at home easier, for example, by moving home or applying for additional HA.
One year after HA, some participants reported that the HA had contributed to engagement beyond their expectations.

The main theme comprises two categories unfolding the participants’ experiences of performance and engagement: “Ability to perform activities experienced as a moving target” (category 1) and “New perceptions and routines open up for engagement” (category 2).

**Ability to perform activities experienced as a moving target**

Several participants anticipated that the HA would improve specific activities that they had problems performing independently. After the HA, participants described that the adaptation, to different degrees, had made the desired outcome possible. The degree of success was, for example, dependent on whether their health had been stable or changed over time, or whether the HA was planned to cover the whole chain of performing an activity or just to solve one part of the problem. This category consists of two subcategories: “Meeting needs for independent performance” and “Changing health status requires additional adaptations.”

**Meeting needs for independent performance**

Before the HA, activity performance was described as troublesome, difficult, risky, vulnerable, exhausting, or even demeaning. The participants avoided doing certain activities in spite of their needs, and they hoped and anticipated that the HA would help increase their independence from others, as well as their feelings of safety when performing activities they wanted and needed to do:

I’m afraid of falling down in the shower … and that’s why I avoid taking showers … there’s no nicer feeling than right after a shower and it’s something I want to do be able to do by myself. (P61, T1 interview)

To varying degrees, the specific HA met the participants’ needs, expectations, and hopes for independence. Before the HA, one participant expressed how difficult it was to always have to ask for help, making her sad and making her feel a burden to her husband: “And for me a big thing too, is not to have to ask for help, because I already find that difficult, it makes me sad as I already feel like a burden” (P2, T1 interview). After the HA, however, she really felt how it contributed both to her independence and her feeling of not being a burden. Others experienced that the HA failed to meet their need for independent performance, completely or partly. Leaving level differences between the floors after the thresholds (i.e., the join between two types of flooring) had been removed and neglecting to mount grab bars at the entrance were a hindrance when going in and out of the home, for example. One woman had several grab bars installed in the year after the HA was installed so that she could hold onto something when she was going out. Between the second interview and the third interview, she fell and broke her hip and could not participate in her usual activities outside the home. Instead of not seeing
people, her solution was to invite friends over to her house. Still, this used up a great deal of her energy and since grab bars were not a sustainable solution, she ended up with reduced participation outside the home:

The idea with the HA was so that I wouldn’t fall … and be independent in getting in and out … you become less isolated when you can get out and meet people … I can’t ask people to come and visit me all the time. (P14, T3 interview)

For other participants, the HA seemed to symbolize a hope for increased independence and engagement, a possibility to go out more frequently. In one case, the participant expressed a wish to be able to go with a partner to the grocery store. However, even if the participant had had a new ramp installed and could therefore more easily go in and out of the house, she still experienced problems, such as the distance from her home in a rural area, and lack of alternatives for public transportation to urban settings. This prevented her getting to the grocery store using her new mobility device (an electric mobility scooter), and she was therefore still unable to go grocery shopping with her partner. This illustrates how the challenge of doing the activity can be a moving target.

Changing health status requires additional adaptations
Over time, some participants faced increasing problems in maintaining performance of activities due to declining health. A common reason for adapting the home was to become independent. However, even after the housing adaptation several participants were still dependent due to a decline in their functional capacity. They experienced both a gradual decline over time and a state of varying capacity from day to day. Because of this, the HA did not always provide a sustainable solution over time, and instead, performance was a moving target. This meant that on good days activities such as self-care and moving around at home could be easily performed, while on bad days getting over the one remaining threshold became too difficult:

Now I’ve had a really bad period the whole summer … and that’s when you notice in another way how tough it is [the threshold] because I’ve had so much pain that I haven’t been able to push myself over it. (P2, T3 interview)

In some cases, the participant’s capacity declined so rapidly that the need for an additional HA arose just as the person received his or her initial one. This meant the person could engage in the targeted activities for only a short period of time before additional HA became necessary.

New perceptions and routines can open up for engagement
In the cases where the HA successfully met the participants’ needs, despite declining health and changes over time, new perceptions of the home as well as new routines were established that sometimes influenced their engagement. Safety, self-confidence and desire to be active outside the home were then supported by the HA. This is elaborated upon in the following two subcategories: “New perceptions
of the home” and “New routines in performance foster confidence for further engagement.”

**New perceptions of the home**

Participants expressed that the HA had affected the aesthetic and practical perceptions of the home. Participants who had a positive experience of enhanced performance and engagement after HA more easily came to the decision to apply for additional HA when such needs came up, despite the appearance of the HA. That is, if the HA served the purpose of helping the participants be more independent and autonomous, what it looked like was no longer as important. Those participants determined to stay put in their own home prioritized the practicality over the aesthetics, even if they sometimes needed time to alter their perceptions. The changing of perceptions can be illustrated by a woman who was reluctant at first to apply for another grab bar in spite of her needs. She said, “I don’t want grab-bars on every wall” (P14, T2 interview). This probably refers to the aesthetics. But a year later, after even more grab bars had been installed, she seemed to have shifted her perspective, prioritizing function more than aesthetics. She now said: “I thought it would be a bit of a pain to have grab bars everywhere … but it helps me get about easier” (P14, T3 interview).

In another case, both the aesthetic and practical perceptions of the home had become more appealing after the HA, facilitating social participation for the participant:

> Yes, I had an extension to the kitchen built [done outside the grant] … and it has proved just as valuable [as the new bathroom which was what was being granted for] … now you can have people here. (P7, T3 interview)

Thus, it was worthwhile for this participant to pay for reconstruction of the kitchen himself, because having a large bathroom besides the kitchen enabled him to use the bathroom in private, without having to ask his guest to go out on his balcony. In this way, the HA enhanced his social life. In other cases, lack of engagement in the HA process or not being able to influence the final solution could lead to discontent with the results, and a constant search for solutions to one’s needs. For example, one participant had a small shower stall installed next to the bathtub, but she had expected the tub to be removed, leaving space for a larger shower area. She had already been through a similar process before, since her now late husband had received such a solution in their previous home.

**New routines in performance foster confidence for further engagement**

Being more self-reliant and having the possibility for self-maintenance in the home, such as taking care of basic hygiene needs, was described as a “normal” life and as “having the same standards as others.” This had implications for feeling more safe and self-confident, and some also expressed how it influenced their well-being and health. In one case, extending the bathroom made it easier to maintain
better hygiene, which in turn increased the participant’s confidence among other people. Subsequently, new routines for engaging in activities outside the home were developed and his participation increased. Increased participation was rarely something that the participants expected to be an outcome of the HA, but came more as a bonus. One example of an HA that gave opportunities for doing things that had been difficult before but beyond what had been expected from the HA came from a woman who described how her self-care activities became easier after the adaptation, and how she therefore shaped new routines for going out:

But if I’m going out somewhere and I want to put some makeup on or do my hair a bit, then I can just roll myself in and sort it out … it’s liberating to not need someone else to help me, and to be able to do it myself. (P2, T2 interview)

Other participants who never expected that the HA would have any effect on their engagement in activities outside the home found that over time they regained energy and motivation to go out after the HA. They started to make plans to routinely engage more in social life outside the home. A woman who first had a shower installed, and then later applied for and received a stair lift, wanted to take the HA even further:

Yes, but it’s just that, now I have to make a serious effort to get a door opener. It’s a bit tricky when you need to come out with the walking frame. You need to hold the door open, and it’s quite heavy. (P11, T3 interview)

With positive experiences of how changes in the home environment enabled activities, the participants saw new opportunities for participating outside the home more often. This can be exemplified by a participant who after the HA changed her views toward mobility device use outside her home, as she did not previously want to be seen with one. As she expressed it:

Not in a million years! I said … There’s no way I can step out the front door with something like that. I’m not that sick. No, she said [the occupational therapist] … You’re not that sick, but you are in pain. So I’ll order one for you, and you can try it out. Oh, I thought … Good Lord! That’s something my mother had! Oh well. But anyway she went ahead and ordered it. I went round here with it and it felt so amazingly good. Yes, anyway, I went ahead and accepted it. And … and I talked to my girlfriends and they thought I was very childish to be so negative about it. (P35, T3 interview)

Still, although the HA fulfilled the most urgent needs for independence in activity performance and brought about new routines for some of the participants, thoughts of moving to sheltered housing remained: “Getting help [in sheltered housing] still means independence … because while it’s better for me, it’s also better for society that the house doesn’t burn down” (P47, T3 interview). This participant concluded that although he now had a stove timer and could cook independently, he was reluctant to use the stove without another person present, based on his previous experience with cooking on the stove.
Discussion

Our findings show that not all of the participants experienced enhanced performance in the activities targeted by the HA. However, among those participants who did overcome their problems to perform activities, new routines were developed and some even experienced increased safety and self-confidence. This increased their engagement outside their home. Thus, the findings suggest that when performance is enhanced by HA, participation may also be increased.

Previous research has demonstrated that HA enhances performance in everyday life and reduces the difficulty of the activities targeted by an HA (Fänge & Iwarsson, 2005b; Petersson et al., 2009; Petersson et al., 2008). While this was true for some of the participants in our study, most of them experienced activity performance as a moving target. Thus, as their health declined, additional HA or other interventions in the home were necessary to maintain their ability to perform and engage, particularly outside the home. Several studies have highlighted accessible home environments as an issue of social justice in recognizing each person’s right to participate in everyday life with meaning and dignity (Bontje, Asaba, & Josephsson, 2016; Gibson et al., 2012; Sixsmith et al., 2014).

The importance of performing activities outside the home has been addressed previously (Szanton et al., 2016). However, the focus on the dynamics in the relationship of personal, physical, and sociocultural dimensions of performance and engagement both inside and outside the home is lacking in the HA literature (Stark et al., 2017). By going beyond merely the performance of targeted activities and including also the subjective view of the client, that is, engagement and participation, our findings show how the HA can contribute to increased self-confidence and motivation to engage with others. Accordingly, the HA not only supported performance but also helped to maintain dignity, as exemplified by increased engagement outside the home. Thus, it seems that HA in this respect has a health-promoting effect. Further research, at a larger scale, is needed to investigate the relation between participation inside and outside the home after a HA.

A recent qualitative study about the decision-making process around HA recognized that applicants expect the intervention to facilitate not only independent performance of activities but also subjective aspects, such as freedom and integrity (Ekstam et al., 2016). Among our participants in this study the expectations of the HA were not always met, and some participants had high expectations of what the outcome of the HA would be. This may be due to an insufficient and untimely HA—for example, by leaving parts of the home unadapted in spite of the expressed need as described in other studies (Granbom, Taei, & Ekstam, 2017; Petersson et al., 2009). This gap between the initial need for an extensive HA and the one they received continuously caused problems in the participants’ everyday life. The participants’ needs can be seen as a moving target. This meant that they had to develop different
strategies to overcome the environmental obstacles, such as having an additional HA or moving to other housing. Thus, overcoming environmental barriers in the home is not a distinct event, but a continuously ongoing process requiring consideration.

Over time, unmet HA needs are often unavoidable due to progressive health decline. However, the fact that they existed/persisted from early in the process is of considerable concern since it indicated that the needs evaluation wasn’t complete. Similar results were found in previous Swedish studies (Ekstam et al., 2016; Fänge & Iwarsson, 2007), highlighting that this could be a systematic flaw in the Swedish HA system. It is a challenge to conduct an HA that is sustainable and flexible when the client’s need are shifting over time, but considering the whole picture and carefully examining every link in the chain could have a positive effect on both performance and participation for the client. Furthermore, when needs change rapidly, it is important that the HA process is both fast and flexible to adapt to those shifting needs.

For those participants where the HA did not result in the improvements they had anticipated and hoped for, the struggle to perform and engage in activities continued. Here, other strategies for participation need to be considered by everyone involved. This is of significant interest for occupational therapy services in Swedish municipalities, since they have an important role to play in helping their clients to perform and engage in activities. The role of a partner, cohabitant, or significant other has been studied before, showing that the HA can have positive effects also on caregivers everyday life, mainly due to their role as care providers (Granbom et al., 2017).

The HA application process has been described as often being preceded by the applicant’s own negotiation process, where varying amounts of time are needed to come to a decision (Ekstam et al., 2016). This adds to the challenge of finding and installing the appropriate HA. There also seems to be an increased risk of not attaining the goal of independent living in one’s own home when the waiting time is prolonged (Petersson et al., 2009). Since participation is an important goal of rehabilitating interventions, all aspects of activity and participation need to be adopted into the HA process. Interventions that include professional expertise in evaluating both the client and his or her home, implementation, goal-setting, training, support, and regular follow-ups are more effective than less comprehensive interventions (Stark et al., 2017). Future research should explore the comprehensiveness of the HA process in Sweden.

**Methodological considerations**

A qualitative approach generates knowledge based on the participants’ unique perspectives, which can contribute to a better understanding of, in this case, participation in everyday life in relation to an HA. The selection of
participants for this study, striving for as much diversity as possible, enabled us to study a range of situations and needs over time. The open questions used in the interviews resulted in rich narratives describing the participant’s situation over time. All interviews were conducted in the participants’ homes, which allowed for statements to be illustrated during walk-arounds. At the same time, interviewing people in their own homes requires skill to preserve their privacy and integrity. The interviewer was an occupational therapist with extensive experience of interviewing people with disabilities in their own homes, and strove to be respectful and keep the integrity while creating a relationship.

The number of participants in the study is limited, and the findings cannot be generalized to all HA clients. One limitation is that the study excluded those not able to communicate and follow instructions in Swedish. This means that the study does not include experiences from, for instance people with severe dysphasia, people with severe cognitive decline, and immigrants who don’t speak Swedish. However, it is our aim and expectation that the findings of our study can be useful on a theoretical level and contribute with understanding of community-living people experiencing barriers to engagement in activities in their homes.

Our choice of a 12-month longitudinal study with interviews on three occasions resulted in fewer participants than expected, due to dropouts during the follow-up time. We considered it important to have data on several occasions during the HA process to better understand how the participants experienced the HA from an occupational perspective. However, it was a challenge to clearly separate time and change between the interviews, as the participants changed their perspectives over time. For example, they talked differently in the interviews 3 and 12 months after the HA about how they performed activities before the HA. However, by using several data collection points, we could show examples of changed views and perspectives.

Data analysis was conducted by occupational therapists, who have a theoretical understanding based on occupational therapy. In order to keep close to the data, keep a scientific openness toward them, and not force theoretical concepts on the data, discussions were held throughout the entire data collection and analysis process. In this way, we aimed to increase the credibility of the findings.

**Conclusion**

HA does not always lead to enhanced independence in everyday life, despite this being the formal aim of the interventions. Overcoming barriers to performance and participation in everyday life at home is not a distinct event but can be seen as an ongoing struggle, as needs change with changing health status over time. Focus on performance and engagement in everyday life at the onset of the HA process
combined with regular follow-ups can enhance participation. Current HA legis-
lation does not address participation, despite its prominent role in health care and
rehabilitation. Our study shows that HA does not always reach all the way through
to performance and participation.

Conflict of interest

The authors declare there are no competing interests.

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