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Clients’ Experiences of Housing Adaptations – A Longitudinal Mixed-Methods Study

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Abstract

Purpose. To explore clients’ experience of the housing adaptations over time in relation to housing and health.

Method. A multiple longitudinal case study, employing an embedded mixed-method design was used. Four participants were included and data from semi-structured interviews were combined with data from structured survey assessments.

Results. Housing adaptation made it possible to maintain valuable roles and activities, to continue to live in the participants’ own homes and to take part in the society. The participants strived for autonomy and control, and in order to do so they needed different kinds of support, in terms of HA and mobility devices as well as support from professionals. HA also challenged the participants’ routines and habits, as well as their perception about how an appealing HA aesthetically. Thus, the decision to apply for a HA was not always straightforward. Instead, the participants were constantly engaged in negotiations with themselves, concerning benefits and drawbacks of different decisions.

Conclusions. Housing adaptations involve complex person-environment-activity transactions, and enhance clients’ activity and independence in spite of functional decline. The knowledge generated is important in order to improve individual housing adaptation, as well as improving the efficiency and effectiveness of the intervention.

Keywords
Home modification, occupational therapy, activity, participation, long term outcomes, interview
INTRODUCTION

Housing adaptation (HA) is a common intervention within community-based rehabilitation, aiming at removing physical environmental barriers in order to provide an independent life in the home (SFS 1992:1574) [1]. The intervention is individually tailored, depending on the ability of the individual, the activities that are to be performed and on the standard and design of the home. Approximately 72,900 HA were granted in Sweden in 2010, to the total cost of 962 million SEK [2]. The largest client group requiring HA is older people, due to successively declining health, while another group includes younger people affected by reduced capacity due to diseases or severe injuries. It is known that over time, many clients need additional HA, however, there is a lack of knowledge on how their living conditions, abilities and needs evolve over time.

HA is an intervention mainly available to those living in welfare states. Each country in which HA is provided has its own regulations and procedures, thus leading to considerable international differences, for example, in terms of availability, funding, construction and integration with other interventions. In Sweden, HA are governed by specific legislation (SFS 1992:1574) [1] closely linked to the planning and building legislation (SFS 1987:10) [3], and are not part of the health care or social services acts. Those requiring HA can apply for a grant covering the full cost of HA from their local authorities. The need for an HA must be certified by a health care professional, in most cases an occupational therapist (OT), although the client is the formal grant applicant. A municipal grant administrator then decides whether the application should be approved or not. In some municipalities the applicant has the possibility to pay for additional costs.
related to the HA e.g. for aesthetic reasons. In many cases, HA are combined with other interventions such as provision of mobility devices, installation of assistive devices, fall prevention measures, information and physical training. In other words, a HA is a highly complex intervention in that the HA differ between clients and contexts, involves many different professionals, and relates to other interventions [4].

The home is important for health and independence [5, 6] and it is the major arena in which older people and persons with disabilities can maintain control and autonomy [6, 7]. However, people in need of many health care interventions and different services in their homes, are at particular risk of losing control over their life situation, due to the many different professionals involved in their lives [8]. When it comes to HA, many people find it difficult to obtain relevant information about the HA process, including whom to contact for advice and applications [6, 9]. This probably has a significant effect on the client’s ability to remain in control during the HA process. Most importantly, in Sweden the client bears the rights and responsibilities for a HA, but there is a lack of knowledge on how HA clients effectuate these rights and obligations, and how they perceive them in a longitudinal perspective.

Previous research has demonstrated that HA improves the usability of the home [10, 11] increases independence in daily activities [11, 12, 13] and reduces the number of falls [13, 14]. However, no studies on long-term outcomes of HA have been presented. In addition, there is a lack of knowledge on how HA clients experience the HA over time. Such knowledge is crucial in order to improve the efficiency and effectiveness of the
individual HA. The aim of this study was, therefore, to explore clients’ experience of HA over time in relation to housing and health.

METHODS AND PARTICIPANTS

Study design and context

This study is a multiple longitudinal case study, employing an embedded mixed-method design [15]. The explorative case study design is used in order to get an in depth understanding of participants’ views. We used a constructivist approach focusing on participants’ context and to capture their perspectives [15, 16, 17]. The embedded design was carefully chosen among other mixed methods designs, in order to capture clients’ experiences of HA over time. According to Creswell [15] an embedded design is the most appropriate design, when there is a need of using both qualitative and quantitative data to answer the research questions.

In this study, quantitative data from structured survey assessments were embedded in data from semi-structured interviews. The study constitutes the fourth step in a longitudinal project on the evaluation of HA in a south Swedish municipality. Quantitative data for 131 HA clients were available, from three prior assessments conducted between 1999 and 2001. In these assessments, data were collected at home visits prior to HA (T1), 2-3 months after the HA was completed (T2), and after a further six months (T3) [10, 11]. Data for the current study comprised of another round of
quantitative assessment (T4) and a semi-structured interview. This data were collected during 2010.

**Sampling procedure and participants**

A stepwise sampling procedure was employed. First, information on which ones of the 131 participants that were still alive, and currently living in the municipality was retrieved from the municipality registers, resulting in 51 possible participants. Secondly, participants for which data were available from T1, T2 and T3 were then identified, resulting in 39 potential participants. Six of them could not be contacted, and this left us with 33 potential participants.

A purposeful sample was used in order to ensure participant diversity with different perspectives [16]. The sampling strategy aimed at; including at least one participant of working age, at least one person living alone, at least one that had moved to another kind of private accommodation since T3, and at least one that had been granted an additional HA 3-12 months prior to T4. To be included in this study, it was required that the participants had no communication problems, and that they should be able to participate in an interview.

Following the sampling criteria four potential participants were contacted. Two of them agreed to participate, while two declined due to ill health. Therefore, another four potential participants were identified, all of them declining participation due to ill health. After a third round of sampling, another four potential participants were contacted, and two of them agreed.
A municipality official contacted the potential participants by telephone to inform them about the study. If the person was agreeable to participating in the study, they were asked a few questions to establish whether they had the communication abilities, necessary for participating in an interview. The first author (CP) then contacted the potential participants via telephone, in order to provide additional information and to make an appointment for a home visit. At this time, written information about the study was sent to the participants, while written consent to participate was obtained later on at the home visit.

**Data collection**

The data collection consisted of two parts.

**Part one** consisted of the collection of quantitative data, targeting the same outcomes as at T1-T3 and was collected using four different instruments, also the same as at T1-T3.

1. *The Housing Enabler (HE) instrument* was used, aiming to describe the magnitude of accessibility problems for each person in its specific environment.

   The HE instrument consists of three different steps and the assessment was performed as follows:

   **The first step:** *Functional limitations and dependence on mobility devices* were assessed dichotomously (present/not present) by means of 14 items in the first part of the Housing Enabler [18] i.e. the personal component of the instrument.

   **The second step:** *Environmental barriers and accessibility problems* were assessed by means of the Housing Enabler in which environmental barriers (188 items) were dichotomously assessed as present/not present. The items concern design features based on
standards/guidelines for accessibility [19] as well as environmental features traditionally defined as domestic hazards (e.g. loose carpets, high thresholds, lack of handrails on stairways).

The third step: Calculation of an accessibility score; all items related to environmental barriers are rated on a scale from 1 to 4, indicating severity in relation to each functional limitation. The sum of these severity scores, gives a score describing the magnitude of accessibility problems for each person in their specific environment. The instrument has been used in numerous studies on the relation between home and health among older adults [20, 21].

II. Usability in My home; Usability is a perceived aspect of the person-environment-activity transactions [19]. It addresses the extent to which the physical home environment supports the performance of activities, here operationalized by means of the self-administered questionnaire Usability in My Home (UIMH) [22, 23]. The instrument consists of 16 items rated on a 7-point scale, from 1 (not at all) to 5 (fully agree), targeting “activity aspects”, “personal and social aspects” and “physical environmental aspects”.

III. Dependence in activities of daily living (ADL) was assessed by means of the ADL Staircase [24, 25]. This instrument comprises five personal ADL items and four instrumental ADL items, rated professionally based on dependence on personal assistance when performing an activity.
IV. Subjective well-being was assessed using the Gothenburg Quality of Life instrument. This comprises 17 questions on, for example, home and family, health, self-esteem and sleep, and each question is rated on a 7-point scale [26].

Part two included semi-structured interviews. The interview questions were open-ended and targeted three overall themes; The aim of the adaptation and the person behind the decision to apply for a grant, the participant’s role in the decision, how his or her needs and preferences were met, and how communication with the different actors was perceived, and finally, the participant’s long-term experiences and perceptions of the housing adaptation in relation to housing and health. Prior to data collection, two pilot interviews were conducted. The first pilot interviews resulted in a minor revision of the interview scheme, but no further changes were made after the second.

Data were collected in the homes of the participants by the first and third authors. Both are OT, highly experienced in conducting home visits and data collection in peoples’ homes. The first author had not met the participants before, and had recently worked with assessment of HA and powered wheelchair, while the third author had met the majority of the participants at the data collection at T1-T3. Each home visit followed the same procedure, i.e. survey data were collected first, followed by the interview. All interviews were conducted by the first author and lasted between 40 and 120 minutes. The participants were all interviewed alone, except for one woman whose husband participated at the end of the interview. All interviews were tape-recorded and transcribed verbatim. Further field notes was made by the first author immediately after each
interview, in order to remember the aspects of the home and participants descriptions while showing their homes.

**Data analysis**

The data were analysed sequentially, according to the guidelines in mixed method embedded design [15]. For each participant, the interview data were analysed first, followed by a descriptive analysis of the survey data, in order to obtain a deeper understanding of each case. Survey data from T1 and T4 were compared in order to detect individual changes. Thereafter, all the data for each individual were embedded, and each case was analysed separately, resulting in narratives with a storytelling approach aiming at describe each participant over time [17, 27]. Further this case-specific analysis was followed by a cross-case analysis, to gain a more comprehensive understanding of the clients’ experience of HA [16].

The content analysis method according to [28, 29], was applied to the interview data. Content analysis with an inductive approach is used when there is little knowledge about the phenomenon [28, 30] and with special focus on the context [29]. First, the interviews were listened to and read through several times, to obtain a sense of, and a general understanding of, the content. The text was then sorted into meaning units, and then condensed meaning units by the first author. The first and third authors then interpreted the condensed meaning units separately. This was followed by comparison and discussion of the interpretations until consensus was reached. In the next step, the second author (OT) scrutinized the new interpretations of the condensed meaning units, resulting
in further comparisons and discussions of the interpretations, until consensus was reached. Thereafter, differences and similarities between the cases, based on the embedded data were found out, resulting in a deeper understanding [17, 31]. In the end, a narrative of each case was constructed, in which the survey data were embedded into the description of each case. In constructing the narratives, all authors were involved to get an in-depth picture of each case, including its context. A cross-case analysis was then conducted, resulting in final themes common to all four cases, constructed as follows. Firstly the latent content (in condensed meaning units) including all interviews were, compared and sorted into codes. Thereafter, based on the content the codes were linked together and also discussed among all authors, resulting in final themes.

**Ethics**

The study was approved by the Regional Ethical Review Board in Lund, Sweden, no. 2010/97.

**RESULTS**

First, the narratives of the four cases are presented, comprising a chronological description from T1 to T4, involving the quantitative data (presented in table 1) which are embedded in the qualitative, interview data. Secondly, the results from the cross-case analyses, involving all four cases is presented.

Insert table 1 about here
David

At T1, David was 59 years old. He was married and had lived in the same split-level house for the past 22 years. Due to a progressive neurological disease, he suffered from several functional limitations, resulting in difficulties in moving upper and lower limbs. He perceived his well-being generally good, but he experienced problems with his memory and physical condition. He used a powered wheelchair outdoors, but was independent in most ADL (table 1). At this time, David faced a multitude of accessibility problems in his housing, and perceived that the house had limited usability, in particular in relation to activities involving mobility and socializing. Therefore, he applied for a HA to adapt the bathroom shower, and to install an automatic garage door opener. David already had some insight into HA when applying for his first grant, and with the support from the OT, he was able to influence the HA. He had to part-pay the HA in the bathroom, to get it according to his wishes, and he wasn’t completely satisfied with this.

At T2, David had almost the same functional limitations as at T1, although he perceived that his general well-being had declined. He still used a powered wheelchair outdoors, and drove an adapted car. He managed the same ADL as at T1 but he perceived the usability in his home to be better.

At T3, David used the powered wheelchair both indoors and outdoors, even though he had maintained his functional capacity. Due to his wheelchair use accessibility was a greater problem, and the usability in the home had deteriorated, in particular with respect to outdoor spaces and activities.
At T4, David was a single living, 70-year pensioner. He had almost the same functional capacity as before, except from the coordination problems that had increased. On the other hand, he perceived his well-being to be better. Since T3 he had moved to a ground-floor flat, due to difficulties in managing the stairs in his former house. When considering moving to the new flat, he was more aware of the demands he could make regarding HA, and took an early contact with the HA administrator in the municipality. He stressed the importance of living an independent life, and being aware of his progressive disease, he considered himself in need of a HA. Therefore HA of the kitchen and paving of the garden were completed prior to him moving in. Thereby, he could establish new well-functioning routines.

At this time he perceived the usability of his home to be good. However, he was not fully satisfied with the HA because he couldn’t reach the upper cupboard in the kitchen, however, he was satisfied with the aesthetic, which he stressed was important. Further the waste storage close to his flat wasn’t accessible for him, and therefore he was dependent on neighbours helping out with his refuse. Due to this he wasn’t fully satisfied with the legal restrictions for HA, and wished it would be possible to apply for a HA to solve this problem. Further, he was grateful for the HA in the garden, which helped not only him, but also some of his friends using wheel chair, and stressed that this could be understood as a detail for professionals, but of great importance for him. He also emphasized the importance of professionals’ attitudes and humankind, and also of well educated administrators accomplishing fair assessments.
Anne

At T1, Anne was 39 years old and lived with her husband and three daughters in a split-level house. She had recently been diagnosed with a severe neurological disorder, and considered her well-being to be very low, particularly in relation to health, memory and sleep. Anne had several functional limitations, such as difficulties in moving upper and lower limbs, impaired balance and limitations of stamina. Due to this she was dependent on others in the majority of ADL (table 1). She used a rollator for mobility indoors and a manual wheelchair outdoors. Anne had applied for a HA in order to remove thresholds and install grab bars at the door entering the terrace. When she applied for the HA at T1, she was not at all familiar with the procedures around the intervention.

At T2, Anne had the same functional limitations and could better manage her ADL. She used the same mobility devices as before and perceived the usability of the home to be better than at T1. An additional HA had been completed in order to facilitate handling the laundry, and a shower as well as a stair lift had also been installed. The stair lift was installed at just the right time, when she felt prepared for it.

At T3, Anne’s functional capacity remained unchanged, but she estimated less pain and improved balance. She still used the same mobility devices, and also managed the same ADL as at T1 and T2. The usability in home remained unchanged, however, the accessibility in the home was much better than before.
At T4, Anne’s social and housing situation remained unchanged. Her functional limitations were almost the same as at T3, but she now used a powered scooter outdoors. Anne emphasized the importance of participating in different activities, both in housing and also outside. Anne had felt some resistance in using mobility devices and also to apply for HA, but later on she expressed her independence due to these interventions. She was grateful for that her views had been met regarding the design of the HA, and that she hadn’t been questioned when she later on decided to dismount the stair-lift. Throughout, her strategy had been to deal with HA and other changes step-by-step, and to take the time required adapting to her new life situation. She wanted to be sure that she made the correct long-term decision. She was grateful for having had an OT that coached her accordingly, and emphasized the importance of continuity among staff. She stressed that follow up was done by the OT regarding mobility devices, but not regarding the outcome of the HA. She now reflected on her current housing situation, and she and her husband made plans to move. She found that living in a split-level house made life difficult, although she perceived the usability of the home to be better than at T3. She was quite occupied with her interests in gardening and handicraft however, she desired a more active life outside home, and wanted to live closer to shops and services. She also wanted to move closer to her children and grandchildren. Anne was well aware of her special needs in a new home, and also their neighbourhoods. In order to reach a decision on where to move, she weighed up the advantages and disadvantages of the different houses they had been looking at.

Helen
At T1, Helen was 49 years old and lived with her husband in a two-story house with basement. She suffered from several functional limitations, resulting in difficulties moving upper and lower limbs, and she also poor balance and stamina. In spite of this, Helen was independent in most of her ADL. She perceived her health and her self-confidence to be low, which had adverse effects on her general well-being (table 1). Helen used several mobility devices such as a stick, rollator and three-wheeled bicycle and had applied for a HA, in order to remove thresholds in the house.

At T2, Helen’s balance had declined, and she used a rollator for mobility both indoors and outdoors. She perceived the usability of the home to be better than at T1.

At T3, Helen had the same functional capacity as at T2 and ADL, and she used the same mobility devices as before. Housing accessibility had improved compared to at T2.

At T4, Helen was still living in the same house, but now on her own. Her functional capacity remained unchanged, with the exception of that since five years she permanently used a powered wheelchair indoors and outdoors. She perceived the usability of the housing to be lower than at T3, in particular with respect to the bathroom. An additional HA, i.e. a ramp up to the front door had been installed, and she had reconstructed the kitchen according to her own design, without applying for a HA grant. Helen had chosen to use the bathroom close to her bedroom on the upper floor. This bathroom was not accessible for her, since she used the wheelchair, and this resulting in that she had to move to another wheelchair, placed inside the bathroom. Helen didn’t feel that this suited
her needs, and was therefore now planning for an HA application. She emphasized that it was important for her to make use of the whole house, not only certain rooms and areas. She also emphasized that the OT gave HA suggestions based on her experience, and also in relation to the easiest and most cost-efficient way, not taking the client perspective fully into account. Helen understood but disagreed. When she then applied for a stair lift, in order to enabling use of her bedroom and her bathroom on the upper floor, and also a shower according to her wishes, her application was turned down. Helen intended to appeal against but didn’t; instead she purchased and installed a stair lift at her own expense.

When discussing HA vs. reconstructing the house at her own expense, she claimed that for her she wasn’t different compared to others, and all house owners had to repair their houses without subsidises. She also stressed the importance of having HA that satisfied her requirements in the long-term perspective. Helen always tried to solve problems herself, and to come up with solutions before contacting the OT for counselling. Thereafter, she wanted to reflect upon the advice she had been given. Since the first HA, Helen had expressed the wish to live in a one-storey house, although she highly valued her current house and the neighbourhood, as she had many social contacts nearby. She also stressed the importance of accessibility, while using her powered wheelchair in the garden, and getting out there getting fresh air. Further, she valued having enough space in the house, to use a powered wheelchair both indoors and outdoors without facing barriers. She therefore did not want to move, even though she was well aware of the challenges in managing independently in her home.
Elisabeth

At T1, Elisabeth was 75 years old, and had lived with her husband in a one-storey house for 12 years. She had difficulties moving her lower limbs and she also had limited stamina. She perceived her well-being to be low, especially in relation to her memory and physical condition. In spite of her functional limitations she managed almost all ADL independently (table 1). No mobility devices were used indoors but she used a stick outdoors. Elisabeth perceived the usability of her home to be rather low, particularly regarding outdoor spaces and activities. She applied for a HA at T1 due to a fall in the shower. The shower was then adapted, and handrails at the front door steps and around the patio were installed.

At T2, Elisabeth had the same functional limitations as at T1. She didn’t use any mobility devices and was almost independent in all ADL. Her well-being was considerably better than at T1, and the usability of the home had improved.

At T3, Elisabeth still had the same functional limitations as at T1-T2, although she considered her overall well-being to be worse, and was no longer fully independent in ADL. She faced additional accessibility problems and the usability of the home had declined.

At T4, Elisabeth was still living with her husband in the same house. Her balance was impaired, and she also had difficulties interpreting information. She had also become partly dependent in ADL. She also considered her overall well-being to be worse. She
used rollator indoors and outdoors, and had a powered scooter for outdoor use however, she had chosen to not use it until spring. During the previous ten years, because of backache, she had to give up some enjoyable activities such as cooking and weaving. In spite of her desire to continue cooking, she had not applied for a HA, since she was not sure that she would be able to manage even so. Instead, she participated or overlooked some activities conducted by her husband. She perceived the usability of the kitchen to be lower than before, and she also faced increasing accessibility problems. Elisabeth was satisfied with the HA of the shower, and that she had not fallen in the shower since the first time. She partly financed the HA in the shower in order to have it according to her wishes, and was satisfied with this. However, upon reflection, she thought that the HA could have been made better, making it even easier and safer for her. She wasn’t sure about if follow ups have been performed or not. Elisabeth emphasized the importance of being independent from authorities, and she therefore tried to manage as long as possible without applying for a HA. First when it had came to her knowledge that a friend of her had got a HA, she also decided to apply. Now she, however, reflected upon if it would be more convenient for her to move to another and smaller housing, but her husband didn’t want to. Elisabeth related her dependence to the demands of her current home. She stressed that when she was tired and couldn’t manage, perhaps moving to a smaller house would make life easier.

**Cross-case findings**

In spite of the participants’ diversity, both similarities and differences in experiences of HA were found. A HA was consistently considered to be valuable and important, for
being able to participate in desirable activities, even if the HA not always was apprehended as optimal. In spite of functional decline and experience of living with this decline, the participants clearly articulated that they were “striving for control and autonomy” which we identified as an overarching theme. In this theme, three subthemes emerged: “striving to remain active”, ”the deeper significance of the HA” and “housing adaptation as a process”.

**Striving to remain active**

The participants had a strong opinion of which daily activities they wanted and needed to perform. Over the years they had developed strategies, routines and habits, and most of all, they wanted everyday life to continue as before. Being able to fulfil desired personal roles was argued as important, and a way to avoid being socially excluded, when discussing HA. All participants experienced that a changing life situation, with increasing limitations, or by being dependent on additional mobility devices, contributed to problems in the housing. This called for additional HA over time, thus enhancing activities in the home. However, each HA, to some extent at least, required the participants to change routines or habits in order to remain active. Their experience was also that they despite HA couldn’t continue to fully perform all activities they wanted. The participants became more dependent on other persons over time, and their experiences of which HA they were satisfied with, or which role the HA played in everyday life, were related to what extent that they could maintain roles and continue to perform activities.
The deeper significance of the housing adaptation

The HA was important in enhancing everyday life outdoors, and implied more than just a physical adaptation, rather meant possibilities to feel involved and participate in everyday life. It enabled them getting outdoors in a more general sense; for fresh air and for socializing and being part of the neighborhood. Living in and being able to move around in a well-known environment implied a feeling of security, in the sense of being familiar with the environment. Based on their experiences of using powered wheel chairs or scooters, the participants described that specific knowledge of environmental barriers outdoors, and which shops and public buildings that were accessible to them, enhanced possibilities for autonomy and control. Being able to independently participate in social life and society as a whole was important, and they stressed that HA contributed to this. These aspects of familiarity in the environment were taken into account, when reflecting upon moving to another kind of housing that, in some senses might be more optimal for them. Since they were aware of the risk of becoming more functionally impaired, resulting in increased dependence and restricted participation, a move to another kind of housing, was considered a way of enhancing participation. On the other hand, it could be more difficult to maintain outdoor activities involving aspects of social life, if they moved. Based on these different considerations, the role of a HA implied a deeper meaning for the participants possibilities to stay put, and be part of their neighbourhood.

Housing adaptation as a process

The formal process
Based on the participants varying experiences of HA, different ways of getting in contact with the professionals (i.e. OT, municipality administrators and workmen) affected the experience of the HA as a process. Having more knowledge about the handling of the HA, or making use of personal contacts implied control, and also influenced the participants’ expectations on the role of the professionals. Having less knowledge often meant being contacted by the professional, when the need for a HA was obvious, which implied a higher need for coaching, or for the professionals to act as advisor and expert and formal decision maker. The less knowledge and experiences, the more coaching and input from the professional were needed, but being in the process of having repeated HA:s, was expressed as a learning journey per se. Independently of the participants’ previous knowledge, professionals and participants formed a team that was constantly collaborating, in order to come up with the best solutions. Over time, this cooperation changed due to changes in needs. The participants emphasized that professionals suggestions were based on their practise and current regulations, however, participants’ experience of these suggestions did not always correspond with the participant’s opinion.

The design or the physical expression of the HA was important, and the participants clearly articulated the importance of receiving a HA that is both functional and aesthetically pleasant. In case of conflict between these aspects, sometimes the participants self-financed the HA. However, they were not fully satisfied with this handling. In spite of the diversity of the HA granted, environmental barriers were reduced, and they experienced increasing accessibility and usability in housing. Furthermore, the grant decisions differed among the participants, and parts of the
applications were sometimes rejected. The participants seemed to be prepared for rejection, and they also had a strategy ready if this should happen. Their striving for autonomy influenced their decision to co-finance HA. Said in another way, high personal integrity and autonomy in decision affected the participants’ experience of HA.

The individual process

Overall, due to the participants’ experience of managing life, they stressed the importance that their wishes, needs and preferences were taken into account. They clearly articulated the importance of finding their own solutions to enhance activity, often resulting in not applying for HA until it was an absolute necessity. The word “myself” was often mentioned, and the participants had a very clear idea about their own current and future needs. The participants also claimed, that their pace and capacity for adaptation to their new life situation were acknowledged by the professionals, i.e. that HA was implemented when the participants’ were ready for it. Furthermore, the participants experienced becoming more impaired, and dependent on other more advanced mobility devices, which caused new problems in housing. This called to continuous considerations about new interventions as showed in repeatedly applying for HA.

Discussion

In this study, the experience of HA was investigated from the perspectives of the HA clients themselves. Each participant in this study had his/her own narrative, and both similarities and differences between the four cases were found. They strived for autonomy and control, and in order to do so they needed different kinds of support, in
terms of HA and mobility devices as well as support from professionals, friends and relatives. HA enabled the participants to maintain valuable roles and activities, to continue to live in their own homes, and to take part in the society in spite of declining functional capacity. HA also challenged the participants’ routines and habits, as well as their perception of an aesthetically appealing HA. Thus, the decision to apply for a HA was not always straightforward. Instead, the participants were constantly engaged in negotiations with themselves and their close relatives, concerning benefits and drawbacks of HA.

An important finding in this study was the participants’ strive to continue to perform activities, and to live an active and social life within and outside the own home. More specifically, they strived to continue performing the same activities as before, and to visit the same places in the neighbourhood. In this desire, they often considered HA to be an enhancing intervention. However, changes in the physical environment, such as HA, challenge well-established routines and habits, and for the participant it implied a reminder of their disability. This might be the reason why some participants did not apply for HA until they had tried other solutions. On the other hand HA may reduce the time required to perform different activities, and allow more energy to be spent on activities that are satisfactory [6, 32, 33]. That is, HA can be both supportive and demanding depending on the client and the activity. Given this, it is obvious that the decision apply for and the efforts required to have HA is complex, requiring careful consideration of benefits and drawbacks, as illustrated by the findings in this study.
Another important finding in this study was that the participants expressed confidence in the professionals throughout the HA process. The participants own needs and preferences were at the centre of their discussion throughout, and depending on the participants’ needs at a specific time, the professionals utilized different support strategies. As expressed by the participants, this client-centred professional approach seemed to enhance their autonomy and control, while at the same time offering adequate, individually tailored support. Previous studies have demonstrated that a client-centred approach contributes to activity performance [7], independence [34] and autonomy [6] and increases the long-term benefits of different interventions [35]. Moreover, even when some needs had not been met, the client-centred approach used by the professionals, seemed to contribute considerably to successful intervention outcomes. It is known that clients very often rely on the professionals’ suggestions, and feel confident that the interventions implemented are those considered to be best for them [36, 37]. This probably contributed to the general satisfaction with the intervention, as expressed by our participants.

Another important finding was that some participants, expressed a conflict between the aesthetics and design of the HA on the one hand, and the function of the HA on the other. This conflict points toward the legal framework for HA. More specifically, current Swedish HA legislation only opens up for the right, to having the most cost-efficient HA to enhance an independent life, and thus aesthetic preferences can most often not be met. Such restrictions can be perceived as being non-compliant with client needs, but among
our participants it seemed as if the rationale for such decisions was obvious. This conflict has also been demonstrated in previous studies [37, 38]

When it comes to the more personal perception of the HA, in this study the participants emphasized that HA was not only a physical environmental intervention, that enabled activity performance in housing; they also stressed that the intervention had a deeper meaning to them, enabling autonomy and control in particular in relation to social activities outside home. Taking account of the social environment [39] as well as the individual meaning of engagement in social situations [40] is absolutely crucial, and such aspects need to be accounted for in the HA process, in order to design the most enhancing HA possible. That is, our findings indicate that it is essential to consider the deeper significance for autonomy and participation, when designing the HA.

Moreover, the participants in our study reflected upon whether they should move to another kind of housing or not. Over the years, a person’s functional capacity, social relationships and activity needs and preferences change, and thus most often the demands from the environment increase [41]. Having experienced more than ten years of functional decline, and needs for additional HA and mobility devices, the participants in our study were aware of the challenges inherent in staying in their current housing. Accordingly, moving to another housing was one option for reducing environmental demands, such as environmental barriers, and consequently to increase activity, participation and autonomy. This illustrates the complex transaction between the person, the environment and the activities (PEA-transactions) [42, 43] among HA clients that
constantly evolve. As illustrated by the findings in our study, changes in either the person, such as declining functional capacity, the environment, such as reducing physical barriers, as well as activity aspects influence the entire P-E-A transaction, thus affecting long-term strategies and outcomes.

When it comes to the participants included in this study, four clients from a previous longitudinal study were contacted ten years later. Asking people to relate to situations that occurred so long ago, can of course be questioned in terms of validity [16]. We were well aware of this however, having only survey data from previous assessment occasions at hand, we decided to conduct retrospective interviews. One rationale behind this decision was the fact, that the participants over the ten years had been more or less constantly involved in situations, where their declining capacity had required different actions over time. Having the results of the interviews at hand, we were surprised by the amount of information the participants gave us, and the details they provided. One reason could be the fact that, three of them had received additional HA during the past ten years, and thus had more recent experiences of the intervention. Furthermore, the interviews were performed in the participants’ homes, which may facilitate the participants to remember their experience of the HA granted. HA alter the design of the home and, to some extent, the way in which activities are performed. This probably this supported the clients’ ability to recall experiences and feelings. Altogether this could be seen as an important aspect, in ensuring the quality of our study.
The mixed method case-study approach applied in this study, supports combining different kinds of data in order to understand complex issues, such as outcomes and experiences related to different interventions in a person’s home. We also decided to apply an embedded design, where the survey data were embedded in the interview data. The integration of different kinds of data in one study has been more common within health care and rehabilitation research, although no standard way of performing such studies has been recommended. However, some studies have quite recently been conducted, which introduce guidelines aiming at enhancing the quality of mixed method studies [44, 45]. We argue that multiple perspectives are needed in order to understand human experiences, and that our design allowed us to achieve greater depth in our understanding, of the experiences of HA. That is, the study design contributed in a valid and efficient way to obtaining our comprehensive findings. We also argue that using both qualitative and quantitative data enhances interpretation of the findings [15, 46]. In order to increase the trustworthiness of the findings, all authors were involved throughout the analysis process, facilitating the attainment of intercoder agreement [15]. We carefully documented all different steps in the analyses, and discussed how the data would be optimally embedded, to generate thick descriptions of each narrative.

However, the fact that all authors are OT deserves attention, since this might have affected the interviews, as well as interpretation and labelling of the findings. The participants were aware of our profession, and also our knowledge in HA. This facilitated interviewing, but also resulted in that the participants withhold some experiences or taking for granted, that interviewers being familiar with HA and understood, which could
be a weakness. However, in-depth knowledge of the investigated field is absolutely crucial for high-quality studies, independently of methodology used.

Since the number of cases included in this study was very few, the findings cannot be generalised. Instead from the constructivist view used in this study, thick descriptions of narratives are important and facilitate for readers making their own generalizations [31].

To conclude, HA are valuable interventions, and enhance activity and independence in spite of the fact, that clients experience functional decline over time. Applying a client-centred approach, where the support strategies of the professionals are tailored according to client needs and preferences is important, calling for professional attention. It is a challenge in designing client’s best HA in relation to client needs and preferences and at the same time balance against current HA legislation. The intervention involves complex person-environment-activity (P-E-A) transactions along the process of ageing with a disability. Such dynamics are necessary to address for successful outcomes of the intervention. While further studies are needed in this respect, the current study generated important knowledge useful for practitioners and researchers involved in interventions in clients’ homes. We stress the importance of a comprehensive view on clients’ needs and desires, taking also functional decline, the use of mobility devices as well as different aspects of the environment into consideration.

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**Declaration of interest**

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Table 1. Characteristics of aspects of home and health (T1-T4) for each case.

<table>
<thead>
<tr>
<th>Data-collection occasion</th>
<th>Environmental barriers, (no.)(^1)</th>
<th>Magnitude of accessibility problems, (no.)(^2)</th>
<th>Usability in my home, activity aspects(^3)</th>
<th>Usability in my home personal social aspects(^4)</th>
<th>Usability in my home physical environmental aspects(^5)</th>
<th>Dependence in ADL, (no.)(^6)</th>
<th>Subjective Wellbeing(^7)</th>
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1. No of environmental barriers in the home. Higher score indicate more barriers (min 0-max 188). Based on data from the Housing Enabler [18].
2. Magnitude of accessibility problems in the housing. Higher score indicate more accessibility problems [18].
3. Higher score indicate better usability (min 0-max 28) [22, 23].
4. Higher score indicate better usability (min 6- max 42) [22, 23].
5. Usability in my home, physical environmental aspects. Higher score indicate better usability (min 4-max 42) [22, 23]
6. Based in the ADL Staircase [24, 25].
7. Based on the Gothenburg Quality of Life Instrument. Higher score indicate higher subjective well-being. (min 18-max 126) [26].