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Caring for data in later life – the datafication of ageing as a matter of care

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ABSTRACT

This article examines the datafication of ageing by drawing on a practice approach toward care. We describe the datafication of ageing as a matter of care, achieved through the local tinkering of actors – technology designers, care staff, older adults, and highlighting the practices necessary to develop, maintain and implement data infrastructures. This paper draws on research conducted in a qualitative interview study in a LTC facility that uses AI-supported sensors to detect, predict and alarm care staff about falls of older residents. 18 interviews with developers, staff, residents and interest groups were conducted, as well as 24 h of participant observation in the care facility.

The results reveal how AI-development for older target groups is characterized by absent data on these populations. Designers turn to practices that decontextualize data from the realities of older adults, relying on domain experts or synthetic data. This decontextualization of data requires recontextualization, with staff and older residents ensuring that the system functions smoothly, adapting their behavior, protecting the system from making false decisions and making existing care arrangements ‘fit’ the databases used to monitor activities in these arrangements.

The ambivalent position of older adults in this data assemblage is further highlighted, as their caring practices are made invisible by different actors through ageist stereotypes, positioning them as being too frail to understand and engage with the system. While their bodily behavior is core for the databases, their perspective on and engagements with the operating system are marginalized, rendering some aspects of ageing hyper-visible, and others invisible.

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Introduction

For the last decades, demographic change has served as a fruitful narrative for technology development. Framing the increase of older adults in European societies as a problem

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that calls for ‘techno-fixes’ (Higgs & Gilleard, 2022), with a shared understanding ‘that the only reliable sources for improving the human condition stem from new machines’ (Winner, 2014[1983], p. 50), technology companies have become increasingly interested in older adults as a target group of assistive technologies in general, and artificial intelligence (AI) in particular. Using crisis narratives around demographic change as rhetorical anchor points, the overriding hope that guides the development of AI technologies for older adults is that it will support health and care professionals in their work and older adults in their wish to live and age autonomously and independently (Rubeis, 2020; Sapci & Sapci, 2019).

The introduction of data-hungry technologies is likely to change the way older adults live, age and are cared for in a variety of ways. Framing these changes as the ‘datafication of ageing’ (Dalmer et al., 2022), research has begun to explore how the processes associated with the rise of big data matter in the lives of older people and re-frame age and ageing in datafied societies (Ellison et al., 2022; Fernández-Ardèvol & Grenier, 2022; Gallistl et al., 2023; Rosales & Fernández-Ardèvol, 2020). As Dalmer et al. (2022) note, there is a need to understand how infrastructures of big data ‘constitute ageing subjects in devalued (...) ways’ (p. 79), particularly since the role of structural ageism in big data infrastructures is well documented (Chu et al., 2022; Rosales & Fernández-Ardèvol, 2019; Stypinska, 2022).

While several frameworks on ethical, fair or responsible AI have been published in the last years (e.g., the ‘Malta Ethical AI Framework’, or the ‘Ethics Guidelines for Trustworthy AI’), researchers have increasingly called for expanding empirical evidence on how AI in the context of ageing is applied and addressed in practice (Lukkien et al., 2021). In practice, algorithmic technologies are not simply ‘parachuting in’ to contexts of ageing (Gallistl, Seifert, et al., 2021), but need continuous adaptation, management, (re-)development and training, as they call for a constant ‘tinkering with bodies, technologies, knowledge and people’ (Mol, 2008, p. 12).

This article makes a novel contribution by engaging critically with the situated, shared and routine data practices that accompany the introduction of data-intensive algorithmic decision-making systems in the lives of older people. Framing these data practices as a matter of care (de La Bellacasa, 2011), we examine the practices of local tinkering (Mol, 2008) that pave the way for the introduction of algorithmic technologies in the lives of older adults and critically question how the datafication of age and ageing plays out at a long-term care (LTC) facility that has introduced AI-supported fall detection sensors in the rooms of older residents. The main argument we put forward concerns the gains that can be made by exploring AI, algorithmic decision-making technologies and their data infrastructures in the lives of older adults as matters of care that are necessarily shared, distributed and ambivalent, and are cared for through technology designers, caregivers and older adults alike.

The datafication of ageing

Research on ageing and data-intensive technologies dates back to the late 1990ies, when the first monitoring and automated alarm systems were developed for older adults living at home (Chan et al., 1998). Since, AI for elder care has vastly diversified and is now applied in decision support systems for medical diagnosis (Chen, 2018), automated

analysis of patients' data for early disease detection and preventive medicine (Pilotto et al., 2018; Rubeis, 2020), robotics to enhance precision in surgery (Chen, 2018), to provide care support as conversational agents (Sapci & Sapci, 2019), or monitoring and surveillance systems for older adults (Manzeschke et al., 2016).

Lately, research has begun to explore the development and implementation of AI for older adults with a focus on datafication, critically questioning how the 'collection, databasing, quantification and analysis of information, and the use of [this] data as resources for knowledge production, service optimization and economic value-generation' (Flensburg & Lomborg, 2021) re-frame ageing in a variety of ways.

Firstly, this concerns how data – and particularly the accumulation of data – has become a component of the political economy of ageing. In the 1980ies, Estes (1979) introduced the concept of the 'ageing enterprise' as a tool to critically analyze the political-economical relationships that are created to serve – and define – ageing and later life. Building on a bio-medicalization and commodification of ageing, the ageing enterprise frames older adults and the processes related to ageing as a commodity that is sold for profit (Estes, 1993; Estes, 2014) by hospitals, care organizations, insurance industries and others. Arguably, datafication opens up new frontiers to this political economy of ageing, as the economic wealth and political power wielded by those social actors who possess (big) data is massive and growing through the accumulation of data capital (Sadowski, 2019; Zuboff, 2015).

This also concerns issues that have been raised about which age-groups are represented in big data infrastructures, who owns and profits from these infrastructures and the potential biases that arise from lacking representations. Chu et al. (2022) note that there is hardly enough data that concerns older adults available to train AI models toward the needs of this population. The data infrastructures that are available often show an explicit or implicit age-related bias, which points to a major structural problem for the creation of inclusive and fair AI systems (Stypinska, 2021; 2022). Studying the datafication of later life from this perspective, hence, focusses on:

- how data ownership, data extraction and value creation through data is distributed in data assemblages that include older adults,
- how data from and about older adults is used to create economic wealth or political power,
- how older adults are represented and included in data infrastructures (and their ownership) available to train AI.

Secondly, research on datafication and ageing highlights the need to study datafication in the context of the quantification of ageing. Katz and Marshall (2018) show, how new ways of quantifying and standardizing measurements of age and the related data intersect with anti-ageing and ageist narratives through positioning ageing as a process that can be managed, measured and ultimately avoided. With the emergence of big data, the human body becomes more exposed to pervasive surveillance practices (Ball, 2009), creating a status where the subject is constantly being made analyzable through quantification. At the same time these measurements function as a normative force which 'concerns how one should live one's life in a way which is also readily encodable in data' (Ball et al., 2016, p. 70), governing individuals' behavior by making (and selling) predictions

about desirable or undesirable futures possible (Mejias & Couldry, 2019). These practices of prediction through quantification are seen as key in the context of ageing and later life (Chen, 2018), where particularly the negative aspects of ageing are ‘othered’ and cast into an unknown future (Higgs & Gilleard, 2014) while simultaneously governing older adults’ behavior in the present, e.g., through promoting physical activity or a balanced nutrition as key to healthy ageing. This highlights the need to study how quantifiable data is used to predict ageing, what normativities of ageing are being encoded in data and how these practices govern older adults’ behavior in the present.

Lastly, it has been widely noted that the role of older adults in actively shaping processes of datafication remains unexplored. In contrast to discourses that portray older adults as frail, incompetent, uninterested or invisible users of technologies (Chu et al., 2022; Mannheim et al., 2022), research has highlighted that older adults – even those who are frail or vulnerable – actively engage with technological innovations in their everyday lives (Gallistl & Wanka, 2022; Gallistl, Rohner, et al., 2021). Instead of framing older adults as passive research participants or invisible consumers of technologies, cultural gerontology advocates for locating older people and their subjectivity at the heart of scientific research and analysis (Twigg & Martin, 2015). This highlights the need to study datafication by focusing on how older adults perceive and make sense of datafication, and how this relates to their subjective experiences of age and ageing.

The datafication of ageing as a matter of care

Moving away from an interventionist perspective that has largely characterized studies on ageing and technology (Peine & Neven, 2019), this paper makes a novel contribution by drawing on a practice-theoretical perspective on care (Mol, 2008; Mol et al., 2010), to explore how datafication of ageing is practically achieved through the constant involvement, negotiating, and local tinkering of actors – technology designers, care staff, older adults. With the concept of care, we explore the affective and ethical ‘enduring work that seeks improvement but does not necessarily succeed’ (Heuts & Mol, 2013, p. 141), which goes into building and implementing data-intensive technologies in LTC.

Our approach builds on recent advancements in critical data studies scholarship that have called to reposition big data and algorithmic technologies as ‘matters of care’ (de La Bellacasa, 2011) and highlighted how different actors form care relationships not only in opposition to, but together with data and algorithmic technologies (Zakharova & Jarke, 2022). They also show the importance of (invisible and gendered) care work that is key for achieving datafication in practice (Metzler et al., 2023; Pinel et al., 2020). Such studies also reveal the tensions that are enacted through care-ful datafication, in which the care for one aspect of the data assemblage can exclude or have negative consequences for another part of the assemblage (Lindén & Lydahl, 2021; Seaver, 2021).

For researching datafication in LTC facilities, such a perspective enables us to analyze the practices of local tinkering (Mol et al., 2010) that go into building and maintaining algorithmic fall-detection systems. This includes the work of technology designers, care staff and older adults, as they all perform care-ful practices of ‘persistent tinkering in a world full of complex ambivalence and shifting tensions’ (Mol et al., 2011, p. 74). This turns our focus on the practices through which data is collected, manipulated and tinkered with. That might be the ‘number crunching’ (Ariztía, 2018, p. 209) to render

datasets useable, the practices ‘of organizing algorithms’ (Neyland, 2015, p. 123) in a way that works for all actors involved, or the activities of ‘people debating the models, cleaning the training data, designing the algorithms, tuning the parameters, deciding on which algorithms to depend on in which context’ (Gillespie, 2016, p. 22).

Such a perspective on care-ful datafication also helps us to reveal that care work around algorithmic systems is not only done in technology development companies, but also by care staff and older adults in LTC facilities who have to make systems work in practice. Puig de la Bellacasa highlights that ‘to engage properly with the becoming of a thing, we need to count all the concerns allocated to it, all those who care for it’ (Puig de La Bellacasa, 2011, p. 90), which might include technology designers, care staff who work in LTC facilities and older adults who live with algorithmic systems in their rooms. We hence move away from a fixed understanding of care givers and older adults that are being cared for, instead reflect on the tensions around how older adults are being considered as a vulnerable group who is in need for care, and examine possible shifts in caring relationships that happen as older adults move from being the ones that are being cared for to being the ones that are forming caring relationships with algorithmic systems in LTC.

Finally, such a focus on datafication as a matter of care highlights the affective and normative nature of care or – as Mol (2021) describes it – the shared visions and understandings of ‘what figures locally as *good*’ (Mol, 2021, p. 64) that structure caring practices. For here, caring practices are those practices that share a notion of ‘*good*’ at their horizon (Heuts & Mol, 2013), which highlights the ethical and affective nature of care practices. This allows to study datafication as practices of collection, manipulation and tinkering with data, but also draws the attention to the affective disposition of these practices (Zakharova & Jarke, 2022).

In the following empirical analysis, we understand care as practices that different actors engage in with the intention to make things fit with a local and situated understanding of ‘good’ (Mol, 2021). This allows us to ask what kind of normative futures are being enacted with datafication practices, with what notion of ‘good’ and for whom such future(s) might be desirable and for whom not. In particular in the setting of LTC, focusing on what ‘good’ elder care is being envisioned by the actors involved in the practice of datafication helps to reveal how professional care work has to function in these new, algorithmically mediated settings,, as well as what ‘good’ data has to be like, to be valuable for the algorithmic system and how technicians care about data of older adults.

Materials and methods

The case of algorithmic fall detection in LTC

This paper draws upon research conducted in a multiple-perspective qualitative interview study (Vogl et al., 2018) in a LTC facility in Austria that uses algorithmic fall-detection sensors to detect and alarm care staff about falls that happen to older adults living there. Used as remote monitoring systems, algorithmic fall-detection software is one of the biggest areas of development in the field of algorithmic and automated-decision-making systems for older adults (O’Connor, 2022).

In our case, the algorithmic system was practically used as a fall detection and prevention system. It aimed at detecting if a resident falls or is at risk of falling and alerts a care

giver in these situations. For this purpose, a physical monitoring device was installed in the residents' rooms, using 3D sensors to collect depth data of the room. Based on this 3D depth data, objects, persons and movements in the room could be identified by means of deep learning models. Besides identifying falls after they have happened, the algorithmic system was also advertised as a fall-prevention system, with the ability to identify (pre-determined) risk factors of falling, which would then also alert a care giver, allowing them to take actions to prevent a fall. For this, care staff and care home management could activate different functions of the fall detection system:

- 'raiseup: This is the earliest alert type. The system alerts as soon as the person raises in bed. Keep in mind that in this setting a restless person will trigger a lot of alerts.
- situp: This alert type is identical to sitting sideways on the bed.
- standup: Here our system alerts if the person gets out of bed' (Fall Detection System Manual, p. 6).

Additionally, an absence detection setting allowed to alert care staff after an older resident has been absent from the field of vision of the system for a certain amount of time. Care staff regularly received notifications of these different alarms on their local call system, while older residents had no possibility to actively engage with the sensor.

The algorithmic system under question ran on 3D depth data, gathered through sensors and, from the developer's point of view, had several advantages compared to other forms of data: 3D depth data was seen as superior to other visual data, such as video data, because the quality of the depth data was less affected by lighting conditions, and thus could be used more easily at night. In addition, the developers saw the advantage of 3D data in enabling better privacy protection for older care home residents. Abstract depth data has the advantage that the immediate identification of the person is not possible. Nevertheless, in practice, identification was very well possible (as developers also noted), because identifiable features were visible (e.g., furniture) and these systems were only installed in a small number of residents' rooms, allowing for a clear identification by care staff.

Data collection & analysis

The empirical work for this study was set in a LTC facility in Austria. The facility hosts around 150 older adults in need of differing levels of care, both for long-term and short-term care. The care provider company that runs this facility had purchased several fall-detection systems, 51 of them were running in the care facility under question.

Fieldwork was conducted between July – October 2022, and included 18 interviews with diverse actors that were relevant in this case (technology developers, LTC staff, LTC residents and interest groups which advocated for the rights of older adults living in LTC) (see Table 1).

Table 1. Overview of the collected data.

Number of interviews (developers/care personnel & management staff/older residents/interest group)	18 (4/7/5/2)
Participant observations (hours)	24
Participatory workshop (hours)	5

The inclusion of the LTC residents' relatives as interview partners was considered, however as the access to the LTC already proved challenging, recruiting relatives of LTC residents for interviews was even more difficult and thus was abandoned. As their view on the use of an algorithmic system as a care-technology for their relatives would have been useful, certainly regarding the tensions enacted through care-ful datafication, their non-inclusion is a limitation of our approach.

The research team also held one participatory workshop with an informatics researcher who worked in collaboration with the fall detection system company to get an insight into how the algorithm functions, and how data to train the algorithmic models is produced and collected. Two researchers also conducted about 24 h of participant observation in the care facility. All interviews were transcribed in German verbatim. Field notes were taken in German. Data collection was inspired by a multiple-perspective qualitative interview design (Vogl et al., 2018), aiming to understand the relational dynamics of diverse actors in complex relational systems, and the different perceptions of people involved.

Data analysis was conducted using situation analysis (Clarke et al., 2015), a qualitative analysis method based in grounded theory. The aim was to identify relevant actors and their relationships in the situations that were encountered during data collection. Particularly, we asked which practices and (human and non-human) actors shape the engagements with algorithmic fall-detection software in LTC facilities and what the relationships between these actors were. For the purposes of this paper, we focused our analysis on caring relationships that different actors formed in these situations, and shared understanding of 'good' that were found in the material. Interviews and observation protocols were openly coded using MAXQDA2022, after which four researchers produced situational maps, detailing the codes from interviews of (a) LTC staff, (b) residents, (c) interest group, (d) software designers in group sessions. In a final step, we produced positional maps for which all interviews were analyzed together.

Ethics

Before starting the data collection, an ethical assessment was done by the PIs and the ethical evaluation committee of the Technical University of Vienna. Data collection included setting up information sheets and consent sheets for the participants of the interviews. The process of data collection at the LTC facility was discussed twice with management of the facility and all the measures for responsible research were explained to the management and all the participants, such as written informed consent, granting anonymity or the right to retract their consent during or after the interview. One interview with an older adult was omitted from the collection and analysis, as their consent was ambiguous throughout the interview.

Results

The results highlight three different sets of care-ful data practices in building, maintaining, and using the database necessary to implement the algorithmic fall detection system in the setting of LTC:

- *Practices of caring for data* detailed developers' views on creating a 'good' dataset, which became visible through their views on which data is available, which data is needed, and which data should be synthetically created to build a valuable algorithmic fall-detection system for LTC
- *Practices of caring with data* highlighted the tensions care staff perceived as they (re-)organized their everyday work in order to align their understandings of 'good care' with the care practices that were represented in data infrastructures.
- *Practices of being cared for with data* showed how older residents formed caring relationships with algorithmic fall detection systems, but also how these remained largely unnoticed by others, as older adults were largely considered as actors in need of care, rather than those who were actively caring for technology

Caring for data

The first set of practices we encountered concerned the ways in which technology designers tried to build a pool of valuable and reliable 'ground-truth' data that establishes the baseline for the development of the fall detection algorithm. In line with Jatón (2021), we considered ground-truth as 'an artifact that typically takes the shape of a digital database' (ibid., p. 294). Ground truths are the foundation and operationalization of a problem in the dataset which ought to be solved by the algorithmic system. When machine learning systems are being trained in their functions – e.g., fall detection – the ground truth dataset is divided in two: a training and an evaluation set. The training set will be used for the algorithm to be trained to detect falls, whereas the second dataset then is used to validate whether the algorithm is capable of automatically detecting falls within this new data. In our present case, this ground truth consisted of 3D data on short segments of people falling.

Building such a ground truth dataset is often a lengthy and tedious process, which includes designing the statistical model and labeling data. In our case, establishing a ground truth meant gathering 3D data about older adults falling – an endeavor that was seen as difficult by designers. Ground truth data had to be collected meticulously by the company and its associated software designers through a variety of ways, which all came with some limitations and required processes of tinkering and adjusting by the designers (Software developer INT 16).

The main concern that guided the practices of ground-truthing was the vision of a 'good' dataset, which included exhaustive data of the real world in order to train the fall detection algorithm properly. In a first instance, a 'good' dataset was considered as including plentiful and readily available data, as '*training always depends on how much data is available*' (Software Developer INT 15), which meant that the developers tend to care about different approaches and practices of collecting data. This, however, was seen as a challenge in LTC settings as developers explained that access to LTC institutions is usually restricted.

Furthermore, developers considered that 'good' data also consisted of varied data, as they often felt that there was so much 'reality' that needed to be covered by training data. The developers and designers of the system hence were constantly concerned about how to collect the necessary features and scenarios in the form of 3D data, for the algorithm to train on:

[T]hat's (...) basically (...) the general problem that you just have to use your training data/ or that's just the weakness with AI: You need massive data sets. (...) You have to show it [note: the AI] almost every scenario and (...) then the problem is often that we want to cover too much. (Software Developer INT 15)

However, it was not only the amount and variety of data developers cared about, but it was also necessary to include the context in which the algorithmic system was to operate, to obtain a 'good' dataset. While the ground-truth consists mainly of 3D data of bodily movements, software developers also shared that this data had to be contextualized to work well in an LTC setting. This knowledge about the particular '*setting*' (Software Developer INT 15) was gained through an active engagement with people in LTC and considered to be important for all interviewed designers. However, this was rarely done by software developers themselves. Instead, software developers mainly had to rely on information from sales representatives, visiting (potential) customers on site for sales talks. During these talks, the sales representatives tried to gain an understanding of the site and the problems the care personnel were confronted with in their day-to-day work. These descriptions were rarely straightforward and required conversational skills to gather this information:

I don't have any contact with the customers myself, but our employees who are on site say that the problem descriptions don't come directly from them [Note: the LTC staff], you have to tickle that out of them. It's more like, they try to get them involved in a conversation and ask them what their daily work routine is like and then maybe come up with suggestions as to what would benefit them. (Software developer INT 17).

Despite all these efforts, the ground-truthing presented by the developers was largely characterized by the absence of data on older adults and falls occurring in LTC settings, and thus required careful consideration of practices of dealing with the absence of data. One of these practices was to establish – temporary – relations with care staff in LTC, who were imagined as being competent experts on LTC settings and who were regularly '*tinkled*' (ibid.) to share information about their daily care routines. Older adults in LTC facilities, however, were hardly imagined as domain experts and thus also not asked about feedback.

Synthesizing data

One central element of the developers' practices of caring for data was thus finding ways to deal with the absence of and the restricted access to data and hence, creating a 'good' dataset for the algorithm to be trained on. Besides the close engagement with 'field experts', providing proxy information about older adults, another strategy was the creation of synthetic datasets. Developers described how they increasingly had to turn to synthesizing training data for their AI models, as this was seen as an easier and cheaper way to gather data.

Data for their ground truth was synthetically created in 3D modeling programs such as AutoCAD, using motion capture technology to capture the necessary data. The synthesizing of data also revealed how the developers further cared for 'good' data and thus were again and again concerned about how to improve their ground truth. For example, one of the developers described wearing a motion capture suit to create data, carefully simulating different poses to try and record the relevant body postures and

movements. The recorded movements could then be transferred to a wide range of different bodies with related movements, all being simulated through the initial data.

These practices of synthetic data development were mainly pursued because older adults living in LTC facilities were being perceived as a hard-to-reach target group and LTC settings in general were – much like hospitals – seen as difficult to get into:

Anyway, everything is overcrowded and also the access is mostly restricted (...) and yes, that's why it's important (...) and that's what we're working on right now, that we create the data synthetically. So, the ground truth, (...) is being produced with synthetic simulations. (...) Because the effort of generating real datasets is always difficult, and with a simulation like this, you can virtually create the scenarios that you want, and you don't have to wait a year or a day until someone falls. (Software developer, INT 15)

Establishing a 'good' dataset purely by using real data is – at least in the circumstances on LTC settings – quite challenging. Which is why the developers have to adapt their practice and change to creating a simulated dataset that matches their standards of 'good' datasets. The simulation of data, as described in the quote above, has the advantage of conjuring scenarios that are deemed necessary by the developers, besides being more convenient to collect and requiring less resources. The care for a 'good' dataset thus leads to alternative practices and creative workarounds to deal with the difficulties the developers encounter to create a dataset that is exhaustive, varied and includes not only bodily movements but also can be used within the context of LTC.

Caring with data

The main concern in the developers care for the system was building good and valuable datasets to train the algorithmic system. LTC staff however, had a different perspective on the data infrastructures that are core to the fall detection systems, largely dealing with the fact that data was mainly de-contextualized from the everyday practices of older adults. This led to divergent 'realities' on the occurrence of a fall, perceived between the care staff and the algorithmic system. LTC staff would report on several cases of 'false alarms' (Care staff, INT 12) and describe instances (Care staff, INT 13, Night shift observation protocol, PROT 1) where the algorithmic fall detection system would 'perceive' a fall and thus trigger an alarm, even though no resident had fallen, or was at acute risk of falling down.

I don't even know if residents really consciously notice this, but when false alarms occur, you have to go into the room about a hundred times say 'you need something now or what? Have you fallen? Are you lying on the floor?' and then there's nothing. (Care staff, INT 8)

I also heard from my colleague, (...) that the alarm went off 15 times on the ground floor, but the resident was upstairs or something. (Care staff, INT 13)

Consequently, LTC staff had to adjust their ideas of 'good care' and re-arrange their caring practices in a way that would make them 'fit' with the data that was used to run the algorithmic system – with the aim of avoiding false alarms. Good care, in combination with the algorithmic system was hence achieved when a false alarm was being avoided.

Care staff described multiple strategies of how to actively deal with these fall alarms, re-arranging their everyday caring practices to keep the probability of triggering a false alarm as low as possible. In these practices of 'caring with data', it was described as a major challenge that the fall detection algorithm, its automated decisions and database

used to train this algorithm were not transparent. Care staff had to guess which behavior would trigger a false alarm, and which behavior would not run the risk of being identified as a fall, thus moving ‘*in a particular way*’ (Care staff, INT 13), hoping that this would not sound an alarm:

Yes, the rooms where it doesn’t really work, I know them by now. And then it depends on how sensitive the settings are and then I know (...) if that’s the case, then I just have to move in a particular way. It’s just ... really stupid. You move a little differently. (Care staff, INT 13)

In some cases, this also included changing the way care staff would approach older residents – as being too close to them, or to the floor around them was seen as a situation that would probably trigger a false alarm:

Did you see that I talked to her standing in front of her bed? Once, I didn’t talk to her standing, but kneeled down right beside her bed. Because I wanted to talk more intimately. But I was too close to the floor and the alarm went off. (Night shift observation protocol PROT 1)

In this example, conflicting notions of ‘good’ care that structured the everyday routines of care staff become visible: On the one hand, being physically close to older care home residents was perceived as ‘good’ care, while on the other hand, avoiding false alarms was also seen as a valuable goal that would structure care practices. These conflicting notions of ‘good care’ called for a constant re-negotiating and re-arrangements of care practices that were described as both exhausting and time-consuming by the care staff (Care staff, INT 13, INT 16).

Being cared for with data

Lastly, our analysis revealed a third tension that was negotiated in care practices connected to the algorithmic fall detection system: While older adults were largely positioned as being the ones who were being cared for, interviews revealed that they formed their own active caring relationships with the system. However, these active and valuable engagements remained largely invisible to both care staff and software developers, mainly through stereotypes that positioned older adults as too frail or vulnerable to engage actively with the system.

Asking both LTC staff and technology designers about how they think older care home residents perceive the algorithmic system, they largely considered residents as uninterested, or even unable to comprehend the specificities of the algorithm fall detection system. Some reported that: ‘*I don’t think they know about it (...) I don’t think they even realize this thing is there.*’ (Care staff, INT 4). Others argue that this changes with the course of time:

‘Interviewer: Do residents care about this system?’

Interviewee: In the beginning: Yes! Because it is new. (...) because we inform them of course. We say: ‘This is (name of the sensor) and this is there, if you fall, then it alerts and then we can come to you faster.’ Some are happy about it, some are not. (...) Yes, it varies and most of the time they forget about it, because it’s only a small sensor and you forget about it over time.’ (Care staff, INT 13)

The care home residents, however, depicted a different perspective on the algorithmic fall detection system in their rooms. They showed their own practices of caring about the sensor installed in their rooms, and the underlying database, as some residents explained how they would often wonder when an alarm would be set off, or try to understand why

an alarm has happened in a particular situation. These engagements were often characterized by the residents ongoing reflection about how they should or should not move in order not to sound a false alarm:

Well, it shows when you fall. Then it flashes like crazy. Sometimes I sit watching TV and they come running like ‘Mrs. XX, has something happened?’ I say no, I’m sitting there watching TV. ‘Well, he reported a fall again.’ But of course, it is a security thing. It’s just that it shows when there’s nothing wrong. (LTC residents, INT 11)

Caring about the system, however, was not easy. Residents stated that they hardly received information about the system, why (and for how long) it was being used, or when an alarm would be set off. Partly, this was due to the fact that some systems were installed when the residents were not in the room: ‘*It was just here when I got here*’ (LTC residents, INT 10), one resident explained. Also, as the sensors were designed in a way that did not indicate if an alarm was set off or not, residents were often left wondering if they had done something that would set an alarm off or not. One resident explained how she sometimes thinks about throwing a ball at the sensor, with the hopes of receiving feedback on how the algorithm works:

You know, in the beginning, I always looked at it, but now, I don’t look at it and don’t really mind it anymore. In the beginning, you always look at it like ‘is it going off now? When does it go off?’ But it never does. And now, I don’t mind it anymore, it never went off and I think it never will (...) ‘Maybe, I should throw a ball at it or something (laughs)?’ (LTC residents, INT 6)

The interviews reveal a somewhat paradox situation where the individuals whose data is at the heart of the development and implementation of the algorithmic system, are at the same time restricted in accessing, or even understanding the system running on their data. This shows an obvious boundary that is established by the system, with a clear cut between actors who were actively addressed as (active) care-takers of a technology – technology developers and (partially) care staff – and those who were being largely positioned as (passive) objects to be cared for through a system – older LTC residents.

Discussion

In this article, we critically engage with the situated, shared and routine data practices that accompany the introduction of AI in contexts of ageing. Exploring the datafication of ageing as a matter of care, we shine light on the manifold care practices of ‘local tinkering’ (Mol, 2008) that involves software designers, care staff and older care home residents and ask how this datafication of ageing is practically achieved through care relationships between these actors.

The results of our analysis reveal how the development of AI for older adults is largely characterized by *absent data* on these populations and its consequences for the development, introduction and domestication of these technologies. Because LTC institutions are perceived as difficult to access, and older, frail adults as too difficult to gather data from, software designers turn to domain experts or synthetically created data to inform their dataset for the development of AI. Both of these practices further de-contextualize data in the database from the lived realities of older adults in LTC institutions.

This decontextualization of data then requires *re-contextualization*. In our example, both care staff and older care home residents ensure that the system functions smoothly,

adapting their behavior in a way that protects the system from making false decisions. This re-contextualization of data requires making existing care arrangements ‘fit’ with the databases that is being used to monitor activities in these care arrangements, and also highlights how notions of ‘good care’ shift from establishing close relationships between humans toward avoiding false alarms and supporting the collection of valuable data through the sensor system.

The results further highlight an ambivalent position of older adults in this data assemblage, as their caring practices are largely made invisible by different actors, particularly through ageist stereotypes that positions them as being too vulnerable, frail or incompetent to understand and engage with the sensor system. This leads to a paradoxical situation for older adults in the actor-network: While their bodily behavior is at the heart of the databases, their perspective, experiences and caring relationships with the system in operation remain largely invisible. They have little to no opportunity to actively engage with the system and the data practices related to it.

The data gaze of AI systems hence renders old age both hyper-visible and invisible. This relates to work that has situated hypervisibility in the context of mechanisms of surveillance and control that regulate behaviors of older adults, particularly those constructed as marginalized (Kia, 2016). In this case too, it is valuable to ask which aspects of ageing are ‘rendered ‘hypervisible’ to neoliberal systems of panopticism and regulation that govern them’ (Kia, 2016, p. 51) and which ones remain invisible in social practices? In our empirical case, it is the older body and its quantifiable movements, that become visible and governed, while the experiences and subjectivities of older adults, are largely made invisible in the examined assemblage.

The results of this study further inform research on the datafication of ageing, questioning the role of datafication practices in the political economy of ageing (Estes, 2014). Data about older adults’ behavior is largely absent and unavailable for the development of databases for algorithmic systems. However, this absence does not result in more efforts to include older adults in datasets for the technologies that are developed for them, but lead to the development of synthetic data, that is seen as easier accessible and economically more viable. The absence and misrepresentation of older adults in datasets for AI is exploited for economic profit, rather than used as an opportunity to strengthen inclusion.

Lastly, with this contribution we aim to pave the way for more empirical studies that investigate AI in the lives of older adults, providing evidence of how older adults live with, care for, make sense of or try to gain ownership of these systems. Most importantly, this includes going beyond viewing older adults as invisible data pools or passive end-users of AI and instead, focus on the shared care practices that involve older adults and innovative technologies.

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No potential conflict of interest was reported by the author(s).

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