


# 'This really takes it out of you!' The senses and emotions in digital health practices of the elderly

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## Abstract

Wearables, fitness apps and home-based monitoring technology designed to help manage chronic diseases are generally considered in terms of their effectiveness in saving costs and improving the health care system. This article looks, instead, at the digital health practices of persons older than 65 years; it considers their actual health practices, their senses and emotions. In a qualitative study 27 elderly persons were interviewed about their digital health practices and accompanied while using the devices. The findings show that digital technologies and ageing bodies are co-productive in performing specific modes of health and the ageing process. The study shows that digital technologies not only encourage the elderly to remain physically active and enable them to age in place, but also that the use of these technologies causes the elderly to develop negative emotions that stand in a charged relationship to ageing stereotypes. Thereby, the sense of seeing has been placed in pole position, while the faculty for introspection declines. This means that age-related impaired vision can result in particularly severe consequences. In the discussion it is debated in which concrete ways that digital health technologies have had a negative impact. The sociotechnical practices associated with wearables conform to the primacy of preventing ageing; passive and active monitoring technologies appear as subsystems of risk estimation, which in turn regulates diverse practices. The conclusion highlights the interrelation between notions of successful ageing and the digital practices of the elderly.

## Keywords

Digital health technologies, health information technologies, health monitoring, doing age, doing health, senses, emotions, gerontechnology, sociotechnical interactions

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## Introduction

Whenever governmental strategies or legal amendments on e-health are published in Europe, they refer to demographic change and thus to a future unbearable burden on health care systems. Government strategists and lawmakers argue that an increase in the number of older people and thus in the number of chronically ill and persons requiring care threatens to wear down health care systems. Only an up-to-date digital restructuring of the administrative structure as well as of care and prevention would be capable of forestalling a collapse. For that reason, the (future) user of digital health technologies should be placed at the heart of a general digital health infrastructure. Placing people at the centre means that their health can be more effectively and adaptively managed and that they can be better

provided with information and opportunities for looking after themselves and taking responsibility for their own health and care. In this process, digital innovations become drivers for empowering members of the health care system. By assuming responsibility for the use of digital technologies, elderly users could improve their own quality of care and act preventively, thus making it possible for them to lead autonomous, independent and self-determined lifestyles in the long run. This ultimately could or should result in a reduction of their

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impact on the health care system as a whole. Such wording can, for example, be found in the *Stratégie nationale de santé 2020*,<sup>1</sup> published in summer 2016, as well as in the German eHealth Act implemented in December 2015.<sup>2</sup>

This apparent win–win situation, it is believed, would also benefit the elderly, who are generally seen to represent the epitome of strain on the current health care system. Current developments and innovations in health information technology (HIT) permit a number of public health interventions to address different groups of the elderly as empowered subjects motivated to prolong their physical fitness and optimise their health with the aid of digital technologies.<sup>3–6</sup> In addition, the market segment that provides digital health technologies designed to compensate physical or mental impairment is growing. Products include various sensors, wearables and apps, such as emergency call wristbands, blood glucose meters, pedometers, ambient assistive living technologies and nursing robots. Digital health technologies promise (future) elderly persons health in a supportive and positive setting, thus preserving their independence. These technologies will create new opportunities for *successful ageing*,<sup>7</sup> i.e. self-determined, healthy, autonomous and self-responsible ageing. Because of such possibilities, ageing without the aid of digital technologies seems to be far less desirable; at the same time, new challenges arise for the elderly.

This ambivalence generated by empowerment in conjunction with the challenges of technology-based successful ageing is analysed in the following from a *sociocultural gerontechnology* standpoint, for example see Joyce and Meika.<sup>8</sup> In this spirit, we will be less concerned with what is technically feasible than with the practices of self-monitoring and their physical, sensory and emotional impacts on the user. This focus will be developed on the basis of three questions: (1) How do digital health technologies co-constitute health practices of the elderly? (2) What sensory perceptions and emotions of the user in response to digital health technologies can we identify? (3) What role do the senses of the elderly play in the interaction with digital health technologies?

I begin with a brief overview of the theoretical background and methods. The theoretical concepts of ‘doing age’ and ‘doing health’ have been chosen for the analysis of digital practices of elderly people. Therefore, I discuss these concepts initially and then expand them with science and technology studies (STS). Following that, I give a brief survey of sensory studies. This subsection is followed by methodological explications, including a subsequent presentation of findings from a pilot study on the digital practices of elderly persons. (The ‘elderly’ is a diverse group; see e.g. Lindsay et al.<sup>9</sup>. The term is used here as a pragmatic

simplification. It needs to be considered that those elderly using digital technologies are mostly middle and upper class and in their third stage of life; see e.g. Urban.<sup>10</sup>) Here I focus on digital practices that can be performed independently, that are largely self-financed and that are undertaken to preserve or regain health, physical fitness and thus independence for the elderly in their own homes. To that end, two application contexts of digital health technologies for the elderly will be examined in greater detail: (a) wearables and health apps in the context of fitness activities; and (b) digital health practices connected to home-monitoring for the diagnosis and management of long-term chronic conditions. In the subsequent discussion I focus on how the digital technologies enable the elderly and how they also put new obligations on the users. Finally, I attempt to answer the questions raised at the outset and I conclude by summarizing the relevance of senses and emotions for *doing digital ageing*.

## Theoretical background, case study and methods

### Theoretical background

To understand how digital technologies co-constitute health practices of the elderly let us first turn to the setting of the digital health technologies. The technologies are praised and put into practice under the heading of ‘successful ageing’, the purpose of which is to promote health, fitness and independence of the elderly. The idea of successful ageing involves a deficit model of ageing that focuses on failing physical fitness and, by implication, a societal burden, on health impairment with a greater prevalence of chronic ailments and on changing psychological structures such as mistrust and lack of flexibility.<sup>11</sup> In both of these concepts, *age* denotes a marker of difference that represents a later phase in life, which, in Western industrial nations, from the late 20th century onwards, begins with retirement. Age in this view is a contingent – i.e. changeable – social phenomenon that depends on historical, social–cultural, political and economic parameters. In the words of the Austrian gerontologist Leopold Rosenmayr,<sup>12</sup> age is a ‘social construct’. With this perspective, age is seen to be determined by public health care, the developmental stage of the capitalist system, and the organisational structure of retirement security and of the labour market in general.<sup>13</sup>

In parallel to these sociocultural ascriptions to old age, ageing describes a highly individual process of changes to the organism that are experienced physically, such as changes to skin and tissue tautness as well as to mental and physiological capacities. It puts into effect its own processes, from a reduction in bone

density to erectile problems.<sup>14</sup> In view of these two different perspectives, the sociologist Silke van Dyk<sup>15</sup> refers to the ‘dual character of ageing’, whereby hegemonic modes of action and processing together with ‘specific interpretive concepts’<sup>16</sup> of age(ing) are interwoven with the physical experiences of ageing. The eminent individual experience can only be lived against the backdrop of institutional processing regulations and interpreted with the aid of cultural representations. For that reason, social invocations and standardisations both enable and limit the experiences and practices of ageing. The body is thus at the same time medium and instrument, product and producer, of everyday experiences and life in old age.<sup>17</sup>

These ideas provide a basis for the ‘doing age’ approach.<sup>18–20</sup> In parallel to the classic definition of ‘doing gender’ by Candace West and Don Zimmerman,<sup>21</sup> doing age can thus be defined as generating age differences (limits, groups, phases) that are not natural or biological, but that, once constructed, are treated as if they were natural entities. Accordingly, people age *performatively* through social interaction. If we apply Hirschauer’s<sup>22</sup> concept of ‘situational gender construction’ to age, this means that age is performed, updated, continued and maintained through significant social interactions. Ageing is thus a social practice, and social structures are reproduced and shaped through situational actions. It is a continuous process of interactive production of material – e.g. physically fit bodies – and non-material aspects, such as the ideal of successful ageing and emotions like pride in one’s own independence. Doing age thus brings together performance – the actual physical practices – and presentation – the use of specific codes, for example, health practices or ageing-in-place.<sup>23</sup>

This ‘embodying of ageing’<sup>24</sup> is characterised by the view that signs of ageing are deviations from the ideal – the youthful and powerful body. Thus the embodying of ageing takes the form of a battle against ageing. This was already stated by Hepworth and Featherstone in 1982.<sup>25</sup> In this struggle, health plays a key role. Health can also be understood in terms of ‘doing health’. This concept, too, starts from the notion that active subjects in real settings model their bodies in accordance with social relationships and specific knowledge. Thereby they naturalise the effects of the practices and health itself gets constituted.<sup>26</sup> So in this sense, doing health becomes an analytical strategy that views a life-world phenomenon such as health as extant only when it is being implemented.

With reference to Judith Butler’s notion of performative materialisation,<sup>27</sup> doing age and doing health in this sense refer to a linguistic and a visual designation, and to a physical action as a perpetually repeating and self-referencing practice. While Butler

is concerned mostly with human social practices and understands matter – whether in our case ageing bodies or digital technologies – ultimately as a passive product of discursive practices, our position in the following is to interpret the material and immaterial, the technological and discursive elements, as co-constituent. With reference to Karen Barad,<sup>28</sup> that which is material will be seen as integral parts of an entire interactive development process: thus, not only ageing bodies, but also digital technologies become co-producers of a continuous process of materialisation of ageing.

In the terminology of science and technology studies (STS), doing age is part of an interrelationship network of society and technologies. This performativity is reflected in the concept of *sociotechnical interaction*.<sup>29</sup> Sociotechnical interactions incorporate values that are generated and stabilised by society.<sup>30</sup> Users with their expectations and practices as well as digital technologies with their algorithms and design are caught in the field of tension between the contexts of their social genesis and actions.<sup>30,31</sup> Users and their practices are not predetermined, and the use of technical devices is not restricted to only one manner of application. However *scripts*<sup>32</sup> exist for the human subjects as well as for the technical devices: they function like a programme of action to justify objectives, practices and corresponding ideas, for example notions of ageing or health. These scripts can be modified, i.e. adapted to habits, requirements or abilities.<sup>33</sup> In this way, the technical becomes interlocked with the corporeal and experiences undergo (re-)coding.<sup>34</sup> To answer the question as to how digital health technologies generate (health) practices, the materiality of the body is interpreted as a process. Therefore the scripts – both of technical involvement and corporeal practices – will be of great interest in the following analysis.

The second and third research questions direct our attention towards sensory experiences and emotions in response to digital health technologies. This is of particular significance because digital technologies are said to threaten a disembodiment of practices: somatic experiences would be reduced to mere data flows and devices. Bodies would thereby simply become codified and rendered digital (compare with Tucker and Goodings<sup>35</sup>). In contrast, in this article the body is thought of as genuinely engaged with the material technological reality. Therefore I will recognise the body as an affective element of experience in a broader assemblage.<sup>36</sup> Its senses and sentiments are understood as meaning or sense making. Sensing is (as much as are material and immaterial aspects) integrated into an interactive process of development; and, at the same time, it mediates the relationship between society and self, body and mind, knowledge and materiality.<sup>37</sup>

The senses therefore reach out as sources of information as well as provide us with a way to make sense of our environment and our inner world.<sup>38</sup> Whereas the senses of sight, hearing, taste, smell and touch are modes to provide knowledge about our external environment, other senses such as the sense of pain, the sense of our own muscles and organs, our senses of balance, movement, temperature, time, etc. give us access to the internal world<sup>39</sup> (compare with Hunter and Emerald<sup>40</sup>). Nevertheless, sensory experiences are intermingled with one another as well as with emotions, meanings and memories.<sup>41</sup> Among the multiplicity of senses, vision or eyesight is considered to be the most important in Western societies, where the progress of science, technology and object-centred thinking matters most.<sup>42,43</sup>

Like the concept of doing age, sensory and emotional practices are identified as being specific to social situations. They are neither simply constructed nor inscribed in the human body; rather, the senses are developed, educated and shaped in the bodily engagements with the world. This creates a structure to the world that both enhances and constrains sensory and emotional experiences.<sup>44,45</sup> Senses and emotions therefore are situated and processual: sensing is a social practice; social structures and culture as well as gender- and class-specific concepts are reproduced; at the same time, sensing is shaped. In other words, 'sensory experience is socially made and mediated'.<sup>41</sup>

Sensory studies point out that bodily conditions like health and illness can be sensed (nociception). This sensing relates to specific forms of knowledge that allow us to translate sensations into a judgement (diagnoses) about a state of being.<sup>46</sup> This judgement is, again, intertwined in sensing one's own body, through practices as well as through devices with which he or she chooses to use (compare with Pols<sup>47</sup>). Subsequently, digital technologies influence the practices and therefore create new sensory experiences. Sensations and senses are highly socially significant; therefore they will be examined in some detail in this analysis. The focus here is on practices, sensations and emotions, and on the new forms of knowledge and subsequent moral judgements that they may generate. Further, the analysis is concerned in particular with the aspects that they stabilise, naturalise and depoliticise, and the objectives that they motivate.<sup>32</sup>

### Case study and methods

Against this backdrop, a pilot study on 'Virtualisation and the Embodying of Digital Health' was carried out in north Germany using a mixed method approach. Interviews with 27 persons over the age of 65 were conducted in 2015 and 2016, surveying their digital practices: (a) as regards preventive health care, particularly

fitness activities; and (b) within the context of home-based care for chronic illness. Even though praxeology is generally sceptical towards the interview as a survey method, in this case interviews are well-suited to the analysis because they aim to uncover emplaced knowledge. Through interviews we might gain insight into how the research participants represent and categorise their lived and situated practices, sensory experiences, emotions and values. (Kathryn Geurts pointed out that senses and sensations even depend on language – not just to articulate them in one's own social context, but to even make sense of their operation.<sup>48</sup>) Interviews are therefore understood as context-dependent representations of experiences. (The interview is 'where multisensorial experience is verbalized through culturally constructed sensory categories and in the context of the intersubjective interaction between ethnographer and research participant'.<sup>49</sup>)

The study participants included males and females, mostly middle class, and in their third phase of life,<sup>50</sup> generally in their late sixties and seventies. The oldest interviewee was an 84-year-old woman. Most interview partners were of German descent; a few had backgrounds of a different nationality. The health conditions specified by the interviewees varied between being mentally and physically fit to suffering from chronic medical conditions. The interviewees were recruited from bulletin board postings in centres for senior citizens and senior citizens' sport associations, medical practices, supermarkets, other contact points and through advertising in a local newspaper. Some interviewees were won through a snowball effect. The selection criteria we used were the level of interest in participation and usage of specific digital technologies.

The survey consisted of semi-structured narrative interviews, lasting between 45 and 95 minutes. The elderly interviewees were asked about self-monitoring practices, physical and emotional impacts as well as sensory experiences. The interviews were transcribed by student assistants using f4 transcription software, and analysed by the author using MAX QDA qualitative data analysis software (details of the software publisher can be found at: <https://www.audiotranskription.de/f4.htm> as well as <http://www.maxqda.de/>). The interview fragments quoted in this article were translated by the author from German to English.

Because semi-structured narrative interviews only permit the examination of explicable and discursive knowledge, the interviews were combined with systematic participatory observations in order to reconstruct daily practice.<sup>51</sup> Each interviewee was accompanied for at least one hour while using digital technologies; one-third of them were accompanied twice within a three-month time interval. Observational protocols were recorded by the author about (a) how the elderly

negotiate with the devices – follow, modify, or resist their inscribed purposes; (b) how the sociotechnical interactions enable fitness or active living at home; and (c) how the sociotechnical practices influence the subjects' sensory and emotional experiences and ideas of health and ageing. The protocols were also analysed using MAX QDA software. Such ethnographic observations make it possible to analyse implied and embodied knowledge rarely translated into cognitive processes.<sup>52</sup> In order to reveal this implied and embodied knowledge, in keeping with the approach of Stefan Hirschauer, localised practices and configurations become the focus of our interest.<sup>53</sup> In other words, descriptions of local processes and effects are at the core of this methodology.<sup>54</sup> The results from the analysis of observations supplement the interpretation of the interviews, because they serve as an additional source of empirical information. For the discussion and conclusion the study results are complemented and underpinned by relevant international literature to relate the results to the current state of research.

### Results: 'Doing age' via digital health technologies

The findings reported here are divided into two subsections corresponding to the digital technologies used by the participating elderly persons: (a) wearables and health apps in the context of fitness activities; and (b) home-monitoring technologies for long-term chronic conditions. Each subsection starts out with a brief introduction of the technical devices and their prescribed usage. The qualitative study design is such that the description and analysis of individual participant data provides an illustration of general patterns found in the overall data.

#### *Wearables and health apps in the context of fitness activities*

Sensory self-assessment and optimisation of practices were not invented by digital technologies, for example see Legnaro<sup>55</sup> and Zillien.<sup>56</sup> A paradigm shift, for example, from diary entries to digital self-assessment results from the fact that sensors and web-based interfaces permit the structural coupling of independently produced personal data with those that have already solidified into norms.<sup>57</sup> Investigations into digital health practices with wearables designed to monitor fitness thus show that the use of digital technologies changes subjects' sensorial self-perceptions;<sup>58</sup> they encourage users to be less influenced by spontaneous individual introspection.<sup>59</sup> Sensorimotor functions are replaced by an objectification of the body. This results from the algorithmic processing of sensory-recorded

bodily functions, which are always guided by an ideal, and thus follow normative body shaping or health behaviour.<sup>60</sup> Correspondingly, physical practices are no longer based on individual biographical experiences and spontaneous desires because, as the result of socio-technical interaction, subjects are no longer addressed individually as coherent and spatially situated selves.<sup>61</sup>

Most studies on the use of wearables and fitness apps have been based on the experiences of middle-aged persons. Therefore, these studies leave unanswered to a significant extent the question of how health practices and experiences of the elderly are shaped by the use of such devices. In an attempt to close this gap, this study identifies and examines responses to digital health technologies by elderly persons.

#### *'So much is merely a claim': The disturbances of the introspection*

Seventy-four-year-old Vasil (all names of interviewees have been changed for data protection purposes), who uses a pedometer (on the advice of his wife) to encourage physical activity, finds himself in serious conflict. The low readings (represented by short bars on computer-based presentations) on his device appeared deficient compared to those of his wife and made Vasil feel both helpless and frustrated. He reacted by resisting, for example, by casting doubt upon accuracy of the sensors.

This wristband means nothing to me. I will not subject myself to being coerced by any modern one-size-fits-all defined limits!... I cannot imagine that I want to be controlled by such a device. With this device, in particular, so much is merely a claim and not sufficiently defined (Vasil, para 16).

Vasil experienced as coercion the call to action that he was given by the device. In his view, his favourite way of passing the time, working on his lathe, was wrongly not taken into account. Before using the wearable he experienced himself as physically active. His activities in the craft room gave him positive sensory and emotional feedback. Therefore the wearable confuses his sensory introspection by calling it into question. After a few weeks of using the wearable, he decided against continuing. This in turn gave rise to a vehement dispute within the family, where Vasil's removal of the wearable was seen as an indication of his unwillingness to actively work on his health. In this conflict, the wearable was attributed with helping Vasil to overcome health limitations from which he has been suffering. In Vasil's view, his wife's concern was transformed into intimidation and duress in the sociotechnical interaction; he felt bossed around and supervised. By

contrast, his wife directed her appeals for more exercise to the wearable. In this tension between the two elderly spouses, the wearable assumed the role of a mediator, but one that undermined privacy and obscured difference in interests. The wearable was supposed to provide the evidence that Vasil does not move around enough. In turn, this was supposed to appeal to his sense of obligation, resulting in him increasing his level of physical activity. However, the sociotechnical interactions led to an increase in Vasil's feelings of guilt. At no point was it discussed, however, whether his back and thyroid gland problems may have been caused by life-long physical labour (and this is highly likely) and whether those ailments could be at all alleviated by an increase in physical activity.

Whereas Vasil's experiments with the pedometer and the visual graphs of his performance gave rise to conflict and guilt and confused his sensory introspection, Ingrid, an active 72-year-old widow, experienced change in the perception of her own body as the result of wearing a heart-rate monitor watch with chest strap. Her socio-technical interactions occurred as part of a walking group for senior citizens. This is her report.

My heart-rate monitor shows the heart, my heart. It shows me what my pulse rate was when I was walking in the park. That's very important to me because, if my pulse rate is too high, this is harmful. It can make me ill because it stresses my heart. And I need to handle my heart with care [laughs]. In the end, I don't want to end up in a senior citizens' home and not be master in my own house.... Marlies Hoffmann [name changed: person from the same senior walking group] can't walk with us anymore, since almost three months ago. I don't know what that other symbol is... I can't remember. Recently, when I had forgotten to put the chest strap on, I had a completely insecure feeling. I wasn't sure the whole time if I was really walking okay. Of course I feel the strain... even without the strap, but it's strange without it. I just have to pay attention that the numbers stay the same. At my age, if you just once can't continue, then you never get back up again. And that happens in old age faster than you think (Ingrid, para 3).

According to Ingrid's interpretation, there is a chain of equivalence linking high numbers, high pulse rate, damage and social exclusion from the walking group. Social exclusion would result from not being able to participate in the exercise; in Ingrid's case, synonymous with the loss of the social contacts she had forged there, as well as losing her independence, culminating in her seeing herself eventually being committed to a nursing care home. In order to maintain her social integration, the *numbers would have to remain stable*. Over an

extended period of time, there should be no diagnosis of any significant change. Within the context of the sociotechnical interactions, therefore, Ingrid's body became a factor of mistrust: on the one hand, it was seen as being responsible for the social exclusion if it failed her; on the other, as a result of mistrusting *sensory* introspection, it was no longer possible to experience whether a stress limit had been exceeded. Sensory introspection was proven, for Ingrid, to be unreliable. Instead, the digital display became a warning system in an area of uncertainty; a permanent change in average readings as well as an unexpected increase in readings triggered fear and concern.

In the course of the interview, Ingrid identified the number 120 as a symbol of health and capability. As the stability of a number now symbolised health, it became a one-dimensional phenomenon that could be interpreted as a controllable form of exercise, thus making it appear as a product of will and self-discipline. Through the use of the digital device, health becomes synonymous with guidance by statistical means. Health was thus turned into something that could be measured rather than experienced. In consequence, the wearable reassured Ingrid that her exercise was a health-promoting activity.

Ingrid did not choose web-based algorithmic data processing to interpret her data because of her limited access to web-based interfaces. Instead, she sought an analogous exchange with her fellow male and female runners in order to understand her readings. The participatory observations showed that this differed from the example of Vasil. The exchange between Ingrid and her group members had a specific character because it occurred in situ and was entrenched in empathetic social relationships. First, the comparisons were based on general descriptions of bodily practices and physical well-being. Stress and worries were cited as reasons for deviations in readings in order to explain unexpected increases. Such explanations in turn made it possible for the others to be reassured, thus strengthening the team spirit. Second, the readings from older people are generally significantly higher even on average than those in the tables given by standard providers of pulse monitors. The senior running group thus generated new average readings on the basis of their own digital graphs. Third, individual characteristics were included in the comparisons: 'Marlies Hofmann had always been a hotspur' was said in the course of the interview, and her pulse rate generally increased faster than that of other runners. This was interpreted by the group as part of her disposition and thus not as a cause for concern. (The sociotechnical interactions of elderly subjects are generally more strongly accompanied by an

analogous exchange than is envisaged for web 2.0-based sharing of individual data, see Copelton.<sup>62</sup>)

Within these sociotechnical interactions, social phenomena such as exclusion and the loss of independence are debated. Health itself is viewed from its negative end, i.e. physical deterioration. Exclusion resulting from the loss of independence and individual effort as the prerequisite for health are naturalised in these sociotechnical interactions. The primary topic is thus not physical capability, but the individual's entry into a low-performance stage of life, i.e. that of frail old age. In this context, the body becomes a potential double-deficit experience. Therefore, despite the fact that virtualisations can be a source of pride and delight if readings are stable (as was evident in the interviews), and that Ingrid felt that the sociotechnical interactions had broadened her scope of action – she could affirm her physical activity as health-promoting and her body as capable and strong – these virtualisations also triggered emotional responses such as worry, anxiety and fear; and sensory introspection was reduced and replaced by enhancing the visual sense. Thus Ingrid's sensory reassurances of well-being regressed while assurances were delegated to the device.

### *'Ok, I'll bring your tea upstairs': Ascriptions of ageing*

Four other paradigmatic patterns are expressed in the sociotechnical interactions that correspond to the ascriptions of ageing. First are difficulties associated with a lack of digital experience resulting, for example, from age-related personal reservations about and uncertainty or suspicion towards the relatively young technologies (compare with Urban<sup>63</sup>). Second, an ageist design of wearables can handicap the user. Interviewees described displays as difficult to read or the devices as difficult to operate with unsteady fingers (see the remarks by Hilde in the following section) (compare with Charness and Czaja<sup>64</sup> and Charness<sup>65</sup>). Third, a repurposing of the digital device scripts was uncovered during the interviews and ethnographic observations: for example, instead of using heart-rate monitor watches to *improve* performance, the dominant motive was to monitor individual accomplishment and bodily functions in order to *maintain* ability or to avoid physical decline. Using the device in a way other than intended by the script signifies an inherently experience of deficit by the user (as illustrated, for example, by Ingrid above). Fourth, reported practices often deviate from the commonly used notions of fitness activities using digital technologies that are designed for young and middle-aged subjects, like able bodies running with wearables and/or training with heart-rate monitor watches. In the sociotechnical demand-

driven interactions, elderly subjects tend therefore to modify the script.

I must admit that during the first days, I tended to say 'Ok, I'll bring your tea upstairs', because that meant going upstairs. And that is 15 steps, equal to 30 points, there and back. Well I may have said that, but it was meant more as a joke. I really don't need that. Ok, it is good to stand up more often and then you can exert a bit of influence. My aim right now is to find out how you can fool that thing. And it is possible. You can swing your arms, but only in a certain way. You have to find out which ones are counted as steps and thus as points. So, you can sit in comfort, watch TV and just do this [swinging of arms]. That is quite ok, I tell myself. This will also increase my muscles soon, if I continue with that. But you are able to chalk up one or two hundred points, just during one TV programme. Or you can get up and walk around the room. We have a large sitting room, and when I do a round in there, it always adds up to, I don't know, 40 steps (Dinja, min 16:35ff).

These sociotechnical practices integrated into the lifestyle habits of an elderly person deviate from the usual imagery of fitness activities shown in the media or in advertising. As a result, Dinja perceives her way of doing health as *cheating*. To sum this up, in all four patterns, the sociotechnical interactions potentially bear negative self-perception.

### *Home-monitoring of long-term chronic conditions*

Let us now turn to digital health practices for the diagnosis and management of long-term chronic conditions, such as diabetes, asthma, Parkinson's and chronic cardiac problems, as well as the long-term management of other critical conditions. Digital technologies intended for home illness management are designed less as self-knowledge-enhancing technologies, than they are as technologies to enable one or others to monitor and assess bodily functions, locations and abilities.<sup>66</sup> The aim of low-threshold, long-term monitoring is, on the one hand, to ensure individual autonomy and thus care and nursing at home.<sup>67</sup> Digital technologies thereby enable elderly impaired individuals to age in place, in a non-clinical setting. The aim is meanwhile to substitute care provided by human carers and/or the use of health and social services (at least in part) and thereby ease the burden on health care systems.<sup>7,68</sup> On the other hand these in-place-monitoring practices open the possibility for new data-assisted diagnoses: a new, much more detailed patient's medical history can either help to adjust medication and/or intervene to prevent decompensation.

### *'Always all day long, three times a day': Elderly as diagnostic agents*

Home-based monitoring technology offers disabled subjects (and their families and carers) the option to identify an emergency on the basis of actual data.<sup>69</sup> Sociotechnical interactions thus help these individuals to transform uncertainties into the ability to act, as evident in an interview fragment from 76-year-old Selina, who suffers from a heart condition.

I am basically predisposed, because my father died from heart failure at the age of 60 years. And my brother has heart problems, too. My readings were always fantastic, 80 to 120, but that has changed with age. My blood pressure jumps – sometimes too high, sometimes too low, rarely normal. And for that reason, it is very important for me to know that, if there is a real problem, I can call for help (Selina, min 4:09).

Her readings allow Selina to cope with a potentially hazardous situation. What was subject to sensory introspection before the introduction of the sociotechnical practice manifesting itself, in this case, as a metric visualisation, now appears as an objective presentation of Selina's state of health. Thus, Selina has reduced her own level of worry and anxiety by replacing sensory introspection and relying on a digitally produced numerical image. This method of data processing reassures the subject by enhancing her own ability to act and thereby calms her. But such practices are associated with an increase in the responsibilities of the subject. The responsibility for assessments previously done by medical staff is transferred to users in general – in this case, Selina – and this new accountability gives rise to new anxieties.

So I have been asked to measure my blood pressure from time to time. ... I basically always found it quite a strain to measure my blood pressure, because it is often too high. Or it jumps, is irregular. ... Always all day long, three times a day, having to measure my blood pressure makes me nervous. I have simply had to do it, but I feel that it is quite a strain. ... I am basically a little bit afraid of negative consequences (Selina, min 13:02).

Sociotechnical interactions are often experienced as an added strain, and they can trigger anxiety or fear. One of the reasons for this is the necessity for the elderly subject to become a competent diagnostic agent. The elderly are required to become familiar with the digital media and acquire new skills. However, many of them remain insecure in carrying out such practices because they really do not completely understand the digital

procedures. Other interviewees also reported having difficulties in understanding the devices.

Which bars mean what and how much and from where.

For example, calorie consumption, I have no idea what that is. Because they can't monitor my food, so it obviously has nothing to do with eating (Helen, min 13:26).

For Helen, a very lively 70-year old suffering from diabetes, the current standard combination of apps with other technologies – e.g. insulin pumps, blood sugar monitors, blood pressure monitors, Cardiogoniometrie (CGMs) and step counters – constitutes a particular factor of uncertainty. As a consequence, Helen not only felt controlled, but she also felt unsure as to how and what data were being generated as well as what the various visuals were telling her. This lack of technical understanding also leads to uncertainty in the timing of individual measurements and self-regulation. These new demands created tensions in Helens life. Her sensory experiences of healthy nutrition (e.g. taste) and experiences of physical fitness (e.g. feeling hale and hearty) were confused by digitally processed recommendations. Moreover, the sociotechnical practices forced her to give up habits she had acquired and become fond of over the years, in order to meet the affordances of the scripts. She interpreted this as a setback of well-proved self-knowledge.

Another interviewee, the lively 72-year-old Alex with a migration background, complained of incompatibility between the sociotechnical practices with the infrastructure and the routines in his less developed country of origin, where he usually spends his summers.

At home, we have no internet. And we eat different. It is like a cure for me. But it is all so different, that my medical routines. ... they don't work out (Alex, min 9:11).

In some cases not only does the integration of these practices become a strain for the subject, but also his or her daily confrontation with the output from these sociotechnical interactions.

It really takes it out of you, if you are constantly being reminded of it. But because I am in this programme, I have to take a blood sample four times and check. ... These are some of the other problems you then have (Alex, min 8:33).

Previously, diagnosis and discussion of results took place in a medical setting like the doctor's office, a place separate from a patient's home environment. Home-based self-monitoring reinforces patients' permanent awareness of their own chronic illness or condition when they are at home. Thus physical impairment



takes on a greater presence subjectively: sociotechnical interactions promote hyper-awareness of one's physical deficits, especially the weakness and frailties of the body. This increased awareness led Alex, for example, to experience severe physical discomfort.<sup>70,71</sup>

### *'They are so very tiny': Enabling, frustration and compensation*

Another phenomenon that was revealed in the interviews and through the accompanying observations was that self-monitoring and the associated self-reliant reading and evaluation of the recorded data gave rise to new risks, because the subject may not be able to cope properly with the devices, the technology or the overall situation in home-based sociotechnical interactions.<sup>72</sup> Hilde, a very cautious lady with multiple impairments, talks about her coping strategies.

But it has taken me two or three days to look at it again. ... I'm not really sure what happens when I press this. And in the beginning, you don't really have the courage. ... But these symbols, I don't know. They are so very tiny. ... Well, that's the way it is. I have accepted that then; that's the way it is. Micha [her daughter] has figured it out; she put it on and kept pressing; I was quite horrified. ... Of course, yes. I did not want to do anything wrong, you know (Hilde, min 28:53ff).

Hilde's coping strategies resulted in her partial inability to deal with the demands of the device. The consequence of this could be lack of provision or care and possibly even an incorrect response to the readings. Hilde's negative emotions and lack of sensory control were succeeded by unreliable practices, for which no sensory experiences could adequately assist her towards health-promoting behaviour.

### *'Or whether that appears somewhere': About scripts, desires and values*

In addition to the active monitoring technology discussed above, which provides real-time responses to biological changes, other aspects become apparent when we consider passive monitoring technology. Passive monitoring devices are marketed as sensors that gather and analyse domestic behaviour and routines over time, so as to alert the user when there is unanticipated deviation.<sup>73</sup> Such monitoring sensors are also known as ambient assisted living or smart house technologies. Some examples of these are passive infrared movement detectors (PIRs), flood detection instruments, fall detectors, bed occupancy sensors, bed epilepsy sensors, chair occupancy sensors, electric use sensors and door contact sensors.

A particular differentiation is made between two generations of passive monitoring technology. Whereas first-generation systems – for example, emergency call devices – are connected to a call centre that relays information, second-generation systems monitor spaces in which an emergency call can be triggered without the active involvement of the impaired person; these devices can summon help for an individual in an emergency situation in which he or she may be no longer able to place the call themselves.<sup>74</sup> Sensors of this generation are able to filter out uncommonly rapid or unaccustomed movements from routine patterns like opening doors, turning over in bed or walking across the floor, encoding deviant movement as problematic; the information is then relayed to web-based interfaces.<sup>75</sup>

However, the scripts of an ambient monitoring system do not always correspond to the value systems of the users. Interviewee Hilde, who lives on her own, suffers from a pulmonary disorder and uses a first-generation emergency call system, provides a good illustration of such a divergence of values.

From time to time, I get coughing fits – have had them for years – that make me panic, because I cannot breathe, and fear that... I notice then that there is an emptiness developing in my head [and] I am afraid of suffocating. In that situation, I have developed a technique in which I pant in order to get more air gradually. I am coping with that quite well, and I do not panic any more. But I still consider the situation quite dangerous at times. Once I was almost about to press the button. But then I hesitated a bit longer. It would have taken the ambulance 20 minutes to get to me, but my brain would have already suffered severe damage in that time. I find that prospect worrying; I'd rather not be there at all. And by and by, my breathing improved, and I was quite glad that I had not raised an alarm unnecessarily (Hilde, min 16:32).

Whereas the script of the technologies includes the speediest possible intervention and thus the initiation of life-saving measures, consequential damage cannot be ruled out in this way. The technologies subscribe inherently to an ethic of saving life at any price, which may diverge from the users' notions of a life worth living. In consequence of such conflicting values, Hilde actually preferred to be in a situation of panic and fear of death without sociotechnical interaction. Just by rejecting the use of the digital technology, Hilde stayed true to her values.

Other interviewees feared that monitoring may make their lifestyle choices public and embarrass them – how clean they were, how cluttered their homes were, what their sexual practices were. In that way, ambient

monitoring systems could potentially undermine individual privacy.<sup>76</sup> Such concerns were raised, for instance, by Helen, who uses a bed epilepsy sensor.

I still want to blow my top and make love. I don't know whether I should switch it off then, or whether that appears somewhere. These things happen. And there are other open questions. I don't know where to get the answers (Helen, min 15:54).

Sociotechnical interactions thus limit the options for lifestyle choices and some bodily experiences. Helen was confronted with digital technologies that show some bodily activities as deviating from statistically normal routines. Her sexual behaviour could be interpreted by the device as physical risk and trigger an immediate alarm because of the way the algorithm works. This built-in element of the device and the corresponding sociotechnical interaction actually precludes, then, the subject's being able to satisfy her sexual needs.

Other elderly persons spoke of their fear that their privacy would be eroded and that the technology could result in misjudgement or false assessment by medical professionals or family members of their state of health – e.g. relaying misinformation about falls or other deviant behaviour. Unwanted alarms triggered by a device can result in increased anxiety and insecurity. An 84-year old interviewee who lives on her own with a first-generation emergency call system talks about an incident that caused her great anxiety. She accidentally pressed the button on her emergency call device – a wearable on her wrist – in her sleep.

Of course this happened while I was asleep. And I don't hear very well. I always leave the door to my room open; but next to my bed, there is part of the room and then there is the hallway. The station for the device is in the sitting room. And I did not hear it. I did hear the phone ring; but, by then, my ears had already missed these other sounds. So, I thought that it was just a prank call in the middle of the night. And some minutes later my doorbell was ringing and the door to my flat was flung open. I lay wide awake in my bed, full of fear. Of course, I was totally shocked. Because I thought that somebody had spied on the phone to see if I was at home and then made sure at the door. [Question by the interviewer: Did the person introduce himself as a paramedic?] That's what she claimed! But I did not believe her. I said: 'I'm fine. I don't need help... [and] I won't let you in'. I had the chain on the door. She said that she could unlock the chain as she had the key for that, too. She was wearing a uniform, but you know that is no evidence these days, either (Ming, min 7:54ff).

Even though the digital technology was employed faultlessly, the sociotechnical interaction posed problems for the user. Whereas for the medical emergency team the alert was over because it was identified as a false alarm, Ming suffered from sleep disorders and remained unsettled as a result of the incident. She developed nervous symptoms, induced by acute awareness of her own defencelessness and frailty, made apparent through the sociotechnical interaction.

Active and passive monitoring technologies also, of course, expand the scope of action of the elderly; the interviewees would not have used them otherwise. But little is discussed in the literature about the effects of sociotechnical interactions that, at the same time, provoke negative emotions such as anxiety, fear or shame. Further, in such constellations, the senses of the elderly do not provide compensatory information or orientation: rather, the sociotechnical interactions create incompatibilities with spontaneous needs or familiar practices, whereby these needs and practices are technically marked as deviations. But above all, digitally recorded deviant behaviour could be taken as indicators of ageing (e.g. the accumulation of clutter or being overstressed). And, in turn, indicators of ageing could be interpreted as signs of the need for intervention – possibly against the will of the persons concerned.

### Discussion: Digital ageing and its obligations and frustrations

As we have seen above, elderly users of digital health technologies are being enrolled as active agents in managing their own diagnosis and treatment in non-clinical settings. This responsabilisation is characteristic of health care today with its notion of patient-centred medicine and patient empowerment. (Next to this, a growing market delivers technologies as internal devices, like pacemakers or implant cardioverter defibrillators, which put much less agency upon the users, see Oudshoorn.<sup>77</sup>) New digital health technologies for the management of long-term chronic conditions have enabled the shift from clinical to home care, and with that a corresponding shift from professional supervision to patient self-help. Thereby, we retrace increasing patient empowerment.<sup>78</sup> Digital health technologies allow new ways to experience the body, and new practices and embodiments of ageing. In sociotechnical interactions, digital technologies appeal to the transformation potential of the individual and raise the hope of extending physical capability and autonomy. In so doing, these technologies address their users as active agents who can perform on their own initiatives.<sup>79</sup>

To understand how digital technologies enable the elderly to become competent diagnostic agents,

we should have a closer look at how these technologies work. With their numerical representations of bodily functions, digital health devices guarantee an apparently objective assessment of hazardous or potentially hazardous situations: diagnostic logic presents something previously invisible in a visually usable manner. Digital visualisations as (apparently) objective presentations carry a high degree of validity.<sup>80</sup> Technically generated presentations, graphs and illustrations are interpreted as neutral; they are seen as endowed with ‘mechanical objectivity’.<sup>81</sup> However, these visuals in particular do not reveal anything about what they doesn’t reveal, namely that it is *not a verdict about the concrete body at all*.<sup>82</sup> Although digital images supposedly process individual data, their reference values are based on standardised bodies.<sup>83</sup> Medical and technical images conceal the highly complex technical, social and cultural conditions under which they have been created.<sup>84</sup> Their process cycles remain hidden, as do their algorithms, picture-processing software, comparative data and compilation. In particular, it is the reaction to such an unquestionable representation of data that may reduce sensory introspection and respectively change bodily experiences as well as physical practices.<sup>85</sup>

Let us first have a look at what this means in our first case, the sociotechnical interactions with wearables and health apps in the context of fitness activities. The interview fragments above show the extent to which sociotechnical interactions interweave the technical with the corporeal. For our elderly subjects (similar to the way in which the technology works for persons in other stages of life), the digital practices enable enhancement of processual materiality, sensory experiences and emotions.<sup>30</sup> But encoded into these digital interactions is a morality that encourages specific practices, and stimulates certain sensory and emotional experiences of elderly subjects within the actual networks into which they and the digital devices are incorporated. In this sense, digital technologies function less as neutral fitness coaches because the digital fitness practices of the elderly are rooted instead in the ‘plasticity perspective of age and ageing’ and originate from the primacy of ‘age prevention’ (compare with Denninger et al.<sup>86</sup>) The implication here is that ageing is something that has to be prevented, or at least delayed. Thus, in accordance with sociotechnical practices, ageing is to be interpreted as a personal decision or rather something controllable. The potential consequences of an elderly person’s failing in these efforts can be loss of social recognition and/or social exclusion. This prescription provoked anxiety and uncertainty among our subjects, or their rejection of the technology. So, although on one hand the digital technologies function as facilitators, on the other hand

they also function as limitations in the form of an amplifier of a hegemonic ideal of ageing.

In our second case, home-monitoring technology for long-term chronic conditions, we discovered new challenges that the digital technologies imposed on the elderly. In ordinary face-to-face consultations elderly patients receive diagnoses and advice from medical professionals whom they have no choice but to trust. (Sarah Maslen presents this in detail, and how doctors use their senses to develop a diagnosis that is therefore much more complex than a data-based one; see Maslen.<sup>87</sup>) But long-term trust-based relationships with professionals usually helped in getting subjects to comply with the therapy. However, there was the inherent risk that subjects would misunderstand the instructions or disregard them. Home-based self-monitoring and the associated self-reliant reading and evaluation of the recorded data gave rise to new risks, because the technologies have the potential of encouraging inappropriate responses and rendering individuals attempting to use them unable to properly cope.<sup>73</sup>

Taking into account other studies, we find similar results. The IN-TIME pilot study on digital monitoring in cases of chronic heart failure shows, for example, how, under consideration of a patient’s medical history, monitoring can trigger interventions – ranging from adjustments in medication to calling for emergency help – once any abnormalities have been detected. The interface to a telemedicine centre not only prevented decompensation, it also made it possible for users to enjoy greater mobility.<sup>88</sup> Another qualitative study from the Netherlands on self-monitoring of blood glucose (SMBG), including self-regulation, showed that many patients measured their glucose concentrations less often than recommended.<sup>70</sup> Many participants in that study did not know how to respond correctly to the glucose readings and, in consequence, often maintained poor glycaemic control.<sup>70</sup>

The interview fragments above show that the gap between the technology scripts – and, by implication, the demands, perceptions and goals of the professionals – and the adaptations of these technologies in the everyday lives of elderly users leads to tensions. In turn, these tensions can have a negative impact on quality of life and an individual’s own choices. In addition, digital health technologies must be integrated into normal daily routines (compare with Webster<sup>89</sup>). Often this process enjoys only limited success because the elderly – as seen in the case of some interviewees – stick to their familiar and long-practiced routines, even if and when they prove to be incompatible with the technical device scripts. Changes of location or to routines are seen as difficult or divisive, creating additional uncertainties.<sup>90</sup>

Questions have been raised in the literature about the ethical implications of ambient monitoring systems as *surveillance technologies*.<sup>91</sup> For example, as we have seen above, users fear that monitoring may reveal to others their personal practices (e.g. sexual expression), habits or lifestyle choices, that they would prefer not to be publically known. In other words, ambient monitoring systems were seen as something invasive, which could potentially undermine their privacy.<sup>76</sup> As a result interviewees felt that limits had been imposed on their lifestyle choices or their emotional and sensory experiences through technological intervention. This happens because passive and active monitoring technologies function as *subsystems of risk estimations*, whereby digital systems function by identifying deviations from statistically determined normal routines. Risks could be indicated by the length of time spent out of bed or outside of the house during designated sleeping periods.<sup>66</sup> These digital technologies are programmed for risk evaluation by professionals and service providers, whose task it also is to minimise any determined risks.<sup>92</sup> For the very reason that they are risk assessment tools, these sociotechnical interactions generate incompatibilities with the spontaneous needs, desires or familiar practices of users. In ambiguous cases, strict application of such risk assessment tools could result in loss of autonomy, independence and self-determination for an impaired person. Some elderly individuals therefore took a very ambivalent stance towards assistive technologies because they tended to highlight failure or decline, symbolising age-related frailty and helplessness, the absence of self-sufficiency and subsequent dependency (including dependency on such technologies).<sup>93</sup>

## 5. Conclusions

Giving the current move in medicine and public health towards digital health technologies, we are dealing with a new form of guidance for older individuals. In terms of a neo-liberal activational imperative, the state no longer guarantees service provisions but offers help towards self-help, conditional upon an individual's personal input. If this successful ageing fails at any stage, the failure is attributed to the elderly individual – whose options for compensatory action are, to a greater or lesser extent, limited.<sup>94</sup> Such an activational imperative fails to consider a disparate distribution of physical, economic, social and educational resources; instead, subjects naturalise the notion of self-governance, for example via their digital health practices: In sociotechnical interactions, individual efforts become meaningful and necessary precisely because they are motivated by individual notions of successful ageing, even though the so-called health-promoting practices invariably proceed with negative emotions such as fear, shame and anxiety.

Whereas, in general, national public health programmes see technical upgrades of home-based monitoring technology as a societal task and millions of Euros are spent on interventions, the emotional and sensory experiences due to digital practices remain mostly neglected. The potential of these digital practices to motivate older persons is thus approached as a purely technical challenge. On that account, systemic dysfunctions are generally perceived to be individual personal malfunction(s) or failure, which requires, therefore, a private solution (or perhaps improvements in the way that the technology is applied). Negative emotions experienced during the sociotechnical interactions thus appear as being symptomatic of old age. Physical discomfort and mental distress, special demands and anxiety are thereby separated from the scripts of digital technologies.

For the elderly to carry out such home-based monitoring, as our examples show, it is essential that the digital health practices are linked to other e-health features such as medical and technical supervision and support.<sup>95</sup> Self-monitoring can only work with additional hands-on medical support and professional back-up.<sup>96</sup> The development of additional digital interfaces such as electronic patient records, other networks and digital interfaces is a vital requirement in consequence of self-monitoring. The lack of such components of the health care systems can evoke serious sources of error and additional strain on the elderly.<sup>97</sup>

Finally, let us summarize the main results in direct relation to the three questions presented at the beginning of this paper. To answer the first question, on how the technologies generate (health) practices, we now can identify two aspects. First, an increasing demand for such sociotechnical interactions arises from the hegemonic value system that regards successful ageing as the product of active, healthy and autonomous elderly persons as *diagnostic agents*. Digital health practices in the battle against ageing thus become the obvious answer to this invocation of the individual as a 'preventive actor'.<sup>98</sup> The sociotechnical interactions turn into a perpetual preventive action loop. Second, the sociotechnical interactions reconfigure the concept of ageing. Inherent in digital health technologies is the notion of ageing as a pathological process that could be overcome or should at least be the responsibility of the individual.<sup>79</sup> In that way, digital technologies confront users with the necessity to compensate by themselves for their deviation from some predefined ideals.<sup>99</sup>

Now, let us recall our second question about the kind of senses and emotions described in these sociotechnical interactions. In sum we can say that, whereas the enabling of autonomy and/or physical fitness, for example, are celebrated as consequences of digital health technologies (compare with, for example, PWC<sup>4</sup>)

negative emotions displayed by our elderly interviewees were treated as personal predicaments. In addition, the data showed that vision was considered the most crucial sense in those assemblages. We also saw that, whereas certain technologies designed especially for the elderly appeal to other senses – mostly that of hearing – even this might not yield the anticipated results, as Ming aptly demonstrated. Digital health practices by elderly users, especially persons with age-related visual or hearing impairments, carry the inherent danger of triggering problematic sociotechnical interactions.

Finally, to address our third question on the role of the senses in sociotechnical practices, we can conclude that senses other than seeing and hearing appear unreliable or inadequate (as best illustrated by Ingrid). This coincides with the state of research on the general consequences of digital self-monitoring.<sup>100</sup> With regard to the interviewed elderly subjects, the data emphasised that this shift could stimulate stress and even anxiety. In keeping with anthropologist Elizabeth Hsu's contention that senses are mediators 'between meaning and materiality',<sup>41</sup> we note that the impact of some of the sociotechnical interactions described above can clearly be heavy: if the mediation through the senses becomes weaker, this can cause severe distress. The title of this article 'This really takes it out of you!' thus acquires a dual meaning: not only are sociotechnical practices demanding and challenging for the elderly; their sensory experiences tend to be abolished as potential aids in those constellations.

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