

DE GRUYTER

# AGING BETWEEN PARTICIPATION AND SIMULATION

ETHICAL DIMENSIONS OF SOCIALLY ASSISTIVE  
TECHNOLOGIES IN ELDERLY CARE

*Edited by Joschka Haltaufderheide, Johanna Hovemann and  
Jochen Vollmann*



Joschka Haltaufderheide, Johanna Hovemann, Jochen Vollmann (Eds.)

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Jochen Vollmann (Eds.)

# Aging between Participation and Simulation



Ethical Dimensions of Social Assistive Technologies

**DE GRUYTER**

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Chapter 1

# 1 The challenge ahead

Joschka Haltaufderheide, Johanna Hovemann and Jochen Vollmann

## 1.1 Introduction

The world's population is aging. According to projections of the United Nations (2017), by the end of the year 2030, the worldwide number of older people aged 65 and over will increase around 56 % from 962 million to 1.4 billion. By 2050 the global population of older people will more than double (Bennett et al. 2017). Western countries, where this development is already in an advanced stage compared to the developing world, will witness an unprecedented demographic change. In the 36 member states of the Organisation for Economic Cooperation and Development (OECD) the share of persons in very old age (80 and over) will reach 10 % by 2050 (Colombo et al. 2011) compared to 1 % in 1950. At the same time, families and social structures are changing. Shifts in childbearing patterns in European countries from the 1950 s in Germany to the 1980 s in Southern European countries led to an overall shrinking share of younger persons (Oláh 2015). A constant increase in different age-dependency-ratio measures (such as the European old-age-dependency-ratio) describing the number of persons aged 65 and over as a percentage of labor force (persons aged 15–64) can be seen, which is set to double by 2050 (Harper 2011). In addition, with changes in partnership patterns, increasing employment rates and a substantial increase in female labor force participation, the demographic development leads to a decrease in people providing care (e. g. in informal settings) and persons providing necessary economic resources for care work (Oláh 2015; Colombo et al. 2011).

As a result, the aging of the population, prolonged life expectancy and overall higher risks of illness in older ages can be expected to result in increasing numbers of older persons suffering from disabilities and diseases (Colombo et al. 2011; Kaye 2013). Persons in this population group will be limited in their motoric, sensory or cognitive skills and will be increasingly reliant on healthcare and support in maintaining everyday activities and in participation in societal processes. According to recent projections for different countries, this will lead to an increase in health-related expenditures (Przywara 2010). For example, long-term care costs are likely to at least double or possibly triple in the European Union by 2050 (Colombo et al. 2011). However, an overall smaller share of younger people, changing societal circumstances and economic factors will lead to fewer people providing care or its necessary monetary resources resulting in a significant shortage. The Western countries' healthcare systems face a resource crisis in which healthcare is likely to become a scarce good which may no longer be available for all members of society (Abdi et al. 2018; Manzeschke et al. 2013).



## 1.2 The promise of socially assistive technologies

In this looming resource crisis, various new technologies are developed. Socially assistive healthcare technologies (SATs) such as smart screen assistants, robot assistants or artificial companions are developed as a means to provide healthcare and support and to relieve resource tensions in healthcare systems (Hülsken-Giesler 2015). SATs promise to preserve individual rights of stakeholders by supporting users in everyday tasks and by supporting or maintaining social participation and individual well-being. Currently, no common definition exists since the growing field of SATs has not yet been properly circumscribed and overlaps with other definitions and categories from the field of assistive technologies or robotics (Feil-Seifer and Mataric 2005). However, several characteristics can be determined to shape this umbrella term. “Assistive technologies” broadly denotes any computerized device or system that “allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed” (Cowan and Turner-Smith 1999, 325). While most of these technologies mainly provide physical help and support, for example by aiding care-workers or their clients in motion-intensive tasks, the purpose of socially assistive technologies in healthcare is to provide less physical and more emotional or cognitive support and to preserve or to maintain well-being and individual autonomy despite impairment (Kachouie et al. 2014; Feil-Seifer and Mataric 2005; Manzoor and Vimarlund 2018). SATs are thus programmable machines equipped with a certain degree of autonomy to act for themselves or on a user’s behalf and integrate into an everyday surrounding to perform intended supportive tasks. Common to all devices is a certain agility or interoperability (e. g. on different screen environments such as personal computer, smartphone or television) to accompany their users in everyday life. Finally, to fulfil their purpose most SATs are equipped with a social interface providing assistance by social interaction; that is, SATs use digital technologies such as artificial intelligence, sophisticated algorithms or facial expression technology to establish an interaction with their users that resembles human-to-human communication. Their functioning is based on their ability to detect emotional, social or psychological states of their users and to answer to these states by displaying reactions which can be interpreted as social, emotional or psychological state. SATs simulate a – more or less refined – subject, person or character as interface (Scorna 2015). Examples for such technologies include the famous animal robots *Paro* the baby harp seal and *AIBO* the robo-dog as well as humanoid robotic platforms like *PEPPER* or *Care-o-bot* and virtual assistants *KOMPASS*, an emotion-sensitive smart screen assistant or *RAMCIP* (robotic assistant for MCI patients at home) –especially designed to accompany persons with dementia.

Advocates of SATs rightly note a suitable match between the abilities of the devices and the needs of older persons caused by impairment and loss of capacity. While, for example, older persons often experience limitations in establishing and maintaining social contacts and societal participation, SATs can supplement this lack

in capacity. They can prevent boredom and depression caused by loneliness or may foster the communication with the device as well as with other persons—even positive effects in vital parameters and increase in overall well-being have been shown to occur (Abdi et al. 2018; Kachouie et al. 2014; Scoglio et al. 2019). In addition, the use of SATs can support caregivers by taking care of routine tasks, may relieve pressure in settings with highly compressed working cycles and can provide opportunity for high quality care work by relieving caregivers from additional tasks (Kachouie et al. 2014; Hülsken-Giesler 2015). Currently they are increasingly used in formal as well as informal care settings, especially in resource intensive ones such as care for persons with dementia (Scoglio et al. 2019; Abdi et al. 2018).

On the other hand, the use of SATs raises serious concerns. First and foremost, skeptics fear that SATs might not only mitigate tensions in resource intensive health-care settings and provide opportunity for high quality care by relieving caregivers from certain tasks; their development and use might lead to a substitution of human care and contact depriving vulnerable persons of essential human contact and caring relationships (Sharkey and Sharkey 2012; Bennett et al. 2017; Coeckelbergh 2010). This applies especially in those situations where physical immobility or psychic inability puts users in a situation of dependence, as is the case with older persons. The second major threat might be a loss of privacy and control as an important part of users' autonomy (Martin et al. 2010). A GPS-equipped device at one's wrist might provide feelings of freedom and security – at the price that every step can be secretly surveilled. Ethical issues also must be raised in regard to the special interface. By resembling human-to-human interaction, SATs might provide a simple way to communicate and to steer a certain device. However, this simulation of human-to-human interaction bears severe risks of misconceptions about the real nature of the device, resulting in deception and manipulation of the users (Grodzinsky et al. 2015; Matthias 2015). Finally, design, research and implementation of devices have to respect the (future) users' right to participate in these processes in an ethically adequate way to avoid exclusion of users' wishes and preferences. Viewed from this critical perspective, it does not only seem to be the case that the technology suggests a tailor-made fit to the needs of older persons but also that its use includes severe risks or might even damage those values it is made to preserve by exploiting the weaknesses of a vulnerable group.

With increasing urgency, decisions about the digitalized future of healthcare and implementations of SATs are becoming focal points of societal and scientific debates and address large audiences. From an ethical perspective, these questions have to be conceptualized as trade-offs between positive effects (in a situation of scarce resources) and potentially negative impacts on basic values such as the value of human care and contact, privacy, individual autonomy and user-involvement. The ethical evaluation, thus, is context-specific, depending on how, why and with whom the technology is used. Such evaluations require a careful weighing of risks and benefits as well as contextualized in-depth ethical analysis including robust empirical data (Manzeschke et al. 2013). However, up to now research on SATs is mostly dispersed over differ-

ent academic fields and disciplines and lacks interconnectedness. A comprehensive overview of discussions regarding values at stake and ethical assessment of recent developments especially in healthcare is largely missing. Against this background, this publication aims to initiate an interdisciplinary discourse on ethical, legal and social implications of SATs in healthcare. Contributions include perspectives from nursing science, social sciences, philosophy, medical ethics, economics and law to present a – to our knowledge – first and comprehensive overview on different aspects of the use and implementation of SATs from an ethical perspective. It aims to combine practically relevant insights and examples from current research and development with ethical analysis to uncover exemplary moral tipping points between promotion of participation, well-being and autonomy and risks and damages to these values.

### 1.3 About this volume

#### Part I – Foundations of discussion: The value of caring relationships

The value of human care and human relationships and its comparison to relationships to machines is at the center of the first part. Against this background **Claudia Dinand and Margareta Halek** report on challenging behavior in people with dementia in informal care settings paying particular attention to the function of interactive human relationships from the perspective of nursing science. Making and keeping contact, as Dinand and Halek conclude, is a key factor and is established in ultra-short moments and at different levels and modes. They show that relationships are essential in understanding behavior to be meaningful and how this contributes to the understanding of challenging behavior in a less stressful way, thereby practically exemplifying the basic values of caring relationships and human interaction.

**Andrea Bertolini's and Shabahang Arian's** contribution opens a second and distinctive perspective on the value of care contrasting these practical insights. Drawing on the distinction of care and cure, the authors discuss general boundaries of caring robots in elderly care and analyze different ways of ethical assessment of socially assistive devices in ethical theory and law with a focus on the difference between substitutional use of technological device and support of existing human caring relationships. The paper continues with an analysis of the aforesaid technologies and makes clear that – given the developed meaning of care and cure – machines may have the potential to interact, and simulate a relationship, but not to establish a real, meaningful one with the user. Finally, policy implications for the further development of robotic caring technology are explored.

**Svenja Wiertz** refers to the notion of trust as an important concept to capture differences between human-to-human and human-machine relations. Following a concept of trust according to Annette Bayer, Wiertz argues that trust can be conceptualized as accepted vulnerability and is an important part of human relationships while it is not possible to trust technical devices. Hence, as reliance on a technolog-

ical device can never include all components of a functioning trust relationship, Wiertz concludes that human-machine relationships should not appear as a preferable option from a rational point of view, but can be an option where a choice between human caregivers and a technological device is given.

## Part II: Practical insights

Insights on existing applications and projects currently under development are given in the following part. **Anna Hauptelshofer and Pascal Meier** report on attempts to promote eHealth literacy by combining the eHealth application *FeelFit* and the concept of a *Digital Nurse*. In this interdisciplinary project including expertise from information science and nursing, *FeelFit* is an application that enables users to access and monitor health-related data in everyday life. However, interpretation of such data is known to require technological understanding and health literacy. The *Digital Nurse* is an educational health management concept to complement these requirements and to provide an additional point of contact for users. Hauptelshofer and Meier present the integration of both concepts by using a fictitious case.

**Amelie Altenbuchner and Karsten Weber** report on their project “Motion Monitoring of Geriatric Trauma Patients” paying special attention to the ethical implications in research. According to the authors, research in the group of older adults using assistive technology is strongly required. It is often assumed that study design must be adapted due to the special characteristics of this group. However, surprisingly often, little is known about study designs and the target group. Altenbuchner and Weber report from a practical perspective and highlight different challenges in conducting a research project on motion trackers in geriatric trauma patients. These challenges concern important elements of ethical research such as information giving in consent, the role of older adults as research subjects and the relationship between participants and researchers.

**Angelika Schley’s and Katrin Balzer’s** chapter refers to the ACTIVATE project (Ambient System for Communication, Information and Control in Intensive Care). ACTIVATE aims to develop and implement a socio-technical system to improve care for critically ill adults undergoing weaning from the mechanical respirator in critical care settings. As Schley and Balzer rightly note, these persons are especially vulnerable. Technological systems like ACTIVATE, therefore, have to be evaluated carefully from an ethical, legal and social perspective before they can be implemented in clinical routine. The authors present the well-known MEERSTAR-model as a guiding framework and examine intermediary findings and experiences in evaluation of the project.

## Part III: Users’ expectations and needs-based development

Authors in the third part highlight the importance of a needs-based development of new assistive technologies, which includes the users’ perspective, their wishes and concerns.

**Sarah Palmdorf and Christoph Dockweiler** explore the needs and demands towards technical devices of people with dementia in home care settings. Attitudes in this population are shown to be largely shaped by weighing of values such as privacy and safety which is often ignored in formal risk assessments of technology. Referring to the example of a GPS-motion tracker, Palmdorf and Dockweiler show how one might include ethical considerations and central value conflicts of stakeholders into technical assessment in different contexts and then critically reflect on the challenges arising from user participation.

**Julia A. Hoppe, Rose-Marie Johansson-Pajala, Christine Gustafsson, Helinä Melkas, Outi Tuisku, Satu Pekkarinen, Lea Hennala and Kirsten Thommes** analyze older people's expectations towards welfare technology and robotic technology in elderly care throughout three different European countries using qualitative analysis. Their results present an inventory of respective expectation and attitudes. The authors' findings reveal that seven different themes steer expectations and attitudes towards technical devices. However, a majority puts weight on the essential differences between the qualities of human relationships compared with technological options.

#### Part IV: Challenging classical concepts

Contributions of the fourth part dwell on the application of "classical ethical concepts" such as informed consent or privacy and challenge their applicability or demand conceptual changes in the ethical evaluation of SATs. Based on the example of a mobile support system for behavior change, **Iris Loosman** shows that this may include a reconfiguration of traditional concepts such as informed consent. The aim is to make these concepts applicable to the digital world. As Loosman reports, currently dozens of so-called persuasive mobile health apps enter the market and bridge clinical and health contexts with everyday life resulting in a blurring of care norms and norms from information technology. The chapter thus investigates whether temporal distribution of consent may be an alternative model and, finally, reflects on how different conceptualizations of consent can inform future research and development.

In her contribution on the reconfiguration of autonomy, **Bettina Schmietow** maps the shifts of autonomy as one of the core concepts in digitalized healthcare. Assistive technologies are analyzed against the background of a "datafied society". It is shown that the use of assistive technologies in the particular context of vulnerability reveals certain limitations of established tools for medico-ethical assessment and evaluation. As Schmietow shows, concepts of autonomy, for example as developed in the well-known approach of principlism, may not be suitable. Contextual adjustments of the underlying ethical concept are required and may enrich the conceptualization and assessment of technologies alongside established ethical frameworks.

**Ricardo Morte Ferrer, Mario Toboso, Manuel Aparicio, Txetxu Ausín, Anibal Monasterio and Daniel López** add to this topic from the perspective of law and data security. They illustrate the shifts in autonomy and data protection law in Europe in

reference to the current technological change. The authors use the United Nations' Convention on the Rights of Persons with Disabilities as normative framework to define and govern the protection of autonomy. However, new assistive technologies record physical as well as habitual data and could therefore impact important facets of autonomy such as privacy, identity and integrity. The authors conclude that it is necessary to broaden the ethical discourse which implies to include privacy regulation norms and Data Protection Impact Assessment as additional guiding forces.

### Part V: Broadening the perspective

The final part aims at broadening the perspective by putting ethical considerations into the wider context. **Hartmut Remmers'** aim is to substantialize the ethical discourse on socially assistive technologies empirically as well as to connect it to political and societal decisions which currently govern the use and development of socially assistive technologies. Remmers concludes that decisions which govern the technical development are currently based on an economic calculus of rationalization. In contrast to this, Remmers presents insights from nursing science and gerontology which should be understood as underlying rationale of technological development.

**Björn Lundgren** draws attention to the differences between a reactive approach of ethics, which is concerned with already existing technologies, their assessment and improvement, and proactive ethics concerned with reacting to possible future developments. Lundgren is concerned with the latter, analyzing an argument by the Silicon-Valley visionary Tom Gruber. Gruber proposes to enhance human memory by use of implantable technology to create artificial extensions of humans' memory capacity. It is suggested that such implants may greatly benefit people by making them more creative, improving their social grace or enabling dementia patients to live in dignity. Lundgren analyses this promise by sketching two different possible meanings of Gruber's idea. He shows that the positive arguments of Gruber may be somewhat dubious under this careful inspection. In addition, the idea of implantable memory extensions can be criticized for its risks of infringing users' privacy and other persons' autonomy.

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## **Part I: Foundations of discussion – The value of caring relationships**



## 2 Challenges in interacting with people with dementia

Claudia Dinand, Margareta Halek

**Abstract:** Adequate and mutual interaction is a key factor for a good and stable relationship between people with dementia and their carers and a prerequisite for living well with dementia. The dominant features of dementia include cognitive impairment and behavioral changes in people with dementia, often referred to as “challenging”. Whether communication is successful or not depends, on the one hand, on the type and degree of cognitive impairment and the skills and resources available to people with dementia and, on the other hand, on the ability of the environment to interpret and understand the utterances and the meaning of the behavior.

In the first part of this essay we begin with a description of the different concepts of challenging behavior and their theoretical assumptions and backgrounds. We then describe the particularities of the nursing perspective and show the state of the art in caring for people with dementia with challenging behavior. We will also consider current evidence on the different views on the phenomenon facing the perspective of professionals, family carers and people with dementia themselves.

In the second part, we alternately describe and reflect on a very short sequence of a micro interaction of a couple at home during a meal. With regard to current theoretical discussions, the example gives a first impression of the tiny, situational and complex interactional attunements and underlines the need for sensitive communication skills of people caring for people with dementia.

### 2.1 Introduction

Dementia has an enormous impact on daily living of people with this disease and for all surrounding them. One of the most prominent challenges in dealing with dementia is the creation of an appropriate and effective interaction. The dementia process causes direct communication impairments due to pathological changes in particular brain regions (e. g. anomia, aphasia, impairments in motor performance of speech). But the major part of communication and interaction problems is a result of misadjustment between dementia related impairments, available capabilities of the person with dementia and the competency of the environment to deal with the communication difficulties.

One of a dominant characteristic associated with dementia are, along with cognitive impairments, the changes in behavior of people with dementia. The prevalence of behavioral symptoms of people with dementia living at home is 53 % in Germany (Teipel et al. 2015; Thyrian et al. 2015) and between 11–90 % international (Borsje et al. 2014). Behavioral changes are one of the first signs of dementia and they accompany

people throughout the entire course of the disease. These behavioral changes have a lot of different names: disturbing, problematic, challenging, neuropsychiatric symptoms, need-driven, reactive, behavioral and psychological symptoms of dementia and many more (Halek 2019, 2019a).

Behavioral changes are challenging for family members and professional carers. They are disturbing and stressful and are responsible for heavy burden (Feast et al. 2016; Thyrian et al. 2015) on formal and informal carers. People with dementia showing challenging behavior are at higher risk for psychotropic drug use and use of restraints (Kunik et al. 2010). There is a higher risk of health problems, increased care dependency and hospital (Toot et al. 2013) and nursing home admissions (Toot et al. 2017). As a consequence, the behavioral changes influence the quality of life, autonomy and self-esteem negatively. For these reasons there are a lot of research efforts with regard to developing interventions which can prevent or decrease the occurrence of challenging behavior. For the home care setting the research activities focused mostly on training and counseling of caregivers on various topics (e. g. coping strategy, handling, and access to the services) (Feast et al. 2016).

## 2.2 What is exactly *this* behavior that challenges?

The numerous terms existing in the literature and daily language are umbrella terms for behaviors like agitation, disinhibition, aggression, irritability, euphoria, resistance to care, apathy, anxiety, hallucination and delusion and many more. The origin of the dementia related behaviors dates to the nineteenth century. The physician Esquirol used the term emotional disorder to describe senile dementia. At the beginning of the 20th century, Auguste D. was described by her doctor Alois Alzheimer in 1901 as a patient with cognitive disorders, aphasia, delusion and unpredictable behavior (crying). She went down in history as the first diagnosed Alzheimer's patient (Möller and Graeber 1998). Since then, behavioral disorders have been an important feature of dementia diagnosis. The behavioral disorder in dementia left its first traces in Medline – the most important article database in health – in 1965. These first articles discuss agitation terms of senile sclerosis. Further topics are psychoses, delusions, or so-called psychohygienic problems in nursing homes. The problem behavior as a topic also appears in the 60 to 90 years without the connection to dementia but in the general connection to geriatric patients or residents of nursing homes. In one of the first studies on “wandering”, i. e. on “apparently aimless or disoriented locomotion”, residents of a nursing home are examined. It was found that although the number and quality of movement of walkers and non-walkers differ greatly from one another, there are no differences between the two groups in the so-called organic brain syndrome: the difference was in short-term memory (Snyder et al. 1978). The research activities in the 1980 s, which marked a boom in research into behavior and dementia, started researching behavior independently of the diagnosis of dementia. One exam-

ple is the psychologist and statistician Jiska Cohen-Mansfield, who initially based her entire agitation research on the population of elderly people in nursing homes. The cognitive limitations emerged as a strong influencing factor in this context. It is also the time of the development of the first important behavioral instruments like Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, Marx, and Rosenthal 1989) or the BEHAVE-AD (Reisberg, Auer, and Monteiro 1996), which is mainly used in pharmacological research. Studies in the 1990s tried to bring some order to the topic. The IPA (International Psychogeriatric Association) introduced a change in term—from problem behavior to BPSD (behavioral and psychological symptoms of dementia) (IPA 2012). The IPA distanced itself after a comprehensible consensus process from terms with negative connotations such as problem behavior or behavioral disorders. Other instruments are being developed, including the NPI (Neuropsychiatric Inventory) (Cummings 1997) which is now the most widely used behavioral assessment tool in research and clinical practice. The development of guidelines on management of dementia related behavior started. The topic of behavior and dementia experienced a further upswing from the turn of the millennium. The discussion about the perspective on the behavior and its changes began. The differences between a medical and social perspective on the behavior were worked out. The term “challenging” behavior as a more psychosocial alternative is proposed (Bird and Moniz-Cook 2008). In addition, the research activities were launched on intervention for dealing with the behavior of people with dementia with strong focus on psychosocial aspects and non-pharmacological approaches (Moniz-Cook et al. 2011). In 2018 the Medline lists approximately 1600 publications with the keywords behavior and dementia in 2018.

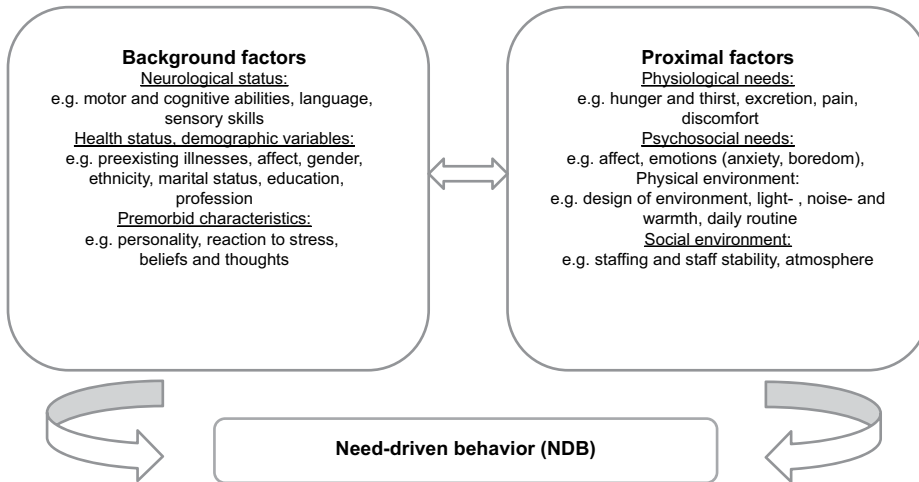
As a result of the comprehensive discussion of the topic “behavior and dementia” different views, definitions and theoretical approaches are developed that exist in the science and in the clinical practice. While the theoretical, scientific perspectives are well documented in the numerous papers and can be extracted, the view of the clinical practice is less examined and can be found in practice reports, popular literature and few scientific papers. The discussion about the “right” view or term or definition is not trivial because how we, the practitioners, families and researcher see and interpret the behavior of people with dementia, results in the way care is provided and determines their quality.

The different disciplines have their own explanatory approaches, which differ but also have things in common. We carried out a conceptual analysis of the phenomenon with the question of what is meant by the phenomenon “behavioral problems”. The literature search covered the years 1965 to 2012. According to stratification by years and disciplines, 10 % of the articles were examined for significance for the question and finally 224 articles were analyzed and the definitions or descriptions extracted. The analysis of the texts emphasized the dominance of the medical perspective. From a medical point of view, behavioral disorders, together with deficits in cognition and effects on daily life, are an essential feature of disease definition. Also in the DSM-5 classification for neurocognitive disorders, behavioral disorders are listed as an ad-

ditional specification feature (Maier and Barnikol 2014). From a medical perspective, behavioral problems are a symptom or side effect of dementia. Symptoms are usually treated medically in order to eliminate or at least minimize them. In the case of chronic illnesses, which include dementia, the aim of the therapy is therefore the greatest possible absence of symptoms. Applied to behavioral problems, it is therefore a matter of preventing, eliminating or at least reducing these symptoms. This understanding is the guiding principle for medical research on possible drugs against behavioral symptoms. The definition of the term neuropsychiatric symptoms and BPSD represent this medical perspective. The term “challenging behavior” is transferred from curative education to dementia care (Wüllenweber 2001). The idea behind this term is to turn away from the attribution of a behavioral problem as a sole feature of people with dementia. The “challenge” of the behavioral presentation lies in the interpersonal context. Challenging behavior is a “manifestation of distress or suffering of the person with dementia or of distress in the carer” (Bird and Moniz-Cook 2008 p. 573), and behavior that is experienced as challenging may frequently be in the eye of the beholder (Bird and Moniz-Cook 2008).

This dependency of the perspective and context is a very important feature that has influenced the understanding of the dementia related behavior and in consequence the research and discussion on this topic. In German context the term “challenging behaviors” (ger.: herausforderndes Verhalten) were introduced in Germany in 2006 with the “Rahmenempfehlungen zum Umgang mit herausforderndem Verhalten” (engl. recommendations for dealing with challenging behavior) of the Federal Ministry of Health (Bartholomeyczik et al. 2007). Since then, the term has spread to various dementia-relevant areas, not without criticism. This criticism refers to the continuing negative connotation of the term as a challenge to fight against dementia related behavior and still focusing on the behavior of *people* with dementia. Although the definition of the challenging behavior is not criticized, the discussion about the right name for the phenomenon is still ongoing, also internationally. Variants such as “behavior that challenges” or “challenges in behavior” are proposed as alternatives. People with dementia and their relatives prefer the terms “changed behavior(s), expressions of unmet need” or BPSD (behavioral and psychological symptoms of dementia) in a clinical context. Terms such as “behavior(s) of concern, challenging behaviors, difficult behaviors” are rejected by the people with dementia and their relatives (Alzheimer’s Australia, n. d.).

The multicausality of behavioral changes is the main feature of the need-driven dementia compromised model published by the research team Whall, Kolanowski and Algase in the 1990s (Algase et al. 1996; Kolanowski 1999; Whall and Kolanowski 2004). This model represents the nursing perspective on behavioral changes and underpins the meaning of needs and the fulfillment thereof. According to the model, the need-driven dementia compromised behavior is “a most integrated and meaningful response possible, given limitations imposed by dementia, strengths preserved from the person’s basic abilities and personality and environmental conditions” (Algase et



**Fig. 2.1:** Need-driven dementia compromised behavior model (Kolanowski 1999).

al. 1996). The key for dealing with the need-driven behavior is the recognition of the underlying needs and their fulfillment. This NDB-model (fig. 2.1) introduces a positive picture of the behavior as a communication aid, as a resource or care. The challenge here is the understanding of the meaning of the behavior and to react adequately. Inadequately addressed needs cause further behavioral problems and intensify the problematic situation (Kovach et al. 2005). Similar to the NDB-model is the newest conceptional model developed by Kales and colleagues (Kales, Gitlin, and Lyketsos 2015). This model underpins the influence of dementia-related degeneration on changes in the ability of people with dementia to interact with others and the environment. The model follows two assumptions: (1) dementia can directly cause symptoms by disrupting brain circuitry involved in behavior and emotion; (2) social and physical environment can trigger behaviors independently or in interaction with the brain degeneration. The authors represent the medical perspective and use the term BPSD (Kales et al. 2015).

The distinguished psychologist Tom Kitwood represents a similar perspective with his famous work on person-centeredness by dementia (Kitwood 1997). As a result of observations in nursing homes he comes to the conclusion that behavior of people with dementia is an expression of unmet emotional needs. He defined five psychological needs which are of a significant importance for well-being of those people: comfort, attachment, identity, inclusion and occupation. The fulfillment of these needs is the best approach in dealing with behavioral changes. Sabat and Harré understand the behavior as an attempt to re-construct the self by people with dementia. The right construction of self needs the right interpretation by others. This requires “willingness and ability of others to cooperate in the construction of a particular self”



(Sabat and Harré 1992 p. 454). The others have to be careful listener starting from the premise that the person with dementia is trying to say something and that there is a coherent reason for the behavior in question. If the joint-construction succeeds, the person is positioned (positioning theory) correctly and the behavior is understood as manifestation of self. This is the perquisite for saving the autonomy, well-being, flourishing and dignity (Sabat and Harré 1992). From the perspective of the constructivist theory the behavior (problematic or not) is mainly a result of the social positioning and not a result of changes in the brain.

The presentation of some of the most important perspectives and definitions and a conceptual model explain the reason why there is no one universal and valid term and definition for the phenomenon “behavior by dementia”. The different understandings of the phenomenon represent two different paradigms: medical and social. The differences lie in the *point of the view*: symptom versus the persona; in the *definitory power*: proxy versus self/joint; and in the *goal setting*: symptom reduction versus coping with the behavior. The common features are the multicausality of the behavior (pathology, state and trait of the person with dementia itself, social and physical factors) and the interaction between them.

### 2.3 The nursing perspective

The definition of the behavioral changes in dementia from the perspective of nursing science has to take into account the specific nursing focus on the caring situation. The nurses' objective is the realization the particular care task, taking into account the personal situation and needs. Success is achieved when the nursing goal (sufficient food, body care, meaningful occupation) is achieved together with the person in need of care in mutual satisfaction. Against this background, changes in behavior are understood as complex situations and the core reason for the behavioral presentation lies in the interpersonal context. The understanding of those situations requires consideration of different perspectives, in particular the perspective of those in need of care and those directly involved in the situation (professional carer or relatives). The triggers for behavioral changes can be the personal factors of the person with dementia itself (health status, personality and lifestyle) and factors from the physical and social environment. The requirement for dealing with the behavior of the person with dementia is the understanding of its function. This process of understanding of the behavior need to be systematically resulting in a common understanding of the situation, common goal setting and common handling of the situation.

The German guidelines for dealing with challenging behavior in nursing homes recommend the process of so-called “understanding diagnostic” (Bartholomeyczik 2006; Halek 2018b). The process follows the traditional nursing process: describe the behavior, analyze the triggers, decide how to act and act. The steps can be found in many other behavioral approaches (e. g. Gitlin, Kales, and Lyketsos 2012; Brechin et

al. 2013; Jackman, Wood-Mitchell, and James 2014). The quality of the understanding process depends on the following factors: (1) taking the perspective of the person with dementia; (2) trying to understand the behavior; (3) using of a variety of behavioral explanatory aspects; (4) objectification of individual observation of behavior (creation of a common perspective on the behavior); and (5) formulation of understanding hypothesis.

Unfortunately there are few research activities that studied the perspective of the nursing and care staff on behavioral changes of people with dementia. Dupuis, Wiersma, and Loiselle (2012) interviewed 48 staff members from nursing homes about their perspective on the challenging behavior of the residents with dementia. The staff interpreted the behavior of the residents in context through a complex process. This process was dominated by a biomedical perspective. The first lens that filtered the behavior was the lens of pathology. The residents were assessed according to their illness (dementia) by every staff member subjectively. The residents with dementia were denied the sense of their behavior because “they don’t know what they are doing”. In staff’s eyes a cognitive impaired resident cannot be aware of right and wrong judgments. On the other hand the staff saw also behavior as a way of communication, as expression of themselves, but still in context of the disease (Dupuis et al. 2012). The advantages of this interpretation are that the staff gets an “other” understanding of the behavior; they do not take the behavior personally and have more patience, it provides another kind of interaction and it shows more compassion. The residents get a “moral status” and need a special “moral person” who is caring for them. The disadvantage of this perspective is a high risk that the behavior is interpreted as a symptom of dementia, related to brain damage and in consequence as a meaningless, aimless brain reaction. The level of challenging behavior was dependent on specific characteristics like intentionality, unpredictability and persistence, level of threatening, social appropriateness and impact on others. Again, the pathological status of the residents with dementia determined how the characteristics were assessed. All these described mean processes are individual and represent the particular perspective of the individual caregivers, resulting in different perspective on one person with dementia and a high chance of different approaches to the person. Additionally, the staff reacts usually in acute crises, which leaves any time to carefully reflect on the behavior and discuss the different variations of interpretation (Dupuis et al. 2012).

The results of this study are similar to Appelton et al. (2017) and are disappointing. Although person-centered care according to the approach described by Kitwood (1997) seems to be the gold standard for care of people with dementia, the approach described by the staff contradicts that in larger parts. The reasons can be sought in the conditions of the organization and in competences and motivation of the caregivers. The challenge of the implementation of the abstract idea of person-centeredness in the particular caring situation lies in the practical aspects, in doing. At the end, the abstract understanding of the situation has to be broken into action steps which hopefully lead to success with, for example, eating situations.

There is scarce research that focuses on the perspective of people with dementia and their behavioral changes. This is due to the methodological and ethical challenges when examining the subjective perspective of people with dementia and their own behavior. Graneheim and colleagues (Graneheim and Jansson 2006; Graneheim, Norberg, and Jansson 2001) conducted some interviews with residents who had dementia and “disrupting behavior”. The main topic of their analysis of data was “being subjected to a collapse of relations to self and others intertwined with occasional episodes of togetherness” (Graneheim and Jansson 2006 p. 1401). The people felt surrounded by disorder, trapped by restriction and set aside. Living with dementia and behavioral changes is to be excluded from meaningful relations with self and others. The others treated them as sick and restricted them. The behavior is an attempt to find freedom, to escape from unpleasant or dangerous situations. Thus, the behavior can be interpreted as a constant attempt to maintain or to rebuild one’s personal self (Graneheim and Jansson 2006). The interaction with others, in particular with the care staff supports the process of personal re-construction or is disturbing and is a key element in dealing with the “disturbing” situation.

Feast and colleagues (Feast et al. 2016) worked out the perspective of family caregivers on challenging behavior of their family member with dementia in a review of qualitative and quantitative studies. According to the results the experiences of behavior as challenging by the relatives is mainly determined by communication problems. The greater the communications problems and the greater the consequences of these problems for the relatives are, the more challenging the behavior is perceived. The communication problems include the lack of interest, repetitive interaction or no meaningful discussion. These led to changes in relationships such as missed companionship and good interaction or the loss of emotional bond of love. The relatives experienced a sense of isolation and feelings of rejection and grief. In addition there exists personal expectation about the level and quality of care that the relatives should or would like to provide and that is hindered by the rejection of care. The level of frustration is also depending on the degree of tolerance and mastery or competency to respond effectively (Feast et al. 2016).

The knowledge about the three relevant perspectives underlines the significance of the view or perspective on the changes in behavior of people with dementia for understanding and dealing with the complex social situation. The attitude and interaction play a key role in this process. The view that people have on the person’s challenging behavior determines the nursing care provided.

Changes in communication due to dementia are one of the main factors that explain the response of caregivers to challenging behavior. The reduction of the quality of interaction results in a decline in the relationship, particularly in families. The assumption is that successful communication and interaction can have a positive impact on experiences of challenging behavior and in consequence on development of challenging behavior. Thus the nursing work with people with dementia must be characterized by attempts to improve interaction both between nurses and persons

with dementia as well as between family caregivers and their family members with dementia.

One step in this direction is to perceive people with dementia as interactional partners by the given change of communicative and socio-cognitive abilities according to the dimensional concept on interaction (Meyer 2014). In this theoretical work the interaction as a sociological term is extended in the four dimensions: (1) thematic continuation; (2) reference to shared knowledge; (3) formal-procedural continuation; and (4) bodily-affective responsiveness. Since the fourth dimension is becoming more and more important as dementia progresses, the work of Döttlinger (2018) is of great importance. She focused on gestural engagement of professional nurses and communication and relationship building with people with dementia. This engagement occurs “when a nursing practitioner symbolically simulates an action by means of symbolic gestures, with the aim of providing a person with advanced dementia with a reference to an action” (Döttlinger 2018). The central result is that the nurse practitioner takes the conductive and communicative responsibility for designing the interaction. Another promising approach emerged in the field of music therapy. Schumacher and colleagues (Schumacher, Calvet and Reimer 2013; Schumacher and Calvet-Kruppa 1999) worked with children with autism and developed a therapeutic instrument to assess the quality of (therapeutic) relationship (AQR) which was also used with people with dementia by Warne (2007). The aim here is to build a basis for coming in contact and develop respectively to keep self and self-efficacy as long as possible using a four-scaled instrument with six consecutive contact-modes from having no contact up to joint experience.

Concurrently a recent developed German nursing guideline for dementia (Expertenstandard) focuses on the fostering and sustaining relationship in care of people with dementia as a fundamental prerequisite for nursing activities in all care settings. The overall aim of nursing activities should be “to ensure that the person with dementia has the feeling of being heard, understood, accepted and connected with others” (Deutsches Netzwerk für Qualitätsentwicklung in der Pflege 2018).

Nevertheless, intervention addressing the caregivers’ need for understanding and managing changes in communication is at an early stage of development and needs more research (Feast et al. 2016). There is no evidence on how to improve the relationship between caregivers and their relatives (Rausch, Caljouw, and van der Ploeg 2017). And there is a need to consider the specific requirements of the different forms and phases of dementia, its subtypes, and the lifespan (late/young onset).

This is the starting point for the research project AMEO-FTD<sup>1</sup>, which was conducted at the working group care interventions at the German Center of Neurodegenerative Diseases (DZNE), Witten between 2015 and 2018 (Berwig et al. 2020).

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<sup>1</sup> Application of Marte Meo®-counseling with people with behavioral variant frontotemporal dementia and their primary carers (AMEO-FTD).

## 2.4 The AMEO-FTD project

AMEO-FTD is a mixed-method feasibility study with the focus on improving the quality of dyadic relationship (one main outcome) by counselling the primary carers of people with behavioral frontotemporal dementia (bvFTD)<sup>2</sup> in sensitive interaction using the application of video feedback according to Marte Meo<sup>®3</sup>.

In the qualitative strand of the project<sup>4</sup> we focus amongst others on the aspect of social interaction between people with bvFTD and their primary carers in a daily life situation (having lunch). Here we wanted to know how people with bvFTD and their primary carers interact intuitively with each other, whether and how they build up a mutual relationship depending on the situation and context, and whether and how they jointly establish social order, or which means or strategies are applied.

Therefore we worked with videography based on focused ethnography (Knoblauch 2001; Knoblauch and Schnettler 2012) for data collection. Within the feasibility study mentioned above, one researcher of our research team visited five couples three times at home. After coming into contact and building trust with the participants and situation at home a video was recorded of a mealtime situation using a fixed camera. The counseling took place in a weekly rhythm over five weeks before the third visit. For the analysis of the intuitive interaction only the data of the first and second visit before the intervention period were used for interpretation. The data were analyzed by video-interaction-analysis (VIA) (Tuma, Schnettler, and Knoblauch 2013).

In the next paragraph we will present a description of a very short sequence of micro-interactions within one participating couple. We will focus on selected challenges the couple is confronted with in a daily life situation – here a mealtime situation – and discover step by step while going through the material, what is going on and how the couple adapt to these challenges or find ways to manage their daily efforts. Afterwards we will discuss the findings in light of some current theoretical considerations on interaction and dementia.

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**2** BvFTD is the most common subtype of young onset frontotemporal lobar degenerations (FTLD), a spectrum of neurodegenerative diseases, associated with impaired behavioral, emotional and language abilities caused by protein deposits localized in the frontal and temporal region of the brain. Clinical symptoms vary individually, but in bvFTD social cognitive abilities are primarily affected in the early stage. In this text, we are not going deep in the particularities of this special dementia subtype and we will not give recommendations on interventions. Here we focus just on a case description which serves as an example to learn about interaction.

**3** Marte Meo<sup>®</sup> (lat: “on one own’s strength”) is a video-based intervention which was initially designed for parents of children with autism to improve interactional sensitivity and create a supportive social environment for the development and maintenance of social-cognitive abilities.

**4** A manuscript of complete project details and research results will be published elsewhere.

## 2.5 Case description – Mealtime at Mister and Misses B's

### 2.5.1 Background

Mr. and Mrs. B. are approximately 60 years old and live in their own house together with two dogs in a rural area in Central Germany. They have been married for a long time and have two adult children who no longer live at home and are already independent. Mr. B. was engaged in his job working in a leading position in a nationwide company until the illness was diagnosed. Mrs. B. worked in her pedagogically oriented profession as long as possible, but after several unsuccessful attempts to allow Mr. B. to be cared for institutionally in long-term care, Mrs. B. gave up her job to devote herself entirely to care for her husband. From time to time a care assistant comes to their home when Mrs. B. can take time for errands or herself. At the time point of the video the disease was diagnosed about two and a half years ago and was already in a severe stage.

The main challenges in the common everyday life of the couple are that Mr. B. shows some degree of agitation both during the day and at night, wanders through the house and has difficulties to finish a just started action, but above all keeping the right amount of something to drink. Moreover, Mr. B. does not speak at all and does not make any other kind of verbal utterance, not even in the video recordings. Another peculiarity is that he always stands during the meal (fig. 2.2).

### 2.5.2 Intro: The table is set – starting with a “still” – time code: 00:00:01

#### Description of room and setting

The scene takes place in the kitchen. In the middle of the picture we see half a wooden table with a large cup with a handle and an imprint of a heart and a bone, a bowl and a spoon on the cross side and another bowl on the right side, both filled with a greenish mushy meal. A chair is placed in front of each, of which only the backrest can be seen. A fragment of a fitted kitchen made of dark brown wood can be seen on the right. On the wall hangs a small kitchen shelf of the same color with a tea towel and a potholder. Below the sideboard there is a tin can, followed by the wood-colored door frame in the middle, from where you can enter a second room, which is partly visible. The door opens inwards and connects to the wall that is on the front of the picture; further to the left is a second, but closed door that closes the picture.



Fig. 2.2: Room and Setting.

### Reflections

What do we perceive and what can we expect or anticipate?

#### **“A prepared meal, but nobody is in the room”**

The atmosphere and design of the room and its interior can be described as rather traditional and rustic and has been modern and customary about 20–30 years ago. The table is set but we don’t know for sure if the meal is for breakfast, lunch or dinner; we see a cup with a heart and half of a bone on it, which can be used for coffee, tea, juice or water, but we don’t see if it’s filled with something. There are also two plates filled with something greenish and semifluid and there is a tin can at the sideboard.

We might associate that the heart on the cup is a symbol and stands for: “I love ...” something; the bone might be a symbol for a dog and so it might be a favorite cup for a dog enthusiast. We can also anticipate that the tin can could be filled with dog food or with soup, stew or a canned dish for the meal of two persons, because of the two plates. Even the shape of the plates might give a sign, because they are more made for eating cereals or something liquid.

But why is there nobody in the room? There might have been an interruption of the action—“having mealtime” somebody must have left the room after filling up the plates—what was the reason for leaving the room respectively and what was the reason for not coming into the room? There are several possibilities: not being hungry, just doing something more important, having a telephone call or somebody has unexpectedly knocked at the front door (post, neighbors, etc.); preparing for a meal and washing the hands; knowing that there is a camera installed and being afraid of it.

We might get some answers when starting the video.

### 2.5.3 Sequence: Coming into the room – timecode: 00:00:01–00:00:16

#### Description

When starting the video sequence, there is a slight humming noise in the background—we can't see where it is coming from.

The kitchen is still empty, but we can hear somebody from outside the room, who is saying: "*Come on, darling, (...) lunch*".

While doing so, a woman appears in the door frame. She is dressed in a soft yellow T-shirt and blue-violet trousers, she wears glasses and her gray hair is braided into a plait that reaches down to the shoulder blades. When she comes into the room, she looks at the camera, supports herself slightly with her hand at the edge of the table and sits down on the chair to the left in the picture.

A man appears in the door frame and also comes into the kitchen. He is tall, wears a T-shirt and short sweatpants; his arms are hanging down his body, his mouth is slightly open and his eyes are directed on the bowl placed on the table.

#### Reflections

A noise in the kitchen might come from kitchenware; it could be a fridge, the oven, the cooker hood, the microwave, a stirrer or a special cooking pot.

The verbal expression "*Come on, darling*" indicates a more familiar and close relationship; "*(...) lunch*" is a common call to initiate the start of a mealtime, like parents do for children, when the meal is ready. Because it is the voice of a woman saying this, we can conclude that she is the one who was preparing the meal.

The first person to enter the room is the woman; she fixes the camera briefly with her eyes, but sits down without paying further attention to it, followed by the man whom she called darling before. The clothing also points to a familiar, less official situation due to sweatpants and T-shirts, which fits the situation of a kitchen as opposed to eating out in a restaurant. At this point in time, we don't know who is the one with bvFTD and who is the carer. But the fact that she is calling out and for instance his body posture (hanging arms, open mouth) may be some first hints, which we need to follow up.

In the following, we will call the man Mr. B. and the woman Mrs. B.

### 2.5.4 Sequence: Starting the meal – timecode 00:00:16–00:00:40

#### Description

As Mr. B. enters the room, Mrs. B. looks at his plate, takes the spoon in front of his plate, puts it in another way round and pushes his plate further to the edge of the table in his direction, looks up briefly, then to the plate and at him again (fig. 2.3).





**Fig. 2.3:** Starting the meal.

Mr. B. walks straight towards the table, grabs the cup by the handle with his upper body slightly bent forward, leads the cup to his mouth and drinks quickly while standing, swallows, looks straight ahead over the edge of the cup, looks briefly at Mrs. B. (she nods), drinks another sip, the body swings slightly back and forth, looks directly into the camera, then back to his wife and drinks several times in a row in large swigs.

In the meantime Mrs. B. grabs her own spoon with her left hand; simultaneously she looks up at Mr. B., leans back and puts the spoon back to the left next to the plate and looks at her husband again, who is drinking, looks straight ahead, then again at Mr. B., nods to him (beeps a little) and says “*Everything is ok*”.

### Reflections

What is happening here and why are they acting in this way?

**Starting a common meal:** Usually one would wait until the other one sits down. If necessary one wishes good appetite and then everyone begins with the meal and eats from his own plate, with his own spoon. By turning the spoon here and pushing the plate forward, Mrs. B. leaves her territorial space and interferes with Mr. B.’s territory. Mr. B. gives no indication whether he has noticed this or whether he is comfortable with it. He goes purposefully to the table and takes the cup that – as it now becomes apparent – contains something to drink.

But if your interpretation relies on assuming a caring act, Mrs. B. prepares here the beginning of the meal and gives Mr. B. a mark to possibly draw his attention—the act becomes a pointing gesture. It turns out bit by bit that Mrs. B. probably has the leading role.

**Sitting and standing:** Mr. B. himself breaks with expectations and does not sit down, even though there is a chair in front of him. Instead, he drinks quickly and in big draughts as if he is in a hurry and drinks standing up as if he wanted to leave immediately. Mrs. B., for her part, gives no indication that she thinks this situation is weird or unusual. On the contrary, she keeps eye contact and also gives a supportive and reassuring gesture of confirmation by nodding to her husband and underpins this

with the words “*Everything is ok*”, which is spoken here in a calming prosody. This is especially interesting, because usually the one who stands has power or dominion, which in this case is exactly the other way around, because Mrs. B. is in a spatially lower position, holds the reins and directs the situation in a gentle way.

Another question here is, what is “everything” and why does it need to be calming? Here we have some context information from the ethnographic talk before with Mrs. B., who told us, that it’s unusual for Mr. B. to be eating in one turn and staying in the room for the whole dinner. Mr. B. is looking into the camera, which can be perceived as a foreign, irritating or disturbing element and could be an additional reason for the reassurance.

**Beep:** There’s a short beep, but permanent noise is ongoing and nobody is reacting to this.

### 2.5.5 Sequence: Diverse interests – eating and keeping contact – timecode 00:00:40 – 00:02:10

#### Description

Mr. B. drinks the cup empty and places it on the table looking at the bowl, while Mrs. B. takes his spoon, fills it with soup and puts it down on the edge so that Mr. B. can grasp it directly. When she was about to lift the filled plate, Mr. B.’s gaze wanders towards the sink and when he takes a step in that direction he is approached by Mrs. B., who puts the plate down again and softly touches the belly of Mr. B. with her flat hand, saying, “*No, now here’s something to eat, Harry*<sup>5</sup>”

Mr. B., who is about to leave, looks at her, turns right again, then to the left, coughs, seems hesitant, takes a step back and looks at the plate that Mrs. B. lifts up again. She asks him to eat again, saying, “*Harry, first – take the plate in your hand, eh?*”

Mr. B. takes it with both hands while Mrs. B. looks at Mr. B., waits until he takes the spoon with his right hand and begins to eat, then she turns back to her own food, eats a spoon herself, and looks up to him again, keeping eye contact as she chews, looks at Mr. B., nods to him and verbally supports the contact: “*Well, it still tastes good, doesn’t it?*”

In the meantime Mr. B. chews, takes another spoonful, pauses, looks at Mrs. B., who also looks at him, keeps eye contact, swallows, steps from one leg to the other and then takes some soup on the spoon with the kick on his own hand several times

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<sup>5</sup> Although all participants gave written informed consent to the publication of the video data, all names are pseudonymized in this manuscript for the protection of the persons involved



Fig. 2.4: Series of Images.

in a row, leads it to the mouth, chews 3–4 times, swallows, puts the spoon in the bowl, takes the plate in the right hand, looks up briefly and puts it back on the table.

Mrs. B. herself eats and changes her view several times and keeps looking up at Mr. B. from her plate, nods to him and finally says, “*There’s plenty left*” (fig. 2.4).

### Reflections

**Keep in touch:** Before Mr. B. finishes drinking, Mrs. B. fills Mr. B.’s spoon with soup without looking at him – it seems she anticipates the next step and prepares with foresight to ensure a smooth eating process. It also seems that she suspects that Mr. B. is about to turn off the cup, so she prepares the spoon and offers him the plate so that Mr. B. can use it directly. Mr. B. has another plan, the target of which we don’t know and which is somewhere out of the picture towards the sink. Mrs. B. is keeping the leading role here and prevents Mr. B. carrying out his plan and directs him by giving him a positive impulse. At the moment when she realizes that she is not being heard verbally, she acts bodily and builds up a barrier with her arm and fingers by gently touching him on his belly. In the end, Mr. B. follows her instruction hesitantly and keeps eating for about the process of eating eight spoons of soup (1.12 minutes), reaffirms himself over and over again by looking at Mrs. B., while Ms. B. keeps in constant contact by looking up again and again, keeping eye contact, nodding approvingly and encouraging him to continue eating through verbal and corporal utterances.

**Add ons – the microwave and the role of the tin can:** In the following scenes we will perceive that Mr. B. again tries to penetrate towards the sink and Mrs. B. again successfully prevents this request in the same way. We will also see the object of desire by seeing that Mrs. B. after Mr. B. has drunk the cup empty, pulls out a glass from behind the sink and fills it half full with mineral water several times in an elaborated and consuming process (picking it up, unscrewing it, pouring it in, screwing it down and putting it back behind the sink).

We will also learn that the sound comes from the microwave used by Mrs. B. to warm up the second portion of soup. But to prevent Mr. B. from running out of the kitchen unobserved while she has to turn her back on him, she has reserved a task for him (bringing the empty tin can into the yellow sack behind the closed door visible in the picture), which she has to assign to him and which he has to complete in this time.

Although Mr. B. does not speak a word, he immediately understands the work order, which is verbally initiated by a pointing gesture, and acts immediately and logically. He must know where the yellow sack is and that cans belong in it. Mrs. B. pursues her concern and at the same time trusts Mr. B. to be competent in taking action.

Knowing that Mr. B. has emptied a whole case of mineral water at once in the past (context information), portioning as a restriction remains a patronizing and restrictive act, but can also be interpreted as problem solving and prevention of a major disaster. Here a dilemma situation is described in which a decision must be made between security and freedom.

### 2.5.6 Concluding considerations

Verbal communication, as described in this case, is asymmetrical and is done exclusively by Mrs. B, who says something to her husband in the context of the eating situation. Altogether Mrs. B. uses predominantly positive descriptions or prompts, like for instance: *“Harry, first – take the plate in your hand, eh?”* Mrs. B. has the guidance and controls the food, for example by portioning it. From time to time they have physical contact; for example, when Mrs. B. touches her husband’s belly briefly and for effect, more often they have eye contact.

There are different rhythms of the eating and drinking act. It seems that Mrs. B. is in permanent attention mode and wants to prevent or counteract the interruption of the action (e. g. running out of the door). She intervenes, uses verbal descriptions and prompts him, comments on what she is doing and asks, but gets no verbal answer. Mr. B. always keeps an eye on his wife, unless he eats or looks into the camera. There are short control glances to be observed that seem insecure (standing and looking; waiting for something to drink) and a few initiated actions (move to the sink). Often Mrs. B. anticipates actions or shows that she has noticed a need of her husband and fulfils it (e. g. by pouring water), but keeping the steering position.

If we consider the present description under the slide of the dimensional concept of interaction (Meyer 2014) then we can see – focusing on Mr. B. – that we cannot find thematic continuation in this scene, because Mr. B. does not speak at all in the video recordings and does not make any other kind of verbal utterance. But what we can find is a situated and context depended understanding of shared knowledge (what to do with the empty tin can), a formal, procedural continuation in eating skills, which can be connected to rituals and a bodily-affected responsiveness, where eye focus and body turns are the main applied communicative skills.

Mrs. B. is constantly trying to keep in touch – like an invisible bond – and she uses a variety of verbal and action strategies, like a complex toolbox. This comes close to what Döttlinger (2018) called “floating attention” in her findings on interaction between people with severe dementia and specially trained nurse practitioners. This concept is characterized by an attentive visual observation of the communication

partner – the professional nurse keeps the contact and remains continuously “in suspension” and keeps contact. At the same time, the nurse remains in “responsiveness with expectation”, which means that a reaction to an “utterance of the person with dementia” can take place immediately when a necessity is recognized from the floating attentive posture. Which reaction is chosen depends on the situation. In our case Mrs. B. is taking this responsibility for the interaction as well, even if there is no specialized training program before. In our video sequence we reconstructed step by step that she is taking the lead to “hold on doing the common meal”, which can be allocated in the broadest sense as what we described in this manuscript as the “nursing perspective”. Before building this kind of skill in a daily care situation, she has to accept that she is “living with a partner who has dementia” and actively take the carer role. The latter is a main result of the AMEO-FTD Study (Berwig et al. 2020, accepted) and one key element in the stability of care arrangements in home care settings (Köhler et al. 2018). That she is doing it in this sequence in a protective but gentle way might depend on some “intuitive caring skills” and her pedagogic background (contextual information). It can also be described as a person-centered approach, oriented on an underlying frame to as much as possible build a symmetric connection in an asymmetric relationship. In ethnomethodological terms, she is repairing the given crisis in a continuous and situational mutual interactive negotiation and so, both Mr. and Mrs. B. create together their own common order.

## 2.6 Conclusion

Finally, we can summarize that the dyadic interaction we perceived in this short video sequence of one person with dementia and his caring wife served as an example of remaining individual and is generated situationally and at a micro level. Yet this confirms once again that an understanding approach to behavioral challenges of people with dementia is a prerequisite for successful interaction, based on a relational and continuous basis, even if reciprocity cannot be assumed or established in all moments. “Making and keeping contact” is a key factor and is established in ultrashort moments and at different levels and modes. If behavior is understood to be meaningful, then the challenge may no longer be experienced in a stressful way. Video feedback is a method of visualizing the microstructure of interaction and has potential to train people with dementia and their carers and might help to stabilize the relationship.

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### 3 Do robots care?

## Towards an anthropocentric framework in the caring of frail individuals through assistive technology

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### Abstract

As a consequence of modern medicine and modern style of living, two demographic trends, namely longevity and a decline in fertility have greatly increased the aging population. The number of older persons aged 60 years or over is expected to be 1.4 billion by 2030 (World Population Data 2017). This demographic change combined with changes in family structure challenges the future of elderly care, and contributes to grounding a case towards the use of advanced robotics and AI to either integrate or radically replace human-provided services in this field.

This paper introduces an anthropocentric framework – as defined by the European Commission in its 2018 Communication on AI – for the care of elderly individuals through assistive robotic technologies. Firstly, the concepts of care and cure are distinguished, followed by a critical analysis of the function of robots in the context of care. The paper continues with an analysis of the aforesaid technologies with the notion of care provided to highlight that machines have the potential to interact and simulate a relationship, but not to establish a real meaningful one with the user. User's deception and deprivation of a meaningful care-relationship is discussed as a potential risk emerging from an incorrect use of technology in the treatment of fragile individuals, and the fundamental legal principle of human dignity is considered with respect to its potential application and impact on policies in this domain, as an objective criterion that poses limits also to the individual's freedom of self-determination.

### 3.1 Introduction

According to the International Federation for Robotics (IFR 2016), between 2016 and 2019, circa USD \$97 million worth of robots will be sold for the care of the elderly and people with disabilities. Due to two parallel and tightly interconnected trends the world is facing, the considerable growth of aging population (Lutz, Sanderson, and Scherbov 2008) and increasing research in assistive technologies, many countries are considering introducing robotic applications in the care of the elderly (Flandorfer 2012). These technologies are intended as an addition to more traditional, human-performed practices, to integrate said services and in some instances as a replacement of solutions that appear burdensome for current and future welfare budgets.

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As the world population ages, the Potential Support Ratio (PSR) or the ratio of the working-age population is reduced. This situation is alarming for policymakers as lower PSR means more elderly persons will become dependent on fewer younger workers. Prior to 1950, PSR was about 12 workers for every pensioner; today there are just 8 and by 2050, the number will be decreased to 4 workers for every pensioner (Yale Global 2015). Moreover, the care management of older adults with multi-morbidity and complex chronic conditions is a more complicated task to perform by non-professional caregivers and it requires in-depth knowledge and expertise in the field of geriatric care (De Vos 2017). Professional and skilled caregivers observe optimal care according to multifactorial geriatric problems of the elderly in their clinical decision-making and implement different clinical intervention based on each individual specific or co-existence condition (American Geriatric Society 2012).

Increased life expectancy and the need for skilled professional caregivers will likely escalate the health expenditure in aged care services. Therefore, many countries around the world are seeking strategies to deal with these challenges and to reduce healthcare costs.

In light of the foregoing, rapid technological advances together with the rise of social and assistive robotics, appear as an appropriately and timely solution, driving a potential shift in the way care is provided (Salvini 2015). Whilst current research addresses product safety and reliability (Bertolini 2013) juxtaposed with perfecting the functioning of aforesaid devices, ethical concerns emerge with respect to the replaceability of human carers in the treatment of the patient (Sharkey and Sharkey 2010).

The proposed anthropocentric framework aims to establish the criteria of “standard of care” for assessing the application of care robots. The framework set out in this paper highlights the relational and emotional dimension of care and the corresponding need to assess the use of robotics in the treatment of vulnerable individuals. Consideration is given to the concept of human dignity in the context of extant legal systems and the legitimizing of care robots for the treatment of fragile individuals. Existing technologies, together with those currently under development, are discussed together with the characteristics they possess and the functions they are capable of serving.

## 3.2 Care vs. cure

To cure is defined as overcoming suffering and restoring well-being (Oxford English Dictionary 2018). Indeed it is a natural human tendency to avoid illness and attempt to improve the overall quality of life. Disease makes people incapacitated and reduces their ability to pursue their goals. For this reason, throughout human history, the vulnerable human species constantly searched for cures and improvements, and medicine emerged as a science to overcome or at least to lessen its symptoms.

Such natural inclination at times transforms into the radical desire of overcoming all vulnerabilities, eventually achieving eternal life and eternal youth. Technology, in

this context, is perceived as the key liberating element that through sufficient funding is able to express its potential without any external restriction or limitation beyond mere scientific constraints and can fulfil the awaited promise (Bostrom 2005). However, such an account is flawed as no technological advancement can ever eradicate all human vulnerabilities since they are inherent to the human condition (Coeckelbergh 2013) and even to human nature (MacIntyre 1999). Indeed, once a scientific advancement tackles one specific limitation, illness or impairment, a new one will emerge as a consequence thereof (Coeckelbergh 2013).

Care is instead a moral characteristic of human beings, and a fundamental element of human relationships. The term itself stems from the Latin word *cura* which has a twofold meaning, namely that of care (attention, treatment) and cure (restoring of health). Care addresses the “multi-dimensional” sphere or overall “well-being” of the person that encompasses the physical, mental, economic, social, political and spiritual condition of any individual (Calzo 2018).

The verb “to care” defines an “attitude of concern for the well-being of another” and “care” is a practice of caring for others (Oxford English Dictionary 2018). Scholars<sup>6</sup> coming from various disciplines provide a number of alternative definitions (Tronto 2015; Engster 2007) all revolving around the notion of the human condition (Arendt 1958) that encompasses the multifaceted dimension of human beings without reducing it to a single physical or psychological parameter. Thus, it is rooted in the relational dimension of every human as a social animal (Aristotle, 1988). It exceeds the notion of cure, for it may not be measured in purely medical terms, and instead amounts to a socio-emotional relationship among a group of individuals that values the well-being of others. Care extends beyond the mere observable improvement in an individual specific medical condition and thus might be defined according to two fundamental dimensions, namely (i) relational, and (ii) emotional.

### 3.2.1 Care is relational

The notion of care would not be objectively taken into account if there is no concern for others. Care is associated with the engagement of at least two parties (Noddings 1984), including parents, children, pets or plants. Relationships depend on the “con-

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<sup>6</sup> Tronto defines care as “species activity that includes everything we do to maintain, continue, and repair, our world so that we may live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.” Engster describes caring as “a practice encompassing everything we do directly to help individuals satisfy their basic biological needs, develop or maintain their basic capabilities, and avoid or alleviate pain and suffering.” Madeline Leininger defines caring as “those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway.

nection” of given objects which typically share some common interests within a given network. However, in some networks, relationships are merely aimed at achieving certain goals and interests, and do not go beyond that specific objective. For instance, taking care of a plant for it to grow and remain healthy requires constant attention. Care in such a context entails improving the plant's environment, reap its fruits and contemplate its natural beauty. However, no trust or respect is established through this exchange. In contrast, other relationships, such as that established between humans are fundamentally underpinned by qualities such as communication, understanding, integrity, solidarity, sincerity, compassion, benevolence, reliability and advancement. The doctor-patient relationship constitutes a good example in this sense, for doctors cannot merely prescribe a clinical treatment without initially building a socially meaningful connection with patients. Indeed, physicians establish effective communication with patients by listening carefully to their feelings and sufferings, and responding appropriately to their needs. Integral to this relationship are both compassion and empathy.

### 3.2.2 Care is a deeply engaging emotion

Compassionate relationships are central to human well-being. Reich describes “care” as “a deeply engaging emotion/idea that has confronted and challenged rationalist, abstract, and impersonal systems of thought, with far-reaching social, political, ethical, and religious implications” (Reich 1995). The concept of care is synonymous with emotional engagement, affection and regard between cared for and cared about. Moreover, human touch is considered a fundamental resource for communication, sociality and care. The emotional dimension is observed in the attitude of affection and regard between carer and cared for, that often presupposes prioritising the needs and interests of the latter over those of the former, and transposes in what is at times referred to as “human touch”; a fundamental resource for human communication, sociality, closeness and therefore, care. Compassionate care in the context of aging parents equates to treating older loved ones with respect and dignity when their health has declined and they are incapable of accomplishing tasks independently. Displaying empathetic and affectionate manners towards them (e. g. kissing, cuddling) gives the impression that they are wanted, and of high priority. This in turn enables the vulnerable individual to preserve a status of well-being that, as defined by the World Health Organization (WHO 1948), does not amount to the mere absence of illness but presupposes experiencing the attention and concern of others who enter this relational dimension.

### 3.2.3 Care is a virtue

The ethics of care is only a few decades old. However, Aristotle uses *Philēsis* and *to philein* to demonstrate what defenders of the ethics of care mean by “caring” and “care” (Curzer 2007). Aristotle defines *to philein* as “wishing for [others] what you believe to be good things, not for your own sake but for [theirs], and being inclined, so far as you can, to bring these things about” (Aristotle 1984).

The ethics of care gives more attention to caring as a foundation for morality (Noddings 2013; Reich 2001). Indeed Reich (2001) stated, “If we do not care about others (and ourselves), or about human tasks or human ideals and goals, we are incapable of any moral knowledge, judgment, or action”.

As Coeckelbergh (2013) asserts, any individual human is vulnerable and acknowledging it simply entails to understand our nature and condition, since in some part of our lives at least, we necessarily depend upon others. We all need to be cared for and nurtured in different moments and circumstances of our lives, from birth to our natural end (MacIntyre 1999). In this regard, frailty is not to be deemed problematic or pathologic, but simply inherent to human nature and allowing for the flourishing of our relational dimension. Humans express themselves through the interaction that bonds one individual to the others, and indeed, the concept of human flourishing, is a practice of such common good, which is served by a network of giving and receiving. The virtues of independence and of acknowledged dependence as MacIntyre claimed, may draw our attention to the moral value of care and concern for the needs of children, the elderly or people with disabilities (MacIntyre 1999).

### 3.2.4 Care for the elderly

Traditionally, the practice of care – in particular for the elderly – was rooted among family members. In traditional proximate families, the exchange of care is constituted by ritualized face-to-face conversations, bodily contact and daily interactions among members characterized by physical co-presence (Falicov 2007). However, massive social changes caused a progressive disruption of the “traditional” extended family, and income inequalities ever more induce young generations to be on the move uprooting themselves geographically, culturally, and economically to find a better life (Fischer and Tronto 1999; Schmalzbauer 2010).

In contemporary societies, institutional care is a substitute for family-oriented patterns of care, in order to provide care for the elderly. While care for older people through non-member family caregivers can be morally understandable, it is important to give the elderly a sense of belonging, regard, and comfort in the vulnerable stage of their lives. The virtue of acknowledged dependence is the commitment of the community to address the needs, values, and best interest of the elderly in providing care for them.

### 3.3 The need for robot carers

As a consequence of modern medicine and modern style of living, two demographic trends, namely longevity and a decline in fertility, have significantly increased the aging population. Furthermore, the number of older persons aged 60 years or over is expected to be 1.4 billion by 2030, more than double by 2050 and to more than triple by 2100 (The World Population Prospect 2017). Globally, the number of persons aged 80 or over is projected to increase to 909 million by 2100, nearly seven times its value in 2017 (UN Aging 2018).

This demographic change, combined with changes in family structure will be very challenging for the future of elderly care. As world population ages, the potential support ratio (PSR) or the ratio of the working-age population reduces. This situation is alarming for policymakers because the lower PSR means more elderly depend on fewer younger workers. Prior to 1950, PSR was about 12 workers for every pensioner; today there are just 8 and by 2050 the number will decrease to 4 workers for every pensioner (Yale Global 2015). More specifically, the care management of older adults with multimorbidity and complex chronic conditions is much more complicated a task to perform by non-professional caregivers and it clearly requires in-depth knowledge and expertise in the field of geriatric care (De Vos 2017). Professional and skilled caregivers shall observe optimal care according to multifactorial geriatric problems of frail elderly in their clinical decision-making and implement different clinical intervention based on each individual specific or co-existence condition (American Geriatric Society 2012).

Increased life expectancy and the need for skilled professional caregivers will likely escalate the health expenditure in aged care services. Therefore, many countries around the world are seeking strategies to deal with these challenges and to reduce healthcare costs.

In such a perspective, rapid technological advances and above all the rise of social and assistive robotics, might appear particularly apt and timely, driving a potential shift in the way care is provided (Salvini 2015).

### 3.4 Care robotics and assistive technologies: An overview

“Care robots” or “social robots” are being considered as facilitators to support the process of caregiving to the elderly at home. Japan is predicted to be the first super aging society with a dependency ratio of about 73 % by 2050 (OECD 2018). To manage this challenge, the Japanese government is currently introducing a nationwide system of robotic assistive technologies for aged care and has intensified its investments of the development of so-called assistive technologies (Flandorfer 2012).

In Europe, where the old-age dependency ratio is expected to reach 49 % by 2050, the European Union is induced to finance the development of assistive technologies,

including those resorting to the use of robots, also through its major research programs, such as Horizon 2020.

Similarly, the United States subsidizes the development of robotic assistive technologies whose innovative potential is presumed to be comparable to that of the Internet and modern media (US Robotics Roadmap 2016); despite its expected old-age dependency ratio it is estimated to reach 34 % by 2050, therefore substantially lower than the two geopolitical areas above recalled.

Whether such approaches are to be adopted as the ideal solution of a clear societal challenge, is a matter that rests on articulate considerations. The theoretical framework provided to define the notion of care, distinguishing it from that of cure, is but one of the two fundamental pillars of the reasoning here more broadly conducted. The second is, however, the technological one. It is therefore necessary to define those functions that robotic assistive technologies are typically called in to perform. In this respect some references of existing application as well as emerging trends are discussed below.

### 3.5 The functions of care robots

The primary functions existing care robots aim at serving are threefold: assist, monitor, and provide companionship, respectively (Sharkey and Sharkey 2010).

Some applications are designed to be an aid in performing daily tasks. A viable example is “Bestic”<sup>7</sup>, a device intended to assist people with some disabilities with feeding themselves autonomously, without the intervention of a human carer. The lack of human assistance in the completion of such a simple yet essential task is empowering, at least so long as the user is not isolated as a consequence thereof. Indeed, on the one hand, achieving independence in quite an intimate sphere positively contributes to the self-perception of the user feeling less incapacitated and limited by his condition. On the other hand, the circumstance that a human carer is not involved in the material completion of the task, favors human interaction. On the premise that another human is present, the meal can develop into an occasion for meaningful

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<sup>7</sup> Bestic is an assistive eating and drinking aid which is programmed to assist the action of picking up food from the plate. The user can pilot a robotic arm that has a spoon attached by pressing a button to pick up the food from the selected area of the plate (Nylander, Ljungblad, and Villareal 2012). Information may be found at <https://www.camanio.com/us/products/bestic/>. There are other products on the market that are similar to Bestic, such as the Meal Time Partner, a battery operated robotic assistive eating device, and My Spoon, a meal assistant robot with similar characteristics that can pick up the desired food from the tray by changing the joystick.



interaction, certainly improving the overall quality of life of the user (Dag, M. et al. 2017).<sup>8</sup>

Other robots are instead designed to supervise and monitor frail individuals. “Pearl” is a nurse robot that reminds seniors about routine activities (e.g. eating, drinking, taking medicine and doctor appointment) (Pollack et al. 2002) and can monitor various health parameters such as heart rate and blood pressure (Mickelburgh 2004). In similar cases, automation still replaces some otherwise purely human occasions of interaction. Typically, a nurse would perform said tasks and, during those very moments, exchange some words and establish some form of human bond with the patient. However, the mere automation of surveillance does not necessarily lead to the radical exclusion of human-human interactions.

Both such applications, attempting to automatize the completion of repetitive tasks, not to establish a connection with the user, may therefore appear to serve a purely instrumental purpose that may eventually – despite questionably, for they are not causing the lessening of disturbing symptoms, or an improvement in the medical condition – amount to cure, certainly not care, as defined above. Overall, their correct use – not instead their abuse, as tools leading to the substantial replacement of professional carers – would also not limit, much less exclude, the occasions of human interactions, ultimately appearing less if not un-problematic on ethical, legal and subsequently policy grounds.

In a different way, the so-called “social companion robots” are specifically designed to challenge, stimulate and interact with the user on a social, emotional, and personal level, either for the purpose of serving a given and peculiar therapeutic use or, more broadly, to contrast the loneliness and isolation of the fragile individual. As per the former, Paro<sup>9</sup>, a baby harp seal-like robot, simulates emotions and responses to external stimuli such as temperature or sound, once it is patted or called. The bot is primarily used in the treatment of patients with dementia (Shibata and Wada 2010) and indeed, studies indicate that Paro has a positive psychological effect on the mental state and well-being of the user (Sheba et al. 2018; Birks et al. 2016; Hamada et al. 2008). Some studies demonstrate the positive effect of the use of Paro in the treatment of patients affected with dementia, and depression, as well as those displaying agita-

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<sup>8</sup> The report of users with intellectual disabilities (ID) and their assistants who experienced using Bestic as their eating aid highlights first of all, according to assistants, eating aid did not increase the users’ independence to decide and making choices in everyday life and as a concept of “self-determination”. However, their assistants mentioned that the eating contributed to the users deciding how often food was put in the mouth. Secondly, the other important problem was in regard to limitation in functionality which was different based on the types of food being chosen. But the main question in this context was whether giving users a long time without any “social interaction” with humans could have affected the users’ willingness and motivation to use Bestic. The study show that users decided not to continue using it. (Dag M. et al. 2015).

<sup>9</sup> Paro Therapeutic Robot, information may be found at <http://www.parorobots.com/>

tive behaviors, as the robot is capable of producing a calming effect<sup>10</sup>. Typically, such beneficial effect is observed with respect to one specific parameter, such as – in the case at hand – “positive affectivity”<sup>11</sup>. At the same time, users also demonstrate verbal and non-verbal empathetic reactions towards the machine, whose artificial nature they are not capable of discerning. (Demange et al. 2018).

However, the range of interactions offered by social robots are quite limited. As such their ability to fully replace humans in care is also extremely limited. Indeed, the reason why designers modelled Paro upon the appearance and behavior of a seal-pup rather than any domestic pet is that, whilst considered cute and thus capable of triggering positive emotional reactions, the limited direct experience the average person has with any wild animal reduces user’s expectations about the robot’s behavior in multiple circumstances. Moreover, the limited user knowledge and understanding of what a seal-pup does simplifies the technological challenge of replicating it in a satisfying way, causing its functioning to become plausible. However, the true challenge companion robots are facing is that of replicating more complex, skilled, and articulate social interactions, of the kind that could be perceived as radically replacing human ones.

An example in that sense is provided by Jibo, an application developed by MIT, intended to become “your new best friend”. The device was designed in collaboration with Pixar and is primarily intended to interact with humans in a home environment to entertain them, and provide company, irrespective of whether they are children to babysit, elderly living alone, or young single adults at the beginning of their independent life. Indeed, Jibo failed to function as expected. The aforementioned issues, however, primarily limited on current technological constraints that further advancements could clearly overcome. Indeed, the intention of developers was to produce a machine whose primary function is that of emotionally engaging the user and ultimately replacing the apparently equivalent and corresponding – yet radically and ontologically different – human relationship.

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**10** According to one assessment conducted by trained neuropsychologist in a geriatric hospital in Paris, the overall “positive affectivity” of patients improved over the three-month period of the treatment. The study also found that the intervention of Paro had a remarkable effect on a group of patients who were suffering from depression and agitative behaviors. In respect to the latter, it must be noted that agitation is more related to disturbing environmental stimuli (e. g. disruption of routines, lack of relatives, or under- or overstimulation), and Paro has a promising calming effect in this regard and could reduce cortisol level due to tactile stimulation

**11** Positive affectivity is a trait that refers to stable individual differences in the experience of positive emotions and active engagement with one’s surroundings. Individuals who are high in positive affectivity tend to be cheerful, enthusiastic, energetic, confident, and alert. (Lopez 2013).

### 3.6 The ethical admissibility of caring through technology

This paper argues that there is a need to critically assess the ethical admissibility of both current and future uses of care robots. Indeed, the authors refute the transhumanist idea that asserts the only constraint in the use of technology should be that determined by scientific and technical advancement itself, for not everything that is technologically feasible should be seconded in an anthropocentric perspective – as defined by the European Commission in its communication of 25 April 2018 (European Commission 2018) – entailing that only those uses that are truly respectful of fundamental values and rights as put forth by EU legislation and constitutional principles should be welcomed. Hence, both research and product design ought to be oriented by such considerations early on.

Having defined the notion of care, in light of its relational and emotional dimension, and having described the essential characteristics of some applications, we need to determine (i) if the different classes of applications here considered do already or could provide care services, and (ii) whether it is desirable and admissible that such services be provided through technological applications, replacing human carers. If a relational and emotional dimension is not only intrinsic to but qualifying of a notion of “care”, it is necessary to determine whether existing and foreseeable devices could indeed meet such standards and thus materially replace human operators before proceeding any further in an ethical, legal and policy debate about the admissibility of the provision of such services through automation,

#### 3.6.1 Does technology care?

Emotions are the product of the cooperation of the cognitive, physiological and biological systems, processing sensory information, that is typical, in varying degrees, of all living creatures.

Emotions also represent a universal language that allows humans to communicate with one another at a fundamental level. They may express understanding through non-verbal cues such as tears conveying sadness or sorrow. People understand the emotional state of others through the same neurobiological system. This ability is often associated with the concept of empathy, as well as compassion, and enables humans to modify their social interactions with others and respond appropriately to their desires (Morrison 2004).

In a sympathetic and meaningful care, we give opportunity to those who are being cared for to express their feelings and emotions (Gaita 1999), as well as we experience feelings and emotions as a result of such interaction, establishing a relation. Therefore, if care presupposes experiencing and engaging such emotions, only those who distinctively hold biological features are capable of providing it.

Evidence suggests that current robotics and AI applications do not possess feelings and emotions (Sparrow and Sparrow 2006) as these devices are unaware of their existence. Robotic and AI are not conscious of perceiving humans, other living beings or even machines as other-than-self. The absolute, radical, objective lack of emotions as well as of self-awareness allow us to exclude the possibility for robots to establish an emotional interaction and thus a true relationship with a human. Therefore, the possibility for current and reasonably foreseeable future machines<sup>12</sup> to provide care services is highly unlikely, as by definition, they do not “care” (Itoh et al. 2006).

In the context of the scope of this research, social companion robots intending to provide “care” pose relevant ethical concerns, besides potential misuses, requiring more attentive consideration, whereas assistive and monitoring devices are excluded from the focus of the succeeding discussion.

The major concerns rest upon the reaction humans might experience when interacting with such robots. Indeed, despite being incapable of feeling such emotions, they can mimic and simulate them, eliciting a reaction in the user, that is deceptive in nature (Bertolini 2018). If robots may not establish emotional bonds, they can effectively induce human beings to establish a purely delusional relationship, that could lead to their disengagement from reality (Gastmans et al. 2018) and this potentially poses a serious threat to human well-being.

### 3.6.2 Dehumanization through isolation: A potential risk

Where social companion robots are intended to replace human interaction, an incorrect use of these technologies could lead to the isolation of the user. Isolation is per se a reason of concern, beyond deception. The practicality, and cost-effectiveness associated with the use of aforesaid technologies as well as the possibility to observe an improvement in one or more aspects of the end-user’s condition, might induce the pervasive replacement of human carers. However, while automation could prove empowering, it should not be deployed at the cost of a reduction of the occasions of human contact. It is commonly acknowledged that humans are social animals, and from the beginning of their lives, they are immersed in social networks (e. g. families, friends, community) (Singer 2018). This interaction develops important social attachment and the proliferation of societies. A substantial reduction in interactions, typi-

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<sup>12</sup> Here we can transpose the reasoning conducted to exclude the possibility to consider machines responsible for the harmful consequences arising from their operation. If machines were strongly autonomous, then they could even possess emotions and establish relationship, ultimately requiring us to consider them as other forms of intelligent life. Yet no existing technological application or reasonably foreseeable one displays that degree of autonomy and sophistication, and the possibility to achieve it is anything but obvious (Bertolini 2013).

cal of aging, afflicts the overall physical and psychological well-being of the person (Tesch-Roemer and Huxhold 2019), which negatively affects and increases the risk of issues such as cardiovascular diseases (Seymour and Benning 2009; Cacioppo et al. 2011), depression (Mehta et al. 2002), and dementia (Cacioppo and Hawkey 2009; Cacioppo et al. 2014).

Evidence demonstrates that these technologies bring a range of opportunities and risks. Opportunities include empowering the users and increasing their interaction, for instance simplifying the dynamics of a meal, allowing more users to dine together, and eventually dialogue with a single carer. However, there is a potential risk in certain contexts, unintentionally, of reducing real-time human interaction.

After all, the concept of being cared for exclusively by robots could lead to a decline in the sense of belonging to human society and undermine elderly human qualities, reducing their self-perception of the meaningfulness of their life (Zadro, Williams, and Richardson 2004). This misuse of assistive technologies clearly violates the notion of care we defined above, causing the individual not to be treated as an end-in-himself (Kant 1785), and squarely opposes an anthropocentric approach to AI (European Commission 2018), but even moreso appears to violate the very notion of human dignity, in both its ethical and legal dimension.

### 3.7 Human dignity as an ethical and legal concept

The concept of human dignity, despite widely debated, is expressly proclaimed in most constitutional charters, including the European Charter of Human Rights (henceforth ECHR), as well as in member states' (MS) constitutions. Being a constitutional principle (Feldman 1999), all ethical theories questioning its admissibility and application (Bostrom 2009) may not be taken into account to inform policy decisions, nor may those efforts be seconded, that lead to an interpretation incompatible with its legal notion. In contrary to the claim by Bostrom (2005), dignity might not allow discrimination among human beings due to age, rationality and mental condition, for it is indistinctively and equally possessed by all. The notion may certainly vary over time due to its interpretation and application in courts, but certain strongholds such as the instances above, might not be questioned without challenging the very foundations of the entire constitutional framework<sup>13</sup>.

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<sup>13</sup> The provision of article 1.1. of the German constitution was introduced by the drafters of the German constitution, right after the collapse of the Nazi regime in the second world war. The notion of human dignity was typically provided as a reaction to Nazism, and its race-superiority rhetoric in order to radically prevent any future occasion of discrimination. The German Basic Law acknowledges human dignity as a guiding principle on fundamental right of the individual which ought not to be sacrificed or discriminated with any other competing rights or values.

A detailed comparative analysis of its application across MS falls beyond the remit of this paper, however it shall suffice to recall how the principle is often deemed an objective, and external criterion, that limits the individual's self-determination<sup>14</sup> (Resta 2015; Fabre-Magnan 2007). A freely assumed decision, by a fully rational, conscious, and perfectly informed human being possessing a personal interest, whether economical or not, may still not allow the violation of said principle, for that protects every other human being, and might not be compromised, much less disposed of. Therefore, the notion applies in the case considered in a twofold manner. On the one hand, it forces the adequacy and admissibility of a given application, and of its potential use in the care of fragile individuals to be assessed with respect to such a parameter, per se insufficient, but nonetheless necessary and unavoidable. When determining whether a patient might be fed by an autonomous machine, rather than a human carer, the possibility that it might violate the dignity of the individual is to be taken into consideration, and excluded to allow that use of technology. In this perspective, while the technology appears neutral and possibly empowering, a use that limited or radically excluded occasions for meaningful human interactions might be deemed violating the principle, due to the dehumanization effect briefly recalled above.

On the other hand, it excludes that a choice of the individual might suffice in authorizing a specific use, primarily when deceptive technologies are taken into account (Bertolini 2018), therefore posing a methodological limitation to any further assessment or consideration. All evaluation needs to be objective and not subjective. Even if the single user desired being cared for by an autonomous system, his choice might only be deemed free and valid, once it is established that the specific practice and use is not in violation of human dignity, objectively defined.

### 3.8 Discussion and conclusions

The progressive aging of western societies juxtaposed with the increased dependency ratio poses significant concerns to the welfare systems, which are challenged with the need to provide adequate care services. Robotics certainly represents a powerful asset to manage such radical societal changes. To this end, however, technology needs to be framed within our value system, as primarily reflected in those fundamental principles that ground our society, recalled in our constitutional charters.

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<sup>14</sup> A prototypical case that is known as *le lancer du nain*, addressed by the French Conseil d'Etat (NVwZ 1993, 98). In such a case the free and informed decision of an adult human being to safely – through the adoption of necessary safety measures – let others, in exchange for monetary consideration, compete by tossing him in the air, was deemed inadmissible by the court, for it violated human dignity, intended in an objective and external sense.

Technology is instrumental and needs to be conceived in a purely anthropocentric perspective (European Commission 2018). Human interaction with technology changes perception as much as people change their way of living through it, by acquiring new possibilities and overcoming what might otherwise be perceived as a constraint and limitation.

The anthropocentric approach calls for policy considerations regarding the kind of technological development society desires and what kind of applications people are willing to welcome into society. In this respect, different approaches are theoretically possible. Transhumanists favor absolute freedom to pursue any advancement possible for any use that a rational and informed party is willing to accept. Alternative philosophical paradigms may be confronted, with the purpose of narrowly defining such an anthropocentric approach, and what measures it could lead policy makers to adopt.

By referring to constitutional values affirmed in our primarily European legal system a specific answer to this theoretical challenge is provided. Indeed, not all philosophical paradigms are equally viable, for they need to fully conform to those fundamental principles and rights previously discussed or be dismissed as unacceptable to ground future policy considerations.

In the case of the transhumanist example, it could be argued that a theoretical system where human dignity is at once deemed measurable (as not all human beings possesses it in equal amount and it is pre-empted by freedom of self-determination), is incompatible to its conception as a fundamental value that belongs to all humans irrespective of any other consideration. It is therefore tainted and may not be applied to determine what uses are admissible.

Having clarified the theoretical paradigm of the analysis, the specific issues of caring for fragile individuals through technology may be addressed. The different functions of care robots have been briefly discussed, distinguishing assistance from monitoring, and caring.

With respect to the latter we have, however, clarified how the notion of care is to be radically differentiated from that of cure. The former entails the emotional engagement, and the relational dimension that at once is the exclusive prerogative of a human being (as only living beings possess emotions, and only humans can establish that essential bond, which also amounts to a virtue) and is so essential to the well-being of the individual, his own self-perception, and self-perceived worth.

It is clear that no application is capable of caring and might only simulate and provide the appearance of such interaction. This could however be deceptive as inducing the individual to engage in a delusional and unrealistic dimension that, within the theoretical framework sketched above, ought to be considered inadmissible, violating the human dignity of the given user and of all other humans overall.

Precisely because of the objective and external dimension of this fundamental constitutional principle, even self-determination would be constrained and limited,

thereby causing informed consent to be insufficient to enable similar uses of technologies. Such uses of robotics should therefore be overall dismissed.

In all other cases, however, where the application is not primarily intended to engage the user on an emotional level and is therefore not intended to establish a bond and a connection by keeping company or simulating friendship or care, a concern of dehumanization by isolation resides, that needs to be carefully tackled.

Indeed, technology can be largely empowering, providing possibilities that increase the independence of the person being cared for and improving the overall quality of their lives. However, should such applications be intended as a way to radically reduce or worse eliminate professional human care, with the primary aim of abiding budgetary constraints grounded on the observed increase in age-related welfare costs, that would also contrast the anthropocentric perspective on the use of technology, and violate the dignity of the user, thereby being inadmissible in light of our extant legal system.

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## 4 Trusting robots?

### On the concept of trust and on forms of human vulnerability

Svenja Wiertz

#### Abstract

We live in an aging society where more and more adults are in need of special care. One strategy pursued in this situation is furthering the development of assistive technology devices that could supply some form of care to older adults. This paper aims to show some of the potentials and limitations of replacing human caregivers with assistive technological devices by looking at concepts of trust and reliance. Trust will be introduced as a moral relation that cannot be realized in interaction with robots. Insofar as care relationships have at least the potential of being trust relationships, replacement of caregivers by care robots can only ever be a partial replacement in regard to some specific function. Care relationships, however, will also often be relationships of dependence, which include a high degree of vulnerability. When we depend on another, we often do not have the choice to leave a relationship where we experience broken trust or mistrust. Such relationships are not perceived as valuable and can inflict significant harm. The option to rely on assistive technology systems instead of being dependent on human caregivers can thus *prima facie* be understood as a valuable option of gaining a degree of independence.

#### 4.1 Types of care robots and the possibility of replacement

We live in an aging society where more and more adults are in need of special care. In Germany, the existing infrastructure and the number of people trained as nurses are not sufficient to meet the current demand and the gap is expected to widen in the next few decades (Pfeiffer 2018; Sahmel 2018; Becker 2017).

One strategy the German government is pursuing in this situation is furthering the development of assistive technology devices that could provide some form of care to older adults (Bundesministerium für Bildung und Forschung 2018). Such technological devices have been successfully developed and implemented. The robot seal Paro is showing promising results as a therapeutic tool in working with patients of dementia (Bemelmans et al. 2015). Robot arms have been introduced in hospitals to help nurses with physically challenging tasks like lifting and shifting of patients. The term “care robot” is used here in a very broad sense. The robot arms are not meant to directly assist people in need of care but to assist the human caregivers in performing their tasks. Other care robots are mainly used for bridging physical distances – like telepresence robots, which are designed to enable communication and to a certain degree interaction between two persons without a need for physical presence. Even

robots developed for tasks like cleaning and transportation are sometimes discussed under the label “care robots” when they are designed to be used in hospitals or nursing homes (Graf and Klein 2018). All these technologies can raise interesting ethical questions, but they will not be considered here.

Only a limited number of assistive technology devices are meant to interact with people directly and autonomously, where “autonomously” refers to the limited sense in which technological devices can function without being directly controlled by a person – a very limited sense of the word that should not be mixed up with the concept of autonomy of persons (Beer et al. 2014; Gräb-Schmidt and Stritzelberger 2018). The Care-o-bot developed by the Fraunhofer-Institut is one example for this kind of care robot. Other devices do not only interact with people in need of special care and they need not be robots. Something like “Alexa” installed on an Amazon Echo system would fall into this category as well. Both have in common that people are meant to interact with them directly, on a regular basis, without any human intermediary. In these cases it is conceivable that the interaction with the device negates the need for human interaction.

In this paper I want to contrast some of the possibilities and limitations of human caregiving on the one hand and assistive technology on the other. To do this, I will introduce a concept of interpersonal trust as a moral concept and differentiate it from the concept of reliance regarding technological devices. I will briefly outline both concepts in their positive form before turning to forms of disappointed trust and misplaced reliance – shedding some light on what can happen when trust relationships go wrong. This analysis will be put in context with a conception of human vulnerability, to show how we as humans are generally vulnerable and how we are specifically vulnerable in trust relationships. We cannot, I will argue, trust in assistive technology devices in the same way we trust in humans. This means that we also cannot be hurt in the same ways. The aim of this paper is thus to identify some potential of the development of assistive technology in spite of its obvious limitations.

## 4.2 Trust

Annette Baier (1996) has defended a view on trust that is not new but still rather influential today. While it has been challenged in numerous ways, it captures appropriately at least some central intuitions on trust. And it is simple enough to mark some central differences between the way we trust other people and the way in which we can rely on non-living objects, which is why I will base my following observations on this account.

Baier points out that there are a number of things in our lives we care about, but the flourishing of which we cannot ensure on our own. This is true if we want to keep potted plants in our flat but still go on holiday in summer. It is true if we care about

the education of our children. It is trivially true of any personal relationship we might want to pursue.

Not denying that in ordinary language we talk about trust in a number of different ways, Baier suggests differentiating between *trust* and *reliance*. According to Baier we can rely on people as well as non-living-objects. Reliance means the expectation of a favorable outcome, without any reference to another person's goodwill. Trust, with Baier, is the narrower term. It is a form of reliance, but a specific one. When we trust, we rely on a favorable outcome to occur because we expect a certain person to *act with a specific attitude towards us*. Trust is the reliance on the goodwill of other persons. If we think that a certain café is going to serve us good coffee just because it is in the owner's and employee's best interest to do so to successfully make money in the future, we are merely relying on something. If we know the barista personally and believe she would never serve us bad coffee out of a specific regard for us, we are trusting her (Baier 1996).

To capture specific instances of trust more clearly, Baier has propagated that it should always be understood as a three-place relation: "A trusts B with valued thing C" (Baier 1996). A is the person trusting. B is the person trusted. C is something with a certain degree of importance to us, the flourishing of which in one sense or another we entrust to B. I can thus entrust the well-being of my flowers to my neighbor while I am on holiday or entrust the education of my child to the school I am sending her to. Insofar as I care about C, trust always involves an element of vulnerability. B is given the opportunity to hurt me by not taking appropriate care of the object or person I entrusted to her.

This analysis might not be the best to capture the deep but diffuse feelings of trust we often encounter in close personal relationships. But it successfully captures a number of relevant dimensions of trust. One aspect Baier focuses on is that an act of trust usually transfers responsibility for something very specific to another person and that this implies the transfer of some discretionary power: B has some leeway to decide how to best care for C. Only in very few cases of trust do we have some exact action of another person in mind.

A second aspect of trust that Baier does not consider but which can easily be integrated into her account is an ascription of competence: even if I believe your goodwill to be boundless, this might not be sufficient for me to trust you with my child. I will do so only if I also hold you to be at least moderately competent in dealing with children. Only then can I trust you to exercise your discretionary power appropriately. Bernard Barber elaborates on this aspect in his book *The Logic and Limits of Trust*. He points out that this aspect is especially important when it comes to trust in competent role performance: if I trust my doctor, an estimation of competence is an important part of that trust (Barber 1983).

While trust might be considered typical for close personal relationships, Baier assumes that we can also trust in strangers (Baier 1996). If I am on a train and I want to use the lavatory, I might ask a person sitting across from me to watch my things

while I am gone. Trust here is still the reliance on the goodwill of that other person. Insofar as goodwill is a moral attitude, Baier presupposes that we stand in a moral relationship to strangers: we are part of a moral community and we often take this as sufficient reason to meet each other with a minimal sense of trust. When we talk about trust relationships, however, we usually have a different kind of relationship in mind: relationships of high trust are relationships between persons who are well acquainted and feel emotionally close to one another. They rely on each other's goodwill not in the sense of a moral attitude shared by all members of a moral community but in the sense that they trust the other to consider their well-being before and above the well-being of strangers. Friendships, romantic relationships and many family ties are conceptualized in such a way.

The relationship between caregiver and a person receiving care will usually fall somewhere in between a weak personal relationship with a minimal sense of trust and a more dense, high-trust personal relationship. We usually trust in caregivers to be at least decent human beings who do not abuse the vulnerability of those they care for. We also wish for caregivers to develop a personal regard for the people they care for and thus hope for them to show themselves to be well-meaning beyond the simple demands of general moral obligations and the specific duties of their role. This is one sense in which we expect them to be *caring* persons. Sometimes, caregivers are even family members with a long-standing trust relationship to the person cared for. This does not exclude the possibility, however, that some care relationships turn out not to be trust relationships at all. Some of them might be relationships of deep mistrust. I will discuss the implications of this possibility later.

On this account, we cannot stand in a trust relationship to a care robot or any other kind of technological device. First of all, because trust requires a reference to the goodwill of the trusted. While science-fiction movies tend to project spectacular scenarios in which robots come to act and feel like human beings, I assume here that we agree that our current technologies at least are not, in the relevant sense, capable of being well-meaning. I do not consider them to be moral agents<sup>15</sup>. The significant difference, I believe, is that we have no reason to hold technological devices accountable for the actions they take based on their programming.

Furthermore, we can point out that the discretionary power we can sensibly attribute to robots is limited. I do not mean to say that they cannot react flexibly to changing circumstances. The whole point of artificial intelligence is to give them the ability to be able to do so. But we should not assume that they could use their empathetic

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<sup>15</sup> I am little concerned here with the much debated question if machines could someday become moral agents. I do not deny that their performance has ethical impact or that their code can be better or worse in regard to avoiding negative impact, I simply deny that this is sufficient reason to talk about them as moral agents. For detailed discussions of this question compare (Moor 2006; Wallach and Allen 2010).

powers to consider how much control we likely intended to give them. Their range of possible responses needs to be precisely defined during development. Lastly, we should not expect care robots to form emotional bonds. They do not have the necessary emotional capacities to care about us as an individual and to prefer us above others. In short: we cannot stand in a moral or emotional relationship to care robots.

### 4.3 Reliance

There are other accounts of trust that do not conceptualize it as a moral relationship at all. When excluding robots as recipients of trust, one might thus wonder if I have not simply chosen the wrong account of trust for the endeavor. Indeed, there is a relevant sense in which we can rely on robots that is often referred to by the word “trust” in everyday language. I will further elaborate on this account of trust now, however, I wish to state that I am not concerned with a fight about words. One can talk about trust in a wide sense and in a narrow sense. Or one can call one relation trust and the other reliance, as Baier does. The importance is not which terms we use but in marking the differences between the two concepts.

One prominent author who conceptualizes trust in the sense that Baier talks about reliance is the German sociologist Niklas Luhmann. Luhmann provides us with an in-depth analysis of why we need trust in our lives: trust enables us to reduce the perceived complexity of the world around us and thus provides us with more options of practical action by allowing us to neglect considering some unfavorable outcomes. Trust, in the wide sense of reliance, allows us to ignore that things could turn out bad. We therefore trust in the bridge not to break under our feet, we trust the public transport system to bring us to work (if not necessarily quite on time), we trust our babysitter not to abduct our child. If we took into account that any of these *might* happen and tried to guard against them, our lives would immediately become much more complicated (Luhmann 2009).

In this account of trust, the goodwill of a person plays no necessary role. It is not of any great importance *why* certain things are not going to happen, it is simply important that we rely on them not to happen. Personal attitudes are not presupposed in this wider conception of trust. In this sense then, we can put our trust in technological devices. To mark the difference between the two concepts, I will from here follow Baier and not use the term *trust* in a narrow sense but instead talk about reliance.

Let us assume I prepare a PowerPoint presentation for a talk and I decide not to print out a handout. I would consider such a handout to be necessary for me presenting well if I did not have my slides. In this case I am relying on my computer. When we enter the phone number of a friend into a smartphone without also writing it down on a piece of paper we are relying on that phone’s memory. Here again it is imprecise to simply say that I rely on my smartphone without specifying in regard to which function I am relying on it. I do not rely on my smartphone to remind me to actually call



that friend. It would be irrational to do so without first setting up a reminder. Nor do I rely on it to tell me when he is sad and might particularly appreciate a call.

So I propose to conceptualize reliance analogously to trust as a three-way relation: A relies on B in regard to C. A, again, is a person. B can now be a person or a tool or a technological device. C can be a specific act or a function. Relying on a technological device then also presupposes ascribing to it the relevant functionality (and me having made use of that functionality), as trusting a person necessitates ascribing to them the relevant competencies.

#### 4.4 Trust, reliance and valuable life options

The inherent value of trust relationships is often stressed, while our dependence on technological devices is often criticized. But both, I believe, can contribute to a good life. Trust relationships, it is often argued, are themselves a valuable aspect of a good life for most human beings. The capabilities approach, for example, assumes that our conception of a good life involves the ability to form close emotional bonds and to live with and for others (Nussbaum 2013). And it seems very reasonable to assume that we do not want those bonds to be bonds of mistrust. But even beyond close personal ties many of us prefer to live in an atmosphere of trust (Hartmann 2011; Fukuyama 1996; Williams 2004). Trust relationships are additionally of instrumental value to us, as Baier points out, because we can only care about a very limited number of things in our life if we do not want to trust in others. The option to have children and to pursue a career, for example, is only available to us if we can entrust the care for our children to someone else while we are at work.

Technological devices are valuable to us only insofar as we derive something of value from the function they fulfill and the options they offer. Riding an elevator is not considered to be of intrinsic value. Without elevators, however, houses with more than six stories seem less like a plausible option for living. Without my computer and the option of emails, I could not stay in regular contact with as many colleagues as I actually do. I can also rely on my TV and Netflix to provide me with regular evening entertainment. While the value of such options is always an instrumental value, they can be valuable and important for a good life nonetheless.

#### 4.5 Broken trust and disappointed reliance

Before I go on to talk about some ethical implications of the differences between trust and reliance I want to carry this conceptual analysis one step further by looking at harm and disappointment as it can occur in both cases. And I am here especially interested in the options open to us when we are faced with such a disappointment.

If our trust is broken, something we value has not been taken good care of and we perceive ourselves as harmed. We become aware of the inherent vulnerability in every act of trusting. We often react to broken trust according to our relationship with reactive moral attitudes.<sup>16</sup> We are not only disappointed and hurt by the outcome, we are also disappointed *in someone*. This disappointment can manifest as a more general disappointment with the community we live in if the person to disappoint our trust is a stranger. It will be directed specifically at the person we trusted if we had perceived this person as deliberately presenting herself as trustworthy in the past. Depending on the circumstances, we might easily forgive a minor breach of trust, or we might decide on some kind of punitive action as a response to it. The reaction I am most interested in here, however, is our option to blame.

I understand blame, following Angela M. Smith, as a moral protest of an agent's treatment of oneself or others:

To morally blame another, in my view, is to register in some significant way one's moral protest of that agent's treatment of oneself or others. Such protest need not be outwardly expressed in any way (...). But what unites all of the behavioral and attitudinal responses we are inclined to categorize as instances of blame (...) is that they share this element of moral protest. (Smith 2013)

The act of blaming encompasses the judgment of some person being *blameworthy* as well as a modification of "attitudes, intentions and expectations of the blameworthy agent" that can be understood as a protest (Smith 2013). This account of blame, like others, presupposes accountability. McKenna formulates clearly what is meant by this:

Moral responsibility in this sense [author's note: in the sense of accountability] involves the possibility of holding an agent to account for her conduct, and thereby seeing her as properly responsive to our demands and sanctions. Such an agent is one who can be expected to acknowledge and comply with others' moral expectations. (McKenna 2013)

Blame then as well as trust needs to be understood in a moral context. It presupposes that we share a set of moral norms and that we perceive ourselves as members of a moral community.

Not always, but often, when we lay blame on a person we expect a reaction. We might confront the person with our complaint and receive an apology. We might voice

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**16** Some of the accounts of blame I am referring to in this article explicitly distance themselves from a reactive-attitude account of blame. My assumption here that disappointed trust typically leads to reactive moral attitudes and to blaming does not contradict those positions. The central question of the debate is not about blame *usually* going along with reactive moral attitudes in a wider sense – hardly anyone would deny that – but strictly about the question if being a reactive moral attitude is a constitutive feature of every instance of blame. This question is of some philosophical relevance but of little practical relevance here.

our blame to others to get acknowledged for its legitimacy. We want our moral protest to be heard, especially if it is directed towards a person with whom we stand in a continuing relationship. Protest challenges an unacceptable moral presumption and ultimately aims at a change of behavior – we demand to be treated better (Smith 2013).

While we can talk in everyday language about blaming artifacts, we do not mean it in the sense just described. If I blamed my computer for not being able to finish this article in time, I would only be claiming a causal relation – my computer was malfunctioning, thus I could not complete my draft. Blame as a moral protest is not applicable here as my computer is not a moral agent and it is thus impossible for me to perceive myself as standing in a moral relationship to it. I do not hold it accountable. I do not expect it to change its behavior because I confronted it with my protest. I will simply be disappointed that it is malfunctioning.

In cases of disappointed reliance, we are also hurt insofar as something negative has happened that we were not expecting. Reliance, like trust, implies a certain vulnerability. Moral protest, however, is not a rational option. We might adopt reactive attitudes for a short moment, when we feel like smashing in the screen of our computer, but we do not seriously believe that our expression of such attitudes in the form of protest might have any effect on the situation. The resulting disappointment can be self-directed: it is my own fault that I bought this model and was relying on it to continue functioning so that I could finish my draft in time. Or we can search for another responsible party to blame: I can blame the people who produced and sold me a malfunctioning device. I can hold them accountable, even though they are distant and anonymous agents. In many cases, however, we will not blame them. Either because we do not perceive them as having done anything wrong, or because we never expected them to act with any goodwill towards us in the first place.

## 4.6 Intermediary conclusion: On the possibility of replacement

As I have shown so far, trust and reliance can be described as two distinct phenomena. Both structure our expectations of future developments, but in their further implications, they differ. Trust is an important component of moral and personal relationships. It refers to the goodwill of a person. Trustworthiness itself is then the manifestation of a well-meaning attitude and can be the expression of a special regard. Trust thus can be regarded as a constitutive feature of inherently valuable human relationships, in which we experience things like love and appreciation for our personality.

In this sense, technological devices in general and care robots more specifically, cannot replace a caregiver to whom we can stand in a trusting relationship. Such devices and my reliance on them can only be of instrumental value in my life. If we consider *replacing* caregivers with assistive devices, we need to be absolutely clear that this can only ever be a partial replacement in regard to some well specified func-

tion. There is no potential of this being a trust relationship. If a person's mobility is limited another person as well as a care-robot could help her regain better mobility. If a person is in danger of dehydration because she does not remember to drink and also lacks the ability to walk to the kitchen to get water, a person or an assistive technology device could remind her that it is necessary to drink and bring water. But it is only in regard to those very specific tasks that replacement is possible.

## 4.7 Trust, vulnerability and dependence

Trust is often praised as a valuable human capacity, but it always includes the risk of being hurt. Trust presupposes vulnerability (Baier 1996; Luhmann 2009; Hartmann 2011). Baier clearly rejects the stoic ideal of only attaching oneself “to what can thrive or be safe from harm, *however* others act” (Baier 1996). Following this ideal we would have no need for trust. But it also leaves us very little that we may actually care about. This is not how most of us wish to live their lives.

The issue of vulnerability in trust becomes even more pronounced when we look at unequal trust relationships. In the discussion on trust, Baier has voiced a central complaint against earlier, mainly contractualist theories of trust: in the context of contractualism, trust was given an important role, but it was always conceptualized as a trust between partners of equal standing with equal opportunity to sanction deviant behavior.<sup>17</sup> Many trust relationships, however, are not between equals. The vulnerability inherent in trust becomes a lot more pronounced in these relationships. Infant-parent relations can be seen as the prototype of unequal trust. Baier points out that for the longest time married women predominantly stood in unequal relationships with their husbands who held positions of superior power (Baier 1996). What should be a trust relationship can become a relationship of repeatedly broken trust or even a relationship of mistrust. We might not believe in the goodwill of a person at all anymore, but still be in a position of dependence where we need to rely on another for the flourishing of the things we care about, among those our own well-being.

Caregiving relationships are often unequal relationships in this sense. People in need of care are in a position of greater than usual dependence. They will have varying degrees of influence on who is caring for them under what circumstances. The

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<sup>17</sup> Baier refers here to Hume's example of two farmers who trust in each other on the basis of a promise: The farmer, who has to help his neighbor first, but has to wait for this help to be reciprocated at a later date. The farmer's vulnerability, however, is reduced by his equal standing: by trusting his neighbor, he first accepts a certain degree of vulnerability. If the promise is not kept he has every option to spread his discontent and harm his neighbor's reputation. Both need to consider options to cooperate in the future among themselves and with others. As far as their relationship is to a certain degree public, there is a second level of vulnerability on both sides: both can threaten the other's standing in society and chances of future cooperation. Hume (2009); Baier (1996).

less influence they have, the more they are vulnerable: they depend on others for their well-being and flourishing somewhat more than most other (healthy and adult) persons. Depending on circumstances, they might also have less power in regard to shaping their relationship to the person giving care and it might be less likely that the moral protests they voice will be heard.

The high degree of dependence that is a necessary circumstance of relationships between young children and their parents seems more difficult for us to accept in old age, no matter if it is the parent now being dependent on the adult child, or someone depending on another family member or a care professional. While we should not forget that relationships to a human caregiver can be rewarding social relationships and can fulfill the need for social relationships we all have, we should also not forget that not all human relationships are perceived as rewarding. Care relationships can turn out to be relationships of broken trust or mistrust. We can be repeatedly hurt in those relationships; we are especially vulnerable when circumstances do not allow us to decide for ourselves if we want to end them. It seems thus reasonable to pursue the thought that access to assistive technology can reduce our vulnerability and allow us more independence.

## 4.8 Vulnerability and types of risks

It seems to be an undeniable truth that human beings are vulnerable (Birnbacher 2012). Nevertheless, references to vulnerability in the context of medical ethics and bioethics have been under critique for over-simplifying matters and stigmatizing groups. Children, people with disabilities as well as pregnant women have repeatedly been classified as vulnerable groups without due attention to specific individual circumstances (Wild 2014). We should thus be careful to classify older adults or people living in retirement homes as vulnerable *per se*.

This difficulty in identifying the vulnerable, however, does not alter our moral intuition that those especially vulnerable have some right to be specially protected (Hurst 2008). It is necessary to assume, though, that there is not one type of vulnerability and that the label cannot be fixed as an attribute to a specific group of people. In thinking about vulnerability it is important to give a clear account of what is meant by the term in a specific context.

Derek Sellman suggests an account of human vulnerability to better grasp its meaning in the context of nursing. He suggests conceptualizing vulnerability in terms of risks: being vulnerable means being open to a certain type of risk.<sup>18</sup> Sellman offers a distinction of three types of “risks of harm” (Sellman 2005):

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<sup>18</sup> I agree with Hurst (2008) that this cannot be considered an exhaustive definition of the term. It will nevertheless be sufficient for the purpose of this article.

- a. First of all, as an individual we are vulnerable to risks we could potentially take precautions against. We are, for example, at risk from traffic accidents but we can choose to be careful participants of street traffic to minimize this risk. A risk can be measured in degrees of probability and minimizing a risk means reducing its probability, even if it cannot be completely eliminated.
- b. In the second category, we have risks that we cannot protect against by ourselves and where we need other people to help us reduce the risk. This is the category of risk to which patients and clients of care are more vulnerable than other people: Their ability to protect themselves is limited in at least some respect. They are thus in need of more assistance to ensure their well-being and potential of flourishing. As human beings we are, for example, vulnerable to the risk of dehydration. Minimizing this risk by drinking regularly does not pose a challenge for most of us. It only becomes visible as a risk of the second category when we lose the ability to determine when we are in need of fluids or the ability to move around our flat to get a glass of water. Many risks are little perceived as long as they fall into the first category and only become apparent through a shift to the second category: they do not appear to us as risks until we lose some ability we had so far been taking for granted.
- c. The third category describes how we are vulnerable to events we cannot influence at all – like earthquakes. When we state that all human beings are vulnerable, we often think about this category more than the first category. We think of our vulnerability to events that are from a personal perspective described as strokes of fate: they appear to be unpredictable and there is nothing much we can do to protect against them.

If trust necessarily involves a component of vulnerability, this particular vulnerability falls into the second category: by every act of trust, we allow our well-being to be more dependent on the actions of some other person. In the context of trust, some authors talk about *accepted* vulnerability (e. g. Hartmann 2011). This shows that the good at stake could potentially be cared for by ourselves (even if the cost might be high), strictly limiting all risk to category (a). While this is possible in a single instance of trust, we should not forget what Baier as well as Luhmann point out: our options to care for things we perceive as valuable would be severely limited if we ever tried not to trust at all. But we can and *do* decide not to trust in specific instances, e. g. by deciding to do something ourselves, by checking on the people we distrust, or by choosing a different agent in whom to place our trust.

The case seems to be different in the context of care: being open to some specific risk we cannot guard ourselves against constitutes being in need of care. When we have lost the ability to protect ourselves against a certain risk, we cannot simply affect a shift back to category (a). Depending on the circumstances we might recover our lost ability, of course. But recovery cannot be understood as a simple decision and might in spite of our best efforts stay out of reach. Looking at Sellman's categories of risk,

the exchange of human caregivers with assistive technology devices then implies an option to reduce vulnerability. When we have the option to rely on a technological device, we regain something equivalent to the option not to trust. As assistive devices are not *other people* their use seems to imply a shift away from category (b): the need to rely on others. They promise greater independence; they provide the option to choose between trusting others to protect us or relying on ourselves and the use of assistive technology.

Is it plausible, however, to interpret the replacing of a caregiver by an assistive device as a shift from category (b) to category (a)? It is not like the specific risk that constitutes our need for care itself has vanished. It might seem debatable if the necessity to rely on an assistive device can really be understood as an increase of our own abilities, thus reducing dependence.

Reliance implies its own kind of dependence and thus, just like trust, can imply vulnerability. Should we not then extend Sellman's categories by a fourth, somewhat like the following:

- d. We are vulnerable against risks that we can guard against by using technological devices.

We would soon have to broaden the category, though, as technological devices do not appear sufficiently different from other tools and objects we rely on. Tools as well can break or malfunction. But if we add every type of tool used by humans into this category, Sellman's suggested category (a) would be almost empty. There are few risks we can guard against by simply being careful. We use a high number of different kinds of tools in almost all areas of our life. Thus, it seems to make more sense to understand the use of tools or technological devices as actions that bridge categories (a) and (b) – we are dependent on others to a degree to ensure the functioning of those tools. But as long as they *do* function and we can use them we gain a degree of independence and the ability to guard ourselves from risks. Insofar as the use of technological devices only implies a partial shift and necessarily includes an element of dependence regarding the functionality of our device, reliability becomes a key factor in evaluating the usefulness of assistive technologies. We are vulnerable whenever our assistive device does not fulfill its function and in regard to this vulnerability we are dependent on the people responsible for the functioning and maintenance of our assistive device.

## 4.9 Potential and limitations of assistive technology devices

In this paper, I set out to consider some ethical aspects of the implementation of assistive technologies in contexts where these are designed to directly interact with humans without standing under the direct control of another person. The paper has focused on discussing some implications of the fact that trust in interpersonal rela-

tionships can be understood as a moral concept and thus needs to be distinguished from the possibility of relying on technological devices. While both trust and reliance refer to the expectation of a favorable outcome I have suggested to follow Baier in differentiating between the two conceptions.

Trust as reliance on the goodwill of others constitutes a moral relationship and plays a great role in the flourishing of things we care about. A trust relationship always needs to be described in reference to some valuable thing we trust to another and presupposes an ascription of competence as well as a conveyance of a certain limited discretionary power to the person trusted. While we can trust strangers in this sense, trust is typically seen in the context of high trust relationships that presuppose intimacy as well as an emotional bond. Professional relationships between caregivers and receivers of care are not usually conceptualized as intimate relationships but are nevertheless generally perceived as relationships of trust. Trust relationships can be perceived as inherently valuable and are often seen as a necessary component of a good life.

Assistive technology devices cannot be considered adequate recipients of trust. Care robots thus cannot be considered to replace caregivers in their function as a person trusted. In regard to these devices we are limited to the option of relying on them. Reliance, like trust, describes the expectation of a favorable outcome and needs to be specified in regard to specific functions of a device. It does not, however, imply the specific attitude only a person can have toward us and neither does it imply the transfer of discretionary power – instead we would often prefer to know exactly how our assistive system is going to react in a specific set of circumstances. It is commonly assumed that reliance does not realize any intrinsic, but only instrumental value.

Trust relationships, as other human relationship, bear the potential of great hurt and disappointment. Not only will the flourishing of the good we care about not be realized when our trust is disappointed, but a breach of trust can also be perceived as denying our moral status. Blame is a common reaction to disappointed trust and a form of protest against the way we have been treated. Blame is a way for us to demand to be acknowledged. Our chances to be acknowledged, however, depend on the particular circumstances of the relationship. The vulnerability that necessarily comes with trust is increased in unequal trust relationships where the person trusting depends to a higher degree on the person trusted. Due to the need of care of one party, care relationships will often constitute unequal relationships in this sense.

Because of the vulnerability and risk to harm not all trust relationships can be perceived as valuable and in many circumstances it is reasonable for us not to trust in others. Especially in unequal trust relationships the option to leave needs to be perceived as valuable. Assistive technology devices can under some circumstances offer us the choice not to trust where without their availability we have no choice but to be dependent on another person to guard us against specific risks and where we possibly have little choice in whom to trust. Regaining the choice not to trust another person



or to end a relationship of mistrust can *prima facie* be seen as valuable as it gives us the option for more autonomy.

As reliance on an assistive device can never replace all components of a functioning trust relationship, they can under this perspective not appear as the preferable option in general, but only where the choice between a human caregiver and an assistive device is given. Relying on assistive technology devices constitutes its own form of dependence and poses its own risks. Relying on them can only be a rational option if they indeed prove their reliability in guarding us against the specific risks that constitute our need for care. As long as they do not perform without fault 100 % of the time they comprise a dependence on the company and people providing supervision, maintenance and repair. If this support is not reliable, again, people are exposed to a risk they cannot guard against.

However, we should also not forget that assistive technology devices might become much better at fulfilling some instrumental functions than human caregivers could ever be. They could in this case still not completely compensate a lost trust relationship, but prove to have other advantages. The best option in many cases would thus appear to be a working trust relationship to a human caregiver as well as the availability of some assistive technology. Nor should we forget that assistive technology devices can harm us or violate our rights in many other ways, as further contributions to this volume show; through deception, through violations of privacy by constant data collection, through reduced access to human caregivers due to budget cuts in lieu of cheaper alternatives – to name but a few issues in the debate.

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## Part II: **Practical insights**



## 5 Promoting eHealth literacy

### Integration of a health monitoring application and the support of a *Digital Nurse*


Anna Haupteltshofer, Pascal Meier

#### Abstract

In Germany, the majority of the population has restricted health literacy. In this context, access to the Internet and new media is becoming increasingly important for information procurement. However, digitization is a challenge for society and nursing care. Against this background, the project Village Community 2.0 (Dorfgemeinschaft 2.0) concentrates on rural areas and human-technology interaction. As a solution, we designed the application *FeelFit* to strengthen eHealth literacy. The application helps users to monitor their health-related data in everyday life. Additionally, we developed a *Digital Nurse*, an educational health management concept. The *Digital Nurse* is a contact point for residents on health and technical questions. As technical developments often only concentrate on a single field, an interdisciplinary approach is necessary for a demand-oriented use of assistive technologies. We combined both concepts to offer older people the possibility to consult a nurse with an affinity for technology, who supports in the personal configuration of the app as well as in the operation and evaluation of the collected data and is sensitized about legal and ethical aspects in dealing with technology. Nurses can take on an informative and advisory function and close the gap between human and technology with their holistic view. In the article, we illustrate the integration of the developed concepts by a fictitious case study. Finally, the results are discussed regarding current research findings.

#### 5.1 Introduction

The demographic change in Germany is characterized by the constantly increasing life expectancy of people, which is likely to lead to rising demand for social and health services in the future. Simultaneously, the number of health professionals, especially in the care sector, is declining, which makes high-quality and comprehensive health care more difficult, especially in rural areas (SVR 2014). This problem is also extended by the digital divide which describes, among other things, the differences in access to the Internet, Internet skills and experiences with the use of information and communication technologies (ICTs) (i. a. van Deursen and van Dijk 2011). The digital divide is particularly apparent for the group of people with medical conditions (Zhang et al. 2011). Against this background, major research funding programs have been launched in Germany in recent years in which research and funding focus on innovation and technology. A technological healthcare system has become a

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solution strategy (German Federal Ministry of Education and Research 2015). More and more technical assistance systems are being developed specifically for nursing staff and outpatient care to support people in need of care and their relatives. In the field of technical assistance systems development, the main goals are to maintain health and support older people to live longer safer and independently at home. The project Village Community 2.0 (Dorfgemeinschaft 2.0) concentrates in this context on rural areas and human-technology interaction. The project comprises an overarching research network with four interdisciplinary research groups (Nursing Science, Ethics, Information Systems, and Logistics). In addition, there are nine other consortium partners and more than 40 associated partners from the fields of local self-government, residents and business management. The project aim is to support people across generations with the use of digital and assistive technologies, to improve social participation (implementation of the inclusion and sharing economy). It also aims to bridge the digital divide between the different population groups in terms of access to and use of ICTs. Due to the infrastructure, such as long distances between residential buildings and educational and health facilities in the region, an online platform will provide digital services to support daily and community life. By linking the virtual space (platform) with the real living space, we hope to promote the social participation of people in their immediate environment and to support local care structures. Our project pilots in the rural area of Bentheim/ south Emsland (Lower Saxony) addressing the entire community concentrating in particular on older people and people in need of care.

To enable the use of the platform in the context of health management, we have developed the educational management concept *Digital Nurse*. The *Digital Nurse* is a contact point for residents on health and technical questions. We also developed *FeelFit*, a mobile health application. The application helps users to monitor their health-related data in everyday life. Many people already do so not only because of their interest in sports but also for health reasons (Bitcom e. V. 2018). By monitoring vital parameters, users can collect health data to participate in their health management. Since older people and people with chronic illnesses have lower health literacy (Schaeffer et al. 2016), we want to support these people in measuring their vital parameters if necessary. In this article, we will present both concepts and their integration answering the following research question: *How can the concept of a health monitoring application and a Digital Nurse be integrated to improve the eHealth literacy of older people (65 years and older)?*

To answer the research question, we will first present the background to eHealth literacy and socio-technical systems. In the following, we will outline the multi-perspective research approach from the perspective of nursing science and information systems and the resulting concepts *Digital Nurse* and *FeelFit*. We then present the integrated concepts based on a fictitious case study. Finally, we will discuss our results and their effects and point out the limitations.

## 5.2 Background: eHealth literacy and socio-technical systems

It is important to note that technology development should not focus only on monetary all-in-one solutions. Furthermore, in this context, 54.3% of the population in Germany has limitations in health literacy (Schaeffer et al. 2016). One of the most frequently cited definitions of health literacy (Sørensen et al. 2012) is the one by the World Health Organization (1998) which describes it as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (World Health Organization 1998 p. 10). This implies that the majority of the population in Germany faces problems finding, understanding, evaluating and using health-relevant information. In particular, older people and people with a migrant background, chronic diseases or a low net income have low health literacy (Zok 2014; Schaeffer et al. 2016). The Shanghai Declaration on promoting health in the 2030 Agenda highlights that health literacy is a socially relevant issue and is part of the context of life-long learning, which should begin in school curricula (World Health Organization 2016). Obtaining health-related information and being able to use it for oneself also means being able to participate in society and act independently – older people are often excluded.

As the use of electronic and mobile health applications has increased in recent decades, the term health literacy has also evolved. Today, there are many definitions of eHealth all about technology (Oh et al. 2005). For Norman and Skinner (2006), contextual factors also need to be considered, such as the medium (electronic resources) and skills that are involved in obtaining health-related information addressing or solving a health problem. This goes beyond a narrow concept of health education and personal behavioral communication to address the environmental, political, and social factors that determine health. They developed the Lily model, which deals specifically with eHealth literacy. The model includes six equal components of core competencies (health-, science-, computer-, information-, media- and traditional/numeracy literacy). If competencies from all areas are available, a good eHealth literacy of the person is to be expected. The researchers point out that improving literacy is a dynamic process. In addition, there is a need for coordinated education, especially for older people (Norman and Skinner 2006).

While each of the different components creates unique challenges, coping with these challenges requires a synergistic approach. Such an approach makes it possible to develop effective digital health education programs for patients and providers. Since an application for increasing eHealth literacy requires a complex interaction between machines such as mobile devices and portable sensors, the user and the environment, it can be considered a socio-technical system (Emery and Trist 1960). This is also the case for most of today's systems. Socio-technical systems consist of two interdependent subsystems, the social and the technical subsystem. In most cases, only the technical subsystem is focused on the development process of the sys-



tem (Eason 2001). However, it is necessary to consider both subsystems to achieve good performance and high utility. In the field of health monitoring systems, there is a rapid increase of interest in technical systems with wearable devices that have flexible functions, e. g. for fitness and medical applications (Liang and Yuan 2016). But these systems usually do not offer the necessary interaction possibilities such as voice input and output as well as good usability for every user. As a result, users, especially those with physical limitations or little computer knowledge, cannot use the system. Moreover, there is no support within the social subsystem for people who do not know how to interact with the system or how to interpret the information provided by the system.

### 5.3 Multi-perspective research approach

Since technological development is often only carried out on one side, an interdisciplinary approach is necessary for the demand-oriented development of assistive technologies. Our work focuses on improving the eHealth literacy of people who want to stay informed about their health status or have health problems and who need support in measuring and documenting vital parameters.

Complementary to behavioral science, which explains how and why information systems work, the design science of information systems focuses on creating artifacts for a specific need (March and Smith 1995). For design science in information systems research, Hevner et al. (2004) have developed seven guidelines. By following the guidelines an artifact in the form of constructs, models, methods, and instantiations is developed in cycles of building and evaluating. These so-called design cycles are supplemented by relevance cycles for meeting the environment's needs and rigor cycles grounding the research in and adding to the knowledge base (Hevner 2007). Our research is applying the design science research methodology by Peffers et al. (2007), which is based on the guidelines (Peffers et al. 2007). First, in our investigation, we designed two artifacts independently of each other. On the part of the nursing sciences the education management concept *Digital Nurse* (3.1) and on the part of the information systems, a system for adaptable wearable health monitoring system called *FeelFit* (3.2) was developed. On both sides, we used use cases to document and implement artifact development. Use cases describe the interaction of an actor with a system to accomplish a specific task. We have adapted the structure of use cases by Jacobson (1993) to our needs so that they can efficiently support interdisciplinary research. Following the development of the concept and the application, we will integrate both with each other pictured by the use cases.

### 5.3.1 Perspective nursing science

In today's digital world, online consulting and social media are becoming increasingly important for both society and care (Risling 2016). In the context of digitization and technological progress in healthcare, it is clear that the structures and tasks of nurses will change in various areas. Nurses will take on new roles in this context, including digital knowledge transfer through inclusion and education to promote patients' health literacy (Mather and Cummings 2017). Currently, there are a lot of research projects for the use of technology and socio-technical arrangements in care. The paradox is that there is a lack of nursing science systematization and positions in Europe for technology development and design. For example, the field of nursing informatics is still in its early stages in Germany, in contrast to the professionalization and specialization that has gone on for more than 20 years in the USA and Canada. Related disciplines and politicians agree that there is a high need for tech-education for the health care professions, especially in nursing. On the other hand, the integration of competencies in the field of nursing informatics into the curricula of nursing education has not been enshrined in law or given more consideration. For example, the German occupational law for higher nursing education only stipulates as objects "to be able to transfer new technologies into professional action" (Federal Ministry of Health 2017, § 37, Para. 3, 3 PflBRefG).

Although international literature already shows that nurses take on different roles in the context of technology use, such as mediator (to access, review and evaluate information), advocate (for clinical judgment, privacy, and security) and supporter (appropriate use of a variety of ICTs) for care recipients and their relatives. In particular, they have an ethical and legal perspective and responsibility of the originary IT competencies<sup>19</sup>. Thereby nurses behave like advocates of system users by including them and their perspective and by aiming to enable them to use technology for their benefit (Canadian Association of Schools of Nursing 2015; Chung and Staggers 2014; Staggers, Gassert, and Curran 2001). In the German-language nursing science discourse, the use of technology in care settings is discussed against the background of a deprofessionalization or professionalization of nursing (i. a. Hielscher et al. 2015; Friesacher 2010). In the international debate, the authors Locsin and Purnell (2015) do not argue for or against increased use of technology in care but point out that carers can be a bridge to the technological world while maintaining the humanity of their patients. Among other things, it is discussed whether the health work of practitioners can and might be replaced by technology in the future.

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<sup>19</sup> The use of technologies is omnipresent in nursing practice, e. g. in e-documentation, monitoring patients, when reading laboratory parameters, when importing patient data, this can be understood as originary competencies.

One thing is certain: nurses are often being torn between the medical dichotomy and mechanistic conception of humanity and their holistic nursing attitude and perspective of unity.

### Methods

At the Osnabrück University of Applied Sciences, we have therefore opted for formative evaluation for the development of an education management concept to promote eHealth literacy. Methodically, we apply qualitative research methods, discussion forums and interviews combined with a systematic literature analysis.

We started with an analysis of the actual situation and needs. We conducted three focus group discussions with citizens ( $n = 58$ ) and one with experts ( $n = 19$ ), stakeholders from the regional healthcare and social system (persons of the district Emsland with the activity field care, ambulant care services, a health insurance company, nursing and social managements, senior citizens counseling and a nursing support point) to identify the needs related to health, technology, and education (Hauptshofer et al. 2019). Additionally, we collected data by an international scoping review to identify the nature and scope in terms of technology and teaching roles and to map relevant literature in the field of nursing informatics competencies. We examined the research question: “What characterizes nursing informatics as an expanding field about the roles and competencies of nurses in technical appropriation processes of older adults to promote their eHealth literacy?” (currently under review). Based on the clustered competence profiles it is planned to design the training of the *Digital Nurse* in the future. In November 2019 we will start with narrative interviews with older people (65 years and older) about their tech-stories, to capture both experiences and self-perception with technology (use) and to gain new perspectives.

### Concept: *Digital Nurse*

We have developed the *Digital Nurse* focusing on prevention, education, and technology. The concept is formative evaluated, which means that the research results are integrated into the conception over the entire duration of the project and influence the entire construct. The results of the analysis of the real situation and needs show that the citizens experience the construct of a good neighborhood as a care-network, but they perceive it as dwindling in the region. Also, there are age-related stereotypes and a negative perception of age. There are two fundamental fears: on the one hand, the fear of being alone and lonely in old age and of being dependent on other people. As a result, people suppress care topics and the need for care, which leads to a late confrontation with personal health management. On the other hand, the citizens were open to new forms of care in the discussion forums. They supported the concepts of a community nurse as the first point of contact and the preventive home visits. About assistive technologies, there is a high demand for information about an application, handling, and their benefits. Furthermore, there is a fear of anonymization through

the use of technology, as citizens have repeatedly stated that relationships between people should not be reduced or replaced by technology (Haupeltshofer et al. 2019). For our concept development, it became clear that older people need a slow introduction and sensitization to technology. Only in this way can fears be reduced and personal benefit put in the foreground. In addition, we concluded that only by looking at the experiences and ideas of older people about technology we will be able to educate technology according to their needs. Furthermore, the literature research showed that nurses play different roles in processes of technical appropriation and already have competencies that need to be examined in the use of assistive technology.

The *Digital Nurse* concept includes that nurses introduce the users individually to the need-oriented technology and support them in dealing with technology. We planned to set up an institutional education and information center with a fixed place (if possible, this will be extended by a mobile unit as a visiting low-threshold offer), which will be supplemented by offers from virtual and non-virtual learning settings and methods. The *Digital Nurse* is a low-threshold point of contact to reduce inhibitions, for example, we plan the institution to be situated in a village center. Thus, it is possible to consult a qualified academic nurse directly, who will carry out health and tech-handling related individual anamnesis. In addition to theme-related basic and advanced training courses on how to use a tablet or workshops on how to use the digital community platform, the focus is on E-Learning and the use of eHealth applications. The basic principle is that those information units are communicated clearly and demand-oriented to older people. In addition, (tele-) consultation hours and webinars will also be offered. This will be supported by online visualization of existing local educational offers (like the social map / Sozialmap.com 2019), existing care and health services, but also, for example, the participation of the offers of self-help groups, which are digitally mapped and communicated by the *Digital Nurse* if necessary. Therefore, the concept aims to ease residents' access to health-related information and to promote their eHealth literacy.

### 5.3.2 Perspective information systems

The degree of digitization of the German population shows that the older generations are on the advance but still stand behind the younger generations. There are several influencing factors for it: younger people or people with a high level of education show a higher degree of digitization than less educated or older people (Initiative D21 e. V. 2019). In this context, it is clear to us that the further development of existing technologies should be based on the needs of users and nurses. It is important to consider the needs of the target group so that the application is used more regularly and successfully. Therefore, when developing the application, we used a process that is oriented to the user's requirements. We emphasize that the application does not necessarily have to be used regularly, but regularity helps to achieve the best results.

## Methods

We used the ISO standard 9241–210:2010 for the human-centered design of interactive systems to develop the *FeelFit* application (International Standardization Organization 2009). The first phase includes the planning of the human-centered design process by defining the topic and setting the general conditions for the design process. We formed a project team consisting of five graduate students and three PhD students for one year to develop the *FeelFit* application. The focus was on the development of an application that helps to measure vital parameters and to display and store them clearly and simply. In the next phase, we carried out a systematic literature review based on vom Brocke et al. (2009) to determine how older people deal with technology in general and with eHealth applications in particular (vom Brocke et al. 2009). The results of the literature were supplemented by a series of interviews with the target group on this topic (phase 2) to understand and specify the context. In order to structure the search and user requirements (phase 3), we created fictitious personas to describe different types of users in the target group. Besides information about the demographics and the bio of the user, the persona describes the goals, worries, and anxieties as well as the motivation and experiences with regard to the use of the application. Based on these results we produced the *FeelFit* application (phase 4). The application consists of various input and output devices which enable a multimodal interaction. In phase 5 we evaluated the application. Therefore, we set up a realistic setting. The participants ( $n = 54$ ) (between 17 and 65 years old) used all functions and evaluated the application in a later questionnaire focusing on application experience (Meier et al. 2019).

## Concept: *FeelFit*

*FeelFit* uses smartphones and wearable sensors to collect vital parameters. It processes and stores them in the user profile and enables users to retrieve the information not only via smartphones but also via other devices such as a smart speaker (voice only) and a smart mirror (visual only). The application includes a conversational agent, such as a chatbot or a virtual personal assistant, for example, Amazon's Alexa, which enables natural voice interaction. By providing a great variety of devices every user can decide which devices he or she wants to use. Further, the variety allows the user to interact with the system depending on the situation. *FeelFit* collects and evaluates health-related data (heart rate, temperature, blood pressure, among others) and informs users about their state of health. *FeelFit* can be used as a conversational agent which enables a more natural interaction than the current mobile eHealth applications (Seeger et al. 2018). This possibility supports people in the system. The user can configure the app to his or her needs and adapt it to possible diseases. Further, the user can link the profile to the personal healthcare provider to grant access who can then get access to the information via a web portal.

The evaluation showed that the application improves the provision of health information to users in their everyday lives. Nevertheless, 57.4 % had never used digital technologies to measure vital parameters. The participants highlighted the multi-modal interaction with the conversational agent and the mirror. However, the evaluation shows that users need to be trained in the use of new technologies such as the conversational agent. In addition to dealing with the technology, however, users must be trained to deal with the vital parameters, which are sensitive information, particularly to older people. This was especially clear in the case of a participant who had his pulse displayed in the mirror and remembered his stay in hospital. Therefore, we link the application with the concept of the *Digital Nurse* to use the application as a help system for supplying information and to integrate it into a socio-technical system.

## 5.4 Integration of the concepts *Digital Nurse* and *FeelFit*

After completing the first iteration of the design cycle by evaluating *FeelFit* in a real environment, we took stock. On the one hand, we had the challenge that especially older people had problems with the handling of the devices and a beneficial configuration of the application. In addition to this finding, we also found that it is necessary and useful for users to be provided with more information about the personal benefit and context significance in addition to the measurement data. This would have been technically possible by adding more health information and interpretation possibilities, but this would also lead to a very complex system. At this point, it became clear that system use to promote eHealth literacy is not possible in this way. There is a need for training in technical use, as well as support in the transfer of the collected data into daily life. This means that there is a need for a contact person who is an expert in health:

To illustrate the impact for citizens in the pilot region the following fictitious case study shows how users can benefit from the use of the mobile health monitoring application with the care and support of a *Digital Nurse*:

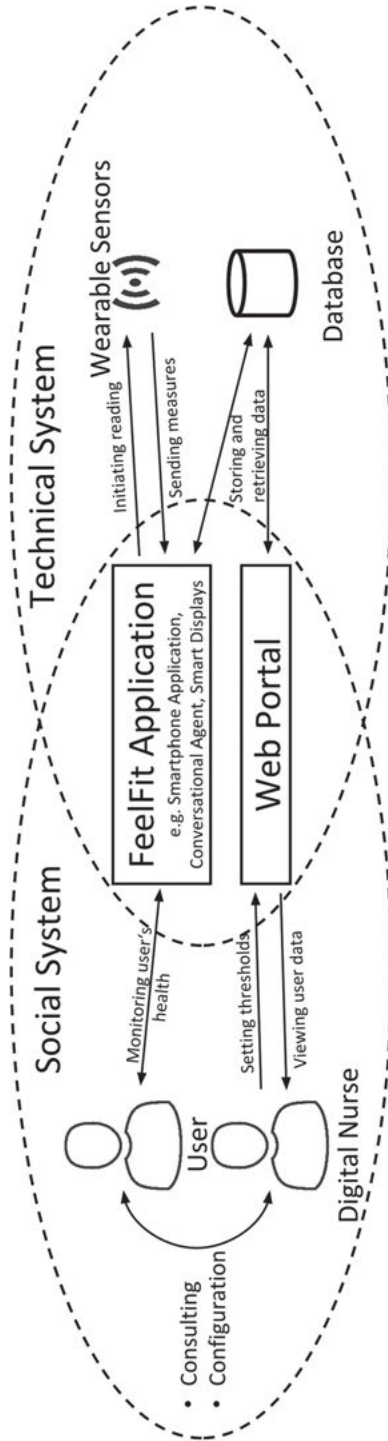


Fig. 5.1: Interaction of the socio-technical system.

### Integrated Case Study

Caroline Peters is 67 years old and lives alone in a house in a small village. She's had high blood pressure for five years. She treats her disease with antihypertensive drugs. In addition, the physician orders her to measure her blood pressure regularly to decide the proper medication. On the recommendation of her children, she buys a smartphone with a digital blood pressure monitor. Together with her daughter, she carried out the first installation, after which Mrs. Peters regularly used the smartphone to measure her blood pressure and store the data. However, there were changes in the application and an error message appeared. Mrs. Peters was confused and became insecure in the use of the smartphone. She was afraid of doing something wrong or unintentionally sharing her data with others. She asked her children to help her, but they were too busy. Mrs. Peters remembered the health kiosk near the town hall, where anyone can try out new technology and get support. The next day she spontaneously visited the kiosk and spoke to the *Digital Nurse*. After a tech-health anamnesis, the *Digital Nurse* recommends Mrs. Peters to buy a heart rate monitor and install the *FeelFit* application. The personal benefit for Mrs. Peters is that with *FeelFit*, the two sensors can be measured and clearly presented in a single application. They talk in detail about where personal data will be stored and which data protection settings are recommended. The *Digital Nurse* supports Ms. Peters in setting up *FeelFit* and adjusts the individual blood pressure and heart rate thresholds. She reminds Mrs. Peters that the application will tell her about exceeding the thresholds and will alert her if necessary. In addition, the *Digital Nurse* explains the possibility of voice commands in the *FeelFit* explanation. Afterward Mrs. Peters uses *FeelFit* for several weeks without complications. However, since the values more often exceed the threshold values, Mrs. Peters visits the *Digital Nurse* again who reports to Mrs. Peters and explains again that there are always normal deviations during measurements. She speaks clearly to her and agrees on a specific measurement value at which it is necessary to consult a physician. With the support of the *Digital Nurse*, Mrs. Peters feels safe using the technology and better informed about her health status.

As the use case example shows, the *Digital Nurse*'s support intends to help people in the three areas of health, science and computer competencies or to compensate for a lack of skills in these areas.

## 5.5 Discussion

In rural areas with long distances to health and education institutions, the use of ICTs often means social inclusion and participation. Only those who can use health-related information in everyday lives can act independently and make health-related decisions; more than 10 % of the German population have already experienced a pedometer and apps for measuring heart rate, blood pressure, etc. Besides, a further 27 % are open for any use of these devices (Initiative D21 e. V. 2019). Even though more older people in Germany are online and the total number of offline people is falling from 25 % to 21 % compared to 2017, the technical and digital competencies in computers of the over 70-year-olds are at a very low level (Initiative D21 e. V. 2018). Despite these numbers, eHealth literacy is rarely approached as a problem of the healthcare



system. Illustrated by the case study, we mapped different levels of activity and inter-related scenarios. On the one hand, it is clear that a digital transformation of nursing is taking place and that the nursing profession will continue to change. On the other hand, there is a lack of political integration in the health system's laws and structures. Promoting health literacy is a nursing imperative (Speros 2005; 2011). We want to note that the lack of health literacy is a major problem in Germany and that there is an urgent need for action. At the national level, this task has not yet been taken over by nursing. In the context of health literacy, however, informed decision-making is playing an increasingly important role (Kolpatzik et al. 2018). In contrast, technology and the healthcare market are developing rapidly. The conditions for a successful demand-driven increase in health literacy must be examined in detail. For example, the digital divide must be considered from a country- and culture-specific perspective, as social disadvantage and a lack of digital infrastructure vary (i. a. Borgida et al. 2002; Denizard-Thompson et al. 2011). The technology introduction requires not only planning and patient education but also the development of cultural sensitivity for the technological values and attitudes of patients (Denizard-Thompson et al. 2011). The *Digital Nurse* takes on an informative and advisory function and closes the gap between human and technology with their holistic view. The practice-oriented reflections of international aspects of the field of nursing informatics and the perspective of the role of nurses in this educational context are therefore new findings for Germany.

The integration of both concepts should be seen as a work in progress approach that can eliminate many existing problems associated with the insufficient and unreliable health information supply as well as technology seen as an end in itself. One of the benefits of support is trust in oneself and in the application. The *Digital Nurse* as contact person increases the eHealth literacy by the support in the interpretation and reflection of data, the advice on privacy and data protection, but especially in the handling of the personal use of technology. Additionally, the focus is on demand-oriented technology development, but also on the individual ideas of the successful use of technology. The results of this study expanded the research in the field of socio-technical systems, through the integrated development of technical and social subsystems. This is also important because, for example, for the widely used eHealth literacy assessment (eHEALS) there is a late study the reliability and validity of which was only recently proven for older people (Chung and Nahm 2015), while previous literature has generally considered only one side, by studying either the use of technology in a social system or to adapt the social system to carry out a technology. Through the integrated approach, the socio-technical system can be examined holistically and adapted to the requirements of both subsystems jointly.

## 5.6 Conclusion

This article presents a case study illustrating how the concept of a health monitoring application and a digital nurse can be combined to improve the eHealth literacy of older people (65 years and older). In our article, we have described different levels and possible challenges in using assistive technologies related to eHealth literacy; we have also developed an interdisciplinary demand-driven solution strategy. Using the illustrated perspectives of both scientific disciplines, we were able to explain why our scenario focuses on the development of *FeelFit* as well as on the specialized and face-to-face support of a *Digital Nurse*.

It can be limited that both concepts are not yet implemented in practice. In the prototype phase, for example, we used test accounts with anonymous health data. As part of further development, data security and data protection must be examined more closely, as health data are particularly sensitive and worth protecting. Also, in Germany the education of nurses in technology-related competencies is still in its early stages, so the integrated solution could not be evaluated under real conditions. As *FeelFit* is still a prototype, it should be examined whether people would use such a multimodal system to monitor vital parameters. Nevertheless, it should also be noted that for older people in technology-occupied settings there is an absolute need for practical and proactive scientifically evaluated approaches. However, the exchange with the use cases and real case scenarios ensure that both the application and the concept are coordinated. Future studies must then examine the long-term use of portable health monitoring systems with the support of a *Digital Nurse*.

Against the background of the social explosiveness of the subject area “assistance systems in an aging society”, we advocate for including a nursing science perspective in technology development. There is also a need to rethink health policy. Apart from the fact that eHealth literacy in Germany must be considered as the next decade of healthcare, the implementation of ICTs and assistive technologies alone is not enough. In particular, structures must be created to educate the population and health professionals in digital competencies.

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## 6 Geriatric trauma patients as research subjects in a technology-driven research project

### A preliminary field report

Amelie Altenbuchner, Karsten Weber

#### Abstract

This article highlights methodological and ethical challenges in research with adults of older and oldest age, by presenting field experiences of the current research project “Motion Monitoring of Geriatric Trauma Patients – Explorative Study on the Rehabilitation Process after Hip Fracture Using Sensor-based Data”. Depiction of the survey situation, with regard to the subjects in particular, can serve as practical examples for designing future research projects.

The group of older adults is a rather large and growing group for which research is required, especially concerning their heterogeneity, their individual autonomy and quality of life. It is assumed, that research designs of studies on the target group must be specifically adjusted, in particular when considering the attribution of vulnerability of the group members. At the same time, it is not clear yet what exact specifics of the subjects and target group must be considered in research designs, as surprisingly little is known about the target group as subjects and corresponding theories have been insufficiently tested.

The exploratory long-term design of the research project presented in the second section of this chapter has a positive evaluation of an ethics committee. Still ethical challenges occurred in the field situation, that are illustrated in the third section of this chapter, by providing information on the patients, their role as research subjects, how they were recruited, how an informed consensus was reached, and in some cases how participation was rejected or abandoned. After a summary, the end of the paper is marked by recommendations on how to design future research projects.

Cumulatively it must always be expected that interaction between researchers and research subjects of this target group can become very intensive, what requires to follow clearly defined procedures and at the same time to be prepared to act flexibly.

### 6.1 Introduction

The geriatric environment is determined by caregivers and relatives, but also by care levels, cognitive impairments and, above all, by geriatric patients as well as the interplay between these groups and numerous social, healthcare and medical conditions. Geriatric patients belong to a heterogeneous group of very old people; therefore evidence-based research encounters various methodological challenges (Deutsche

Akademie der Wissenschaften 2015). In addition, there are frequent prejudices and biased views of older people in society that influence caring processes and medical interventions (Trojan 2002) as well as geriatric research. Therefore, it seems reasonable, first, to further advance the development of research guiding hypotheses for geriatric research and, second, to do so in a morally informed approach in order to gain robust empirical knowledge about geriatric patients.

To begin with, a definition of geriatric patients and a brief overview of the terms to describe the feature “age” of these patients. A person of a so-called oldest age of 80 or more years of life can be a geriatric patient by definition. Actually, chronological age does not define a geriatric patient completely, but rather a health condition called multi-morbidity and an age above 65, in general from 70 years of age on (Sieber 2007). Persons in this age group are called “older persons” or “older people” or “persons/people of older age”, according to suggestions of Avers et al. (2011), who criticise the use of the term “elderly”. Multi-morbidity means that there are two or more health conditions, often chronic, that require treatment (Eckardt and Steinhagen-Thiesen 2012). A central goal in the treatment of geriatric patients is to preserve autonomy and quality of life, especially when it is at risk due to an increased vulnerability (Denkinger et al. 2018). Therefore, if an age-associated physical and cognitive decline emerges, as well as a growing state of vulnerability, a patient defines as geriatric too (Sieber 2007). This situation is called *frailty* which is a term that as yet lacks a precise definition (Denkinger et al. 2018). Statistics show that most industrialised countries, as well as many other, particularly developing, countries, are undergoing strong demographic change (Central Intelligence Agency 2018; The World Bank 2018). As a result, the number of older persons and adults of the oldest age is growing tremendously and at the same time the average life expectancy of these people is increasing. In other words, more of the older people live longer. It is very probable that this trend will be associated with an increase in geriatric diseases and multi-morbidity among the oldest agers (Hayward and Warner 2005). At the same time, there is hope that geriatric measures to improve health can maintain quality of life into old age (“healthy life expectancy”). To put it in the words of the World Health Organization (2012): “Good health adds life to years”. In order to manage these changes and developments, medical and technical innovations are increasingly being sought to help to take care of older persons and oldest persons. The employment of technology in care will undoubtedly change the lives of patients and many other stakeholders as well as the work of caregivers (Abeles et al. 2017; Barth and Doblhammer 2017; Becker and Pfeiffer 2012; Claßen 2012; Normahani et al. 2015).

Therefore, it should be a research priority to closely examine the use of such technologies for geriatrics, whether in the form of pilot projects or laboratory experiments (Duh et al. 2006; Becker and Klenk 2010), in order to be able to make judgements about age-appropriate design of technology and to ensure that autonomy and quality of life of all stakeholders are preserved (Schulz et al. 2015).

It is to be expected that innovative technologies such as motion trackers or devices for the Internet of Things will be integrated into the lives of older people in the future (Schulz et al. 2015). Researching these technological innovations has become a high priority in geriatrics recently, mostly as pilot projects or under laboratory conditions; particularly, age-appropriate design and whether and how technology can sustain autonomy and quality of life of prospective users are examined. However, it is precisely in such research that methodological challenges arise. Among other things, the fact that assistive technologies are not yet widely disseminated (Becker and Klenk 2010; Weber 2017) makes research in actual care settings and under real conditions extremely challenging (Altenbuchner et al. 2019). Research in this area is also hampered by the fact that it is not always clear whether the results are essentially attributable to the technology used or to the patients or their personal traits. Another challenge is the vulnerability of patients with geriatric trauma, as there are many ethical aspects affecting research in these cases – this is true for laboratory research, but even more so for field studies.

It is the aim of the project described in this paper to explore physical motion of older and oldest persons as well as the measurement instrument, which is a customary motion tracker. Due to a research and knowledge gap concerning physical activity and behavior patterns in the actual living environments, it is necessary to conduct such studies. Thus, the following section will present preliminary results in order to shed light on the methodological challenges of research with older and oldest people in general and in connection with technology in particular. Although the research design of the project, which is described in the following section, was positively evaluated by an ethics committee of the University of Regensburg, it has to be noted that the handling of the project's target group poses multiple ethical challenges. In order to better illustrate these challenges, the third section provides detailed information on the patients, their role as research subjects, how they were recruited, how an informed consensus was reached, and in some cases how participation was rejected or abandoned. After a summary, the end of the paper is marked by recommendations on what needs to be considered in future research projects.

## 6.2 The research project: Motion monitoring of geriatric trauma patients – explorative study on the rehabilitation process after hip fracture using sensor-based data

In a nutshell, the aim of the project is to formulate assumptions and hypotheses about the mobility of geriatric trauma patients after a hip fracture. Although this is a rather large group, surprisingly, there is very little valid evidence on the mobility of geriatric patients, although mobilization is an essential part of treatment and an important therapeutic objective after a hip fracture (Hahn and Winker 2000; Rapp et al. 2012). Rapp et al. (2019) provide a systematic literature review on the epidemiology of hip



fractures. On the one hand, in western countries, 75 % of hip fracture patients are female. It is suspected that such injuries are typical for women, as they have a higher average life expectancy in Western countries, but older women at the same time often suffer from diseases such as osteoporosis. On the other hand, it is known that men in retirement and nursing homes fall more often and have a higher mortality risk six months after a hip fracture than women. A person who already suffered from a fracture has a higher risk of a secondary fracture. Current fall prevention programs and medication seem to be not sufficient to reduce the large number of hip fractures. Moreover, demographic change over the next three decades is expected to result in an increase in hip fractures (Lohmann et al. 2007). Only a few recent studies examined physical activity with body-worn sensors, and these have methodological limitations. Benzinger et al. (2014), who measured physical activity after hip fracture, used a pre-post-design at admission in a hospital and two weeks later. No continuous measurement was possible and therefore no variability in physical activity can be demonstrated. During the two days of monitoring, the time frame was only up to nine hours per day and patients of the geriatric rehabilitation centre had to perform different types of mobility assessments. Taraldsen et al. (2011) evaluated whether a body-worn sensor could be used to monitor mobility of persons suffering from neurological impairment. They found the sensor to be valid in measurement but mention the limitation that activities could not be tracked under everyday life conditions. Both studies recruited their patients on the ward and were ethically approved.

In the project described here, mobility is operationalized with the variables *steps* and *time*, which are measured with sensors that are built into a commercially available motion tracker. The study is designed as an explorative long-term study that does not include medical intervention. The methodological approach is descriptive and explorative and is performed in a geriatric trauma department in a hospital with patients living there while they are on the ward and undergoing initial rehabilitation as well as after they have returned home. Participation is voluntary and based on an informed consensus obtained by signing a consent form. Information about the project given to the patients emphasized the right to withdrawal without further consequences. Although no medical or physical treatment is part of the research design and wearing the device as well as follow up visits at home posed only a minimal risk to the patients, it has to be admitted that a greater than minimal risk occurs due to the continuous monitoring of vital data of the patients. During the study, the data collected is read once a month from the motion tracker. On this occasion, patients receive feedback on their mobility; they are told how many steps they have taken. Patients can see their individual achievements through time. The regular visits and the feedback might add value to the participation of the patients. For some of them those visits are a rare opportunity to have social contacts. In addition, the information about the level of activity can motivate patients to achieve even more. Both aspects would support the principle of beneficence because patients' well-being would be improved. However, it needs to be considered that this can also be a certain risk since

increased motivation can lead to overburdening activities; furthermore, the insight that a patient has achieved nothing or not much can also demotivate which can lead to even less physical activity. In both cases the principle of non-maleficence would be violated because patients could be harmed.

It should also be emphasized that the data collected in the project do not yet allow for medical and/or therapeutic interpretation; the purpose of the study is first to create an explorative database that can be used to derive research hypotheses and possible medical indicators. Furthermore, it should be noted that even a preliminary interpretation of the data communicated to patients may have effects that could lead to bias in further data collection or demotivate patients to the extent that it could cause harm to patients. For up to a year the motion tracker continuously collects data on how many steps have been taken. The opportunity of long-term recording and the low cost of the motion trackers used motivate the utilization of commercially available devices. The motion tracker is worn and looks like a wristwatch, which increases comfort. This helps to ensure that it is not forgotten and that data collection is not interrupted. With those motion trackers used in the study GPS location monitoring is impossible.

To reduce risk, data can only be read out by two project members knowing the necessary passwords and project e-mail accounts, that belong to the University of Applied Science Regensburg (OTH); the patients are not able to do this due to a lack of technical knowledge and access credentials. But even if they had this knowledge, they would not be able to access the data because most patients do not have computers, laptops or similar devices – but their mostly younger relatives have such devices. If a research subject would want to have digital access to the data, then it would be necessary that they had access to the Internet at home. Due to data protection regulations and requirements from the ethics review, patients would have to log in via the University, as the data can only be accessed there. This would therefore entail a considerable effort for the patients. However, to this day no research subject wanted access to the data, but were satisfied with oral feedback.

The credentials do not contain any personal information; they only refer to the motion tracker identifier. For example, the username as a pseudonym could look like this: “Mr. Tracker Twenty”. The personal data of the patients are stored exclusively on paper separately from the collected data, so that data protection is guaranteed. All statistical evaluations use only pseudonyms so no digital data linking with personal and health-related data is possible. As soon as the project is finished, all accounts will be deleted. To meet DFG (Deutsche Forschungsgemeinschaft) standards, raw data sets will be stored on University servers.

The continuous, individualized and objective measurement of motion data aims to discover clusters using explorative data analysis (EDA) and to develop predictors for the quality of treatment and therapy after a hip fracture. In addition, further hypotheses for research will be formulated, especially with regard to cognitively im-

paired patients (e. g. dementia or delirium), as these persons are often not considered in corresponding geriatric assessment tools.

Preliminary results on how to measure physical activity with a commercial motion tracker can be found in the text of Altenbuchner et al. (2018). The data collected so far show that after a very uniform period of time at the beginning of the measurement, patients begin to behave very differently. Cluster analysis shows three-cluster solutions with significant differences for the average amount of steps per patient during time. It is hoped that the long-term study will provide more data that can be used to examine the three-cluster solution. Possible hypotheses might be found with regard to predictors for rehabilitation; this might help to find out in what stage of rehabilitation the monitoring of physical activity could be used to predict the potential success of individually adapted rehabilitation (Altenbuchner et al. 2019).

## 6.3 The Patients

### 6.3.1 Geriatric trauma patients as research subjects

Patients involved in the study are on average 86 years old ( $\pm 7.1$ ) and suffered a hip fracture. Treatment and therapy of such injuries with regard to the age group is complicated due to side conditions like dementia and special care needs. It is expected that these factors will increase up to 70 % in the next three decades and even 150 % for people over 80 years (Lohmann et al. 2007). Suffering an injury like a hip fracture increases the risk of a subsequent fracture (Kretschmer et al. 2017). Postoperative mobilization is essential in preventing muscular atrophy and contractures (Hahn and Winker 2000). Patients with dementia also benefit from physical activity therapy (Clare 2017; Bork 2017; McGilton et al. 2013). A continuous measurement and therefore observation of mobility would allow the development of complex and personalized interventions (McGilton et al. 2013). Geriatric mobility valid assessment tools and tests exist but due to everyday variability, individual conditions, time aspects or cognitive status they often cannot be employed. Furthermore, they only provide information about mobility and physical ability with regard to a particular moment in time. Thus, the question of how to adequately measure physical activity with regard to geriatric patients and persons of the age group to a large extent remains unanswered (Altenbuchner et al. 2018).

The design of the project described here does not include medical intervention or physiological treatment, but oral and written feedback on the data collected. Patients get to see how many steps they took on average week by week; differences in comparison to the last month and a graph showing the development since the first day of measurement are also provided. The feedback is provided as a slide show presentation on a tablet PC in order to allow the patients to slide back and forth and zoom in easily. Additionally, they get a printed version to keep and to show their relatives. It

is quite likely that the feedback motivates patients to be more active and to take more steps as they would without the feedback, which poses a methodological problem. However, the feedback is necessary from an ethical point of view for not providing it would violate the principle of beneficence since the feedback might improve the quality of life of patients.

Irrespective of such details, the fundamental question is whether such vulnerable patients (Wild 2014) should participate in a long-term study of this kind at all. Patzig (1986) argues that participation is morally expected, as it could contribute to the common good. Patients who are treated in university hospitals or general hospitals where research is carried out expect the best possible treatment based on state-of-the-art of research and science. Therefore, these patients in particular would be obliged to participate in research projects, even if they did not benefit from them themselves. Even older people who could no longer benefit from positive results and findings of such studies would have a moral obligation to society of the future (Laslett 1995). The common good is often used as an argument in the human sciences and medicine with reference to public health (Osieka 2006).

There are specific moral guidelines for research with cognitively impaired patients; the decision to participate in studies and research projects should not be taken easily by legal guardians or caregivers (Patzig 1986). The German Ethical Council also emphasises this with regard to patients with dementia (Deutscher Ethikrat 2012) whose right to self-determination (Freier 2014) has to be taken into account. In the best interest of the patient this right can also be exercised on behalf of the patient by a legal guardian, but nobody should be urged into participation, even if this would mean that research progress is slowed down (Patzig 1986).

Within the project, those patients who did not wish to participate in the project always informed the project staff directly and confidentially. In some cases, however, it may be assumed that the consent of some patients to participate was given far too thoughtlessly. In one case, a relative said not to be caring whether a patient would participate or not, so the decision was ultimately up to the project staff. From a moral point of view, this is of course unacceptable, as the right to self-determination would be so disregarded. Either the patients have to decide for themselves or those persons who have to decide on their behalf but not the project members. For that reason, the patient was excluded from the sample. Some patients said that they would participate as long as there was no effort for them. These experiences suggest that the idea of informed consent is an ideal that is not always fully realized.

A patient suffering from a physical impairment requested detailed information about the project, but a relative refused to accept to take the information and therefore the patient did not receive it. Although the aim was to involve all new patients admitted to the ward in the project, another patient in the hospital was not informed that there was an opportunity to participate in the project because the patient suffers from a psychiatric condition that leads to delusions (as a relative informed us). The relative still wanted the patient to take part in the study. However, a situation where

strangers visit at home in order to get data from the motion tracker can be horrifying and does not meet the principle of non-maleficence that demands the reduction of suffering (Osieka 2006). Thus following Freier (2014) sometimes autonomy – in this case autonomy to take care in the study – has to be restricted by the researcher, if circumstances show that the situation caused by a previous decision can be overwhelming for the patient, even if the caregiver would agree anyway. Due to the occurrence of a flu wave, some other patients who were in poor health and therefore had to be considered particularly vulnerable could also not be included in the study. This shows that participation in research must ultimately be decided on a case-by-case basis (cf. Wild 2014).

### 6.3.2 Recruitment

The recruitment of the patients took place in the geriatric trauma ward of the cooperating hospital. Before the study began, meetings were organized on the ward and in the department. With the help of letters containing photos, telephone numbers and e-mail addresses, the project members introduced themselves to the nursing staff, physiotherapists and ergotherapists. It was important to build trust so that the project staff could move freely around the ward. A good relationship with the healthcare professionals was essential for the project, as they were responsible for encouraging patients to participate. They were the first to ask the patients whether they would agree on whether the project members would be allowed to inform them about the study. Some patients also asked nurses or doctors if they thought that patients should participate. Since the aim of the project was to carry out a full survey all patients or their guardians had to be contacted. The full survey should also include patients with cognitive impairments, as this group of patients can also benefit from physical therapy (Clare 2017; Füsigen 2008; Huxhold 2012). To date, only two patients could not be invited to participate because they had to be isolated due to health reasons. In general, it was important to always remember that patients were recovering from a fall resulting in a hip fracture and subsequent surgery which meant they were in a difficult situation.

During recruitment, patients are usually visited in their hospital rooms, as these are the only rooms where a certain level of privacy can be provided. However, this privacy is limited because it is very likely that another patient will be in the room as well nurses, visitors or other patients might enter. Many patients know the project staff and the project because they have already met them in the lounge and heard about the project. All in all, it can be said that the conditions under which patients can be recruited are very far from the ideal of existing moral guidelines or other regulations. However, it is hardly possible to create better conditions in everyday clinical practice. Further elaborating Patzig's (1986) argument that patients have a certain duty to participate in research if they are treated in university hospitals it might be assumed that

it may be common knowledge that usually research is going on there and that social conditions are far from being optimal.

Recruitment followed a standardised and binding procedure for the project staff, which included a salutation, the question of current well-being and a brief introduction. Patients also are given an explanatory text, printed in large font, containing telephone numbers and photos of the project staff. This personal contact between the patient and the project member is very important as the patients are invited to participate in a long-term study that includes home visits. In order to be able to take the personal circumstances of the patients into account, all agreements with the patients require the willingness to work outside normal office hours. During recruitment, patients are also given the opportunity to get to know and try out the motion tracker. Although this procedure is standardized, flexibility in implementation is necessary if certain preconditions exist on the part of the patients:

- visual and hearing impairments
- poor health conditions
- ongoing nursing and medical procedures
- uncertainty and mistrust
- fatigue
- concurrent involvement in other studies
- visits of relatives or other persons.

### 6.3.3 Process of obtaining informed consent

Attaining informed consent usually takes up to a week, as patients want to talk to their relatives or even expect them to make the decision even though patients do not have a legal guardian, but find it difficult to make their own decisions. In such cases, appointments must be made with relatives. Some patients and/or relatives may want to talk to the senior ward physician who knows the study first; some also address ward nurses. Some relatives would like an oral explanation of the above-mentioned written statement in a private conversation or they would like to see the motion tracker. Although this process is time-consuming, it can help to protect the autonomy of the patient and/or the person making the decision (Osieka 2006), as the individual's decision is actually placed at the center of recruitment (Scorna et al. 2017). If the patients then wish to participate, the last step is to let them sign an agreement in order to document informed consent. This agreement was drafted in collaboration with the hospital's legal department. Finally, the motion tracker is attached to the patient's wrist and data collection can begin. It must be emphasized again that the study does not include any medical intervention.

Although very extensive verbal and written information is offered, it remains to be stated that some patients do not know exactly whether the project team members belong to the OTH Regensburg or are employed in the hospital, as is the case for ex-

ample for the nurses, social workers or medical students. At least that is an impression that arises because some patients still address the team members after three days as “nurses”. This uncertainty or misunderstanding is amplified by other scientists on the station accomplishing research for their medical graduation or other purposes. Some patients are very sure that they have agreed to participate in a particular study, even though they have actually given their consent for another study. Other patients basically do not want to know details about the project but still want to participate. Fava and Guidi (2007) have already described this behavior and concluded from their observations that too much (medical) information would put patients under too much stress. Wearing a motion tracker is not information in the strict sense, but the many explanations about its purpose seem to be too stressful for some patients. Again, this situation is far from being optimal when it comes to informed consent and participation in studies and research projects. From a moral point of view, the circumstances described above appear to be deficient; ultimately, one has to conclude that the implementation of moral ideas must always be striven for, but can usually not be fully achieved.

#### 6.3.4 Rejection and cancellation of participation

Although it should be a matter of course, it must be stressed that patients who did not want to participate in the study were treated with particular consideration and sympathy. As described above, recruitment takes place in a situation of limited privacy. Sometimes this leads to family members requesting further information even though a rejection has already been expressed. While recruitment must therefore take place under suboptimal conditions, on the whole patients and their relatives seem to be able to deal with this inconvenient situation.

During the previous recruitment process, in 28 cases it was possible to document the reasons for a refusal to participate. Fifty percent expressed a lack of interest and respectively did not want an explanation about the study at all, which can be counted as a kind of disinterest. Fear of excessive effort on the part of the patient, especially after the spill that led to the fracture, was expressed in 18 % of the cases of refusal. Eleven percent expressed the feeling of “bad timing” because the situation with regard to the time after the discharge from hospital had not yet been clarified. Another person said that the time spent on home visits was too great an investment. Two patients did not want to take part due to their health conditions. One patient did not want to “be controlled”. One patient deceased during recruitment and one patient was discharged before recruitment was finished.

During the ongoing study four patients deceased; one patient migrated to another locality. Another person dropped out after she had been wearing the motion tracker at home and then ended up in the emergency room a second time. The motion tracker was reported lost and relatives did not want the patient to take part in the study any

longer with a new motion tracker. A dependent of another patient called in to cancel the participation providing the information that the patient had constantly forgotten the motion tracker and therefore did not wear it on a regular basis – however, the recorded data shows that the tracker was used regularly. The relatives of some patients justified the withdrawal of participation with the fact that the future situation of the patients concerned was not clear and they therefore no longer wanted to participate.

Without additional information, the figures just mentioned are difficult to put into perspective. Schulc et al. (2016) reported that in their study on preventive home visits for people over 70 years of age only 9% of those contacted with a letter answered at all. Recruitment therefore had to be supported by gatekeepers and word of mouth. As reasons for these problems, the authors state that, on the one hand, the purpose of the intervention for the target group was unclear and, on the other hand, the target persons were afraid of losing autonomy if the need for assistance was determined. Further reasons for non-participation can be found in a paper on pulmonary rehabilitation by Taylor et al. (2007): almost one-third of the non-participants did not understand either the purpose or the approach of the study. About a quarter feared that their health would be negatively affected by the study, although this contradicted the intervention. Interestingly, more than half of the non-participants only wanted to participate in a study that did not use rehabilitation measures but administered medication to improve their own health. Although not all of the reasons just described apply to the study documented here some similarities can actually be identified: lack of knowledge, incomprehension, aversion to certain types of treatment as well as fear of loss of autonomy and the fear of great effort.

## 6.4 Summary

Demographic change is taking place in many countries, making many people living longer. However, since the risk of disease or injury usually increases with age, it is important from both a medical and a care perspective to be prepared for the treatment of these diseases and injuries. This is the only way to ensure that age does not generally have to be equated with the loss of quality of life. It is therefore all the more surprising that in many areas of interest there is a lack of knowledge about older and oldest age adults. This applies in particular to people with cognitive impairments. In addition, if technology is to be used to improve the life and quality of life of this target group, studies on the effectiveness of the use of technology must be carried out. Many methodological and moral challenges have to be overcome, some of which have been described above.

In order to ensure the participation of as many people as possible in such studies, it is necessary to examine the reasons for refusing to participate in order to develop policies and practices that will help to increase the willingness of older people to participate in such studies. It can already be said that the living conditions of many older



people make it difficult for them to participate in research; therefore, the respective study design must take such difficulties into account. However, participation in studies or research and development projects must always be voluntary. In addition, it can be said that the design of technology to support older people in their lives or to contribute to therapy should increasingly involve participatory approaches. The acceptance of such technology will depend on the participation of prospective users in the design of this technology (Altenbuchner et al. 2019). This applies in particular to the consideration of moral entitlements not only of prospective users but of all stakeholders. There are already several methods for incorporating such factors into technology development, like MEESTAR (Weber and Wackerbarth 2015). Although there are already many development projects concerning age-appropriate assistance systems, specific geriatric requirements are rarely taken into account, so there is a particular lack of research in this area (Barth and Doblhammer 2017). Better and more profound knowledge of the target group of older and oldest age people, as research subjects as well as potential users of technology, could support the necessary research.

These last paragraphs mentioned older and oldest adults as a group of future challenges and research interest. Obviously, the individual patient as a subject in human research has to be taken into account too.

Increased attention should therefore be paid to answering the following questions: what conditions need to be established to make patients more willing to participate in studies? To this end, it would probably be useful to bring in the debate on nudging (e. g. Sunstein 2014, 2015; Thaler and Sunstein 2009; for an overview see Barton and Grüne-Yanoff 2015). It will also be necessary to ask what information must be provided to be able to speak of informed consent, and what information may do more harm than good. It will be even more difficult to answer the question about the role of researchers who visit patients at home as part of a long-term study. Methodological questions of influencing the results, but certainly also many moral challenges, arise here. Finally, without any doubt it should be noted that this list is not complete, but that it will be indispensable to clarify this issue, because demographic change is a fact that poses new challenges to societies as well as to science.

## 6.5 Lessons learned for future research

The project just described is designed as a long-term study with exploratory character in which an attempt was made to include all patients during the duration of the project in order to gain a broad data basis. Although the design of the study was successfully ethically assessed, normative problems were identified that cannot always be avoided, but can nevertheless be solved.

In cases of quantitative studies, researchers seem to be uninvolved because they collect data using standardised methods. There is a great distance to research subjects and interactions between researchers and research subjects do not seem to take

place. Of course, this is a false perception. Yet it is most obvious that interactions between researchers and research subjects are usually much more extensive and intense when qualitative methods are used. With regard to oldest adults who are most often at risk of losing autonomy and quality of life due to reduced mobility, unfavourable environmental conditions or an aging body with its physical and psychological handicaps, it must always be expected that interaction between researchers and research subjects can become very intensive and that predefined processes must be deviated from. In such cases, it is not enough to use light language or large fonts on documents; instead, means need to be found to shape the relationship between researchers and research subjects. Often, not only patients but also their relatives demand special attention and care. This starts with the help, for example, if a patient has lost his glasses and ends, in extreme cases, with the death of a patient. However, special consideration of such vicissitudes of life can massively influence the results of a research project. For some patients, the monthly visit of a researcher becomes a welcome and important event, not because feedback is given on their own physical activity, but because this visit offers the opportunity for a chat; sometimes the freshly brewed coffee is already on the table. For the researcher, this is a psychologically and morally challenging situation, as there is a potential conflict between objectivity on the one and care on the other hand, and between the mission of research on the one and beneficence as well as nonmaleficence on the other side.

Situations such as those just described require very precise field descriptions, which can later help to interpret the results obtained. The research design of studies on older and oldest people must be specifically adjusted for the target group. At the same time, it must be kept in mind that there is still too little empirical knowledge about this age group and that corresponding theories have therefore been insufficiently tested. In order to counteract the blurring of research on the one hand and social interaction with research subjects on the other, it is mandatory to define precise processes that are adhered to. Simultaneously, measures must be taken to address the particular vulnerability of the target group.

In short: in the context of qualitative research projects on oldest adults, researchers need to consider a life situation that is generally not (yet) their own. To do this with the greatest care is a fundamental moral requirement of such projects. Although it may seem self-evident for qualitative field research, it is essential that researchers have social skills to deal with situations such as those outlined above. Those who work with oldest adults must expect to be directly confronted with suffering, grief and sometimes even death. Again, it is helpful to follow clearly defined procedures and at the same time be prepared to act flexibly.

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## 7 Using MEESTAR for early evaluation of ethical, legal and social implications of a socio-technical support system for mechanically ventilated patients

### Lessons learned from the ACTIVATE project

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#### Abstract

In intensive care units (ICU), mechanically ventilated patients undergoing weaning from the respirator represent a highly vulnerable population. To support their early re-orientation and participation, the ACTIVATE project aims to develop and pilot a socio-technical system that facilitates the communication between these patients and the ICU health care team. Such digital health technologies (DHT) need to be assessed in terms of ethical, legal and social implications (ELSI) before they can be introduced in health care practice. In the ACTIVATE project we chose the Model for Ethical Evaluation of Socio-Technical Arrangements (MEESTAR) as guiding theoretical framework to assess relevant ELSI. Based on our intermediate findings and experiences, the objective of this article is to reflect on the applicability of MEESTAR to the assessment of ELSI of support systems targeting the acute care for critically ill patients. Following the Socratic approach, various data sources and research methods are iteratively applied for the ELSI assessment of the ACTIVATE system under development. Numerous positive implications and potential challenges, varying with the perspectives of patients and health professionals, especially nurses, were identified. Based on the preliminary findings and experiences, we expect that the implementation of the Socratic approach in combination with MEESTAR will ensure that relevant ELSI of the ACTIVATE system will be early detected and taken into account in the development and adaptation of this support system.

### 7.1 Introduction

A rising number of digital health technologies (DHT) with various fields of application and diverse user groups are already available or under development (BMG 2019). DHT can be classified by function, ranging from (i) system service technologies such as electronic health records, through (ii) DHT which are intended to help users understand healthy living and illnesses by providing information and resources, to (iii) DHT which aim to prevent and manage diseases, or (iv) DHT that directly aid diagnostics or treatment of diseases, such as implants, robots for surgery or electronic decision aids (NICE 2019). The overall aim of these different technologies is to improve the proce-

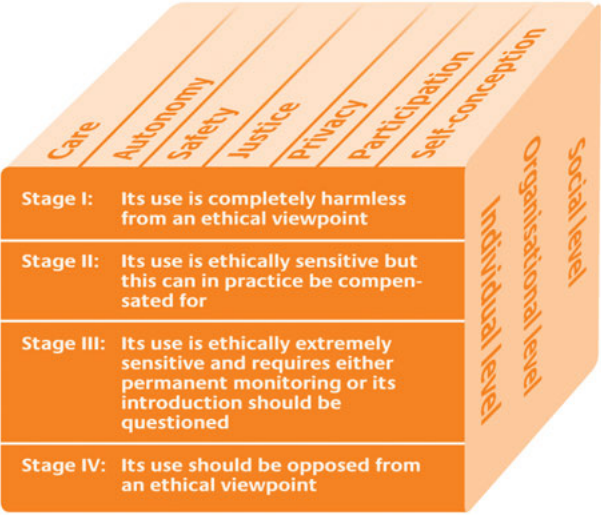


dures and outcomes of health care services (Bräutigam et al. 2017; Daum 2017). However, despite these desired benefits, the echo to this technological transformation of health care is ambivalent due to a number of ethical, legal or social concerns (Kunze 2017). Especially in the area of care for elderly or seriously ill people, DHT may affect sensitive issues related to being human, for instance autonomy or privacy (Assasi et al. 2014; Linke 2015). Furthermore, concerns related to data security or excessive demands on patients or staff members are expressed (Bräutigam et al. 2017).

Technologies are neither neutral nor value-free. Technologies, as they are developed and used, are the result of interests and values of developers and users. These interests and values as well as that of any other individuals involved and the society as a whole have to be taken into account in the development, assessment and implementation of DHT (Wright 2011). Addressing moral issues can increase the transparency of the assessment of the technologies' consequences and allow better informed decision-making about their implementation and reimbursement in health care by early and comprehensive identification and discussion of potential ethical pitfalls (Assasi et al. 2016; Bellemare et al 2018). It is thus of importance to integrate a systematic evaluation of ethical, legal and social implications (ELSI) in early stages of technology development (Brey 2017; Enam et al. 2018; NICE 2019).

The increasing awareness of the need to incorporate an evaluation of ELSI, or more specifically, ethical implications, into the assessment of (digital) health technologies goes along with a growing array of methods used or recommended for conducting such evaluations. Methods reported in the literature differ significantly in terms of philosophical approach, structure and scope (Assasi et al. 2014). Assasi et al. (2014) identified 43 conceptual frameworks or practical guidelines, varying in approach, structure and comprehensiveness. The choice of the framework and methods for data collection and analysis has to take into account the context, the purpose of the analysis and the availability of resources and required organizational capacities.

Emerging technologies are new, innovative and still in development (Brey 2017). Thus, they are still a promise. Evaluation of ethical implications at early technology development stages cannot be conducted on the basis of experiences with an already implemented and therefore entrenched technology. There are no data about existing products, its uses and its impact on ELSI. However, there is also no one right method to evaluate ethical implications of emerging healthcare technologies (Assasi et al. 2016; Hofmann 2008). One potentially suitable model is the Model for the Ethical Evaluation of Socio-Technical Arrangements (MEESTAR). MEESTAR was developed during a ten-month study in 2012. The main aims of the study were to identify key ethical problems taken into consideration with regard to the use of systems for ambient assistance and care in elderly people and, furthermore, to provide researchers, developers, suppliers and users of those systems with a tool that enables them to identify ethical challenges and discuss them constructively (Manzschke et al. 2015).



**Fig. 7.1:** MEESTAR: x-axis: dimension of ethical evaluation; y-axis: stages of ethical evaluation; z-axis: levels of ethical evaluation (Manzeschke et al. 2015).

The MEESTAR model comprises three axes as shown in figure 7.1. On the x-axis seven ethical dimensions are presented which were identified as being essential for the assessment of ambient social support systems: care, autonomy, safety, justice, privacy, participation and self-conception. The y-axis represents an assessment scheme to classify the overall ethical threats related to the technology of interest. It consists of four ordinal-ranked categories, with the lowest (best) being “its [the system’s] use is completely harmless from an ethical viewpoint” and the highest (worst) being “its [the system’s] use should be opposed from an ethical viewpoint”. The z-axis reflects the focus of assessment: individual people, organizations, or the society.

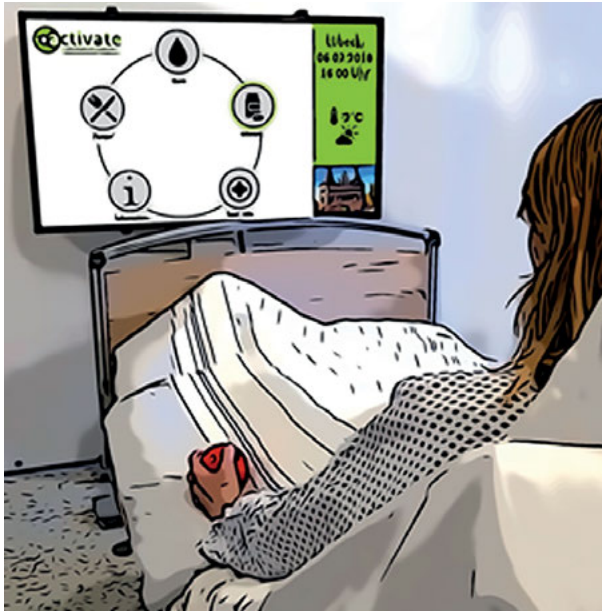
For the application of MEESTAR to a technology under evaluation, Manzeschke et al. (2015) offer detailed explanations and a set of questions related to each ethical dimension. In the final analysis two key questions shall be answered: is the use of the given system ethically doubtful or harmless? And, can the identified ethical problems be mitigated or even resolved before completion of technology development? To make sure that ethical challenges resulting from technological functions of the socio-technical system of interest can be eradicated, MEESTAR should always be used in an iterative manner throughout the development and evaluation process (Manzeschke et al. 2015).

Although MEESTAR was primarily developed for social-technical systems targeting the home care setting, it may also help guide the evaluation of ethical and other legal or socio-cultural implications of digital technologies developed for use in other health care settings such as acute hospital care. Due to a lack of alternative models, we chose MEESTAR as theoretical framework for the evaluation of ELSI in the ACTIVATE project. The acronym ACTIVATE stands for a multi-disciplinary project aiming to develop and pilot an Ambient System for Communication, Information

and Control in Intensive Care (<https://projekt-activate.de>). The project specifically addresses the communication needs of patients who undergo weaning from invasive mechanical ventilation during the treatment in intensive care units (ICU). Patients receiving mechanical ventilation are not able to express themselves verbally due to an endotracheal tube or tracheal cannula. Both the patients and the health care staff, especially nurses, perceive the communication with each other as challenging and often frustrating (Bergbom-Engberg and Haljamäe 1993; Guttormson et al. 2011; Holm et al. 2018), particularly since effective devices to facilitate this communication are lacking (Happ et al. 2011). However, ineffective communication is distressing to many ventilated critically ill patients, especially during the highly vulnerable process of being weaned off from the ventilator (Rose et al. 2014; Tsay et al. 2013), and assumed to increase the risk of deterioration and complications such as delirium (Nilsen et al. 2014).

Therefore, the core objective of the ACTIVATE system is to support the early communication between ventilated ICU patients while undergoing weaning from the ventilator and nurses who usually have the closest and most frequent contact to them during this process and thus allow more sufficient patient-nurse communication and patient involvement in nursing and medical care. The basic assumption is that this facilitation of communication will improve patient-relevant outcomes such as re-orientation and patient participation or the risk of adverse events, and reduce nurses' work-related burden.

The technical infrastructure of the ACTIVATE system is being designed based on the results of initial user and context analyses, user preference studies and joint workshops of project members (Kordts et al. 2018). In its current shape it consists of an ensemble of newly developed devices, among them a Ball-shaped Interaction and Rehabilitation Device (BIRDY) for data input by ventilated patients in very early weaning stages, a monitor screen as output device as well as speakers and headphones for auditive output. In clinical practice, the ACTIVATE system will be applicable via three major routes: first, the patients can directly activate the support system by themselves and use it to express their symptoms, wishes and other needs while undergoing weaning from the respirator. Second, nurses, other health professionals and relatives can use specific applications of the ACTIVATE system at the bedside to get into contact easier with the patient, gather more patient-reported information about her or his symptoms and needs, and thus develop a better understanding of her or his experience during the mechanical ventilation and weaning procedures. Third, the support system allows to provide the patient regularly with auditive and visual information, e. g. about the actual date, place of treatment or primary nurse, and with music or other preferred stimuli to help early re-orientation. These three routes can be used independently from each other but may also be combined, depending on the patients' cognitive and communication abilities. Fig. 7.2 illustrates how they are assumed to be implemented in clinical practice.



**Fig. 7.2:** Possible interaction between a patient and ACTIVATE<sup>20</sup> (Kordts et al. 2018).

The ACTIVATE project is being conducted by a multi-disciplinary team involving university partners from information, nursing and health sciences, the nursing research and IT service units and several ICUs of a university hospital, as well as industry partners for the design, manufacturing and later distribution of the support system. The three-year project follows the principles of human-centered design (ISO 2009) and includes three main phases: requirement analysis, development and piloting, and clinical evaluation. Throughout all phases, potential ELSI are repeatedly assessed, discussed and taken into account in upcoming development and evaluation steps. A multi-disciplinary advisory board, including experts from nursing science, intensive medicine, psychology, speech therapy, data security and patient representatives, is involved in the evaluation of ELSI through annual meetings and telephone conferences. Based on the experiences and research findings accumulated in the AC-

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**20** The patient holds BIRDY in her left hand. Through rotating BIRDY left or right, she or he can navigate through the menu structure and, for example, select the item for pain to communicate current burden due to pain. If the nurse is at the bedside, the patient will be able to communicate via the ACTIVATE screen with the nurse. For situations when the nurse is not in the patient's room, the nurse will be equipped with a smartphone to get information about the patients' interaction with the system and about the type and content of the signals sent by the patients via BIRDY. After receiving a message that the patient has selected the item "pain", the nurse will visit the patient to get into direct contact for communication. Another feature of the ACTIVATE system is that relatives will have the opportunity to upload patients' own music, photos and videos into the system to stimulate patients' re-orientation and support their emotional well-being.

TIVATE project so far, this paper aims to reflect on the applicability of the MEESTAR model for identification and discussion of ELSI related to the ACTIVATE system, i. e. a socio-technological support system that targets another health care setting and user groups than those ambient support systems originally addressed by the model.

## 7.2 Methods

For the continuing assessment of potential ELSI, a combination of iterative inquiries using different methods and involving various target groups and stakeholders is used in the ACTIVATE project. Methodologically, this stepwise process is based on the Socratic approach as recommended by Hofmann et al. (2014). The conceptual planning of data collection, data analysis as well as discussion of the findings was guided by the MEESTAR model. Fig. 7.3 provides an overview of the chronological order of the conducted and remaining evaluation steps, including the data sources used. A detailed description of the methods used for ELSI assessment within the ACTIVATE project will be published elsewhere. This chapter summarizes key information on the methods applied in the evaluation steps carried out so far.

The identification and evaluation of ethical implications and challenges within the ACTIVATE project started right at the beginning to assure the earliest possible identification especially of perceived risks related to the use of ACTIVATE. As a first step of the ethical evaluation, relevant stakeholders were identified. These include the main target groups of the ACTIVATE system, i. e. mechanically ventilated ICU patients and ICU nurses, as well as physicians, therapists and relatives who were also identified as being prospective users of ACTIVATE. Other relevant stakeholders important for the technology development were also identified, such as computer scientists, data protection experts or speech therapists. All of these stakeholders' perspectives will be considered throughout the evaluation of ELSI, either by respective study samples or by the members of the project team and the advisory board.

As a next step, baseline data regarding the target groups' expectations about the potential benefits, challenges and harms related to the intended ACTIVATE support system and potentially relevant context factors were gathered and analyzed within the first six project months. Various information sources, comprising both secondary (aggregated) and primary data, were used in this evaluation step. For secondary data analysis, two scoping reviews were conducted to get an overview of existing research evidence on (i) the views and experiences of mechanically ventilated patients and informal caregivers during the ICU stay and (ii) digital technologies developed to facilitate the communication with ICU patients who are unable to orally verbalize their needs, symptoms or wishes. Each scoping review consisted of systematic literature searches in several electronic databases and complementary searches via Google Scholar and reference lists of eligible articles, followed by systematic two-step selection of relevant articles and standardized data extraction (Tricco et al. 2018). The

primary data collection comprised (i) 10 semi-structured, non-participating observations by members of all project team partners in two ICU wards, (ii) semi-structured topic-guided face-to-face interviews with 16 ICU patients directly after being successfully weaned off from a respirator and 16 relatives of such patients, (iii) three focus groups with 26 nurses, one physiotherapist, and one chaplain, and (iv) semi-structured topic-guided face-to-face interviews with 6 ICU physicians (Henkel et al. 2018). The main purpose of the observations was to ensure that key members of all project partners share a basic understanding of the ICU care environment, the goals and procedures of nursing and medical care for ventilated patients and the symptoms and needs of patients undergoing weaning from mechanical ventilation. Both the focus groups and the interviews aimed to provide deeper insights into the perceptions, experiences and expectations of the patients, relatives (informal caregivers) and hospital staff related to the weaning process, the challenges in the patient-nurse, patient-staff or patient-family communication during this process, and potential advantages or disadvantages of digital support of this communication. All interviews were recorded as audio files and then transcribed verbatim. The data gathered from the qualitative inquiries were thematically analyzed and aggregated with the findings from the scoping reviews. An inductive-deductive approach was used for this thematic analysis, with the ethical dimensions of the MEESTAR model serving as theoretical framework for the grouping of inductively identified themes relevant to ethical or related implications.

In a successive step, the preliminary list of potential ELSI arising from this analysis was discussed with the project team and the multi-disciplinary advisory board in a structured workshop using the World Café method to ensure that the perspectives of all participants are sufficiently reflected. This workshop took place approximately 11 months after project start. The questions recommended for ethical reflection by the MEESTAR model and the Socratic approach were used to guide through the discussions. Based on the workshop results, the preliminary ELSI list was revised and fed back to all workshop participants, including those responsible for the development of the technical infrastructure of ACTIVATE.

To keep abreast with the advancing of the technology development, qualitative inquiries were repeated several times in order to validate the preliminarily identified ELSI against the detailed personas, application scenarios and technical features developed in the meantime. Until now, two focus groups involving 10 nurses and two physiotherapists, and one speech therapist were conducted in project month 15, and another two involving 10 nurses in project month 28. For project month 31, individual interviews with former ICU patients undergoing weaning from the respirator are planned. The participants were/will be asked to discuss, with an ethical viewpoint in mind, potential challenges and benefits of the ACTIVATE system. Again, the interview audio files were /will be transcribed verbatim and then analyzed by means of the same methods as described above. In addition, two further structured discussions

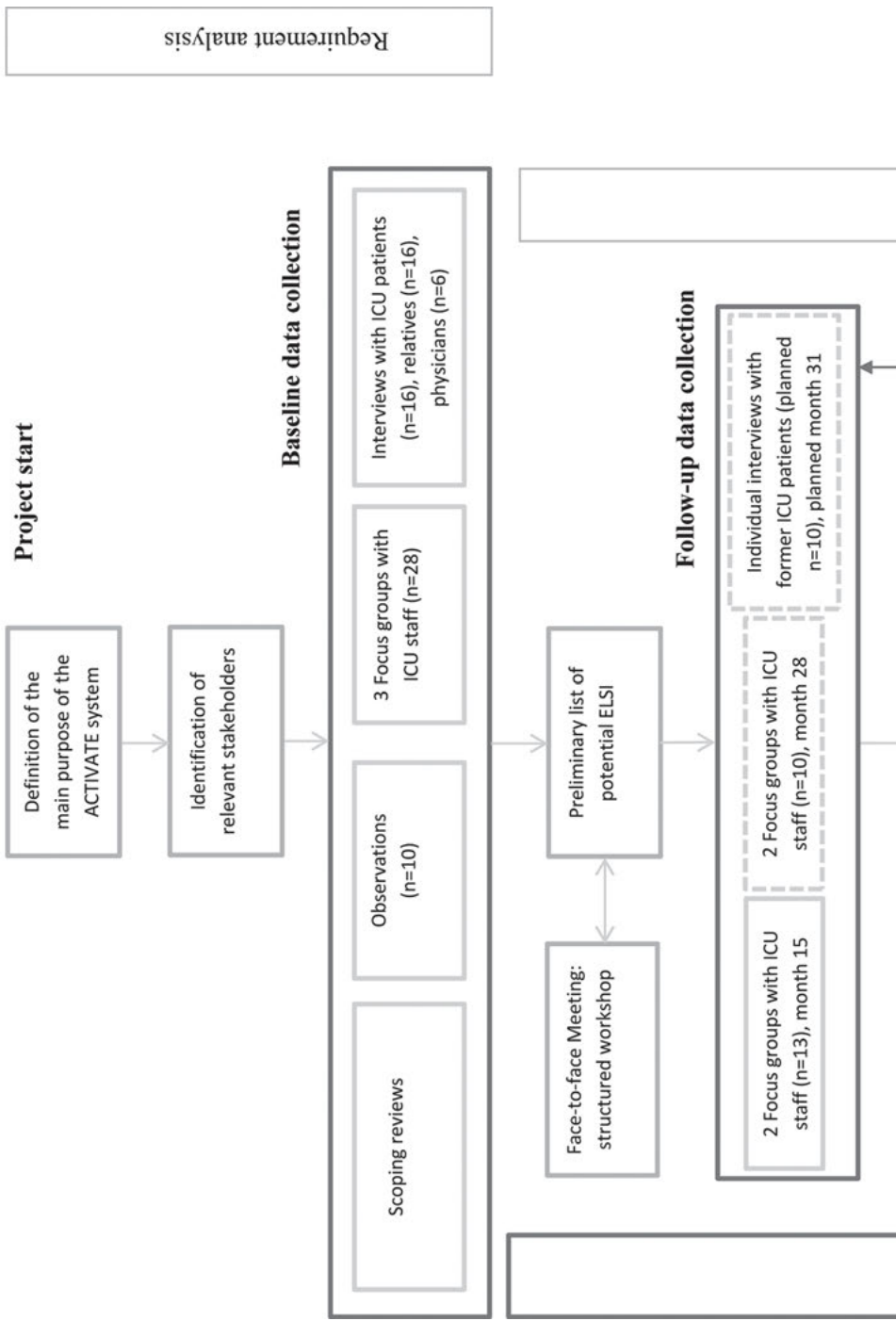
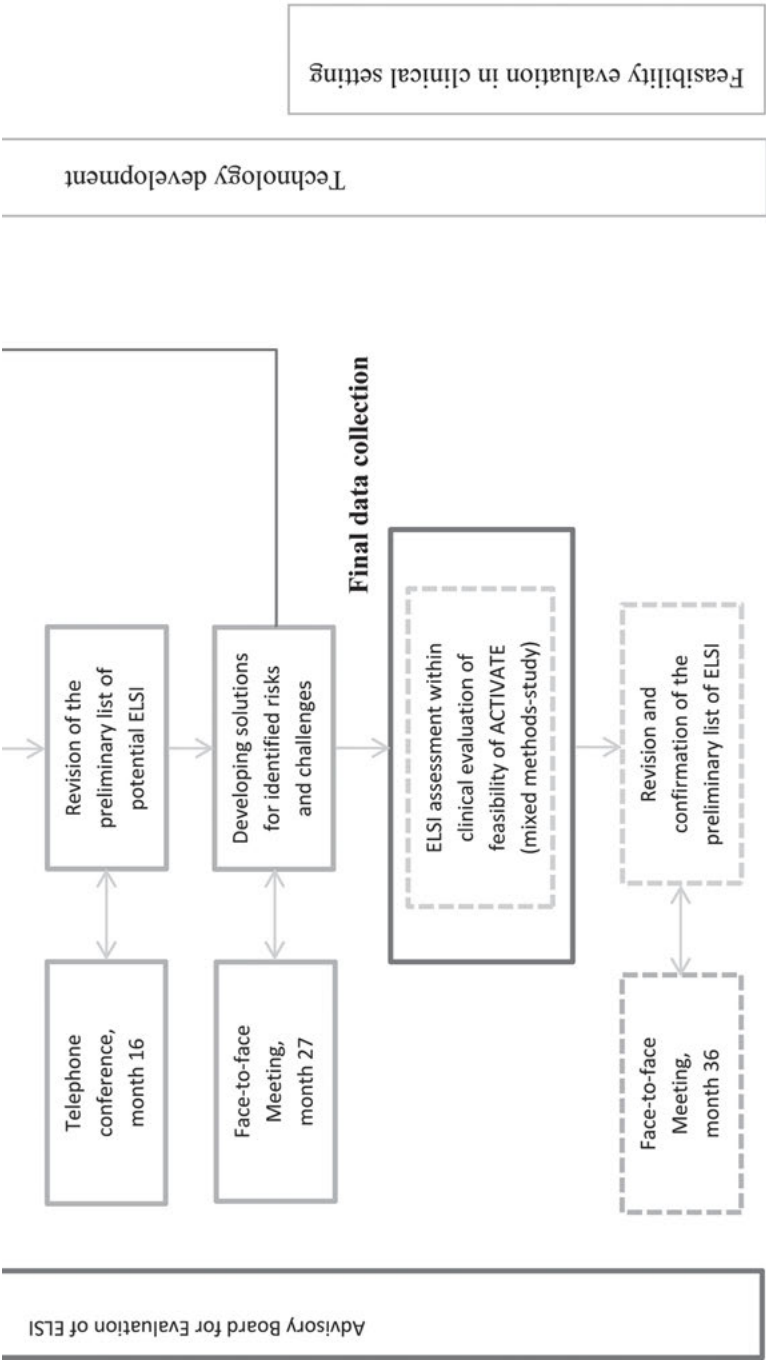


Fig. 7.3: Relevant steps of ethical evaluation within the ACTIVATE project.





of the preliminary ELSI list with the advisory board, took place, one via telephone conference and one face to face.

In the final step, the iteratively list of potential ELSI will be taken into account during the clinical evaluation of the feasibility of the ACTIVATE system during the project months 33 to 36. For this study a mixed methods design will be used, consisting of a cohort study complemented with semi-structured non-participating observations of patient-nurse communication episodes, focus groups with nurses and other professionals, semi-structured interviews with patients and a survey among ICU patients' relatives. The protocol for this study is still under development. However, results of this study will also be used for a final discussion of a reflection on the list of ELSI together with the advisory board.

### 7.3 Results

In this chapter, we report a summary of intermediate findings from the analysis and the within-project discussion of the data gathered until project month 15 (figure 7.3). While the findings presented below are still preliminary, they already reflect a synthesis of the views and expectations of all stakeholders involved in the early ELSI evaluation of the ACTIVATE system under development. In the iterative process of data analysis and discussions with the project team and advisory board members, it emerged that the ELSI of the intended support system partially differ between the stakeholders. In particular, two major points of views have to be distinguished: that of the patients targeted by the ACTIVATE support system and that of the health professionals, especially nurses, intended to use this system in their care for these patients. Therefore, themes emerging from the data analyses and discussions were grouped according to these two perspectives. Although the findings assigned to each perspective are rooted in an amalgam of all stakeholders' views and expectations, it has to be recognized that the perspective of the patients is mainly informed by the primary and secondary data directly gathered from (former) ICU patients with weaning experience and their informal caregivers (relatives), while the staff perspective largely reflects the findings from the focus groups and interviews with nurses and other ICU health professionals carried out in this project. Until now, our analyses and discussions did not provide indication of ELSI uniquely linked to informal caregivers. Instead, the views and expectations expressed by these caregivers or by others taking on their perspectives largely resemble those found for the patients' perspective and were therefore assigned to this perspective as well. The staff perspective is dominated by data gathered from nurses who were purposively included in a larger number in the qualitative inquiries than other professionals since they represent the main target group of the ACTIVATE system among the ICU staff. However, the ELSI derived from the whole body of data analyzed so far are quite consistent across the various professions involved in our studies and discussions. Therefore, no distinctions were made between the pro-

fessions in the synthesis of the preliminary findings, and the terms “staff perspective” and “nurses’ perspective” will be used synonymously in the following.

The evaluation of ELSI revealed numerous implications, positive and negative, with regard to the prospective use of the ACTIVATE system. Not all ethical dimensions of the MEESTAR model appeared to be of equal importance from each perspective. While from the patients’ perspective, all of the seven dimensions were noted except justice, the staff perspective was not linked to three dimensions: care, justice and participation. Thus, based on our preliminary findings, the dimension justice is not viewed as being relevant from either perspective. It was indeed mentioned that the ACTIVATE system shall be available to every ICU patient undergoing weaning, and it was also stressed that all staff members shall have access to this system, but this is more a requirement for the future than an ethical issue at this time of the technical development. The ACTIVATE support system, once implemented, is planned to be part of the routine hospital infrastructure. Thus there shall be no access restrictions due to financial reasons.

The dimension care was, as already mentioned, not raised as a topic relevant to ELSI from the staff perspective. But from the patients’ perspective, both positive and negative implications associated to this dimension were brought up. On the one hand, there is the expectation that patients’ needs and symptoms will be better recognized and met when the ACTIVATE system is in use. On the other hand, concerns were expressed that this support system might replace nurses as a communication partner, leading to a reduction of patient-nurse communication and hampering the building of trustful relationships between patients and staff.

The dimension privacy was only associated with implications related to data protection, from both perspectives. It was acknowledged that the ACTIVATE system will record and process personal und sensitive health-related data. Particular data protection threats were noted due to the risk that with the ACTIVATE system in use patients may generate data without being aware of it, especially at early weaning stages when they have not yet fully regained their consciousness.

Like the MEESTAR dimension care, participation was only linked to the patients’ perspective. Furthermore, it is the only dimension which was exclusively viewed positively. The expectation is expressed that the ACTIVATE system will assist patients to participate in decisions affecting their treatment and care. Furthermore, the support system is expected to enhance the communication between the patients and their informal caregivers, provide access to individual media as music, photos or videos and facilitate remote participation in family life.

The dimension self-conception includes different implications depending on the perspective taken on. From the staff perspective, it is understood as professional self-conception with regard to the field of nursing. The identified implications reflect ambivalent views and expectations, varying between an improved job satisfaction through enhanced patient-nurse communication and accordingly optimized care on the one hand and deep concerns that the ACTIVATE system might replace nurses

through taking over the communication with the patients on the other hand. Self-conception from the patients' perspective is understood as the feeling of being an active agent despite all of the impairments and restrictions entailed by the critical health conditions and the invasive treatments in ICU care. Being able to communicate, to participate and therefore to take on active roles, instead of being merely a passive recipient of nursing care and medical treatments, is being viewed as a positive implication from the patients' perspective. The feeling of helplessness should be reduced to a minimum. However, the patients' perspective includes some ambivalence, too, since concerns were also expressed that the ACTIVATE system may hurt the individual self-concept of patients not willing to communicate by means of a technological system.

Regarding the dimension autonomy there is one strong positive implication from the patients' perspective: the possibility for the patients to communicate wishes and needs and to choose whether or not to communicate them as well as how to communicate them. Empowerment and self-determined acting and communicating are the desired benefits related to this dimension. But some concerns were also raised, among them the risk that a patient might feel forced to use the ACTIVATE system. Furthermore, patients admitted as an emergency case cannot be made familiar with the support system *ex ante*, they may be not able to provide their informed consent to the use of this system right at admission. Both the positive and the negative implications noted regarding this dimension are relevant to patients and the ICU staff

Positive and negative implications were mentioned, relating to the dimension safety. Positive implications mainly affect the patients' perspective and are associated with an optimized patient-nurse or patient-staff communication, respectively, which may lead to earlier and more accurate symptom assessment, more appropriate responses to patients' needs and therefore to an optimized nursing care and medical treatment. A major concern from the patients' perspective is that the ACTIVATE system might overstrain the patients due to its various features and related visual or auditory stimuli. The risk of reduced monitoring of the patients was also mentioned. Staff might rely on the patients' ability to use ACTIVATE and eventually reduce their efforts for patient observation and nursing assessment. Further concerns mentioned from the patients' perspective relate to the risk of developing a device-related pressure ulcer or an elevated exposure to radiation. From the staff perspective, similar concerns were noted as from the patients' perspective, altogether resulting into the worry that the ACTIVATE system may put excess demands on the staff, especially nurses, on top of the already existing workload and technical systems in ICU care.

## 7.4 Discussion

The early evaluation of ELSI related to the prospective use of the ACTIVATE system indicated numerous positive implications but also potential challenges. To summarize, from the patients' perspective clear-cut benefits in terms of almost all MEESTAR dimensions are expected from the ACTIVATE system, with participation being exclusively viewed positively. With regard to potential negative implications, a number of threats were noted from the patients' perspective as well, many of them affecting the dimension's safety, autonomy and privacy. From the staff perspective, the preliminary list of ELSI includes potential benefits and risks regarding the MEESTAR dimensions self-conception, privacy, autonomy and safety. For some of these implications, the underlying considerations resemble those behind the patients' perspective as they are also linked to the assumed impacts of the ACTIVATE system on the patient-nurse communication. From both perspectives, the potential of communication improvements by implementation of this support system has been recognized and judged as being relevant in terms of ELSI, for example by facilitating a more person-centered care and thus enhancing the participation, safety and autonomy of the patients as well as nurses' work satisfaction and professional self-conception. On the other hand, potential downsides related to the effects on the patient-nurse communication were also mentioned and discussed. A major concern is that the socio-technical support system may replace face-to-face communication between patients and nurses or other health professionals, respectively, by patient-machine communication, thus leading to a reduction of direct patient-nurse contacts at the bedside. From the patients' perspective this may increase the risk of insufficient symptom and needs assessment and thus comprise the safety, participation and autonomy of the patients. Furthermore, from both perspectives the idea of patient-machine communication partially substituting patient-nurse communication challenges fundamentals of nursing care and, from the nurses' perspective, nurses' professional self-conception. Also, across both perspectives concerns were brought up that implementation of the ACTIVATE support system may change the normative standards of preferred routes of communication, with socio-technical support systems becoming compulsory to use in the care for highly vulnerable patients such as ICU patients undergoing weaning, irrespective of individual preferences for or against this mode of communication.

All of the ELSI noted so far for the ACTIVATE system could be classified under one of the ethical dimensions of MEESTAR. No implications were detected which refer to ethical, legal or socio-cultural subjects not covered by this model. Thus, our preliminary findings suggest that MEESTAR provides a suitable framework to guide the early evaluation and adaptation of the ACTIVATE system in terms of ELSI although it was originally not conceptualized for the assessment of socio-technical support systems to use in acute care settings (Manzeschke et al. 2015). This indicates that the MEESTAR model is less context-bound than expected. Instead, our findings underscore that it is based on ethical considerations and moral values universally required for the use

of DHT in conditions fit for human beings. However, as all of our inquiries and discussions were mainly guided by MEESTAR, there is still a certain risk that we missed implications of the ACTIVATE system outside this theoretical frame. In our project, we strive to limit this risk by use of the Socratic approach which implies that divergent stakeholders and various data sources are systematically incorporated throughout all steps of ELSI assessment in this project (Hofmann et al. 2014). Furthermore, the Socratic approach includes more than 30 moral questions which we take into account in addition to the ethical dimensions of the MEESTAR model in the collection, analysis and discussion of the assessment data. Therefore, while the focus of our ELSI assessment of the ACTIVATE system is theoretically guided by MEESTAR, our methods aim to ensure that it is not limited to this model.

One ethical and also legally relevant dimension which has to be further examined is privacy. By use of the ACTIVATE system, the promotion of patients' ability to communicate their needs and wishes is exchanged for a loss of privacy related to the generation of data. In MEESTAR, privacy is defined as an inviolable zone established around people (Manzeschke et al. 2015). Following this definition, we have to get more insights into the meaning of privacy from the perspective of ICU patients undergoing weaning from a mechanical respirator and then proceed to discuss how privacy, as understood by the target patients, can be maintained by the ACTIVATE system as much as possible. Another dimension to be discussed further is self-conception from the patients' perspective. Although our findings indicate that ACTIVATE might have positive impacts on patients' self-conception through providing better possibilities to actively participate in care and treatment decisions, the opposing argument was voiced that this support system might have a negative impact on patients' self-conception if patients do not want to use such technology for communication. In the remaining inquiries for the ELSI assessment, we will collect quantitative and qualitative data on patients' responses to the introduction of a prototype of the ACTIVATE system into laboratory and routine ICU care conditions and thus get a more accurate account of patients' concerns and reservations regarding this kind of digital care support.

Aside from the strengths and limitations already discussed above, a further strength of the ELSI assessment within the ACTIVATE project is the continuous involvement of relevant stakeholders from early beginning onwards, among them representatives of the targeted patients and health professionals. Following the framework of participatory technology development, it has to be ensured that technology is developed not only for but also with the target group(s) (Compagna and Derpmann 2009). (Potential) Users might perceive and judge the impact of a technology differently from developers or suppliers. Recent requirements by the National Institute of Health and Care Excellence (NICE) ask developers and suppliers of DHTs to demonstrate that representatives from intended user groups were involved in the design, development and testing of the respective technology. Fulfilment of these requirements is regarded as a minimum evidence standard to increase the acceptability among users (NICE 2019).

However, in the baseline and early follow-up focus groups and interviews with the (former) patients, informal caregivers and health professionals we noted that it was difficult for them to imagine the actual shape, features and potential applications of the intended ACTIVATE system since at these early project stages we had no prototype at hand and could only present theoretical ideas about the intended design, functions and future use of the ACTIVATE support system. Thus, the very early ELSI assessment has been conducted based on speculative information (Brey 2017). It is thus prone to some uncertainty inherent to these theoretical assumptions and the perception of this information by the study participants, and this uncertainty may limit the validity and completeness of the ELSI revealed by our inquiries so far. But, on the other hand, only this very early ELSI assessment offers the possibility to influence the technology development from the very beginning. The further the technology is developed, the better risks, challenges and benefits can be identified, but it is more complicated to change the technology (Brey 2017). In the remaining assessment steps and especially within a pilot study to evaluate the feasibility of the ACTIVATE system in routine ICU care, a variety of quantitative and qualitative data will be collected from the patients, informal caregivers and health professionals to examine the validity and completeness of the preliminary list of ELSI. For example, we will be able to verify whether the concerns revealed reflect actual potential threats originating from the ACTIVATE system or are rather due to prejudices expressed by individual participants.

## 7.5 Conclusion

This article reports the methods and intermediate results of the early ELSI assessment carried out along the development of the ACTIVATE support system which aims to facilitate the early communication between ICU patients undergoing weaning from a mechanical respirator and the health professionals, especially nurses. In particular, this article aimed to reflect on the question whether the MEESTAR model chosen to theoretically guide this ELSI assessment is suitable for the assessment of a socio-technical support system targeting the acute care for critically ill patients.

So far, several positive implications as well as perceived risks of the ACTIVATE system have been identified by our ELSI assessment. Although not all dimensions of the MEESTAR model seem to be of equal importance for the use of the ACTIVATE system, both from the patients' and the staff perspectives, all of the identified implications could be categorized into one of the seven MEESTAR dimensions. This underscores the universal relevance of the ethical dimensions reflected by MEESTAR and suggests that this model is also applicable to DHT targeting the setting of ICU care. As the ELSI assessment has been implemented since the very beginning of the project, all of the identified challenges and risks were and are still being taken into account in the system's development. In the further course of the ACTIVATE project, the preliminary list of ELSI will be subject to further quantitative and qualitative inquiries to ex-

amine its validity and completeness and thus provide a robust body of knowledge for the final ELSI assessment of the ACTIVATE prototype before this DHT will be released for large scale evaluation and implementation in ICU routine care settings.

## 7.6 Ethical Statement

All studies were conducted in accordance with the ethical standards of the institutional research committee (file number 17–098). Informed consent was obtained from all individual participants included in the study.

## 7.7 Acknowledgment and funding information

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## **Part III: Users' expectations and needs-based development**



## 8 Challenges arising from the use of assistive technologies by people with dementia in home care arrangements

Sarah Palmdorf, Christoph Dockweiler

### Abstract

People with dementia living at home are potential users of assistive technologies, as are their informal or professional carers. However, the development of these technologies is oriented more towards what is technically possible as towards the needs of the subsequent users. This is due to the fact that including this group of patients in the development is subject to particular challenges because of their vulnerability and the symptom changes. In addition, weighing the use and the actual application of technology raises both ethical and legal challenges. This implies the formulation and articulation of an informed consent, the emergence of ethical problems depending on the actual system and its application, equal resources and equal opportunities. These ethical problems will be discussed in the following and lead to considerations of the challenges arising from the participation of users and the demands made on technologies and users. So far, the ethical and legal challenges of using the technologies have not been discussed adequately with the user group. There are also no established concepts supporting people with dementia and their relatives when making a decision about using a system, helping them reflect on the possible consequences or finding an alternative that would facilitate self-determined care. Another issue, which has yet to be dealt with, is how decisions made at the onset of the disease should be implemented in the home care setting during the further course of the illness.

### 8.1 Introduction

In Germany, 1.7 million people suffer from dementia (German Alzheimer's Association 2018). Dementia is an umbrella term identifying a syndrome usually of a chronic nature in which there is a disturbance of multiple higher cortical functions: memory, thinking, orientation, language, judgement and learning (Robinson et al. 2015). The sense of self steadily deteriorates, distancing the people with dementia (PwD) from their former selves and, in turn, their relationship with friends and family (Quinn et al. 2009; Wadham et al. 2016). Further to this, the prevalence of challenging behavior such as anxiety, hallucinations, delusion or disinhibition is high (Savva et al. 2009; van der Linde et al. 2016). Due to the disease, PwD are restricted in their activities of daily living and rely on support from other people. These can be informal carers like family members or professional carers. This potentially leads to a stressful situation for the family and professional carers alike (Gilhooly et al. 2016), but PwD want to stay

at home as long as possible (von Kutzleben et al. 2012; Wiles et al. 2012) and moving them to a new setting increases confusion and disorientation (Helvik et al. 2018). For this reason, interventions are needed to support PwD and their relatives in home care. This is where technical systems can be a solution.

In recent years, technical developments have progressed rapidly, whereby the health-related use of communication and information technologies pursues broader targets. These include: a) promoting the efficiency and needs-orientation of prevention and care; b) enabling equal opportunities healthwise; c) strengthening participation and empowerment; d) increasing the economic viability and efficiency of healthcare; e) promoting and disseminating evidence-based healthcare; and f) facilitating specialization in healthcare. PwD and their families are also target groups for technical support systems and these show manifold potential for shaping lives and care. Digital health technologies (DHT) can reduce disease-related risks, e. g. burning down the kitchen or getting lost (Meiland et al. 2017), promote independence (Godwin 2012; Ienca et al. 2016), avoid or postpone residential care (Abbott 2007; Ienca et al. 2016), prolong social inclusion (Abbott 2007) or promote social justice (Godwin 2012) by facilitating access to existing interventions such as telehealth. Research on the use of assistive technology among cognitively impaired users is in its infancy. The current evidence is far from being extensive and the methodological quality of studies has been reported as low (Meiland et al. 2017). Studies with these patient groups are time-consuming and have to fulfill high ethical standards. This impedes the participation of the subsequent user group in the development and research of technical systems.

Because of their illness, PwD have difficulty in using new technologies. This concerns problems with learning, remembering and orientation, e. g. they cannot remember, or only partly, any earlier instructions in connection with technology, have difficulty in understanding verbal instructions and cannot easily recognize audio-visual prompts (Nygård and Starkhammar 2007; Riikonen et al. 2013). Furthermore, they may have other cognitive or physical impairments that influence their use of the technology, e. g. in the case of Parkinson's dementia (Ienca et al. 2016).

All in all, this leads to PwD and their relatives hardly being involved in the development of technical systems. Consequently, systems are developed that do not meet the needs of the later users (Ienca et al. 2016; Meiland et al. 2017). Against this background, ethical implications are found at various levels, which are systemized and discussed in the following. This includes the following aspects: (1) formation and expression of an informed consent; (2) effects and side effects of assistive technologies; and (3) resource access and equal opportunities. Subsequently, ethical problems are made clear by a concrete assistive system. The second part of the chapter deals with the challenges that arise when users are included in product development and evaluation. This results in demands on the technology and the user. At the end of the chapter, the findings are summarized in the form of practical implications for ethical discourse.

## 8.2 Formation and expression of an informed consent

The user's statement of intent regarding the use or non-use of technical assistance systems presents a challenge for PwD and their relatives. Presumptions that are necessary for setting up and expressing an intention may not be fulfilled because of the existing cognitive impairments. This implicates (1) access to information about the system, (2) the competence to understand the system and (3) reflect the reasons for its use against the background of one's own disease, and (4) the assessment of one's own vulnerability and that of relatives.

Access to information can be problematic at multiple levels. There is still an information deficit for both the users and the professional carers with regard to existing technical systems that could present a solution for the current healthcare problem (Godwin 2012). Access to care-related information is largely dependent on the individual competences of the user groups in the identification and application of the (health-related) technologies. The term "competence" refers back to the concepts of health literacy research. This relates to the knowledge, motivation and competences people need in order to find, understand, assess and apply the relevant health information in its various forms; they can then make judgments and decisions in everyday life relating to healthcare and health promotion, disease management and prevention, which maintain or improve their quality of life throughout their lives (Zamora et al. 2015). Here eHealth literacy can be regarded as a field of health literacy that refers specifically to the use and acquisition of information and knowledge within online-based health communication; this, however, calls for extended competence in the application and understanding of information and communication technologies (Neter and Brainin 2012). This includes computer and media competences (the knowledge and ability to find and use technologies and various online-media), information competences (knowing how online information is organized), literal competences (the knowledge and ability to understand online information) but also scientific competences (the basic knowledge about the significance and classification of scientific findings) (Norman and Skinner 2006). Up to now, there are no methods for a standardized assessment of eHealth literacy of PwD, nor are there any concepts for promoting this.

People with dementia and their relatives might have problems with the autonomous search of information, especially on the internet (Kim 2015). Currently, this generation of PwD has few biographic experiences on which they can rely regarding this topic. This will change in the following generations. Furthermore, it is not clear how the information, especially that regarding the use of more complex systems, should be prepared so that it is understandable despite cognitive limitations. This includes information concerning data protection for the acquisition, processing, transmission and storage of data, whereby the question here is to what extent data acquisition on humans is automated. If health-related (and other relevant) data are collected without the user being actively involved (e. g. automatically via cameras), then safety is

objectively increased, although in the end the desired emancipation and self-determination is not achieved. On the contrary, competences are no longer supported and care is often completely beyond one's own control (Siep 2007). It is also unclear how to ensure that the information relating to the handling of the data has been understood.

Reflecting whether the PwD has the competence to form a will about the use of technical systems is also problematic, especially when changing symptoms are taken into account. In addition, the verbalization of expressions of intent may be limited due to communicative restrictions caused by dementia. When considering the reasons for use, the dependence on support from relatives or professional carers must be borne in mind, since both are also part of the decision-making process on the use of assistive technologies. When weighing the various interests, the question arises to what extent a free choice for or against the use of a system actually exists, if the supporting person or organization has its own interest in using the technologies or when there is a dependency on the supporting system that increases as the illness progresses (Niemeijer et al. 2010). For instance, the PwD might decide to use a global positioning system (GPS) because he wants to relieve his relatives who feel easier if the PwD has the help of a GPS. Or an outpatient care service might use a form of communication technology to expedite internal processes without which they could not offer their services. This is followed by the question as to what effects the non-utilization of a technology would have on the care situation and whether this would result in poorer care, so that there is *de facto* no freedom of choice about using the technology or the person at least feels compelled to use it. This might be the case if clinical monitoring can only be realized digitally (e. g. by means of a video consultation) because the PwD is restricted in his mobility or lives too far away.

Although it is difficult to set up and express an informed consent, the main target remains: to maintain and promote the autonomy of the PwD (Nuffield Council on Bioethics 2009; Zimmermann-Acklin 2005); they are afraid of losing their independency and control of their lives or that their wishes will not be respected. However, studies have shown that PwD are indeed able to decide about using a technological system and that to generally reject the ability to make decisions is not acceptable (Godwin 2012).

### 8.3 Effects and side effects of assistive technologies

Compiling the effects and side effects of using assistive technologies according to the principle “do-no-harm” is impeded by the changing dementia symptoms and the high prevalence of challenging behaviors. Interpreting behavior depends on each individual situation, since behavior can be influenced by internal and external triggers, which are not necessarily connected to the use of the technology (Kales et al. 2018; Sachweh 2019). This makes it difficult to explain a behavior with regard to the accep-

tance of the technology or its impact on PwD. In addition, the disease can make early verbal articulation difficult (Szatloczki et al. 2015), which hampers the assessment of the effects and side effects of technologies for this group of people. It is particularly problematic if the PwD lives alone and side effects only become noticeable during this time, e. g. due to diurnal disorientation, and the PwD develops a fear of the technology because lights or acoustic signals are not recognized as part of the system. Side effects may therefore not be noticed by relatives or professional carers. Other side effects may be more subtle and do not result in strong outward-directed behavior. For instance, a living area that is equipped with sensors, cameras and mobile devices no longer provides the feeling of “being at home” that had been the original reason for being cared for in the own home. Another side effect might lie in the PwD becoming too dependent on the technology, whereby the possible impact on the self-image and on the handling of the disease has not yet been investigated. Further side effects may result from the possible dependency of the PwD on the technology. Up to now, there have been no studies dealing with the possible effects to the self-image of the PwD or with how he copes with the disease, nor have any long-term studies been conducted that investigate the effect of assistive technologies on the course of the disease. This makes it difficult to assess the effects, effective relationships and side effects on PwD who use assistive technologies.

### 8.3.1 Resource access and equal opportunities

A further ethical area of conflict arises in the interaction of social, health and digital inequalities and the resulting question of resource accessibility for different population groups. The patient possibly has to pay for the technology as well as its maintenance on his own. Depending on the cognitive and motoric abilities of the PwD, support from the family is required (or is deemed to be required individually) in order to ensure the handling of technological health solutions. The lack of these resources can lead to unequal opportunities for the affected persons. Health services to improve the care situation should be accessible to all patients and at all times, regardless of the state of health or location. In a predominantly rural area with a low concentration of specialist physicians, the possibility for consulting a specialist about information and communication technologies during the course of the treatment is an important aspect of healthcare. Due to the networking of various types of health personal on different levels or sectors, digital health technology can contribute towards ensuring care safety and quality in the sense of services to the public even in areas with little medical and nursing infrastructure (AGENON 2009).

Inequalities of access to DHT can be ascribed to diverse living conditions at various levels. Assuming that technical, individual and social resources are subject to a socio-economic gradient, this can first lead to discrimination against people with lower socio-economic status in such a way that they are less able to master health



technologies and therefore benefit less from them. The same applies to a second dimension of inequality with regard to socio-demographical characteristics (e. g. age, gender). This reveals disparities with regard to the technology-related self-efficacy, the perceived assessment of potentials and risks of the health-related use of technology and, ultimately, its use (Wewer et al. 2013). A third dimension, which can grow to be an inequality with regard to DHT, is the culture, i. e. the entirety of the values, norms, attitudes and beliefs of a person from a specific cultural area. Direct interrelations between culture and the accessibility of technology exist in the form of language barriers or (even) culturally shaped technology orientation. Indirect influences from the cultural environment are to be assumed against the background of individual values, e. g. with regard to the desired relationship between doctor and patient or the general attitude or affinity to technology (Kummer 2010). A fourth dimension of inequality can be found in the geographical influences within the phenomenon of the digital divide. While the use of DHT lifts geographical healthcare barriers, an adequate coverage of the basic digital technologies (e. g. broadband connections, mobile data networks) is, nevertheless, a prerequisite (Westermeier 2014).

If assistive technologies were to be used everywhere in the care of PwD, the aforementioned influences would have to be questioned with regard to discrimination against a group of people. This applies especially to the access to resources, since up to now none of the technologies is partly or entirely financed by the health insurance in general; and since the disease potentially leads to a financial burden (Kim and Schulz 2008), people with low financial means would not be able to use the technologies. This is the actual healthcare situation at the moment, since assistive technologies can still only be purchased through private financial means.

A further risk of inequality exists for PwD who have a migration background. Even in the early stages of the disease, the affected people can lose the ability to communicate in their second language, which at the same time is considered shameful (Forbat 2003). Technologies that require the use of the second language might exclude this group of people. If this problem were taken into consideration during the development of assistive technologies, it would provide a chance of overcoming language barriers.

In the following, the ethical problems concerning specific technology will be presented and discussed.

### 8.3.2 Ethical problems in using global positioning systems (GPS)

Taking the use of GPS as an example, it becomes clear what ethical problems exist with the individual use of a concrete system. The individual application is the deciding factor whether the GPS is used for the PwD's deception in promoting freedom and autonomy or as a restraint. The deception of the PwD might be the fact that the PwD is unaware of the system being used; for instance, he is not told that the "watch" can be

used as a tracking device or that it's hidden in his clothes. The relatives might choose to deceive the PwD if they are afraid the use might otherwise be rejected. The family members would then be in a dilemma: if from their point of view the PwD needs but rejects the use of a GPS, the use is ethically justifiable because the PwD would forget he was using the technology (Godwin 2012; Niemeijer et al. 2010).

The concrete use and the respective system are also decisive for whether the system is used in the sense of maintaining and promoting space for movement or as a measure restricting freedom. Significant here is the question of when an alarm is activated and what reactions occur as a result. For example, a system might give an alarm if the PwD leaves a certain area, or stays longer than usual in one particular place, or leaves the building. The relative could then wait and see because he knows that the person usually leaves the house for half an hour. Or he accompanies the PwD back into the house immediately because he is of the opinion that the PwD would get lost outside. The respective reaction to the alarm and the alarm itself are the key to whether the system is used for maintaining or restricting freedom of movement. In addition and with regard to the restriction of freedom, consideration must be given to other measures the relative might use as a result of the pressure to act and prevent the PwD from leaving the house – locking the front door or administering sedatives, perhaps. Assessing the alternative measures complicates the ethical risk assessment for the use of a system. The evaluation of the technology by the relatives is also important in this context; generally, they are more likely to estimate technologies that promote autonomy as being ethically acceptable. To what extent the use is ethically correct has to be judged according to the possible consequences. If the various values have to be weighed up against each other, then safety usually has the highest priority (Godwin 2012). Furthermore, due to the challenges with cognitive abilities the relatives do not generally trust the PwD to make a decision e. g. with regard to using a GPS (Landau and Werner 2012). This means that the evaluation of the possible use on the part of the PwD and their relatives can therefore vary. As a consequence, conflicts can arise that can be an additional strain on the care situation. Up to now, there is no established procedure in the practice that can support the PwD and their relatives in estimating the use of a certain system.

### 8.3.3 Challenges in user orientation and participation

One of the difficulties in the development and evaluation of technical solutions for improving care in the case of a dementia illness lies in realizing the demand and needs of the user groups and in adapting existing technologies or developing new ones in order to fulfill these demands.

In order to promote user orientation in research and development it will in the future be crucial not only to explain the attitudes, perceptions and needs within the framework of health services research but also to integrate these productively in the

development stages of healthcare innovations. Such fields of intervention particularly require an inter- and transdisciplinary discourse between science, politics, practice and business that starts as early as possible in the planning and development of innovations. This includes innovative forms of cooperation between practice and science, the co-production of knowledge as well as the participation of relevant user groups. For this purpose, methods of participatory healthcare research appear to be of particular significance.

There are various approaches in participative research that follow the principle “knowledge for action” and not only “knowledge for understanding” (Cornwall 2008), whereby the interventions should be designed participatively, have an assured quality and be structured in a way that is related to the world in which we live (setting-based) (Rosenbrock 2010); additionally, the practice-relevant people and/or groups should take part as active co-designers and/or decision makers (depending on the degree of participation) (Bergold 2007; Compagna and Kohlbacher 2015). However, the interpretation of “participation” on which this approach is based is very divergent (Unger 2014). Among other things, it seems expedient to consider participation as a continuum within research processes. Depending on its nature, it moves between the extremes of mere information giving to the participants, via listening to and taking in of attitudes and opinions (e. g. via surveys) up to co-determination and partial decision-making power (Wright et al. 2010). According to this interpretation, the degree of participation is to be measured, among other things, by the extent to which someone has influence on the different decision-making processes within research projects.

Participative processes in research are thus directed towards the planning and implementation of a cognitive process together with those people and/or groups whose social (health-relevant) actions and their life and work experiences are the subject of investigation. The term “participation” emphasizes the active attendance and the involvement in the research; it characterizes the relationship between the researchers and the participants in respect of both sides: on the one side, the participants’ cooperation in the research process, on the other side the involvement of the researchers in the processes and social contexts of the settings being explored (Bergold and Thomas 2012). This means for research practice that research-relevant interest in knowledge develops from the interaction of two (at first sight possibly incongruent) perspectives – science and praxis. The research process thus becomes (at best) a win-win for both sides: the “practice” (e. g. physicians, nurses, patients, people from the technology development field), which has long since become an object of knowledge in its relevant fields of action, contributes its individual knowledge, skills and perspectives to the related problems of life in science itself (Bergold and Thomas 2012). The objectives of the participative designing of research processes are the promotion of an individual and collective learning process with the relevant people and groups in each field of research as well as the consideration of the variety of opinions, attitudes and interests in order to better understand the societal processes

and problems and to design strategies with more practical relevance. Furthermore, participation in application-related research should help to avoid conflicts arising (e. g. through developing intervention strategies that are not tailored to the needs in the practice) (Blackstock et al. 2007). The required interlacing of perspectives in science and practice in participative research designing cannot be created simply by the decision to participate. In fact, it is a methodically challenging approach (Östlund et al. 2015); it develops successively in the actual research process via the encounters, interactions and understanding processes, possibly breaking with traditional roles in research, and thus placing complex demands on research processes and all those involved. The range and definition of problems does not primarily take place in the context of the scientific interest in knowledge, but according to social needs. A process which, according to its importance for the needs-related design, implementation and use of assistive technologies, is still inadequately represented today.

## 8.4 Demands on the technologies and users

On the societal level, there are clear demands regarding the use of technical systems. They should maintain privacy, promote social participation, and should ensure safety for the person with dementia and their data. The technology does not aim to replace human attention or promote isolation. The system should not initiate any action or decision without the user's consent. The responsibilities and liability issues should be clear and the explanations should be in understandable language. Furthermore, the costs (of the system) should be ecologically comprehensible and transparent. The user must have the opportunity to try the product out before a decision is made (Hansen et al. 2017). On the other hand, general requirements are expected of the technology user who should be able to act and decide autonomously and should understand the technology. The user should agree to use the technology, and conflicts between user groups should be communicated open-mindedly and proactively in order to find a solution. The user should be able to switch either the whole technology or individual parts of it off or on (Hansen et al. 2017). These requirements should ensure that the user can influence the technology so that it can be applied according to his needs. Fulfilling these requirements might be a challenge for PwD in the homecare setting and ethical issues might arise. In addition, the developers themselves and professional health service providers (i. e. who use data to optimize their processes) have a responsibility to meet these requirements. Coping with these challenges can result in a burden for the PwD and their relatives.

## 8.5 Practical implications of ethical discourse

As a result of technical developments, the repertoire of intervention options is expanding so rapidly that discussions about their social and health-related consequences are often only conducted afterwards. At the same time, such fields of research and development require an inter- and trans-disciplinary discourse between science, politics and practice that commences as early as possible in the planning and development of innovative care settings and within which the perspectives and ethical conflicts of the various user groups can be identified and taken into account.

The prerequisites needed to use assistive technologies are manifold. A distinction must be made between requirements that are: a) in relation to the usage context; b) in support of the product; and c) located directly with the users. This could include for example creating easier framework conditions (e. g. legal security, transparency regarding data flow and quality, remuneration within healthcare, technical infrastructure, establishing responsibilities), designing the technology (e. g. usability, technological interoperability due to uniform standards) and the implementation of the innovations in healthcare to meet the demands and needs as well as prerequisites of the users to provide a far-reaching perspective on the conditions of use. This also includes the analysis of effectiveness and efficacy of assistive technologies. In addition, the question must be asked as to how the relationship between man and technology is configured and what relevance user orientation has in the development and introduction of assistive technologies.

The more specifically an intervention meets the demands and needs of a target group, the more comprehensively and transparently framework conditions are created to facilitate action and the more potential burdens are reduced. The clearer the benefits of an intervention are presented and communicated, the sooner the specific reservations and fears of a target group are identified during the planning of digitally supported care settings and incorporated into an ethical, trans-disciplinary discourse. In result, the more rigorously these are addressed within communication and participation processes, then the more likely does a successful process of technology use become.

Besides the broad repertoire of research methods for the explication of the user perspective on innovative supply technologies, the question of the methodology of participation is just as crucial. By enabling participation, the necessary mutual learning process of the various actors can be promoted further. The existing diversity of opinions and interests can also be taken better into account in research and development, and potential conflicts and obstacles in the implementation of care concepts can be identified in advance and reduced accordingly. Participation thus represents a central step towards ensuring that the healthcare needs and requirements of different population and patient groups are met, and ultimately also towards clarifying and solving the ethical implications of the technologies.

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## 9 Assistive robots in care: Expectations and perceptions of older people

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### Abstract

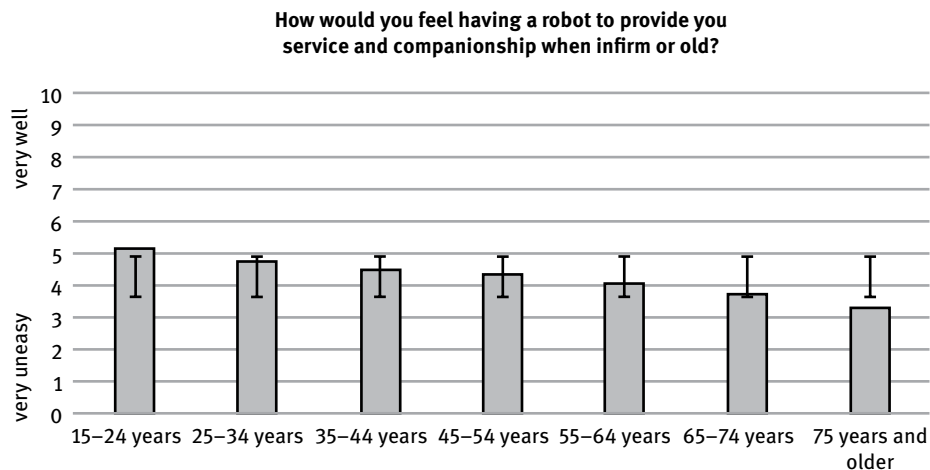
This chapter analyzes older people's expectations and perceptions about welfare technology and in particular about robots in elderly care. Assistive robots may serve as a means to prolonged autonomy in old age as well as support for nursing staff. Justified by a rapid change in the health care sector, the need to focus on user driven and not technology driven development of assistive robots must be emphasized to ensure an adequate and sustainable orientation process toward assistive robots. This study presents an inventory of the expectations and perceptions of older people regarding assistive robots, by conducting a qualitative approach with focus group discussions. Our findings reveal that seven themes in particular need to be addressed in order to improve older people's perceptions of robot technology: (1) independence and safety, (2) physical and mental assistance, (3) communication and socialization, (4) relief to nursing staff, (5) individual's right to decide, (6) data protection, and (7) liability. Additionally, the focus group interviews stress that dissemination of information on how robots can provide assistance may change older people's attitudes towards technology.

### 9.1 Introduction

The importance of the topic of utilizing robots in welfare services refers to the rapid digitalization, as well as technology development of the health and welfare sector. The discussion is mainly technology driven, and less driven by needs of users (Östlund et al. 2015). The need for more research on robots in elderly care becomes apparent when looking at the contemporary trends in industrialized societies, characterized by an aging population, rising care costs and a decrease in qualified employees (Neven 2010; Sparrow and Sparrow 2006). These challenges need an innovative approach in welfare technology, which lies predominantly in the new organization of health care, for example by integrating assistive robots into the existing health care structures (Miskelly 2001). New areas are emerging in which technology is being applied in elderly care, for example in private homes as well as in providing new functions like social incentives and entertainment, video-monitoring, electronic sensors, remote health monitoring and equipment such as fall detectors (Nordic Centre for Welfare and Social Issues 2010).

Harrefors, Sävénstedt and Axelsson (2009) indicate that the new technology strategy broadens the possibilities of older people to be more independent, for exam-

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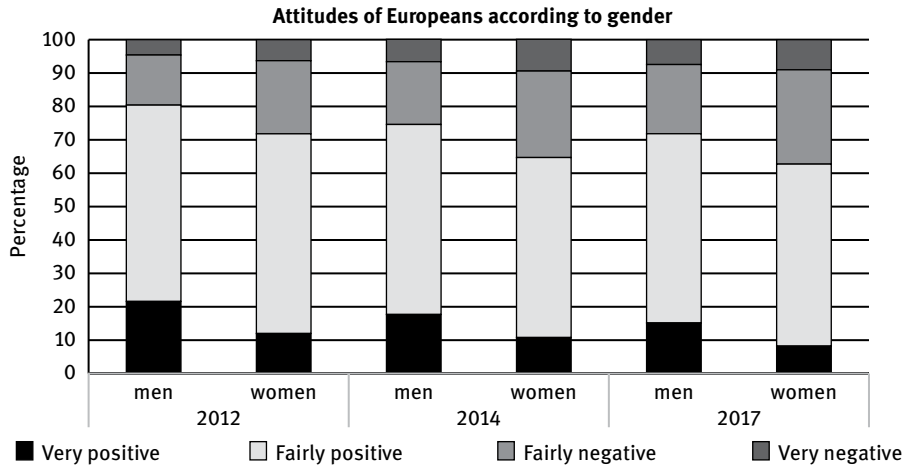
**Fig. 9.1:** European attitudes toward assistive robots by age groups (Mean).

ple by prolonging life in their familiar environment or by enabling remote communication with caregivers or family doctors from their homes. They state that one major problem that impedes the implementation of robots in elderly care is the population's fear towards robots in care in general and older people's fear in particular (see also Nomura, Kanda and Suzuki 2006).

The recent Eurobarometer (2017), for instance, reveals that younger people tend to be more open-minded with regard to assistive robots than older people, but still are unsure. People also tend to get more skeptical with more life years (European Commission and European Parliament 2017) (fig. 9.1).

Moreover, the Eurobarometer (2017) shows significant gender differences in peoples' attitudes towards robots. Fig. 9.2 illustrates that the attitudes towards assistive robots among Europeans are more negative among women than among men (European Commission and European Parliament 2017). Given that women have a higher life expectancy than men, this will aggravate the need for effective orientation. The result of the gender gap is attributed to technology related fears. While women express more negative emotions towards assistive technology (Hohenberger, Spörrle and Welpé 2016), men associate more positive emotions with automated systems, although both women and men show a slight increase in the proportion of negative attitudes over time. However, the proportion of women and men who indicate very positive and rather positive attitudes towards robots always predominates (European Commission and European Parliament 2017) (fig. 9.2).

Thus, the orientation of older people towards robotic care needs to be understood. Assistive robots in this context encompass any electronic device, partially or completely autonomous, that takes on care or assistive activities for people in need of help (Goeldner, Herstatt and Tietze 2015). The definition of assistive robots in this



**Fig. 9.2:** Attitudes of Europeans according to gender.

study refers to the support of older people and care staff with emotional, cognitive and physical tasks (Glende et al. 2016).

In this paper, we explore older people's perceptions and attitudes regarding robotic care in Finland, Sweden and Germany by organizing focus group discussions with older people as participants. There are several aspects to examine, including how older people imagine their life when getting older and needing help in their daily lives, and how welfare technology and especially assistive robots could be a part of these (home) care services.

The remainder of our paper is as follows: First, we briefly review assistive robots in elderly care. Second, we discuss the problems, needs and challenges of assistive robots. Third, we present our method and show which themes are the most important for older people regarding their perceptions and expectations of assistive robots in future life. Finally, we discuss our findings and conclude.

## 9.2 Contemporary demographic and technological development

In a few years, the relative population of older people in Western Europe will rise due to the aging population as well as increasing life expectancy. In approximately 30 years, there will be more people in the world over the age of 60 than under the age of 15. When focusing on elderly care, a gigantic shift in technology must be proceeded to meet the societal demographic challenges (United Nations Department of Economic and Social Affairs, Population Division 2015; United Nations World Population Prospects 2015). Currently, due to economic and social mobility, more people live alone and far away from their families and relatives, implying that family care is not

available. However, current developments in technology may contribute to mitigate the problems ahead, but along with technological challenges, societal resistance also needs to be understood to explore the opportunities and limits of technology assistance in elderly care.

In this context, this paper focuses on the contribution to efficient care services by examining the authentic needs of stakeholders to provide orientation towards welfare technology. These orientation themes should support older people in deciding about robotic care as well as other stakeholders by exploring contemporary needs and emotions of older people. Orientation is fundamental with regard to a successful implementation of such assistive welfare technologies in care services (Acatech and Körber-Stiftung 2018; ZEW 2012).

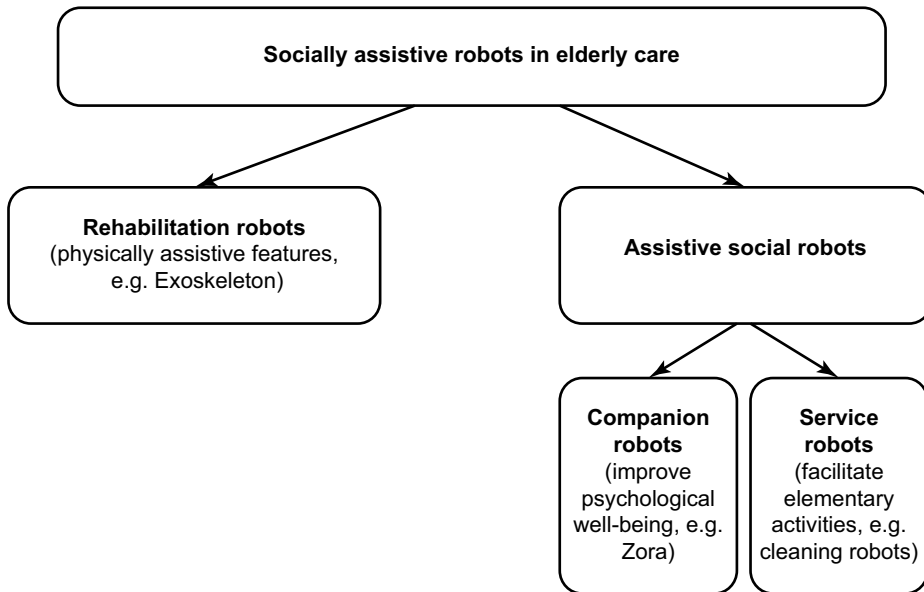
### 9.2.1 Robots in elderly care – a brief review

Socially assistive robots (SAR) can be distinguished into two main categories according to Kachouie et al. (2014): rehabilitation robots and assistive social robots, which can again be subdivided into companion robots and service robots (fig. 9.3).

Rehabilitation robots focus on physically assistive features to maintain and increase mobility. Furthermore, they are designed to support regaining diverging physical characteristics, such as muscular strength and flexibility. One example is the Exoskeleton, a smart robot system aimed at enhancing gait performance and daily activities (Lee et al. 2017; Sale et al. 2012). Besides their rehabilitation purpose, these robots are designed to facilitate tasks at home, for instance lifting and transporting objects (Huo et al. 2016).

Companion robots, often resembling animals or human bodies, are designed to improve older people's lives by increasing health and psychological well-being as well as decreasing loneliness (Fischinger et al. 2016). Dautenhahn, Campbell and Syrda (2015, p. 1) note that the role of companion robots is characterized by "both long-term and repeated interaction". Additionally, these robots can be used to facilitate social interactions with others. The JustoCat, a companion robot specifically developed for dementia patients, acts like a cat, is capable of reacting to being stroked and supports staff regarding remembrance (Abdi et al. 2018; Gustafsson, Svanberg and Müllersdorf 2016). Companion robots can also be used for persons without dementia. With respect to their functionality, they serve as entertainment purposes. One prominent example is the robot *Zora*, which stimulates exercising and leads to reminiscing because of its child-like character (Melkas et al. 2016).

Conversely, service robots are aimed at facilitating elementary activities, including eating, bathing or housework as well as supporting mobility, monitoring of people and maintaining safety (Kachouie et al. 2014). Although the spectrum of users' requirements in the field of housekeeping or physical support for daily tasks is broad (García-Soler et al. 2018), there are rarely any service robots available. During the re-



**Fig. 9.3:** Assistive robots in elderly care.

search there were little to no service robots especially targeted at tasks of daily living. Currently, cleaning robots such as vacuum robots are widely available for households, but robots that facilitate personal hygiene are still lacking (Kachouie et al. 2014).

Another crucial area to prolong the independent life of the older people is fall detection (Webster and Celik 2014). New technologies eliminate former deficiencies, including older people being incapable of using safety-alarm buttons in the case of falling or forgetting to wear support devices (Bajones et al. 2018).

### 9.2.2 Meeting problems, needs and challenges of robots in elderly care

The problems and challenges concerning the use of robots in elderly care can involve ethical issues as well as technological obstacles that need to be overcome in the future. As an example, Huo et al. (2016) conclude that, on top of the optimization of already existing exoskeletons' accuracy, one vital obstacle to overcome in the future is the development of more portable robots of higher efficiencies. Bedaf, Gelderblom and De Witte (2015, p. 97) state that the use of robot systems is questionable for any fields of elderly care "which do not require physical movement and/or force exertion". The authors predict that these robots, solely offering non-physical assistance like reminders, monitoring or fall detection, will not succeed in extending older people's independent living, but rather physical support is crucial for this aim (Bedaf,

Gelderblom and De Witte 2015). The handling of fragile patients as one example of physical support is one of the next hurdles to overcome in the upcoming years of development of robot assistance systems. This is especially applicable for the category of service robots.

Besides technical difficulties in the field of robots in elderly care, legal, financial and safety concerns arise (Goeldner, Herstatt and Tietze 2015). One additional major problem that still hinders the successful use of robots in elderly care is the fact that many people are reluctant towards the idea of robot service or companionship. Looking at Europe, half of the population feels uneasy with the thought of robots in elderly care (Niemelä, Määttä and Ylikauppila 2016). One reason might be that older people are not efficiently integrated into the development process of new technologies (Östlund et al. 2015). The research of Compagna and Kohlbacher (2015, p. 20) clarifies the engineers' view towards older people as

“a weak and deficient user group [...] go[ing] hand in hand with a stereotypical and prejudiced view of older people that leads to a distorted way of including them in the development process. Developers may therefore not be able to grasp and appreciate the real meaning and value of older users' assessments of the new technologies and thus lead to non-desirable results”.

Moreover, there is often an imbalance between perceptions of older peoples' technology needs and knowledge about their actual needs. The supposed user employs the technology according to the manufacturer's idea of how the item should be used. However, this is distinct from the real user, who is actually using the technology, and may for instance change the purpose of the technology (Dekker 2015). If diversity in users is incorporated at all, it is most often based on basic social distinctions such as age and gender differences (Flandorfer 2012). However, communication on equal levels and users' participation in the development process could decrease users' resistance. Vandemeulebroucke, de Casterlé and Gastmans (2018) suggest “democratic spaces” – spaces where stakeholders of elderly care can interact – as a way of overcoming existing boundaries between the different parties as well as the technology, to establish a shared vocabulary and, finally, accomplish a new view on robots in elderly care.

Bajones et al. (2018, p. 2) sum up, that “one of the biggest challenges is offering sufficient useful and social functionalities in an autonomous and safe manner to achieve the ultimate goal of prolonging independent living at home”. This goal can only be achieved as soon as the new technology is accepted by the individual users and the society at large. Therefore, it is of great importance to involve the future users of assistive robots in the developing and implementation process. If these processes are planned carefully, older people can benefit from assistive technology by means of promotion and improvement of health (Herstatt, Kohlbacher and Bauer 2011). However, there is a lack of useful indicators of good social technology solutions for older people (Taipale 2014). Additionally, the most convincing argument to motivate older

people or care staff to use any type of technology is the individual benefit. Frennert (2016) stresses that this process is self-enforcing: older people are motivated to learn more about robot assistances if the robot has already proven capability of being useful for their special needs. Therefore, initial assistive robots need to fit into the environment of care staff and older people and meet certain needs. Moreover, when considering the needs of today's and future older people there might be a change, with regard to acceptance of technology for social needs and the strong western cultural value of being independent, which might be an incentive of using robots in everyday life. Once this is achieved, assistive technology is no longer considered as a single island, but rather as a support of care to provide new types of services (Melkas 2011).

## 9.3 Method

### 9.3.1 Design

In order to explore the contemporary expectations and perceptions of older individuals towards assistive robots, we follow a qualitative approach according to Mayring (2003). We use focus group discussions (FGDs) which are particularly suited to the study of attitudes and perceptions as they increase the diversity of opinions in a group. In addition, interaction within the groups of like-minded people, in this study in the sense of people of the same age, can help to talk more openly about a topic and clarify their own attitudes in ways that would be less accessible in individual interviews (Kitzinger 1995; Krueger and Casey 2014). The FGDs were conducted by two female researchers in each considered country, one as a moderator and the other as an assistant moderator. The moderators of the FGDs were female professors from nursing, innovation and economic departments. They were held in the participants' native language.

### 9.3.2 Participants, procedure and data analysis

In this paper, we focus on the perspective of older people living at home, therefore a targeted sampling was used to recruit the participants in Sweden, Finland and Germany. They were acquired through oral and written enquiries (e. g. through cities' retirement organizations and political voluntary retirement groups who were informed by their group leader or through an information e-mail form the ORIENT research team). Inclusion criterium for the selection of these groups was a minimum age of 60 years. In total, 24 older people participated, with four to seven participants in each group. All of them were living self-determined in their familiar environment, not needing any home care services. The older people had an average age of 72 years, 10 of them had a university degree, 10 of them a vocational education, three a secondary



school certificate and one finished elementary school. Eight participants were male; 16 participants were female.

The self-developed interview guide includes opening, introductory and transition questions, as well as key questions following the recommendations of Krueger and Casey (2014). The interview guide is developed from pre-existing literature on the orientation process of assistive care robots, notably based on Melkas et al. (2016) as well as Raappana, Rauma and Melkas (2007). This guide was important, since the consistency between the settings in the three countries can be assured as the FGDs were conducted in Sweden, Finland and Germany.

At the beginning of each FGD all participants were asked to sign an informed consent form and to provide background information about themselves. The moderator of the interview then informed the participants about the aim of the discussion. The discussion followed the interview guide (Krueger and Casey 2014), moving from general to more specific questions. First, the participants were asked to brainstorm about the use and need of assistive robots in elderly care. This was followed by transition questions regarding the use of robot technology. Next, a short video and pictures of various types of care robots were shown and their possible support were shortly explained to the older people. The key questions focused on the general level of knowledge of care robots and if as well as how they should be introduced in elderly care. The FGDs in the three countries took between 60–140 minutes and were audio recorded, and then transcribed verbatim and processed as texts. Moreover, the FGDs were conducted in each country's national language, but the transcriptions were translated to English. For the analysis of the FGDs we used an inductive coding following Gioia, Corley and Hamilton (2013) with a semantic approach (Braun and Clarke 2006). Thus the following themes were developed from the datasets of the FGDs. We used the semantic approach, because the themes are identified within the explicit or surface meanings of the data, which means that the researcher is not looking for anything beyond what a participant has said. The goal is to theorize the significance of the patterns and their broader meanings and implications (Braun and Clarke 2006). The transcribed text was read a few times by the researchers to find statements regarding the attitudes and expectations and perceptions of the older people towards assistive robots. Meaningful statements regarding attitudes, expectations and perceptions were marked and initial codes were generated through all FGDs. Afterwards, the codes of all three countries were grouped together and discussed until theoretical saturation. Seven topics concerning attitudes and expectations and perceptions have been created.

## 9.4 Results

**Table 9.1:** Displays themes evolved in the FGDs.

Theme	Example quote
(1) Independence and safety	<ul style="list-style-type: none"> <li>– “I would accept a nursing robot if I started having trouble with moving at home. So that it would be helping me to go to the toilet or to wash myself. Of course it would never replace having a conversation. But I would understand that it would be safer after all, if I had problems like that” (FIN 2018).</li> <li>– “So it’s definitely going to produce security. If it wouldn’t be there, you were more insecure than if you know someone is there when I tumble or can help me in case of emergency. This safety issue should not be neglected” (GER 2018).</li> </ul>
(2) Physical and mental assistance	<ul style="list-style-type: none"> <li>– “I would also rather make use of an assistive robot than using a wheelchair. This would give me the opportunity to be mobile” (GER 2018).</li> <li>– “I might accept it at some point, if it picked up my garbage from the floor. When I drop things, then I have to somehow try to pick them up myself. In that regard I’d take it” (FIN 2018).</li> </ul>
(3) Communication and socialization	<ul style="list-style-type: none"> <li>– “The last one here [Furhat], for example: I can imagine that it is interrupting loneliness. I live alone. There are days, where I don’t speak to anyone at all, if I don’t call anyone. I don’t necessarily feel lonely now, but I am always happy when there is someone around who speaks. Maybe in a way, it replaces my need for human contact” (GER 2018).</li> <li>– “I don’t know whether I could talk to a robot. [...] Of course I would hope that someone would visit me in person” (FIN 2018).</li> </ul>
(4) Relief to nursing staff	<ul style="list-style-type: none"> <li>– “I think that one of the first tasks will probably be to relieve the staff of physically heavy work. Just something like lifting or, carrying” (GER 2018).</li> <li>– “In my opinion, technology helps the caring staff, if they have good equipment” (FIN 2018).</li> </ul>
(5) Individual’s right to decide	<ul style="list-style-type: none"> <li>– “I can envision that older people can use robots without any problems. But for dementia patients, I think it is shameful and inhuman to use robots. I think that we should not use that in Germany” (GER 2018).</li> <li>– “I think – yes, only if I can choose myself. Being able to say yes or no thank you, that is very basic for me” (SWE 2018).</li> </ul>
(6) Data protection	<ul style="list-style-type: none"> <li>– “One aspect that certainly plays an important role is security, data security. Because these electronic things work via WIFI or similar things” (GER 2018).</li> <li>– “About the legal aspects and data protection, that’s probably a story, I can’t influence, probably a political decision will be necessary or courts will have to decide what the robot may and may not do” (GER 2018).</li> </ul>

**Table 9.1:** (continued) Displays themes evolved in the FGDs.

Theme	Example quote
(7) Liability	<ul style="list-style-type: none"> <li>– “What happens if the robot makes a mistake, e. g. delivers the wrong medicine? Who is liable? Actually, it is obviously the caregivers in the case that they provide the wrong medicine. But if the robot gives a wrong drug, who is liable then?” (GER 2018).</li> <li>– “Because the person who programs the algorithms cannot be held responsible in the end [...] I believe that, as with autonomous driving, it will ultimately be a legal issue to be solved” (GER 2018).</li> </ul>

### 9.4.1 Independence and safety

The implementation of welfare technology in general, and in particular assistive robots in everyday life was perceived as a tool to support a prolonged independent life, which, from the point of view of older people, is associated with a higher degree of autonomy and integrity. Moreover, some imagine receiving support from a robot in hygiene, for instance in cases where nursing services are perceived as threatening integrity.

Of course, there are also older people who prefer the presence of human staff and reject the use of welfare technology. Another important aspect, when discussing support of assistive robots in everyday life, was the argument of safety. Older people perceived the tools of monitoring, saving health data (e. g. blood pressure and blood glucose), or the reminder function for medicines as added security.

### 9.4.2 Physical and mental assistance

Another aspect in which almost all participants have a common view, relates to the simplification of tasks through the assistance of robots. Practical tasks like picking up things from the floor, cleaning the floor, as well as mobility supportive tasks were discussed as enormously useful in daily life. In addition, the support of people with cognitive impairments was also mentioned as a possible application area for assistive robots.

### 9.4.3 Communication and socialization

With regard to better communication, older people mentioned on the one hand shorter communication channels as beneficial, by using the tablet of an assistive robot to connect them with care staff or facilitate communication with relatives and on the

other hand the increase of possibilities for their social life, for instance through entertainment and mental stimulation. However, there were also participants who perceived the monitoring function of an assistive robot as dangerous. The topic of conversation with assistive robots was also perceived differently in the groups. Some of the participants would prefer a conversation with a robot than having no conversation at all. Others cannot imagine communicating with robots. The participants also had divided opinions about social robots. Some thought that social assistive robots could reduce the feeling of loneliness, while others would not interact with social robots. A further concern was the fear of not being capable of handling assistive robots and the risk of becoming even lonelier.

#### 9.4.4 Relief to nursing staff

The older people perceived assistive robots as a great advantage in supporting professional caregivers in daily standard tasks, as professional caregivers can invest more time in patients therefore human resources will only be used where they are really needed. The participants suggested that support of assistive robots is conceivable in the area of physically heavy work, personal cleaning, hygiene and service.

It was also mentioned that robots can be a good support in times of shortage of skilled workers. However, concerns were expressed whether assistive robots could also replace skilled workers. This consideration was based on the assumption of the older people that robots are in the long run probably cheaper than care staff. However, some participants in the FGDs argued against the fear of replacing care staff by robots, because robots cannot provide human warmth nor interpersonal relations or psychological support.

#### 9.4.5 Individual's right to decide

A crucial theme in the orientation process of assistive robots are the regulations. Thereby a common view of the older people is that each user must have the right to decide whether to use assistive robots when getting older or not. There are different attitudes: some older people could imagine using robots later in life, others prefer assistance of human staff. Hence, the appropriate time in the estimation process of the individual situation is needed to find a convenient moment to give an orientation regarding assistive robots. Moreover, the use of assistive robots with regard to cognitive impaired people, like dementia patients was discussed. Some participants thought that dementia patients should be involved, while others would judge the use of assistive robots for dementia patients.

However, a few participants had the perception that there should not always be the possibility to choose, therefore some things should be established.

#### 9.4.6 Data protection

The theme of data protection mirrors different aspects of data protection when using an assistive robot. Many older people of the FGDs felt a great uncertainty, which should be solved through politics, as well as the law by setting legal limits and regulations. One important question was “Who can access any videos made by a robot, can the older people delete some sequences?” (GER 2018).

#### 9.4.7 Liability

The FGDs with older people emphasized that liability must be legally defined and communicated as the older people were very insecure about this topic. Also, malfunctioning due to technical errors or power shortages were discussed heavily and the question of liability was a major obstacle to older people for using robots.

### 9.5 Discussion

During the FGDs, the different levels of knowledge of older people about welfare technology and especially assistive robots was determined. There were both positive and negative attitudes towards this topic. The negative attitudes did not refer to robots in general, but to robots in care in particular. This suggests that the use of robots in elderly care is not as accepted as in other areas of health care (European Commission 2015). With regard to the themes analyzed by the statements of the older people, it could be observed that the topic of data security was only addressed by the German participants and there were no mentions about liability in the Finnish statements.

However, with regard to the older people of the FGDs, a big change in attitudes was recognizable with the dissemination of information. Some indicated that they had a negative attitude towards assistive robots in care at the beginning of the group discussion. Qualitatively, men in the FGDs were notably more open to welfare technology in general and robotic technology in particular. However, this attitude changed over the course of the group discussion due to their increased level of information and a clearer understanding of what is meant by welfare technology, especially by assistive robots in elderly care and how it can be used to assist daily life. In addition, the tendency of the perceptions of almost all older people towards the use of robots in elderly care is much more positive. The results of these FGDs show that there is a general acceptance of assistive robots. However, a better orientation for the persons concerned is urgently required. This is in line with the results of Melkas et al. (2016) and applies above all to groups involved in the implementation processes in the field of elderly care, such as relatives and professional caregivers. This could be supported by storytelling of older people, relatives or care staff who had contact with such

assistive technologies which at the same time could be a good method to get reliable information. Also the media which has an extensive range that could increase the dissemination of knowledge and information.

After discussing the themes generated through the FGDs, the interviewees were open to an implementation of selected technologies and could envision themselves as potential users. However, some important aspects should be considered for a successful implementation. One case that must be ensured with regard to the development and implementation of welfare technology is the improvement of daily life for older people and working life for caregivers and relatives. According to the perceptions from the FGDs, needs that can be improved by assistive robots refer to a higher autonomy, a certain safety and security through the presence of a robot as well as through the ability to independently manage daily life and improve working life. Our findings reflect the view that during the development and implementation of robots in elderly care the authentic needs of later users should be focused on (Gustafsson 2015). To ensure the authentic needs it is inevitable to involve end-users, older people, caregivers or relatives in the processes of welfare technology (Kristensson, Matthing and Johansson 2008). These users of welfare technology should ideally be involved in both the development process from the beginning as well as in the ongoing (Kristensson, Matthing and Johansson 2008; Elg et al. 2012).

Until July 2019, assistive robots were only prevalent in a few nursing homes except for some pilot projects with Zora or Pepper. Much more common were companion robots such as Paro (Wada et al. 2010) or JustoCat (Abdi et al. 2018; Gustafsson, Svanberg and Müllersdorf 2016). Other service and companion robots, as well as rehabilitation robots, just recently passed pilot studies.

## 9.6 Conclusion

The characteristics of assistive robots are different to other technologies in elderly care, especially as an emotional connection may arise. When investigating the implementation of robots with regard to the acceptance of society, different factors like social and hedonic ones must be considered, which are usually not included in technology acceptance models (Melkas et al. 2016; Parviainen et al. 2016). The structure of co-creation of assistive robots is different to other co-creation processes, because several people (relatives, caregiver) are involved in this process and not only the customer or in this case the older people. Of course, this also poses major challenges in comparison to other co-creations, but only if these stakeholders work together a comprehensive overview of technological opportunities and authentic needs can be ensured. As long as this cooperation does not have the same influence on the developmental processes, there cannot be a successful implementation of assistive robots in care. Additionally, Raappana, Rauma and Melkas (2007) researched the implementation of welfare technology and found that a good orientation (dissemination

of knowledge, training and information before implementation) prevents the appearance of negative effects. This is based on the fact that without knowledge, training and information people would develop feelings of incapability and overcharging. This unilateral process of developing assistive robots impedes the implementation of robotics in care, whereby the integration of stakeholders would improve the implementation process by supporting authentic needs, as well as by reducing the fear towards the implementation of assistive robots in care (Harrefors, Sävenstedt and Axelsson 2009; Nomura, Kanda and Suzuki 2006).

Regardless of the country, the representatives of care should identify and communicate authentic needs in care, which could be solved by adding welfare technology and especially assistive robots. This would give care staff more time for tasks that really need human affection and could hand over simple auxiliary tasks to the robot to relieve nursing staff (United Nations Department of Economic and Social Affairs 2015; United Nations. World Population Prospects 2015). However, this does not solve the demographic problems; there are many other aspects that need to be considered in elderly care. For instance, the implementation of regulations to decide by themselves if assistive robots are wanted or not, as well as regulations for data protection and liability of assistive robots. Notably for data protection and liability, we found differences in the perceptions of older people, while the older people in the German FGDs discussed data security and liability in particular. The issue was not mentioned in the FGDs in Finland and Sweden. Therefore, future research should investigate why some issues are more pronounced in certain countries. The reasons may be attributed to different penetration of digitalization in different countries in general, different experiences or a different public discussion. Our FGDs also suggest that trust in the general health care system affects trust in innovations in the health care sector such as in assistive robots. The FGDs also indicated that financial responsibilities must be determined.

For the innovators it must be considered that older people of future generations have grown up with digitalization in contrast to today's generation (Porrás et al. 2014). Therefore, the selection of stakeholders in the process of technology development should be considered carefully; it would not be enough to include only today's generation of older people.

Additionally, referring to the results of this study we can conclude that today's older people are open-minded with regard to welfare technology and especially assistive robots, provided that they have sufficient knowledge and information on how robots can support daily life. Nevertheless, there are also older people who cannot imagine being supported by robots and prefer human care even if they are sufficiently informed about assistive robots.

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## **Part IV: Challenging classical concepts**



# 10 Rethinking consent in mHealth:

## (A) Moment to process

Iris Loosman


### Abstract

The field of mobile health promises a transformation of the healthcare industry, by providing health-related information and services directly to individuals, through digital mobile devices. This presents society with new platforms for persuasive systems for healthy behavior change. Before such systems' full potential can be utilized, however, the question of how to consent to their use needs to be addressed. In this paper, I argue that one-off all-encompassing consent moments at the start of use of persuasive mobile health services do not suffice, given the functions they present, and the context in which they are used. Persuasive mobile health services are not only data-intensive, they are also designed to influence the user's behavior and health. Informed consent should be temporally distributed, in order to improve the quality of the user's autonomous authorization, that this context requires.

### 10.1 Introduction

Every day, hundreds of new mobile health applications enter the market. Many of these use persuasive techniques to initiate healthy behavior change for their users. Mobile health promises a transformation of the healthcare industry and is predicted to enable more personalized, participatory, preventive and less expensive care (Malvey and Slovensky 2014). Its systems bridge the clinical context on the one hand, with the context of everyday life on the other, through digital applications. One consequence of this bridging of contexts is the blurring of care norms and general information technology (IT) norms. As a result, the norm-based expectations that normally frame and ground informed consent to a treatment may not be clear, or may even be absent altogether (Voerman and Nickel 2017).

In this chapter I examine the need to rethink informed consent in mobile persuasive technologies for healthy behavior change. In particular, can the *temporal distribution* of informed consent improve autonomous authorization in these technologies? The chapter will be structured as follows. In section 1, I give a short overview of the relevant developments from the field. Sections 2 and 3 contain the main line of argumentation. Here I examine the features of mobile health apps more closely and argue that these features require improved autonomous authorization. I then expand on autonomous authorization and argue that its meaningful achievement requires appreciating informed consent as a process rather than a moment. Finally, I reflect on how these ideas can inform future design of informed consent in applications. I conclude this chapter with final remarks in the closing section.

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## 10.2 Background

Mobile health (henceforth: mHealth) is the practice of delivering health-related services to mobile phones and wearables. According to Oinas-Kukkonen and Harjumaa: “A growing number of information technology systems and services are being developed to change users’ attitudes or behavior or both” (Oinas-Kukkonen and Harjumaa 2009, p. 485). These systems can be especially useful within health contexts, for example to help prevent or manage chronic diseases, or keep healthcare costs down. The emergence of services designed to replace clinical treatments (so-called *digital therapeutics*), and services assisting patients with disease self-management, are two promising examples. Not only are these services ubiquitous and can involve artificial intelligence, they also collect extensive data with many potential uses, which are difficult to describe exactly and evaluate in advance. This makes it difficult to trust them and to consent to their use.

In this chapter informed consent is broadly taken to be the authorization of an activity, based on an understanding of what that activity entails, and absent of control by others (Grady 2015); in other words, an *autonomous authorization* (Faden and Beauchamp 1986). Faden and Beauchamp (1986) distinguish consent as autonomous authorization from legally or institutionally *effective* consent. Consent is effective when the procedure through which it is obtained satisfies the rules and requirements of a specific institutional practice (Faden and Beauchamp 1986). It is legally transformative, but not necessarily morally transformative (Edenberg and Jones 2019). Effective consent is often referenced in connection to (information) technology domains (Flick 2016; Edenberg and Jones 2019).

Debates on consent in data-intensive contexts reflect the difficulties of ensuring meaningful consent. Criticisms of the feasibility of achieving meaningful consent through ticking an “agree” box are common (Bashir et al. 2015; Custers 2016; Grady 2017; Ploug and Holm 2013). There are worries of consent desensitization, and routinisation – the amount of consent requests presented to users, together with the way these requests are set up, are not inviting users to engage the way they ideally should. Some authors argue this process might not be in line with what informed consent should ideally achieve:

Given the speed with which technology becomes integrated into our daily lives, often the values and expectations embedded in the technology itself become the default—whether or not we as a society have taken the time to think through the appropriate conditions for sharing personal information in exchange for access to digital services. It is easy to adopt as a given whatever terms of service are offered by the services we turn to on a daily basis. Individuals often feel powerless to negotiate these terms (Edenberg and Jones 2019, p. 1).

As a result, the resulting consent falls short of most normative standards of morally transformative consent (Edenberg and Jones 2019, p. 1). Using an mHealth service is most often preceded by the step of downloading an application, followed by the dis-

closure of Terms and Agreement, and a moment to click “agree”. As mHealth is in essence an IT development relying on large dataflows, consent setups must adhere to data protection rules (Mantovani and Quinn 2013). However, a data protection perspective is not the only relevant perspective when looking at the quality of consent. mHealth has the potential to persuade consumers and patients alike (together: users), to achieve health-related goals, and to offer them treatment-like solutions. The bridging of health and general information technology contexts challenges traditional (often clinical) ideas about informed consent.

In this chapter I consider rethinking the informed consent often found in apps as a process, rather than a moment, with the goal of improving the quality of informed consent as an autonomous authorization. This implies that temporally distributed consent should offer a user multiple discrete consent moments over time; but in addition, it should also consider informed consent to be a process in which both the user and the technology develop over time.

### 10.3 Rethinking consent in mHealth: Why, what and how?

The current conception of consent in mHealth services is problematic for (at least) two reasons. The first can be described in terms of suboptimal user behavior – e. g. the user’s clicking of “agree” without considering the consequences, without reading or fully grasping the Terms of Agreement. This behavior is a given, and is not properly addressed or mitigated by current consent setups (Bashir et al. 2015; Grady 2017). The second reason is that the current conception of consent shows insufficient consideration of the normative significance of the context of mHealth. The mobile services here discussed are capable of influencing users with potentially far-reaching consequences, which are supposed to be covered by a consent setup. Even in a world in which a user of mHealth behaved ideally, she still would not have meaningfully consented to all the relevant implications.

In section 2.1 I address these reasons under two themes: treatment (expectation) and persuasion. Here I discuss what I take to be normatively significant functions<sup>21</sup> of mHealth, and the kind of consent these functions require. In section 3 I offer some thoughts on mitigating suboptimal user behavior in the design of consent processes.

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<sup>21</sup> In this chapter the term “function” is used to mean “intended purpose”.



### 10.3.1 mHealth's functions

#### Treatment<sup>22</sup> and expectations

mHealth services are designed to perform functions that ethically require consent from their users: for example to monitor them, and to collect, share and store their data, whereby the extent and future purpose may often be unknown. These services provide the user with feedback in the form of knowledge, diagnoses and advice. This feedback is sometimes based on automated algorithms, without human oversight or the involvement of human judgment. These functions of mHealth can be viewed as counterparts of medical treatment, which would require a participatory action of the patient, within a clinical context.

Furthermore, many mHealth services, especially those that are direct-to-consumer, present themselves as a kind of therapy that improves health-related conditions (Martinez-Martin and Kreitmair 2018; Sax, Helberger and Bol 2018). The problem, according to Martinez-Martin and Kreitmair, is that “consumers may assume that their interactions with the service involve the kind of ethical obligations that are a part of professional therapy, making it particularly important to ensure that users understand that those obligations do not apply” (Martinez-Martin and Kreitmair 2018, p. 71). Looking at the treatment-like features of mHealth discussed above, it is not surprising that mHealth is often perceived this way. However, there are repercussions to misinterpreting what the system has to offer. There are risks associated with services that change health-related behavior, especially for users suffering from one or more diseases. Feedback, advice, or diagnoses can be wrong in general, or wrong for a particular patient, not taking her condition into account. Where a user expects to receive expert advice, this feedback is often the result of an algorithm, based on statistics, rather than one's personal circumstances. In that sense, using an mHealth service comes closer to self-diagnosis and self-treatment, with all the risks associated with those practices (Ruiz 2010).

A potential counterargument to this point is that because many of these services exist outside of medical practice, the responsibility is down to the user, and current consent setups fit with this assignment of responsibility. To this I would reply that responsibility-taking is only valid to the extent to which the user gets the opportunity to really understand what this means. Users of mHealth services must be facilitated to form reasonable expectations of what the systems actually offer, in order to meaningfully consent to their use.

Often the fine print of mHealth apps includes a statement regarding the non-medical nature of their services, in order to avoid liability. However, especially considering that mHealth apps are often sought by users suffering from health issues and seeking help, special attention should be paid to ensure that an appropriate overview

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<sup>22</sup> The term “treatment” is here used in a broad sense, to include diagnostics.

of risks and benefits is provided (Martinez-Martin and Kreitmair 2018). Especially with the rise of digital therapeutics and assistive technologies, the vulnerability of potential users of mHealth services means extra attention must be paid to increasing understanding of what the app is, and what consenting to it entails. However, simply adding more information to the already top-heavy consent moment preceding use, is not making a real effort towards improving autonomous authorization.

### Persuasion

The importance of consent in contexts of persuasion has been widely discussed (Oinas-Kukkonen and Harjuma 2009; Spahn 2012; Timmer, Kool and van Est 2015). Spahn (2012), for example, argues that the user of such technology should always be informed about persuasion, and should give consent to being subjected to it. Emphasis is placed on ensuring that users are able to choose their own goals, and the methods of persuasion, in order to maintain respect for autonomy. With the developments of persuasive mHealth systems, to be downloaded directly onto users' personal mobile devices, the possibility for more data intensive data collection, and thus more personalization, opens up. According to Sax et al. (2018) it is to be expected that these personalization strategies will become more frequent and more powerful.

Oinas-Kukkonen and Harjuma (2009) write that from an ethical point of view “it is necessary that the overall goal is made clear at all steps of incremental persuasion.” They add: “Persuading a user is indeed a multi-phased and complex task, and different factors, such as the user's goal, may change during the process” (Oinas-Kukkonen and Harjuma 2009, p. 488). As a system learns and adjusts its methods to reach optimal results in behavior change, so too may a user of such a system change her motivation and goals. Can we reasonably expect a user of this technology to predict this at the initial moment of consent, and to understand what the unfolding persuasive strategies might entail?

The idea that the user's goals may change during the process of using mHealth apps is also emphasized by Sax et al. (2018) who identify three distinct stages of mHealth apps usage. These are: “(1) the decision to install an mHealth app; (2) the decision to start using an mHealth app; (3) and the decision to continue using mHealth apps for longer periods of time” (Sax et al. 2018, p. 114). The authors introduce this distinction to avoid “talking about ‘the use of mHealth apps’ as if this is a unitary phenomenon. At these different stages, different user motivations and different strategies to influence users can be observed” (Sax et al. 2018, p. 114).

Implementing one-off consent in mHealth services fails to acknowledge that different experiences and motivations can exist at each of the stages of mHealth usage. It is hard, if not impossible, to predict these beforehand, to understand what they entail, and to meaningfully decide. Sax et al. (2008) write: “Through usage, a sort of ‘relationship’ between user and app develops over time” (pp. 114–115). This relationship allows the app to make more accurate persuasive suggestions, but it could

also mean that the user can more accurately judge whether or not this app matches expectations, for example. Compare a relationship with a physician, in which a bond of trust develops over time that can influence a patient's willingness to (continue to) consent. There, too, a patient can choose to alter or terminate her treatment, when her goals change, or when she or her physician determines it is not the best path of action. To facilitate a similar development in mHealth services, a user's informed consent should be able to develop over time.

### 10.3.2 Improved autonomous authorization

In the beginning of this chapter, I argued that current consent set-ups in mHealth services resemble what is described as effective consent more than autonomous authorization. However, because of suboptimal user behavior and insufficient addressing of mHealth's normatively significant features, neither sense of consent is taking place in a successful way. I also discussed several of mHealth's normatively significant features requiring improved consent. These features are related to treatment – on the level of the functions themselves, but also on the level of perceptions and expectations with regards to these functions – and related to persuasion. In what follows, I consider autonomous authorization in further detail, before moving on to presenting temporal distribution as a way to improve it.

According to Faden and Beauchamp (1986), informed consent as an autonomous authorization requires substantial understanding, substantial absence of control by others, intentionality, and an authorization of a professional to undertake a certain action. It is an effective communication of an intentional transfer of rights and obligations between parties, transforming the moral landscape between them, making actions permissible that otherwise were not (Edenberg and Jones 2019). But it does more than that. Consent in this sense is a way for a person to autonomously authorize a physician “to undertake diagnostic or therapeutic interventions” (Emanuel 2012, p. 5). That way, a patient can demonstrate understanding that she takes responsibility for her decision, while at the same time empowering another to implement it (Emanuel 2012).

Effective consent on the other hand, emphasises the written documentation of consent – disclosure, accompanied by a token of agreement. This is compatible with a more passive consent setup, in which the focus is on disclosing information and awaiting consent in return. Effective consent is not necessarily accompanied by autonomous decisions (Grady 2015), nor is it necessarily morally transformative. In order to facilitate the dynamic nature of decision-making, consent set-ups need to move beyond one-off, all-or-nothing decisions.

To illustrate this point in more detail, imagine a physician handing a book filled with terms and conditions for a certain procedure to a patient, leaving the room, and awaiting a token of informed consent in return. It is then up to the patient to make

the information her own, to understand what risks and consequences the procedure will have, and to determine whether she trusts the physician with this procedure, for example. Let us assume the patient then chooses to go ahead with the procedure. In hindsight, it may turn out the patient may have overlooked or misunderstood that piece of crucial information that was so relevant *for her*. Perhaps the procedure has consequences for her practicing her favourite hobby. Perhaps it has consequences for her family, somehow. “Well, but you consented” the physician might say. This is in no way a realistic scenario for a clinical context. And yet this is what is expected of users of mHealth services, which, as I have discussed, contain many counterpart functions of clinical treatment, and can have far-reaching effects on health-related behavior.

To ensure that meaningful and morally transformative consent can take place in persuasive mHealth services, given the features discussed up until now, I argue the best way forward is to improve autonomous authorization, by temporally distributing consent in a developing process.

### 10.3.3 Meaningful consent: Temporal distribution

Thinking about temporal distribution of consent for mHealth requires the rethinking of informed decisions. Decisions are best understood as continuums or ongoing processes over time. The theory of distributed decision-making, found in psychology and sociology, supports this idea. According to Rapley (2008), decision-making is an ongoing event, distributed, amongst other dimensions, across time. Rapley describes that we could “expand the idea of ‘decisions’ beyond the ‘solo’ cognitions and actions of individual, rational, autonomous human actors that occur in relatively atemporal and ahistorical consultations. Moving beyond our present static research focus on ‘orphan’ consultations, to a more distributed vision, may offer new opportunities to actively engage with, support and research decision-making-in-action” (Rapley 2008, p. 432).

Approaching informed consent as a static state in which a user takes the amount of time needed to review all information on offer, and comes to an informed decision, is unrealistic. Decision-making is something that takes place in action and over time (Rapley 2008). In line with this idea, I argue that a more dynamic process of consent, that is temporally distributed, has to satisfy (at least) three requirements. It should offer a user multiple discrete consent moments over time (1); and it should consider that both the user (2) and the technology (3) develop over time. I will briefly address these requirements in turn.

The first requirement, of offering multiple consent moments, would entail that a user or patient is able to start using a service with a low threshold of decision-making. Downloading and starting to use a service should be possible without first giving one’s full and everlasting consent. However, merely distributing decisions over a number of discrete moments in time, is not going to improve the quality of consent.

The act of offering information does not necessarily lead to informed decision-making (Manson and O'Neill 2007), no matter how many times it is asked of the user. This links to the second requirement.

Taking into account the gradual learning and the experience that is needed to make a decision, I suggest breaking the single consent moment in mHealth down into a process, and facilitate the *learning process* of the user. Thereby moving beyond multiple consent moments spread out over time, to ensure that the user is facilitated or equipped to make the relevant decisions, when they come up. As a user starts to learn more about the service through experience, about its functions and methods, so too can consent be required for more complex aspects. Not only does the user learn about the technology and what it entails through its use, she can also formulate new goals or expectations of using the technology. Being able to modify her decisions and change direction is key to facilitate this development.

To satisfy the third-mentioned requirement, a temporal distribution of consent must facilitate that not only the user is in constant flux, but the technology as well. As the user starts formulating certain goals and expectations, these could influence persuasive techniques employed by the service. Adjustments in the methods of persuasion, or for example in the purposes of data collection, mean informed consent should also be adjusted. As these aspects develop along the way and are hard to foresee and predict, they cannot be covered by a single decision in time.

These three requirements point towards a more interactive process, where consent interplays with both the user's as well as the service's development over time. Given the many technological possibilities that mHealth technologies provide, it might be possible to combine different kinds of consent within an innovative design. The precise content of this design would be topic for further research.<sup>23</sup> Essential for mHealth is to ensure that the process is relevant for the individual user, giving her the opportunity to form a reasonable expectation, increasing understanding and intentionality.

Keeping the user and their vulnerabilities and uncertainties in mind is crucial in developing a consent process that can actually result in meaningful autonomous authorizations. Ultimately, the goal is not to increase quantity, but quality – to give users an opportunity to consent meaningfully. As persuasive mHealth apps are introduced in medical and non-medical contexts, to a wide range of users, from patients to life-style-focused consumers, this ethical hurdle should not be overlooked.

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<sup>23</sup> Examples of design ideas for other, related contexts can be found in the “dynamic consent” interface for biobanking (Kaye 2016), and “informed consent for information systems” (Friedman, Lin and Miller 2005).

## 10.4 Towards design

A potential objection to the temporal distribution of informed consent can be found in the worry that too many consent transactions with too much (written) information could lead to consent routinization (Ploug and Holm 2015) and desensitization (Schermer, Custers and van der Hof 2014, pp. 176–7). Custers (2016) describes what happens with consent in online environments:

Due to the large number of consent requests, users often do not really consider the questions asked, do not read the information provided and do not seem to think through the consequences of providing (or refusing) consent. [...] This is obviously problematic, as such consent no longer has any meaning (Custers 2016, p. 3).

In other words, this could cause the suboptimal user behavior mentioned in the beginning of this chapter. Increasing the number of consent requests does not necessarily increase the meaningfulness of consent.

The meaningfulness of consent is not helped either by requiring an expert decision prior to even having opened the service. The very least that can be done is to ask for re-consent over the course of use. To this end, Custers (2016) introduces the idea of consent expiration dates and re-consent opportunities. Even though this approach acknowledges that there are elements involved in consent that might change over time, re-consent could potentially just be another checkbox for disengaged users (Custers 2016). Even though this does solve *some* problems with one-off consent, it does not necessarily make consent any more meaningful.

My response to these worries is that temporally distributing consent is not a quantitative change alone; it is crucially qualitative too. One of the goals of temporally distributing informed consent is to prevent the occurrence of consent overload and desensitization altogether. Providing users with stimulating informative materials, and actually *supporting* their decision-making processes, rather than overwhelming them with a bulk of information and sole responsibility for the consequences of their consent, are elements to incorporate in the design.

Not every instance of informed consent will be ideal, but with increased opportunities for autonomous authorization, there will be several benefits even for those who fall short of the ideal. First, there will be a general improvement in the realization of autonomous authorization. Even those who fall short of the ideal might improve how well they understand and relate to their treatment. Second, having the option to reconsider and reflect on consent, even if this option is not always exercised, improves the situation of the user by giving them the freedom (not) to exercise the option. And third, there will be side benefits from those who do approximate the ideal, for others who will not, by generating knowledge and expectations that spread.

## 10.5 Concluding reflections

The goal of this chapter has been to open up the debate for meaningful consent in the mHealth context, given the many complexities and ethical issues it provides. mHealth is about more than data protection. It bears a resemblance with medical treatment, and has the potential of being introduced into medical settings. Given mHealth's features, and its possibilities of influencing its user, it is unrealistic to believe that this can be dealt with in a one-off all-encompassing decision. There is an ethical significance to mHealth services for health-related behavior change that needs to be addressed. A reconsideration of an ethical notion of consent, such as autonomous authorization, can inform this project.

In this chapter, I have argued that temporally distributed informed consent is an approach that could support the realization of this ethical notion of consent. However, as the title of this chapter suggests, the aim here has been to rethink consent in mHealth, rather than to offer a ready-made solution or design. The ideas posed here will need to be refined in light of empirical testing. As mHealth promises a transformation of the healthcare industry and is predicted to enable more personalized, participatory, preventive and less expensive care (Malvey and Slovensky 2014), this would be a worthwhile follow-up study. Given mHealth's promises, we should make sure that informed consent processes work in favor of achieving those ends.

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# 11 Reconfigurations of autonomy in digital health and the ethics of (socially) assistive technologies

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## Abstract

In this contribution the ethical impact of socially assistive technologies is analyzed against the background of digitalized healthcare and medicine in a thoroughly “datafied” society in general. Socially assistive technologies such as smart home sensors and carebots raise ethical issues which are continuous with other technologies in this cluster (e. g. health-related apps, telemonitoring) but their application in the context of particularly vulnerable populations such as elderly persons also appears to expose the limitations of established medical ethics and technology assessment tools starkly. While some specified analytic and ethical tools have already been developed, the meaning and scope of the underlying ethical criteria and reference concepts themselves is changing further. This will be illustrated by focusing in on reconceptualizations of (personal) autonomy such as the shift from patient autonomy to user or consumer autonomy, the vision of empowered autonomy in participatory, democratic care and medicine, and the effects of a prospective “autonomy” of the devices themselves. A broader discussion of assistive technologies along these lines may help accommodate the often precarious internal capabilities for self-determination in the elderly and/or vulnerable, and avoid neglect of important contextual and external factors to support and promote autonomy as an ethical cornerstone also in digital health.

## 11.1 Introduction

Socially assistive technologies are projected as a part of addressing the growing need for care and especially elderly care in many regions, which results from the increasingly older population with similarly increasing numbers of dementia patients and other vulnerabilities and disabilities (Bennett et al. 2017; Matarić 2017; Abdi et al. 2018). Technological assistance is also expected to help realize supported rather than substitute decision-making for people with disabilities following the UN Convention on the Rights of Persons with Disabilities (Bennett et al. 2017). “Assistive technologies” (including social or intelligent social assistive technologies) refers to devices or systems which allow to increase, maintain or improve capabilities of individuals with cognitive, physical or communication disabilities, and include devices such as GPS trackers, monitoring devices, sensors and wearables or technology for smart homes. They can take the form of self-contained devices or distributed systems and often link to software applications (Dorsten et al. 2009; Ienca et al. 2017).

Assistive technologies with a focus on sociality and interaction are used for affective therapy, cognitive training, as social facilitators, for companionship, and physiological therapy. In the form of robots they include machine-like, human-like and animal-like robots with and without learning responses (Abdi et al. 2018; Buhtz et al. 2018). In terms of both functionality and ethical, social and regulatory or legal issues there is overlap with other technologies in this cluster. Due to the basis in (mobile) data collection and analysis, they are raising challenges in data security and privacy protection, and in what a broad use of such managerial rather than human-centered tools will mean for individual self-responsibility, care relationships as well as prevailing conceptions of health, disease and normality in the healthcare system and society as a whole (cf. Bennett 2017).

Digital health or medicine 4.0 is characterized by the use of devices and approaches that often involve (real-time) monitoring, enhanced flexibility of application and/or ubiquity, as well as the combination of different purposes that may span lifestyle and healthcare “proper”. This is apparent in the thriving field of mHealth with its strong focus on helping to personalize, simplify and enhance care by strengthening self-monitoring and increasing access to health-related knowledge and advice, but also liberating users from traditional care structures. (Socially) assistive technologies carry a related promise in relation to autonomy broadly conceived, covering personal and cost-effectiveness<sup>24</sup> and even social and political empowerment or participation. Yet, as previously described for mHealth (Schmietow and Marckmann 2019) – sometimes assumed to be mainly for lifestyle use or chronic condition management – the underlying ethical concepts and values, in particular principlism in medical ethics, are undergoing change, and cannot be straightforwardly applied to digital health or assistance technology that should support a variety of user groups, including the elderly, frail and/or vulnerable. Some of these shifts will be the topic of this chapter, with a special focus on the kinds of autonomy at stake in the context of digitalized care.

In terms of structure, the starting point for this investigation will be the few existing (as well as adopted in practice) ethical frameworks integrating technological and social change as medicine and care are becoming datafied and progressively technology-mediated. Since they still require specification for sub-contexts and different stakeholders, this paper will proceed by introducing such models for analysis and evaluation, before presenting specifications and additions to the ethical debate on digital and assistive technology, both in terms of the role of individual autonomy as a value and as a signifier of a multitude of capabilities in health and care. Moreover, these shifts can be organized along a continuum or escalation, but are then shown to also involve a number of complexities, ambivalences and perhaps contradictions,

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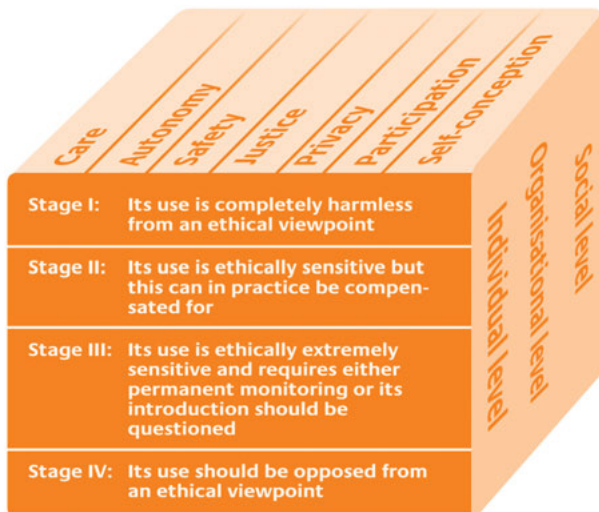
<sup>24</sup> For a contrasting perspective, cf. Ho and Quick 2018.

which are of particular relevance for the elderly, vulnerable or cognitively impaired user or target of such technologies.

## 11.2 Autonomy in existing evaluative frameworks

Manzeschke et al. (2015) focus on the following moral issue: how can we serve elderly people in their neediness and help them to live lives on their own (as well as delay entry into institutional care)? Their aim is to provide a toolbox that can and should be adapted to social and technical change.<sup>25</sup> The background to their specific study and ethical assessment model are the manifold applications being developed and made available primarily for elderly people to help them live autonomously in their own households for longer (also known as ambient assisted living). Independence and autonomy are strongly highlighted as both the motive and the objective of this development: “Independent life can be taken as a reference to the key socio-political terms of autonomy and social participation” (Manzeschke et al. 2015 p. 8). More generally, age-appropriate systems should be seen as “socio-technical arrangements” which implies that these are “social” in that they are used by the elderly themselves as well as by relatives and healthcare or nursing staff.

The diffusion of this technology may raise issues of privacy protection and thus informational autonomy through complex and/or intransparent ambient data processing. In particular cognitively impaired persons could be deprived of control over



**Fig. 11.1:** The MEESTAR model (Manzeschke et al. 2015: 14).

<sup>25</sup> “The model should always be embedded with an iterative process [...] to ensure that the ethical status quo is observed and constantly evaluated as social, individual and technical phenomena develop” (Manzeschke et al. 2015 p-21).

the (sensitive health-related) data flows surrounding them and connected to them. Especially in case prospective technology users are unable to consent or their ability to consent is restricted, there may be a difficult trade-off between the importance to autonomy of being able to remain in one's home environment in exchange for a (potential or factual) loss of privacy as a form of restricting autonomy. Overall, the proliferation of assistive technology could lead to changing and indeed expanding expectations of what constitutes "good care", including "the attributed and increasing autonomy of people who are learning to take care of their own health" (Manzeschke et al. 2015 p. 12).

Against this backdrop, Manzeschke et al. developed MEESTAR, a "model for the ethical evaluation of socio-technical arrangements" as an analytical and practical tool to be applied to assistive technologies and beyond. This model is highlighted here since it provides a clear methodology for *normative* assessment and has also been applied to a certain range of technologies in specific studies (Weber and Wackerbarth 2017). The tool foregrounds seven ethical dimensions – care, autonomy, safety, justice, privacy, participation and self-conception – which were identified as essential from the results of theoretical ethical work as well as a series of qualitative interviews with stakeholders. Four levels of ethical sensitivity of the arrangement from complete harmlessness to complete ethical unacceptability and three levels of analysis and evaluation – individual, organizational, and social – are distinguished.

The dimension of autonomy here refers primarily to the following interpretations in current debate: an individual's maximum freedom of decision and action, its role as one of four bioethical principles (principlism), as well as the socio-political discourse around the integration and inclusion or social participation of individuals with disabilities. Although the authors do not propose a specified definition, they outline relevant questions in relation to autonomy when applying the tool:

- How can people be assisted in their autonomy on the basis of practices oriented consistently around the individual's right to autonomy?
- How can people be supported in their autonomy when their usual criteria of autonomous decision-making and action have become questionable or even untenable?
- How do we deal with the fact that ascribing autonomy can conflict with the right to care and support? (Manzeschke et al. 2015 p. 15)

They further emphasize as part of their overarching recommendations that (in this case) age-appropriate assisting systems should help users to lead an autonomous life (i. e. decide and act autonomously) and specify that the assisting systems themselves should not make decisions, unless this has first been configured with the consent of the user, and that fully automatic, self-deciding systems require separate assessment. In case of restricted autonomy on the part of the user the systems should only be used to help cognitively impaired people following a dedicated assessment taking into consideration the probable wishes of those who are expected to interact with the device.

Finally, this analysis points to the necessary balance between aspects of empowerment or disempowerment and the additional concern of a delegation of autonomy to technology:

Care must not be subverted by the structures and surroundings of a care system which, although well intentioned, aims to return the activity of caring back into the autonomous and independent charge of those receiving care [...]. What is at issue is to shape the structures of care systems such that both poles, autonomy and care, are treated sensitively so that care does not become a type of besiegement and autonomy does not become a means by which to cloak our ignorance of the needs of others. (Manzeschke et al. 2015 p. 31; cf. Perry et al. 2009; Mittelstadt 2017)

The proposal for the systematic evaluation of eHealth applications such as for example, telemonitoring and mobile health by Marckmann (2016) chiefly consists in an evaluation matrix combining aspects of medical ethics (i. e. principlism with its four principles respect for autonomy, non-maleficence, beneficence, and justice) and ethics of technology or respectively technology assessment. It is based on a coherentist approach described as building on moral convictions found in a particular community rather than invoking some ultimate basic moral principle, with the purpose of connecting the former in a coherent structure of reasoning (cf. Marckmann 2016 p. 86f).

Similarly to the MEESTAR model and analysis, although developed with reference to eHealth, it is assumed to function in a flexible manner and be able to accommodate

**Table 11.1** Ethical criteria and their justification for the evaluation of eHealth applications. Translated and adapted from Marckmann (2016).

Criteria for ethical evaluation	Ethical justification
Functional capability	Means-end rationality
Possible alternatives	Means-end rationality
Potenzial benefit	Beneficence
Potenzial harm	Non-maleficence
Integrity of doctor-patient-relationship	Respect for autonomy; beneficence
Respect for/ promotion of autonomy	Respect for autonomy
Privacy/ data protection	Informational self-determination
Data security	Non-maleficence
Cost-benefit-ratio	Efficiency; distributive justice
Autonomy of medical decision-making	Beneficence
Medical decision-making competency	Non-maleficence; beneficence
Attributability of responsibility	Non-maleficence
Equal access and distribution	Justice

technological innovation. In any case, since it suggests a stepwise approach bridging contextualization and evaluation of the technology, a specific description of the technology in question and also an adjustment or “fine-tuning” of evaluation criteria is part of the approach. The process includes six steps: the description of the technology to be examined, a specification of the evaluation criteria, an evaluation for single criteria specified, a synthesis regarding the overall evaluation, recommendations for development and application of the technology, and monitoring (as well as potentially adjusting) the concluding ethical implications.

Some aspects that are relevant to such adjustment for (socially) assistive technologies will be outlined below. The adapted framework could eventually be tested out in theoretical scenarios of application and/or empirical case studies.

### 11.3 Reconfigurations of autonomy in digital health and assistance

Ethical assumptions around autonomy and especially a potential for strengthening it continue to play a prominent role in academic and public debate on the impact of digital health and socially assistive technologies. Yet, the more concrete meaning of “autonomy” in this context is often pre-supposed or left open to interpretation. This might be due, on the one hand, to the importance of informed consent in medical ethics as a main means of realizing the principle of respect for autonomy, and the relative lack of tools for the ethical evaluation of digital health applications that also explicitly cover aspects of technology assessment. The focus on the procedure of competent and informed decision-making, however, may not apply analogously to digital assistants and apps used outside of traditional care contexts, where conditions of data collection and use in relation to consumer products are not mediated by a health or care professional (or where this is the case, these might not have the adequate expertise) (cf. Groß and Schmidt 2018).

On the other hand, if approached from a broader perspective of health-related technology in a thoroughly datafied society, these technologies appear to be characterized by a strong ambivalence between enhancing some form of autonomy and undermining or diminishing it by, for example, fostering self-care and simulating valuable social interaction, or by creating dependence on technology and blurring the boundaries concerning responsibility for health and care.

Yet, what kind of autonomy is at stake here, and how can we approach this apparently very ambivalent potential of digital applications in the care context? Is it possible to base such judgment on a unified conception of autonomy and the autonomous user?

### 11.3.1 A multi-stage model of enhanced autonomy

To approach an answer to these questions, in the following a contextualization and possible limitations to applying core assumptions of the value and ability of autonomy in medical ethics to digital health use are considered, before outlining shifts in background assumptions about the ethical impact on autonomy in this debate. These shifts can be systematized as forming a multi-stage model of enhanced autonomy by way of digitalizing healthcare, moving from patient to user or consumer autonomy, via increasing health literacy, and the empowerment of users, to eventually lead to significantly democratized, participative medicine and healthcare.

A starting point for this discussion is the mainly procedural and action-oriented conception of autonomy often based on principlist medical ethics as developed by Beauchamp and Childress in the 1970 s. Differently from a conceptual and normative characterization of autonomy as of moral value and as a general ability of individuals, it strongly focuses on the concept and procedure of informed consent to treatment or research participation or contribution. Autonomy as realized through informed consent is therefore conceptualized as being based on competent decision-making, voluntariness, understanding of relevant information provided, and freedom from external influence in coming to a decision. While there are various philosophical accounts of autonomy such as for example those in post-Kantian, relational or feminist terms, these are sometimes considered as too demanding and/or narrow to provide practical guidance in real-world clinical, research or healthcare contexts. Still, patient autonomy plays a central role in current models of relationships in medicine and healthcare, either by way of informed patient choice or by the even stronger emphasis on autonomous decision-making and individual responsibility in the consumerist model of doctor-patient-relationships or respectively relationships in healthcare (Krones and Richter 2008).

Digital healthcare technologies focusing on social assistance display similar characteristics to other areas of eHealth such as often enabling real-time monitoring and enhanced flexibility and comfort through the possibility of ubiquitous access and communicative interfaces. These interfaces may also exceed former communication patterns in healthcare by involving health and care professionals flexibly into everyday contexts, while at the same time being able to connect more easily with other patients or users of similar technology via dedicated networks or platforms. This flexibility may have an impact on how these applications are used and categorized, and even on how they are regulated because they may transgress the medical and healthcare realm and its evidential and ethical standards. A carebot and the relevant software may monitor medical parameters and feed these into standard care; but they may additionally provide lifestyle, social and mental support or gather data on behavior preemptively, i. e. without, for the time being, established or specific medical or care use. The increasingly blurry boundaries of health and care are widely suggested to help sustain or increase abilities relevant to autonomous action and the respect for



it by healthcare professionals and relevant others. At the same time, continued and routinized use of the technologies already presupposes such capabilities and may require supplementary training and customization in the vein of “patient-centricity” (Pino et al. 2015).

### 11.3.2 Consumer autonomy, empowered care, and democratized medicine

A first shift in the ethically relevant concepts of autonomy in this field is marked by the distinction between patient autonomy and consumer autonomy. The latter model has been gaining a certain prominence in medical ethics but appears to be of particular relevance to the extent that healthcare is complemented and delivered increasingly through direct-to-consumer and digital services and technologies (Ho and Quick 2018). The autonomous patient and the autonomous consumer however are relying on considerably different background assumptions in terms of values and necessary capabilities to realise the status of “autonomy”. Patients are assumed to be in a situation of involuntary need or even emergency, which often involves forms of insecurity or powerlessness as well as limited information on remedies, benefits and risks. Even if their level of relevant knowledge is relatively high, the special situation of often in this sense dependent patients includes them being likely to discount or ignore costs – in terms of financial or other investment – to anything that might be able to help them.

While simplified, clearly the basic situation of the prototypical consumer is on the opposite side of a spectrum of individual autonomy and responsibility. Consumer choices as part of transactions or contractual relationships in healthcare or elsewhere are assumed to be fully voluntary, well-informed and thus imagine confident independent action on the side of the consumer. Healthcare and medicine, on the other hand, are charged with normative assumptions – and regulations – around concepts such as trust, collaboration and compassion rather than the maximization of mutual and usually quantifiable advantage in transactional relationships.

Corresponding to these values are dedicated patient rights such as the right to emergency care, confidentiality or being informed about the availability of alternatives to a treatment. Transparency concerning what is involved in the purchase and use of a consumer product, on the other hand, is usually determined by the provider (Goldstein and Bowers 2015). Klugman et al. (2018) accordingly note that “informed consent is primarily for the benefit of the patient, but user agreements are primarily designed to benefit the companies” (Klugman et al. 2018p.40). Overall, the consumer therefore tends to be seen as ideally autonomous and as such fully self-responsible, whereas the patient can rely on the protection of her welfare and autonomy, which are widely considered fundamental values in healthcare and medicine. These areas of life are enjoying a special status and corresponding safeguards, which are called into question by what has been called the “lifestylisation of healthcare” (Lucivero

and Prainsack 2015), as exemplified by the distinction of apps and assistance systems into medical and/or lifestyle products. An assistance technology that is convenient but used without a clear medical purpose would not require regulation and informed consent to treatment based on the traditional conditions outlined above, and instead straightforwardly ask for agreement to data processing and acceptance of terms and conditions. Apart from regulation and questions of payment or refunding, autonomy and responsibility are conceptually and practically transferred to the realm of lifestyle and consumer transactions, in which users or consumers are relatively independent and able to navigate different positions of power.

Since assistive technologies rely on the datafication of health<sup>26</sup> and the interactive nature of digital devices, an increase in personal autonomy is also linked to an emphasis on digital and health literacy (Kim and Xie 2017; Ho and Quick 2018). The relevant health competences can be defined as the “knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion” (Kim and Xie 2017p.1074). These are both a precondition and a result of some form of technologically mediated enhanced autonomy. Health and digital literacy were arguably part of realizing autonomous patienthood *avant la lettre*. Yet, the use of assistive devices in more flexible contexts of care means that a further stage of autonomy as empowerment makes health and digital literacy a virtually indispensable demand, especially if technology serves to replace traditional personal care.

The promise of such independence on a social and political level again hinges on self-management or even self-tracking in user-friendly, participant-centric contexts. Autonomy can then take the form of “empowerment” which has long been discussed in some parts of health research, and before the advent of digital health applications was also a main normative tenet associated with personalized medicine.

### 11.3.3 Ambivalences and limitations

The shift to be noted here concerns the emphasis on health maintenance and prevention through active and responsible self-care. Although no general definition of empowerment has been agreed upon, the expectation of advocates of such self-care by means of technology is that it may lead to a “post-informed-consent-medicine” and instead help create “P4-medicine” which is predictive, preventive, personalized and participatory (Hood and Flores 2012; Topol 2015). Some commentators claim that

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<sup>26</sup> I. e. the conversion of qualitative aspects of life, in particular clinical and self-care practices, into quantified data (digitization) and the processing of data to generate new information and knowledge from data already made available by means of predictive analytics (Schmietow and Marckmann 2019).

this may be the beginning of a new form of participative and democratized medicine and healthcare (Topol 2015; Ho and Quick 2018). On the other end of the spectrum, technology-mediated empowerment has been criticized not only as interfering with autonomy as underlying the protection of privacy, leading to a depersonalization of medicine and care, and a pathologization of daily life (cf. Rubeis et al. 2018), but could even be seen as contradictory since it also presupposes demanding forms of autonomous capabilities such as health and technology literacy.

This raises the question whether empowerment as active health management can address relevant target groups such as those most in need or may on the contrary increase inequalities in health (Manzeschke 2015; Ienca et al. 2017; Ho and Quick 2018). The delegation of social interaction and partly medical decision-making to technology could eventually lead to an undermining of autonomy or even disempowerment by way of automated, decontextualized health assessment and care (Pino et al. 2015). A further concern is an accelerated regression of basic abilities, especially those of elderly users (Manzeschke et al. 2015 p. 28; Mittelstadt 2017). Again, the ambivalence and delicate balance in technologically assisted care as outlined by Manzeschke et al. (2015) cannot be realized by a care system that “aims to return the activity of caring back into the autonomous and independent charge of those receiving care—and that includes if this is done by way of technical support” (Manzeschke et al. 2015 p. 31; cf. Godwin 2012).

In summary, traditional ethical approaches to the use of socially assistive technologies for elderly and/or vulnerable populations are undergoing change, which adds to the existing complexity of autonomy as a key reference concept for ethical evaluation and socio-political orientation. This is illustrated most clearly by the focus on procedural, formal and internal (i. e. capability-oriented) aspects of individual autonomy in principlist medical ethics. Previous work has added important considerations of the social context – and thus the dynamic “external” aspects – of technology development and implementation specifically for assistive technology and digital, data-based applications (Manzeschke et al. 2015; Weber 2015; Marckmann 2016).

The implications of assisting primarily non-fully autonomous users with such technology against the background of economically and politically driven digitalized (health-) care should be integrated even more extensively into bioethical debate. As can be illustrated with the help of an “escalation model” of assumed autonomy via technology use, individual autonomy (based on mainly formal criteria) appears to rather straightforwardly generate a vast potential for empowered patienthood or sometimes even a true paradigm shift towards fully bottom-up medicine and care. Yet, the various forms of enhanced autonomy in this model spanning consumer power (rather than patient dependence) through to personal health management (rather than social systems of care) can also be analyzed as ambivalent or in fact harboring internal contradiction.

These limitations are exposed most clearly if future scenarios involve elderly or vulnerable users. Health literate users and consumers of digital technology suggest

market-conform “ideal” autonomy while it is improbable that such target groups will have a wide spectrum of relevant choice available to them, even if they retain some forms of autonomy and should be respected as autonomous agents as such. Will they have access to or the necessary capabilities including social, economic and intellectual capital to use the market to their own advantage?<sup>27</sup>

## 11.4 Conclusion

The assumed increase in empowerment thanks to broad use of assistive technology mainly refers to datafication as well as optimized self-care and self-responsibility. This quantum leap, however, presupposes that already very capable individuals are not the primary target group. Care relationships, including non-digital ones that foster social participation would need to remain central, particularly if there is a risk of simply delegating care and user autonomy to technology that in turn becomes invisible rather than obtrusive and increasingly “autonomous” (cf. Weber 2015; Mittelstadt 2017). The superior level of democratized healthcare for all on this basis therefore appears as highly disputable in relation to the elderly and vulnerable. In addition to a variety of risks to interference with informational privacy and decisional autonomy if tracking-based, it may even be considered a sort of category mistake, i. e. the attempt of a chiefly technological “solution” to the social and political at least as much as individual problem of fostering self-determination and participation.

This paper has sketched out some of the shifts in discussing autonomy as an ethical cornerstone also in digitalized healthcare. These concern the shift from patient autonomy to user or consumer autonomy, the vision of empowered autonomy in participatory, democratic care and medicine, and the effects of a prospective “autonomy” of the increasingly interconnected devices themselves. The concept of autonomy as conceived in principlism in particular may, however, not be able to accommodate the often precarious internal capabilities for self-determination in elderly and/or vulnerable user groups, and in addition contribute to the ethical neglect of the various contextual and external factors in helping respect and promote patient and user autonomy in the application of socially assistive devices.

By way of contrast, it was suggested that this context is key: conditions for autonomy should be established with reference to a specific application, and external in addition to merely internal conditions for self-determination should be highlighted for ethical assessment and policy intervention. These factors are the impact of social-

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<sup>27</sup> Cf. Manzeschke et al. (2015): “As long as age appropriate assisting systems continue to be organised through a co-payer or selfpayer market, we can expect people with little capital (social, economic and intellectual) not to participate sufficiently in this care (cf. Bauer, Büscher 2008)” (Manzeschke et al. 2015 p. 12).

ly assistive technologies on existing care structures (on a system and individual level), user control and participatory technology development, as well as digital technology and health literacy. Adjustments of this type may enrich the conceptualization and assessment of the technology alongside established ethical frameworks, and would ideally be tested out in further work as part of dedicated, empirically informed ethical scenarios. Not the least, a broader conceptualization of the ethical impact of framing autonomy bears on regulation, such as the importance of both informed consent and user agreements or self-responsibility versus recovery of costs by the state or community for the use of digital and assistive technology.

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## 12 Personal autonomy in elderly and disabled: How assistive technologies impact on it

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### Abstract

Technological change has been notable in recent decades, including the field of assistive technologies aimed at promoting the autonomy of the elderly and disabled people. Personal autonomy is possible thanks to ethical-juridical protection through reciprocally recognized human rights (civil and political, economic, social and cultural, third generation). The current technological change could produce an alteration in the exercise of personal autonomy, putting at risk its normative protection, since some of these rights currently require technological mediations to be able to be carried out. Nowadays, the UN Convention on the Rights of Persons with Disabilities (CRPD) governs as the international normative framework that defines and protects the autonomy of people with disabilities, mostly elderly, and includes important references to technological developments. New assistive technologies, that can be used to record physiological variables or to monitor habitual patterns of life, are suggested as devices that promote personal autonomy. Health monitoring could impact privacy, identity, integrity, and the protection of personal data. Therefore, it is necessary to broaden the ethical reflection from the CRPD to the relevant regulations on privacy and data protection (General Data Protection Regulation [GDPR] and Draft Privacy Regulation ePrivacy) and the Data Protection Impact Assessment (DPIA) provided in Art. 35 GDPR, which is especially relevant for the realm of assistive technologies. In this contribution we show how technological change affects some aspects of personal autonomy, its normative protection, privacy, and care.

### 12.1 Introduction

In recent years, technological change has been notable, including the field of assistive technologies aimed at promoting the autonomy of elderly and disabled persons. In this contribution we show how this change affects some aspects of personal autonomy, its normative protection, privacy, and care.

Taken as the possibility of self-government, without illegitimate interference, to decide on and execute one's life plan, personal autonomy is possible thanks to ethical-juridical protection and through reciprocally recognized human rights (civil and political, economic, social and cultural, third generation, corresponding primarily to rights of a collective nature: rights to a healthy environment, economic development, self-determination). The current technological change could produce an alteration in the exercise of personal autonomy, putting at risk its normative protection, since

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carrying out some of these rights has followed a constant process of increasing need and dependence on technological mediations (Winner 2007). Nevertheless, the elderly and disabled have been absent from these reflections over time, assuming their limited ability to exercise autonomy. Nowadays, fortunately, the UN Convention on the Rights of Persons with Disabilities, (CRPD) (UN 2006) governs as the international normative framework that defines and protects the autonomy of people with disabilities, with the highest rates of disability among the elderly resulting from the accumulation of health risks over a lifetime of illness, injury and chronic illness, and includes important references to technological developments (see, for example, CRPD, arts. 2, 4 g, 4 h, 9, 20b, 20 d, 21a, 26.3, 29a.ii).

New assistive technologies, such as robot companions, smart screen assistants, or wearable technology with sensors that record physiological variables to monitor habitual patterns of life, are suggested as devices that promote personal autonomy. The recorded data, once processed, can offer information about health, habits, etc., and allow, in principle, to make more autonomous decisions about one's own well-being and quality of life, relying on the information provided by the processing of data obtained from personal patterns of behavior. But this technological scenario claims an extreme protection of personal autonomy too, since health monitoring could impact privacy, identity, integrity, and the protection of personal data. Therefore, it is necessary to broaden the ethical reflection: from the CRPD to the relevant regulations on privacy and data protection (General Data Protection Regulation [GDPR] and Draft Privacy Regulation ePrivacy) and the Data Protection Impact Assessment (DPIA) provided in art. 35 GDPR, which is especially relevant for the realm of assistive technologies. All these regulations have the essential goal to protect the affected individuals in the asymmetric power relations which they face with the organizations and governments that develop, implement, and manage assistive technologies. In this kind of relationship, it seems especially important to ensure the effective protection of the personal autonomy of the elderly and disabled.

The technological scenario, which affects rights such as privacy, identity, integrity, and data protection, requires new forms of "care". Not only traditional forms of personal and intersubjective care, but also social care, that is, normative measures that help secure those rights, so that new technological devices do not become instruments of surveillance and control, diminishing the autonomy they intend to promote. The basic ethical principle of non-maleficence involves the need to protect people from damage and harm in her interaction with assistive technologies. As in the case of medical iatrogenesis, the technological mediations could cause harms (on the people's privacy, identity, and integrity). This is the primary ethical duty about the use of assistive technologies: *primum non nocere*. Moreover, these technologies should be available without any kind of discrimination in order to fulfill an elemental ethical principle of justice.

To achieve this goal it is important to consider the "public" dimension of autonomy and its relational character, related to the social participation of the elderly and

disabled in the public debate on assistive technologies, in all phases of their development, in terms of “social appropriation” of technologies or inclusiveness. Autonomy should be considered in an intersubjective and collaborative way instead of an individualistic and solipsistic one.

## 12.2 Technological mediation and the capability approach

Generally speaking, a community’s approach and relationship to a certain technology can be viewed as mediated and filled with meaning by means of intertwining sets of values, representations and social practices. This way of understanding the relationship allows us to talk about the community’s “discourse” (Lynch 1988) about this technology. But there is an analogous (instrumental) discourse (Winner 1980), linked to the whole set of characteristics of the technology in question, which also brings with it practices, representations and values coming from the communities responsible for its idea, design, development, manufacturing, marketing and commercialization.

Different environments for activities and social participation, such as: urban, domestic, educational or work environments; environments for public, political, social and economic participation; or environments for culture, leisure or health can be considered “functionings environments,” in the sense of the capability approach developed by Amartya Sen and Martha Nussbaum. This concept deals with spaces (real or virtual) in which we carry out actions and practices we consider to be important and valuable for our well-being and quality of life (Sen and Nussbaum 1993). In this approach, well-being consists of evaluating life conditions defined by functionings. These represent what a person achieves or becomes in the course of their life, which can be considered a set of interrelated functionings (Sen 1987, 1998).

The introduction of technological elements into functionings environments condition the way in which these actions are carried out and, consequently, can modify the evaluation of the functionings mediated by such elements (Toboso 2010). If in a given environment the situation arises in which mediation from a device is obligatorily needed to perform a certain functioning, the limitations of this device will define the limitations of this act. In the most extreme case, if the device is not available, the performance of the functioning will be nullified, which will negatively affect the scope of well-being associated with its achievement. Barriers of access or use will create discrimination and inequality in the user communities, as a consequence of their technological dependence on such devices. The sum of inequalities of access and use may produce an inequality of greater importance: an inequality of opportunities for the affected people or communities, as a consequence of such barriers that restrict the opportunities to access the use of technologies (Toboso 2010).

Demanding genuine equal opportunities brings up important questions related to ethics, politics and social justice, and to the question which value frameworks

should be considered the most relevant when considering what is needed for equality. The aspects that a community of users can evaluate in their relationship with any type of device are numerous. Among them we highlight some values (Echeverría 2003), in connection with access and use, and linked to security and privacy: availability, affordability, necessity, appearance, simplicity, ergonomics, accessibility, usability, versatility, efficiency, quality, reliability, security, intimacy and privacy.

The realization of values, such as those referred to, can be interpreted as the concurrence of the community's discourse and the instrumental discourse, and is the basic condition for "social appropriation" of the devices, which we should differentiate from the simple concept of "adopting" them (Salovaara and Tamminen 2009). Adoption happens through the practice of use, while appropriation happens by means of the co-constructive combination of practices and values, requiring realization of these values in practices, and also involves social representations that are favorable towards the device in question (Tiles and Oberdiek, 1995; Oudshoorn and Pinch 2005).

### 12.3 Current frameworks on the rights of the elderly and persons with disabilities

More than mere instruments, assistive technologies are mediations which open up new possibilities in human functioning. Today, numerous functionings are mediated by them. In the environments in which people who are dependent, the elderly or those with disabilities are cared for, the introduction of assistive technologies is generally encouraged as a substitute for traditional human care (de Asís Roig 2014). Resorting to these devices should contribute to a "democratization of care" (Tronto 2013), that overcomes the enormous gender bias that has befallen this fundamental activity for social reproduction (Kittay 1999), and should not be a source of new discrimination regarding access to basic care and attention.

The Convention on the Rights of Persons with Disabilities (CRPD) is an international regulatory framework with legal repercussions in the majority of countries in the world. To responsibly advance the development of assistive technologies, in terms of well-being and justice, professionals involved should receive training in this legal document, given the importance socio-technical mediations have for the full enjoyment of human rights (Winner 2007). This technological development will have to take into account the regulatory framework of the CRPD, and prospectively orient itself towards facilitating autonomy in the achievement of human functionings in inclusive environments, guaranteeing conditions for good care, derived from an international human rights normative framework.

With respect to the values in the CRPD to be taken into account in developing assistive technologies, we point out the following: (1) Respect for every type of human functional diversity. Technologically assisted care must deal with the wide diversity of human functionings. (2) Inclusion requires universal accessibility and universal

design. Assistive technologies must be accessible and promote, in addition to health, autonomy and social inclusion. (3) Social participation of people receiving assistance demands having a voice in all the phases of development and implementation of technologies. It is necessary to include these people from the first developmental phases of technological innovation (Chavarriaga and Millán 2016), in consonance with what is indicated in the CRPD (Preamble, Parts n and o, Art. 3.c). The importance of participation in the technological design process on the part of users with disability must be emphasized. The users themselves know best how technological devices can contribute to their greater autonomy, quality of life and level of participation in society, and can assist in evaluating their advantages as well as their drawbacks in the earliest phases of their development. As the ones most familiar with their own reality, users help to create technological solutions that are more feasible in not only their technical but also their financial and social aspects. User participation also contributes to generating demand for those solutions which, in turn, stimulates their introduction into the market and inspires new lines of research (Toboso 2010).

The underlying theoretical discourse of the CRPD, based on the social model of disability (Abberley 1987; Barnes, Oliver and Barton 2002; Swain et al. 2004), interprets disability as a result of the interaction between people with different bodily or mental functions and discriminatory social structures. The juridical-moral approach of the CRPD endorses overcoming the traditional medical-rehabilitation model, which limits disability to the individual sphere, and highlights society's responsibility to eliminate all social barriers – physical, legal, political, economic, cultural or attitudinal – that affect persons with disabilities. Accordingly, in the Preamble (section 5) the CRPD states that “disability is an evolving concept” and that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.

Hence, speaking about “disability” and “persons with disability” we should henceforth consider that the current recognized normative framework is the CRPD and no longer about considering disability as conceived in the medical-rehabilitator model, even though it is still present to a large extent in the collective imagination and societal practices (UN 2006). As such, it should be concluded that implementation of socially appropriable assistive technologies must take into consideration the model underlying the CRPD.

## 12.4 Rethinking autonomy in technological functionings environments

According to what is expressed in Article 20.b, the CRPD recognises the right to have access to “assistive technologies, technical devices and quality mobility aids, including by making them available at affordable cost”. Articles 4.g and 26.3 also call on the

States Parties to promote assistive technologies and devices for people with disabilities “as they relate to habilitation and rehabilitation”. Nevertheless, the proclamation of such rights does not imply a relapse into traditional medical-rehabilitation model outlined above. Consequently, although assistive technologies may be focused on rehabilitation or assistance, they must be oriented, in accordance with the principles of the CRPD, towards the respect for and facilitation of individual autonomy (Art. 3a) in the usual spaces for activity and social participation of persons with disabilities (Art. 3c), and in concordance with the other relevant principles: dignity, non-discrimination, equality of opportunity, respect for differences, accessibility, equality between men and women, and respect for the evolving capacities of children with disabilities (Art. 3).

Assistive technologies are also used to improve the functional autonomy of people with some types of motor disorder or neurodevelopmental disorder. Some applications based on brain-machine interfaces allow motor pathologies to be restored, and to restore communication through writing on a computer screen (Hochberg et al. 2006) or as a physical response to control an effector (Wodlinger et al. 2015). Other applications that have been used for decades are stimulation interfaces such as cochlear implants (Gifford et al. 2008) and deep brain stimulation, which relieves symptoms for people with Parkinson’s disease, dystonia (Arle and Alterman 1999) or depression (Trapp, Xiong and Conway 2018).

These techno-scientific artefacts require an ethical examination (Jonas 1997) that clarifies the risks involved in their use, determines morally acceptable conditions for their adaptation and helps to increase the level of commitment for responsible performance in techno-scientific work by designers and developers in the social framework (Agazzi 1996). Any reflection concerning change in the technological area should be accompanied by a parallel ethical reflection on the aspects affected by these technologies. Given the large amount of possibilities to use current technology, such a change creates the obligation to deal with important questions such as autonomy, privacy and data protection, as well as the new neurorights (see below) and cognitive liberty. The adoption of an ethical-legal framework should be aimed at providing technologies to support the autonomy of persons with disabilities. Moreover, it should guide techno-scientific work towards the purpose society as a whole should be committed: the inclusion of persons with disabilities into a variety of different social environments.

The change in discourse the CRPD has brought about allows the ideas of care, autonomy, dependence and vulnerability to be redefined. Care is now conceived as a right that is, in turn, reinforced by the set of rights promoted by the Convention and by technological mediation. Thus, what is stressed is a “public” vision of care, as opposed to another traditional vision that is benevolent and with an enormous gender bias (see Kittay 1999). Limitations on personal autonomy in dependent people are no longer conceived as pure destiny or as an inherent characteristic of these limitations, but rather as a contextual condition that can be modified or is the focus of attention in the framework of human rights. Furthermore dependence, as a situation that requires

care, is no longer conceived apart from the possibility of an independent life. There is also a growing awareness that physical or mental vulnerability interacts with social vulnerability which in turn results from stigmatization and from the discriminatory configuration of the socio-technological environment (Nussbaum 2007).

Some implications of this conceptual redefinition for assistive technologies are: (1) The technologies in question need to contribute to improving the social task of caregiving; (2) They need to facilitate the autonomy of people receiving assistance in the social environments in which they develop; and (3) They need to be part of the socio-technological foundation that supports their rights as a whole.

### 12.4.1 Privacy and data protection

We begin by recalling an essential principle of privacy in continental Europe, starting from legislation on the subject in 1970 s Germany. This principle is called prohibition with the exception of authorization (*Verbot mit Erlaubnisvorbehalt*). This means that processing of personal data is prohibited unless there is an exception that authorises data processing. The traditional examples were that the affected person had given their consent or that a legal regulation authorized the data processing.

The GDPR (in Art.6.1.f) has introduced or extended the possibility of arguing for a legitimate interest on the part of the organization that is processing personal data. It is worth pointing out that it is necessary to be able to clearly document the existence of this interest, as well as that it does not imply a disproportionate risk to the rights of the people affected. If this documentation is impossible, it is likely that from the start of its implementation the processing implies a violation of privacy legislation. The point of this clause is to show that control regarding the subject of privacy should be done prior to implementation—in fact even prior to doing any test with real data or real subjects who will be affected by an assistive technology.

### 12.4.2 Data protection targets

To reflect on the essential points regarding privacy, we draw upon what are known as safety goals (in German, in the original: *Schutzziele*, Rost Op. Cit).

- Transparency. In the field of privacy, this concept (included in arts. 5, 25 and 32 of the GDPR) is understood as the possibility to control (from the point of view of those responsible for processing, as well as from the perspective of the subjects affected and from an external body such as a data protection authority) any processing of personal data. This control is usually guaranteed by means of documentation and different types of protocols.
- Unlinkability. Included, among others, in the GDPR articles mentioned above, this implies that in regard to privacy, personal data collection must be intended

for specified purposes and not further processed in a manner that is incompatible with these purposes. To be able to fulfill this goal, it is essential that the purpose of the processing is defined as precisely as possible, guaranteeing its legitimacy and legality.

- Integrity. (see GDPR articles mentioned above) This refers, on the one hand, to the requirement that information technology processes and systems continuously comply with the specifications that have been determined for the execution of their intended functions. On the other hand, integrity means that the data to be processed remain intact, complete, and up-to-date. Deviations from these properties must be excluded or at least ascertainable so that this can either be taken into consideration or the data can be corrected.
- Confidentiality. (Ibid.) This is guaranteed in the sense of the principle of Privacy by Design (Art. 24 GDPR), when processing of personal data has been planned and implemented in such a way that only authorized people can access the functions (this is a technical term, we may also write procedures) and systems related to it.
- Ability to intervene. In addition to the previously mentioned articles, arts. 18, 20 and 21 of the GDPR should also be noted. In regard to privacy, this implies that the processing of personal data, if necessary, can be modified or stopped.
- Availability. (see arts. 13 and 15 of the GDPR, among others). This is the requirement that personal data must be available and can be used properly in the intended process. Thus, the data must be accessible to authorized parties and the methods intended for their processing must be applied.

The data protection goals mentioned here establish a list of criteria to follow for the development and implementation of personal data processing that is easily interpretable, including for the use of assistive technologies, without delving too deeply into the legal aspects of the problems that may arise if the data protection goals are not implemented/respected (e. g. lack of confidentiality). Also implied is the possibility of implementing a control procedure that follows the principles in the PDCA cycle (Plan, Do, Check, Act) (Breut, 2017 Op. Cit) that allow regular controls to be done, in fact continually, on the processing that is developed and implemented.

### 12.4.3 Data protection impact assessment

Article 35 of the GDPR establishes that given the probability that processing “is likely to result in a high risk to the rights and freedoms of natural persons”, it will be necessary to carry out a DPIA before the processing is started. This obligation is aligned with the principle of privacy, which has the goal of analyzing processing from its design phase onwards and of guaranteeing proper management of the risks as well as

the fulfillment of the principles of necessity and proportionality. A DPIA should include:

- a systematic description of the envisaged processing operations
- an assessment of the necessity and proportionality of the processing operations in relation to the purposes
- an assessment of the risks
- the envisaged measures to address the risks, including safeguards, security measures and mechanisms to ensure the protection of personal data.

It should be highlighted some types of personal data processing can involve high risks for the subjects affected and as such need a DPIA. The Article 29 working party (Art. 29 WP) was the independent European working party that dealt with issues relating to the protection of privacy and personal data until 25 May 2018 (after entry into application of the GDPR its new name is European Data Protection Board) issued a document in respect to this (European Commission 2017) in which they mention different criteria to follow in order to assess the risks involved with regard to certain forms of personal data processing. In the following we mention two that are relevant for assistive technologies:

- “A systematic and extensive evaluation of personal aspects relating to natural persons which is based on automated processing, including profiling, and on which decisions are based that produce legal effects concerning the natural person or similarly significantly affect the natural person” (Art. 35. 3 GDPR)
- Processing on a large scale of special categories of data referred to in Article 9, section 1, or of personal data relating to criminal convictions and offences referred to in Article 10.

It should be remembered that found among the types of data mentioned in Article 9.1 of the GDPR are data concerning health. The two points mentioned above indicate that any processing of personal data in which assistive technologies are used should be accompanied by a DPIA. Carrying out this assessment forms part of the legal basis for development and implementation of the processing, and not completing the assessment could imply that this processing constitutes, or could constitute, from the moment real personal data is utilized, a violation of current legislation on the subject of data protection.



## 12.5 On the recognition of new human rights: 'Neurorights' and cognitive liberty

The first step towards possible recognition of new human rights related to neuroscience take form in the debate on “cognitive liberty”. According to Bublitz (2013), this concept, at times also called “mental self-determination”, includes two closely-related aspects:

- The right of individuals to use emerging neurotechnologies
- The protection of individuals against coercive use of these technologies and the possibility that the technology could be used without their consent.

Bublitz (2013) summarizes this in the following manner: cognitive liberty is the principle that guarantees “the right to alter one’s mental states with the help of neurotools as well as to refuse to do so”. The second aspect of cognitive liberty is related to a reconceptualization of some already existing rights and to the creation of new fundamental “neurorights” (Ienca and Andorno 2017):

- The right to mental privacy
- The right to mental integrity
- The right to psychological continuity.

### 12.5.1 The right to mental privacy

If we consider the problems posed to reach adequate protection of the traditional right to privacy, it appears evident that it is necessary to adapt regulations to achieve the same type of protection for mental privacy. This protection should cover any type of information obtained from the brain by means of neurotechnologies and distributed by digital means. It means protecting people in the face of illegitimate use of for example their cerebral information and preventing possible filtrations of this data on the Internet.

### 12.5.2 The right to mental integrity

Intrusions or actions on a person’s brain can create not only a violation of their privacy but also a damaging change to their neural computation. The presence of damage is a necessary condition for a violation of the mental integrity of the person to have taken place. Ienca and Haselager (2016) have introduced the idea of “malicious brain-hacking” to describe neurocriminal activities on the neural computation of users of neurotechnologies, just like what hackers do with computers. Focusing on brain-computer interface (BCI), which could also be used in conjunction with assistive technologies, they have identified four types of malicious brain-hacking on dif-

ferent levels or for different types of BCI. In three of these types the attack is done on the measurement, decoding and feedback levels and can cause manipulation of the person's neural computation if the attacker, without authorization or knowledge of the person, intercepts the signal sent by the BCI-controlled apparatus.

The rights that should arise from this new scenario must be the basis for a new regulation that provides adequate protection in the face of aggressions by means of neurotechnologies. The incorporation of neurotechnologies into the digital world and availability on the Internet of the information created can cause the mental integrity of the individuals to be subject to a higher level of risk if the appropriate protective measures have not been adopted.

### 12.5.3 The right to psychological continuity

In addition to mental privacy and mental integrity, the perception that an individual has of their own identity may also be affected by an incorrect use of neurotechnologies. These technologies can be used to monitor brain signals as well as to stimulate or modulate brain functions. As such, changes in brain functions produced by brain stimulation can, as a consequence, create changes in critical mental states for the personality (Decker and Fleischer 2008). Specifically, it has been observed that brain stimulation can have an impact on psychological continuity, that is to say, on the essential requirement for personal identity to perceive oneself as a continuous and persistent entity, and “as the same person”, over time (Klaming and Haselager 2013).

This right implies protecting the personal identity and continuity of personal behavior in the face of non-consensual modifications by third parties. This is closely related to the right to mental integrity and, at times, they might overlap as both rights seek to protect individuals from non-consensual alterations of their mental dimension.

The subject of new fundamental neurorights has not been picked up, for the moment, in regulation or legislation, but we believe it should be taken into account as soon as possible in the development and implementation of neurotechnologies such as BCIs in order to be able to analyze and manage risks as comprehensively as possible.

## 12.6 Conclusions

The mediation of technological devices, such as assistive technologies, in functioning environments determine the character of the assisted functionings and the way they are carried out. This involves modification of the original functionings, which will transform into “mediated” ones. In general, this mediation implies adaptation of the users' discourse to the artefactual discourse materialized in the devices (Winner

2007), which produces a transformation not only in the landscape of practices in the environment, but also in the panorama of its values.

More than one hundred years ago, Schumpeter spoke about processes for innovation as “creative destruction” (Schumpeter 1934). Recently, Javier Echeverría has been reflecting on the good and bad of innovation, assuming that all innovation has its beneficiaries but also those who are harmed (Echeverría 2014). The question that concerns us is how to distribute the benefits and the harms. It would be desirable for this to be done in a just and equitable way toward the conditions of functionings environments, on which the well-being and quality of life of people may critically depend.

In caregiving environments, the supposed advantages of new assistive technologies such as affective robots, robotic assistants, caregiving robots and others are already being advertised. But this is being done without taking into account that caregiving relationships imply elements that are essentially human and intrinsically intersubjective, and to care for a person with Alzheimer’s, to name one case, the best “technology” is another human being (de Asís Roig 2014). As we indicated in the Introduction, the current technological scenario affects rights such as privacy, identity, integrity and data protection, and requires new forms of care. In addition to traditional and familiar personal care, appealing to normative measures, such as the CRPD, which help to guarantee these rights, we also raise the need for social care, which assumes the importance of the public dimension of autonomy, related to the social participation of older and disabled people in the public debate on assistive technologies. The last threshold is the prevention of harm and damage (by action or by omission) involved in the ethical principle of non-maleficence (*primun non nocere*). We should avoid the adverse effects of assistive technologies in elderly autonomy, identity, and integrity as a case of “iatrogenesis” by means of a social and participative appropriation of that device.

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## Part V: **Broadening the perspective**



## 13 Technical utopias – political illusions?

### What can we expect from autonomous assistance systems for older people?


Hartmut Remmers

#### Abstract

This article aims to justify the thesis that the development of autonomous assistance systems for older people has so far been largely determined by rather irrelevant rationalization logics (e. g. cost economy, standardization and streamlining of processes) and political preferences (economic development) than by sufficient attention being paid to the actual needs, abilities and interests of the addressees. Undesirable developments result from a narrowing to aspects of the functional substitutability of nursing activities and insufficient knowledge, especially of gerontological findings. According to these, the development of technology should, on the one hand, consider the creative potential of old age as technically innervatable resources (empowerment approach) and, on the other hand, consider the fragility and vulnerability of the elderly, especially the very old, as the absolute limit to the substitutability of human attention and psychophysical support. The limits of the use of a therapy robot are shown using the example of an artefact constructed for rehabilitative gait training.

#### 13.1 Introduction

In my contribution, I would like to deal with sociological and studies from psychology of aging in the sense of an empirical foundation of the ethical discussion. Firstly, I will briefly outline the demographic, epidemiological and health services research starting position of “age-changed societies” (Kuhlmey), in order to outline directional decisions and political preferences for the development of age-related assistance technologies. It is argued that decisions for concrete technological developments depend on certain rationalization calculations or logics in the field of health care, i. e. on assessments of, for example, functional substitutability of nursing activities. I will, therefore, deal more extensively with gerontological, in particular psychogerontological findings, and highlighted characteristics of nursing as constitutive prerequisites of technological development and the assessment of their appropriateness to the needs and demands of older people. Against this background of theoretically differentiating prerequisites, I will then briefly outline the state of development of autonomous assistance systems and examine the question of which of the needs and interests of older people are to be assumed in the development of technology. Finally, I will use the example of an artefact constructed for rehabilitative training to demonstrate its limited usability.

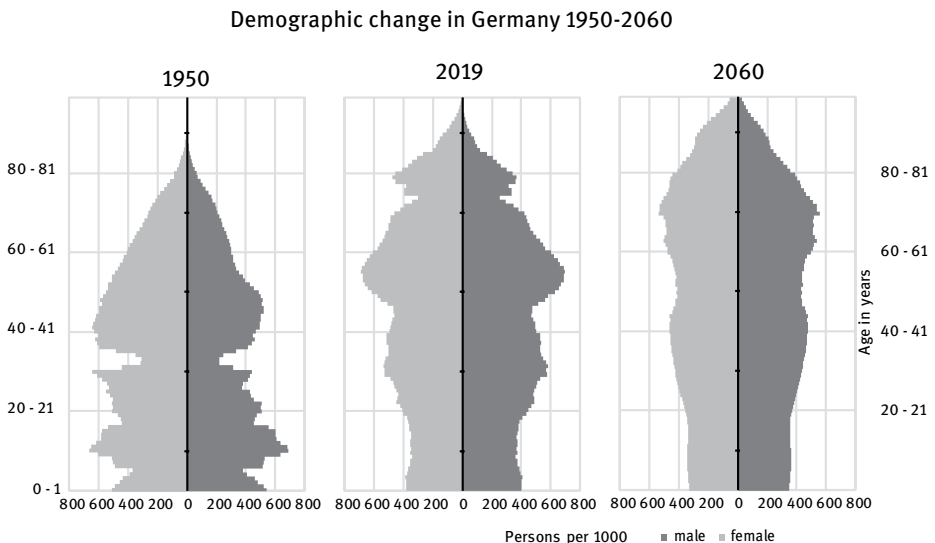
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<https://doi.org/10.1515/9783110677485-013>



## 13.2 Starting Position

The current demographic change – as is exemplified here by the German situation – is characterized by a continuously increasing average life expectancy with the consequence of an increasing proportion of older people and a simultaneous decline of the younger population (see figure 13.1).

It should be noted that for many older people, the life years gained mean a longer period of individual and social activity. Of course, the consequences of old age also (1) consist of a growing need for social and health care in this part of the population. As late as 1980, Fries (1980) had expected that the disease phase would become more acute in old age as a result of better health prevention (morbidity compression). This hope does not seem to be fulfilled (Crimmins and Beltrán-Sánchez 2011; Niehaus 2012; Strobelberger et al. 2012; Geyer 2015). (2) Demographically, we are also dealing with a shift in the relationship between the younger and older generations. As a result, a gap is widening between an increasing number of people in need of care, on the one hand, and an increasing shortage of skilled nursing staff because of a decreasing number of young professionals, on the other. (3) Regarding nursing care problems, a construction error in the social nursing care insurance system is drastically noticeable: Even when the law was introduced in 1995, it was assumed that families would be the central long-term care system. In fact, however, the proportion of domestic care provided by relatives will decline in the future due to the growing mobility of the younger generation and the increasing employment of women. Social long-term care



**Fig. 13.1:** The demographic change in Germany from 1950 to 2060 (moderate development) data source: Statistisches Bundesamt (Destatis), 2019.

insurance is based on a traditional (historical) image of women and families (Backes et al. 2008).

According to serious statistical studies, a shortage of 300,000 to 500,000 FTE in nursing staff is expected by 2030, also taking into account technological and organizational rationalization effects (Pohl 2011; Ehrentraut et al. 2015)<sup>28</sup>. However, federal politicians believe they can assume that the widening personnel gap will, at least, be partially closed by technically autonomous assistance systems.<sup>29</sup> In accordance with this logic, a generous funding program was established in Europe (European Commission 2010). New assistance technologies are intended to ensure the longest possible independent life in old age in a self-chosen environment, even with increasing impairment. Functional losses in older people are to be compensated, everyday skills maintained, and preventive and rehabilitative measures more effectively supported.

It is also expected that modern information and communication systems will enable all actors to be more effectively integrated into the health care system (Remmers 2016). There is no doubt that the systematic exchange of medical and nursing information urgently needs to be improved. It is also expected that assistance systems in the vicinity of robotics will relieve the physical and cognitive strain on nurses in particular – an important concern in view of the premature departure of many nurses due to high occupational stress.

### 13.3 Path Dependency of Technology Development

The objectives of technology promotion and development mentioned above are undoubtedly significant and worthy of respect. However, if we look back over a longer period of technological promotion in this area, the question arises: What has proven to be useful so far? What has proven itself in practice? Answers to these questions can hardly be given sufficiently without, at the same time, dealing with the ideas and

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**28** These demand calculations are supported by a recent prognostic calculation of the additional demand for nursing staff in the federal state of Lower Saxony. According to the State Care Report, an additional 19,000 specialists will be needed in outpatient care and 31,000 in inpatient care by 2030, i. e. a total of 50,000 specialists. As a rule, Lower Saxony accounts for 10 % of nationwide demand. The occupational age structure will have a devastating effect on future development: In 2018, 38.35 % of nursing staff in Lower Saxony will be 51 years and older. With the same career drop-out, more than 40 % of the nursing specialists working today will no longer be able to exercise their profession in 15 years. A figure of 5,000 new entries per year as a result of completed training and recognized foreign nursing staff are not enough to compensate for this (Parliament of Lower Saxony, 18th parliamentary term, printed matter 18/3574).

**29** Also see the press release of the German Ethics Council No. 05/2019 of 25 June 2019: “The number of people to be cared for will increase dramatically in the future. Care techniques promise ways out of the impending care crisis,” according to Council Chairman Peter Dabrock.

desires of members of our society regarding a good life in old and extreme old age emphatically expressed: Age with dignity.<sup>30</sup> Only then would there be a basis for a technology funding policy oriented towards comprehensive, and not merely selective, needs.

The promotion of so-called geronto technologies, however, was classically path-dependent, i. e. in accordance with the system imperatives of economic growth as a driver of innovation (Ropohl 2009). A closer look reveals that research and development programs which are primarily intended to serve health care security in old age are directly or indirectly intertwined with the funding interests of high-tech industries. It is no coincidence, for example, that representatives of the high-tech industry have been routinely included in prominent positions on the political agenda of the European Commission (2010). Representatives of interest groups of older people or of various caring professions have been sought in vain.

This confirms the findings of technical sociology which state that the success of technical action is defined by the respective reference system and its evaluation framework (Kornwachs 2013). From the point of view of the technical-industrial production sector, technical success is measured by different criteria than in the personal health services sector, especially under conditions of human fragility and vulnerability. According to the technical sociologist Ropohl (2009), technological developments have a directionality that is dependent on the economic exploitation of new technical products. Following on from this, Kornwachs (2013) also states that accelerated technological development is a result of accelerated capital dynamics. In his eyes, therefore, it is doubtful whether the development of the technology will be in accordance with its own laws. One driving force is the growing interest in certain technologies that make it possible to replace a cost-economically expensive labor force by apparatus, for example, when machine investment costs are significantly lower than the labor costs saved as a result. Technological innovations are, therefore, strongly driven by economic factors (Nemet 2009). According to Kornwachs (2013), a seven-fold increase in labor productivity has been achieved by technology both in machine production and process innovation in the Federal Republic of Germany from the 1950s until today. What is propagated as innovation obeys those system imperatives of growth through technological progress and is increasingly dependent on globally operating super-enterprises.

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**30** See, among other things, the contributions in Kruse et al. (2012).

### 13.3.1 Political Preferences: Technology Promotion Versus Nursing Promotion

The highly economic path dependency of technological development is obviously dictated by the 'logic' that the German government has been following in its high-tech strategy for many years. This applies all the more to the interdepartmental "Forschungsagenda für den demografischen Wandel" [Research Agenda for Demographic Change] adopted in 2011 with the dazzling title: Old Age has a future. Demographic change, which is often associated with concerns and fears among the population, is being relabeled as a "demographic opportunity."

What concrete opportunities should be associated with the federal government's technology funding policy aimed at supporting older people? The funding area of the Federal Ministry of Education and Research (BMBF) "Forschung für Innovationen, Hightech-Strategie" [Research for Innovation, High-Tech Strategy] includes the funding for projects such as "Innovation durch neue Technologien" [Innovation through New Technologies] in the title group (TG 20). The BMBF's funding line, which is largely geared to age- and care-related technology development, operates under the title "Mensch-Technik-Interaktion" [Human-Technology Interaction]. The share of this funding line in the total BMBF budget for 2018 amounts to 1.24 %, which, at first glance, appears to be rather marginal compared to the BMBF's total annual budget of 17.6 billion Euro. Technical and social innovations are particularly promoted with the following focal points: 1. Self-determined life, 2. assistance systems in the domestic environment and 3. intelligent mobility. To a certain extent, many of these innovation priorities are upstream of inpatient intervention scenarios for the long-term care of the elderly. Further support for age- and care-related technology development can be found in other funding lines, such as "service innovations."

It should not be overlooked that innovation funding, which is not exclusively geared to technology development, is provided in fields of work in the social and nursing professions, which is reflected in federal research and development funding specifically addressed to universities of applied sciences, such as "Soziale Innovationen für Lebensqualität im Alter" [Social Innovations for Quality of Life in Old Age], with an annual funding amount of 5 million euros.

The program for the promotion of technology in nursing fields can be contrasted with a recent initiative by the Federal Government to finance 13,000 additional nursing places for medical treatment in inpatient long-term care facilities, which was taken under considerable pressure from the public in the face of an increasing nursing care crisis. It should be emphasized that this measure is not financed from a special fund of the Federal Ministry of Health but from current surpluses of the statutory health insurance funds. The costs for the additional costs of staffing the health care institutions are estimated at around 640 million euros (Handelsblatt 2018). Facilities with up to 40 residents will receive half the allotted amount for a complete institution; facilities with 41 to 80 residents will receive the full equivalent of a complete institution; facilities with 81 to 120 residents one and a half times a complete institution; and

facilities with more than 120 residents twice the allotted amount for a complete institution (GKV-Spitzenverband 2019). Based on the total number of inpatients in need of care, this means that an additional six minutes per day are available for wound care, medication or blood pressure measurement for each resident of a nursing home. Even if a differentiation has to be made depending on the degree of care of a resident, it is true that the residents of nursing homes have an average high degree of need for care. This does not yet take into account the communicative share of nursing work beyond the performance-related specialist medical care, i. e. personal attention. This ad hoc initiative cannot, therefore, be regarded as a significant and, above all, permanent improvement in nursing care.<sup>31</sup>

### 13.3.2 Premises of Different Rationalization Logics

By contrast, the promotion of technological innovations is tacitly carried out under the condition that Germany must not miss the boat regarding global markets. The preferential system of research funding also appears to be subject to these market-law imperatives.<sup>32</sup> However, the transfer of the rationalization logic that is decisive for commercial areas of production, distribution and administration and the technological innovations that are interwoven with it to areas of health care and nursing seems to be highly problematic. The procedural peculiarities of medical and nursing services as human services and the indispensable structural prerequisites for them, which show decisive differences, are misjudged. Turning care processes into objects of technical rationalization calculations would mean misjudging the highly personal, i. e. individualizing character of help, support or advisory tasks. The technical substitutability of such services by robotic systems, for example, in order to achieve personnel savings is, therefore, subject to strict limits. It would certainly be justifiable to replace certain functional tasks, at least in part, by machines. Mechanical aids for embarrassing toilet visits or for merely repetitive, less technically demanding tasks, such as determining vital signs, would possibly be welcome.

In all this, on the one hand, differentiated needs and acceptance analyses must be insisted on, namely from the evaluation perspective of all those concerned. On the other hand, with this evaluation perspective, as already indicated, the question will be connected with what is understood in our society by a good, humane age.

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<sup>31</sup> A reason why, in the meantime, the much too small political value of the care is also deplored in a high-ranking technical periodical of the medical professional organization. See: *Ärzteblatt* (2019)

<sup>32</sup> See EPL 30: Funding areas and priorities of the Bundesministerium für Bildung und Forschung (2017). [https://www.bundeshaushalt.de/fileadmin/de.bundeshaushalt/content\\_de/dokumente/2017/soll/epl30.pdf](https://www.bundeshaushalt.de/fileadmin/de.bundeshaushalt/content_de/dokumente/2017/soll/epl30.pdf) (03.01.2020).

## 13.4 Conditions for Technological Innovation in Support of Older people

Experiences from a large number of research and development projects on assistive technologies for older people can be summed up as follows: At best, the technical competencies of the addressees were examined as prerequisites for the successful implementation of the artefacts developed (Meyer 2016). Less attention was usually paid to nontechnical prerequisites, i. e. those to be developed in the social environment of the addressees and their concrete psychophysical constitution. Their exploration takes place in a social-scientific-psychological approach (Künemund 2016), which is why, in this context, the undoubtedly important ethical assessments, for example, of the consequences of assistive technologies for older people in terms of a balance of opportunities and risks, are initially of secondary importance (Remmers 2018, 2016; Nagel and Remmers 2012). In the following, I would like to concentrate on the nontechnical requirements of technological innovations and let myself be guided by the following questions: Which gerontological, in particular psychogerontological, findings on age and ageing processes must be considered when developing age-appropriate technologies? Which equally elementary insights into structural and process-related peculiarities of care for the (elderly) person must also be considered in the development of technology?

### 13.4.1 Phenomena of ageing and old age

#### Development potential

One of the most important results of gerontological research is that age in our time is characterized not only by physical, cognitive and psychological decline and losses but also by development potential at different age levels which are effective in the working world and in individual educational contexts (Börsch-Supan and Weiss 2010; Tippelt and Schmidt-Hertha 2010). There are biological and socio-emotional changes in old age which offer considerable opportunities for development, particularly self-stabilization, even in old age (Rott 2010). It should always be borne in mind that old age is actually a relatively young phenomenon in view of the early mortality of humans many hundreds of years ago. Nevertheless, ageing is biologically unavoidable regardless of the socio-historical developments.

There is some evidence that people are invariably able to compensate for the losses associated with old age: On the one hand, on a social level by reorganizing the living environment and, on the other, by a process of development taking place in the personality system of the elderly person. Older people are in a position to change goals or set new goals, and to develop different patterns of action and routines than those they have acquired in earlier life years. They are more and more able to compensate for the increasingly biologically limited capacities. The development model

formulated by Baltes and Baltes (1990) is: Selection and optimization of possibilities while simultaneously compensating for losses in other functional areas.

This evolutionary selection has an effect on life in old age, for example, more abilities are being acquired to help others competently. A pool of experience and knowledge of one's own is passed on to younger people. The importance of emotional and social goals also grows with increasing age in comparison to instrumental goals.

The time perspective also changes in older people: Thinking is more oriented towards the future well-being of other people and questions of how lasting things can be created (Kruse 2017; Biggs 2010; Kohli 2005).

Based on their experience, older people have the skills to deal with boundaries in both private, public and professional life. Such skills find greater opportunities for realization in old age because creative action at this stage of life is no longer associated with the risks characteristic of young people's development phases, such as career failure. The processing of biographical borderline experiences, thus, enables them to deal more calmly with fears and analyze problems in a sober way. The need for new information in decision-making situations is assessed in a more controlled way. Creativity and a moderate serenity form a certain mixture. According to the principle of generativity, such attitudes can be passed on as virtues of maturity (Biggs 1999). However, ageing processes are very heterogeneous. The influence of social differences increases with age. Especially in old age, social inequalities with poverty and health risks have an increasing cumulative effect.

If one disregards social structural 'determinants,' people in old age show themselves to be capable of development in certain areas. Even under conditions of health losses, they are often able to perform creatively.

As far as the development of geronto technologies is concerned, Kruse and Schmitt (2015) come to the conclusion that development potentials do not yet represent a systematic approach for the technical-constructive use or stimulation of, for example, the creative capacity of older people. To communicate electronically with relatives, friends, etc. by means of key commands is by no means to be described as creative or creativity-promoting.

### Experiences of interdependencies and dependencies

On the other hand, we will have to deal with less pleasant phenomena of ageing and old age. seem to be abhorred by the technical sciences in a certain way due to a structural 'optimism' anchored in the world view of the scientific community. Knowledge about the fragility and vulnerability of the elderly is rather marginal. One explanation could be that in modern societies, which in one way or another are protected by the welfare state, individualistic lifestyles are overaccentuated – possibly as a reaction to postindustrial overflowing flexibilization strategies and the associated pressures to adapt (Bröckling 2007).

Faced with proven trends of individualization, i. e. the decoupling of work and life as well as personal life from natural communities, it is important to be aware of the fact that human life ultimately takes place under historically varying conditions of physical and social dependencies. People experience mutual dependencies in very elementary areas of their lives. These experiences manifest themselves in moral attitudes. The more people become aware of their mutual dependencies and dependencies on assistance, the more they become aware of their vulnerability.

Principles of both solidarity and protection can be considered as a response to this fundamental background of experience. In this context, the social significance of a purely biological fact can also be highlighted: Already at birth, man is dependent on help, attention and recognition of his social environment, and he remains so in varying degrees depending on predictable and unforeseeable crises (Habermas 2001).

### Vulnerability

While the creative development potential of old age has so far been emphasized, it is now necessary to become aware of opposing development criteria, such as the fact that the risk of multiple illnesses increases, especially at an age of 80 and over. Chronic degenerative diseases, including neurodegenerative diseases of the Alzheimer type, increase exponentially. Old age is especially characterized by increasing vulnerability with limited mental resistance (Kruse 2017).

However, vulnerability is also a component of the basic human constitution. There is no other way to understand caring behavior towards sick people in need of help and care. Care work is part of human culture. It also includes instrumental practices of compensation for human exposure and defenselessness – an aspect that is decisive for a technology philosophy oriented towards functional interpretations (Grunwald 2013). It will be necessary to consider the fact that techniques are not determined solely by their tool character but also by the fact that they become a structuring part of human lifestyles. The functions of a subject and object are no longer easy to oppose, but rather form a kind of “action programme” (Nordmann 2008, 68; with reference to Latour 1969).

Old age is the phase of life in which physical, cognitive and social losses are increasingly being dealt with. Emotional vulnerability is of particular importance here. There is widespread agreement that certain living conditions have a direct influence on the degree and forms of vulnerability. Vulnerability can be the result of a lifelong development or a current life situation, for example, an acute illness. It should be borne in mind that individuals can also do something in old age to avoid, alleviate or compensate for certain forms and manifestations of vulnerability in such a way that a largely self-determined life under conditions of social participation is possible.

Social participation is, therefore, of great importance. It is undisputed that a lack of opportunities to participate in the level of development and prosperity of a society is a decisive reason for pronounced vulnerability. However, people react very dif-



ferently to objectively comparable pressures. Stress does not always have to lead to high emotional vulnerability. This is shown by the results of resilience research, i. e. the investigation of complex processes of individual stress processing. To put it in a nutshell, it turned out that certain processes of stress processing are linked to social networks and the support they provide (Kruse 2017; Oswald 2014). It should always be noted that the emergence and maintenance of resilience is linked to an interplay of psychological, social and institutional factors. Above all, older people are dependent on an environment of familiar or/and trustworthy people. Under these conditions, as the Berlin Ageing Study (Lindenberger 2010) has shown, older people are capable of productive adaptation even in the face of various losses. Resilience, thus, proves to be a specific result of the plasticity of human performance and organizational capacity (Staudinger et al. 1995).

The previous presentation of gerontological findings provides starting points for the development and use of technical assistance systems. However, it is important to warn against false conclusions and exaggerated expectations. Ageing processes cannot be manipulated arbitrarily in old age if vulnerability increases or resources decrease. This fact has been given far too little consideration in the design of technical assistance systems and false assumptions have often been made. Technical constructions are often too strongly oriented to questionable models of human self-optimization. Instead, requirements for technical assistance systems arise under the following questions: Are they suitable for supporting and stabilizing individuals, for example, in already initiated prevention strategies? To what extent can technical assistance systems support older people in mental and spiritual growth processes? To what extent do they help people to cope better with stressful situations (Kruse and Schmitt 2015)?

#### 13.4.2 Some typological characteristics of nursing work processes

A further problem of the federal government's previous technology support programs aimed at supporting people in need of care is a lack of knowledge about the structural characteristics of nursing work processes (Hülksen-Giesler and Krings 2015). From an anthropological point of view, care is an elementary component of human reproduction. There is a special need for nursing services in the event of restrictions caused by illness or irreversible degradation processes in old age. The focus is on the need for security and the successful handling of losses. Nursing care is, therefore, rightly characterized as relationship work that focuses on the basic needs of people in need of help, with specific emotional requirements. In addition, the direct contact with physically severely restricted people represents a high physical strain. To a certain extent, care takes place in the medium of physical reciprocity with risks of unlimited psychophysical expenditure (Remmers 2015, 2006).

Further difficulties result from the cyclical structure of nursing activities. These activities are geared to the natural, cyclically recurring basic needs of people in need of care, which vary in nature and urgency. Due to this situation-bound nature, i. e. its contingency character, care is difficult to plan and formally control. In contrast to the production of material goods or the processing of administrative processes, for example, the results of work are fleeting. They lack the vividness of success in infirmity and physical or mental decay.

The complexity and limited plannability of nursing work processes can, thus, only be illustrated in part. It can first be assumed that the use of electronic data processing systems in hospitals will lead to a rationalization of clinical workflows with qualitative improvement and cost-saving effects (Flemming 2015). Nevertheless, fundamental concerns arise: To what extent, for example, can the logic of professional relationship work be reconciled with a logic of economy and planning administration that manifests itself in technological programs (Hülsken-Giesler and Krings 2015)?

Perhaps these questions can be answered by some technical theoretical considerations. According to Grunwald (2013), it can be assumed that technology functions according to the principle of situation-invariant regularity. This means that the results of technical procedures can, in principle, be repeated at any time and in any place. Technical functionality requires context independence. This is the only way to make the results of technical processes calculable, thus, creating certainty of expectation, which has a positive effect on labor economics and labor psychology. Frequently observed resistance of nursing staff to the technification of their work seems to have something to do with the aforementioned situation-invariant regularity of technologically preformed processes. Many healthcare professionals fear that this will devalue professional principles of individualization and contextualization of care activities.

There is no question that, for example, labor-saving mechanical support technologies for lifting, turning and moving patients are perceived as beneficial (Krick et al. 2019). By contrast, nursing professionals react very ambivalently (Pols 2012) when friendly technical companions occupy, so to speak, original, identity-creating areas of nursing action; when they touch those structures of reciprocity, of responsiveness (Waldenfels 1994); in other words, that reciprocity of feeling and being felt, of touching and being touched, whose physiological and psychological correlates are of high therapeutic value. Admittedly, assistance systems in nursing are perceived as relieving and productive when their use provides greater scope for development and decision-making (Pols 2012).

## 13.5 On the State of Development of Autonomous Assistance Systems

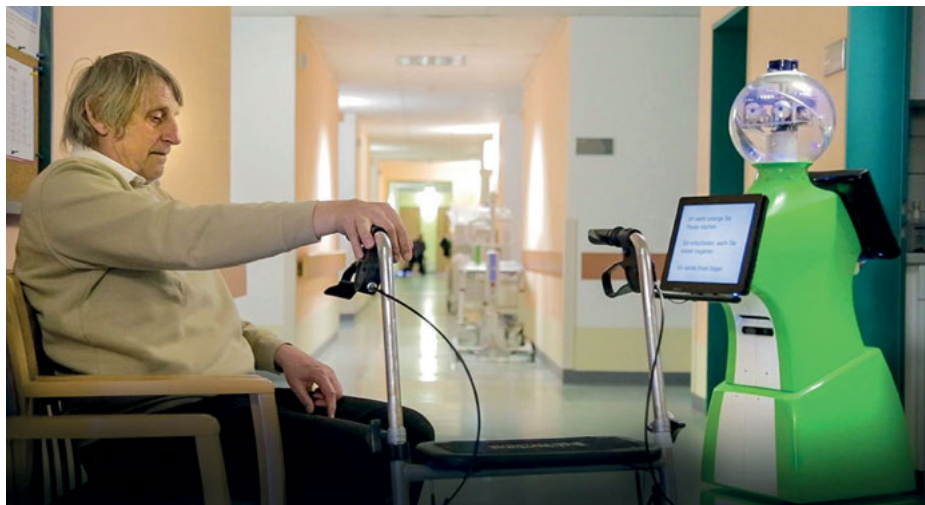
Autonomous assistance systems exhibit a great diversity that can be classified into various technologies (Hülsken-Giesler and Remmers 2016).

### 13.5.1 AAL-Technologies

So-called AAL technologies for the compensation of age-specific losses and the support of an independent life at home will not be discussed in more detail here. There are overlaps here, for example, with e-health, telemedicine and telenursing. On this information technology basis, opportunities for networked health care by multi-professional teams are opening up – a major topic for future security of medical services. I will leave it at key words such as case management, intersectoral treatment paths and cross-institutional electronic health records.

### 13.5.2 Robotic

In the meantime, technology development for the physical and cognitive support or relief of nursing staff and elderly people has made considerable progress. Regarding these autonomous assistance systems, a distinction should be made between assistance robots, therapy robots and interaction robots. An example of an assistance robot is Care-o-bot 4 (Fraunhofer IPA 2019), which performs manual activities such as gripping or enriching food and beverages on command. Intelligent care trolleys keep care utensils in stock and document their consumption. There are assistance robots for physical support of home and inpatient care, such as lifting and carrying a patient. The development of advanced human-machine systems, such as exoskeletons or exoskeletons, does not fall into the narrower circle of robotics. Exoskeletons combine human intelligence with machine power to support or amplify the movements of the wearer. These systems are used where human work cannot be meaningfully replaced



**Fig. 13.2:** Therapy robot ROREAS.

by robotic systems, such as in subareas of industrial production, and in physically heavy work in the construction and care industries. Tracking systems are used for the local self-control or external control of cognitively impaired, possibly slightly demented people. Therapy robots are used, for example, to support mobility. One example is the ROREAS robot (Technische Universität Ilmenau 2019), which supports patients during gait training in rehabilitation and serves as a reminder or navigation aid.

The emotion robot PARO (Parorobots 2019) developed for dementia patients should also be mentioned. PARO reacts to tactile and verbal speech with its own movements (eyelids, extremities, lifting and lowering of the head) and with sound formation.

The interaction robots include the ALIAS robot platform (Rehrl et al. 2011) with three core functions: (1) Communication (with web-based access to social networks), (2) physical and cognitive activation through games on the display, and (3) assistance through reminders of medication or planned appointments. Relatives can control or use these functions themselves via remote access.

## 13.6 The Needs and Expectations of Older People in Need of Care

The question as to what technical support and assistance older people actually need and what they want in terms of their circumstances has been answered rather abstractly so far, Brändle et al. (2016) in a critical balance state. Almost in unison, interviewees say that a self-determined, independent life with opportunities to participate in public life is very much desired among their peers. Technical support systems to compensate for physical and psychological losses are also desirable. However, an interest in personal security is more strongly emphasized by the relatives of older people than by the older people themselves (Hülsken-Giesler 2009). What quality of life means for older people *in concreto*, however, can only be understood through methodically differentiated surveys and observations (Paetzold and Pelizäus-Hoffmeister 2016). Gradually, more recent social science studies are focusing their attention above all on diverse forms of life design and personal, biographically varying life plans in old age as influencing factors in technical support needs (Koppenburger et al. 2016).

Since the development of fewer target-oriented assistance technologies has swallowed up immense financial resources, a certain sensitivity towards scientifically sound technical development needs seems to be emerging from the BMBF and the VDI/VDE/IT (Birken et al. 2016). Previous “user scenarios” were almost always characterized by negative age stereotypes (Künemund and Tanschus 2013). Up to now, psychological questions of human adaptation to technology have been strongly in the foreground (Robert 2018). However, questions of construction or adaptation must be answered from primarily the original perspective of different users (user-centered

design). In the meantime, the number of social science studies that focus analytically on the spatial-material life context of older people, on their spatial-social radius of action and on habits that are suitable for mastering recurring challenges of everyday life is growing (Heinze and Hilbert 2016; Saup 1999). Older people are proving to be extraordinarily imaginative in dealing routinely with obstacles or limitations, including the effect of cognitive training. Brändle et al. (2016), therefore, regarded it as groundbreaking to pay much greater attention to the “nontechnical needs for technology,” for example, to focus less on a telematic replacement of authentic social relationships than on telematic support in establishing and maintaining living social relationships. A further challenge will be to find out how older people can be technically supported in their creative handling of everyday problems without taking over the problem solving for them, rather to support them in their creative wealth (Remmers and Hülsken-Giesler 2012). On the agenda is a real user-orientation, a real transition to the so-called demand-pull approach. The technical support that can really be provided to elderly people in need of care and their relatives must be explored through methodologically elaborated studies in the context of a process evaluation (Künemund 2015). It should be borne in mind that research and development are always embedded in a normative framework. This also includes tacitly technology-optimistic assumptions that need to be examined (Mast et al. 2014). This results in a kind of signpost function for future age-related technology developments. A first normative prerequisite results from the fact that people up to an advanced age are cooperative beings, even with limitations. Another fundamental insight is that age itself is not yet a predictor of technological readiness or rejection (Erdmann et al.). In this respect, technical innovations make sense for the purpose of compensating for various socially or biologically induced limitations or disadvantages. However, a fixation on deficits should be avoided. Rather, even at an advanced age, stimutable activation and creativity potentials should be constructively taken up. The guiding aim is to enable people to participate in social life processes and, under these conditions, to lead a meaningful, good life. This would bring ethical-normative requirements to bear, for example, in the “Capability Approaches” established by Nussbaum (2011). Technologically, it is about functionalities that address the individual in his/her potentiality, in his/her tendency towards self-updating, in short: In his/her adaptability (Kruse and Schmitt 2010).

### 13.7 Paradigm Shift in Health Policy Innovations

Development potential and vulnerability belong in different forms to the psycho-physical constitution of older people. These facts, which vary greatly from person to person, must be met within the framework of nursing interventions. In view of the worsening problems, especially in nursing care, the question arises: Must social solution strategies be found that are primarily tailored to those social problems that are caused by demographic and socio-structural change? It goes without saying that

improvements in the production of material goods and their distribution aim at precisely this instrumental level of production and distribution as a rationalization approach. Improvements in the living conditions of older people, especially their care, must be based on completely different constitutional conditions, i. e. social life processes must be distinguished from technical production processes *par excellence*. The attempt to solve nursing care problems caused by a growing shortage of personnel through technological replacement strategies with low and differentiated effectiveness is illusory in nature. The fact that the world in which older, often frail people live is quite different from the technical world of industrial production and logistic distribution, which forms a secret framework for the development of geronto technologies, is misjudged. Both worlds obey completely incomparable laws, because they are incommensurable. They are, therefore, only, if at all, transformable into each other in a very limited way.

This is finally demonstrated by the example of a technical, in this case, robotic support of rehabilitative care. At the same time, this example serves as a kind of contrast foil in comparison to the guidance and support provided exclusively by personnel in early post-stroke gait training.

We chose the recently developed robot ROREAS as an example. As already mentioned, ROREAS belongs to the genus of therapy robots. It serves patients by supporting gait training in rehabilitation facilities and, at the same time, as a reminder and navigation aid. For demonstration purposes, we relied on a five-minute video that is strongly focused on product advertising. The video begins with a telephone call from the robot, which signals its presence in front of the door at the patient's room and invites him to a training session. The robot greets the patient on the ward corridor. The clinic manager is then shown, who praises the advantages of using robots against the background of a "tightly knit" therapy plan for staff shortages. According to his statements, the robot should not replace therapists or nursing staff. Rather, it is intended to encourage independent training in phases in which therapists or nurses are involved with other tasks. A social scientist accompanying the robot development emphasizes the patient-fair operation of the robot, which is, therefore, also suitable for humans with or without cognitive impairments. It can be experienced intuitively and also gives pleasure. The robot now navigates the patient through numerous intersecting ward corridors and tells him the route. A faded-in technology developer praises the orientation ability of the robot which recognizes existing or emerging obstacles. The robot can also cope with difficult tasks, for example, by recognizing people with walking aids. The robot is able to communicate the current whereabouts on the ward corridor. It waits for the patient to take the necessary personal breaks. A representative of a health insurance company, who was once again shown on the screen, emphasized that this completed development project was intended to actively involve patients in technical innovations in the health care system. By technically combining different functions, it would be possible for patients to walk faster and become mobile faster, not only with the help of people but also with technology. In the meantime, the

robot's monitor shows how many gait meters the patient has managed in which time. Finally, another technology developer emphasizes the many years of experience of his institution in the development of service robotics in retail and industry.

No personal address of the patient is recognizable in the cinematic demonstration of ROREAS. The patient appears to be depressed throughout, slightly indifferent, which could possibly be interpreted as a reaction to his (possibly stroke-related) reduced mobility. The patient is only able to respond to the one-sided response by the robot by standardized response specifications in the form of key commands. The patient reacts to further requests from the robot regarding the extent to which he (the patient) has understood information or wishes to receive further information without any internal movement. According to the gestural expression, the behavior can be interpreted as a reaction to standardized information or requests that is rather "obligatory." There is no communication with the following or leading therapy robot, rather it is reduced to purely reactive behavior. It is not clear whether and to what extent therapeutically highly significant instructions, support and aid are given in the process of the ultimately wordless gait training. The robotically staged training reflects a mute mode of relationship that reifies the patient as the pure addressee of instructions (Rosa 2016). A mood of indifference, of apathy dominates the scene. The patient does not receive any attention as a personality. What is missing is what is also indispensable for a therapeutic space: A resonance space created by situational concessions, consideration, encouragement and enhancement.

The situation is completely different in the scenic space of a rehabilitative training with personal guidance and support using the example of walking exercises using a stick (see figure 13.3).



**Fig. 13.3:** Walking with a stick.



Patient and therapist form a rehabilitative unit at the basal level of physical cooperation. In this immediate cooperation, the learning of trunk stability through physically controlled movements is fed back directly to repetitions of ontogenetic experiences, i. e. to elementary sensations of touching and being touched, feeling and being felt. The motor regaining of gait and, thus, balance security is coupled to the physical presence of a cooperation partner who perceptibly follows one's own movements. The reappropriation of motor skills takes place in the manner of an indispensable resonating behavior of a partner. The sensory stimulations produced in this way ('autobiographical' feeling) are coupled with cognitive training during accompanying communication. The physical balance work, which takes place and can be guaranteed in the form of a dyad alone, cannot be achieved at all without that intrapsychic correlate, a mental balance that is simultaneously established. It is this direct physical cooperation that enables the very elementary experience of self-efficacy. Not only much more stable but also more lasting effects of interpersonal-based gait training can be expected precisely because of a far more effective emotional experience.

### 13.8 Quintessence

Attempts at a technical substitution of therapeutic-rehabilitative measures to regain basic possibilities of movement, by means of which physical stability and security of balance are established, are based on abstractions; ultimately on a disregard for the fact that humans exist as bodily beings constituting themselves through mutually intertwined self-perceptions and external perceptions; that as such bodily beings they develop relationships with one another in a "physical and social space" which, depending on the quality of the relationship, is characterized by certain moods (Rosa 2016). The quality of the relationship, and this is highly significant for the therapeutic space, is measured, so to speak, by the degree of intensity of the resonance of the individuals included, participating in and addressed by this space. To a certain degree, interpersonal and, as such, controlled mergers cannot only be used therapeutically, but can also be of essential importance in exercises of rehabilitative reappropriation of autonomous abilities.

Responsivity, understood precisely also as resonance, forms the structural basis for a relationship between people in which the other communicating in some way represents an elementary prerequisite of self-experience and self-interpretation (Rosa 2016). The social anthropological foundation of inalienable resonance relationships, which are constituted in a bodily sphere of personal self-experience and interpersonal self-interpretations, draws very narrow limits regarding the possibilities of their technical substitutability, especially in therapeutic-rehabilitative and nursing contexts. The current discussion about the technical possibilities of supporting older people, including those in need of care, is based mostly on the results of methodologically conventional needs and feasibility studies. However, they are on a theoretically



subcomplex level. There is a great lack of clarity regarding the physical situation and vulnerability of the (above all elderly) person; a lack of understanding of the relationship of the inner and outer behavior conveyed by all senses in the case of physical and mental losses, homeostasis, an “adaptive fluid equilibrium” (Bertalanffy); ultimately: Sovereignty can be maintained (Claessens 1980). The maintenance of homeostasis is, so to speak, tied to the activation of an evolutionary mechanism: to the caring behavior of a human being who, in active services of support, which may include symbiotic acts of fusion in the sense of physical reciprocity (body to body, side by side), passes on “his own homeostasis” to a “next being” (Claessens 1980)

Utopias of technical feasibility, on the other hand, live from abstractions and associated distancing, which are external to the processes of self-stabilization and self-assurance that take place through reciprocity. This would also mark the limits of the use of autonomous assistance technologies to support older people and their carers: They result from social-anthropological facts of a human striving for balance that is dependent in elementary areas on physical presence, which, with increasing age, requires special attention of the social environment as a personal shelter.

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# 14 Against AI-improved Personal Memory

Björn Lundgren

## Abstract

In 2017, Tom Gruber held a TED talk, in which he presented a vision of improving and enhancing humanity with AI technology. Specifically, Gruber suggested that an AI-improved personal memory (APM) would benefit people by improving their “mental gain”, making us more creative, improving our “social grace”, enabling us to do “science on our own data about what makes us feel good and stay healthy”, and, for people suffering from dementia, it “could make a difference between a life of isolation and a life of dignity and connection”.

In this paper, Gruber’s idea will be critically assessed. Firstly, it will be argued that most of his pro-arguments for the APM are questionable. Secondly, the APM will also be criticized for other reasons, including the risks and affects to the users’ and other’s privacy and the users’ autonomy.

## 14.1 Introduction

In 2017, Tom Gruber – one of the creators of Siri<sup>33</sup> – held a TED talk in which he suggested that AI technology should be used to enhance our memory functions. Gruber suggested that this technology would be beneficial for people suffering from dementia, but that it would also be beneficial for healthy adults (Gruber 2017; henceforth all quotations from Gruber are from this reference).

In this paper I will critically assess Gruber’s idea. This paper will be structured as follows. First, I will briefly summate Gruber’s talk, with a focus on what is relevant for the upcoming discussion. Second, I will briefly discuss the challenges of ethical analysis of future technologies. Third, I will present a critical evaluation of Gruber’s argument and the overall idea. Fourth, and lastly, I will end the paper by a summation and concluding discussion.

## 14.2 Background

Gruber’s TED talk was about what he calls ‘humanistic AI’ – AI technology that collaborates with and augments humans. Thus, instead of asking “How smart can we make our machines?” Gruber suggests that we ask, “How smart can our machines make us[?]”

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<sup>33</sup> Siri is virtual assistant that can respond to voice commands.

Gruber supports the idea of using AI technology to augment or enhance humans, by noting that AI and human combined often can get better results than an AI or a human alone. For example, with cancer diagnosis the “partnership eliminated 85 percent of the errors that the human pathologist would have made working alone”, while also improving upon the results of AI working alone.

Gruber’s idea that AI should be used to enhance and improve humanity is a good response to the fear that many have that AI will compete with humans and, for example, cause mass-unemployment. While the general idea of improving humanity by technology is an idea worthy of discussion, this paper will address Gruber’s specific suggestion about how to improve humanity.

So how can AI improve humanity? Gruber’s suggestion is that AI can improve our memory functions. As Gruber argues, “Human memory is famously flawed” and this could be improved by AI-technology that would enable us to “remember every person you ever met, how to pronounce their name, their family details, their favorite sports, the last conversation you had with them” (henceforth I will refer to this technology as ‘APM’ – AI-improved personal memory).

Gruber thinks an APM would help us “reflect on the long arc of [...] relationships” and give us “social grace”. He argues that since we could “retrieve anything [we’ve] ever seen or heard before”, this would enable us to make “new connections and form new ideas” – increasing our “mental gain”. He also thinks that for those “who suffer from Alzheimer’s and dementia, the difference that augmented memory [i. e., APM] could make is a difference between a life of isolation and a life of dignity and connection”. Lastly, Gruber thinks that an APM would enable us to improve our bodies because we “remember the consequences of every food we eat, every pill we take, every all-nighter we pull”, which would enable us to do experiments on our own bodies on how to make us feel good and stay healthy. Indeed, he thinks “this could revolutionize the way we manage allergies and chronic disease.”

Thus, we have a set of four arguments: social improvement, mental gain and creativity, help for the sick, and benefits from self-experiments. Lastly, Gruber suggests that this technology is not a dream, but “that AI will make personal memory enhancement a reality”. While he “can’t say when or what form factors are involved”, he thinks “it’s inevitable”, in part because we already “lead digitally mediated lives, in mobile and online.”

The description of the APM is somewhat sparse. Analyzing the ethical challenges or benefits of a technology with so many unknown factors is difficult. Thus, in the next section we will turn to this challenge. But before doing so it should be noted that while Gruber clearly uses the concept of enhancement, I believe it is fair to think of this simply in terms of improvement. Although there is a substantial literature on enhancement issues that could be relevant to this discussion, I will – because of word limits – ignore most of that literature to be able to focus on a broader set of issues. However, one distinction worth keeping in mind is that between “doing less worse”

and “doing better”, where the former can arguably be applied to the sick and the latter to the health (see Dekkert and Olde Rikkert 2007 p. 149).

### 14.3 The challenge of analyzing future technology

When doing applied ethical analyses of technology, we can either be *reactive* (i. e., analyzing a technology that is already available and accessible) or *proactive* (i. e., analyzing a technology that is not yet available and hence inaccessible).<sup>34</sup>

In this case the technology is not available, so we must either wait to do a reactive analysis, or our analysis must be proactive. On the one hand, doing a reactive analysis is beneficial because we can have access to all relevant information about a technology and hence – at least in theory – make a complete evaluation of all ethically salient factors. On the other hand, doing a proactive analysis has the benefit of making it possible to make ethical analysis before the technology is available; it allows us to evaluate technologies that are bad or harmful, before they hit the market.

The proactive approach should optimally be balanced by discussing all ethically relevant ways a technology could possibly be realized.<sup>35</sup> While that is a requirement that is practically implausible I will attempt to satisfy part of it by introducing a basic distinction on how this technology may be developed (with a focus on how the “information” or “memories” from the AI is fed to the user or host):

- APM-MEM: Achieves a seamless integration with its user
  - That is, the information from the APM-MEM is fed to the brain in a manner that makes it phenomenologically indistinguishable from the host’s biologically stored memories.
- APM-INF: feeds information to its user
  - That is, the information feed from an APM-INF is phenomenologically distinguishable from the host’s biologically stored memories.

While the APM-MEM may strike many of you – for good reasons – as science-fiction (requiring not only advanced AI-technology, but a brain-machine interface that allows the translation of computer-stored information to something cognitive experiences similar to memory-experiences), I am not using this distinction to highlight the most plausible ways the APM could be developed, rather I am highlighting an ethically important distinction. In this case the APM-MEM should be thought of as a

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<sup>34</sup> It should be noted that this distinction is not purely dichotomous. As implied by the formulation, some technology may be available but not accessible. In other cases, a technology may be only partially accessible (e. g., because of its complexity).

<sup>35</sup> There are arguably a lot more to be said about *reactive* and *proactive* ethical analyses, but that is beyond the scope of this applied analysis.



brain-machine-interface, connected directly to our brain, while the APM-INF may be thought of as working pretty much like a set of Google glasses, feeding information through our senses. While APM-INF is likely what Gruber has in mind, we could think of APM-MEM as a further-away future possibility.

This distinction also enables us to make further distinctions. For example, we may ask if the APM stores something closer to an “objective” version of events that we have participated in (e. g., similar to a film of the events) or our “subjective” experiences of these events. Arguably, only an APM-MEM would allow for the latter. However, to simplify I will avoid this and other possible distinctions in the paper.<sup>36</sup> Let us turn to the evaluation of the technology.

## 14.4 Assessing the APM

In assessing the APM I will use the above distinction – between an APM-MEM and an APM-INF – when it is relevant for the particular discussion. I will also discuss another point made by Gruber, his suggestion that “We get to choose what is and is not recalled and retained.” How this should be understood is not entirely clear, but we could imagine that it means that we have some control over the AI and that we can delete the memories and/or information contained within. Gruber might also simply mean that the AI should respond to queries (which would imply that an APM-INF is the more realistic alternative). In the upcoming evaluation, we will see if increased user-control will provide a benefit and/or resolve some of the potential challenges. Below I will turn to discuss both challenges and benefits, focusing on Gruber’s four pro-argument for the APM.

**No help for the sick.** According to Gruber, the technology is supposed to supply help for those suffering from dementia (i. e., the APM would help the sick to do less worse). However, that conclusion is questionable. Indeed, with the APM-INF, having a constant reminder would likely cause you pain. Bier (2016) addresses the challenges of caring for a person that suffers from dementia. For example, you may be faced with a choice of lying or telling them the truth that their life partner died a long time ago, which – if they accept it – would cause them to grieve as if they had not heard the news before. To protect the patients against psychological harms and continued and repeated suffering, we should conclude that lying or withholding certain truths can sometimes be an important element of care, for patients suffering from dementia. Because of this an APM-INF would arguably provide a lower quality of life. The ability to

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<sup>36</sup> PCBE (2005) offers various possible distinctions of better or perfect memory, such as “remembering only what we desire” and “remembering things ‘as they really are’ or ‘as they actually happen’”. Although they recognize the (biological) implausibility of these accounts of perfect memory, they may nevertheless be relevant to keep in mind when reading this paper.

control it – that is, to choose what to remember – would offer little help in this case, since a person suffering from dementia may not be in a position to make those types of choices.

One possible alternative is to focus on an APM-INF that only provides a substitute for so-called “procedural memories” (i. e., memories that guide our actions, such as eating with a spoon). While this could be helpful, it would be an example of a much more limited technology. Indeed, although it would be a memory-help for these types of patients, it would not be a personal memory. Hence, it is not an argument in favor of an APM. Also, procedural memories are more resilient against dementia than other types of memories (Alzheimer’s Society 2015).

APM-MEM may prove more helpful, since with a seamlessly integrated memory one would not be reminded, one would remember. However, it also means that one would have to live through and be aware of one’s cognitive decline (since even if not reminded specifically of their diseases, one would likely experience a discrepancy between perfect memories and the cognitive decline one would have to go through). Indeed, memory decline is but one of several symptoms associated with the diseases (dementia affects “memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” [WHO 2017]). While being aware at an early stage of dementia can be helpful in planning for one’s future self, it is not obvious that being reminded of one’s decline – at a later stage – would be helpful. It is questionable, as Gruber argues, that it would lead to a “life of dignity and connection.” With all the other symptoms, an APM offers little help. It may even decrease the quality of life, because it is not obvious that it would be beneficial to remember everything at such a cognitively confused state.

**Forgetting is healthy.** Let us turn to healthy people, whom Gruber also thinks would benefit (i. e., do better) from the technology. While our memory function does decline with age, we also need to keep in mind that forgetting is healthy. Indeed, “forgetting” is part of a process of moving on from painful memories. Being reminded (APM-INF) or just having a perfect memory of it (APM-MEM) would be a hindrance to such processes. Imagine people returning to a perfect computer memory of their break-ups over and over again, re-experiencing the death of loved ones, etcetera. While we may think that user-control and an ability to choose what to remember, either via an APM-MEM or APM-INF would resolve this problem – it is questionable if people are in position to make fully rational choices in cases such as these. Also, even if we could make perfectly rational choices, the process of “moving on” is not a matter of binary deleting or keeping a computer memory, it is a process that involves precisely what Gruber thinks of as a problem and wants to resolve (i. e., the imprecision that is involved in recalling and reconstructing long-term memory).

In this case it is illustrative to keep in mind that perfect memory often is a cognitive flaw. Indeed, as is popularized in the movie *Rain Man* (1988, USA, Barry Levinson), having a perfect memory standardly comes with certain social deficits. In fact,

perfect memory among so-called savants – and, indeed, the real life ‘Rain Man’ – are associated with brain damage and absence of various functions, rather than additional brain function (cf. Treffert 2009 p. 1351). We should, of course, be careful not to presume that just because perfect memory is associated with brain damage, that there is a necessary trade-off. But it is reasonable to think that there are some worries here, relating to the social aspects of life – which I will return to as we turn to that argument.

**Perfect memory as mental gain or the creativity of forgetting?** Gruber also thinks that improved memory functions would add to our mental gain and the creation of new ideas. But forgetting seems to be a central tenement in creative processes. Indeed, consider the following quote from experimental filmmaker Robert Breer:

Somewhere, in all my work, I tried to amaze myself with something, and the only way you can amaze yourself is to create a situation in which an accident can happen. (Mekas and Sitney 1973)

The idea promoted by Breer is that mistakes are not a hindrance, but a help in creative work. But if that is true, then perfect memory makes “creative mistakes” harder. Indeed, it seems that often when we create new ideas, we are starting off with some sort of mistake. For example, when deducing new theorem in logic or finding a new solution to a difficult problem, the start of that process can often be a misconception of the idea you were thinking of. It is this misconception that allows you to be creative and see new ideas, to amaze yourself.<sup>37</sup>

Of course, it should be granted that in writing this paper I would have been benefited by a function that would enable me to find precisely those quotes from Gruber that I was looking for. However, such a function could plausibly be satisfied by a more limited technology. Also, even such a limited technology might affect our creativity, since it may hinder the creative process of creating new arguments and relevant distinctions that start off as a misunderstanding.

**Social grace or social decline?** Gruber also thinks that we will improve our social grace, because we will remember the last conversation we had, their favorite sports, etcetera. Hence, we can continue where we left off last time. Again, it is true that we sometimes forget things about our acquaintances and the conversations we had. However, social relations are more than exchanges of facts. Indeed, it is not obvious that our relations will improve because we do not repeat our questions from the past, given that social relations also include elements of repetition. It may turn out that we have nothing to say to add to previous conversations. This does not have to reflect the fact that this relation is not worth further pursuing, it could just be an example of the fact that our social interactions are a bit more complex (which also reflects why

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<sup>37</sup> I owe the example of deducing new theorems to Paul Syverson.

control over an APM might not offer much help). For example, it is perfectly plausible to have a meaningful relationship that includes a high level of repetition (e. g., telling the same jokes over and over again).

There are, of course, occasions when it might help, such as remembering someone's name or when you wish to impress on someone their importance, but how impressed would they be that you remember their name, when they know you are aided by an APM?<sup>38</sup>

More importantly, by having an APM we would remember everything everyone has done – in perfect detail – including other's misdeeds or embarrassments. This would not only put strains on our social relationships (here we can note that forgetting is not only part of a healthy psychological life, but also part of a healthy social life), it would also affect other's privacy. Indeed, everything anyone has ever done in front of a person with an APM would be “recorded”.

While Gruber recognizes that “a personal memory is a private memory” and that “it's absolutely essential that this be kept very secure”, this fails to address the fact that while the APM contains a lot of private information about the user, it also contains, and enables the collection of, a lot of private information about other people. Thus, let us turn to the next topic.

**Privacy and autonomy.** Arguably, an APM device would be detrimental to other people's privacy and be an infringement or violation upon their right to privacy on most standard theories. Take for example the idea that (the right to) privacy is defined in terms of control (see, e. g., Matthews 2008; Moore 2008). An APM (in either form) would increase your control of information about others, affecting their privacy and infringing upon or violating their right to privacy.

An alternative is that (the right to) privacy is about limited access (see, e. g., Macnish 2018; Gavison 1980). On these accounts of privacy, the issue becomes a little bit more complex – because while an APM (in either form) would give you control over other people's private information, it is not evident that you will access it. However, the information is already accessed upon the moment of experiencing it and the control, or possession, over it (which both forms of APM grant) would be detrimental to others and, at least, imply a substantial risk. This risk is highly relevant when it comes to the right to privacy, since it is reasonable to argue that a person has a *pro tanto* right not to be exposed to risks (cf. Hansson 2003 for defense<sup>39</sup>) and that this should arguably apply to the right to privacy as well.

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<sup>38</sup> At IACAP 2017, Anne Gerdes argued that our memory reflects our social priority of people.

<sup>39</sup> Hansson actually talks of a *prima facie* right not to be exposed to risks, following the traditional usage of *prima facie* in moral philosophy (following, e. g., W. D. Roos). However, as pointed out by Kagan (1989 p. 17) a *prima facie* is an epistemic concept, so something that appears to be a right at first sight, while *pro tanto* indicates something that has genuine weight (but may not be decisive).

An alternative to control and limited access are so-called contextualist accounts of privacy. One of the most well-known is Helen Nissenbaum's account of contextual integrity. Like other contextualists she focuses only on the right to privacy and refuses to define it, but she argues that a right to privacy "is a right to live in a world in which our expectations about the flow of personal information, are, for the most part, met" (2010 p. 231). On this account, we should conclude that an APM (in either form) violates normal privacy norms and as such is an infringement or violation of people's right to privacy.

As previously noted, the user's privacy is also at risk. Although Gruber recognizes the importance of keeping this information secure, we should recognize that no device can ever be completely secure. Thus, an APM (in either form) would also put the user's privacy at risk. This risk also raises related worries. If people can access the information from our APM, they potentially yield a trove of information that would enable them to either blackmail us or simply manipulate us; because they now know so much about us, they can predict how we would behave in various situations. Indeed, technologies that predict facts about us are already fairly powerful on the basis of much less information. This raises substantial challenges about our ability to maintain our autonomy if these devices are misused (cf. Lundgren forthcoming).

Furthermore, if the devices can be hacked, it would not only enable access to the content, but also the potential of manipulating the content or the devices as such – feeding us false memories. With an APM-INF users could be misled or manipulated by being fed false information. It is not obvious that we would be in a position to discover subtle changes to the information in an APM-INF. If it is tailored to fit the current memory-narrative, this would arguably be worse for people with declining memory functions. This is a serious threat against individual's autonomy, because it would affect an individual's self-control.<sup>40</sup>

With APM-MEM it is even worse. Indeed, users could be fed false memories, which they cannot discern as false. As such, an APM-MEM would enable something close to "mind-control". Furthermore, even if we could protect against hacking, it is not obvious that the devices themselves will not be manipulative. These worries about autonomy are so serious that they provide a debunking reason against the broad application of the technology that Gruber has in mind.<sup>41</sup>

Lastly, while one may think that risks to an individual's autonomy should be a decision that the individual should have a right to make, we can question whether we

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**40** It is, of course, a substantial question precisely how much manipulation that is compatible with a sufficient degree of autonomy (which will vary with different conceptions of autonomy). However, if I am correct, then substantially (whatever that is) changing someone's memories should on any reasonable account of autonomy count as such a serious form of manipulation that it conflicts with self-control.

**41** There may, of course, be more limited applications for the technology (such as for research).

have a right to give up our autonomy. This is a complex question that also depends on specifically how manipulative the technology is. But when it comes to privacy issues, we do not have a right to engage in activities that would violate other people's right to privacy.

**Facilitating experiments.** Finally, Gruber argues that an APM would enable us to do detailed research on personal health data. Indeed, it would make many types of (scientific) experiments easier if people can grant access to their data (ignoring privacy problems). However, more limited technologies could achieve this too.

In this case, depending on external access function, the APM-INF may be preferential, since it may allow the extraction of information for external analysis. However, this obviously has serious consequences as discussed previously.

That was the bulk of the arguments by Gruber and some related problems. Let us turn to a summation of the evaluation.

## 14.5 Summation and concluding discussion

Based on the above evaluation it is fair to conclude that while an AMP certainly would offer some helpful functions, it offers less help than Gruber suggests. Also, the technology would likely yield very serious harms.

Indeed, it offers little, if any, help (APM-MEM) or no help (APM-INF) to people suffering from dementia. It is highly doubtful if it would improve our mental gain. Likewise, it is highly doubtful that it would benefit our social lives, which relates to the most serious challenge – privacy and autonomy. Indeed, the privacy and autonomy concerns are so serious that on the basis solely of these problems we ought to conclude that these types of technologies should not be used.

Conversely, an APM does offer some benefits. For example, the ability to do detailed research on our health data and it would be helpful whenever we are looking for exact information, such as quotes. However, an APM is much broader than these functions require. The benefits of an APM could arguably also be achieved by a weaker technology. Thus, we should conclude that the potential harms clearly dominate the potential benefits of using the APM-technology (all things considered). But there may be room for a more limited technology or more limited applications (such as for research).

Lastly, it is important to point out that any public release of an APM may lead to a lose-lose situation because individuals may need to use the technology for various benefits (e. g., on the labor market), even if overall it leads to a situation that is all things considered worse for everyone.

The APM-technology is an interesting example since it offers an extreme example of a fundamental trade-off of an AI: the trade-off between using (our and other's) information to provide a benefit. As such it illustrates many of the challenges we will

face with future AI-technology. Even if the trade-off for other AI-technologies will not be as extreme as in the case of an APM, the fundamental problems will be present in many other AI-applications. What complicates things in all such cases, however, is the privacy effects for non-users (because they are not given a chance to opt-out and because it creates an asymmetric distribution of harms and benefits). This is but one of the substantial issues mentioned in this paper that will require serious analysis in the future.

Other issues discussed that may be worthy of further discussions include, for example, the idea of the benefits of imperfection, which relates the paper to debates on human enhancement; risks and the right to privacy; the problem of AI-technology and information aggregation; and the more methodological discussions of reactive and proactive ethical analyses.

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