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Electronic Health and Ambient Assisted Living: On the Technisation of Ageing and Responsibility

Mobile health systems, electronic health systems and technologies for so-called “ambient assisted living” (AAL) are schemes based on information technologies that focus on “empowering people’s capabilities by the means of digital environments that are sensitive, adaptive and responsive to human needs” (Parisa and Mihailidis 2013, 579). Tools developed under this paradigm are designed to offer supportive human–machine interaction technologies, which help users to cope with their daily environments and tasks including medical care and self-care.

Senior citizens today are confronted with a range of such mobile health technologies developed for their benefit. Many of these intend to support the prevention of disease (e.g., by continuously monitoring chronic conditions such as high blood pressure or diabetes) or are designed for supporting the delivery and effectiveness of therapies or improving adherence. A major reason for older people to use these tools might be their expectation that modern, highly technical, web-based mobile solutions could increase their quality of life better than the use of conventional support methods (Ammicht Quinn et al. 2015). Simultaneously, in advertisements, public media and popular culture, ageing is propagated as a dynamic and modifiable process such that senior citizens are increasingly being represented as active and responsible for their own well-being. Thus, push and pull effects regarding the use of mobile health utilities by the elderly seem to go hand in hand. Besides their obvious advantages, however, the use of these devices is also linked to some ethical considerations.

In the following, we intend to focus on ethical questions related to the use of ambient mobile and electronic health technologies by people of advanced age. Our goal is to evaluate their usage in the context of intergenerational responsibility. We consider intergenerational responsibility to be a key concept to include within an ethical evaluation against which the goals of AAL tools must be tested. The major propagated goals of health-related technologies for the aged include securing privacy, autonomy, participation and justice. In our assessment, we will focus on these values and discuss them in the broader context of moral responsibilities.

Responsibility

Moral responsibility is the idea that “a person is morally responsible for her behavior, [which] involves – at least to a first approximation – attributing certain powers and capacities to that person and viewing her behavior as arising [...] from the fact that the person has and has exercised these powers and capacities” (Matthew 2019). It is a capacity usually attributed to humans only and only to those who have the power and capacity to adopt or reject certain actions.

Like many ethical concepts, that of responsibility has ambivalent features. It can be a duty, it may become a burden and it may be a shield to hide behind after some actions performed in the name of responsibility prove wrong in the end. According to the philosopher Robert Spaemann, the concept of (moral) responsibility has gained increasing importance in modern societies (2007, 39–41) – in the least, the term is being used more and more in public debates. One reason for this trend might be that modern technologies have enhanced the number of possibilities to provoke change in and/or influence humans, their destiny and their environment substantially. Another reason could be found in the supposed expansion of the possibilities of human foresight and the early recognition of dangers and risks, which means that actors cannot rely on ignorance anymore.

Meanwhile, Spaemann suggests a more differentiated justification for the increase in responsibility in modern societies, offering four intertwined explanations linked to the social development of Western societies over the last 70 years that are captured at its best by the sociological concepts of individualisation and the development of a risk-oriented society. First, our living conditions have become more complex over the years, resulting in relatively high individual and public discretionary powers. We have also experienced the further differentiation of social subsystems with the consequence that an individual must fulfil a multitude of roles simultaneously, which may lead to decisional conflicts. Our orientation toward assessing risks (instead of dangers) has brought about an increasing level of knowledge of the results of actions (as far as risk estimations are concerned). Finally, social acceleration and accelerated innovation cycles of technologies have led to a hastened outdateding of norm-sets or sets of rules. Therefore, more abstract principles – like responsibility – have gained importance as reference frames for the moral evaluation of actions and results.

Ideally, responsibility refers to both the past as well as the future. The concept has a retrospective alignment when applied to past actions and a prospective orientation when applied to the assessment of plans and future actions. Regarding past actions, deontological moral structures determine what is considered as a responsible action. In the realisation of the obligatory (“to

deon” = the duty), the actor realises the commandment without paying attention to the success or failure of that action. Actions are carried out and attributed because they fall under general rules that specify what is to be done in the individual case. Actions are evaluated against these rules as either responsible (following the rules) or irresponsible (neglecting the rules). In contrast, responsibility regarding the future is normally evaluated following teleological moral structures, directing action toward the achievement of preferential goals (“to telos” = the goal, the purpose). An action is teleologically necessary and thus considered responsible if its implementation leads to an excess of positive versus negative consequences. Responsibility in this sense can only be linked to actions, the consequences of which could have been foreseen by actors under normal circumstances. Therefore, a responsible action requires either the obeying of a rule or an orientation toward desired consequences while avoiding risks (Birn-bacher 1995, 143–183; Frankena 1994; Spaemann 1975, 323–335).

Responsibility is a highly relational concept, one that relies at least on a triple relation constellation in which there is the responsible subject, the object of responsibility and the authority who assigns and judges responsibility, respectively. Additionally, the concept includes temporal and moral dimensions. Basically, responsibility asks “who is responsible (subject) for what (object) to whom (authority), when (time) and how (mode)” (Figure 1) (Werner 2006, 521–527; Zimmerli 1993, 92–111).

Figure 1: Web of responsibility (The figure was created based on Zimmerli 1993, 102).

The constellation presented in Figure 1 may change over time on all levels. Mechanisation and secularisation processes, for example, have a major influence on some elements of the concept: at the level of the authority, God, for example, has been replaced by the totality of all rational beings. Additionally, the object of responsibility is extended by technologies. Above all, the division of la-

bour, especially in the field of technology, together with its associated risks and the unpredictability of the consequences of its use has changed the responsible subject. In modern societies, it is no longer possible to limit the responsibility for certain actions to an individual. Furthermore, it can be difficult to determine the responsibility for actions with unpredictable consequences. In summary, the relational aspects may cause tensions in the attribution of responsibility. Basically, only subjects – either individuals or groups – who can act can be imbued with responsibility. In this case, responsibility is either taken by a subject or attributed to the subject by other individuals or groups within a certain area. This results in the responsible subject's need to legitimise actions concerning the object to an "authority", which can again be installed by the individuals or groups attributing the responsibility. In societies, this constellation is generally guided by the often implicitly stated idea of subsidiarity. The most immediate subject takes responsibility first for the immediate object in front of the most immediate authority (Zimmerli 1993, 92–111).

Responsibility of ageing and the link to intergenerational justice

The concept of responsibility can be applied also to intergenerational questions of society or the duties and roles of different age groups in a given society. The generational order in societies determines the institutionalised distribution of rights and duties among different age groups. It is, in effect, a cornerstone of the social order establishing obligations or commitments including intergenerational solidarity (Eisenstadt and Binder-Krauthoff 1966); yet, the generational order also constitutes fundamental inequalities in a society, giving rise to unequal duties or rights (Leena 2009, 159–174).

In this context, for a long time in Western culture, younger family members have been considered to be the primary source of support for older people; indeed, this constituted a responsibility for them. Traditionally, those who were old and frail had to rely on being taken in and cared for by their own children to continue experiencing some quality of life. In practice, however, this was not always possible, either because the families were too poor or for other reasons. In such cases, churches, local authorities or charitable foundations sometimes intervened. At the same time, however, older people had to care for young children as well. Thus, the middle generation carried the responsibility of caring for both the old and the young at the same time. This image is best represented in popular culture and media by the image presented in Greek mythology of Ae-

neas carrying his father away from the burning Troy while at the same time holding his child's hand. This cultural icon has been reproduced in various forms until today.

With the development of social welfare schemes and health insurances, the responsibility of citizens caring for their own parents was eased at least in states that have subscribed to social welfare. In other words, society took over some of these responsibilities. Moreover, elderly people in need of care can also now rely on insurances and societal support. However, the claim for this support involves the examination and determination of the conditions necessitating the claim according to social laws. As a consequence, the rights of the subject in need and the collective liability become the guiding formula instead of individual responsibility of, for example, the family members. Similarly, in privately funded social systems, older people only have the right for the support they have paid for. Here, responsibility is eclipsed or accountability is distributed in a manner where the responsible subjects become opaque or are hard to identify.

From the perspective of the younger population, this shift of responsibility from (family) subjects to social insurance systems is a relief. Some social health insurances advertise this freedom from responsibilities to care for others. Instead of the well-known Aeneas motif, they display happy people caring for themselves instead of others. Figure 2 shows an advertisement by a German public health insurance company, Allgemeine Ortskrankenkasse (AOK). In the image, a lady is lying relaxed in the bathtub and the accompanying text can be translated into English as: "Take a breath. The father is well taken care of. Thank you, AOK. 52 nursing consultants are on-site" (figure 2).

A context factor for such a shift in responsibilities and the subsequent emerging imagery of the generational order might be seen in the demographic development in many industrialised countries. Medical advances, better nutrition, improved housing and working conditions have improved the average life expectancy steadily since the middle of the nineteenth century and researchers focusing on ageing assume that this trend will only continue. Forecasts made by the United Nations say that, in countries like Austria, Germany or Sweden, an increase of a further 5% in the average life expectancy until 2050 is possible (United Nations 2019). The relatively long life expectancy in existence now has already led to a significant increase in the absolute number of older people in the industrialised world. This trend, reinforced by low birth rates, will lead in the future to a significant long-term increase in the proportion of older people in the population. The – current and future – demographic shifts are seen by some politicians as a danger or an obstacle for further globalisation and European integration and drivers of new demands for occupational flexibility, region-

Figure 2: Advertisement from AOK (Odeonsplatz Munich, foto taken by HF 22.10.2016)

al mobility and migration (European Commission Report on the Impact of Demographic Change 2020).

The implications of these demographic changes are of particular interest for the sociology of the family, life-course research and ageing sociology. More old people meeting with fewer younger people who at the same time need to remain mobile, active and flexible given a globalised job market challenge the classical generational order. This development instigates the demand for a division of caring tasks and responsibilities between the family, the welfare state and the voluntary sector.

The demand becomes even more urgent when considering the increase in the number of people suffering from dementia, which comes along with the increase of older people in a society. The term “dementia” encompasses a whole group of disease patterns, in which important brain functions such as memory, orientation, language and the ability to learn are gradually and irretrievably lost. Most dementias are associated with advanced age. The probability of developing dementia increases dramatically after the age of 65 years and, due to the greater life expectancy associated with female sex, statistically more women are affected than men. Because the group of children, children-in-law, grandchildren or professional caregivers does not grow as fast as the number of older people due to the aforementioned demographic development, a “caring gap” exists (World Health Organization [WHO] 2011). In other words, the question is “who cares” if neither families nor welfare systems have enough young people available to

meet the caring needs of the elderly. Although there is an intergenerational responsibility to care for the elderly, there is simultaneously an understanding based on intergenerational justice that this responsibility cannot result in younger people giving up all of their own needs and expectations for the sake of the elderly.

Technical solutions

Even in nursing homes, the lack of staff and funding together with time pressures have made it difficult to meet the demand for a dignified existence for all residents (Schüssler and Lohrmann 2017). This is especially true for people with dementia, who require special attention from caregivers. To give an example: many people with dementia feel the urge to move. Walking helps them to relieve tension, to perceive themselves and the environment. They strive to get outside, but, outside, they get lost easily and can even endanger themselves and others (Sütterlin et al. 2011). As the sense of balance diminishes, the risk of falling also increases. At home or in nursing homes, falling in old age can easily lead to dreaded hip or femoral neck fractures (Petersen et al. 2020). Responsibility for care means, in these cases, that either these people are accompanied when walking around or are prevented from walking. When staff and time are short, the idea of pulling up the bed barrier or closing the safety belt of a wheelchair is obvious. According to studies, 12% to 49% of all residents in nursing homes and homes for the elderly are fixated in some way. In Germany, it is 26% to 42%, including 5% to 10% of whom are fastened with belts (Sütterlin et al. 2011). Even if the fixation is justified with the security of the elderly person in question, such means an unwanted coercive restriction of autonomy and freedom in the moral as well as in the life-practical sense, which is possible, for example, in Germany only within strong legal limits (BMFSFJ/BMG 2019; Walther 2007). Fixation creates stress. In addition, the forced immobility aggravates balance problems and the muscles regress, exacerbating the degree of physical instability.

Ways out of the dilemma between coercion and autonomy or safety and freedom include activating methods such as adopting a special way of communicating with demented residents/relatives that encourages them in their actions. This also includes accepting strange behaviours. If language is no longer possible, addressing sensory perceptions is an option. Physiotherapy strengthens balance and mobility. Finally, structural changes such as exterior doors that are somewhat concealed, long corridors leading around in circles or special “tangle gar-

dens” create the possibility for these individuals to move safely and without endangering others (Walther 2007).

However, all of these measures are, again, time-consuming to enact and require either personal engagement by relatives or enough qualified personnel in nursing homes. Because both human resources are scarce in an ageing society, politics have tried to address the problem with the help of information technologies like AAL systems. For example, by promoting “age-appropriate assistance systems for a healthy and independent life”, the German Federal Ministry of Education and Research supports holistic solutions based on new technologies, services and benefits. The development of regional networks is also encouraged. Providers of complete systems, companies, service providers, the housing industry, doctors and health insurance companies together with the users themselves should cooperate and be involved. Technical tools to help in caring for the elderly with reference to the previous example include sturdy shoes, built-in hip pads or sensor mats that signal to the staff that a resident is leaving their bed.

Technological developments that unobtrusively support the everyday life of elderly people address several goals and values that may be summarised as increasing the quality of life. According to the inventors and producers as well as users, key values addressed by, for example, AAL systems include autonomy, safety/security, social contact, participation and wellbeing (Lee and Kim 2020; Siegel et al. 2014; Gaßner and Conrad 2010). Furthermore, evaluation models emphasise factors such as effectiveness, patient perspective and organisational and economical aspects (Kidholm et al. 2017; Manzeschke 2015, 263–283). As a political goal, justice may be added to that list. The tools should be made affordable and accessible to everyone.

The range of systems that have been developed so far is huge and new start-ups that offer new AAL solutions continue to pop up. Available products include tools for information assistance, which provide information and services that a person needs in their current situation, or intelligent environmental behaviour systems capable of learning from user actions and offering appropriate functions (e.g., when the owner gets up in the morning, the system turns the lights on, radio on and bathroom light up). Other systems predict emergency situations based on changes in behaviour (of the user) or changing physiological data. For example, a peak in blood pressure may suggest a future emergency situation. Intelligent environments should also detect unusual situations and act accordingly (promptly). Particularly, older people seek security, especially when they are physically and mentally challenged. Technologies addressing this need include, e.g., the recognition of an unlocked door or effective authentication mechanisms. From the perspective of responsible caregivers, surveillance of the behaviour of the elderly might also contribute to safety. Bracelets measuring

pulse and reporting irregularities or intelligent companion puppets can address this requirement. Door sensors show when an individual is leaving a property and how long they are absent, helping to alleviate concerns about wandering or to confirm when action is needed as well as letting family and professionals know whether scheduled care calls and visits have been carried out. Finally, social contact can also be simulated with AAL systems; for example, there is an AAL product under development that was promoted by the German Federal Ministry of Education and Research in 2016 known as the companion puppet “which is capable of sensing the emotional and health condition of the care recipient. This puppet can also detect states of unwanted situations (e. g., the care recipient is agitated) and can animate the care recipient to perform certain activities [(i. e., the care recipient is asked to play a simple card game or describe images etc.)]. In the case of a stressful or critical situation, the puppet will try to calm the care recipient and at the same time ... offer support to the caregivers. Apart from the puppet, [this] system [is] also comprised of a central computing unit (e. g., a smart home gateway) capable of sensing and controlling the environment” (BMBF 2016).

Tensions between values

We could extend the list of technical aids and AAL systems infinitely, but the given examples may already illustrate certain tensions that are central elements of almost all of these technological solutions. These tensions concern finding a balance between the pairings of

- Security and freedom
- Support and disenfranchisement
- Control and indifference
- Standardisation and individualism
- Enabling participation and enforcing the use of technologies

Moving too much to either side of a pair becomes problematic if responsibility does not only include the physical safety of an old person but also their psychological and social wellbeing. Support, understood as total appropriation, which wants to take away all burden from a person, overlooks the fact that a certain burden belongs to life. Responsibility for the care of older people might in this way have its limits when it results in the pressure to be satisfied with certain technical aids and thus remain socially inconspicuous.

The danger of enforcing the use of these technologies on the aged is present due to the limited human or financial resources, the reasons of which were given

above. It might even be morally justified if we turn the idea of responsibility around. Intergenerational responsibility does not only demand that the young care for the old but also that the older generation tries to limit the burden for the younger generation. An example where senior citizens are reminded of this responsibility can be seen in public health campaigns that attempt to nudge older citizens in the direction of leading a healthy way of life. The preventive “active ageing” approach propagated by the European Union and the WHO is based on the idea that it is possible for individuals to shape and plan their lives. Accordingly, old people are nudged to be active to prevent or at least delay their individual dependence on other people. The term “active ageing” is thereby often linked to the terms “healthy” and/or “successful” ageing (WHO 2002; European Commission 2012; European Commission 2019).

Thus, leading an active life becomes a responsibility of the older individual. In this way, the risk of age-related dependency (fostered by inactivity) is also individualised. The collective social risk of age dependency is rhetorically transformed into the individual responsibility to reduce the risk through activities. As a consequence, responsibility is taken away from society and children and attributed to the elderly. Here, again, technology is offered as an aid; “wearables” such as health trackers, step counters or motivation systems have been designed to foster active ageing. The European Commission for example promotes a strategy that explicitly states: “Digital technology can help older people to stay healthy, independent and active at work or in their community for longer and it helps to improve our quality of life” (European Commission 2019). Old people are assigned the responsibility to use these aids for the sake of intergenerational justice. Otherwise, they have to subscribe to the promises of AAL and other systems, whether they want to or not. Here, we see a classical catch-22 situation: old people can either use the technology to improve their activity and keep their self-determination or they have to use the technology to relieve the burden of care from the young. Thus, the technisation of old age can increase or decrease intergenerational justice.

Conclusion

The relations of responsibility are based on the question of who is responsible for what to whom, when and how. During the development of technologies to care for the elderly, not only the old themselves but also the younger generation are the responsible subjects. Moreover, other responsible parties include caregivers, physicians, engineers and manufacturers. The authority to whom all these groups have to justify their responsible behaviour is constituted by human rights

and human dignity. If the goal of AAL technologies is to enable wellbeing, safety and an autonomous life for older people and at the same time to limit the burden of care for younger people, all measures to achieve these goals need to be evaluated against these authorities and conflicting values. The main goal conflicts discussed in today's moral debates include tensions between privacy and transparency as well as between autonomy and control in the use of data collected via the technical products to support the elderly and to control the vital parameters. The risks of application must be proportionate to the expected benefits, which, in turn, means that valid and reliable information must be used beforehand to be able to make such a decision in the first place.

Above all, technology should not overtax the assisted person. Consent to the use of the systems at stake must remain voluntary and must not be enforced in a paternalistic sense “for one's own good”. In addition, the technologies should not be based on economic utility but instead solely on the well-being of the potential users. The idea of responsibility for the care of older people also means that there is a need for clear, human-bound, transparent and interruptible decision-making hierarchies in the use of technological systems. Otherwise, the old person might be eclipsed by an efficient and time-saving yet unwanted caring system only responsible for a limited set of elements within the meaning of care.

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