



# Care Stories: Understanding People's Hopes and Fears for Technologies of Care through Story Elicitation

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## ABSTRACT

For a long-time HCI discourse has viewed ageing and elderly care through a medicalised lens in which care is broken down into distinct problems, such as activities of daily living and addressing accessibility problems. Increasingly, this approach is criticised within the HCI community. Adding to this critique, we asked non-experts to imagine the life of Lor, a 189 year old woman who needs support in her daily life, through an adapted story elicitation method. The resulting stories present care as a network which is set against a backdrop of societal changes and environmental factors, such as climate change. In this paper, we distil the rich worlds developed in these stories into reflective questions to support designers to “stay with the trouble” of caregiving and reflect on their own work as well as creating novel grounds for the engagement with care technologies.

## CCS CONCEPTS

• Human-centered computing; • Human computer interaction (HCI); • Empirical studies in HCI;

## KEYWORDS

story elicitation, ageing, care giving, speculation, fiction

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## 1 INTRODUCTION

Currently, many technologies are developed to support elderly care. This includes a wide range of artefacts such as technologies that support ‘ageing in place’, i.e. people living on their own or with informal caregivers such as family and friends as well as tools that support professional caregivers in care homes or medical institutions in their care work. Elderly care is rarely defined, but instead broken down into different “activities of daily living” (ADL) [41], e.g. support with eating, bathing or mobility. This “care fragmentation” [42] is problematic as it does not address the complexities of daily life. The way care and ageing are framed in HCI has further

been recently criticised as it often addresses accessibility issues or age-related illnesses and therefore views ageing as problematic and medicalised [21, 33, 44]. While design for elderly care has long been informed through professional caregivers or informal caregivers, such as family or loved ones [21], increasingly, elderly people are involved in the process, e.g. through co-design methods [24, 33, 43]. While this might help to overcome the “othering” [19] of elderly people, the overall fragmentation of care is in many instances carried through.

To overcome these limitations, we turned to non-experts to draw up visions of care-giving. Developing a cloze text and story stem, we extended story elicitation method (e.g. [14]) to support people to write short near future fictions about care. We pose the question: **What can technology design learn from narratives about care giving in elderly care?** to overcome the fragmented and medicalised view on care giving.

## 2 BACKGROUND

As Martin, Myers and Viseu [28] note, care is hard to grasp and “any attempt to define it will be exceeded by its multivocality in everyday and scholarly use”. In this paper we address elderly care specifically and the way it is framed in HCI research, where increasingly, technological interventions are suggested to support caregiving. While care is rarely explicitly defined in HCI as well, it is often broken down or fragmented [42] into specific problem fields that can be addressed through technology design. Righi et al [33] critique that current technologies often address ADLs, which are defined as: “life-sustaining self-care activities such as feeding, grooming, bathing, dressing, toileting, and ambulation” [41]. This might be placed in care homes to support caregivers in their tasks or in the home, specifically to support “ageing in place” (for a critique see e.g. [12, 25, 44]). Framing users as elderly or talking through the lens of compassion [34], further has the danger to “other” [21] elderly people. Technologies developed in this way are often rejected by elderly people, especially when they are reframed as “not for me” [31, 33], but instead for people who are older, frailer or less healthy. A body of literature starts to emerge that critiques this approach by opening up the discussion of how HCI as a field frames and addresses ageing and design for health [21, 33, 44]. Here we add to this critique by turning to creative methods as well as future speculation to disrupt the fragmentation of care.

Future visions in many shapes and forms have been developed to explore how we might interact with these technological changes, which enables one to explore potential changes before these technologies even exist [39]. Many companies have presented visions, such as the “Health Future Vision” [29] by Microsoft, which focusses on the technological advances and their implementation, mainly presented in a Westernised, idealised and affluent world. These



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visions to a large degree affirm the “*status quo*” (see also [13]) and present a world in which technological advancements happens without taking societal changes, such as climate change into account. Others have tried to develop more critical views of the future to stimulate debate. One well-known example is the “*Uninvited Guests*” video by Superflux [46], which explores how people might resist nudging technologies. Compared to most vision videos, it deploys more elements of storytelling, such as a main character that leads through the whole story. While the example is also episodic like many of the vision videos, it is further structured around a specific place and time frame, i.e. a day, instead of giving fragmented visions of different aspects of life. Problematising the relationship between care and robots, the first author [36] was involved in a fictional review of future robots with the aim to stimulate a discussion of what elements of care are personified in the robots we build – and potentially could build. All these methods share that they turn to world-building as a means to suspend disbelief that these technologies could potentially exist (see also [11, 13]).

HCI is increasingly deploying methods of world-building and (near)future speculation. One prominent example is design fiction which focusses “*not just on product functionality but potential social consequences of use*” [5]. As many technologies for care are currently in development, but not yet widely distributed, this method offers useful insight to explore this field as a whole. Design fiction has been applied to the topic of care for example by [35, 36]. Design fiction can be used for ideation, but has also been used as a tool to stimulate discussion (e.g. [9, 27]). This approach is mainly undertaken by domain experts or designers who generate the artefacts (stories) for examination, but participatory design fiction is starting to emerge and has been undertaken with elderly people or in the context of (health) care (see e.g. [24, 30, 43]).

In the study presented here, we turn to story elicitation as a method to generate near future fictions with a similar aim. Story elicitation or story completion is a method from social science research, which has also made its way into HCI research (e.g. [6, 40, 45]). While it lacks the design element of design fiction as it is not essential for an artefact to be (conceptually) designed, it offers an opportunity to explore how people draw on imaginaries and their experiences to develop future visions of care. In contrast to participatory design fiction, it offered the opportunity for participant anonymity as well as a method to allow participants to write a story – available through an online survey – in their own time and place. This method is often applied to sensitive topics [7, 45]. Taking on a fictional persona through which the story can be told, allows many participants to be frank and open. While care giving might not be as sensitive as some of the topics previously explored through this method, it is an area which touches on people’s fears about frailty and the need for support, potential conflict and potentially illness and death, which we expected to be topics that could be more easily explored through stories.

For this study, we deliberately wanted to go beyond domain experts, e.g. caregivers or those developing technologies for care, to learn which imaginaries exist outside of the technology domain. Going beyond what is currently technically feasible, we wanted to give a platform to peoples’ fears and wishes. As we placed the stories in the (near)future, we also did not deliberately seek out people in need of care now, but invited people of all ages to imagine a future.

In the following we describe how we adapted the method in depth, before presenting the findings of the study.

## 3 OUR METHOD

### 3.1 Study Design

We developed an online exercise, taking inspiration from the story elicitation method (see e.g. [7]) We chose the format of an online survey as it allowed us to widen the reach of participants as the story could easily be advertised online. In addition, it allowed participants time and anonymity to express their wishes and fears freely as well as experiment with the writing process if it was new to them. The story was open to everyone above the age of 18 years old, available in both German or English.

### 3.2 Participants

Previous studies using story completion or story elicitation as a method have applied various strategies of recruiting participants matching their aims. This can include recruiting participants with a specific interest or experience in a topic, such as education [14] or participants with experience in writing [45]. We instead wanted to recruit people outside of these domains but rather members of the general public (see also [6]). To do so, we deployed convenience and snowball sampling, starting with the social network of the research team, both online and offline. Participants were self-selecting and filled in the survey in their own time. Table 1 gives an overview of the participants’ demographics when given. Stories marked by an \* were submitted in German and translated manually by the first author who is fluent in both languages. Only one participant identified as author. Nonetheless, 14 specified that they write professionally. A further three specified that they only write frequently, while two more picked that they rarely have the time to write. We did not ask for people’s nationality and/or location, but the calls were mostly distributed throughout Europe and the UK, which might have influenced how participants conceptualised care.

The study was based at an organisation without Ethics Committee, but the researchers ensured that guidelines, such as informed consent, minimisation of risk to the participants and anonymity were adhered to by discussing possible harms and benefits within the research team.

### 3.3 Materials

Story elicitation method or story completion is mostly executed by presenting a “story stem” (see e.g. [7]) to the participants, which they can complete in their own words and their own time. The story stem is a prompt that sets the scene and introduces the topic the researchers want to learn about. These prompts can be as short as a few words, as for example shown in [7]: “*David has decided to start removing his body hair . . .*”, while others are presented as short scenarios which the example from [45] illustrates: “*Jack starts up his new virtual reality headset and positions it carefully over his head. He isn’t quite sure what to expect. He’s about to have his very first virtual reality porn experience. . .*”. For this study we adapted this method slightly as we wanted to give participants who might be unexperienced in writing some guidance, especially supporting them with the world-building. We therefore led them through the exercise. We first introduced the central character Lor and the

**Table 1: Demographics of the story authors**

#	Age	Gender	Occupation	Living Situation
S1	50	male	Employee / University	Family
S2		female	Employee / Higher Education	Alone
S3	39	female	Employee / Lecturer	Partner
S4	62	female	Employee / Education	Partner
S5	31	female	Employee / Lecturer	Other. Living with husband and children
S6	45	female	Employee / Care Studies	Family
S7	27	female	Employee / Research	Partner
S8*	35	female	Employee / Uni	Family
S9	25	male	Employee / IT	Partner
S10	34	non binary	Employee / Information Technology	Other: cooperative housing
S11	50	female	Employee / Nursing research	Family
S12*	49	male	Self-employed / IT	Alone
S13*	–	–	–	–
S14*	61	female	Other	Partner
S15*	47	female	Self-employed / Author and coach	Partner
S16*	67	female	retired	Partner
S17	36	Prefer not to say	Employee / Dentistry	Partner
S18	–	–	–	–
S19	30	female	Employee / Researcher (Postdoc)	Partner
S20	58	male	Other	Partner
S21*	–	–	–	–
S22	24	female	Apprentice / PhD in the field of HCI	Partner
SX	–	–	–	–

Get to know the protagonist of your story: Lor. Lor recently celebrated her 189. birthday. Yes, you read that right. Some years have passed and medicine and society have moved on, so that this age feels very normal right now. All in all Lor feels well, but there are things she cannot do on her own anymore. She needs a bit of help to manage her everyday.

Imagine the situation: Where is Lor? How does she get help in her everyday? What are her goals and wishes?

Fill in the gaps of the story below and invent Lor's world. The story is fictional. You do not have to stick to what is technically possible, morally acceptable or lawful today. Let your imagination run free.

Lor wakes us. She yawns and stretches before she opens her eyes and looks around. Her  looks the same as always. She takes stock. Overall she is fine, but she is a bit relieved that  helps her. Lor is happy that today . She smiles and  helps her to get up.

**Figure 1: Screenshot of the first page of the survey in which participants were introduced to the main character and could start filling in their first ideas as to what shape caregiving might take.**

aspect of caregiving (Figure 1), before guiding people to consider the wider world through which Lor could move (Figure 2). The text asked people to imagine in what situation Lor lived, who she spent time with, what she enjoyed doing and further information, such as her favourite meal. The full text can be found in the figures below, which are screenshots of how the prompts were presented to the participants. In a last step we presented the story stem and the idea of an extraordinary day (Figure 3). The first two steps extend the original method. The last step introduces the story stem, which prompts a story in a world the participants had already explored.

After some demographic questions, e.g. on work background and writing experience, a series of questions, which invited participants to reflect on their story and their motivations for it, concluded the questionnaire. The survey was delivered online using the tool [soscisurvey.de](https://www.soscisurvey.de).

### 3.4 Procedure

Participants could select the language of the survey, either German or English – both of which the research teams speaks fluently. After information sheet and consent form, participants were guided

**Now that we have a first impression of how Lor lives, how she gets help and what she likes, imagine a day in the life of Lor. Fill in the gaps and imagine a typical day of Lor.**

After she gets up and finished her morning rituals, she begins her day as always with a . Later she meets with . She takes a  to get to . She treats herself to her favourite food . Afterwards it goes back into her . She goes to bed as always  and is happy about a successful day.

**Figure 2: Screen shot of the second page of the survey in which participants were asked to imagine a wider range of the world in which Lor lives.**

**Now it is time to tell Lor's story. After we know now what happens on a normal day, imagine an extraordinary day. Lor gets up, prepares to start the day, when suddenly...?**

Use the text box to tell a story form Lor's life. The story is fictional. You do not have to stick to what is technically feasible, morally acceptable or lawful today.

**Figure 3: A screenshot of the last part of the survey in which we asked participants to fill in a free form text box to tell an extraordinary day in the life of Lor.**

through the cloze text, before they were prompted to write a story. Participants were reminded that they “*do not have to stick to what is technically feasible, morally acceptable or lawful today*”. In the end they were asked to provide demographical data, as well as given the opportunity to provide background on their story and their writing motivation before they were thanked for their contribution. After 59 days, data was downloaded for analysis.

From the original 25 submissions, we excluded 2 as they did not give sufficient data for analysis. From the remaining 23, 6 (S6,9,13 and 21) did complete the cloze text, but did not write a story, but we included this data into the analysis as it gave a good idea of how care was perceived on a normal day. One participants (SX) provided less data as they did not complete the cloze test fully, but we decided to include the data in the in the analysis as it was extensive before it broke off. The analysis was done iteratively, through bottom up coding, adapted from thematic analysis [8], which is a common approach to analysing stories generated this way [7]. After translating the German entries to English, the three members of the research team familiarised themselves with the stories individually after discussing first impressions during one in-person meetup. This session was used to note things that were unclear to the researchers, highlight items that stood out individually and collectively group stories to find initial relations between them. Second, the first author started coding the results from the cloze texts and the stories individually. First, they explored the similarities and discrepancies in the cloze texts to understand how Lor was perceived and what aspects were common to each world. Using open coding, they coded aspects that represented Lor's needs and

wishes, the role technologies played in the world and how care was understood. While the format of the story has its benefits as we outline below, we did not evaluate whether the submissions would formally count as stories (see e.g. [3]). We focussed on the content and the discourses that were evoked more than formal aspects of storytelling. In a second step the first author applied the codes generated to the stories to learn to what extent they confirmed, contradicted or extended the codes. After this individual work, in three online meetings between the research team, the applied codes were discussed and ambiguous interpretations clarified. Third, the first author derived themes by synthesizing the discussions and through initial memo writing. The three themes we derived are presented below and form the basis for the reflective questions we derived, which are highlighted in bold.

## 4 FINDINGS

### 4.1 The Stories

Overall, 23 participants filled in the cloze text and of those 17 submitted stories of which 7 were in German (indicated by \*) and translated for the analysis by the first author, while the remaining 10 were submitted in English. The stories varied widely in length, with the shortest story counting 98 words and the longest story counting 420 words. The average length of a story was 205 words. First, we give a summary of each typical days (the text provided in the cloze text) and of the extraordinary days (the freeform stories), based on our own understanding of the story (see table 2 for an overview).

**Table 2: A summary of each submission, developed by us**

#	Description of a typical day /cloze text	Extraordinary day / freeform	Word count
S1	Lor and her friend enjoy a day together going to the cinema.	Lor and her friend Susie have an exciting day at the old university.	166
S2	Lor enjoys a slow morning before meeting her friend Lis.	Lor is needed by the Unit Manager of the complex where she lives.	252
S3	Lor receives a delivery before meeting friends and family.	Lor's cat has a disease, but has infected no one.	98
S4	Lor spends a day in her community housing, with friends and the garden.	Lor has pain over night, but is helped by the nurse and supportive technology.	408
S5	Lor spends the morning with her daughter before heading into town with a friend.	Lor is reminded of her old glories when a plumber comes to visit.	256
S6	Lor takes a walk with her exoskeleton before visiting Thailand.	–	–
S7	Lor spends a day on her own with her dogs.	Lor has to decide if she wants to live forever.	114
S8*	Lor goes to a restaurant with a friend.	Lor's insurance has run out and her family has to make a decision about her life.	115
S9	Lor spends a day surrounded by her roommates and her friends.	–	–
S10	Lor spends a day surrounded by plants.	Lor is asked to take on a job of a creative technique called "leaf blowing", which she has to do rapidly.	166
S11	Lor spends a day surrounded by people and technology.	Lor feels weak and is supported by her droid Orag.	182
S12*	Lor exercises before meeting her friends.	Lor gives advice to her neighbour's daughter Johanna.	352
S13*	Lor is met by her lover.		
S14*	Lor spends a day with a friend in a climate friendly manner.	Lor is not recognised by the technology controlling her life and visits a friend to get help.	352
S15*	Lor spends a day at the communal living project with a large garden.	Lor is not recognised by the technology controlling her life but gets support from a human network around her.	125
S16*	Lor exercises before meeting her sister in town.	Lor's robot Robbie has a malfunction, so Lor spends a day outside with friends until the technology has repaired itself.	155
S17	Lor spends a day her mobile apartment with other travellers.	Lor travels the country in her mobile apartment, collecting stories	108
S18	Lor spends her birthday with Pol and Eng.	–	–
S19	Lor spends a day surrounded by avatars her mind generates.	Lor feels she is only mind, while her son is dissatisfied with the treatment she receives at the hospital.	420
S20	Lor steps out of her liquid to spend a day with her family.	Lor is in engulfed in the liquid that normally maintains her and has no one to turn to.	165
S21*	Lor spends a day surrounded by people in a virtual environment.	–	–
S22	Lor spends a day with her fiend Nikki surrounded by technology.	Lor finds that her friend Nikki presumably attempts suicide and sends help.	265
SX	Lor spends a day surrounded by family.	–	–

The survey further included questions on the motivation behind the stories. Most participants (n=11) considered their story to be neither utopian nor dystopian, three considered their story to be explicitly utopian and one considered it to be dystopian. Of the remaining eight, five did not give a response and three classified their story as other. Few gave information as to why they classified the story as such, but S16\* wrote: *"will hopefully happen like this"*. S19 described their story as *"both real and both fiction"*, thereby classifying it in different terms.

When asked how they decided on this type of story, some participants argued that it had not been a conscious choice (e.g. S8\*) or wrote just *"what came to mind"* (e.g. S3). Others were much more explicit as to their motivation and what influenced their stories. Here many explained that they drew on *"family experience"* as well as their own research experience (S2):

*"She [my grandmother] is deaf and recently broke her hearing aid, only for them to say it would take months to fix in the NHS [National Health Service, public health provider in the UK]. So she sat in a home, confused and*

*in silence, with bad eyes. . . . My memories of her are slowly being re-written by this drugged up body in a hospital bed with glassed over eyes screaming occasionally for help. . . . I wrote this story trying to imagine what it is like as her” (S19).*

Other participants instead wrote “*with hope for my own life*” (S15) or explaining that “*I hope the future for Lor is enriching, social, and highly active*” (S1). S4 specified the relationship between themselves and Lor, arguing that: “*It just came naturally. I can see myself being like Lor, although I do not want to live so long. Even if my health would be perfect, I wouldn’t want to.*” Even though few information about Lor was given beyond her name and her age, participants drew on their own experiences – and often in an empathic manner – to gain inspiration for the stories. Even though we tried to create a rather neutral name, it inspired people and had an influence on how they perceived Lor as for example S10 described: “*The name Lor inspired me to think about a non-urban setting in a distant future where we have universal basic income and services.*” Her age had an impact, as it led participants to question whether such a long life would be something to aspire to. S22 described this the most explicit: “*I think it’s important to consider what happens to the meaning of our lives when they become practically endless. What is still worth living for if you’ve lived long enough to have had three whole lives? How does it change the way we view death and is it really such a blessing?*”. Often this was linked to other factors and experiences, such as S19’s experiences with the NHS or S10’s exploration of Universal Basic Income. S17 grounds their story in larger current factors: “*I think for me it was challenging to think someone would love [live? sic] to that age. We are in a pandemic and by the time I reached that age we would be long into climate and ecological collapse. I don’t think Lor would survive that long she has chronic illnesses*”. While we observe a wide range of motivations as to how and why participants shaped the story the way they did, a lot of the stories appear to be grounded in the present – deliberately or implicitly. In the following, we look in more depth into the stories itself to explore how they took the wider environmental factors into account.

## 4.2 Care in Times of Social and Environmental Changes

Climate collapse, financial stability, structural changes in the organization of waged work and the current Corona Pandemic all made their ways into these visions. Neither we, nor any of the participants did specify when the stories were to take place. When giving out the task, we hinted at a near future, outlining that Lor was 189 years old. While we are therefore unsure about the timeframe in which these changes are expected to take place, some participants build in some changes explicitly into their stories. This was for example done in direct contrast to what is possible today:

*Again, Lor thought back to her grandmother’s experience of elder care, as a resident in a residential home. It was comfortable, yes, but she had lost all opportunity to contribute to society. She had become totally dependent.” (S2)*

In this story the view of elderly people has drastically changed in comparison as to what is possible today. Another example of this is in S1 in which Lor spends a day at the “*learning mall*”, which is

the new name for universities. Many stories refer to the climate catastrophe: “*Lot [sic] is childless because of chronic conditions she was not given the approval to have children after the climate collapse started.*” (S17). In many instances though, this is done more positively, by indicating that people take measures to improve the situation, e.g. “*a crowd discussing the history of air travel before the trains took over*” (S1), Lor living in a treehouse (S10), having a climate neutral summer house (S14\*) or eating predominately self or local grown food: “*Spaghetti Bologna [sic], a green salad from the raised bed she caters for, afterwards cherries and apricots, harvested by the young lady from the flat above*” (S15\*). In most stories, Lor is well off, which is indicated through her living in a “*glamorous mansion*” (S7) or “*beautiful glass and steel home and its wonderful view of the ocean*” (SX). Her activities do not seem to be hindered or influenced by her funds. One exception might be in S17, where she treats herself to “*(very rare) cacao*”. While we do not know whether she treats herself rarely or whether cacao has become rare this is one of the few mentions of abstinence or lack in Lor’s life throughout the stories. Nonetheless, it is rarely mentioned how she afford her life financially. Sometimes, we learn about networks that cater to seniors, such as a “*free senior taxi*” (S21\*). Only one story breaks with this pattern as we learn that society has adapted a “*Universal Basic Income*” (S10) and that Lor “*usually works three days a week*” which gives her “*additional spending money*”. The worlds developed in many of the stories therefore seem to be ‘post scarcity’, a common trope in science fiction, Star Trek maybe being the most referenced example. This is in part – and in some examples – made possible through a turn towards autonomy and greener living.

Through these interpretations we see aspirations for alternative living styles that overcome some of the problems we are currently faced with, such as the unemployment a lot of people might deal with (exacerbated through the Corona pandemic) and the looming climate catastrophe. These do have an influence on the way care is given and received. In S17, mentioned above, Lor is childless and also travelling around in a mobile home. This of course would require different technological support as to what might be needed in, for example, a care home. In contrast to vision videos which often present a more conservative vision of how things might unfold, our participants were more open to extrapolate their fears and wishes about current topics. **Can we afford to look into care as a standalone practice? Could it be beneficial to consider practices linked to social and environmental changes to reimagine what could be possible in care giving?**

## 4.3 Caring Networks

With the exception of S19 and S20, all stories contradict the stereotype of the lonely elderly person. Lor is instead embedded into (care)networks made up of people, specialised technology and general infrastructures alike. Lor sets out to meet a wide range of other people and entities during the day, the majority being human friends (n=8). While some of these friends remain anonymous, others are explicitly named or even assigned activities and shared goals: with her friend “*Margeret*” she “*plan[s] for their trip*” (S10), or she meets with “*an artist friend to discuss a new project*” (S13). Contact with friends can therefore be understood as an indication for an active lifestyle, hobbies and interests. Lor also meets with



family in some stories. Even though she meets with her “grandchildren” (S21) and “her parents, her offspring and their offspring” (S20) this also includes “her sister” (S16, S3). Family is not only an intergeneration construct, but also goes beyond that, especially in S3, where the contact is described as “her sister and her best friend”. While not as diverse as the range of friends, we see through these stories different interpretations of what family means. But the stories provide a third range of contacts beyond the family and friends: an informal network surrounding Lor’s living place. Through these contacts, we learn a lot about the way Lor lives. She meets with “other travellers in her caravan” (S17) or “Nikki, her neighbour who is always in the same homeplace as she is” (S22). In other stories, Lor lives more stationary, but is nonetheless connected. In S15 she meets with her “neighbour, who also lives in the non-profit living project in the country close to a small town” or she has a “cup of tea” with “Jean, her 89-year-old neighbour” (S4). Neither of these examples indicate that Lor has a wide outreach, but within her world, she is embedded into a variety of social networks.

This becomes even more diverse when we look beyond the question of who she meets explicitly, but who else is in her network. The day described in S13\* focuses on the visit from Mo, Lor’s lover, who “visits regularly which helps her to feel good”. Lor here is not only interested in positive and friendly encounters with family and friends, but is a sensual being with needs and sexual desires. In S1, Lor meets up with “her business partners to work on her startup”. These stories present an active and integrated picture of an elderly woman that is quite different from the visions that are presented in many papers to justify the development of care technologies. From these aspirations the following questions could be derived: **How would care technologies change, if we develop them for people with such an active lifestyle? How can we develop technologies that enable and support this lifestyle, e.g. by making communication possible beyond a close circle of family and friends?**

Most stories present an interplay of human and technological intervention. This becomes the most explicit in cases where the technology breaks down. S14\*, S15\* & S16 made this the focus of their exploration. S16 is the most techno-positive as even though the robot breaks down, Lor not only gets through a very pleasant (technology-supported) day with her friends, but the robot has also repaired itself when she comes back. S15 shows the interplay between people and technology the strongest, as Lor contacts support when the robot breaks down. But here, the contact is not only about the repair of the robot, but is much more personal than that: “A couple of minutes later a young man enters Lor’s flat with an emergency code, cares for her and repairs the AI robot. They laugh” (S15\*). S14 appears the most critical of technology as a device breaking down stops Lor from accessing anything:

*“Coffee! But the machine does not even know that she got up. Normally her food is prepared automatically for her in portions. . . . But not today. She was hungry and everything hurt. If there were pain killers in the food? Probably (S14\*)”.*

As the last point suggests, the system is highly invasive and is in the remainder of the story vaguely linked to surveillance. Here the interplay between humans and technologies is evoked when Lor

smuggles herself onto public transport and visits a friend “who is just 100 and is not so strictly under surveillance” (S14\*). Together they plan to find out what happened to Lor tomorrow. These three stories exemplify many of the aspects of human technology networks in the stories. Through these stories we learn what worries people about technology breakdowns, but also how they are always imagined in the combination and collaboration with human actors. Through these considerations, the following question could be derived: **How will care technologies sit within or change existing networks?**

Two stories in particular stand out in which care technologies have grim outcomes for the users of the technology. S8 starts like many others with Lor feeling weak. In contrast to receiving medical support as is described in the section below, the information is delivered through the “automatic surveillance system” (S8\*) to her family and her health insurance. Through these repeated dizzy spells, Lor has lost her insurance and it is up to her family to decide whether they want to take the risk of keeping her alive. In a dramatic turn, the story ends with: “A couple of days later, Lor steps on the conveyor belt, but she cannot choose a destination: she knows her family has made a decision” (S8\*). Here the author paints a dystopian vision in which market values are extended to the care sector to the extent that they influence questions of life and death. Participants are aware that care is not only undertaken on an individual level, but instead is impacted by wider concerns and constraints. S22 shows a similar critical image when Lor tracks her friend Nikki through her smart watch when Nikki is late. Finding Nikki “on a cliff somewhere on the other side of town” (S22), a suicide watch is arranged to rescue Nikki. Realising the implications, Lor “suddenly feels very sad that even the freedom of dying has been taken from them” (S22). Through both these stories we can observe that technologies are deliberately seen as entities that can make a difference between life and death. But the struggle is not inherent in the technologies themselves, but rather is understood and presented as an outcome of the underlying market values. **How can technologies change existing networks, to the question of who is served by care technologies? How and to what extent care technologies impact on the autonomy of the person in care?**

In this section, we have shown that participants were highly aware of the necessity, benefits and pitfalls of understanding care as a network: technological and human, embedded in a society. Currently, many technologies that are developed, are presented more or less in isolation, as stand-alone pieces. In the next section, we look deeper into the subtleties with which our participants framed and understood care.

## 4.4 Care does not equal Care

**4.4.1 Support with ADLs.** As the cloze text included many prompts that touched on practical tasks, such as getting out of bed or having lunch, some aspects of ADLs were covered in some stories. Within those, we see different levels of technology advancement as shown in the table below.

Some of these ADLs were prompted in the cloze text as for example how Lor gets help when getting out of bed in the morning, which we focus on here first as an example how help is imagined through self-help, people and technologies. First, in three instances, Lor does not need any help but herself to get up, using “her wish to

**Table 3: Selected ADLs and corresponding low- and high- tech solutions from the participants' stories**

ADL	Low Tech solution	High Tech Solution
Mobility	mobility chair and then the lift (S4) lift (S7) Bike (S12) the bus (S5, S9) or the bus mobile (S16) Free senior taxi (S21) moto-taxi (S10) Uber (S11)	exoskeleton [sic] (S6) autonomous car (S1) Self-driving bike (S22) air taxi (S6) conveyor belt (S8) Monorail system (S14) Mobile apartment (S17) Touchpad that controls the bed (SX) biocheck (projected on to the ceiling - her bed takes readings overnight) (S2) her automated bed (S7) Morphing bed (S22) The liquid she sleeps in (S20)
Getting Up		messaging through closed network on subdermal chips (S2) voice box (S16) kitchen robot (S21) displays to order food delivered by robots (S16) Mobile ice cream parlour (S21) refreshment centre in the kitchen pod (S11)
Communication	include phones (S5, S22) as well as future developments such as the iPhone 30 (S1) video software (S15)	her house robot (S4) her robot (S6) small robot Swazi (S14) Basel, her robo-plant (S10) her AI robot (S15) the robot "Robbie" (S16) her Android Carer (AndCare) (S2) Orag her droid – converts into a chair, messenger (transmits the son's face), walker (S11) Lor 2, her clone (S17) The avatars (S19) VR movie night (S21) air beds (S16) Computer generated characters (S20)
Cooking & Eating	coffee machine (S14) shopping delivery (S3) food freshly prepared (S14)	
General Assistance	Alexa (S2)	
Entertainment	audio book (S4, S15) listening to podcasts (S11) Cinema (S1) books, online materials (S19)	

see what will be in the shopping cart" (S3), an exercise described as a "spirited twist" (S12\*) or a sip of warm water and air biking (S13\*) to help her get up. Second, we learn that she is helped by a range of human and related agents, such as her daughter (S5) or "Susie" (S1), her friend. From her wider network, she receives help from "her roomie" [i.e. a person she shares her flat or house with] (S9). In other instances, she is helped by "Lor2", her clone (S17) or she allows "the avatars to help her" (S19). Third, in the category of technology, we see examples as varied as "Alexa" (S2) and "her exoskeleton" [sic] (S6), which are to a large extent already available today or at least already in the news. Participants either seemed to build on what they already know or have picked from existing science fiction tropes. In the stories we observed many technological and scientific advances that are common tropes, such as clones (S17), android and robots (see below or methods of transportation such as conveyor belts (S8) or monorails (S14). The technologies people imagine are

therefore not always the shiny futures we imagine now, but can also be derived from the science fiction futures of other generations.

Two frequent tropes were technology that is embedded into the furniture and robots. While the level of automation and sophistication varied, many participants imagined care technology to be integrated directly into the furniture; e.g. from a touchpad close to her bed she can touch to raise it (SX) to a "morphing bed" (S22) or "automated bed" (S7). The largest group of individual technologies that are mentioned are robots: Robots are described either factually, e.g. as "the house robot" (S4) or "her AI-robot" (S15) or as more social entities. Robots are introduced as "Orag" (S11), "her small robot Swazi" (S14) or even the colloquial "Robbie" (S16). Robots are predominately present in many ADLs, such as a "kitchen robot" (S21), who helps with food preparation, the aforementioned "Orag" (S11) who can be a communicator, walker and much more and a robot



explicitly called “*Android Carer (AndCare)*” (S2). Robots have influenced the imaginaries of care, but the way they are understood and the tasks they do varies widely. As participants re-imagined robots in many shapes and forms, we pose the question: **How can we integrate technologies more seamlessly into the environments in which care takes place?**

**4.4.2 Medical Support.** In the description of the writing task, we specified that Lor is overall healthy, but that she needs some support. Some participants interpreted that to include medical information into the accounts. S2 includes a section in which Lor received a non-invasive knee surgery. S14 centres around her waking up and being in pain. While first receiving aid from her robot, such as bringing medication and putting on her favourite music, her illness is so severe that she has to receive aid from a medical professional, who is projected into her room as a hologram, enters her data into the “*Electronic Record*” and delivers medication via a drone. The experience is a highly personal one as after the diagnoses, Lor

*“settles back in bed and asks the nurse about her career: why did she choose to go into nursing. The nurse’s hologram sits on a chair next to her bed and tells her a story from her childhood about what made her decide to be a nurse until Lor is fast asleep”* (S14).

In other instances, Lor feels dizzy, but does not have to seek out medical help as she gets the support she needs from her Android “*Orag*” (S11). Orag not only diagnoses and “*reassures both [Lor and her son Emu] that Lar [sic] is stable and needs rest and fluids*” as well as “*rechecking her vitals which are stabilizing*”. In these two examples of stories that deal with medical emergencies or breakdowns of Lor’s health, we can observe varying solutions as to what medical support might look like, ranging from technical support in the home to an extensive network of tele health solutions. But overall, we can observe that medical support is seen as an element of care, which in turn is embedded into wider care network: in the first story Lor is cared for both by her robot and the hologram nurse, while in the second story, a robot and her son are concerned and taking care of her. Medical support is an important factor of care, but it is closely linked to emotional support. We therefore pose the question: **What supports people in giving affective care?**

**4.4.3 Emotional Support & Self care.** Not all the caring acts described in the stories were practical acts of ADLs or lifesaving acts of medical support, as, we encountered many acts of kindness that leave Lor feeling cared for. The fact that her lover Mo is meeting her, for example, helps her “*to feel good*” (S13). SX words the entry in the cloze text carefully to say that “*some of her 56 grandchildren take it in turns to care for her need and this*” helps her. This involves again even members of her larger community, such as when she is “*in the community cafeteria at lunch, being served by one of her younger neighbours, who just got into college and always cheers her up with funny stories*” (S4). Comparable, in story S2, she goes back to her “*suite*” in the evening, because “*she enjoys the mix of privacy and communal living*”. Communal living appears to be as important as the physical care. In S5 we learn through a plumber who is called to visit a broken pipe that Lor used to be a “*famous suffragette*” whose picture was taken by his father. This memory of her past leaves Lor to feel good about herself: “*Lor has tears in her eyes as she*

*thinks back to that period of her life*”. Caring words, small gestures, and memory work are as important parts of care work as the care for the physical body.

While Lor needs help herself, we seen in many instances, that she is also taking care of other people. Lor is projected in many stories as a caring person, who has advice to give. In S1, she founded a start-up with other people and “*agrees to work on the code again with Graham, she still has a sharper eye for statistics. Graham is only 12 but learns a lot from Lor who is approaching 76 this year*”. In S12, she comforts the daughter of a neighbour who just got laid off from her job. Lor is described to “*listen carefully*” and to “*gently place a hand on her shoulder*”. In some stories she has pets: in S1 she begins the day with “*the cats at her feet*” or S7, where she meets with “*her dogs*”. S3 deals mainly with her cat who has “*a dreadful disease*” and has to be quarantined, but luckily did not “*contaminate*” Lor. While in the last example we see quite obvious similarities to the Corona Pandemic, it can also be read as a story about a woman who has taken on care responsibilities for an animal and fulfils them even in harrowing circumstances. **How can technologies be used to enable people to actively give care while also receiving care?**

But Lor is not only reliant on other people for care and support. To get a first insight into Lor’s interests, we initially looked at the rituals in her life, i.e. the things she does when she gets up and before she goes to bed. Many of the morning rituals evolve around food, such as a “*cup of tea*” (S10) or a bit more futuristic, taking discourses about eco responsibilities into account, a “*coffee with protein powder made from insects*” (S14). When eating, Lor has breakfast that is “*light*” (S4), “*made from fruit, oats, coffee*” (S15) or “*balanced*”, which is being “*prepared by the kitchen robot*” (S21). In addition to taking care of her physical body in a mindful manner, Lor also cares for her mind and spirit, e.g. through a “*period of quiet contemplation*” (S20), “*mediation practice*” (S7) or “*breathing exercises on the balcony*” (S12). Nature plays a large role in this as she takes walks in the “*woods*” (S3), a “*park that is close by*” (S13) or a “*stroll around the environment that her house is in today*” (S22). Through most of these morning exercises we get the image of a quite wholesome person, who is taking care of herself and is rather sensible. The evening activities show a similar picture. When prompted as to how Lor would go to bed, many stories highlighted that she goes to bed “*early*” (S12,14), between 9 and 10 pm (S5, S9 S18, S3; S10) or a bit more ambiguous: “*just after sunset*” (S7), “*after the movie night*” (S21) or “*right when her watch warns her that her energy is running low*” (S22). Only in few instances is she allowed an indulgence, only in S2, when she takes a “*nip of whisky*” (S2) or goes to bed “*after Mo’s visit happy and satisfied at about 2 am*” (S13\*). This again indicates that, often, elderly people are perceived to live a rather wholesome life that is driven by rituals. This might have been due to the task that was very focused on finding out what a typical day in Lor’s life was like. Alternatively, it can be read as an aspirational life, in which one has the time and opportunities to take care of one’s mind and body. **How can we support people in taking care of oneself as well as others?**

## 5 DISCUSSION

In this paper, we have shared the findings of a study in which we asked participants to fill in a cloze text to do initial world building

and share a story based in this world. From our key findings we derived questions to enable reflection and speculation when designing technologies for care. Instead of focusing on one aspect of care, or addressing specific ADLs, the stories expand the view of care entails. The reflective questions therefore encourage reflection on networks of care and other environmental factors and further encourage to break open the strong binary between caregivers and care receivers. It therefore extends the call for community of care as expressed by [31] as well as trends within HCI to address “*more-than-human*” design (e.g. [10, 17, 32]). We further consider this paper to fall within a range of papers that expand the way we do “*design futuring*” [22] and what lenses we see the future through [19]. Like many design fiction projects, this project deployed “*world-building*” as a means to enable reflection (see also [3]). But the focus was less on the development of artefacts, whether this would be serious or “*anti-solutionist*” [4], but instead stayed on the level of story writing. This might have added to the variety of stories and underlying narratives. In addition, it enabled us to undertake the survey completely online, which was not only useful during distancing measures of the Corona Pandemic, but also as a means to guarantee anonymity to the participants.

Another way in which the stories expand current discourses about elderly care, lies in its acknowledgement of intimacy. Technology development often focuses on family as the main contact for elderly people (see for example [44]). The stories presented here paint a much richer picture which includes lovers, friends and neighbours – not only as social contacts, but also as potential caregivers. As intimate relations become more diverse (see also [20]), this might have a strong impact on how we imagine intimate relation and care. Additionally, this removes care further from the medical view of caregiving and into a more open, distributed and potentially reciprocal task. Through this paper, we encourage researchers and designers in HCI to expand visions of care. This falls within a growing body of literature to incorporate feminist [1] and queer [23, 37], among other approaches. In addition, current research often gives us a ‘sanitized’ version of care giving, which leaves out the sometimes messy and physical reality. We can therefore see these stories as a first attempt to “*stay with the trouble*” [15, 16] of caregiving. While the stories presented here, might not be informed by the actual realities of ageing and caregiving, we nonetheless observe a more ‘embodied’ stance here, as Lor’s needs, desires and motivations are foregrounded. Whether we learn how Lor takes her breakfast or whether we learn that she is visited by her lover, our understanding of Lor grows beyond her (medical) needs that are so often the focus of design for elderly people (see e.g. [44]). As suggested in the speculative short film “*Uninvited Guests*” by Superflux [46], these desires might stand in contrast to a needs-based technology design and should therefore be heard and acknowledged in the design of technologies.

The method of adapting the story elicitation method has been useful in generating a wide range of stories, which touched on many instances of care. Adding the cloze text to the traditional story stem, enabled participants to do a lot of world building before writing the story. This allowed us to compare between the mundane and the extraordinary of care giving. The way we phrased the prompts might have had an impact on how the participants conceptualised care, e.g. when addressing ADLs, but we also saw a wide range of

responses as well as participants using the prompts creatively to fit where they wanted to set the focus. Instead of having other entities help Lor getting up as we expected, participants for example interpreted the prompt to share how Lor was motivated rather than helped. While future studies with a more thorough questioning of how participants experienced the survey and how they derived their responses might be useful to develop the method further, we see great potential in this extension to generate rich and varied stories. This also helped to some degree to overcome the relatively low number of responses we received as the data was quite rich. While the survey enabled us to generate a wide range of stories, it is understood that our participants represent a well-educated section of the population with a strong interest in care. The stories indicate an environmentally conscious, left-leaning mindset, which might leave out other visions of what care might look like. Nonetheless, the stories show a wide range of visions already, for example from the techno-optimistic to the techno-negative. In addition, our study was based on a Western, specifically Western European, understanding of caregiving and our participants’ views to a large degree appear to have mirrored that. To overcome these sampling biases, future work could expand on this by e.g. recruiting participants through crowd-sourcing platforms, offer the survey in more diverse language or seek out real-life writing groups to take part in the survey.

While we see potential in this method to give impulses to overcome the fragmentation of care, the question of how it deals with the othering of elderly people is more complex. While methods such as co-design and participatory design make space for the experience of people in care, traditionally research has often focused on the perspective of the caregivers [44]. The wide variety of stories we received, which ranged from near-future fictions to creative explorations of alternative realities suggests that participants were able to find novel starting points to explore what care means to them. The prompts were written in the third person perspective, but participants drew on their own experiences. While participants’ stories might include misconception of the current state of caregiving, this approach has been useful to opens up new areas of exploration that might be ‘unthinkable’ by experts in the field. As many of the stories are highly aspirational, we can also assume that they take the perspective of the person receiving care, but they might still include many of the “*not for me*” [31] mindset that often shines through current participatory work with elderly people. We suggest future work in the field which not only includes people currently in need of care, but also more thorough understanding of people’s position to the character in the story.

While the stories were quite diverse and offer inspiration as to how technologies can be embedded into the environment, the predominance of robots stands out: ranging from kitchen aids to moving seamlessly between tasks. Robots have long played a role in our social imaginaries through their predominance in popular science fiction (see also [2]). This in turn has inspired the development of robots, specifically in care [26]. Participants drew on these imaginaries, but their understanding of robots varies widely and so does their acceptance of such devices. The stories suggest that robots which are stand-alone devices bring with them the perceived danger of dependence on the system. Robots that are only one factor in a caring network that is still overlooked or combined

with humans are more accepted. Hornecker et al. [18] suggest that machines in care are used not as stand-alone devices, but rather as “*triadic interactions*” and the stories presented here give further insights into what these interactions could look like. Following these insights, care robots might be rethought as a tool in care rather than the “*miraculous*” [38] support they are presented as today. Su et al. [38] further make a distinction between service robots and companion robots – among others. This implies a strong divide between the institutionalised side of care giving where service robots are useful and the social robots which in turn focus nearly exclusively on the emotional side of care. The stories presented here not only deliver novel framings of what care entails, but also suggest that care is less fragmented than this image suggests. In the everyday understanding of participants presented here, care is a complex interplay of body and mind, health, support, needs and interests. While this may be outside of the scope of current technologies, we want to encourage a rethinking of these distinct categories towards more holistic care technologies.

While the stories presented here only show a facet of how caregiving can be imagined, they already provide inspiration to rethink caregiving and expand the idea of elderly care as it currently presented in the development of technologies.

## 6 CONCLUSION

In this paper, we presented rich and diverse stories about elderly care giving generated through the story elicitation method. These stories go beyond the fragmented and narrow way in which elderly care is currently often presented in HCI research. We distilled the stories into questions for reflection and future speculation, which focus on three key parts: Through these stories we extend the frame of what care giving might mean by including concepts such as self-care and also problematizing the relationship between care giving and receiving care. In addition, we suggest to acknowledge the interplay and relationship between technology and other infrastructures, may it be human or systemic, such as housing. Further, these questions invite reflection on changes in the near future, e.g. care in times of climate change or other societal and environmental changes. Through these reflective questions we invite designers and developers to ‘stay with the trouble’ of caregiving to develop technologies that fit better within people’s vision, hopes and dreams for their futures.

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