# 1 The challenge ahead

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## 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 1950s in Germany to the 1980 s in Southern European countries led to an overall shrinking share of vounger 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 healthcare 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 different 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 ultrashort 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 technological 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 Haupeltshofer 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. Haupeltshofer 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, Aníbal 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 visionaire 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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