

Title: Older individuals' experiences of engagement during the assistive technology device service delivery process

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Abstract

Providing assistive technology devices to older individuals living in their ordinary homes is an important intervention to increase and sustain independence and to enable ageing at home. However, little is known about older individuals' experiences and needs in the assistive technology device (ATD) service delivery process. The purpose of this study was to investigate older individuals' experiences during the service delivery process of ATDs.

Nine older individuals were interviewed three times each throughout the ATD service delivery process. The interviews were analysed within a hermeneutical phenomenological perspective. The results show that the service delivery process could be interpreted as an enigmatic journey and described in four themes: "hope and optimistic expectations", "managing after delivery or needing additional help", "having available help versus being abandoned" and "taking charge or putting up".

The results emphasise the need for occupational therapists to maintain an individualised approach toward older clients throughout the service delivery process. The experiences of older individuals were diverse and related to expectations that were not necessarily articulated to the occupational therapist. The situation when the ATD is delivered to the client was highlighted by the clients as an important event with the potential to facilitate a successful service delivery process.

Key words: client-centred practice, community health care, occupational therapy

Introduction

The importance of everyday rehabilitation for enabling older individuals to age at home is being increasingly recognised, along with the role of the occupational therapist working in the community (1-5). Providing ATDs is one of many interventions occupational therapists use to rehabilitate older individuals and has the promise to be a cost-effective and constructive part of the solution to future health care challenges (3, 6-9).

In Norway, the provision of ATDs for individuals with disabilities is publicly funded, and the municipalities are responsible for all aspects of the service delivery process (10, 11). The National Insurance Administration in Norway defines an ATD as “a device or solution that helps to reduce the practical problems faced by a disabled person” (10). Norwegian and international guidelines for ATD service delivery recommend that the service delivery process include assessing user needs, choosing the ATD suitable for the user, applying for the ATD, adapting the ATD to the user, training the user, following-up, providing repairs and technical services as needed and evaluating the ATD according to the goal the client and occupational therapist set (6, 10, 12). The client and their needs should be the main focus throughout the process (6, 10, 12).

Despite the importance of these issues there is a paucity of knowledge regarding older individuals' experiences during the ATD service delivery process. Such knowledge would enhance evidence-based and client-centred ATD provision and would prepare health care services for the challenges of an ageing population. Insight into how older individuals experience the ATD service delivery process may contribute to improvements in client-centred ATD service delivery. To enhance the understanding of how the older individual perceives and experiences the service delivery process after the application for an ATD, rich

descriptions of the experiences during the service delivery process must be elicited and explored.

Previous studies have shown that starting to use an ATD may be a complex process for the older individual that may involve an ambivalent experience, negotiation and a transition period of adjusting to the ATD (14, 15). To facilitate client-centred ATD service delivery, the occupational therapist should work in a close and collaborative relationship with the client during all stages of the service delivery process (16-18). However, clients report that the follow-up for prescribed ATD varies or is lacking (19, 20). In one survey, 69% of clients reported that they did not receive any follow-up on the ATD after it had been prescribed (20). Clients have also reported that they are less satisfied with the follow-up services in the ATD service delivery process (20, 21). More knowledge is needed to understand the experiences of older individuals during the service delivery process after the decision to apply for a device has been made.

Although standardized instruments such as the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (23-25) and the Satisfaction with Assistive Technology Services (21) have been developed to assess and explore client experiences of ATD service delivery, these instruments do not give rich descriptions of client experiences.

This study aimed to investigate older individuals' experiences during the ATD service delivery process.

Materials and methods

A hermeneutical phenomenological approach guided the study (26). This approach assumes that both the researcher and the participants have pre-understandings that influence what is perceived (26). Drawing on her previous experiences of working as an occupational therapist in the community, the first author had sometimes discovered discrepancies between the users' expectations of her, and vice versa. She was therefore curious to investigate how the users of ATD services experienced their situation and their relations with the health care professionals. The researchers must work to ensure reflectivity regarding their own pre-understandings and strive for openness and sensitivity towards the multiple and diverse meanings of the experiences of the participants (26).

The participants were recruited from August 2009 to June 2010 in two regions of Norway among a purposeful selected sample of individuals >67 years old living in their ordinary homes who experienced difficulty in performing everyday activities, who had applied for a new ATD to compensate for these difficulties and who were able to give informed consent to participate in three qualitative interviews. To recruit participants, the first author approached occupational therapists working with ATD service delivery in the community and informed them of the project. No present or previous working relationships existed between the researchers and the recruitment personnel. During the service delivery process, the occupational therapists informed 11 potential participants of the project and distributed to them a letter describing the project, a consent form and an addressed return envelope with prepaid postage. Nine individuals signed the consent form and returned it to the first author during the recruitment period. The recruitment personnel reported that the reasons for declining participation included a lack of comfort discussing disabilities and the binding

commitment to the project necessitated by the length of the study. One participant died after the first interview, and another could not be contacted to make an appointment for the third interview. The first author performed all interviews between November 2009 and January 2011. The characteristics of the participants and their situations are presented in Table 1.

TABLE 1 ABOUT HERE

The study included three qualitative in-depth interviews with each participant. The first interview occurred after the participant had applied for the ATD, but before the ATD was delivered. The second interview occurred after the ATD was delivered. The third and final interview occurred after the participant had the ATD for at least two months. Interview guides with open-ended questions were developed for each of the three interviews that aimed to elicit rich descriptions of the participants' experiences during the service delivery process.

Hermeneutical phenomenological research aims to illuminate the meaning of having certain experiences (26). After careful consideration of the variation and depth in the data material, a sample size of nine participants was deemed sufficient to allow for an exploration of the research questions and to yield insights that would enhance the knowledge in this field (26).

The interviews were conducted in the home of the older individual, except for one interview, which was conducted in the first author's office at the participant's request. For cases in which the participant lived with a spouse, the spouse participated in the interviews if the participant requested the spouse to be present and after the spouse was informed of the study and provided their written consent to participate. The interviews lasted between half an hour and two hours. The first author audiotaped and transcribed all interviews verbatim. The detail

level of the transcription was determined by the aim of the study, which focused on the participants' experiences during the service delivery process (27). To provide contextual detail to interpret the data, the transcripts included laughter, pauses, sighs and certain incidents, such as noting that the spouse entered the room, or that the telephone rang (28).

The Regional Committee for Research Ethics and the Norwegian Social Science Data Service approved the project and the participants were treated in accordance with standard ethical guidelines. Some participants told that they were afraid that telling about negative experiences with the occupational therapists and the help they received could lead to retributions from the health care professionals. To maintain participant confidentiality, names of people and places and other details were changed during the transcription process. Throughout the study, the researchers emphasised being open to the experiences of the participants as they told them.

Data analysis

As understanding has always already begun, analysis was conducted throughout the research process (13). The interview transcripts were approached with the intention of understanding and describing the participants' experiences during the ATD service delivery process. van Manen notes that interpretation is involved in all descriptions, and involves transforming "personal meanings and experiences from interview texts into disciplinary understanding" (29 p139).

To elucidate themes or descriptions of important aspects of the experience in question, a highlighting approach according to van Manen was chosen (26). First, all of the transcripts were read several times to obtain an understanding of the material both as a whole and for each of the participants. The transcripts were then reread, and statements that related to the

question “How and in what way could the experiences of the participants provide insights of their experiences and involvement in the ATD service delivery process?” were identified and highlighted (26). Working with these highlighted statements for each participant and across the sample, four themes arose that described the diverse experiences during the ATD service delivery process. This work consisted of writing and rewriting, questioning the texts critically and rereading the transcripts to ensure that descriptions of the evolving themes captured the experiences in focus (26, 30). The evolving themes were discussed among the researchers until a consensus regarding the ordering and relevance of the themes was reached.

According to van Manen, metaphors can enhance understandings and bring us closer to the meanings we seek to describe (26). In the later stages of the analysis process, and drawing on the four themes, a metaphor inspired by the German philosopher Hans Georg Gadamer’s notion of the enigmatic character of health (31) evolved to enhance understanding of the themes describing older individuals’ experiences during the ATD service delivery process.

Findings

During the analysis, four themes evolved that described experiences during the ATD service delivery process. The themes are ordered consecutively, as they build on one another.

Experiencing the ATD service delivery process could be interpreted as engaging in an enigmatic journey; a journey which could take unexpected turns, challenge clients’ previous understandings and provide opportunities to learn more both of oneself, and of others. This enigmatic journey was an unfolding process in which past, present and future were entangled and influenced the experience, rather than a stepwise linear sequence of events. The themes describing experiences during the ATD service delivery process were “hope and optimistic expectations”, “managing after delivery or needing additional help”, “having available help

versus being abandoned” and “taking charge or putting up”. Throughout the Findings section, quotations are followed by a letter in square brackets that refers to the participant label.

Hope and optimistic expectations

All of the participants looked forward to receiving the ATD for which they had applied. They believed that the ATD would make life easier and would enable them to perform their desired activities. The participants were confident they would be able to manage using the ATD.

The participants felt that it was important to be optimistic that the ATD would improve their lives. Some participants had endured difficult and painful situations for a long time, and the ATD held promise for them that their quality of life would be improved. One of the participants said, “I think it is going to work out just fine. You know, you must have a positive attitude to the things you get” [G]. Another participant stated “I am really looking forward to receiving the ATD. I have been looking forward to it since the summer” [B]. The participants were eager to obtain and try their ATDs

All of the participants had faith that they would be able to use their ATDs and manage potential difficulties either with assistance from the occupational therapist, on their own or with the help of their social support systems. The expectations concerning the type of follow-up and training that they would receive differed among the participants, and none of the participants recalled that follow-up arrangements were discussed with the occupational therapist during the appointment when the ATD was selected. One participant said that although she did not believe that she needed any training, “the occupational therapist will follow-up on me; she will. She is very competent” [D]. Another woman was asked whether she expected training to use the bidet she had applied for, and she answered, “Yes, I reckon

that I will get some training. I have just... figured that I will" [E]. Another participant did not expect any follow-up at all and added, "I honestly think that I will be able to manage the ATD on my own" [C].

The participants were confident that their families would help them if they needed assistance. A woman who had applied for an electric lift chair said that if she had trouble understanding the user manual, her technically oriented grandchildren could help her. One man was asked what he would do if he experienced difficulties with the ATD for which he had applied, and he answered, "I will talk to my daughter, and she will talk to the occupational therapist" [F].

The participants' engagement in the service delivery process at this stage of the process, after they had applied for the ATD but before it was delivered, was directed towards the ATD and the impact that they hoped it would have on their daily difficulties. The participants hoped that the ATD would diminish these difficulties and expected that they could manage the ATD on their own or help from others would be available.

Managing after delivery or needing additional help

All applications were approved, and the ATDs were delivered to the participants' homes by the occupational therapist, a janitor or a technician. Some of the participants did not need or receive additional assistance from the occupational therapist. Other participants found that obtaining the ATD was not sufficient to ease their difficulties or to meet the expectations that they had for the ATD. A continuum was noted between the ability to use the ATD effectively after it was delivered and experiencing a need for additional help.

Managing after delivery was related to experiencing competence in the use of the ATD and receiving adequate training and guidance from professionals. Being told, shown or taught how to operate the ATD was emphasised as being pivotal for successful device use. Managing after delivery also referred to the ability of the person who delivered the ATDs to answer questions. A man who applied for a lift chair reported that he was satisfied with the training he received and said, “The janitor who delivered the chair, he showed me a little bit, and afterwards, the occupational therapist came and taught me how to use it” [F].

Experiences of needing additional help were related to feeling that the ATD did not meet the participants' expectations or that the ATD had broken. Experiences of needing additional help also involved not knowing how to use the ATD. One man received a wheeled walker instead of the sock puller he thought he had applied for and said, “I do not know why I got the wheeled walker. It was just delivered here”[A]. Although he acknowledged that the walker might be useful when he was walking outside, he still experienced a need for an ATD that would enable him to get dressed. One woman [H] was not present when her ATD was delivered, and she was disappointed because she experienced difficulties using the ATD that she would have liked to address upon delivery.

This theme describes the participants' experiences of whether expectations regarding both the ATD and the professionals were met. Their encounter with their ATD and the person who delivered it either confirmed the participants' positive expectations or surprised them when their expectations that the ATD would ease their everyday life were not met.

Having available help versus being abandoned

After the ATD was delivered, there was a continuum of experiences that ranged from experiencing that occupational therapists were available and approachable to experiencing a sense of abandonment by the therapist and being left alone even if additional help was needed.

Experiencing that help was available was related to knowing where and to whom to turn for assistance. Having the name and contact information of the occupational therapist contributed to this experience. The information was distributed by the occupational therapist, or the participants had previous knowledge of the occupational therapist's position or location in the community. One woman said of the occupational therapist, "Her office is right next to the physiotherapist that I see every week, so I talk to her all the time" [D]. Another participant reported that he did not know the name of the occupational therapist, "But I know where her office is" [I]; thus, the therapist was perceived as being accessible.

Experiences of being abandoned were related to not receiving any follow-up and not knowing to whom to turn when additional help was needed. One woman who experienced difficulty in managing the ATD contacted the occupational therapist after waiting for several weeks while believing that the therapist would contact her first. She confronted the therapist regarding her expectations: "But I asked her, don't you check if the ATDs fit? No, when she did not hear anything, she figured that everything was fine. No, I was waiting for you to contact me and ask if I got the ATD and how it was! Oh no, that was not how it worked. She was so busy, so she did not have the time for that. Oh well, alright then" [H].

Another participant who experienced difficulties using the ATD said, “That occupational therapist, she never called me and asked how I was doing and if the ATD suited me. I did not hear anything. I mean, it is her job to contact me” [E].

Some participants had expectations that the occupational therapist would be engaged in the clients’ situation throughout the process by adopting a comprehensive view of the clients’ situation and designing customised measures to improve the situation. One man was satisfied with the service he received but added, “It would not be harmful if they were more assertive and came around to us old people to show us some ATDs because they know that we are here and that we need help” [I]. Between the second and third interview, this participant realised that he was more restricted in his activities than he thought. He reported planning to contact the professional again to apply for more ATDs that could increase his independence, but he was disappointed that the occupational therapist cut her visits short and failed to address his other difficulties.

The experiences of the participants in this theme could be considered to centre on the expectations toward the occupational therapist who was involved in the process of providing the ATD. Whereas some of the participants felt that professional help was available to them, other participants felt that their expectations regarding professional involvement were not met. These latter participants were not involved in the service delivery process; rather, they were abandoned by the occupational therapist during this process. These experiences of being abandoned concerned the inability to obtain access to the professional expertise and knowledge or support and care expected from a health care professional. The expectations may have been very high, but these expectations were not articulated to the occupational therapist until such expectations were not met.

Taking charge or putting up

When the participants experienced difficulties in handling the ATD, a continuum was noted that ranged between taking charge of the situation and putting up with it.

Taking charge of the situation involved contacting someone who could help; this issue was related to having available help and social support and to participants who referred to themselves as assertive people. One woman said that the bidet she had applied for broke: “And then I called the technician right away because I had his business card, and he was very clear about that. If I had any problem, I should call him at once. And that worked out just fine” [D].

Taking charge of a difficult situation also related to the extent to which the participant valued the ATD and the importance of managing activities of everyday life and participating in a meaningful occupation. Consideration of the ATD as being necessary and important became a persuasive motivator when the ATD broke or did not work. The woman who called the technician about her broken bidet said: “I cannot live without it. When I was waiting for it to be fixed, it... it was some nasty weeks” [D].

Knowing who to call or where to go for assistance did not guarantee that the participant contacted someone to correct difficulties. Putting up with a difficult situation included hesitating to contact the occupational therapist when the ATD did not work the way the participants expected it would. For some participants, contacting the occupational therapist because they needed additional help was considered to mean that they would be perceived as rude, ungrateful and subject to negative consequences. These concerns could make the

participants delay or entirely omit contacting the professional to correct the situation. One of the participants explained her reluctance to contact the occupational therapist by saying, “I am not one of those that complain. I never was. Complaining is just not my style” [H]. To explain why she delayed contacting the occupational therapist to help with an ATD that did not work to her satisfaction, another woman said, “I am not like that... I am not pushy and aggressive. I can't... nag to get what I want. That is the worst thing I know” [E].

One of the participants said that a previous comment about assistance that she had received resulted in retribution from the health care professionals. This experience led the participant to assume a submissive position towards encounters with health care professionals. When probed to elaborate on why she was afraid to contact the occupational therapist regarding issues relating to the ATD, the participant said, “I am afraid of... I am afraid that a harsh tone [will be used with me] when they get here” [E]. She depended on regular and substantial help from the health care system in her municipality. Because of her fear of jeopardising her relationship with the health care professionals on whom she depended, the participant simply put up with the situation when she received an ATD that she did not know how to use.

The participants' experiences manifested as reflecting on, negotiating and choosing whether and how to act upon unsatisfactory situations related to the ATD. Some participants experienced themselves as owners of the process, taking charge of problematic occurrences and claiming responsibility for the service delivery process by contacting someone who could help them. The ATD service delivery process could also be experienced as passive receipt of health care, i.e., placing the responsibility of the service delivery on the occupational therapist. In this case, taking charge of an unsatisfactory ATD service delivery was considered

to cause the participant to be perceived as ungrateful and to place the participant at risk for retribution from the health care professional.

Discussion

The purpose of this study was to investigate older individuals' experiences during the ATD service delivery process. The results show that user experiences during the ATD service delivery process could be understood as an enigmatic journey. The experiences were diverse, changed throughout the service delivery process and were related to an evolving understanding of expectations of both the ATD and the occupational therapist.

Gadamer used the term enigmatic to describe the hidden and mysterious character of health. He pointed out that "our conscious self-awareness remains largely in the background so that our enjoyment of good health is constantly concealed from us" (31, p112). However, health nevertheless show itself in being "forgetful of ourselves, scarcely notice the demands and strains which are put on us" (31, p112). Thus, he denotes health as "a condition of being involved, of being in the world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks" (31, p113). The process of the ATD service delivery process could be explicated in metaphorical terms as a journey with similar enigmatic characteristics. The enigmatic journey might or might not involve unexpected events which could challenge both the expectations of the health care professionals as well as preconceptions of one self.

None of the participants expected the ATD service delivery process to be a challenging or difficult one, and with unexpected events, each had to identify, negotiate and deal with the difficulties. Taking charge could prove to be challenging when one was faced with a difficult

situation, contrasting the constructive and vigorous attitude of the participants before the ATD had been delivered. The metaphor of the ATD service delivery process as an enigmatic journey emphasise the hermeneutical insight that “each of us is, in a mysterious way, unknown both to ourselves and to others” (32, p164). In our everyday lives we respond to “innumerable and incalculable effects and influences, burdens and problems. There are always unpredictable elements which play their part” (32, p164).

The clients’ positive expectations and optimistic outlooks towards the ATD and the service that they would receive led to surprise when unexpected outcomes occurred. Some expectations first surfaced when they were not met, which makes it difficult to prevent problems and emphasises the need for the professional to be available and proactive. This circumstance may require home visits to evaluate the actual usage and impact of the ATD rather than calling the client or expecting the client to make contact if they need further assistance.

The unanimous attitude of hope and the positive expectations towards the ATD noted in this study contrast with previous research findings suggesting that older individuals hold mixed attitudes towards ATDs and report difficulties accepting ATDs (14, 33, 34). This contrast may relate to the timing of the first interview and the scope of this study. When the participants in this study were first interviewed, they had already made the decision and the commitment to apply for an ATD. However, the deliberations that they may have made prior to deciding to apply for the ATD were not addressed in this study.

The results of this study indicate that the situation when the ATD was delivered or installed was a crucial point in the service delivery process that could either affirm or reverse the clients' positive expectations. When the person delivering and assembling the ATD focused on both the ATDs and the recipients by helping the users test and incorporate the ATDs into their everyday lives, the clients felt that they managed to use their ATDs more easily, had help available if they needed it and could take charge of unexpected outcomes. It can thus be argued that delivery is a crucial point in securing successful ATD service delivery in addition to the assessment of needs. Previous research has emphasised the importance of testing the ATD to ensure a good match with the user (17). It has also been argued that testing and adjusting the ATD are complex processes that influence both the ATD and its user (35). Both of the previous studies mentioned here focused on wheelchair prescriptions. The results from the present study indicate that these considerations are relevant for all prescribed ATDs.

Previous research found that although follow-up is lacking, clients may use ATDs as intended (19). The results from this study confirm that some clients learned to use their ATDs and thus overcame their occupational performance difficulties with minimal assistance from the occupational therapist. Other clients experienced feeling abandoned and had to handle difficult and unexpected outcomes without asking for help that may have been available to them. Such unwanted situations represent wasted resources and prolonged or even enhanced suffering. To decrease the likelihood of such situations, the results from this study suggest that follow-up should be individualised.

Some participants in this study were involved in the service delivery process in ways that were expected of a resourceful and active client. Other participants expected the occupational therapist to be the proactive party. To ensure successful and client-centred ATD service

delivery, the occupational therapist must possess good clinical reasoning skills and must continue to develop these skills. The diversity of client experiences shown in this study represents a challenge for the occupational therapist which must be able to address this diversity and strive to ensure that clients' unique needs are met. Following from this, the ATD service delivery process should be individualised and client-centred throughout to ensure that unexpected events or new emerging needs could be identified and dealt with. As ATD needs may change rapidly, follow-up should address possible future outcomes and needs (36). These findings are in accordance with the results of a focus group study of stakeholders in ATD provision who recommended that ATD service delivery should be approached as a process that includes training, evaluation and follow-up as key services (18).

Norwegian health policy suggests that older individuals who will receive health care in the future will be more knowledgeable and economically resourceful than individuals in previous generations; these individuals will also be proactive and committed to sustaining good health and preventing illness (37, 38). It can be argued that as younger generations age, they will incorporate the new consumer-patient role (37). However, the experiences of illness and disability entail a profound existential component that indicates that these experiences will be consistent across generations (39).

The results of this study confirm the hermeneutical insight that humans are not only natural objects but are also enigmatic in ways that are unknown to themselves and others (32).

Human reactions, responses and understandings are incalculable; although humans may hypothesise how they will react to events, they may be taken by surprise (32). Because rules are insufficient to explain human life, understanding plays a profound role. Understanding is never truly finite; therefore, it must be expected that clients in the ATD service delivery

process may be enigmatic to both themselves and the occupational therapist, which indicates the importance of the professional being open to a multiplicity of client experiences.

The aim of hermeneutical phenomenological research is to focus on uniqueness and varieties of experiences and to produce descriptions that resonate with the readers' sense of lived life (26). The experiences as told by the participants were detailed and varied which provided a solid base to investigate these experiences. We approached experiences during the ATD service delivery process as ways of being in the world that entailed involvement, choice and commitment. With this approach, aspects of client experiences were identified that extend beyond understanding client involvement as participating in decision-making, being satisfied with the services and determining whether follow-up is experienced. The hermeneutical phenomenological research approach gave way for investigating the ATD service delivery process firmly based on the user's experiences. However, it was beyond the scope of this study to investigate the experiences of the occupational therapists in ATD service delivery or the interactions between users and health care professionals. The knowledge gained from such studies would further enhance our understanding of the dynamics and processes of the ATD service delivery.

The findings of this study challenge the notion of satisfaction with ATD service delivery as being easily accessible and measurable, as there may be several complicating reasons for older individuals not to acknowledge unsatisfactory experiences in the service delivery process. The investigation of client experiences during the service delivery process uncovered diverse experiences related to expectations, disappointments, fear and abandonment but also hope, mastery and resourceful and dynamic self-management of care.

Our results highlight the importance of the situation where the ATD is delivered to the client and suggest that occupational therapists should emphasise this stage to support the clients and to ensure successful ATD provision.

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Table 1 – Characteristics of the participants, age range 69-91 years

Participant label	Gender	ATD they applied for
A	Male	Wheeled walker, shower chair
B	Male	Electrically powered wheelchair
C	Female	Wheeled walker
D	Female	Bidet
E	Female	Bidet
F	Male	Lift chair
G	Female	Wheeled walker
H	Female	Lift chair
I	Male	Pillow to get out of chairs

Table 2 - Findings

Overarching theme:	The ATD service delivery process; an enigmatic journey
Subtheme 1	Hope and optimistic expectations
Subtheme 2	Managing after delivery or needing additional help
Subtheme 3	Having available help versus being abandoned
Subtheme 4	Taking charge or putting up