An Autonomy-Perspective on the Design of Assistive Technology: Experiences of People with Multiple Sclerosis

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ABSTRACT

In HCI and Assistive Technology design, autonomy is regularly equated with *independence*. This is a shortcut and leaves out design opportunities by omitting a more nuanced idea of autonomy. To improve our understanding of how people with severe physical disabilities experience autonomy, particularly in the context of Assistive Technologies, we engaged in in-depth fieldwork with 15 people with Multiple Sclerosis who were used to assistive devices. We constructed a grounded theory from a series of interviews, focus groups and observations, pointing to strategies in which participants sought autonomy either in the short-term (managing their daily *energy reserve*) or in the long-term (making *future plans*). The theory shows how factors like *enabling technologies*, *capital* (human, social, psychological resources), and *compatibility with daily practices* facilitated a sense of *being in control* for our participants. Moreover, we show how over-ambitious or bad design (e.g., paternalism) can lead to opposite results and restrict autonomy.

CCS CONCEPTS

• Human-centered computing~User studies • Human-centered computing~Field studies

KEYWORDS

Autonomy; Ambient Assisted Living; Active and Assisted Living; Multiple Sclerosis; robotic toilet; grounded theory.

1 INTRODUCTION

Research in Human Computer Interaction (HCI/CHI) and Ambient/Active Assisted Living (AAL) or Assistive Technologies (AT) ultimately seeks to enable people, who have been affected by some kind of condition or disability, to live a life as autonomous as possible. Hence, the mission statement of the AAL program of the European Union (EU) is to "... [extend] the time people can live in their preferred environment by increasing their autonomy, self-confidence and mobility" [42]. To this end, the EU decided to invest 700 million Euros in hundreds of promising projects over six years starting from 2014 [43].

Given the prominence and capacity of the field, it comes as some surprise that projects in HCI/AAL hardly investigate the concept of autonomy *per se*. In our perspective, this promotes a too simplistic view of this important notion. According to Hornung et al., who looked into this topic recently, "... autonomy is mostly interpreted by the researchers and designers as independence or its meaning is not further specified" [26, p.421]. A search on the ACM Digital Library [1] using the keyword "autonomy" leads to similar conclusions. The term is mostly used from a technical perspective, e.g., in the design of autonomous cars and robotics [32], but not further elaborated. This was also the motivation of a recent CHI workshop that made a call for more elaborated investigations of autonomy: "[a] better understanding of how to support and develop autonomy would clearly benefit the work of our community ..." [6, p.40].

So it is also our belief that a more detailed understanding of autonomy will reveal promising leverage points for the design of technology, in particular in the domain of AAL and Assistive Technology. To respond to the above-cited call for action, we conducted a series of 25 in-depth interviews with 15 people (ranging in age from 45-75, average age 59.5 years) affected with progressed Multiple Sclerosis (MS) in a daycare center. All of our 15 participants were experienced in the use of Assistive Technology, since the study of this paper was conducted as part of a design project where we developed and deployed a robotic smart toilet system for people with limited mobility. We made use of this unique situation to engage people with MS in discussions about their perspective on autonomy and the role of technology.

The contribution of this work is twofold. Firstly, we articulate a more nuanced understanding of the complex concept of autonomy to improve the design of interactive systems, in particular in AAL and Assistive Technology. Beyond that, an advanced understanding of the dimensionality of autonomy should be useful for the general domain of design (not only AAL/AT). This understanding is captured through the categories of the grounded theory. Secondly, we contribute to the HCI literature on how to design for people with MS – a research topic, which seems equally underexplored within the community.

2 BACKGROUND

As stated above, there is surprisingly little work in HCI/AAL investigating the *concept of autonomy*, given the importance of this complex design goal. It seems as if researchers were designing for it, however, without clarifying what precisely it is that they are designing for [26]. We will go on to describe both research from HCI designing for autonomy, and work explicitly exploring or unpacking the construct of autonomy in the context of design. Subsequently, we will briefly review literature from other fields like philosophy and bioethics, which have a stronger history in dealing with questions about autonomy. Before we go on to report our study, we will also provide background information on MS and how this condition is targeted within the HCI community.

2.1 Supporting Autonomy vs. Unpacking Autonomy in HCI

There is much research in HCI and in AAL, which aims at *supporting* people's autonomy; either in a direct fashion as a declared design goal or more indirectly. For example,

Rogers and Marsden [36] and Rogers et al. [37] explored how electronics assembly kits could empower older people to solve some of their hindering everyday problems (cf. [39] for a review about empowerment in HCI). Similarly, Güldenpfennig [22; 23] made use of modular kits to construct customized accessible computers to enable older people to use the Internet etc. autonomously.

Examples of *indirect* support of, or service for, autonomy are much more numerous. Recently, Ayobi and colleagues [4], for instance, investigated how participants with MS used consumer health technology to make a positive impact on their condition. They found that their subjects "regained a sense of control by intertwining self-care practices with different self-tracking technologies" [4, p. 6889]. Other researchers pointed out that the users' autonomy could potentially be infringed by design [35], and user behavior is shaped by the decisions of the systems' designers [15]. Ultimately, it can be argued, much research aims at fostering the users' autonomy by supporting one of its constituting ingredients (e.g., being able to understand the own medical condition [4]) without *directly* investigating the overarching design goal of autonomy and its complexity.

The aforementioned CHI 2014 workshop [6] is one of the very few examples in HCI which explicitly tries to *unpack* the concept of autonomy to aid design. They concluded that the design of technology impacts people's/the users' autonomy in at least "four different spheres" [6]. (1) The users can be enabled to make autonomous use of a *software environment* (i.e., providing a sense of control), (2) they can be supported in their independence *in their daily life* (e.g., through Assistive Technologies), (3) they can be empowered to *create their own technology* which makes them more autonomous (e.g., through smart assembly kits like [22;23;37]), and finally, (4) the authors see a potential to "design technologies that foster autonomy as an overarching characteristic of psychological development and flourishing" [6, p.38], but they also acknowledge that "... many questions surrounding design for autonomy remain unanswered" [6, p.37].

Hornung and colleagues [26] are among the rare exceptions that carefully pulled apart different layers of autonomy in a series of future workshops with 10-12 older people; in their case, in order to generate design ideas to support seniors with "life gadgets" (e.g., water intake tracking devices, smart shopping lists, etc.). In their discussion, they draw on work of the social scientist Damberger [13] to reflect about three different "levels of

autonomy" potentially impacted by their design ideas: self-determination, self-responsibility, and independence. By this means, they were able to realize, e.g., the pressure that is potentially being exerted by a water monitoring device, and the consequent reduction in autonomy, when the older person is constantly reminded to drink more fluids.

The paper on hand connects to the work summarized above by picking up considerations about design for autonomy. We extend it by conducting an in-depth qualitative study unraveling the concept of autonomy for people who make use of AT in their daily life (people with progressed MS). In the subsequent section, we will also report additional literature about autonomy from outside of HCI in order to inform the analysis of our study.

2.2 The Concept of Autonomy outside the Borders of HCI

Etymologically, the notion of autonomy stems from Greek "autos" (self) and "nomos" (rule of law), that is, it translates to "having its own laws" and thus refers *to self-governance* and *independence.* In old Greece, a city possessed "autonomia" when it was allowed to design its own laws [17]. As an analogy, an autonomous person is able to adhere to his or her own "laws", values, and plans. What this means, however, and the conditions necessary for fulfilling such a life, without restricting the autonomy of others, has been subject to an old philosophical debate. Given the complexity of the construct of autonomy, it has led to a multitude of different definitions and interpretations [33]. Since the research on hand was conducted in Europe in a healthcare institution, the Western liberal understanding of autonomy, in particular in a biomedical context, shall be of special relevance for us. This understanding dates back to the Enlightenment project of the 18th century when great thinkers like Immanuel Kant extended the idea of "autonomia" from the self-governance of cities to individuals and thereby to ethics [13]. Following the ideas of Kant, it becomes evident that *self-determination* can be considered an important additional dimension of autonomy next to self-governance and independence, since it is *pure reason* and the *categorical imperative* that makes people autonomous. And, as people voluntarily choose to obey to this law/imperative of their own accord, they are hence self-determined [13]. This leads to some conclusions that Dworkin drew in his seminal work about the theory and practice of autonomy [17]. According to him, autonomy encompasses the idea that a person should be able to make higher-order reflections and evaluate the own behavior, and moreover, to alter one's desires to change their own actions [17]. He explains:

"By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are" [17, p.20].

In biomedical settings this can, however, lead to ethical issues, since the necessities of care can conflict with the independence and self-determination of the patients. For example, in a well-cited paper about autonomy in long-term care, Collopy asked: "Should the self-determination of the elderly or the decisions and standards of the caregivers have priority?" [9, p.10]. In order to protect patients from well-meant paternalism and "conceptual and philosophical naiveté about … ethical foundations" [9, p.10] he formulated a refined conceptualization of autonomy. This framework presents a nuanced view of how people act autonomously by being in control of decision making and keeping agency. Among other things, Collopy [9] contrasted *decisional* and *executional autonomy*, whereby the first kind of autonomy denotes decision making without external coercion, and the latter the (physical) ability to carry out this decision in practice. He points out that the autonomy of the patient or older person can and should be protected, if caregivers enable people to make decisions even though they need assistance in carrying them out. Moreover, Collopy [9] juxtaposed *direct* and *delegated autonomy* in order to highlight that when care recipients "authorize others to make decisions and carry out activities in their place" [9, p.12] this should not be interpreted as surrender but as a form of indirect agency. A further pole as proposed by Collopy is *authentic* vs. *inauthentic autonomy* [9]. By means of this conceptualization, he aims at sensitizing caregivers that they should develop a "protective response to the value history of the elderly clients … and [document] a value inventory to aid caregivers in identifying authentic choices (particularly those which are highly idiosyncratic)" [9, p.11]. Collopy also differentiated between *immediate* and *long-range autonomy* to describe a conflict often found in choices with respect to their short and long-term effects. Immediate autonomy, e.g., rejecting a particular medical treatment *today*, can have an effect on events in in the distant future; and vice versa, long-term decisions can have an impact on the very present.

Perkins and colleagues [33] also conceptualized a relational model of autonomy, which we will connect with later. In short, we can see a vibrant discourse about the concept of autonomy in the bioethical/biomedical literature. In the findings and in particular in the

discussion section, we will return to these considerations and explain the value of bringing such ideas to HCI/AAL. Next, we provide background information on the medical condition of MS.

2.3 Multiple Sclerosis (MS)

The participants of our study were people with progressed MS (see also study section), a degenerative inflammatory disease of the central nervous system (brain and spinal cord). In this disease, auto-immune processes lead to a demyelination of neuronal cells and grey matter atrophy, which lead in turn to a malfunction in neuronal signal procession [2]. MS is unpredictable and can often result in permanent disability, since its causes are still unknown and medical treatment is not effective for all patients. For this reason, people with MS are often expert users of AT, and hence, interesting expert-participants for the sake of our study into autonomy. A leading symptom in MS is the *loss of mobility*, which was a significant design factor in our robotic toilet system (see also next section for further information). Another common and relevant symptom in MS is urinary tract dysfunction like overactive bladder syndrome [14] and states of exhaustion or fatigue [29]. In addition, patients often have to cope with depression [2], which is linked to fatigue among other factors [29]. Next to obtaining medical treatment, patients are often trained in self-management strategies like fatigue management, coping, and medication management to improve health outcomes and strengthen their patient autonomy [34].

In summary, MS and related disabilities pose significant challenges to the affected individual as well as to social welfare systems [28; 44]. Considering those human and societal costs, it comes as surprise that there is relatively little MS research documented in the HCI literature. The work of Ayobi and colleagues [3; 4] marks a recent exception where the authors investigated self-tracking devices to technologically strengthen self-management. They found that through technology participants can regain a sense of control in their condition [4]. Their focus was, however, on the role of Personal Informatics [31] in learning about the body and not on technology-mediated autonomy as with this paper.

3   STUDY

Project background: The research of this paper is part of a 30-month EU funded research project with the goal of designing a smart robotic toilet to be autonomously used by people with disabilities and limited mobility. E.g., to enable independent transfer from a walker or wheelchair without the assistance of a nurse, the toilet features adjustable supportive handlebars and also the toilet's height can be altered according to user needs. This function is driven by motors and can be controlled manually and with voice commands. Alternatively, the toilet can be adjusted automatically according to a preset user profile. Moreover, the system features additional components for hygiene (e.g., a bidet function) as well as for administrative purposes (e.g., patient documentation).

The project is being conducted in two locations in Europe, involving two public care institutions for prototype deployment – a rehabilitation clinic and a MS daycare station. For the paper at hand only the MS center is of relevance, as explained in the next section.

Currently, the project is in its final evaluative phase with two completed user studies of the final working prototype, running four weeks each, at the rehabilitation clinic and at the MS center. The evaluation is primarily concerned with user satisfaction and engineering proof-of-concept. This summative evaluation is being conducted independently by our project partners, and it is not part of the data of the paper at hand. Rather, we used this setting as a unique opportunity to additionally investigate the experiences of people with severe disabilities with technology interventions to promote autonomy. To guide our research we posed the following central question:

How do people with MS, who are experienced with Assistive Technologies, use technology to gain autonomy?

Thereby, we both refer to how participants passively experience technology as well as how they actively make use of it (e.g., being lifted into an ambulance transport or steering a motorized wheelchair). We left this central question open by intention as we followed an exploratory, experiential, and qualitative research agenda. We never asked about "autonomy" directly, but engaged in open discussion around disability and technology. In line with this strategy, we waived a priori hypothesis in order to be able to respond to surprising and unexpected insights as the study progresses [19]. We employed a grounded theory methodology [8; 11; 20] for concept-centric analysis of the participants' account and our own observations (detailed later in this section). That is, in the following we explain present phenomena drawing on theoretical frames which are established in the process of inquiry [11]. Salient themes emerged in the course of research and were not evident from the beginning.

3.1 Participants and Data Collection

Participants and research setting: The participants (n = 15) were recruited by *Caritas Socialis*, a healthcare provider that runs a MS daycare center (among other institutions). People with MS visit that center and spend up to eight hours a day there, engage in therapy (physio-, occupational, psycho-, and art therapy), have meals together, and participate in other forms of socializing (playing board games, discussion rounds, etc.). Inclusion criteria for participant selection were having a severe motor disability according to the Expanded Disability Status Scale (EDSS) classification [30] and a high chance of potential benefits from using the smart robotic toilet. Table 1 presents an overview of the people participating in the study. In fact, *Caritas Socialis* found a larger number of people interested in partaking in the study than the final 15 participants. We were in the comfortable situation to choose from that pool of people according to our theoretical sampling strategy [8; 11; 20]. E.g., we invited participants who explicitly said that they were pleased with the toilet as well as those who voiced criticism to contrast different opinions and to elaborate the theory.

A working and public prototype of the robotic toilet was installed at the MS center. Hence, all of our participants were diagnosed with MS and also experienced with Assistive Technology, since they used the robotic toilet and also other aids like wheelchairs, walkers, wearable alert buttons, special phones, etc. They voluntarily participated in the study and gave their written informed consent. There were alternative restrooms for daycare patients who did not participate in the study. Of course, our participants could also use one of these conventional toilets if they wanted to.

Field work and in-depth interviews: After the robotic toilet had been deployed, one of the authors started to regularly spend time at the daycare center in order to get to know this institution, its people, and its daily practices on-site. Prior to deployment, this author was not part of the project, and he joined the team explicitly for the study presented in this paper. While he familiarized himself with the setting, he "hung out" at the daycare center over the duration of four weeks, talked with the staff and patients, shared some meals, played some group games (e.g., word finding quizzes), and gave the patients a helping hand when needed (e.g., reaching for handbags, bringing drinks). After the toilet had been deployed for one month, the authors started to schedule individual interviews with the participants in Table 1. These were designed as loosely structured in-depth interviews and

ID	Age	Gender	EDSS	ni
Susanne	67	Female	7.0	2
Mike	73	Male	7.0	2
Hugh	67	Male	6.5	2
Raphaela	51	Female	6.5	1
Katharine	57	Female	6.5	2
Victor	57	Male	6.5	2
Karl	46	Male	7.0	2
Claudia	47	Female	6.0	1
Zahra	57	Female	6.5	2
Fiona	48	Female	6.0	2
Daniela	63	Female	6.5	1
Roland	70	Male	7.0	2
Sandra	69	Female	7.0	2
Eric	45	Male	7.5	1
Klaus	75	Male	7.5	1

Table 1. Overview of the participants (names changed for anonymity). Column "EDSS" denotes their degree of disability caused by MS, and "ni" indicates the number of scheduled interviews (many additional informal conversations took place that are not captured by this table).

conducted at a separate quiet room at the MS daycare center. According to our research question, these intensive and iterative interviews [8] were centered on the experience of Assistive Technology in the context of their disability. For example, we were interested in where they saw the benefits of Assistive Technology and whether they could identify potential dangers in the use of technology. Naturally, we talked a lot about the robotic toilet in this context. However as indicated above, the toilet project also served as an excellent "conversation starter" for engaging in discussions about technology, disability, and autonomy on a more general level. For example, we talked about topics like "care at a healthcare institution versus care at home". In the course of the interviews, we made some modifications to our interview guideline, allowing us to explore themes that seemed particularly relevant. The patients were invited to speak freely about whatever issue they thought important, and we interrupted them as little as possible. We did not directly introduce the notion of "autonomy" during the interviews and explicitly avoided leading questions. We recorded the interviews on audio for later transcription when the participant was comfortable with this. Due to the sensitive topics of the conversation (toilet use and disability) and because of the stress-sensitive nature of MS, we were careful to put no pressure at all on the participants and took hand-written notes instead of audio-recordings at the slightest signs of discomfort of the participant. We held a total of 25 interviews lasting

between 20 to 90 minutes each. Subsequent to the interviews, we conducted two final focus groups in order to present our preliminary analysis to the participants and to ask for their interpretation of the findings. Again, this feedback was used for further analysis and led to the final grounded theory.

In addition to audio recordings and interview notes, we also took field notes and photographs when we spent time at the care center and added them to our data collection for analysis. This additional material comprised notes on informal discussions with caregivers and encounters with participants or interesting observations and ideas that came to mind for later exploration.

3.2 Analysis

Epistemological positioning. Creswell suggested researchers should make explicit their underlying ontological and epistemological philosophy to aid the reader in understanding research decisions and actions [12]. In the case of this paper, we follow a constructivist grounded theory approach to understand how disabled people experience Assistive Technologies. In short, this means "[...] more than looking at how individuals view their situations. It not only theorizes the interpretative work that research participants do, but also acknowledges that the resulting theory is an interpretation (Bryant, 2002; Charmaz, 2000, 2002a). The theory depends on the researcher's view; it does not and cannot stand outside of it" [8, p.130]. In this context, it is important to note that current research was conducted in order to understand people's experiences of autonomy and technology with the goal in mind to inform future designs. Thus, we aim to reconstruct how sociocultural/psychological factors led to our participants' individual accounts, while at the same time we don't suppress (and won't be able to do so) considerations about consequent implications for design.

Coding process and constant comparison. Grounded theory has evolved over the years departing from the classic publication by Glaser and Strauss [20] with its positivist focus on empiricism and discovering patterns as embodied by the data to more constructivist interpretations of the methodology ([5; 8]). We adhered to the latter and more recent developments and adapted a coding scheme as proposed by Charmaz in her influential methodological and constructivist book [8]. Technically, we used *Weft QDA* and *Word* tables to manage data and support the qualitative analysis process. Data was primarily textual, apart from some images of the daycare center, which we
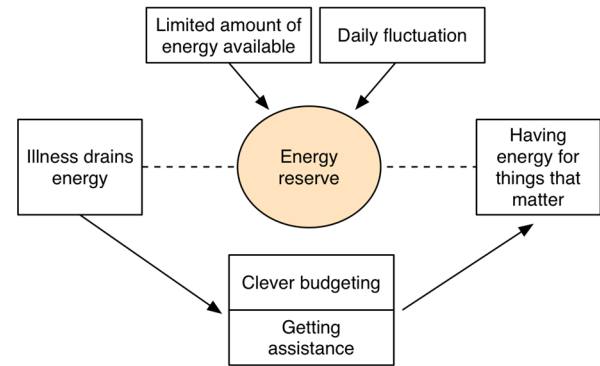

Figure 1: Axial coding for major category 'Energy reserve' following a coding paradigm by Strauss and Corbin [40]. We used this coding scheme as an intermediate step during *focused coding* to proceed to the final grounded theory of MS patients' experiences.
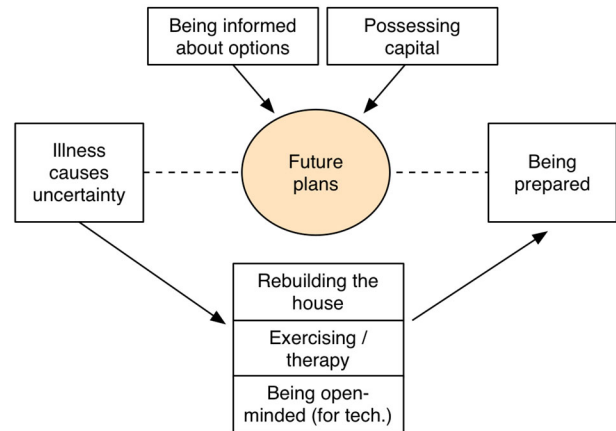

Figure 2: Axial coding for major category 'Future plans' following a coding paradigm by Strauss and Corbin [40].

used during discussions between the authors for illustrative purposes and for aligning ideas.

In detail, we employed *initial coding* as soon as the first interviews were conducted, allowing us to "... mine early data for analytic ideas to pursue in further data collection and analysis" [8, p.46]. We then initiated theoretical integration by *focused coding* and grouped "... the most significant or frequent initial codes to sort, synthesize, integrate, and organize large amounts of data" [8, p.46]. During that later phase, we also iteratively engaged in an adaptation of *axial coding* as employed by Strauss and Corbin [41] and which is described as an optional step by Charmaz [8]. We found it was a valuable device to help us contextualize phenomena entailed in our data. By investigating the *conditions*, *actions/interactions* and *consequences* [8] that are linked to a certain phenomenon, we related categories to subcategories and fleshed out the dimensionality of these main themes. Figure 1, e.g., shows

how we arranged one of our main categories **'Energy reserve'** along an axis with further categories 'Illness drains energy' (*condition*) and 'Having energy for things that matter' (*consequence*). This axis is framed by *context* or *intervening conditions* 'Limited amount of energy available' and 'Daily fluctuations'. In the study, our participants responded to this situation by specific *actions* or *strategies*, which we assigned to categories 'Clever budgeting' and 'Getting assistance'. Figure 2, shows another major category or phenomenon that we named **'Future plans'**. We will elaborate more on these in the subsequent section. Throughout the process we also employed the *constant comparative method* [8; 20] between data, codes, memos, and participants. Such comparisons were the backbone to the development of the theory grounded in the data, and they provided contrasts necessary for allowing the categories to emerge. Gradually, during *focused coding*, this led to the theory as presented next.

4   MS PATIENTS' EXPERIENCE OF AUTONOMY AND TECHNOLOGY

People with MS are often severely disabled by their disease [28; 44], and so were our participants. As emerged from the analysis, they created strategies to live a life as autonomously and worth living as possible, despite or because of their situation. Here, two temporal dimensions were of particular relevance. For one thing, they sought to accomplish certain aims on a short time scale like one day or so, since they only had a limited **'Energy reserve'** (i.e., short-term management of resources) at their disposal (Figure 1). For another, due to increased uncertainty in their life because of the unpredictable nature of their disease, people with MS aimed to increase their future agency (**'Future plans'**, i.e., long-term management of resources) by being prepared for whatever comes around (Figure 2). These strategies gave them a sense of **'Being in control'**, that is, living an autonomous life despite their many dependencies.

In carrying out these strategies, Assistive Technologies often played an important role, and given technological advancements, they can be expected to become increasingly relevant in the future. Given our interest in design, we go on to describe our findings while pointing to interesting technical features and opportunities. This occurrence of technology comes at little surprise, as our study goal was to explicitly investigate how technology is experienced in the context of autonomy. Hence, in what follows, we will neither see purely social findings
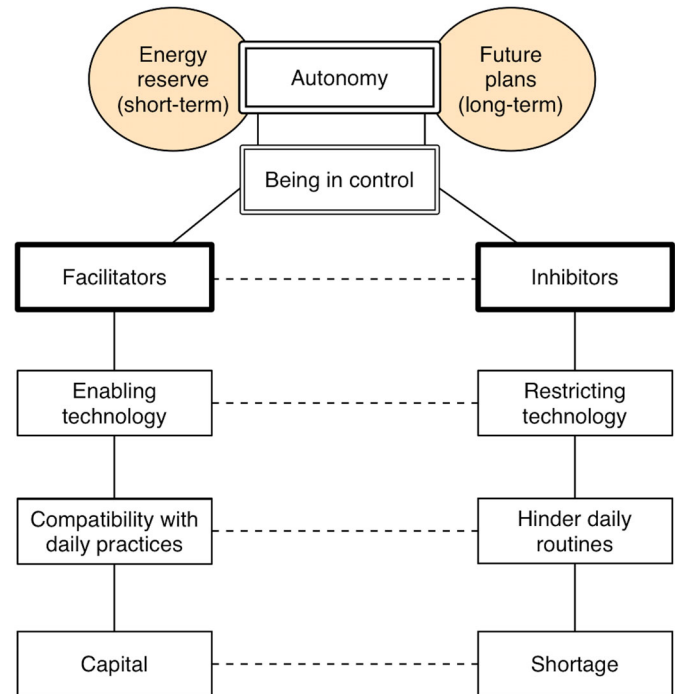

Figure 3: Conceptual model for MS patients' experience of autonomy and technology inspired by Whitburn's work [45].

considered with people's life and disability nor will we find isolated technical elaborations neglecting the people who use it. Rather, the emergent theory is an interlocking of multiple layers of social and technical aspects. A conceptual representation of the theory is provided in Figure 3. We will explain it subsequently by going through its main components or categories. While 'Being in control' or 'Autonomy' are central in this model, the remaining categories are arranged peripherally and can be regarded as pairs with largely opposite features: 'Energy reserve' (short-term) *vs.* 'Future plans' (long-term), 'Enabling' *vs.* 'Restricting Technologies', 'Compatibility with daily practices' *vs.* 'Hinder daily routines', and 'Capital' *vs.* 'Shortage'. These categories except 'Energy reserve'/'Future plans' are either 'Facilitator' of 'Inhibitor'.

4.1   The Importance of Being in Control as Felt Autonomy

At the daycare center, our participants were embedded in a complex system of **'Facilitators'** and **'Inhibitors'**, of exercising and resting, receiving and giving, self and others. A sense of **'Being in control'** was the crucial feeling that the participants experienced when this system was well balanced. As we will show, in such a state, the participant was not reduced to being a petitioner, but made use of the resources at their disposal confidently,

hence, feeling autonomous. They employed Assistive Technologies when they suited them well, but they were not interested in technology-focused, automated interventions without "contact persons". Participants were not interested in being the target of over-ambiguous paternalism. Rather, 'Being in control' also meant taking care proactively and taking responsibility for others:

"If all you have to do is push a button and every need is then fulfilled automatically, is this then true independence … are you back to life then? … For me healthcare should be part human and part technology … getting help, but also taking care of the back of the nurse … We have a right for support, but we also have to care for others." (Katherine[1])

Thus, for Katherine 'Being in control' of her life, and therefore what we understand as 'Autonomy', meant experiencing the right "mix" of technological support, support by human beings, personal rights, but also own responsibilities. We go on to take a detailed look at these related aspects or categories that in conjunction determined our participants' felt autonomy, both on the short- and on the long-term perspective.

4.2 Short and Long-term Management of Resources: 'Energy reserve' and 'Future plans'

We already pointed to these two categories when explaining the axial coding scheme in the above methods section (Figures 1 and 2). They concern all other categories to some extent, because people with MS or similar disabilities have a limited **'Energy reserve'** at their disposal due to pathological processes in their body and because of lost abilities. Their condition can fluctuate from day to day, and in the short-term, they need to prioritize things that matter most to them at the cost of other activities. For example, a patient might skip a session of physiotherapy in order to have enough energy to go outside in a garden (or vice versa). Claudia expressed this issue with these words:

"I accept my disability and make use of special needs devices. I know that others insist on struggling with using a regular toilet – because they want to prove that they can still handle it. And afterwards they are all exhausted and can't do anything but rest … I prefer using a motor toilet and not wasting my power in the bathroom … Or, when I go out at night, sometimes I choose my wheelchair over my walking sticks, because then I am strong enough to join a little dance here and there." (Claudia)

We can see here that Claudia makes use of auxiliaries that others might find stigmatizing in order to manage her **'Energy reserve'** and to be able to do things that are important to her (e.g., to dance at a party).

During the interviews, the participants often reported issues that related to this theme. Karl, for example, explained:

"Well, my wheelchair has an auxiliary motor. I can make use of it when … for example earlier this day when I was shopping … I can use it when I have to go uphill. Without it I wouldn't be able to make it or at least it would be very tough and it would take me a long, long time to recover. So, if there is technology, yes, I am not against using it. Then again, I never make use of the motor when I move on level grounds … because I want to sustain the strength in my arms … the impacts of my MS speed up when I am not exercising … On the other hand, when I do exercise, things can improve even … For example, at one point after a strong relapse, I firmly adhered to exercising and then eventually I got good results. I could again control better my legs. And I thought to myself: 'Look! There is a possibility here!'… if I am proactive and try hard." (Karl)

From this quote we learn that Karl as well makes use of Assistive Technology to manage his energy. He selectively adds his auxiliary motor depending on his aims. We can however see another aspect in how our participants dealt with their capabilities. Karl was aware of the progressive nature of his illness. MS is a degenerative disease and unfortunately for many patients symptoms are likely to worsen [10]. So in the long-term, they make **'Future plans'** to preserve capabilities and to be prepared (exercising to build up competencies). Our participants, for example, regularly referred to construction measures they have implemented or planned. Overall, our participants were characterized by an active engagement with their future. Being open-minded and interested in technology (cf. Figure 2) was, for example, one of their strategies, next to rebuilding their environment and exercising, for changing things for the better and being prepared. Of course, being informed about certain possibilities and having access to further capital like money or a strong social network was crucial for their planning and acting both in the short-term and in the long run. This theme will be further elaborated in below section "The Importance of Diverse Resources as Capital".

From these short reports, we can already sense that maintaining 'Autonomy' and 'Being in control', in particular when disabilities are involved, is a complex

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[1] All interviews have been translated into English. All participant quotes presented in this paper are taken from the individual interviews.

challenge that involves, beyond appropriate behavioral strategies, many contextual variables like daily fluctuations in energy level or having access to resources. Such contextual variables or conditions guided us in our subsequent analysis and led to the identification of set of **'Facilitators'** as well as **'Inhibitors'** that had a significant effect on the way people could mange their 'Energy reserve' and 'Future plans'.

4.3 The Mixed Roles of Technology

Perhaps, to little surprise, two of the categories directly refer to technology. While this certainly relates to our study design, it seems nevertheless necessary and valuable to make this distinction, because it allows for elaborating fine nuances in the ways Assistive Technology can enable or disable autonomy.

'Enabling technologies' remove barriers from the life of our participants. This can happen in many different ways. Ronald, for example, explained this drawing on the example of our robotic toilet:

"The toilet lifts me up and in this way I am able to push through my knees. As soon as I can do this I have enough strength to pull up my pants on my own, and so on. Without the new toilet system I would need assistance, because I cannot get up all the way on my own and if I can't do that, I can't push through my knees … or I would need a handle bar, but then again, I don't have free hands to take care of my cloths." (Roland)

Technology hacks: Participants also made use of simple technology "hacks" to increase (enable) their autonomy. E.g., to be able to live alone, Roland placed a number of old mobile phones with prepaid carrier cards along his flat at locations where he is most likely to fall. Hugh asked a friend to create a simple wooden ramp to be able to access his flat more easily using a wheelchair. This leads to the larger scale construction measures mentioned above, which the participants implemented in their environment to be enabled by design in the future. Overall, we identified a strong open-mindedness to technology in our interviews, which was reflected in the ways participants appropriated technology and by their interest in the robotic toilet project.

Fewer errors by increased sense of security: Another salient facet of 'Enabling technology' was its capability to assist people, next to compensating physical disabilities, on a psychological level:

"I have to say, it is very helpful that in case of an emergency, there will be an automatic alert [in the bathroom]. I think this is very useful. It removes pressure from you. You move around more easily, when you are aware that there will be help in case of an emergency. And this is exactly why, as a consequence, there are fewer errors. If you know there will no one around to help you, you are under fire and this leads to mistakes." (Karl)

As evident from this quote, technology can also play an important supportive role and build up self-confidence. Moreover, from a psychological perspective, our participants also valued 'Enabling technology', because it removed some of the finality of lost abilities, since they could be brought back to some extent.

It is also imperative to address the role of technology directly in our grounded theory, because it became apparent that technology can also have a negative impact on the life of people and their autonomy. Hence, **'Restricting technology'** disabled our participants, even though underlying design intentions were well meant.

Rules by technology: As mentioned earlier, Karl was a big supporter of our toilet's fall detection algorithm (and so reported all of the participants in principal). The downside of the algorithm however meant certain restrictions to the people's behavior:

"The toilet triggers an alarm, if you don't sit down to pee. You have to behave and sit down to pee; there is no other way. Unfortunately, due to my disease, this makes things much harder for me than they had to be." (Hugh)

Hence, the technical implementation of the fall detector required a person to sit on the toilet seat. Otherwise, the algorithm would infer some kind of problem like a possible fall and trigger an alert.

While fall detection was a welcome feature to all participants, five of them nevertheless reported reservations regarding *surveillance*. Due to the sensors, RFID check-in, and various logging mechanisms they felt observed, at least to some extent: "I feel uncomfortable with people being able to see when and how often I go to the bathroom. It feels like, this is my business only" (Zahra). Thus, when designed inappropriately, a mechanism, which was meant to make people feel secure, can also restrict them in experiencing agency or autonomy (e.g., because they feel observed and restricted in their freedom by a fall detection monitor).

4.4 Compatibility with Daily Practices and Hindering Daily Routines

MS and disability can strongly restrict daily life. Furthermore, therapy usually takes up additional time.

Our participants each spent almost two full days per week at the daycare center with schedules full with different therapies. As a result, participants repeatedly reported how they managed bringing together their daily routines and the necessities of their disease:

"As long as you can do [...a certain task] on your own, you should do it. This makes sense from a therapeutic perspective. We don't have to do extra exercises then. In the gym or so. If you exercise as part of your daily routine, you don't have to do as much afterwards ... We have to build exercises into our routines ... I want to do something, I want to contribute anyway. I am cutting the vegetables, I am folding clothes. I am exercising all day long." (Sandra)

Claudia as well explained how she turned the mundane activity of cooking into therapy:

"I love cooking. To me, this is occupational therapy. I very much enjoy engaging with nutrition. This is pure passion. I constantly invent new recipes. I wouldn't want any assistance with cooking." (Claudia)

Hence, it soon became obvious that whatever design, be it a made object (e.g., an Assistive Technology) or an activity (e.g., a plan for occupational therapy), it should fit together with people's daily routines in order to function as a 'Facilitator' of autonomy. We formed the category of **'Compatibility with daily practices'** to highlight the participants' strength in getting the most out of their days. However, this in turn also implies that interventions are likely to be rejected, should they **'Hinder daily routines'** and thereby act as an 'Inhibitor' for living life autonomously.

4.5 The Importance of Diverse Resources as Capital

Participants drew on a variety of different resources. Here we borrow terminology from Perkins et al. [33] (see later discussion section) and talk about this as capital. Capital is an important factor in managing an autonomous life, both in the short- and long-term, in creating successful daily routines despite disability, but also in creating a meaningful life in general. Thus, our participants too were dependent on **'Capital'** to be able to accomplish as much independence as possible. Besides obvious financial capital (money), they also mentioned a number of additional resources that were crucial for them as 'Facilitators'. Or, to put it the other way round, the lack or **'Shortage'** of those resources clearly were 'Inhibitors' to autonomy.

Thus, money is of no use, if you don't have **'Access to information'** and you don't know which product or service to buy. When talking about an alert button that

Hugh had in his house, he said that first he had no idea that such devices existed at all: "I didn't know that something like this was available. But when I went to rehab, a doctor there told me that I should get one of these for my own safety" (Hugh). During the interviews, the participants asked us over and again for technical advice and the latest news about developments in Assistive Technology. This reflected their aforementioned open-mindedness for technology, but also pointed to a potential shortage of information about relevant products or services of this particular user group.

Moreover, **'Social capital'** was an invaluable asset. It should be obvious that caring social networks contribute significantly to every person's autonomy and welfare, impaired or not. We nevertheless want to highlight that our participants repeatedly stated that in their estimation social aspects had particular implications for the design of Assistive Technology. In this context, Karl pointed to a "paradox", reflecting on his experiences of being hospitalized and hardly being able to move his arms or legs for many weeks:

"I think, in particular in healthcare, human contact is very important. Too many technological replacements for social interaction wouldn't be good ... I mean a robot could easily help with simple tasks like serving food for a person who is bound to bed. And I think it is exactly those people they are inventing such robots for ... but the thing is, exactly for these people social interaction is most important." (Karl)

Other interviewees also described the importance of being able to contribute back to their family and friends. Fiona, for example, used the art therapy sessions at the daycare center to create self-made gifts for her loved ones, because this was something she "... can do in order to show her appreciation for all their support" (Fiona). Similarly, as mentioned above, Sandra described how she contributed to housekeeping. In turn, she has no problems in accepting help from her family: "All my life I have worked so hard for them, I have no problem at all calling my son to ask him for a favor like giving me a car ride" (Sandra). This quote exemplifies that in the context of care, coping with a disease with the help of others, was seen as a reciprocal act, involving taking but also giving. In this light, participants carefully "made use of" their 'Social capital'. Claudia described how she carefully asked friends for favors, which were necessary but at the same time *fun* (e.g., going shopping together). She said "I don't want to use favors for real dull jobs like carrying something heavy upstairs, if I can avoid it. This is something where I would rather use technology like an elevator or robot" (Claudia).

Somewhat relatedly, Fiona answered when ask for envisioning useful novel Assistive Technology "lighter electrical wheelchairs so that company can lift it in the trunk of the car without hurting their back" (Claudia). Others stated that they accept Assistive Technology and information systems like the automatic documentation system of our smart toilet, because they want to free the nurses from the labor of creating health recordings manually.

While 'Social capital' is an external factor contributing to welfare, **'Psychological capital'** is the intrinsic strength we found in our participants that enabled them to look ahead positively against all odds ("You have to make the best out of your situation, the other things you just cannot control" (Mike)). Considering autonomy and self-efficacy, Daniela stated that it is important for her that "… from time to time we can skip […Assistive Technologies] for proving ourselves that we can still do it without help even though it exhausts us. This is very important for the confidence of many of us" (Daniela).

5   DISCUSSION

In line with Calvo et al. [6] and Hornung et al. [26], we made the case for elaborating a more nuanced understanding of autonomy instead of equating this concept simply with "independence", which is often done in the HCI/AAL literature. To contribute to this endeavor, we created a grounded theory of the experience of people with MS in the context of Assistive Technology. We agree with Dourish's arguments [16] and don't believe that the results of ethnographic or qualitative research should directly be mapped to implications for design. Thus, subsequent ideas are meant for sensitizing designers, instead of prescribing strict design rules. They reflect the major themes from the findings and these can (ideally) be supported or (less ideally) be undermined by technological design. It is our aim to highlight their relevance and encourage designers to be more reflective about assumptions they make regarding the role of Assistive Technology with respect to autonomy. In the next section, we also revisit some of the above-described autonomy literature from outside HCI, because many seminal considerations there related closely to what we saw in our own observations regarding patient autonomy. Even though this literature was not addressed at designers of technology, it might be of great value and enable new perspectives when brought to the design of Assistive Technologies.

5.1   An Autonomy-Perspective on Design

We learnt from our participants' expertise in using Assistive Technologies that there are multiple facets to autonomy. Adapting such a multi-dimensional understanding of this concept is important to designers, because it shows us that designing for one facet of autonomy can be at the cost of another facet, as we will explain in the following, drawing on some examples.

5.1.1 Performing Tasks and Delegating Tasks

It is surely an honorable goal to design a device that allows people to live independently in the long-term, e.g., by creating a robot for housekeeping. As we found in the study, our participants were however reluctant to be purely passive receivers of services. For one thing, being active was crucial for maintaining their self-concept; participants wanted to reassure themselves that "they can still do it" (Daniela) and not be labeled what Shippee called a *needy identity* [40, p.422]. For another, they emphasized on many occasions that they were eager to do certain tasks on their own as an exercise for maintaining skills. From a psychological perspective, this is also in accordance with the *self-determination theory* [38], which highlights the importance of *competence*, *autonomy*, and *relatedness* to others (cf. also next section) in well-being. Then again, our participants highlighted the value of delegating exhausting and dull tasks to manage their 'Energy reserve' in the short-term (c.f. report about residential care inhabitants [24, p.423]). Thus, supporting one particular facet of autonomy might impede another aspect, and in this way the most honorable design goal might lead to negative consequences, should the implementation lack a certain degree of flexibility. Collopy's framework [9], which contrasts different poles like *immediate* and *long-range autonomy* could be a useful reference from gerontology research for supporting AAL designers in such considerations.

5.1.2 Paternalism and Designing for Responsibility

We learnt that supporting people with disabilities does not imply that they should be freed from all responsibilities. On the contrary, our participants insisted on taking on responsibilities, for themselves as well as for others. This was not only the consequence of a sense of duty, but also a necessity for becoming a truly autonomous person and is line with the literature that we have reviewed [13; 17; 27]. The work by Collopy [9] marks an important cornerstone in the shift from default paternalism to autonomy in bioethical thinking. Hence, Assistive Technology should pay attention not to be over-

ambitious, that is, avoiding paternalism and instead taking people seriously. This idea also acknowledges that autonomy does not only comprise independence, but also *inter*-dependence between people, because we as human beings are not isolated but woven into a web of social relationships (c.f. [25]). So Cardol, de Jong, and Ward [7] stated that "[t]he liberal-individualist account of autonomy over-emphasizes physical independence and does not sufficiently recognize the inter-dependency of all people, including those with disabilities" [7, p.970]. They stressed, in line with e.g. Damberger [13] and Jameton ("To act autonomously is to act responsibly.") [27, p.19], that this again means that the client also has responsibilities towards him- or herself and others. These theoretical considerations as well as our findings also connect to insights from AAL and psychology research that described the value of reciprocity in the care of older people [18] and mental benefits in being able to provide some kind of service to someone compared to "just" receiving help [21].

5.1.3 Autonomy and Rules

The organization of healthcare requires calculations, structures, and compliance. Hence, not surprisingly, there are many rules to follow. For example, in a nursing home food cannot be served at any time. However, unnecessary rules and restrictions can also be introduced by careless design. Shippee [40] described how residents suffered from non-transparent decisions about health-status and patient classification. In our study, we saw how the robotic toilet made Hugh sit down on the toilet even though he didn't feel comfortable, and we learnt about technology that forced people to take certain routes or to take their devices to maintenance regularly. From a more global perspective, Ho [25] criticized the individualist model of autonomy as too narrow. In her argumentation, autonomous decision-making can even be challenged by at times subtle social influences of the manifested power structures of an institution. That is, the client is gently pushed in a common direction (e.g., by conventions). Hence, when we design for autonomy, we should to keep in mind that interventions for autonomy can also introduce rules, restrictions, and subtle manipulations.

5.2 Concluding Remarks on "Received Theory"

There has been a long controversy in the grounded theory literature to what extent the researchers should consider former work in the development of their own grounded theory [8]. Glaser and Straus propagated not to use any former ideas ("received theory") in theory development.

However, they have increasingly been criticized for viewing researchers "as a tabula rasa" [8, p.167] who can remove all former information from their mind. We agree with this critique and conclude this discussion by pointing to two references that had influence on our analysis. Whilst we did *not* use this work as a guiding framework, we drew on some of its terminology to label our categories and in doing so connect our findings to the broader literature.

(1) In the context of aging research on assisted living, Perkins and colleagues [33] conceptualized a relational model of autonomy, which centered around the goal of "maintaining the self". Some of our findings related very closely to their work, so we borrowed some of their terms when writing up our analysis. According to their model, the individual draws on *human*, *social*, *psychological*, and *material capital* [33]. (2) In his research about the experience of schooling of children with vision impairment, Whitburn [45] identified *facilitators* and *inhibitors* which were crucial for creating an *inclusive school culture* and *seamless access to academic as well as social recourses*. While his work is only loosely related to ours content-wise, we still borrowed the notions of *facilitators* and *inhibitors*, and how they can be employed to describe poles of influential factors (cf. Figure 3). In our estimation, this constitutes a powerful representation of the distribution of resources.

5.3 Limitations and Future Work

This paper presented a grounded theory of autonomy as experienced by people with MS in the context of technology design. It depicts a qualitative and exploratory interpretation of findings specific to the current case and is not aiming at contributing generalizable findings. While we observed many different facets of autonomy in the behavior and account of our participants, further studies, e.g., involving different populations, are likely to reveal additional aspects of autonomy that are important for design. Promising starting points for future research might also be marked by the above described categories, for example, how to make better use of **'Social capital'** in the design of Assistive Technology.

6   CONCLUSION

To recapitulate, the notion of autonomy "… translates into a whole family of value-laden ideas: individual liberty, privacy, free choice, self-governance, self-regulation, moral independence" [9, p.10]. Autonomy is at the heart of many AAL research projects. However, it is often

translated to "independence" without any further differentiations. Drawing on a grounded theory of people with MS and related work from mostly (bio)ethics, we argue that it is timely for HCI to develop a more nuanced perspective on what it means to live autonomously. We described how specific factors could either facilitate or inhibit autonomy on different levels. This analysis is relevant for HCI, because these factors and different levels can directly be addressed within technological design. It reveals specific levers for improvements as well as pitfalls stemming from a too naïve idea of autonomy. While we regard our work as a timely and meaningful contribution, more research is needed on how designing for different facets of autonomy impacts people with or without disabilities.

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