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CASE REPORT



# Challenges in the provision of digital technologies to elderly with dementia to support ageing in place: a case study of a Swedish municipality

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## ABSTRACT

**Purpose:** The aim of this paper is to identify structural problems and challenges for the delivery of digital technologies for ageing in place to elderly with dementia.

**Methods:** To that end, I conducted a case study in a Swedish municipality.

**Results:** The results showed that elderly with dementia are not exploiting their full potential of receiving help in the form of technology, since the four conditions of the Consumer Direction (Control and Direct services – Variety of digital technologies for ageing in place options – Information and Support – Participation in systems design) were met to a very low degree.

**Conclusions:** I propose that the municipality in question creates a proper knowledge-sharing platform so that occupational therapists are well informed about digital technologies for ageing in place, to allow them to provide accurate information and support to elderly with dementia, resulting in a possible increase in use of technology and subsequently support the empowerment goal of Consumer Direction. I also believe, according to the findings of this study, that the module of Information and Support should be treated as the most important condition for achieving increased Consumer Direction.

## ARTICLE HISTORY

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## KEYWORDS

Elderly; dementia; empowerment; consumer direction; digital technologies for ageing in place; provision

## ► IMPLICATIONS FOR REHABILITATION

- Elderly with dementia and their relatives do not receive sufficient information about digital technologies for ageing in place (DTAP). There is not enough information regarding the available options and their use. This often denies elderly with dementia and their relatives the services they are entitled.
- Occupational therapists knowledge about DTAP affects the variety of options presented to elderly with dementia and their subsequent use.
- Once a person is diagnosed with dementia, physicians tend to suggest medicinal solutions, overlooking the dissemination of DTAP information. Thus hindering their early access to DTAP.

## Introduction

According to the European Commission's 2018 Ageing Report [1], the demographic old-age dependency ratio - which is people aged 65 or above - is projected to increase significantly in the EU over the coming decades. While this demographic shift shows that people live longer and healthier lives than in the past, it is not problem-free and comes with new societal challenges that need to be addressed. One of these challenges is the rise of elderly with cognitive disabilities (mainly Alzheimer's or dementia) [2]. Predictions show that the worldwide number of people with dementia will increase from 66 million in 2030 to 115 million in 2050 (see [3,4]). Dementia is a disease that may lead to vague and empty speech, dwindling vocabulary, defective linguistic reasoning, changes in word association patterns and disordered discourse [5–7]. People suffering from those cognitive disabilities are usually not an active part of society and are often portrayed as frail or vulnerable, causing them to be stigmatized [8]. To tackle this immense pressure on the healthcare system, extensive research has been conducted (see [9,10]) on digital technologies for ageing in place (DTAP), which are increasingly being used to

support relatives and elderly with dementia in daily life [10]. The main areas in which DTAPs have been developed are: (1) reminding, (2) social contact, (3) safety and (4) daily activities [11]. Regardless of the existing types of DTAP, many elderly with dementia do not use these technologies because they do not match their needs and capacities or because they are unattractive; furthermore, these shortcomings could be caused by their lack of involvement in systems design [12].

According to many authors (see [13–17]), users should be involved in the design process so that the technologies can be accepted and fit end-user requirements. As Dong, Cassim and Coleman [18] state, a “deep engagement with human diversity” is needed by technologists and designers. Such involvement is suggested to increase their autonomy and empowerment [19,20]. People with mental disabilities have defined empowerment as consisting of self-esteem/self-efficacy, optimism, and control over the future [21], as well as having decision-making power, learning skills, changing others' perceptions, and rejecting the role of a passive service recipient [22,23].

Consumer Direction Theory of Empowerment (CDTE) is a theory aiming to promote the empowerment of people with

disabilities. According to Kosciulek [24], consumer direction (CD) is a framework that can enable people with disabilities to develop the skills to take control of their lives and environment. In a consumer-directed system, individuals with disabilities are the ones who assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received [25]. In this study, the word “services” refers to the provision of DTAP to elderly with dementia. Even though there is an increasing amount of scientific articles regarding the participation of elderly with dementia in research, we have not identified any study that uses the CD as a model to identify challenges within service delivery.

The aim of this paper is to investigate structural problems and challenges with service delivery of DTAP to elderly with dementia. Hence, the main research question of this paper is: *What are the challenges within DTAP delivery to elderly with dementia according to key actors in a Swedish municipality?*

The rest of the paper is structured as follows: “Challenges for service delivery” introduces relevant research on challenges within service delivery. “Consumer-Directed theory of empowerment” discusses the Consumer Direction Theory of Empowerment. “Methods” is devoted to presenting the case as well as the data collection and analysis methods used in this study. “Results” presents the results of the interviews conducted in Örebro municipality followed by “Discussion” with a discussion about CD, the study’s contributions and suggestions for improvements. Finally, the study limitations are highlighted and suggestions for future research are provided.

## Challenges for service delivery

This section provides a description of challenges that can be associated with service delivery of DTAP. It begins with a general description of challenges affecting the service delivery and then moves on to challenges that are in alignment with the CD framework, which is further described in “Consumer-Directed theory of empowerment”. The purpose of DTAP is to empower different actors and increase their independency and quality of life. Some important challenges that can hinder the service delivery are context-dependent. These challenges could vary in nature. Some challenges could be attributed to the cost and accessibility of these technologies [26,27], other challenges could be about the ethical implications of these technologies; such as limiting one’s privacy [28].

One important factor connected to the delivery of DTAPs is their variety. DTAP options vary from reminding technologies, technologies for social contact and safety technologies to technologies for activities of daily living [10]. It is important that this variety exists so that the elderly with dementia have the freedom to choose between technologies, thus not feeling restrained.

Another challenge associated with service delivery is the ability of elderly with dementia to control and direct DTAP delivery [29]. This control is often associated with the concept of empowerment. Empowerment, as presented in the introduction, contains elements of self-efficacy and decision-making power, rejecting the role of a passive service recipient [22,23]. As Bengtson et al. [30] state, the empowered individual sees oneself as capable of change, able to use his or her knowledge and skills to solve problems and meet goals, and to work in partnership with professionals (in this study: occupational therapists).

Regarding challenges from the professionals’ point of view, Frennert [31] and Thorslund [32] state that the transition from the traditional to a more digitalized model can affect the existing

personnel and that there is a need to provide accurate information and guidance regarding how these services need to be used. It is also crucial for care personnel to have the right skills and abilities that will further ensure the implementation of DTAP [33]. Access to the right information is crucial in deciding the type of treatment or technology to be used for elderly with dementia. A European survey conducted by Bond et al. [34] showed that family caregivers or people with dementia had insufficient information about the benefits of treatment and care interventions that were actually available to them. Gjesten et al. [35] suggest that a positive attitude and the ability to explain the profits and benefits for both caregivers and care receivers (in this study: elderly with dementia) assist the implementation of DTAP. Wolfs et al. [36] conducted an empirical study about empowerment of elderly patients with cognitive impairments and concluded that most patients and caregivers were not aware of the treatment options available to them. They also suggested that early awareness of the available treatment options is necessary for the empowerment of patients suffering from dementia or a mild cognitive impairment [36]. These results can be easily interpreted in this context, since DTAP are also used to assist a person. Jarvis et al. [37] conclude in their research that occupational therapists have a conservative approach to technology regarding dementia and that there is a limited understanding about available technological interventions for this group. Another important factor that contributes to access to information can be identified in a review by Shearer et al. [38] that reported findings of published empowerment interventions studies with community-dwelling older adults. In that review, a health education component was included to foster empowerment, by increasing knowledge to make informed choices (right to information). According to Frennert and Östlund [39], clear instructions need to be communicated to facilitate understanding, commitment, and encouragement to implement DTAP. Lastly, Söndergård et al. [40] state that some obstacles identified in the implementation of DTAP deal with lack of routines for technology introduction, limited knowledge of the benefits of technology support, lack of user involvement and lack of user understanding of what features the users need.

In the past, lack of user involvement was rather challenging and frequent as elderly with dementia were largely excluded from research [41] and until the 1990s, research tended to overlook their perspectives [42]. This lack of involvement of people with dementia was attributed to a phenomenon of anticipated distress [43], to an increasing cognitive impairment or frailty [44], and the stigma attached to dementia itself [45]. As the times have progressed, there is an increasing consensus in academia that elderly with dementia should be included in research as active participants [19] and it appears that this involvement of people with dementia in the development of IT devices leads to their empowerment [11].

## Consumer-Directed theory of empowerment

The CDTE is a theory used to promote the empowerment of people with disabilities and guide the development and evaluation of disability policy and rehabilitation services [24]. It is based on four components; (1) CD (See Figure 1), (2) Community Integration, (3) Empowerment and (4) Quality of Life.

According to Kosciulek [24], increased CD leads to: (1) community integration – which means that individuals with disabilities are integrated and are a part of the community they reside in. Followed by (2) empowerment – which is conceptualized as

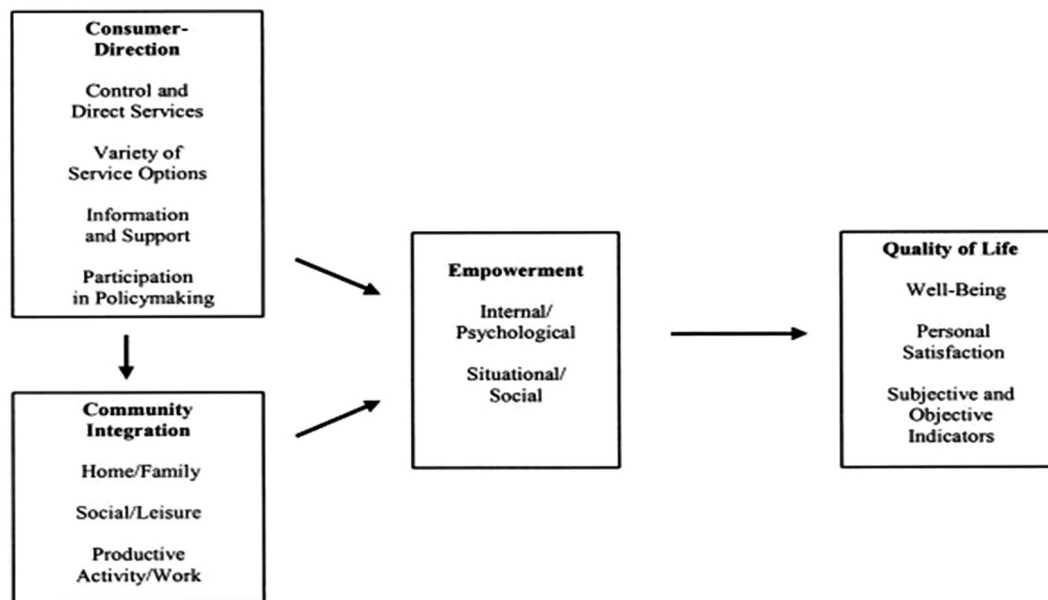


Figure 1. Structural model of the Consumer-Directed Theory of Empowerment [24].

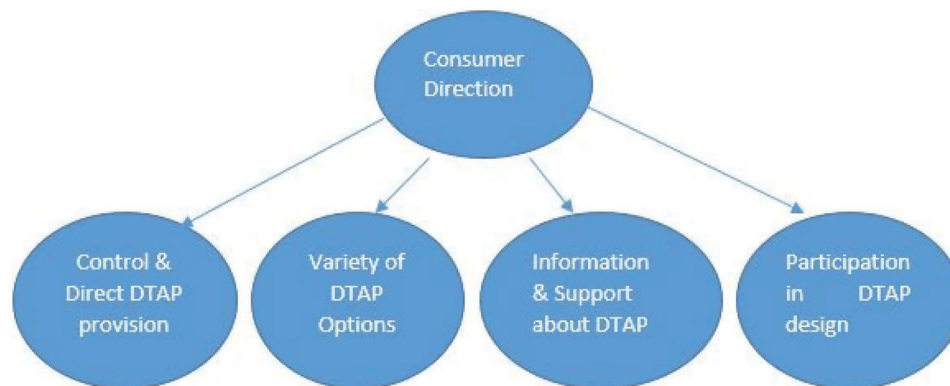


Figure 2. Adaptation of CD.

involving internal/psychological (sense of control, competence, confidence, responsibility, participation, solidarity and community) and situational/social (control over resources) aspects. Finally, the last outcome of the CDTE focuses on the (3) quality of life among people with disabilities – which is defined as an overall general well-being consisting of objective and subjective evaluations of physical, social, material and emotional well-being. From the CD standpoint, disability is seen as a natural part of the human experience. It refers to the activities where consumers with disabilities can develop a sense of personal control and acquire the opportunity to influence social and political systems. The main theoretical assumption of CD is that informed consumers have control over the policies and practices directly affecting their lives [24]. This theoretical assumption of CD is highly in alignment with the purpose of the study since it examines the issues that affect the control that elderly with dementia have or should have, over the policies and practices which affect their lives. An additional reason why this framework suits the particular situation is its ability to adapt to different contexts. Tenets of CDTE have been used for example in different venues such as disease management, health and social care, to tourism and business and economics (see [46–50]).

Kosciulek [51] describes CD consisting of four modules (See Figure 1); when all four are fulfilled, CD is achieved. In this study,

CD is used as an analytical framework applied to categorize challenges in the provision of DTAP to elderly with dementia. An indirect goal of this study is also to see if there is an increased CD, which in turn, according to Kosciulek [24], leads to the empowerment of the consumer (in this case: elderly with dementia). To provide a better understanding of how CD is perceived in this study, I describe how the four modules of CD are adapted and used in this specific context (See Figure 2). These four modules are: (1) *Control and Direct DTAP provision* – The ability of elderly with dementia to control and direct the delivery of DTAP, (2) *Variety of DTAP Options* – The variety and type of DTAP options available to elderly with dementia, (3) *Information and Support about DTAP* – The availability of appropriate information and support; and (4) *Participation in DTAP design* – The ability of elderly with dementia to participate in DTAP design and service allocation.

The module of *Control and Direct DTAP provision* relates to the amount of control elderly with dementia have over how, when and by whom services are delivered. It also focuses on the extent to which elderly with dementia determine the type of DTAP and influence the quality of services received. The *variety of DTAP options* refers to whether elderly with dementia have a choice from a range of viable DTAP options and limitations regarding DTAP options, risks (regarding the coverage of needs and the

incompatibility of DTAP options), or restrictions (regarding the purchase of additional DTAP). The *Information and Support* module are associated with (1) the availability of information, (2) the provision of support but also (3) the personal, legal, and financial issues associated with each option. Lastly, the fourth module of CD consists of the level of *participation in DTAP design* by elderly with dementia, the allocation of financial resources and the decision-making power that elderly with dementia within DTAP design.

## Methods

### Case study

#### *Elderly with dementia and digital technologies for ageing in place in Sweden*

According to Sweden's national strategy for digitalization and DTAP [52], there is a tremendous potential for elderly with dementia to maintain their independency and have increased participation in the society [13,16,53]. While DTAP appears to be a good solution, they do not avoid criticism, such as leading to impersonalized care where a person's integrity is threatened and insecurity increases [52]. One of the biggest challenges that Sweden faces with DTAP and elderly with dementia is the generational challenge. While the future generations of elderly will probably feel more comfortable with DTAP, today's elderly may have difficulties in understanding and seeing the possibilities that these technologies offer [54]. According to the National Board of Health and Welfare in Sweden [52], this leads to elderly with dementia having difficulties in maintaining an active role in the development of DTAP as part of the required technical inputs and further hinders them from receiving support in the form of DTAP. This concern aligns with Reid and Green [55] regarding people with severe intellectual disabilities that may not experience the same level of involvement in systems design or realize the quality-of-life benefits.

#### Case description

I decided to focus on Örebro municipality in this study. A case study is an empirical inquiry that investigates a contemporary phenomenon in its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident [56]. The depth of the focus, its natural settings, its holistic ability and the multiple sources of data collection [57], are usual characteristics of a case study. Örebro is the seventh largest city in Sweden and one of the largest inland hubs of the country, with 117,543 inhabitants. The size of Örebro municipality was also considered for allowing a degree of generalization for the study results. In addition, Örebro municipality has a free-of-charge policy (not all municipalities have this policy, making Örebro a special case study) for loaning DTAP to its citizens. The funding

structure of Örebro municipality makes it specifically interesting since within CDTE people with disabilities (in this case: elderly with dementia) are viewed as consumers but in this context people with disabilities tend to be a hybrid mix between consumers and patients. One issue that needs to be addressed is that each municipality in Sweden is managed (has different directions) differently and the range of DTAP options varies within municipalities. This, in a way, makes each municipality a unique case. According to an information document provided by Örebro municipality [58], the municipality has a responsibility to offer DTAP to everyone suffering from a disability and residing within the county. The municipality offers housing solutions for people with (cognitive/physical) disabilities, where trained personnel (occupational therapists) tend to the needs of elderly with dementia. In most cases, the municipality tends to prioritize people residing in their own homes so housing solutions are offered as a last resort. The main authority for the provision of DTAP regarding cognition and communication impairments to Örebro municipality is the centre for assistive technologies. To receive DTAP without charge in Örebro municipality a prescription is required by an occupational therapist, who performs a needs assessment. Occupational therapists are then responsible for assessing the needs for DTAP, customizing the DTAP so needs can be met, providing information to users and a close person or caregiver on how the DTAP is to be used and maintained. They are also responsible for following up and evaluating their use and finally, informing users and caregivers of their responsibilities and the terms and conditions regarding the loan of DTAP. If for example a person staying at their own home has received DTAP but their situation then becomes so that they need to be tended by trained personnel and need relocation, the DTAP (as long as the relocation is within Örebro municipality) follows the person to their new location.

#### Data collection

To gain a better understanding of the existing DTAP provision conditions within dementia care and the different workplaces, it was deemed necessary to collect data through interviews. One common type of interview is the "key informant interview", which depends on open-ended questions [59,60]. The use of a case study also allowed the researcher to get a better contextual understanding since, in order to conduct the face-to-face interviews, the researcher had to visit the workplaces shown in Table 1. The interviews took place between December 2017 - May 2018. The interviews were semi-structured and were followed by an open discussion (See Appendix – Table A1 for interview themes/topics), which gave the interviewees the freedom to express themselves without being restrained by the questions. This format also allowed the interviewees to demonstrate DTAP if

Table 1. List of interviewees.

Number of participants	Role	Workplace
4 (individual f-2-f interviews)	Occupational therapists	<ul style="list-style-type: none"> <li>• Centre for dementia (Demenscentrum)</li> <li>• Ängens memory centre/reception (Ängensminnessmottagning)</li> <li>• Centre for assistive technologies (Centrum för hjälpmedel)</li> <li>• Mikaeligården (Dementia care centre)</li> <li>• Örebro municipality</li> </ul>
3 (one focus group)	Case workers (2 case workers + 1 case worker/accommodation coordinator)	<ul style="list-style-type: none"> <li>• Mikaeligården (Dementia care centre)</li> <li>• Örebro municipality</li> </ul>
1 (Skype interview)	Researcher/Developer	<ul style="list-style-type: none"> <li>• Technology developer company</li> </ul>
3 (focus group: one information meeting + opinions of relatives)	Spouses of people with dementia	<ul style="list-style-type: none"> <li>• Centre for relatives (Angörigcentrum)</li> </ul>

they wished. The interview included themes related to the theory, such as:

1. *Control and Direct DTAP services module* – Level of control elderly with dementia have regarding the direction of DTAP services. What processes need to be followed by elderly with dementia to receive DTAP
2. *Variety of DTAP options* - Provision of DTAP to elderly with dementia
3. *Information and support module* – Information and support received by occupational therapists regarding DTAP
4. *Participation in DTAP design* - Participation of elderly with dementia in the design of DTAP
5. Lastly, (5) there were some discussions regarding the acceptance of DTAP by elderly with dementia.

Qualitative data were collected from four different groups, (1) occupational therapists (OTs), (2) case workers, (3) researcher/developer at a major technology provider and (4), relatives of people with dementia (see Table 1). Regarding the selection basis, occupational therapists are the ones who are in charge of assessing the needs of elderly with dementia regarding DTAP provision and they are also responsible for customizing the DTAP according to the users' needs and lastly, providing them training on how to use DTAP. In one case, access to occupational therapists occurred by snowball sampling [61], since the first interviewee (occupational therapist) provided us with contact details for the rest of the interviewees. Relatives were selected due to their level of intimacy, occurred from residing with elderly with dementia (in this case: spouses of people with dementia) and because of the fact that they already had some expertise in the field of DTAP. The selection of relatives was initiated by a call of interest drafted by the author and sent to the relative centre (a place where people with different needs can receive support and advice that makes everyday life easier and meet other people in the same situation where they can discuss similar issues with) within Örebro municipality. The relative centre distributed the call to the relatives of people with dementia who then decided upon their participation. The meeting with the relatives took place in the relative centre of Örebro municipality. Moving on to the next group, caseworkers were selected on the basis of their expertise with municipality rules and regulations regarding the provision of DTAP. Caseworkers are also the ones who assess if a person is in need of DTAP. Finally, a researcher/developer from a technology developer company was selected based on his expertise in the field of developing DTAP and the involvement of elderly with dementia in the process. The technology developer company is also one of the major DTAP provider in Sweden and so an interviewee from such company seemed beneficial. All the above are key actors in DTAP delivery within the municipality and acted as "proxy" informants [62] and thus participation of elderly with dementia at this stage was not necessary. In addition to that, this study explored the structural problems and challenges within DTAP delivery and was focussed on the municipality's perspective. The interviewees were approached through email and, with their consent, the interviews were recorded digitally and transcribed verbatim. The interviews were conducted in Swedish, then transcribed verbatim, and further translated into English. The interviews lasted from 40 min to 1 h and 30 min, depending on the questions that would emerge from the discussion between the researcher and the interviewees. The interviewees were anonymized for this study, but agreed to provide their role and workplace for the interview transcript.

As shown in Table 1, the participants were mostly from Örebro municipality and provided a representative cross-section thereof. Örebro municipality was also chosen for demographic convenience, such as accessibility and proximity. All workplaces are central examples within the municipality. Interviewing people from different workplaces allowed an immersion in the context of DTAP delivery. As also shown in Table 1, data collection with caseworkers and relatives are distinguished as focus group interviews. The focus group interview with the caseworkers took place in their working environment. The interview started with participants providing some information about themselves and their work responsibilities. After the introduction, the discussion moved towards the themes presented in the beginning of "Data collection" and followed an open format where each participant was able to raise their opinions. Regarding the focus group with the relatives, the meeting was set up in two sessions. First, the author together with another researcher presented the available DTAP (of the municipality) to the participants, and then proceeded to having a discussion on these devices but also the experiences of the relatives in regards to technology use by their partners. The reason for including focus group interviews was because the participants were of similar status and that helped in gaining a better understanding of the context in which the research was taking place, but also helped in generating consensus views and more varied responses [57,63]. As Oates [57] states, a suitable number of participants would be around three to six people since it is very hard for the interviewer to facilitate group discussions and keep notes at the same time, and so for these reasons the focus groups were consisted of three participants.

### Data analysis

Following an interpretive approach, the interview transcripts were analyzed through the lens of the CD [51] (See Figure 1) for allowing the categorization of the challenges of Örebro municipality brought up by different actors within service delivery to elderly with dementia. Interpretative studies identify, explore and explain how all factors in a particular social setting are related and interdependent, in order to create a rich understanding of a possibly unique context [57]. The author transcribed all interview material and then proceeded to place each stakeholder interview within the categories of CD. In the end, the author had a document that was divided into 4 categories; each category included quotes from the interviews with each stakeholder individually. This allowed the identification of differences or similarities in each stakeholder interview. As explained in "Consumer-Directed theory of empowerment", the modules of CD consist of a set of subcomponents. These subcomponents were included in the analysis of the interview transcripts. "Results" is written so that these subcomponents can be identified while reporting the results from the interview. The results include perspectives from all stakeholders with no group being removed from the analysis. The workplace of the occupational therapists was also important since the centre for assistive technologies is responsible for training occupational therapists and for the provision of DTAP. Visiting the workplaces also offered the author a better contextual understanding of the background. In some cases, it was hard to categorize interview quotes from all stakeholders in all parts of CD. For this reason, the origin of each quote used was provided. Each subsection of the results is then broken into different paragraphs corresponding to the different subcomponents of the CD modules.

## Results

This section presents the results from the interviews, matched to the four components of CD. Quotes have been provided to highlight the importance of various aspects and the challenges within service delivery in Örebro municipality.

### Control and direct DTAP services

There was a general consensus from the interviews with all stakeholders that elderly with dementia are the ones who have control over DTAP services that they wish to receive.

*"It is up to the patient to decide"* – Occupational therapist (Demenscentrum)

*"The person with dementia is the one who takes the final decision regarding the use of DTAP"* – Occupational therapist (Centre for assistive technologies)

*"We can offer the solutions but if the patient (elderly with dementia) does not want them, then we cannot do anything else"* – Caseworkers (Örebro municipality)

Even in cases where their level of dementia does not allow the elderly to decide for themselves, they still have power over decision-making and that power is not transferred to their relatives/caregivers.

*"The relatives are not allowed to take decisions"* – Occupational therapist (Mikaeligården)

The interviews with the occupational therapists and the representative from the technology developer clearly showed that elderly with dementia should request DTAP while the dementia is at an early stage, since they are better able to determine the DTAP type they need. However, it was also argued by occupational therapists and caseworkers that the relatives and elderly with dementia do not know what DTAP exist since they do not have any previous experience in the field. Furthermore, the relatives are the ones requesting assistance. According to the occupational therapists and caseworkers, this knowledge gap has a clear effect on the determination of the appropriate DTAP.

*"The patient does not have so much knowledge of DTAP and these things, relatives/caregivers the same, they do not know what exists and how it can relieve."* – Occupational therapist (Ångens)

*"It is rare that an application comes from the person who is sick, rather it usually comes from the relatives/caregivers."* – Case workers (Örebro Municipality)

This statement, combined with the fact that elderly with dementia or their relatives request DTAP in a later stage of dementia, hinders the control of DTAP services. The aforementioned knowledge gap implied that elderly with dementia or their relatives usually request DTAP at a rather late stage of the dementia progress, thus resulting in an inability of elderly with dementia to receive and properly use DTAP. Lastly, it should be mentioned that, as stated by occupational therapists, this lack of knowledge or insight usually occurs because of the disease progression, which leads in a persons reduced insight.

### Variety of DTAP options

This section discusses the variety of DTAP provided by Örebro municipality. From interviewing the occupational therapist at the dementia care centre (demenscentrum), the interviewer was given a list of available DTAP options (about cognition) in Örebro municipality, which occupational therapists can prescribe if requested by the elderly with dementia. The list had five different types of DTAP options available to elderly with dementia (electronic calendars, electronic

planning systems, adjustable and user-friendly mobile phones, adjustable and user-friendly mobile phone applications, electronic clocks with the option of recording personal messages). Therefore, from this list, it could be assumed that there was a clear range of options and different products supporting different needs within dementia.

Based on the interview findings with occupational therapists from Ången and the centre for assistive technologies, the range of options is somewhat affected by the occupational therapists who are in charge of prescribing the DTAP. Even though there is a range of available options, it can be limited due to the prescribers' sometimes-insufficient knowledge. This means that the sometimes-insufficient DTAP knowledge of the occupational therapists can reduce the range of options for elderly with dementia. While interviewing the occupational therapist at Ången, it was understood that if the occupational therapists were not involved with new technologies, they would most likely not prescribe them.

*"If a new technology comes and you are not much involved with it, then of course as an occupational therapist one will have doubts about prescribing it"* – Occupational therapist (Ångens)

Another issue that surfaced during the interviews (centre for assistive technologies and Mikaeligården) was that there is a bigger need for DTAP than the municipality can actually cover. As stated by the occupational therapist of the centre for assistive technologies, this was due to economic and bureaucratic reasons. Since Örebro is a budget-based municipality, it cannot extend far beyond its own assortment of DTAP, limiting the DTAP options given to elderly with dementia and eventually not meeting their needs.

*"We need to use the items that exist in our assortment, so we cannot go outside too much. Otherwise the providers can file a lawsuit against us for not sticking to our agreed assortment."* – Occupational therapist (Centre for assistive technologies)

The problem of limited assortment leads to the municipality not being able to provide more solutions to elderly with dementia even though such solutions are available in the market. Thus limiting the variety of options for occupational therapists.

*"There are so many items in the market which could be really helpful."* – Occupational therapists (Centre for assistive technologies and Mikaeligården)

Overall, it seems that there is an extensive need for DTAP, which sometimes cannot be covered because there are not enough companies that can compete with larger, more established companies in the field.

*"The development of DTAP is really slow in Sweden, you usually get stuck because .... the biggest company does not allow so many other small companies to compete in the field because they are not strong enough to compete with them."* – Occupational therapist (Centre for assistive technologies)

Another problem faced with the available assortment of DTAP options in Örebro municipality is that of their incompatibility with each other. Since there is no holistic coverage, additional DTAP need to be acquired.

*"There are technologies which are not compatible with each other because they are built by different companies. It would be nice to have one smart system that you could connect different technologies into it"* – Occupational therapist (Mikaeligården)

Unfortunately, the interviews with the occupational therapists at the centre for assistive technologies and Mikaeligården revealed that the limited technology coverage in Örebro municipality actually affects the DTAP options of occupational therapists (stated by the occupational therapist in Mikaeligården). It also contributes to the frustration of relatives, who believe that the

provided DTAP are outdated and that the development of DTAP is slower than in other developed countries.

### Information and support

This section describes the level of information provided to the elderly with dementia and the level of information occupational therapists have regarding technological options. The interview with the occupational therapist from Ängen's memory reception clearly showed that once elderly with dementia ask for assistance, the memory reception goes through a very detailed list of needs provided by them and then suggests possible solutions for further prescription. They offer information about which DTAP could be used in certain cases, allowing the elderly with dementia to direct whether they want to use them. Another point raised in the interview with the occupational therapist at Ängen was that once a person is diagnosed with dementia, the diagnosing physician focuses on prescribing medicine and overlooks the provision of DTAP related information. Regarding the occupational therapists in charge of prescribing DTAP, it was mentioned that not all have the same knowledge regarding DTAP about cognition (dementia), or that they are "afraid" of using technology, thus causing a knowledge gap or even an inability to handle technologies among them which limits the distribution of information. One interviewee linked this gap with the unavailability of information on DTAP.

*"Occupational therapists can use assistive technologies but are a bit weak when it comes to assistive technologies for cognition." – Occupational therapist (Ängens)*

*"Occupational therapists who meet people with dementia are a little afraid of technology." – Occupational therapist (Ängens)*

In the discussions, the relatives of elderly with dementia mentioned that the process of receiving assistance is lengthy, leading to frustration. This occurs because different organizations are involved and communication between them is sometimes slow, insufficient and not prioritized. Lastly, there were occasions where the relatives were actually informed by other people (not prescribers/occupational therapists) regarding where to look for information about receiving or getting DTAP prescribed, because no one else had previously informed them.

*"It takes a long time until you reach somewhere." – Relatives*

*"No one collaborates, you have to go in circles to receive help." – Relatives*

In the interviews, all stakeholders mentioned that occupational therapists are responsible for providing training to elderly with dementia regarding the use of DTAP and for following up with people who have already received DTAP, for measuring the extend of DTAP usage. Although long-term support is a task that should be provided by occupational therapists, this is not always the case, as two of the interviewees stated:

*"We do not follow up on a yearly basis, but we expect that there is a responsibility from the relatives or the personnel, they should contact us if the needs change" – Occupational therapist (Mikaeligården)*

*"Occupational therapists carry a big responsibility, there are many occupational therapists but some just give the technology too early without a proper introduction and then it does not work as it should" – Occupational therapist (Centre for assistive technologies)*

A possible reason behind the occupational therapists not giving a proper introduction could be attributed to their lack of education in DTAP use. As a solution to this educational gap, the centre for assistive technologies offers seminars addressed to

occupational therapists. However, an interviewee revealed that occupational therapists do not always attend these seminars.

*"Maybe occupational therapists do not feel so comfortable with the technology and maybe they do not tell us that they need training." – Occupational therapist (Centre for assistive technologies)*

Regarding the personal, legal and financial implications, the elderly with dementia do not have to pay a fee to use DTAP, but are required to pay a small fee for the visit to the memory reception (Ängen) or by the occupational therapists, which is the prerequisite for acquiring DTAP. Besides this fee, once the elderly with dementia have received the DTAP, they are responsible for some minimal costs, such as the replacement of batteries or other sundry expenses. If the DTAP breaks down or becomes dysfunctional during use, the municipality replaces it. If users cause the damage, they are charged with the replacement costs. The rest of the costs are delegated to the municipality, since Örebro is driven by a set of policies dictating that they offer DTAP free of charge.

### Participation in DTAP design

This section discusses the participation of elderly with dementia in DTAP design. The interview with the representative of the technology developer revealed that elderly with dementia are actually active participants in the research process prior to the production of a new DTAP. Elderly with dementia have active roles, providing the company with direct feedback during DTAP testing. Their participation though is not required when they want to create or develop a new version of an existing product.

*"If it is a new product, a completely new one, then we involve people very early and let them share their ideas, how things should be and maybe even more with personnel who work with these people and ask for their opinion." – Technology developer*

On another note, the interviewee at Ängen pointed out that the development of DTAP lacks guidelines from the authorities, hence leaving occupational therapists in an uncertain situation regarding their way of working.

*"The development of assistive technologies happens all the time, we cannot keep up with it" – Occupational therapist (Ängens)*

The same interviewee claimed that Swedish authorities are not efficiently promoting the use of DTAP among elderly with dementia. It was also stated that the development of DTAP would not wait for elderly with dementia to catch up, so there is a big risk that they will remain on the outside and be excluded from using DTAP.

*"Sure, it takes time, especially for this group, they will end up being outside." – Occupational therapist (Ängens)*

This last comment is also backed up by the relatives of elderly with dementia, who said that "(Swedish) municipalities do not invest a lot in dementia", expressing their frustration about the municipality not allocating enough resources for this disease.

### Discussion

This paper reports the results of a case study in Örebro municipality regarding challenges for DTAP delivery to elderly with dementia. The interviews revealed a number of interesting findings (See Table 2).

Starting with the ability to control and direct services, it was unanimously agreed by the occupational therapists that elderly with dementia were in charge of their services and had an active role as service recipients [22,23]. However, in a number of

Table 2. Summary of results.

Consumer Direction	Challenges within service delivery
Control and Direct Services	<ul style="list-style-type: none"> <li>• Lack of available options</li> <li>• Requesting DTAP at a late stage of dementia</li> </ul>
Variety of DTAP options	<ul style="list-style-type: none"> <li>• Their use can be limited though if the occupational therapists do not know how to use them</li> <li>• The needs are bigger than the municipality can cover</li> <li>• Assortment cannot be expanded further since the municipality has contract with deliverers</li> <li>• Development of DTAP is slow – Not many new options available</li> <li>• Incompatibility between systems</li> <li>• Outdated DTAP options</li> </ul>
Information and Support	<ul style="list-style-type: none"> <li>• Usually once a person is diagnosed with dementia, physicians focus on medicine and overlook information of DTAP</li> <li>• Unbalanced level of knowledge by occupational therapists regarding DTAP</li> <li>• Occupational therapists afraid of technology regarding dementia</li> <li>• Receiving support is rather slow</li> <li>• No collaboration between different organisations</li> <li>• Not all occupational therapists conduct follow-ups of DTAP use</li> <li>• Not everyone feels comfortable saying they need training about DTAP</li> </ul>
Participation in DTAP design	<ul style="list-style-type: none"> <li>• Involved only when it is a completely new product</li> <li>• Fast development leaves elderly with dementia outside</li> <li>• Relatives feeling outside/excluded from the dementia development process</li> </ul>

occasions, when relatives or elderly with dementia requested assistance, the disease had already progressed too far causing a diminishment in the decision-making ability, thus hindering the DTAP delivery. Regarding the variety of DTAP options, Örebro municipality offered a number of DTAP free of charge, mostly focussed at reminding events/medication [10] even though there should be a variety for other types of DTAP. In the end, the municipality could not meet *all* needs due to their limited assortment, as shown in the results. Of all the CD modules, Information and Support were the one most parts of the interviews could be associated with. Besides its frequency in the interviews, this module seemed in a way to overpower the rest of the modules discussed in the interviews. The interviews showed that the occupational therapists responsible for prescribing DTAP were insecure about DTAP regarding cognition (dementia) and that there was also insufficient knowledge on DTAP use. Unfortunately, this issue was traced back in time in research [34]. This knowledge insufficiency further created an inability to disseminate information regarding DTAP to elderly with dementia, an issue also discussed by Frennert [31] and Thorslund [32]. For these reasons, it is argued that the module of Information and Support should be concerned as the most important condition because it affects all the other modules and thus has an impact on CD.

From another point of view, the module of Information and Support was found to be controversial. That was because different stakeholders were included and their opinions varied. From the occupational therapists alone, the workplace actually appeared to influence the level of knowledge in the group. Even though they had the same occupation, there was a consensus that the gap in DTAP knowledge within their occupation was rather large. The results indicate a consensus about the lack of right skills among those responsible for prescribing DTAP to elderly with dementia. As Sävenstedt et al. [33] state, it is crucial that the care personnel have the right skills and abilities to implement DTAP. This lack of skills or knowledge about DTAP could be attributed to various reasons, such as heavy workload and insufficient personnel - matters reported by a number of occupational therapists in the interviews. To tackle this problem, the centre for assistive technologies offers educational seminars for occupational therapists, but it was reported that attendance was limited, although no particular reason was given for this statement. On another note, occupational therapists are responsible for training elderly with dementia and their relatives on how to use technology and for monitoring its use. Interestingly though, this monitoring was not so consistent when described in the interviews. It was also reported that

sometimes physicians tend to other needs by looking at what medicine can do to assist, thus disregarding other options (such as DTAP options).

The results of this study seem also to be in line with Frennert and Östlund [39] about the dissemination of clear instructions by the authorities but also with Gjosten et al. [35] regarding the attitude one needs to have when presenting the profits and benefits of using DTAP. It was evident that once a person is diagnosed with dementia, there is no formal information regarding DTAP use.

Lastly, regarding participation in DTAP design, this study showed that elderly with dementia are not excluded [41] or overlooked [42] in the research of new technologies. The assigned attributes of anticipated distress [43], frailty [44] and the stigma of dementia [45] did not hinder elderly with dementia from participating in research as active participants [19], which additionally contributes to their empowerment [11]. Depending on the stage of dementia, elderly with dementia prove to be a useful source of data collection, providing feedback to researchers. However, dementia was only considered for completely new products, while if adjustments were made to existing ones, they would not be part of the research.

From another point of view, if one reads the CD as shown in Figure 1, the modules do not interact with each other and it seems that if one module disappears from the image, the rest will remain unaffected. Earlier in the discussion, I raised the issue that the module of Information and Support should be considered the most important within CD, since without it, the rest of the modules also seem to fall apart and eventually do not lead to increased CD and to the subsequent empowerment of elderly with dementia.

## Conclusions

Through the discussion section, I argued that the module of Information and Support should be the most important condition and emphasized in the provision of DTAP. Based on the interviews, it is concluded that without proper information and support, elderly with dementia are not able to control and direct DTAP services, they are unaware of the variety of DTAP options and are not entirely active participants in DTAP design, since their participation was only required for completely new technologies.

According to Tierny and Rhoads [64], empowering research should answer some specific questions. One example of such a

question is: *How will the research improve and/or empower the lives of those under study?*

In essence, this study reconfirms the knowledge gaps established in the literature but also shows how these issues have changed or remained the same over time. However, for this reason, I want to introduce the following suggestions, which, if taken into consideration, can greatly benefit elderly with dementia, contribute towards their empowerment (which is a subsequent effect of increased CD) and advance the literature on elderly with dementia and DTAP. As a first step, people need to realize that the elderly population is not as tech-savvy as younger people and so the responsibility for disseminating information lies with the healthcare staff (occupational therapists). To tackle the lack of accurate information that is in line with the conclusions of Jarvis et al. [37], which I stated in the beginning of the discussion, I propose the following actions:

- The first step is the actual training of healthcare staff, as also suggested by Shearer et al. [38] regarding the inclusion of a health education component; to be able to respond to the needs of the elderly population, being able to handle technology easier, more efficiently and as the interviewees mentioned more than one time, to make them less afraid of technology and clearly mention the benefits of DTAP [40].
- Secondly, once a person is diagnosed with dementia, the diagnosing physician should also provide the patient directly with proper information regarding DTAP. It is crucial for this to take place at an early stage; today, this is not the case, as information is provided too late to allow them to reap the benefits of DTAP use. That is also in alignment with the recommendation by Wolfs et al. [36] regarding early awareness of the available options.
- Lastly, there should be a communication channel between different public organisations [30]; for example, if a person is diagnosed with dementia, then this diagnosis could be sent directly to the respective memory reception (in this case: Ängens minnessmottagning) to allow them to intervene at the right time.

Regarding this study's contributions, there is a difference between the data collection methods used. Traditionally, when using CD, a researcher would involve observations and a set of questionnaires (surveys) while I have conducted face-to-face interviews with different stakeholders, which allowed having a broader perspective of the current situation and immersion in the context of this case. This also allowed the cross-referencing of data from these interviews among stakeholders. I argue that the adjusted version of CD can be accounted as a theoretical contribution since it was easily adjusted to this context (See Figure 2) and could be a useful tool for investigating the provision of DTAP with focus on elderly with dementia and their subsequent empowerment.

### **Limitations and future suggestions**

One limitation of this study is its low number of participants. I propose that future researcher involves more stakeholders such as advisors in the community and the municipality healthcare system. This study was conducted in only one Swedish municipality, managed according to certain directions, thus not being a representative sample of the entire Sweden. Additional suggestions for future research could be to include elderly with dementia in the study population to capture their perspectives as receivers of DTAP and include a higher number of participants. I do want to

argue though that a large number of participants of the same stakeholder type could lead to saturation depending on the size of the community where the study will be conducted. Lastly, the involvement of different municipalities managed according to different directions than this case would be crucial in creating a representative sample and results that are more concrete.

### **Disclosure statement**

No potential conflict of interest was reported by the author.

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## Appendix

Table A1. Interview themes/topics with each interviewee.

Interviewees	Interview themes/topics
Centre for assistive technologies	Basic introduction of the interviewee's role. Responsibilities of occupational therapists in regards to training users in DTAP use. Responsibilities the centre for assistive technologies carries in regards to training occupational therapists to use DTAP. Existing difficulties for elderly with dementia and DTAP use. DTAP limited offer (assortment) and coverage of needs. Decision making power that elderly with dementia have over DTAP use.
Centre for dementia (Demenscentrum)	Basic introduction of the interviewee's role. Different stages of dementia and their differences (background information). DTAP use by elderly with dementia. Occupational therapists responsibilities in regards to training users (elderly with dementia) in DTAP use. Introducing DTAP to elderly with dementia. How to? Feedback regarding not using DTAP. Concerns regarding DTAP use. How are DTAP prescribed? Does the user pay?
Memory reception (Ängen)	Basic introduction of the interviewee's role. Involvement of occupational therapists in the process of technology development. Occupational therapists level of knowledge and information surrounding DTAP use. How to find information about use of DTAP once diagnosed with dementia. DTAP prescription process. Challenges in DTAP use by elderly with dementia. Challenges in distributing DTAP information to the elderly with dementia at an early stage. Responsibilities of occupational therapists regarding training users to use DTAP. Elderly with dementia and societal exclusion.
Mikaeligården (Dementia care centre)	Basic introduction of the interviewee's role. Challenges in DTAP use by elderly with dementia. Decision making power of elderly with dementia. Occupational therapists receiving training before being able to prescribe DTAP. Who initiates the DTAP process (elderly/relatives)? Challenges within different types of DTAP. DTAP assortment within municipality.
Technology developer	Basic introduction of the interviewee's role. How does the technology company carry out new product research? Degree of the involvement of elderly with dementia in DTAP research (which stages of development). Settings for DTAP use under research time (who and how long uses the DTAP). Responsibilities of occupational therapists regarding training users to use DTAP. Experiences or challenges from elderly with dementia using DTAP. Who initiates the DTAP process or request? Feedback regarding turning down a DTAP after its use/test. Challenges that elderly with dementia face in everyday life.
Case workers (Örebro Municipality)	Basic introduction of the interviewee's role. Experiences of working with people with dementia. Decision making power of elderly with dementia. Who initiates the DTAP process or request? Sharing DTAP information at an early stage of dementia. Positive effects and challenges of DTAP use.
Relatives	How can DTAP help or assist? How technology could be used or customized for their specific cases. Examples of their everyday life experiences with a person with dementia. Process of receiving DTAP. Variety of DTAP options within the municipality. How to receive information about DTAP?