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Co-Creating Futures of Care with Older Adults

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ABSTRACT

Designing for care futures in older adulthood often begins and ends with techno-solutions for use in formal care systems, while older adults and their informal care networks are often excluded contributing their own visions for care and the future. In this workshop, we will explore how we can better design not only for but with care in older adulthood, applying the PDC 2022 'Senti-Pensar' (thinking-feeling) lens, to ask 'how can we enact and represent design practice that is difficult to describe but is heartfelt and passionate?' We aim to challenge current narratives of care in HCI, embracing the diversity of experiences of older adults, and facilitating discussion around a future of care that values interdependency, relationality, and thinking-feeling in design. By considering multiple perspectives on care in older adulthood, we will speculate on the role of technologies within future ecosystems of care, where care is the concerted and organising principle.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI); HCI theory, concepts and models.**

KEYWORDS

older adults, care, futures, participatory design

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1 INTRODUCTION

Care is often conceptualised as being 'provided to' older adults, without consideration for their agency in the design of their care or their own interpretation of their care futures. These care futures look increasingly technology-mediated, where emergent designs such as artificial intelligence, machine learning, the Internet of Things, and big data [30] significantly influence the lives and care of older adults and have the potential to replace many existing modalities of care (e.g. automated medicine dispensing, fall detection through smart homes). Researchers are now asking what this means for designing the future of care (see e.g. [18]).

While several HCI design innovations focus on well-being and care beyond the physiological or clinical [3, 13, 17, 26, 32], champion perspectives that rethink ageing and older adulthood [11, 19, 21, 22], and endeavour to amplify older people's agency in the design process through participatory and co-design approaches [2, 8, 20, 23, 25, 29], the majority of design with older adults still focuses on health-care and clinical outcomes. Design for care with older adults is often commodified and quantified, rather than qualitatively explored, and older adults rarely have a say in their privacy and control over what, when, and how data is collected and processed [30]. Older people are often passive recipients of technologies that tend to monitor or observe them from a distance, without enquiring about their rich experiences (their thinking and feeling on design which impacts them) or supporting them to shape these experiences.

This is an issue particularly when we consider that care does not lend itself to being neatly quantified. For example, a fundamental

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issue in many care systems is that formal care provision - such as governmental healthcare or residential care - is often drastically under-funded [27] and informal care provision - such as unpaid family or community care - is relied on to fill the gaps in failing care systems [7]. This idea of 'everyday care' is an area of nascent interest in design communities [33] but is very difficult to quantify, define and reproduce, as it involves individual and collective values, emotions, practices, and views on dependency and interdependency [9, 14, 15].

We suggest that these values and emotions are of particular salience when considered through the lens of the PDC 2022 theme 'senti-pensar' ('thinking-feeling'), which asks 'how can we enact and represent design practice that is difficult to describe but is heartfelt and passionate?'. Both formal and informal care practices are influenced by feelings and emotions from those who are involved in older adults' care networks (for example, joy, love, duty or burden) [24]. As Maria Puig de la Bellacasa proposes, "Care is everything that is done to maintain, continue, and re-pair 'the world' so that all can live in it as well as possible. That world includes... all that we seek to interweave in a complex, life-sustaining web" ([28], p.161). This idea of care as a 'complex, life-sustaining web' is particularly relevant when considering the nuanced care networks through which older adults care, care about and are cared for. How can design better support these complex webs, now and in the future? To answer this, we suggest that we must first understand what older adults themselves think and feel about design's role in their care.

At the intersection of older adulthood, design, and care, we suggest that *care-full* design approaches will involve complex aspects of thinking-feeling from the perspective of multiple stakeholders. As designers and researchers, we must consider the thinking-feeling we bring to our participatory practice around care and the emotion work therein [4]. We must also acknowledge that design work can reveal tensions in how people may experience and make sense of care in their everyday lives [16].

One way to explore these notions of thinking-feeling in care and design, and to understand how these may impact care futures, is to engage in futuring. Futuring methods elicit understanding, feelings and personal values about future life and technologies in the form of Design Fictions or Speculative Designs that can be used as tools for speculation, critique or reflection [1, 5, 6, 12, 35]. We hope to engage in conversations around such methods and to apply these in our workshop, in essence 'futuring the future' of care and design with older adults.

In this workshop, we aim to challenge the current narratives of care in and through design and propose approaches that will surface the subtleties and intangibles in the care process that matter to older people - the heartfelt and passionate. We will embrace the diversity of experiences of older adults, and facilitate discussion around a future that values the interdependencies of agents of care and thinking-feeling in design with older adults and their care networks. We will examine technology's role in a future where care is no longer a commodity, but an organising principle [10].

We will address three core topics:

- Thinking-Feeling on Care - What is care and how should it feel? How do our own concepts of care impact the work we

do or the experiences we have? How do formal and informal care networks intersect and how can design support these in 'heartfelt and passionate' ways? For designers or technologists, how do they consider 'thinking-feeling' in their work on care? What are the challenges and barriers of work in this context? We will draw on Tronto's Ethics of Care [34] as a starting point to discuss the overlaps and disparity between *caring for*, *caring about* and *caring with* and expand on this throughout the workshop.

- Care-full Approaches - Which methods can we use to understand care in context of ageing and design? We are interested in approaches that lead to designs that unveil the rich nuances and subtleties of care and that foster meaningful engagement within care networks. We would like to re-imagine our approaches for application and implementation in the rapidly-changing future of care and older adulthood. We believe that care should not merely be provided, but rather be co-created - a multi-directional negotiation between older adults and those who endeavour to support their agency. Hence, we not only need methods which develop existing care services, but which navigate the evolving aged care landscape.
- Futuring Care Futures - How do we use design to enact meaningful change in care futures? How do we move forward to consider the scalability of a 'design for one' to 'design for many' in careful and meaningful ways? Similarly, how do we use our insights in design to enact real change in deteriorating systems of care across the globe? How can participatory design help interweave formal and informal care into a symbiotic network? How can we engage policymakers and other stakeholders in conversations on care which are led by older adult insight, need, and imagination?

2 ORGANIZERS

Dr Cara Wilson is a Postdoctoral Research Fellow at the Institute for Design Informatics and at the Advanced Care Research Centre at the University of Edinburgh.

Dr Diego Muñoz is a Postdoctoral Research Fellow in the Swinburne Living Lab at the Swinburne University of Technology.

Dr Aloha Ambe is a Postdoctoral Research Fellow at the Centre for Data Science at Queensland University of Technology (QUT).

Professor John Vines is Chair of Design Informatics at the University of Edinburgh.

Professor Sonja Pedell is Director of Swinburne University's Swinburne Living Lab.

Professor Margot Brereton leads the Design Participation Lab of Queensland University of Technology (QUT).

Dr. Larissa Pschetz is a Lecturer in Design Informatics and Edinburgh Futures Institute Fellow at the University of Edinburgh.

3 PRE-WORKSHOP PLANS

We welcome participation from people across diverse backgrounds with an interest in care futures and older adults, such as designers, technologists, participatory researchers and industry experts. In-keeping with our ethos of participatory design and inclusivity, we also warmly welcome participation from those out of the

sphere of design, such as older adults, aged care providers, and other stakeholders, and we will endeavour to actively seek and support such attendance, financially and in terms of accessibility. We will disseminate our call for participation through personal contacts, professional social media accounts, and other appropriate channels.

Individuals interested in attending the workshop are invited to respond to an online Q&A (or in a self-selected accessible format), providing their perspectives on care, older adulthood and future-focussed participatory design. In addition, participants will be asked to share a photo/image/postcard - an 'image of care' - that they feel represents care. This visual aid will be discussed in the workshop. Potential participants will submit their responses, using the template provided on our website and answers will serve as preparation for the workshop activities.

4 WORKSHOP STRUCTURE

Depending on participant locations, we will conduct two separate workshop sessions that would cater to different time zones. An asynchronous plenary session for all will be designed so everyone can discuss and synthesise outcomes from both workshops.

Each workshop will be structured as follows:

- **45 minutes - Welcome and introductions.** The participants will share their submitted image of care and explain to the group how this relates to care and its relevance to their current work/experience. They will also share one answer from their responses to the questions in their position paper.
- **45 minutes - Session 1: What is Care? (whole group).** We will conduct a group activity following the do/be/feel method [31] to generate a diagram that conceptualises a shared understanding of what care is for all participants and what role technologies play in a system of care.
- **15 minutes - Coffee break.**
- **60 minutes - Session 2: Concretising the Future of Care (individual, then whole group).** Based on Session 1's discussions, participants will work on a Miro board to introduce their perspectives on how methods can contribute to the design, evaluation and scalability of technologies for the diversity of experiences of care. Then, we will lead a group discussion on each of the topics.
- **60 minutes - Meal break.**
- **90 minutes - Session 3: Challenging the Future of Care.** Participants will break out into teams and will be asked to use a Miro board to build a provocation on technology design, care and the future - exploring how technology design can impact the future of care. These can be drawings, poems, stories, design sketches, reflections - anything which challenges current concepts of care and older adulthood, based on concepts of futuring and design fiction. Each team will present their provocation to the whole group. We will foster discussion after each presentation.
- **15 minutes - Workshop summary:** We will lead an overall discussion of the outcomes of the session.

We emphasise that the above can be modified with consideration for asynchronous participation, as necessary and depending on participant preference, time zones and abilities.

5 TECHNICAL CAPACITY AND ASYNCHRONOUS ENGAGEMENT

Synchronous engagement will be through video-conference and online collaboration tools. For video-conference, participants will join via Zoom or Microsoft Teams. We will create a Miro board for each of the sessions and will share links with participants to join the boards during the workshop.

Should asynchronous engagement be needed, we will disseminate a protocol that will guide participants to go through the activities in their own time. We will include screenshots of the Miro boards and examples of use. An asynchronous plenary session for all will be designed so everyone can discuss and synthesise outcomes from both workshops. In addition, we will set up a Slack server for asynchronous communication within participants and organisers.

6 POST WORKSHOP PLANS

The organisers aim to publish the synthesised output of the workshops presenting concerted yet diverse perspectives of future of care, older adulthood and the role of the PDC community. The organisers have many years' collective experience in orchestrating such publications and workshops.

We will continue our discourse post-workshop and will maintain the workshop mailing list. We will connect participants and encourage collaboration in publication, projects and grant funding applications. The organisers will seek opportunities that may benefit participants, the PDC community and beyond (e.g. linkage with the aged care sector, projects with community groups, etc). With participants' permission, we will showcase the participants' images of care and reflection of care on the website, alongside their responses to the position paper questions. Considering the outputs from the workshop, in these sessions we may discuss the potential of organising a special issue journal to present in detail the plurality of perspectives.

7 CALL FOR PARTICIPATION

This workshop aims to challenge the current narratives of care, embrace the diversity of experiences of older adults, and facilitate discussion about the future of care, from the perspective of thinking-feeding in design. We will examine technology's role in a future where care is no longer a commodity, but an organising principle.

We will explore our understandings of the future of care and the role of technologies, how we can work towards this future, and provoke discussions about our own speculations of a technological future of care. Further details about the workshops and organisers can be found at <https://carefutures.wordpress.com/>.

We welcome participation from people across diverse backgrounds with an interest in care futures and older adults. This workshop will run at PDC 2022 and thus we invite submissions from designers, technologists, industry experts. However, in keeping with our ethos of participatory design and inclusivity, we warmly welcome participation from those out with the sphere of human-computer interaction, such as older adults, aged care providers, and other stakeholders, and we will endeavour to support such attendance, financially and in terms of accessibility.

Participants are invited to respond to a Q&A form, answering questions about their definitions of care, methods for supporting care in technology design, and about the future of care in the context of older adulthood. In addition, participants will be asked to share an image that they feel represents care.

Responses can be submitted using the template provided at <https://bit.ly/CareFuturesWorkshop> on or before 13th June 2022. Participants will be notified of acceptance by 20th June 2022.

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