Reframing Robots for Care

Situating Informal Caregivers in the Development of AI-driven Technologies

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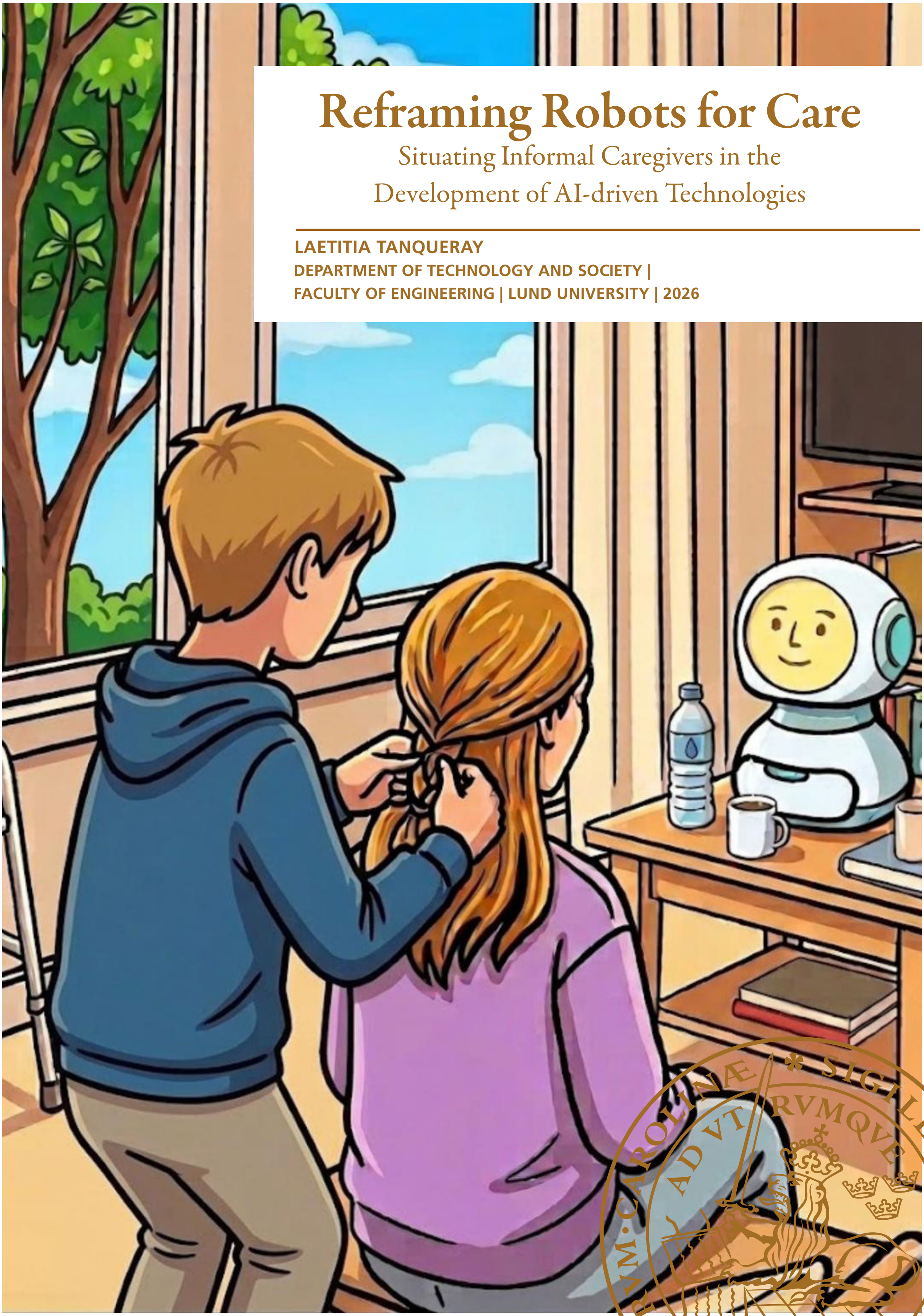
DEPARTMENT OF TECHNOLOGY AND SOCIETY |
FACULTY OF ENGINEERING | LUND UNIVERSITY | 2026



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by Laetitia Tanqueray

LUND
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Abstract

The current framing of AI-driven technologies situates them as solutions to a looming care crisis. However, this overlooks informal caregivers' key role to current State budgetary deficits impacting healthcare services happening in Europe. As States increasingly rely on informal caregivers to provide care before the necessary involvement of healthcare services, there is already well-established research on the growing care demands on informal caregivers. Yet, in the development of AI-driven technologies, little attention has been given to this group. To attend to this gap, this thesis situates informal caregivers in order to reframe current developments of AI-driven technologies for care. The aims of this thesis are therefore grounded in visibilising and situating informal caregivers within the development of AI-driven technologies. This is achieved in two ways: (1) by conducting interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in Human-Robot Interaction on health care as well at times Human-Computer Interaction; and, (2) shedding light on current societal challenges on care regarding informal caregivers, especially informal caregivers under the age of 18 (referred to as young carers), to the development of AI-driven technologies. The first aim is directed at the academic community, whilst the second aim is directed towards society by empowering specific stakeholders in envisioned AI-driven technologies as artefacts. To answer to those aims, a socio-legal STS theoretical lens is established, to bring forth the power of law, social norms, plans and situated knowledge and care. The findings are based on four scientific papers, which report on HRI research practices on health care (Paper I), a theoretical framework to account for norms within adaptive technologies (Paper II), positioning young carers into AI-driven technologies (Paper III), and finally, an empirical study on young carers' perspectives of robots for care (Paper IV). These ultimately showcase that the development stage of this technology provides a pivotal opening to include informal caregivers, ahead of deployment. This thesis offers hope on how to attend to an overlooked stakeholder, namely informal caregivers. This includes reflections on including a group that has previously been neglected from AI research, namely young carers, and how to do so ethically.

Key words
Human-Robot Interaction, Informal Caregivers, young carers, Sociology of Law, STS, qualitative, power of law, social norms, plans and situated knowledge, care, focus groups, literature review

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A doctoral thesis at a university in Sweden takes either the form of a single, cohesive research study (monograph) or a summary of research papers (compilation thesis), which the doctoral student has written alone or together with one or several other author(s).

In the latter case the thesis consists of two parts. An introductory text puts the research work into context and summarizes the main points of the papers. Then, the research publications themselves are reproduced, together with a description of the individual contributions of the authors. The research papers may either have been already published or are manuscripts at various stages (in press, submitted, or in draft).

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Dedicated to
my (guiding) Star

Contents

Abstract

The current framing of AI-driven technologies situates them as solutions to a looming care crisis. However, this overlooks informal caregivers' key role to current State budgetary deficits impacting healthcare services happening in Europe. As States increasingly rely on informal caregivers to provide care before the necessary involvement of healthcare services, there is already well-established research on the growing care demands on informal caregivers. Yet, in the development of AI-driven technologies, little attention has been given to this group. To attend to this gap, this thesis situates informal caregivers in order to reframe current developments of AI-driven technologies for care. The aims of this thesis are therefore grounded in visibilising and situating informal caregivers within the development of AI-driven technologies. This is achieved in two ways: (1) by conducting interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in Human-Robot Interaction on health care as well at times Human-Computer Interaction; and, (2) shedding light on current societal challenges on care regarding informal caregivers, especially informal caregivers under the age of 18 (referred to as young carers), to the development of AI-driven technologies. The first aim is directed at the academic community, whilst the second aim is directed towards society by empowering specific stakeholders in envisioned AI-driven technologies as artefacts. To answer to those aims, a socio-legal STS theoretical lens is established, to bring forth the power of law, social norms, plans and situated knowledge and care. The findings are based on four scientific papers, which report on HRI research practices on health care (Paper I), a theoretical framework to account for norms within adaptive technologies (Paper II), positioning young carers into AI-driven technologies (Paper III), and finally, an empirical study on young carers' perspectives of robots for care (Paper IV). These ultimately showcase that the development stage of this technology provides a pivotal opening to include informal caregivers, ahead of deployment. This thesis offers hope on how to attend to an overlooked stakeholder, namely informal caregivers. This includes reflections on including a group that has previously been neglected from AI research, namely young carers, and how to do so ethically.

Popular science summary

Artificial intelligence (AI) for health care is often framed as the solution to the care crisis that is fast approaching. In the past few years, the promises of AI-driven technologies have seemed more within reach, especially with the success of large language models–such as ChatGPT and DeepSeek. This makes AI-driven technologies a likely contender to help alleviate the looming care crisis, especially with an ageing population and insufficient healthcare professionals. It is therefore anticipated that robots, and other smart devices, will be able to overcome this challenge. This includes, for example, social robots providing care for older people, or tech-companions combating loneliness. In a nutshell, it is envisioned that AI-driven technologies will be the saviour of care. Yet, this projection overlooks an important stakeholder: informal caregivers.

Informal caregivers are family relatives and friends that provide care to someone who needs it. Informal caregivers can be adults as well as children under the age of 18. Care responsibilities can range from taking the person to their medical appointments, to monitoring medication, to ensuring overall wellbeing, without having training to do so. Informal caregivers are not trained to provide care, and usually are not compensated for their care responsibilities. Yet, they have been increasingly relied upon by States, as States face budgetary issues leading to a decrease in available public healthcare services. The idea goes that because informal caregivers have to provide care, States only have to intervene when absolutely necessary and thus save money. This has been ongoing for many years, demonstrating that we are living in a care crisis already, and informal caregivers are the ones who have been, in part, the saviours of care.

Consequently, on the one hand, AI-driven technologies are painted as the solution for care receivers' needs as well as healthcare professionals' duties to be fulfilled; on the other, there is an already increasing responsibility on informal caregivers to help alleviate responsibility from States. The two issues should not be separated–though they currently are for the most part. Indeed, the two issues instead need to be studied together. This becomes a question of reframing the current discourse around AI-driven technologies in order to account for informal caregivers. This thesis stands at this intersection by investigating informal caregivers in AI research. Put differently, this thesis looks into the development of AI-driven technologies, by investigating the inclusion of informal caregivers.

This thesis, *reframing robots for care*, is based on two empirical studies and two theoretical-based papers. It investigates current AI-driven research practices into health care, as well as offers how to include informal caregivers into the development of AI-driven technologies. The thesis is based in critical social sciences in order to reflect and question the current status quo on health care technological developments. The empirical studies have been conducted within the field of human-robot interaction, which investigates possible robotic solutions for society in the future. The first study investigated how this research community involved informal caregivers. The findings indicated an overlook of informal caregivers generally, yet they were expected to be relied on for the successful deployment of robots. The second study introduced informal caregivers under the age of 18 and how robots could be designed to include their needs. The first theoretical paper introduces *socio-legal robotics* as a concept to warn developers of AI-driven technologies that adaptive technologies will reflect norms, which need to be accounted so that these technologies do not reflect unwanted norms. The second theoretical paper draws on the first one to showcase how *norms-in-the-loop* need to account for informal caregivers under the age of 18. Altogether, this thesis demonstrates that there is a possibility for informal caregivers to be included in AI research, and how AI-driven technologies can be developed to help them directly.

Reframing robots for care offers new insights and critical reflections on the tech-positive discourse for health care, by directly situating informal caregivers in it. Informal caregivers have been and will continue to play a vital role in care provisions. AI-driven technologies can directly account for them so that their care burden does not increase, as well as acknowledge their relationship to the care receiver. This thesis also offers new insights into how development of AI-driven technologies must also account for informal caregivers under the age of 18.

Populärvetenskaplig sammanfattning

Artificiell intelligens (AI) för hälso-och sjukvård framställs ofta som lösningen på den hotande vårdkrisen som snabbt närmar sig. Under de senaste åren har löften om AI-driven teknologi verkat mer inom räckhåll, särskilt med framgångarna med stora språkmodeller – som ChatGPT och DeepSeek. Detta gör AI-driven teknologi till en trolig kandidat för att bemöta den hotande vårdkrisen, särskilt med tanke på en åldrande befolkning och otillräcklig vårdpersonal. Det förväntas därför att robotar och liknande teknologiska AI-drivna lösningar kommer att kunna tackla denna utmaning, till exempel assistent-robotar som ger vård till äldre, eller tekniska kompanjoner som bemöter ensamhet. Kort sagt, förutses det att AI-driven teknologi kommer att bli vårdens räddare. Ändå förbiser denna prognos en viktig intressent: informella vårdgivare.

Informella vårdgivare är anhöriga och vänner som ger vård till någon som behöver det. Informella vårdgivare kan vara både vuxna och barn under 18 år. Vårdansvar kan variera från att ta vårdtagaren till läkarbesök, att övervaka medicinering, samt att säkerställa deras allmänna välbefinnande, utan att ha utbildning att göra det. Informella vårdgivare är inte utbildade att ge vård och får vanligtvis inte ersättning för sitt vårdansvar. Ändå har många samhällen i allt högre grad förlitat sig på dem, bland annat på grund av budgetnedskärningar i hälso- och sjukvården. Tanken är att eftersom informella vårdgivare måste ge vård, behöver staten bara ingripa när det är absolut nödvändigt, och därmed spara pengar. Detta har pågått i många år, vilket visar att vi redan lever i en vårdkris, och att informella vårdgivare delvis har varit vårdens räddare.

Följaktligen framställs AI-drivna teknologier å ena sidan som lösningen för vårdtagarnas behov samt vårdpersonalens skyldigheter, å andra sidan finns det ett redan ökande ansvar för informella vårdgivare. De två aspekterna bör inte separeras – även om de för närvarande ofta gör det – utan istället studeras tillsammans. Detta handlar om att omformulera den nuvarande diskursen kring AI-driven teknologi, för att ta hänsyn till informella vårdgivare. Denna avhandling tar plats i denna skärningspunkt och undersöker informella vårdgivare inom AI-forskning. Med andra ord undersöker denna avhandling om och hur informella vårdgivare är inkluderade i AI-driven teknologi och bidrar med möjliga perspektiv på hur de kan inkluderas.

Avhandlingen *reframing robots for care*, är baserad på två empiriska studier och två teoretiska artiklar. Den undersöker hur nuvarande AI-baserade forskningsmetoder fungerar, samt visar ett alternativt sätt att inkludera informella vårdgivare i AI-driven teknologi. Avhandlingens ramverk är baserat inom kritisk samhällsvetenskap för att reflektera och ifrågasätta den nuvarande status quo för vårdens tekniska utveckling. De empiriska studierna har genomförts inom området människa-robotinteraktion, vilket direkt undersöker robotars möjliga implementering i samhället. Den första studien analyser hur detta kan involvera informella vårdgivare. Den visar att informella vårdgivare i allmänhet förbises, men samtidigt förväntads ta ansvar för framgångsrik användning av robotar. Den andra studien fokuserar på informella vårdgivare under 18 år och hur robotar kan utvecklas för att inkludera deras behov. Den första teoretiska artikeln introducerar *socio-legal robotics* som ett koncept för att uppmärksamma utvecklare av AI-driven teknik att adaptiva tekniker återspeglar normer, vilka måste beaktas så att de inte återspeglar oönskade/problematiska normer. Den andra teoretiska artikeln bygger på den första och visar hur *normer-i-loopen* behöver ta hänsyn till informella vårdgivare under 18 år. Sammanfattningsvis visar denna avhandling att det finns en möjlighet för informella vårdgivare att inkluderas i AI-forskning, och hur AI-driven teknik kan utvecklas för att hjälpa dem direkt.

Reframing robots for care erbjuder nya insikter och kritiska reflektioner kring den teknik-optimistiska diskursen för hälso- och sjukvård, genom att direkt placera informella vårdgivare i centrum. Informella vårdgivare har spelat, och kommer att fortsätta att spela, en viktig roll i tillhandahållandet av vård. AI-driven teknik kan direkt ta hänsyn till dem så att deras vårdbörda inte ökar, samt erkänna deras relation till vårdtagaren. Denna avhandling erbjuder nya insikter i hur utvecklingen av AI-driven teknik också måste ta hänsyn till informella vårdgivare under 18 år.

Kindly translated to Swedish from the English-language popular science summary by Alva Markelius, the best work wife ever known to (wo)mankind.

List of publications

This thesis is based on the following publications, referred to by their Roman numerals:

Paper I **In Search of Informal Caregivers in HRI: A Critical Narrative Review of HRI Conference Papers**
Laetitia Tanqueray, Stefan Larsson & Katie Winkle
International Journal of Social Robotics, 2026 18(1), 9.

Paper II **Towards a Socio-Legal Robotics: A Theoretical Framework on Norms and Adaptive Technologies**
Stefan Larsson, Mia Liinason, **Laetitia Tanqueray** & Ginevra Castellano
International Journal of Social Robotics, 2023 15(11), pp.1755-1768.

Paper III **Accounting for the Unaccounted in AI & Care: Bringing Young Carers into the AI Realm**
Laetitia Tanqueray & Chris Papadopoulos
Under review.

Paper IV **Young Carers on Social Robots: Introducing Teenagers as Informal Caregivers to HRI**
Laetitia Tanqueray, Chris Papadopoulos, Stefan Larsson, & Katie Winkle
2025 20th ACM/IEEE International Conference on Human-Robot Interaction (HRI) 2025, pp. 381-390. IEEE.

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Author contributions to Papers

Paper I: In Search of Informal Caregivers in HRI: A Critical Narrative Review of HRI Conference Papers

LT, SL & KW contributed to the initial idea of the study and the study design. The articles were collected and analysed by LT. Initial analysis and review of analysis was conducted alongside KW. Once the review performed, LT, SL & KW contributed to further analysis and interpretation of data. LT wrote first draft. LT, SL & KW contributed to review and revision.

Paper II: Towards a Socio-Legal Robotics: A Theoretical Framework on Norms and Adaptive Technologies

SL, ML, LT & GC contributed to the initial idea of the paper. SL led the paper writing. ML contributed to Gender Studies, LT to SoL and HRI, and GC to HRI. SL wrote the first draft. SL, ML, LT & GC contributed to drafts, reviews and revision.

Paper III: Accounting for the Unaccounted in AI & Care: Bringing Young Carers into the AI Realm

LT & CP contributed to the initial conception of the position paper. LT wrote the first draft. CP reviewed and contributed to draft.

Paper IV: Young Carers on Social Robots: Introducing Teenagers as Informal Caregivers to HRI

LT, CP, SL & KW contributed to the initial idea of the study and the study design. The focus groups were conducted and transcribed by LT. The data was analysed by LT. Once the analysis was performed, LT and KW contributed to further interpretation of data. LT wrote first draft. LT, CP, SL & KW contributed to review and revision.

Other publications not included in this thesis

What Norms are Social Robots Reflecting? A Socio-Legal Exploration on HRI Developers
Tanqueray, L. & Larsson, S.
Social Robots in Social Institutions, 2023, pp. 305-314. IOS Press.

Gender Fairness in Social Robotics: Exploring a Future Care of Peripartum Depression
Tanqueray, L., Paulsson, T., Zhong, M., Larsson, S., & Castellano, G.
17th ACM/IEEE International Conference on Human-Robot Interaction (HRI), 2022, pp. 598-607. IEEE.

Sociology of Law for Human-Robot Interaction

Tanqueray, L. & Larsson, S.
Encyclopaedia of Sociology of Law, *(Forthcoming, 2026)*.

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I am so incredibly grateful for this PhD journey, all the lows were met ultimately with far higher highs. I got to be ridiculously optimistic throughout, and that is mostly owing to my surrounding village made up of friends, colleagues, family and the Swedish PhD system.

To my supervisors, Stefan Larsson and Katie Winkle, thank you. I remember the day that I decided to reach out to Stefan to see if he had opportunities for research interns. That decision will change my life. Through this opportunity, he believed that I had the capabilities of being a researcher. A capability I truly did not believe I possessed, but decided to believe him since he seemed to know a few things. Once a PhD student, there were many occasions to travel together, leading to trips all around the world, from Japan, to the USA, without forgetting Wales–leading to an array of anecdotes. The capability Stefan might have underestimated was my curiosity, often leading him to tell me jokingly in the aftermath that, *possibly*, I did not need to ask such questions. So Stefan, thank you for your support, thank you for allowing me to explore and cheering me on, and thank you for the long chats–I cherish it all. Turning to Katie, I first got to see Katie at a conference, and was blown away by her pioneering vision in HRI. Over a year later, Katie moved to Uppsala University, where I was given the opportunity to have her as my co-supervisor. This offer was obviously taken with both hands. Since then, Katie has hosted me in a boot-camp-for-academics manner: I would go there for a week, write for 25 minutes at a time, during which she would review my work, and give me feedback in our allocated five minute breaks. I did feel like I got the equivalent of abs in those short spurts. So thank you, Katie, for your unwavering belief that my work was such a necessity to the HRI community and beyond, and making me an academic Olympian. Thank you for all your kind words and support, and thank you for being my actor to depict a mum in my scenarios for the young carers, despite our similar age. Thank you to both of you, it has been a joy to navigate this journey with you by my side. I look forward to what the future holds.

To my mentor, Chris Papadopoulos. I first came across Chris in a newspaper article on robots for care. I reached out to him to see how I could do similar work, and possibly do a research visit with him. During our virtual coffee, I told him how I would like to do work on young carers, but it would unlikely be my PhD thesis. Chris gave me an ultimatum: I could work with him, as long as I did my study on young carers. This was the loveliest gift, as it allowed me to do what I am most passionate about as my PhD thesis: empowering teenagers who provide care. Thank you, Chris, for hosting me at the University of Bedfordshire. I learnt a lot in those months, and your unshakeable optimism was much needed; thank you for allowing me to believe that anything is possible–even with focus groups.

My most important thank you, my study participants. They were nothing short of incredible people. I often think back in awe of them. When times got tough, the words of those young carers carried me through, especially as I needed to share their words with the world. I often tell people that I believe teenagers are the best people to be around as they are kind, compassionate, clever, optimistic and still believe in this world. I am often rebutted, but then I remember that it might be because, at the end of the day, these teenagers are young carers who share their wonderful virtues on their sleeves that I had the privilege to witness. Thank you, my dear participants, for having faith in me to share your voice. I can only hope that you feel heard, and that the next generations of young carers will too, as the development of AI-driven technologies continues to boom.

I also take this opportunity to thank the charities I closely collaborated with, Liz, Sally, Leanne, Scott, Tom and Jane. I am grateful to all of you for taking time to speak with me and bring my project on young carers to life. Thank you to Andy McGowan for helping me find collaborators and giving me feedback on my research. Your work is so invaluable, your resources are scarce, but you make this world a better place. It was an honour to work alongside you.

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A PhD journey comes with milestones along the way. These milestones take the form of (friendly) examinations. Possibly why I can call them friendly is because of the incredible examiners/discussants I had, Katherine Harisson for my midway seminar and Ericka Johnson for my final seminar. Both these scholars are incredibly sharp, whereby they will point out nuances and complexities, as well as offer much needed insights. It made both these occasions a challenge I did not want to miss the mark on. So thank you, for your eagle eyes and your kind support, you made me a better researcher.

To my colleagues, how can I put five years of interactions into a single paragraph? I hope you know that I would indeed be asking this question to you all as a group if I could–in part so that I could collect my answers and find a trend. However, now is the time to pay tribute to and crystallise all those moments together. First, to the AI & Society research group, thank you to Charlotte, Ellinor, Jim, Kash, Kasia, Jim, Izabella and Jason. Thank you for sharing my excitement, including my illustrations for this thesis (!), it made all the mundane feel more sparkly. Second, to the wider team, Ingemar, Åsa, Malin, Riikka, Rebecka, Annika, Fredrik (x3), Erik, Rasmus, Alex thank you for all your wisdom during our lunches. And finally, a very very special thank you to Monika Baranowska, whose office I became very familiar with as she kept my PhD life in check.

To the WASP-HS community, thank you. This community that not only includes generous funding, but also consists of incredible social scientists and humanities researchers on AI in Sweden. It is a community that comes together through courses and conferences, and where friendships are made to last. Thank you for the funding, which allowed me to see a whole new world and undertake my study with young carers. Thank you especially to Ericka Johnson and Eva Sjöstrand for being the dream team behind all these opportunities. I must also thank you both personally for accepting to take part in our demo even though I knew that the robot would fail. It truly wasn't you, it was the robot (and my team, I suppose).

Thank you to my hosts during my research stays. Thank you to the Oñati International Institute for the Sociology of Law, Spain, for your hospitality, and your incredible library for Sociology of Law. Thank you to Prof. Ogata for hosting me at Waseda University, Japan, for showing us your latest state-of-the-art care robots and your pioneering research team. Finally, thank you to Dr. Papadopoulos for hosting me at the University of Bedfordshire, England, where I was immersed among wonderful Public Health researchers who taught me so much about perseverance and patience when undertaking qualitative studies.

To the scholars I met along the way, I would like to think that if you are reading this far and I met you at a conference, workshop, or other academic endeavour, then this is for you. I have had the privilege of being among leading researchers–both junior and senior–who taught me so much and welcomed me at their (metaphorical) table. You challenged my thinking and helped me position myself as an interdisciplinary researcher as well as find my voice as a critical social scientist and making it heard.

To my teachers, thank you. I was lucky enough to attend a distinguished high school in the heart of the Brecon Beacons, Wales, with inspiring teachers. Life as a young carer was complicated, but my teachers' love for education was contagious, so much so that here I am today. Thank you for all the support, and generosity, making it a possibility for me to attend.

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Succinctly, thank you to all of you for being part of my walk of life.

What an honour it has been.

Now, let's get to it!

With love and gratitude,
Tish
In Lund, March 2026

Abbreviations

AI	Artificial Intelligence
APPG	All-Party Parliamentary Groups
EU	European Union
FG	Focus Group
HCI	Human-Computer Interaction
HRI	Human-Robot Interaction
SoL	Sociology of Law
STS	Science and Technology Studies
UK	United Kingdom
UN	United Nations

Reframing Robots for Care : Situating Informal Caregivers in the Development of AI-driven Technologies

Preamble

This PhD is a building block of my academic life: I studied law, more precisely English and Welsh Law (LLB) as well as French Law (Master 1), where I became interested in the rights of young carers; I went on to study Sociology of Law at Lund University as a Master's (MSc), where I became an intern for Dr. Stefan Larsson and got introduced to Prof. Ginevra Castellano and robots. This flourished into a collaboration forming the foundation of my master's thesis on bridging Sociology of Law and HRI as well as a paper on design implications of robots for peripartum depression. I was fortunate to stay in the same team for my PhD, with the incredible Dr. Katie Winkle added as my co-supervisor. This allowed me to work with a stellar team on HRI research from a socio-legal STS lens and bringing in my own intellectual interest.

Being part of a prolific interdisciplinary team allowed me to gain insight into *being* a roboticist. I have been a not-so-quiet fly on the wall, and publishing in HRI venues has opened doors to being viewed as part of the HRI research community. This cannot be underestimated, as it will mark the very foundation of my own PhD journey: how to be among the HRI community in order to advance it. Whilst I am a critical scholar, I do not aim to undermine the HRI community, instead I aim to bring a reflection on how we can make better research for society, rather than only for certain stakeholders. This reflection demands grounding in social sciences as well as staying up-to-date with relevant literature and current HRI research practices. However, at times my scientific endeavours forced me to go beyond HRI in order to integrate young carers in AI–hence the title including *AI-driven technologies* and not just *robots*.

My curiosity throughout this journey was to combine HRI, Sociology of Law, and Care. To accomplish this, I was fortunate to do research visits, one at the International Institute for the Sociology of Law in Oñati (Spain) to gain more knowledge on Sociology of Law, both in books and from scholars at the Institute. Another at Waseda University in Tokyo (Japan), hosted by Prof. Tetsuya Ogata, to work alongside robot engineers and experience their work practices. And finally, at the University of Bedfordshire, hosted by Dr. Chris Papadopoulos, where I got to work alongside public health scholars and conduct my research on young carers. I spent over five months at the Institute for Health Research, where I got to experience how scholars in public health involve the community to conduct research. This experience trained me to see the importance of going slow and steady to make sure that communities are respected and heard.

Though my community is HRI through socio-legal STS lenses, I must also position myself beyond my academic credentials. I was a young carer during my adolescence in Wales (UK) and later I became a project leader for a summer camp to offer young carers respite during my Bachelors in England (UK). These experiences allowed me to do my Bachelor's dissertation on young carers' legal status in England and France–a dissertation that marked either a lack of law altogether (France) or a gap between the law and implementation (England), leaving many children having to provide care and not getting the necessary support. I became aware of my own of privilege: I am one among thousands of young carers, and I am lucky to have managed to stay in education to the point of becoming a PhD student. I am an exception because I managed to stay in higher education–I do not say this part with pride but with sadness that young carers by default have more obstacles to overcome. This lived-experience along with the immense literature on young carers has made me an advocate for young carers as I did not see other people in the rooms that I get to be in bring them (us) up. I was time and again with scholars who had not heard of young carers, sometimes telling me that it sounded like I was speaking of illegal child labour. This ignited a fire in me that caused young carers to be an important focal point in this thesis. I therefore chose to undertake focus groups with young carers in England and Wales that was facilitated by my network of young carer charities and only possible by my generous funding.

Besides me being a researcher and a young carer, I have now become the equivalent of the cool aunt by working with robots among friends and new encounters. Casual conversations on robots usually begin with a reference to various science-fiction films. I usually end up having to explain that films are part of the creative industry and create these amazing-beyond-realistic images of possible futures. I also elect myself to be the party pooper, as I then go on to tell them about the capabilities of current robots: Pepper robot, though it has hands and arms, cannot hold anything that is heavier than a letter; Furhat robot goes from one emotion to another in a rather distressing and unrealistic manner when left to do so autonomously (at the time of writing this thesis); not to mention that current commercially available robots' autonomous capabilities are usually animal sounds when touched. Nevertheless, my roles point to an imaginary, a norm that forms people's conception of robots. These very imaginaries should not be underestimated as they play a role that as robotic researchers we can directly feed into. Especially as these imaginaries create a sense of unease from people that do not work with robots, and thus result in more funding to the robotic communities. I will not object that I have benefitted from this myself. Nevertheless, in my eyes, I see the current state as too much of a win-win for roboticists: everyone thinks that roboticists' jobs are really cool and they get funding to keep showing that this is indeed cool. But at what cost?

Chapter 1

Introduction

Introducing a thesis on robots should open with a reference to science fiction literature or film that capture the (imagined) terrifying essence of robots overtaking the world. To my readers, I apologise in advance, I do not find that leap helpful. Instead, I open this thesis with a reflection on an article I read at the beginning of my PhD journey, entitled "*Intellectualizing about the Moon-Ghetto Metaphor: A Study of the Current Malaise of Rational Analysis of Social Problems*" by Richard Nelson (1974). Nelson, a policy scholar, published this article in 1974 to compare the successful moon landing to the ongoing societal issues in ghettos in the US. Nelson showcased the issue of attempting to use rational, technological, and systematic methods that had succeeded in engineering projects–such as the moon landing–to solve complex societal issues (Nelson, 1974). Nelson remarked, "[i]t may simply be enormously more difficult to design policies to equalize educational achievement or to eliminate prejudices, than to design a spacecraft to go to the moon" (Nelson, 1974, p.376). I would dare to argue that this paper could be published in 2026 and still be highly relevant. Indeed, this thesis takes a similar line of argument. It marks the crossover between AI-driven technologies posited as solutions for caregiving on the one hand, and the ongoing societal issues regarding informal care on the other. One follows rational and scalable approaches, the other is local and contextual. One gets continuous appraisal, the other is overlooked.

Writing in strict binaries may be too reductive, though I think speaking of AI-driven technologies on the one hand and informal care on the other is suitable to set the complex scene. Thus, let us then embark on a journey with two beginnings: AI-driven technologies and informal caregivers. The two beginnings mark the current moment, that is 2026 in Europe, neither acknowledge each other much, but both are far from fictional.

One begins with the vision of robots as the saviour of care, which are part of AI-driven technologies. This places robots in the trenches of demographic change, as–*it is often suggested*–there will be too many older people and not enough healthcare staff to be able to meet their needs. Robots are deemed to be a feasible solution, and research continuously showcases this: Pepper robot as the rehabilitator (Sato et al., 2020), the caregiver (Cascone et al., 2021), the companion (Bechade et al., 2019).

The other begins with the current realities of being an informal caregiver. Informal caregivers englobe family relatives and friends that provide care to someone who needs it. This can range from taking the person to their medical appointments, to monitoring medication, to ensuring overall wellbeing, without having training to do so. Due to budgetary deficit, States are increasingly expecting informal caregivers to step in and provide care that would previously have been provided by the State if it has an established welfare system such as the UK and Sweden (Calvó-Perxas et al., 2018; Pavolini & Ranci, 2008). Covid-19 illustrated this, where public services became mostly unavailable and informal caregivers had to step in to fill in that void (Bergmann & Wagner, 2021).

The two beginnings must converge, and this requires a turning point. This thesis is the plot twist: the two protagonists, AI-driven technologies and informal caregivers, are in fact entangled. This thesis shines a light on how we cannot ignore this entanglement and showcases how to ensure that this entanglement is representative of informal caregivers' needs. This rewrites the narrative: AI-driven technologies are not the only saviour of care and informal caregivers are already the saviours of care. Furthermore, informal caregivers will be key to ensure the successful deployment of such intrusive AI-driven technologies into care receivers' daily lives–and by extension, informal caregivers' too.

Let us delimit briefly this thesis. It is an interdisciplinary critical social scientific endeavour situated in health care, bridging informal care and AI-driven technologies (illustrated in Figure 1.1). Firstly, I scrutinise research practices themselves related to health care in HRI, where I am able to critically reflect on current practices as well as suggest alternative possibilities. Secondly, I investigate informal caregivers, in particular those that are under the age of 18 years old. This subgroup has been neglected across AI research, thus I attempt to show how harmful this can be and how it overlooks opportunities to directly help them in that role. This thesis offers some reflections on care receivers and healthcare professionals, but it is only secondary. I did not see my expertise being needed there as researchers attempting to develop AI-driven health care solutions already include those stakeholders.

I am aware that by stating AI-driven technologies and informal caregivers must converge, this overlooks care receivers. Care receivers' role should not be dismissed, how-

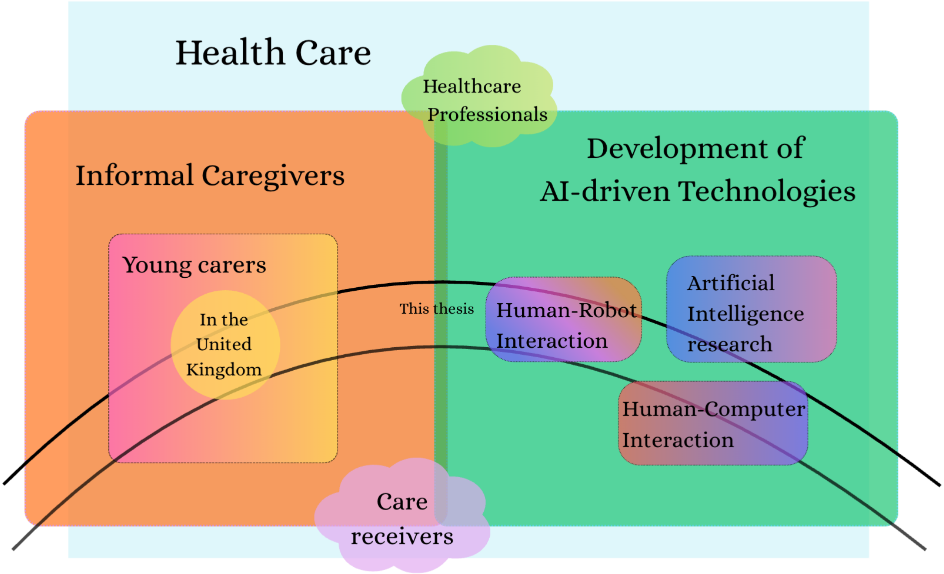


Figure 1.1: An illustration of the thesis' project: bridging informal caregivers to the development of AI-driven technologies in health care, though acknowledging healthcare professionals and care receivers.

ever, the position of this thesis is that AI-driven technologies will likely become part of care receivers' daily lives and will very likely by default impact informal caregivers' as well. I do not take away care receivers' agency, these tools may indeed help care receivers; but I do not account for them, so that I can clearly situate informal caregivers in AI research. Furthermore, speaking in terms of informal caregiver/care receiver is dismissive of the (long) established relationship and the reciprocal care between them. However, for scholarly writing, and need for clear categorisation, I will be reducing their relationship to that (harsh) binary labelling. Consequently, I posit that the convergence of AI-driven technologies should support people in their role as informal caregivers.

Informal caregivers under the age of 18 years old are referred to as "young carers" in the UK. Since my work mostly takes place there, I will use that term. Young carers represent at least 6% to 8% of the child population and is usually a hidden form of care in society (APPG, 2023; Leu & Becker, 2017; Leu et al., 2023). Across the UK, young carers have a specific legal status in an attempt to prevent children from caregiving. Though if children must provide care, laws in the UK posit that local authorities must identify those children and support them to avoid excessive care responsibilities.

This thesis is aimed especially at social scientists in HCI and HRI. This is therefore an interdisciplinary thesis by default. The benefit of this is the bridging of disciplines, demonstrating how one discipline can inform others. The disadvantage is for readers to try and follow the connections I see as essential for my own line of argument, and also the possible dilution of social scientific concepts. Possibly why I have not yet explicitly revealed the theories underpinning this thesis. I want to make sure I lay the ground work to show how I create the story of two beginnings with a mutual ending.

I rely on Sociology of Law (SoL) and Science and Technology Studies (STS) to attend to the development of AI-driven technologies and bridging it to informal caregivers–especially young carers. I refer to this as a *socio-legal STS* framework. SoL allows to in part show the legitimacy of law, whilst also showcasing that having laws in place is not enough to appreciate the realities of the situation. In this instance, having laws in place for young carers does not take away fully the difficulties they face due to their caregiving responsibilities, thus social norms also need to be accounted for. STS on the other hand allows to scrutinise the envisioned use of technologies and impact on human relations as well as reflect on research practices. This is attended to through plans and situated actions as well as STS' conceptualisation of care.

As I infer in my preamble, I do not expect readers to be familiar with young carers. I also expect the readers to question why young carers should be involved in the design and/or evaluation of AI-driven technologies in their role as caregivers and not as children. The short answer: simply because researchers do not want children to provide care, this does not mean that children are/will not be expected to do so. We would simply be amplifying the silence around young carers. The slightly more alarming answer is that commercial companies are increasingly being recruited by public services to find patterns from the data and what can be done. This most likely includes data on young carers, which should be somewhat steered by research findings, and ideally, policies. However, for now, AI researchers are not part of this discussion to do so. Instead, the use of young carers' data and how that data is aggregated is a black box with unknown consequences.

Overall, this PhD project contributes to the discussion of developing AI-driven technologies for care, and how to include less obvious stakeholders. I place myself within the HRI community generally, however, I at times have to go beyond HRI and step into Human-Computer Interaction (HCI) as I have had to start a new research avenue in the AI literature to incorporate young carers. Though, I am also conscious that AI-driven technologies are more likely to be deployed from HCI first, thus knowledge in HCI is also at times furthered in this thesis. Overall, HRI is my testbed for empirical work, HRI and HCI carve my theoretical contributions, and informal caregivers are the stakeholders I attend to.

1.1 Clarification of Concepts

1.1.1 Definition of Key Concepts

Throughout this thesis, I will be using terms for which I expect a common understanding. Here, I provide a table with clear working definitions of these concepts. As those are concepts and not theories, I do not elaborate on them. It is possible to have a different definition for each of those concepts, but for this thesis these are the set definitions.

Table 1.1: Definition of concepts used in this thesis.

Concept	Definition
Health Care	The space between 'health' and 'care' is to demonstrate that it goes beyond that of institutions, such as hospitals or residential care facilities and formal diagnoses of particular diseases or medical (in)capacity. Instead, health care encapsulates providing care for someone to support their healthy living. Such care might relate to overall wellbeing, preventative health care, temporary support following for example an injury or longer-term support associated with ageing and/or long term health issues. (influenced by Tanqueray et al. (2026)). 'Health care' and 'care' are used interchangeably in this thesis.
Informal caregiver	"A person of any age, adult or child, who provides unpaid support to a partner, child, relative, or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse" (Royal College of General Practioners, 2011, p.1).
Young carer	"Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has a chronic illness, mental health problem or other condition connected with a need for care, support or supervision" (Becker, 2000, p. 378).
Artificial Intelligence (AI) research	"[AI] has focused on two efforts: one scientific and one practical. On the scientific side, AI researchers are investigating the mechanisms of 'natural' (that is, biological) intelligence by trying to embed it in computers. On the practical side, AI proponents simply want to create computer programs that perform tasks as well as or better than humans, without worrying about whether these programs are actually *thinking* in the way humans think." (Mitchell, 2019, p.19).
HRI	"HRI focuses on developing robots that can interact with people in various everyday environments. This opens up technical challenges resulting from the dynamics and complexities of humans and the social environment." (Bartneck et al., 2024, p.7).

Table 1.1: (Continued) Definition of concepts used in this thesis.

Concept	Definition
HCI	Similar to HRI, HCI is also a field of study, except that the platform is not only robots but any computer systems. This makes the HCI field a lot wider than HRI, as it can involve smart phones, or drones, or computers–digital interfaces.
AI-driven technologies as artefacts	In line with Suchman (1987) and Winkle (2025), this refers to the appearance of intelligent artefacts. In 2026, this can take the form of a robot that appears to be able to provide care. The type of technology used is ambivalent here, the importance it that is imagined to perform tasks as well as or better than humans.
Social Robot	"A social robot is an autonomous or semi-autonomous robot that interacts and communicates with humans by following the behavioral norms expected by the people with whom the robot is intended to interact" (Bartneck & Forlizzi, 2004, p.592). This definition includes socially assistive robots and word 'robot'. Those artefacts appear intelligent but often do not have the anticipated capacities yet.

1.1.2 Understanding AI-driven technologies

There is an important delimitation in this thesis on what makes up the development of AI-driven technologies. This includes disciplines which rely on AI research methods as well as AI-technologies as artefacts. Though artefacts are still part of research endeavours. This is depicted in the figure below:

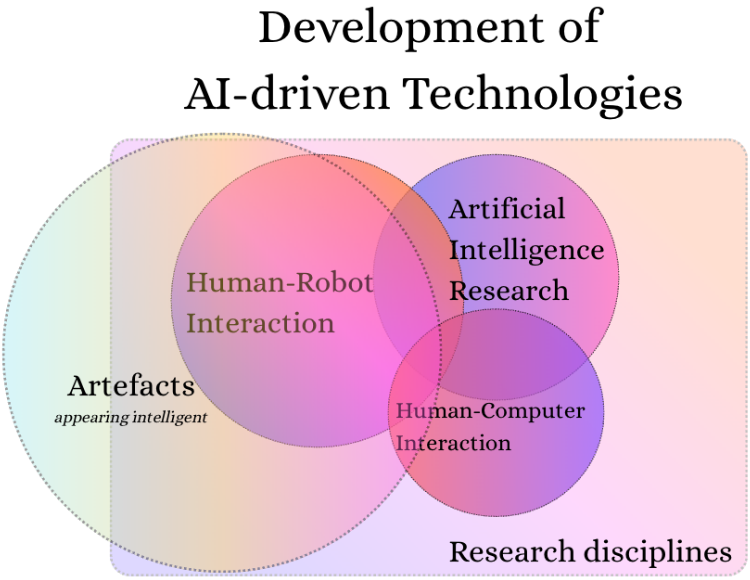


Figure 1.2: Understanding what constitutes AI-driven technologies in this thesis

As Fig. 1.2 illustrates, the disciplines which utilise AI methods in this thesis are HRI and HCI. These are two established fields of research, and are increasingly including AI research within their studies. The use of the word *AI* here is in a research context. An example of this is by incorporating large language models in social robots so that a robot can converse with a human in real time. When mentioning research disciplines involved in the development of AI-driven technologies, I will specifically refer to them as such (i.e. 'HRI' and 'HCI').

Within these research disciplines in Fig. 1.2 are AI-driven technologies as artefacts. The word *AI* here is to be understood in more of its hyped form and does not pertain to a specific research field. These artefacts are hyping an imaginary of *appearing* intelligent. These artefacts which appear to be AI-driven, of interest in this thesis, are developed in research settings to conduct studies, which usually imagine a future use. An example of this is a made up interaction between a social robot and a young carer (see methods section regarding Paper IV). 'Artefacts' are part of the development of AI-driven technologies–which includes robots–and is used as an acknowledgement that these are not neutral and are dependent on discourse (e.g. the looming care crisis, showcased in Paper I) and imaginaries (e.g. science fiction). Not all AI-driven technologies fall under the category of artefacts *appearing* intelligent, since more and more technologies are commercially deployed from HCI and other AI research fields–which is not yet the case for most social robots.

Consequently, the *development of AI-driven technologies* includes various research fields–of interest here HRI and HCI as well as artefacts appearing intelligent–that are still being developed. Social robots materially embody promises that AI-driven technologies are envisioned to do, robots are therefore symbolic artefacts of AI-driven technologies. Though, at times there are discussions of AI-driven technologies beyond robots, since those are closer to deployment. Attending to research disciplines and artefacts allows for a reframing of AI-driven technologies for care in scientific discourse.

1.2 Research Objectives

I have made a point of this thesis being part of social scientific work. Thus, I would like to share this helpful quote on what social scientific endeavours intend to achieve:

> The social sciences predominantly achieve external impacts by influencing people to think about things in a different, more precisely reasoned and better informed way, one that will (hopefully) produce better decisions and societal outcomes than would have been achieved without the presence of these disciplines (Bastow et al., 2014, p.273).

Social sciences therefore tend to bring forth societal issues in the hope of bringing better outcomes to another discipline. In this instance, I use SoL and STS in the fields of HRI, and at times HCI, in the hope to develop AI-driven technologies that are better adapted to demands and needs of end-users–which I demonstrate in this PhD project will include informal caregivers. Yet informal caregivers are overall neglected from the development of AI-driven technologies. By situating informal caregivers into this development, I position myself as a critical social scientist.

Being a critical social scientist implies questioning the status quo, from research practices to the current expected norms in society. As Serholt et al. (2022), scholars who coined *critical HRI*, frame it: "if stakeholders are not involved in design before a robotic solution exists, there is no space for them to reframe the problem or change the design idea" (Serholt et al., 2022, p.420). Put differently, critical scholars question who has been included and excluded, and its possible consequences. I position myself as a critical scientist within the HRI community, and as I attempt to be part of advancing that field, I must look at HCI (an older and more established discipline) to understand how scholars have been critical to make technologies that are more responsive to societal challenges. This thesis showcases my critical social scientific lenses, deriving from SoL and STS which shaped my PhD project, even if those lenses are less predominant in my publications.

Both Bastow et al. (2014) and Serholt el al. (2022) describe the difficulties this thesis faces: a critical social scientific endeavour informs how overlooked stakeholders need to be included in the development of AI-driven technologies; here in the hope that engineers include informal caregivers in their development of AI-driven technologies. In other words, my research attempts to inform the development of AI-driven technologies, but I am not the one to implement these changes in the development of technical systems.

1.2.1 Research Aims

The research aims are grounded in visibilising and situating informal caregivers within AI-driven technologies. This is achieved in two ways: (1) conducting interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in HRI on health care as well at times HCI; and, (2) shedding light on current societal challenges on care regarding informal caregivers, especially young carers, to the development of AI-driven technologies. The first aim is directed at the academic community, whilst the second aim is directed towards society by empowering specific stakeholders in envisioned AI-driven technologies as artefacts.

1.2.2 Research Questions

To answer the aims, here are the following research questions steering this thesis:

RQ1. How are informal caregivers currently framed in HRI studies for health care?

RQ2. How can critical social sciences assist in the development of AI-driven technologies to situate informal caregivers?

RQ3. How can AI-driven technologies, especially social robots, be developed to assist young carers directly?

Each of these research questions are founded on the four papers that make up this thesis along with a socio-legal STS theoretical framework introduced in this thesis.

1.3 Thesis Outline

This PhD project should be understood in two parts. The second part is made up of four published articles–or under review. These articles are the foundation of the first part, which is a meta overview of all four articles–this is what I refer to as the thesis. In the thesis, I offer an introduction to the problem in this chapter. Chapter 2 is a literature review of the relevant research on informal caregivers and AI-driven technologies. The following chapter, Chapter 3, offers the theoretical underpinning to the thesis, namely from SoL and STS. Then, Chapter 4 describes the methods for the empirical work undertaken for this PhD project. Chapter 5 summarises the research findings from each articles that compile this thesis. Chapter 6 provides a discussion which ties the theoretical underpinning, methods and findings together. The final chapter marks the conclusion of this thesis.

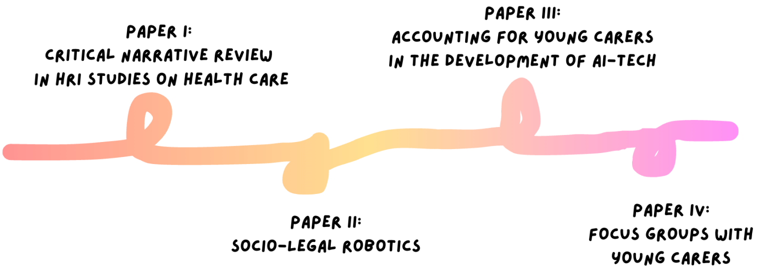


Figure 1.3: An illustration of the four papers included creating the foundation of this thesis.

Chapter 2

Literature Review

This chapter ordinarily has to demonstrate the latest state-of-the-art research that is the focal point of the PhD thesis. As is clear from my introduction and aims, the object of this thesis is to bring awareness of informal caregivers into the development of AI-driven technologies. In part 1, I showcase the realities of informal caregivers, especially on young carers. This is followed by part 2, which focuses on state-of-the-art research on the development of AI-driven technologies in health care; as well as critical literature within AI-driven technologies, especially HRI.

2.1 Part 1: Background on Informal Caregivers

The definition used in this thesis regarding informal caregivers includes children as well as adults, who are partners, relatives or friends, to the care receivers. Informal caregivers will usually provide care due to "frailty, disability or serious health condition, mental ill health or substance misuse" (Royal College of General Practioners, 2011, p.1), though will not be trained to do so.

A vital point when speaking of informal caregivers is their established relationship to the care receiver. This relationship is beyond the care they provide. This is in stark contrast to healthcare professionals, who are not expected to create any meaningful long connection to their patients. This has consequences on how we can view informal care: due to the lack of clear boundaries of the relationship between the informal caregiver and the care receiver, what the informal caregiver does can be easily overlooked. A study specifically recorded the hours of care from both the care receivers and informal caregivers' perspective (Urwin et al., 2021). On average, informal caregivers were recording 10.5 hours more per week than the care receivers (Urwin et al., 2021), demonstrating the difficulty of conceptualising what falls under caregiving and part of the relationship. This section aims to demonstrate why this is a huge disservice to informal caregivers, and researchers need to attend to people in their role as informal caregivers.

Hoffmann and Rodrigues (2010) claimed that 80% of the care in Europe is provided by informal caregivers, though it is likely that with increased austerity, this number is somewhat higher. Informal caregivers, unlike health professionals, do not have set tasks. Caregiving can therefore range according to the condition(s) being cared for, or the time available to the informal caregiver, or the resources available. This can therefore range from “household chores or other practical errands, transport to doctors or social visits, social companionship, emotional guidance or help with arranging professional care” (Broese van Groenou & De Boer, 2016, p.271), as well as helping with medication and/or rehabilitation exercises, by either administering or monitoring. The description of informal caregivers’ tasks is not supposed to be exhaustive but to give an idea of what is expected of them. Their very role “help[s] prevent or delay the need for institutionalisation of people in need of care or support and are enabling them to remain living at home” (UNECE, 2019, p.2). Though, it is worth pointing that even if the care receiver is formally taken care of in a professional residence setting, informal caregivers will still be present and assisting that person (Coe & Werner, 2022). Coe and Werner (2022) relied on this to caution policy makers against total visitor bans during Covid-19 as families are not merely *visitors* but an invisible workforce in residential and nursing homes.

2.1.1 Realities of Informal Care

An important component when introducing informal caregivers is the budget cuts at State level, if the State has a welfare state in place. As States are attempting to curb public spending, this results in a *new found* reliance on relatives to provide care and a private care market (Pavolini & Ranci, 2008). I emphasise new found in an ironic way regarding family dependence. Part of the establishment of the welfare systems from the 1960s–explained in a rather reductive manner here–was the ‘recognition, rights and redistribution’ of women’s labour so that women could partake in public life (i.e. paid employment) this in turn would lead to the rise of State responsibilities for care provisions (Williams, 2010). However, now States are reversing this trend, and expecting friends and relatives to step in (Broese van Groenou & De Boer, 2016). This first component means that States are trying to find ways to alleviate care responsibilities from State actors, and move that responsibility to individuals–and make it part of civic responsibilities (Giesbrecht et al., 2012; Pavolini & Ranci, 2008). These provisions mean that the care receiver’s family and friends become caregivers by necessity, not because they have capacity to do so (De Poli et al., 2025).

The next component is the issue of identifying and labelling someone as an informal caregiver. Carduff et al. (2014) mapped out three barriers that create obstacles when attempting to identify people as informal caregivers. This was achieved through reviewing caregiving literature, hosting a workshop with researchers who have undertaken research with those caring at the end of life, and focus groups with carers and health professionals. From the results, the first problem with identification is that the increased responsibilities of taking care of someone is often gradual, leading to the informal caregiver identifying more in terms of their relational role to the person they take care of (i.e. spouse, child of, friend) rather than as a caregiver. This labelling thus often emanates from State actors, such as social care workers. Second, as the care receiver's condition deteriorates, the role of informal caregivers will become more encompassing, leaving little time for the informal caregivers to attend to their own needs–which would include being assessed to be recognised and supported as an informal caregiver. Finally, third, there are issues regarding the legitimacy of informal caregivers' needs among health professionals and whether it is for health professionals to attend and identify those needs. This leads to reactive responses from general practitioners rather than proactive. These results are concerning when looking at literature on informal caregivers, where reported negative impacts of care are both physical and emotional (Bom et al., 2019; Deeken et al., 2003). One meta review uncovers the negative impacts of caregiving with higher amount of stress and depression reported experienced by informal caregivers across studies (Pinquart & Sörensen, 2003). More recently, Liu, Heffernan and Tan (2020) undertook a review to conceptualise the term *caregiver burden*, to enable healthcare professionals to assess informal caregivers' needs more precisely. From the review, they found that caregiving results in negative change, due to decreased State care provisions, decreased quality of life–where the authors also point out to insufficient financial resources from informal caregivers–as well as physical and psychological health deterioration. This component, the issue with identification and impact of care, demonstrates how ill-equipped society in general is to cater for the needs of informal caregivers. This is a matter of concern as State provisions increasingly expect families and friends to intervene in caregiving.

There is also an intersectional component. Research has time and again pointed out that informal caregivers are primarily women (Greve, 2017; Pavolini & Ranci, 2008; Sharma et al., 2016). In practice, this leads to modern inequalities, such as women being expected to balance unpaid caregiving for elderly parents as well as provide child care alongside their employment. This has steered scholars, such as Jennifer Nedelsky (2023), to demand reevaluation of care so that care labour can be part of every adults' duty in economic and legal terms, and thus does not only impact women so heavily. Though Nedelsky does not acknowledge that children may be providing care, only that they will need to receive care. Public health scholars have also pushed for more intersectional approaches of informal caregivers to understand their context beyond the gender of the person (Hengelaar et al., 2023). This is important as age, gender, religion, marital or household status, education level, socioeconomic status and ethnicity influence and impact the person differently. One scoping review by Wittenberg et al. (2018) examines informal caregivers' perspectives on how care responsibilities are divided between themselves and healthcare professionals. It finds that roles and responsibilities are often unclear and insufficiently discussed, and that professionals do not consistently incorporate caregivers' views into care planning. From an intersectional perspective, only certain types of individuals would be able to discuss roles and responsibilities to be shared between healthcare professionals and informal caregivers–unlikely to be young carers. To me, this component showcases a core issue of informal caregiving generally: it has a huge potential of reproducing structures that deprives already marginalised people.

There is a final component that is also worth mentioning at the level of informal caregivers generally, which is the amount of care responsibilities that informal caregivers are expected to take on. A good illustration of this is that informal caregivers get a lot of information at the time of diagnosis from health professionals, but this often omits specific information that they would like to have (Crotty et al., 2020). A cross-sectional study in twelve European countries attempt to give three possible solutions on how to support informal caregivers: (1) provide them with some free time, (2) help them to deal emotionally with caregiving, and (3) give them skills to both improve the care situation and to deal with it better (Calvó-Perxas et al., 2018). The reason for the emphasis on providing free time, is due to only four out of 12 countries providing some financial compensation to informal caregivers, though most with specific caveats, as usually the compensation is directed at the care receiver (Calvó-Perxas et al., 2018, p.9). Providing respite and/or training to informal caregivers enhanced quality of care and, according to the authors, is attainable in State provision (Calvó-Perxas et al., 2018). This component is to show that whilst we are aware that current institutions do not respond to informal caregivers' needs, attempts at policy changes are underway.

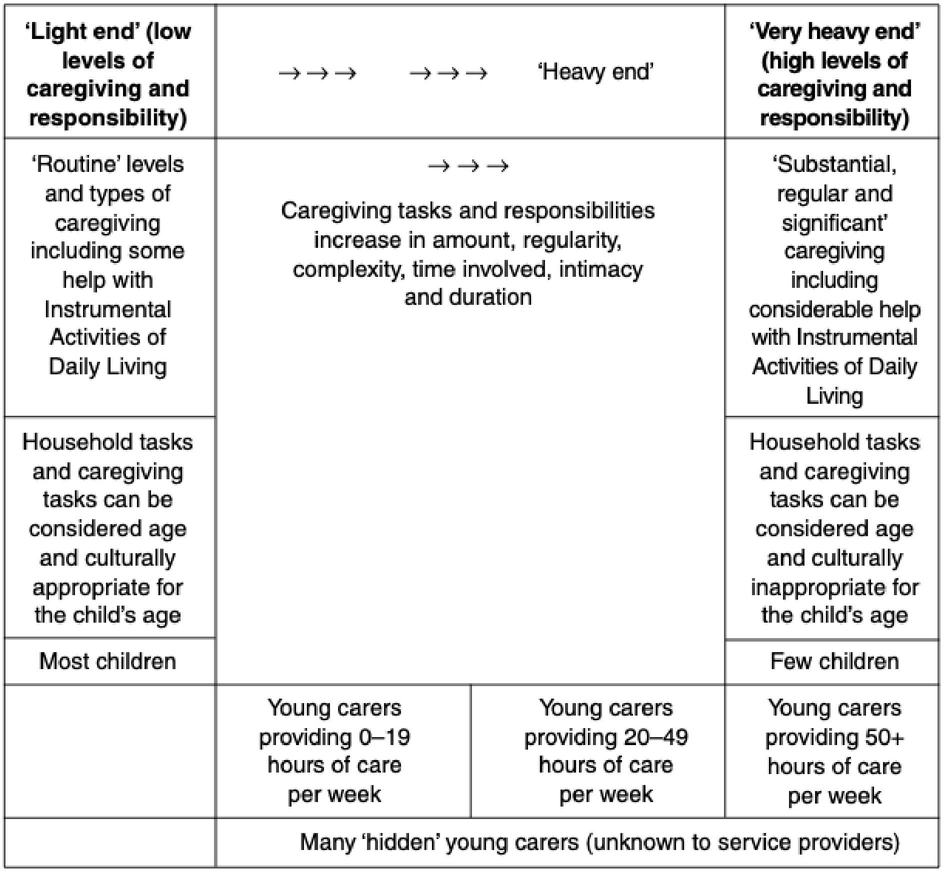
2.1.2 Bringing Young Carers into Focus

Informal caregiver is an umbrella term to refer to any person providing care, whereas young carers delimitates it specifically to children under the age of 18 who provide care. This very fact means that there are slight differences in the care the person is able to provide and attend to since a young carer is under 18-years-old. Young carers might provide care for a sibling, parent, friend, or/and grandparent. The care they provide is essential, especially as public institutions are facing budget cuts–as discussed in the above section.

It is worth pointing out that some disability scholars critique young carer services as they potentially undermine the role of the parent, even if the parent requires some assistance (Keith & Morris, 1995; Prilleltensky, 2004). I therefore want to specifically state that young carers are persons first, part of a family, before being caregivers (this is also recognised in young carer reports, see for example the APPG report (2023)). However, not accounting for children that do provide care is a disservice to them. Consequently, I directly attend to young carers specifically. This becomes more pertinent as young carers are reported to overlook their own needs in order to prioritise others (APPG, 2023, p.36). Ultimately, if young carers are not advocating for themselves, and are overlooked in research, their needs become neglected.

A good starting point to introduce young carers is to differentiate the role of a young carer and the role of a child. This is well sketched by Becker (2007) in Figure 2.1. The Figure shows that household chores are part of children's realities, regardless of whether they are young carers (Becker, 2007). The difference is the increase of tasks and responsibilities, meaning that household chores increase and are more regular and more complex, whilst also involving more intimate responsibilities. An example of this is the child dressing a care receiver or lifting a parent after a fall. Though, Aldridge points out that the impact caregiving responsibilities have on the child should also be an important point to take into account (Aldridge, 2018). Consequently, the tasks of young carers are the same as informal caregivers described above, which can include practical help and emotional support to the care receiver.

Legislation on young carers has been closely monitored and mapped out at two different points by scholars to give an exhaustive list of which States are neglecting, acknowledging or legislating on young carers. The first mapping exercise was published in 2017, where Leu and Becker found that no country achieved the highest categorisation where young carer supported is 'incorporated/sustainable' (Leu & Becker, 2017). The second level down was 'advanced', which includes: (1) exhibited widespread awareness and recognition of young carers, (2) has laws in place and (3) good research base (Leu & Becker, 2017). Only the UK was part of that category. The third level, 'intermediate', included Sweden, which does not have legislation in place, with only some awareness and recognition of young carers among public, policy makers and professionals, for example. In 2021, the mapping was updated and published, marking that no country had achieved the highest category, and still only the UK was in the 'advanced' category, and Sweden still at the 'intermediate' level (Leu et al., 2023). The reason for this scrutiny by young carer scholars is that a lack of formal recognition of young carers leaves children to care without support (Nordenfors & Melander, 2017). Nordenfors and Melander reflect on the case of Sweden and refer to this lack of legal



'Light end' (low levels of caregiving and responsibility)	→→→ →→→ 'Heavy end'		'Very heavy end' (high levels of caregiving and responsibility)
'Routine' levels and types of caregiving including some help with Instrumental Activities of Daily Living	→→→ Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration		'Substantial, regular and significant' caregiving including considerable help with Instrumental Activities of Daily Living
Household tasks and caregiving tasks can be considered age and culturally appropriate for the child's age			Household tasks and caregiving tasks can be considered age and culturally inappropriate for the child's age
Most children			Few children
	Young carers providing 0–19 hours of care per week	Young carers providing 20–49 hours of care per week	Young carers providing 50+ hours of care per week
	Many 'hidden' young carers (unknown to service providers)		

Figure 2.1: Becker's illustration of "A continuum of children's caregiving" (Becker, 2007, p.33)

recognition as as a paradox: by not recognising the child as a caregiver, the child is potentially left with more caregiving responsibilities (Nordenfors & Melander, 2017). Hence the choice to specifically use the UK as a context, since it is well established that as a State, it does the most to legitimise the role of young carers in an attempt to support them.

However, having specific legislations for young carers does not mean that the situation is ideal for young carers in the UK. The UK context presents a complex socio-economic environment. For instance, Vizard et al. (2018) conducted an intersectional analysis of child poverty in the UK, which included a chapter specifically on young carers. This chapter notes that although key characteristics of young carers were recorded, they were rarely analysed separately in public statistics and are often under-represented due to small sample sizes. Nevertheless, Vizard et al. argue that it is essential to explicitly include young carers in data collection and analysis. Their findings reveal that young carers experience the highest poverty rates compared to other groups of children, with poverty in their households increasing over time. The report also highlights that, prior to the 2008 global financial crisis, young carers were relatively protected from poverty–underscoring a deterioration in welfare provisions (Vizard et al., 2018, Chapter 4). Furthermore, research indicates that families requiring care often lacked adequate publicly-provided support (Brimblecombe et al., 2018; Burchardt et al., 2018). This situation worsened during the COVID-19 pandemic, as reduced access to public services forced young carers to assume even greater responsibilities (Carers Trust, 2020; King, 2021). Collectively, these insights illustrate how young carers frequently become the default caregivers due to insufficient formal care services in the UK.

In November 2023, the first ever enquiry from the All-Parliamentary Group, a cross-party platform at Westminster for MPs and Peers, was published (2023). The report highlighted severe under-identification in schools, significant educational and employment disadvantages for young carers, and growing concerns about inadequate care provision. For example, the report points out that 79% of schools did not keep records on young carers, as well as an up-to six-month waiting lists for some children to access young carer needs assessments. The report stresses the urgent need for better data, targeted support, and systemic changes to ensure young carers are better accounted for and supported.

Issues with identifying young carers in public services are well reported. For example, attending school is mandatory up until the age of 16 years old in the UK, however, it is reported time and again that young carers have poorer school attendance (APPG, 2023; Kaiser & Schulze, 2015). Furthermore, a study involving 800 teachers in the UK, found that almost half of the teachers said that they would not feel confident that they could recognise a young carer; this study also found that 57% of those teachers said that young carers will hide their situation from figures of authority (James, 2017). Stevens et al. (2024) conducted focus groups and interviews with 133 young carers and 17 parent care recipients to understand their experiences of services and support. Support from schools, from the sample of participants, was appreciated and useful (Stevens et al., 2024, pp.15-16), though some point out that teachers are too busy (Stevens et al., 2024, p.25). With regards to health settings, the APPG report (2023) has pointed out lack of adequate identification and support for young carers. About health settings, Stevens et al. (2024) found that participants faced difficulties accessing Child and Adolescent Mental Health Services', and if they did, the service provided was mostly negative (Stevens et al., 2024, p.14).

Stigma is also important to mention. The person can feel stigamised due to being labelled as young carer (c.f. (Kettell, 2019, p.23)). This 'otherness' (i.e. stigma) has been explored by researchers. This may be because of (1) being a carer or (2) by association to the person they care for; both of which can lead to young carers withdrawing from their social world (Bolas et al., 2007). There might also be (3) a normalisation of the care responsibilities the young person has (Phelps, 2017). This latter may mean that young carer view caregiving and does not discuss it with others. Overall, however, this may be aggravated by the lack of available services for care receivers resulting in young persons filling that care void and thus not identifying as a caregiver (Phelps, 2017).

There are negative impacts associated with being a young carer, such as higher absenteeism and drop-out rates from school (APPG, 2023), as well as anxiety (Masterson-Algar & Williams, 2020), depression (Bowman Grangel et al., 2024) and social exclusion (Hutchinson et al., 2016). Though, there are some possibilities of positive impacts. Cassidy, Giles and McLaughlin demonstrated that there is increased resilience in young people who provide care, as long as it is not overly excessive *and* is socially recognised (Cassidy et al., 2014). Leu et al. accentuate current research on the positive impacts of being a young carer, which include increased maturity, closer relationships to parents, feeling more prepared for life, as well as being more empathetic and compassionate (Leu et al., 2023, p.3). This demonstrates that supporting children in their care role will allow for those children to be able to fulfil their own needs, and not only the needs of others.

2.2 Part 2: Background on AI-Driven Technologies

We now turn to the development of AI-driven technologies. This has a very different tone to the last section. Here the research reports on some insightful findings to demonstrate potential AI-driven tech solutions. These insights are divided into two subsections: one from HRI and HCI, with a focus on their inclusion and exclusion of informal caregivers. The second part shares insights from critical scholars investigating AI-driven technologies. This critical part should not be seen as merely a spoilsport, but a genuine interest in understanding how these technologies can better society rather than reproduce the status quo. The status quo here being what is described in Part 1 of this literature review.

2.2.1 Trends of AI-driven Technologies for Care and Involvement of Informal Caregivers

I begun at State funding issues regarding care provisions in part 1, and therefore begin with funding opportunities on AI-driven technologies. The main trend concerning AI-driven technologies for health care can be summed up as: extremely well funded.

This is not only at national level but also at supranational level, such as the EU, that fund these projects. Here is an extract of a current funding opportunity by the EU, Horizon Europe project, regarding the use of generative AI in healthcare:

> Healthcare professionals face important challenges related to efficiency, patient safety and provision of quality care with limited health systems' resources. Multimodality of health data combined with the available high-performance computing capabilities have the potential to empower effective and accurate use of trustworthy and ethical Generative AI-based solutions, augmented by other AI tools to address these challenges. Generative AI may benefit patients, healthcare professionals and health systems. (European Commission, 2025).

This extract showcases the difference in realities between funding tech-driven solutions and revoking funding on public services. Importantly here, health care is viewed primarily as something concerning healthcare professionals and care receivers, in the call referred to as patient, and not family or friends–some of whom informal caregivers–surrounding the care receiver. On an optimist note, I do hope with all the funding being provided to AI-driven technology, researchers manage to find a solution. However, the framing is too reductive of the realities: caregiving cannot (and should not) be diminished to an individual within a healthcare setting, especially when there is already limited healthcare resources which has led to an increase in informal caregivers to fill that void.

In a similar vein to the funding opportunities, literature reviews in AI research demonstrate that research mostly revolves around patients and healthcare professionals. For example, Al Kuwaiti et al. (2023) reviewed AI-driven technologies in healthcare generally, to demonstrate how revolutionary AI is and will continue to become. To the authors, AI tools can play a role in: "(i) medical imaging and diagnostics, (ii) virtual patient care, (iii) medical research and drug discovery, (iv) patient engagement and compliance, (v) rehabilitation, and (vi) other administrative applications" (Al Kuwaiti et al., 2023, p.1). Another review aims to compare AI-driven technologies to clinicians in disease diagnosing (Shen et al., 2019). Their findings suggest that AI-driven technologies are comparable to that of a clinician. A scoping review on the use of AI-driven technologies for elder care suggests that "AI technologies can satisfy the growing unmet healthcare needs of older adults and compensate for the current situation of insufficient healthcare resources." though the authors remark that more randomised trials are needed to back up this conclusion (Ma et al., 2023). These reviews point to AI-driven technologies as the saviour of care. In turn, this feeds into the narrative that more funding must go into AI-driven technologies since they may help alleviate a care crisis. However, this makes this literature review complicated on understanding the role of informal caregivers within AI research applications, since they are not reported on.

Turning to informal caregivers in HCI research. Issues about informal caregivers have already received some attention. In 2014, Schinkinger and Tellioğlu (2014) published "Design Implications to Systems Supporting Informal Caregivers' Daily Life" to bring awareness of informal caregivers and the importance of designing for them, as they will also be the ones to adapt to the new technology targeted at care receivers. Schinkinger and Tellioğlu point out that this technology can also directly help informal caregivers in order to communicate with professional care services, be part of self-help groups or also monitor among other applications (Schinkinger & Tellioğlu, 2014, p.349). A recent scoping review specifically on informal caregivers was conducted by Premanandan et al. (2024) reviewing 82 articles to outline what IT (information technology) available applications for informal caregivers, along with their use. Their findings point about informal caregivers use IT applications to optimise their information access, such as relevant information related to caregiving, as well as access social support to feel less alone in their situation. Though there were also barriers, which relate in part to privacy concerns, lack of trust in application and lack of time to use the application, to name a few.

HCI researchers have investigated the use of technology by informal caregivers. LaValley et al. (2023) investigated technology-facilitated strategies used between family caregivers and older adults for medication management. The participants pointed out that they were reluctant to use new, targeted digital technologies (such as smart phone apps) because of the time it requires for the caregiver to understand how to use it and then show the care recipient how/when they should use it. Instead, some speak of the makeshift technology they create themselves. Shaffer et al. (2018) used the USA's Health Information National Trends Survey in order to assess age-based variations in caregivers' internet use, both generally and for seeking health-related information. Although the older informal caregivers were less likely to use the internet generally, over 67% of those who did used it to access health information about others. This insinuates that the internet is being used as a platform by informal caregivers for their role as caregivers. Additionally, Messina et al. (2022) reviewed 'iSupport', an evidence-based online intervention developed by the World Health Organisation, in order to provide support and self-learning tools to informal caregivers of people living with dementia. However it was found that informal caregivers were reluctant to use it, as it created a "high level of burden; sense of duty; fear of being misunderstood by others; and difficulty in reaching information" (Messina et al., 2022). These studies demonstrate that technology is being used and/or appropriated by informal care givers, but also suggest a need to better consider informal caregivers' needs and requirements when it comes to targeted intervention design.

There are two studies on young carers which could be said to fall under HCI, although they are not published in typical HCI venues–though neither include AI systems. The first relates to the iSupport app, where researchers consulted young carers to understand how to make that smartphone application accessible to them, such as a design that reflects their own reality, namely illustrations of children caring (Masterson-Algar et al., 2022). The other study was in part interested in creating a phone application that met young carers' psycho-social needs, with the aim to provide support regarding mental health and wellbeing among adolescent young carers (Hanson et al., 2022).

Some HRI studies have included informal caregivers to some extent–Paper I goes into depth on this. Amabili et al. (2022) investigated the use of eWare, a lifestyle-monitoring technology embedded in a social robot with the aim of reducing stress and improving quality of life for both informal caregivers are well as people living with dementia. They report that "the impact of the system in reducing the caregivers' burden needs to be deeply investigated" (Amabili et al., 2022, p.1). Papadopoulous et al. (2019, 2020) tested and evaluated culturally competent socially assistive robots among older adults, describing in one study how they involved informal caregivers (Papadopoulos et al., 2020), although the findings on their involvement are unclear. Laban et al. (2022) investigated the deployment of a social robot to elicit self-disclosure for informal caregivers over five weeks. The preliminary findings showed a positive trend, where informal caregivers shared more and more about their feelings over time. This demonstrates the possibility for robots to help alleviate the care burden through supporting the informal caregiver. Finally, two HRI studies have specifically investigated care receivers and their informal caregivers, which demonstrated conflicting views and interest between the two groups on the design of robots for care (Lee et al., 2023; Winkle & Moradbakhti, 2023).

There is another study that falls within HRI, though it was published to understand the usability and impact of low-cost pet robots (Koh et al., 2022). Koh et al. (2022) set out to do so by analysing reviews of consumers on commercial websites of low-cost pet robots for older adults. Whilst the authors did not explicitly mention informal caregivers, their analysis included the following extract of a review: *"It's really sad that this cat did not last. My elderly mother is devastated....Really, really, really disappointed. [Reviewer 207]"* (Koh et al., 2022, p.10). This points to informal caregivers being directly involved in the use of new care technologies–by being the ones possibly buying the product; leaving a review; and providing emotional support due to robot failure.

2.2.2 Critical Lenses into AI-driven Solutions

This subsection is part of the development of AI-driven technologies, both regarding ongoing research and the artefacts that appear intelligent. Critical scholars have attempted to demystify the promises technology will apparently bring. This subsection presents a fraction of the literature, though remains on the shoulders of giants. It will become apparent that my critical lenses mostly derive from scholars critiquing HRI, which targets mostly robots as artefacts for care.

Within the HRI and HCI communities, scholars warn about advancement in their own fields and demand of their community to hold themselves accountable. One seminal paper by Shaowen Bardzell entitled "*Feminist HCI: Taking Stock and Outlining an Agenda for Design*" (2010) introduces feminism and demonstrates practically *how* feminism can attend to questions within design in HCI (Bardzell, 2010). Bardzell uses a definition of feminism that is targetted specifically at the oppression against women. Since then, HRI and HCI have welcomed this paper and built on it, to include oppression that occurs against but also beyond women.

Building on Feminist HCI in HCI is Dombrowski, Harmon and Fox (2016)'s concept of Social Justice-Oriented Design. Their starting point is that research projects examine or intervene in large scale issues–such as healthcare–which require scholars to engage in (or against) State and/or personal level politics. Especially as those designs will create "new technological objects [which will] afford new practices, social habits, and ways of living and interacting" (Dombrowski et al., 2016, p.1). This must be confronted by the designers and developers, through social justice as a multi-dimensional concept. Here, the authors rely on Lötter's conceptualisation, "at its core, Lötter's conception of social justice centers on the social concerns, obligations, and ethical commitments created through social interactions" (Dombrowski et al., 2016, p.3). This scrutiny must be done at a systematic level, and not only at an individual level. By doing so, the HCI community can hold themselves accountable and create sustainable design for change.

Within the HRI community, this level of reflection and scrutiny was put forward in 2023 by Winkle et al. (2023), in their paper entitled "*Feminist Human-Robot Interaction: Disentangling Power, Principles and Practice for Beter, More Ethical HRI*"–a clear homage to Bardzell. It is worth mentioning that Winkle et al. are quick to explain the importance of having a HRI specific feminist approach as robots, through their embodiment, bring their own challenges. Feminist HRI encapsulates being sensitive to power structures; this can be at an institutional level (i.e. systems and institutions) and individual level (based on gender, sex, (dis)ability). Power is therefore referred to as the *current* configuration of structures, whereby whilst it might benefit some groups, it might also oppress others (Winkle et al., 2023). Winkle et al. (2023) thus offer practical ways for the HRI community to scrutinise their own way of developing and how to challenge the status quo.

There have been numerous critical scholars reflecting on the artefact that is a robot and its promises in and beyond care. Beyond care, Rhee (2018)'s book explored themes around how cultural and technological imaginaries of robots intertwine with histories of dehumanisation and exploited labour, tracing connections across literature, film, and art. Rhee in part argued that anthropomorphising robots–making them seem human–paradoxically reinforces racialised and gendered hierarchies, shaping who counts as "human" and who is rendered disposable. Winkle (2025) relied on sociotechnical imaginaries to demonstrate to the HRI community that HRI work is speculative in nature for now, since robots are not yet deployed. Thus, there is a possibility to reimagine those speculative designs to imagine a different future that challenges expected norms and dominant narratives.

Within care, Sparrow and Sparrow (2006) present a seminal paper among the HRI community as it reflects and argues about the unethical aspect of robots providing care instead of human caregivers. According to them, as robots become more embodied and socially integrated, this raises questions about responsibility, consent, and moral status. Sparrow and Sparrow emphasised that traditional ethical frameworks, developed for human-human relations, struggle to address scenarios where robots touch, assist, or care for humans, and called for proactive engagement regarding autonomy, vulnerability, and dignity in human-robot interaction. This article dates back to 2006, however this offers initial exploration on the then emerging, and continuous, ethical challenges posed by physical interaction with robots. Šabanović (2010), another seminal paper in HRI, introduced the concept of *mutual shaping* between the robot and society. Robots embody social values and norms, and their design and use influence–and are influenced by–care practices, ethics, and expectations. The paper calls for participatory, context-sensitive approaches to human-robot interaction to avoid reinforcing stereotypes or neglecting real-world complexities. Johnson's article *Pepper as Imposter* is boldly asking readers to reflect on bringing Pepper robot into care settings, where Pepper might not perform according to expected outputs. Pepper performs scripted gestures and conversations that simulate care, but does not undertake the care work it supposedly will alleviate. Put differently, *imposter* is used not in the sense of deception, but as a result of robotic applications being created by policies, HRI researchers' expectations and funding opportunities–which might not present actual solutions. Hence, Pepper imposters on the event, instead of alleviating the said issue.

There have been critical reviews on the promise of robots for care. One narrative review by Frennert, Persson and Skavron (2024) was conducted on assistive robotics design, demonstrating the need to look at underlying assumptions on the framing around disability and how to account for more user-centred–as well as the meso and macro systems at play–to ensure that these technologies will be used in the future. Another review, by Maibaum et al. (2022) critically examined the promises and assumptions behind introducing robots into health care, arguing that techno-optimistic narratives often overlook the complexity of care work and the relational, ethical dimensions of caregiving within elderly care. Concluding that elderly care solutions are often driven by top-down demands rather than grounded in demands from those directly involved in providing care.

Critical scholars empirically investigating robots for care target elderly care. Arnelid (2025) explored welfare technologies in municipal care organisations and robotics research. This exploration showcased how technologies are imagined and implemented in Swedish elder care, revealing how these innovations often renegotiate traditional ideals of relational, human-centred care into more efficiency-driven, task-oriented models. Shin and Jeon (2024) undertook ethnographies to understand the use of robots for companionship in the home of older people in South Korea. Their results point to what they refer to as a *robotic multi-care network* that connects older adults, caregivers, welfare institutions, family members, and technology providers; showcasing that robots are not stand-alone devices but nodes in a sociotechnical system which require human assistance. Persson et al. (2023) explore through observations and interviews how professional caregivers' skills and judgments shape the use of robotic animals in dementia care. It shows the dependence on caregivers' ability to interpret residents' needs, adapt interactions, and integrate the robots into care routines. This echoes Shin and Jeon, whereby for the successful deployment of care robots, they require human care. Finally, Wright (2023)'s book, boldly entitled "*Robots won't save Japan*", reports on ethnographic work done in robotics research labs and elder care facilities as well as analyses government strategies and policy frameworks promoting care robots. His work demonstrates that technologies reconfigure caregiving into a more mechanised, efficiency-driven model, undermining human relationships and social interactions. Wright concludes that sustainable elder care solutions must go beyond techno-fixes to prioritise human-centred care.

Chapter 3

Theoretical Lens

This chapter outlines the theoretical lens of this thesis. As Figure 3.1 attempts to depict, it is an exercise of wearing two different types of lenses that make up (my) pair of glasses–in this case Sociology of Law (SoL) and Science and Technology (STS)–to frame and converge informal caregivers and the development of AI-driven technologies. This chapter marks the foundation of this thesis to answer the aims, which are (1) to conduct interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in HRI on health care as well at times HCI; and, (2) to shed light on current societal challenges on care regarding informal caregivers, especially young carers, to the development of AI-driven technologies.

SoL and STS are both their own disciplines that by the end of this chapter I bring together, and refer to as a socio-legal STS framework. I, in essence, create a puzzle from different puzzle pieces. In other words, each individual puzzle piece (marking a theoretical concept) has its own importance within the overall puzzle. Altogether, these puzzle pieces create a bigger and clearer picture which marks the very foundation of this thesis. This endeavour demonstrates the nature of interdisciplinary work: a dynamic mix of theories (in this case, rooted in critical social sciences) to inform a particular field, here HRI and at times also HCI, to situate informal caregivers.

In this chapter, there will be two sub-theoretical concepts from each discipline. From SoL, those will be (1) the power of law and (2) social norms; from STS, those will be (1) plans and situated actions and (2) care. Both disciplines derive from the social sciences, and ultimately aim to study people, their interactions and their communities. SoL focuses on various social and legal norms emanating from society and subgroups–the importance here is that SoL targets human relations. Whilst STS focuses on the mediation of (human and other beings') relations through technology as well as prac-

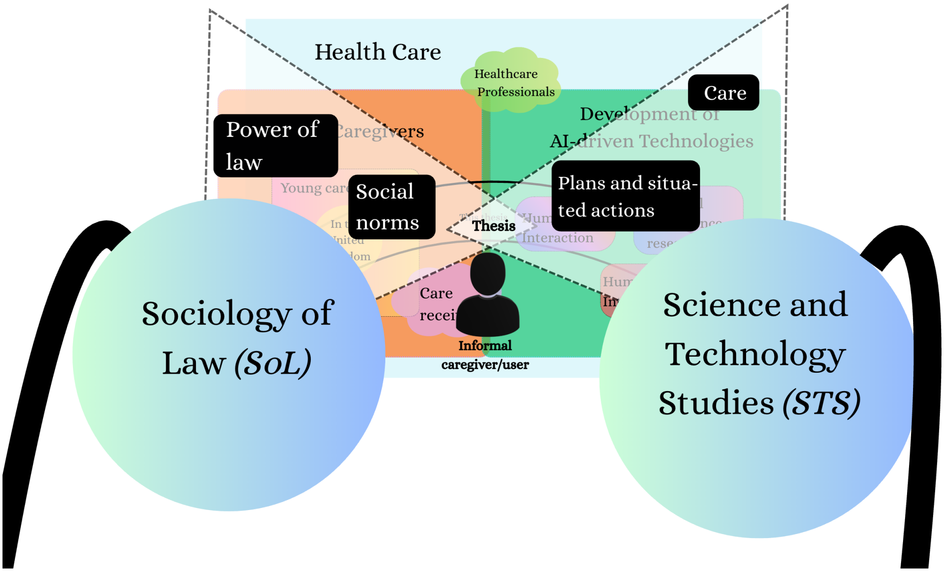


Figure 3.1: An illustration of the theoretical lenses used in this thesis. The lenses are represented through a pair of glasses showcasing two major disciplines, namely SoL and STS, and theoretical concepts used within those to give a clear (over)sight in this interdisciplinary thesis on informal caregivers in the development of AI-driven technologies.

tices by researchers to provide insights on how to attend to those. Both are compatible and both play an important role in legitimising stakeholders and technologies I investigate in this thesis.

The compilation of papers in this thesis do not have one specific theoretical framework running throughout. However, they share a common red thread, rooted in critical social sciences. Consequently, when concluding this chapter, and the reader is familiar with my socio-legal STS theoretical framework herein, I will demonstrate how the translation of critical social scientific theories were achieved in the compilation of papers founding this thesis. This showcases that the theoretical underpinning–the blue print–of my own intellectual thinking was present throughout the research process, from conceptualising to writing these papers, it simply could not make itself seen until now.

3.1 Sociology of Law

As someone who began her academic journey as a law student, I have great sympathy for engineers, as I was taught to think of law as something that simply is, and is apolitical. This follows Kelsen's neat description of law, whereby law expresses 'oughts'-statements, meaning that law prescribes, it does not describe. Therefore it is shielded from politics, economics and social matters, since it *merely* creates obligations on individuals to be able to coexist in harmony. This marks the starting point of Kelsen's much acclaimed work, *The Pure Theory of Law* (1941), and the foundation of legal positivism today. Allow me to draw a comparison to engineering here. To me, legal positivism is similar to how engineers are taught, whereby the *ought*-statements are replaced with *if, then*-statements: engineers prescribe instructions through codes which seemingly do not describe society but merely produce a function for the tool to work in society. Unfortunately, law nor engineering are so *neat*. Neither are shielded from influences deriving from society, economics or politics.

I am not particularly interested in whether law is useful or allows equality. Enough research has explained law on informal caregivers and technology separately. On young carers for example, ample of literature has included the recognition and benefits of directly accounting for them. Whilst for regulation of new digital innovations, again quite a lot of literature and opinions are out there on how this can add barriers or opportunities. What I am interested in is that the law in England and Wales gives a particular legal status to young carers. This has power since it is a legal obligation from the State, yet nowhere in HRI literature (and HCI for that matter) do we find a recognition of this legal status on young carers, or young carers generally in the development of AI-driven technologies. Therefore whilst the regulation on young carers attempts to shed a light on them in society generally, research within the AI realm is silencing them. This dismisses young carers, bypassing the legal status of their role, which in turn demonstrates norms within engineering research communities. I therefore rely on the power of labelling through law that offers an entry point on why this oversight has to be remedied (puzzle piece 1)–especially prevalent in Paper III and paper IV, though first theorised on in Paper II. To then turn to the social and legal norms, and its consequences on both young carers and the research community on new digital technologies (puzzle piece 2).

3.1.1 Law and its Power

Turning briefly to what Law *is*. For the purpose of this thesis, I will only mention law in the context of Nation States (laws deriving from States as opposed to international Institutions such as the EU or UN). As Vago (2009) points out, there are probably as many definitions of law as there are theorists of law. A traditional dictionary definition states that law is:

> A rule, usually made by a government, that is used to order the way in which a society behaves (Cambridge Dictionary, 2025).

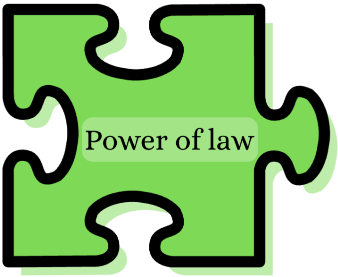
This sentiment is echoed by legal scholars, whereby law is *exclusively* a product and responsibility of the State (Bastiat, 2012). Bastiat defined law as "the collective organization of individual rights to lawful defense. [...] to defend his person, his liberty and his property" (Bastiat, 2012). This definition pinpoints the apparent need for judicial institutions for individuals to exercise their rights; the need for courts and lawyers to interpret laws, but also the role of States in creating laws. Sociologists of Law accept this definition, though even among us there will be nuances. In this thesis, a wider understanding of law must be taken: lawyers nor courts are necessary to exercise the law, but a law still creates and imposes important duties on relevant State actors and institutions. In short, my working definition of law is that law is part of the State and creates obligations on specific actors that will (hopefully positively) impact recipients of the said-law.

Turning to the impact of Law: Patricia Ewick and Susan Silbey (1998) point out that law refigures an event. Often law seems distant to most, but impedes on events when certain norms have to be redefined in legal terms (Ewick & Silbey, 1998, pp.13-14). An example of this is a divorce between parents of young children: parents have a duty to take care of their children, which is more of a *norm*, until the divorce procedure demand that same duty to be defined in *legal* terms. This shows a duality between social norms and legal norms, which will be discussed later on.

Law's impact is dependent on fulfilling specific conditions. As Carol Smart reflects, law can resist and disqualify accounts which do not fall into its set categories (Smart, 1989, p.4). Put differently, law imposes its definition on events so that those events can rely on legal remedies. In this thesis, informal caregivers have a specific legal status in England and Wales, those must be fulfilled through an assessment by the State for the person to be recognised as such and get support.

Puzzle piece 1: Power of law

I am heavily influenced by Carol Smart's approach on understanding the effect of law. Throughout her book, *Feminism and the Power of Law* (1989), she acknowledges that law is not always the best remedy for women or children, and it should thus be carefully considered if law should be relied on at all. However on the flip side, which Smart acknowledges, law holds power:



> [I]t [law] constitutes a kind of institutionalised and formalised site of power struggles–which can provide resources for women, children, and

> men albeit differentially–then it is possible to acknowledge that it [law] remains an important strategic element in political confrontations (Smart, 1989, p.138).

Law therefore presents a strategic entry point to legitimise issues, especially as it is formalised within the remit of the State. Relying on law makes an event part of a legal system by default. In the instance of young carers, this results in a State obligation to identify and assess a person providing care. In turn, this recognition will entitle the person to specific services, such as having regular support or having access to respite activities (usually provided by charities), or even, taking part in my focus groups which required a legal recognition of the teenagers being young carers. Law's power was consequently used strategically throughout this project to confront the current framing of the development of AI-driven technologies and its overlook of an important societal issue.

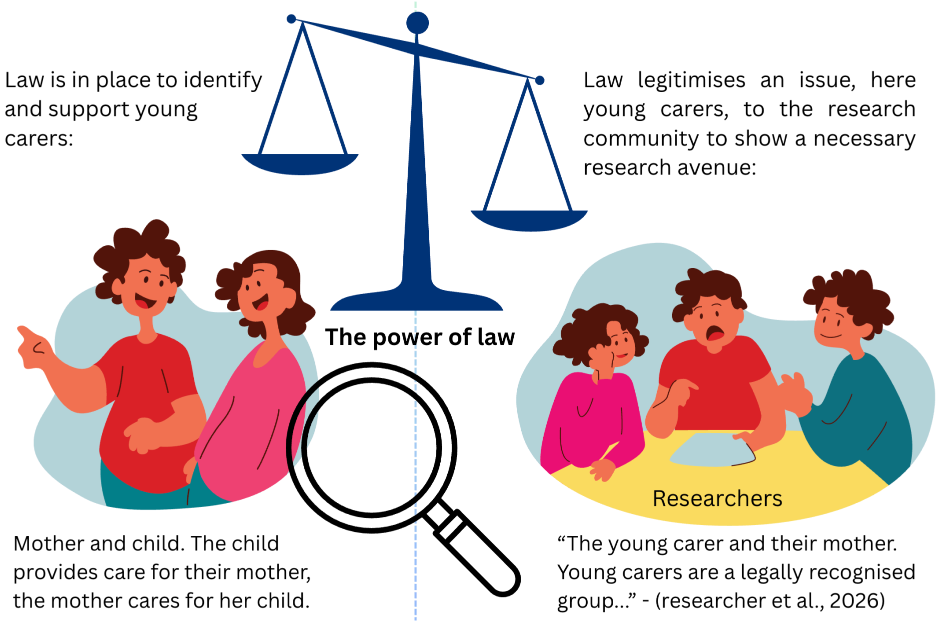


Figure 3.2: An illustration of the concept of the power of law (puzzle piece 1). The scale (symbolising law) is tipping towards researchers to demonstrate that this project uses law to legitimise informal caregivers to the research community. The power of law does not seek to refigure the care relationship, here depicting a child and their mother, but to report on young carers' realities.

As Fig. 3.2 attempts to showcase, law is not used to understand its impact on relations between the caregiver and care receiver. These individual relations are only acknowledged–in Paper III and Paper IV, we mention the reciprocal care ongoing between the care receiver and informal caregiver. Instead, law's power itself is utilised and relied on, in part to showcase that young carers are recognised in legal terms in England and Wales, and in another to legitimise that young carers are an important stakeholder within health care. This legitimisation of young carers has allowed me to hold focus groups with legally recognised young carers and report on their perspectives to the HRI community directly.

3.1.2 Sociology of Law and Norms

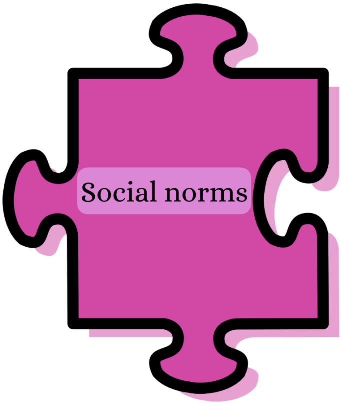
Now that we have established specificities of the power of law, Sociology of Law can be introduced. SoL is a mix of sociology and law. On the one hand, we have law, which has been discussed above. On the other, sociology, which as a discipline recognises that humans affect and shape each other (Banakar & Travers, 2014, p.3). Navigating human interactions and what arrangements are made for humans to do so is part of sociological academic endeavours (Stolley, 2005). SoL thus finds itself in the tension of both disciplines in my opinion (an opinion shared by an esteemed SoL researcher, Banakar (2015)).

Relying on SoL as a researcher means that to fulfil the sociological aspect, research is empirical to provide insights on the workings of society, whilst on the other, the legal aspect is more focused on particular details of doctrinal law and its interpretation to showcase a united legal corpus. Possibly, my thesis seems to lean more towards sociology, since there is little recognition of young carers in the development of AI-driven technologies, I become more interested in reporting on everyday norms young carers face to change research practices so that AI-driven technologies account for them.

I would define SoL in my project as understanding the norms within and beyond law: being legally recognised as an informal caregiver puts a duty on the State to assist and support. The power of law discussed above attends to this legal aspect–though it falls into a SoL endeavour, since it is used as a resource and not scrutinised. Social norms around informal caregivers are also another important aspect in this thesis. In part to understand everyday realities of being a young carer and in another to understand and scrutinise research communities involved in the development of AI-driven technologies, to investigate their own norms and who they account for.

Puzzle piece 2: Social norms

There are two types of norms of interest in this thesis: social norms and legal norms. Legal norms are less abstract and more tangible. Those refer to interpretations and applications of legal texts (Hydén, 2020, p. 412). These legal texts include legal instruments, or applications within the realm of law. Social norms are in contrast a lot broader and can fall in this category.



Turning to social norms, this began as a journey questioning legal positivism, led in part by Eugen Ehrlich (1862-1922). Ehrlich questioned Kelsen's legal positivism, and theorised about how communities came to regulate themselves (Ehrlich & Ziegert, 2017). There is a clear influence from his cultural heritage in his theory; he lived in an area where he could 'observe nine tribes' living together, and politicians of Vienna attempting to enforce their own laws on these heterogeneous ethno-cultural groups (Banakar, 2015, p.137). Ehrlich's focus was therefore on communities/social associations (and individuals being part of those communities) beyond State law (Banakar, 2012, p.18).

In his book, *Fundamental Principles of the Sociology of Law* (2017), Ehrlich begins from the assumption that law dominates life itself, though it is not State law, but what he coined as "living law". Ehrlich viewed legal rules as a subcategory of social norms, meaning that the 'centre of gravity' for laws is social relations and processes (Banakar, 2015, p.35), and not the source of law (such as written regulation). Consequently, a social norm can have characteristics of legal norms even if it does not have the *form* of a legal norm in the State law sense. *Living law* expresses types of legal norms that emanate from outside of the State but have normative power for social associations; Banakar (2012) describes living law as follow:

> a socio-cultural norm [becomes] legal when the group which had introduced it as a standard of conduct attached great importance to its application (Banakar, 2012, p.19).

This showcases that social norms are (1) a standard of conduct by the group and (2) has a great importance to that group (Larsson et al., 2023, p.1758)(Paper II). This enables these groups, referred to as social associations, to be regulated and controlled (Deflem, 2008, p. 110). What is important to note is that (1) State law is not necessary to bring order in society or groups, and (2) social norms are a basis for order/standard of conducts in society and in groups. Though (3) I also want to nuance these first two statements by adding that social norms and legal norms are interlinked. Dobrak (2006) explains that law and social norms influence one another, thus law can also change social norms as well as social norms allow for laws to be created or amended. Changing norms (social and legal) can therefore provide an opportunity to empower

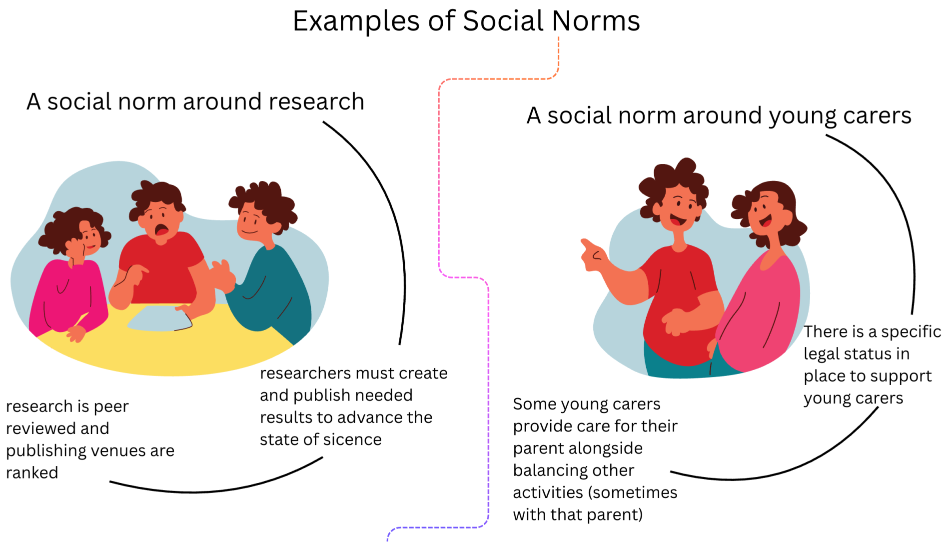


Figure 3.3: An illustration of the concept of social norms (puzzle piece 2). Social norms are applicable to a group of people as a standard of conduct. In the image, on the left side, this depicts an academic publishing standard, whilst on the right it depicts an expectation on young carers.

excluded groups (Wickenberg et al., 2009, p.17). In the context of this PhD project, there are no set legal expectations on what an informal caregiver has to do. However, the development of AI-driven technologies can account for their care responsibilities, through research communities creating and reviewing knowledge, which in turn can change norms to hopefully empower informal caregivers in society generally. There is therefore a duality of norms in this thesis: (1) from the research community, and (2) informal caregivers, as depicted in Fig. 3.3.

Whilst Ehrlich has made important foundational work, I would like to inform readers that this work dates from the 19th century and more work has been done since. Ehrlich's definition should therefore be understood as a building block. Nowadays SoL is an established discipline, and scholars have legitimised the practice of investigating various norms at play in particular settings. The SoL department at Lund University has historically been interested in defining and researching social norms, (c.f. Svensson, 2016, p.39) including the importance of accounting for children's rights (see for example Wickenberg et al. 2009). SoL aims to in part "translate law to reality", meaning that the sociology aspect of SoL complexifies the context of the law in place (Hydén & Svensson, 2008, p. 28). As well as this, this thesis scrutinises the role of social norms in what researchers report on, as well as the reality of young carers' day-to-day lives and how/if the development of AI-driven technology can attend to those.

3.1.3 Takeaways from Sociology of Law

Through SoL, which I use as a synonym to socio-legal, I have been able to challenge the status quo. SoL is my lens for understanding the world. It has informed me on how to use the power of the law to demonstrate the need to take an issue seriously; whilst nuancing the promise of law with social norms in a specific context. This allows to attend to current realities of young carers in the UK and the HRI community.

SoL can be both a bottom-up and top-down approach. A top-down approach aims to highlight policies and role of experts. Since SoL is still quite nascent to issues around AI, there is a need to still attempt to map out how it can do so. Larsson, a SoL scholar, has theorised on the power held by AI developers as they have normative powers in choosing what to reflect of society in their tools (Larsson, 2019). A bottom-up approach aims to uncover what is going on with communities themselves. Myself and colleagues showcased that screening for peripartum depression through robots carries many normative ideas on what it means to be pregnant and have symptoms of depression (Tanqueray, Paulsson, et al., 2022)–not part of this thesis compilation. I also attended and reported on the HRI Conference as an observer to understand how the HRI community 'regulates' itself when little laws (at the time) are in place to guide them (Tanqueray & Larsson, 2023). SoL thus provided a framework on the ordering of human relationships and communities.

SoL in this thesis increasingly becomes engrained in bottom-up traditions to attend to current practices in communities. At first, there is a need to establish that there are likely practices that are overlooking informal caregivers and relying on other (very likely valuable) stakeholders (Paper I), to then tease out more explicitly the need to account for social norms in the development of AI-driven technologies (Paper II), to then introduce directly young carers into this social facet (Paper III), to finally include young carers directly in HRI research (Paper IV).

Therefore, SoL within the context of this project attempts to uncover social practices between individuals and groups of individuals that characteristically forms important norms in their environment. The next section, STS, attends to how technology will mediate and impact those relationships.

3.2 Science and Technology Studies

Science and technology studies (STS) as a discipline has enabled scholars to provide thick critical descriptions of what is going on with a particular technology and in turn how this can directly impact human relationships. As this understanding is required for this thesis, STS provides a necessary conceptualisation key to the theoretical lens to understand and situate informal caregivers in the development of AI-driven technologies.

Briefly, STS attends to the entanglement of science and technology. Science has two meanings: (1) science in the sense of academic knowledge production: how science and technology shape the social world we live in by investigating certain phenomena, which in turn will shape further scientific knowledge production and development of new technologies; and (2) the science of humans (and other beings): the interaction between technology and the being(s) who use or are around that technology, and in turn how that technology impacts human relations. Put differently, there is a continuous full circle moment with STS.

A well-known illustration of this is by Winner's scrutiny of technology in the article *Do artefacts Have Politics?* (1980). In typical STS style, the title is intended to be ironic, as *of course* artefacts have politics due in part to the social, political and economical system embedded in the artefact. One artefact Winner scrutinises is the mechanical tomato harvester, which picked many more tomatoes than manual labour. The harvester was researched and developed in universities, through public funding (through public taxes)–which attends to the scientific academic knowledge production. However, the harvester cost so much that only big established farms could afford it, and were the ones to majorly increase their profits at the loss of smaller farms–affecting human relationships due to technology. This is a direct illustration, as seen in Fig. 3.4, of the reinforcement and entanglement between scientific knowledge, technological inventions, human relations and corporate profit, which are political in nature and rely on various power.

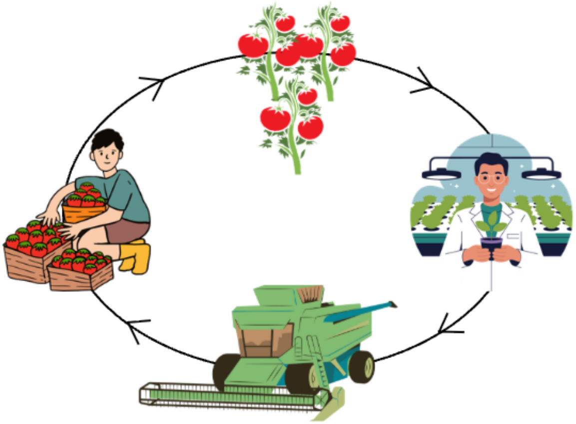


Figure 3.4: Illustration of Winner's mechanical tomato harvester. At the top, the tomato harvest. To the right, a scientist. At the bottom, the mechanical harvester. Finally to the left, the farmer who can afford the mechanical harvester. All is interlinked and affects human relations.

From STS, I will rely on two conceptual frameworks. Firstly, *plans and situated actions*, which attends to the context in which technology operates alongside humans. Secondly, *care* framed in STS, which attends to knowledge production by experts. In this project, STS empowers specific stakeholders regarding the use of technology for care purposes, whilst in another, holds accountable academic researchers who have power to silence certain stakeholders. The word *situated* becomes central, as it emphasises that technology cannot be merely scaled up regarding matters of care, but must be contextualised and critically reflected on for their successful development, and in turn, deployment.

3.2.1 Plans and Situated Actions

In 1987, Lucy Suchman published *Plans and Situated Actions: The Problem of Human-Machine Communication*. In this book, Suchman challenged the foundation of cognitive science in AI research which assumed that human action could be captured and encoded as planning models embedded in machines–a popular belief back then, and a belief still present to this day (Suchman, 1987). Instead, Suchman coined the term *situated actions*, to add nuance to human action: humans will take actions in specific, local and contextual circumstances that cannot be necessarily pre-empted, and consequently, not planned.

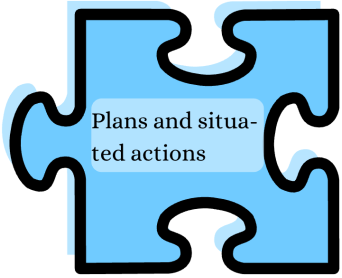
Suchman's work is pioneering, it has been foundational in demonstrating why user studies are a necessity, and not an added bonus. Plans and situated actions questions what is envisioned during the development of technology as well as the (planned) role of the user. Importantly, Suchman states that actions are situated, not necessarily planned, meaning that it is not possible to plan for certain how users will act. Though, Suchman recognises that plans can be part of situated actions, but will not be the sole part of situated action:

> [I]f we are interested in situated action itself, we need to look at how it is that actors use the resources that a particular occasion provides–including, but crucially not reducible to, formulations such as plans–to construct their action's developing purpose and intelligibility. (Suchman, 1987, p.3)

This quote is to be understood as both for (1) the human, how they choose a certain course of action, as well as (2) the machine, that designers will programme to interact with the human in a way that is intelligible to the human in order to make use of the machine.

Another important point is that designers aim for the machine to be self-explanatory. Meaning that it should be clear how to use the tool as needed/expected, so that the human can choose the right course of action for that tool. This will require the designer to imagine the use of a specific machine to anticipate a potential failure. To Suchman, this becomes an issue, as planning is in part 'imagined projection' and in another part 'retrospective reconstructions' of a situated action (Suchman, 1987, p.39), requiring unanticipated conditions to be re-planned in the machine (Suchman, 1987, p.29).

Puzzle piece 3: Plans and situated actions



Suchman's book is based on an empirical study of people using a copying machine which she grounds within the realm of AI, though it is an artefact merely presenting the *appearance* of intelligence (Suchman, 1987, p.3). 39 years on, we do not view copying machines as the most advanced technology available. Yet, as Winkle (2025) points out, roboticists are still at a speculative stage, as roboticists aim to understand how to bring robots into society. Consequently, what roboticists put forward to envisioned end-users are also mostly appearances of intelligent artefacts–much like the copying machines in the 1980s.

Suchman reports on her observations of various end-users operating a copying machine; a machine that is supposedly able to *know* based on a pre-defined planning model to ensure a successful copying experience. However, she demonstrates the flawed assumption of planning models, whereby users face many complications when attempting to copy or remedy their copying issue, and the planning model does not *know* how to assist in most cases. She thus showcases the asymmetry between the people's situatedness and the machine's pre-emptive configuration:

> To get an action *in situ* requires accounts not only of efficient symbolic representations but of their productive interaction with the unique, unrepresented circumstances in which action in every instance and invariably occurs. (Suchman, 1987, p.189) (original author's emphasis).

This underpins the issue of imagining what a *correct* representation of expected users is, whereby the prediction is likely to fail once *in situ*–meaning in the pre-empted real life context. To Suchman, it is possible to account for the unique and unrepresented circumstances through observation. This allows researchers to conceptualise issues rather than imagine, as depicted in a satirical manner in Fig. 3.5. This marks my deviation from this theory: to use the theory to its full potential, I should have observed

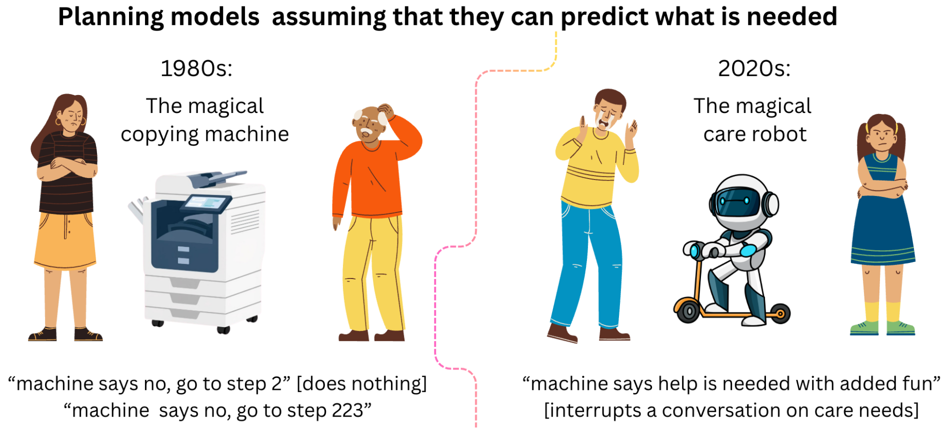


Figure 3.5: An illustration of the concept of plans and situated actions (puzzle piece 3). This is satire, it showcases absurdly badly designed technology, but demonstrates that planning technologies’ actions must be situated in the expected context with end-users for it to adapt to their unique needs.

how informal caregivers generally, and young carers specifically, interact with robots. However, as will be discussed more in-depth in the methods chapter, informal caregivers have not been investigated enough, nor are care robots ready for deployment, to be able to get ethics approval on understanding situated actions for informal caregiving. Instead, I in part rely on past user-studies and undertake focus groups with young carers to understand their own situatedness and how AI-driven technologies–especially robots–can accommodate. This is now possible because of thorough user studies in HRI–which were not being reported on back in the 1980s. My PhD project consequently includes enough on unrepresented circumstances, for now, to showcase that there is a lack of situated knowledge included in the development of AI-driven technology regarding informal caregivers.

3.2.2 Care in STS

Care is one of those abstract terms in STS that is well theorised on, and at times feels overwhelming. Lindén and Lydahl highlight that there is no clear definition of “care” as it is context dependent; though themselves are aware of such a shortcoming, stating “What is *the point* of the notion of care if it can be *anything*?” (2021, p.4, emphasis by original authors). As someone doing her PhD in health care settings, it seems that care is very obvious and very tangible (I can see how I come across as somewhat too positivist here–this could be said to be remnant of my law days). However, I am making a point of bringing STS’s theorisation of care, which showcases that something in the abstract word *care* hides something that this thesis requires to bring understanding to and knowledge to bring forth how as researchers we *need to* *care.*

Fischer and Tronto's definition is often used to define care generally. This is "everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment" (Fisher & Tronto, 1990, p.34). According to Puig de la Bellacasa this definition allows researchers to probe questions such as "[w]hat is included in "our" world? And why should relations of care be articulated from there?" (Puig de la Bellacasa, 2017, p.4). From an STS perspective, Puig de la Bellacasa, demonstrates that the notions of "we" and "our" can allow for non-humans in this definition, though this does not–and should not–discount human's important role in caring (2017, p.217). This mode of *knowing* is often referred to as *posthuman*. Posthuman includes robots as part of providing care and support (DeFalco, 2020). Consequently, care here is to be understood in relation to technology as well as humans, hence why care has to be rooted in STS for this project–as it is not merely about humans.

Puzzle piece 4: Care

Care is often explained in STS through a two-dimensional paradigm. Puig de la Bellacasa's two-dimensional paradigm is situated on who needs to be investigated by researchers. She explains that attending to care as researchers involves the first dimension, which is more obvious: accounting for those who will do the care work and how they will do so. The second dimension is trickier, as it is more subtle: "care connotes attention and worry for those who can be harmed by an assemblage but whose voices are less valued, as are their concerns and need for care" (Puig de la Bellacasa, 2011, p.92). This second dimension, about the assemblage, is to be understood as relations and environments that technologies will impact. Puig de la Bellacasa therefore asserts that care includes less obvious stakeholders. In practice, this means that as researchers, we should attend to the obvious people involved in care, such as the person trained taking care of someone or developing AI-driven technologies for care, but also attend to who is neglected when these technologies are being developed. In this project, the less obvious stakeholder is informal caregivers–depicted in Fig. 3.6.

Lindén and Lydahl also take to a two-dimensional paradigm, but theirs offers insight on operationalising care. They conceptualised a "double vision of care", whereby engaging with care "is both *situated* and *critical*, staying with the practices, specificities and potentialities of care while simultaneously critically interrogating those practices

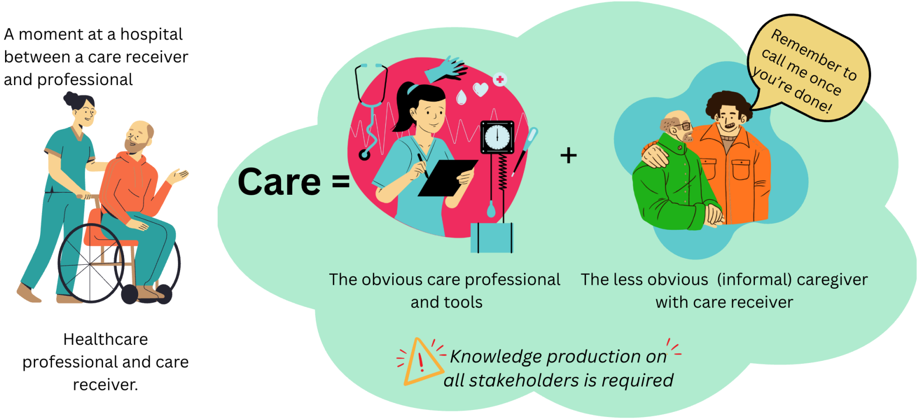


Figure 3.6: An illustration of the concept of care (puzzle piece 4). This attempts to illustrate an event at the hospital, which showcases a patient and healthcare professional. However, it also showcases that someone, an informal caregiver, gave them encouragement and support ahead of the appointment.

when needed" (Lindén & Lydahl, 2021, p.8). Simply put, when investigating care practices, the context is paramount and must be reflected on. Double vision of care's operationalisation of care has two consequences: (1) care that functions in a certain setting might have disastrous effects in another setting, and (2), care practices need to be interrogated and the various layers of care should be reported on.

The bottom line of these two-dimensional paradigms point to the same conclusion: care is not universal and we cannot try to standardise it. Fig. 3.6 attempts to illustrate this by showcasing a snapshot of a care receiver/patient going to a medical appointment: there is the *obvious* stakeholders involved in care, namely the patient and healthcare professionals; but also the informal caregiver in the background who will ensure that the care receiver can get to their appointment and provide some emotional support. Conceptualising care in STS allows for this thesis to situate informal caregivers in a contextualised manner, which in turn offers a *re*framing of care as it posits that researchers involved in the development of AI-driven technologies need to include less obvious stakeholders.

3.2.3 Takeaways from STS

STS has attended to this thesis' objectives by investigating (1) research practices regarding the development of AI-driven technologies for care, and (2) how those envisioned AI-driven technologies risk overlooking unique, unrepresented circumstances that informal caregivers are in.

Plans and situated actions as a theoretical concept demonstrates the issue of planning for a specific action to a situation which AI-driven technologies could replicate.[1] As AI-driven technologies are being developed for care (at this point, mostly still at research level), there is an expectation to find a solution for care receiver and healthcare professionals mostly (see Chapter 2), which will be further expanded on in Paper I. However developing without including informal caregivers' situated knowledge overlooks an important aspect of care.

Care as conceptualised in STS showcases that it is not only the situated context about the anticipated users, but also critically interrogating practices as a whole, which go beyond intended end-users of envisioned technology (Lindén & Lydahl, 2021). This requires researchers to go beyond the obvious stakeholders, to include the overlooked and overheard voices (Puig de la Bellacasa, 2011).

Together, *care* and *plans and situated actions* address realities of incorporating technologies into daily situations. As Chapter 2 discusses, informal caregivers usually lack information and/or training to understand the condition of the relative they help take care of; yet, they know the care receiver well enough to potentially choose something that would suit the care receiver better than another action. Their knowledge is thus by default situated, and does not often fall into a clear pre-existing plan. An illustration of this is the study mentioned in the literature review in Chapter 2 regarding medication management, and how informal caregivers would rather create their own makeshift technology than have to learn about a new tool (LaValley et al., 2023). This displays their inclusion in the technology's assemblage, even if it is not planned for.

Another important takeaway within the conceptualisation of the care is: how as researchers we take care of our community, our participants, our work. Care is truly all around, and it is not simply informal caregivers in this thesis. It is also how I communicate respectfully the shortfalls I see, how I attempt to steer future work to include informal caregivers more, it is also how I share my knowledge and gain knowledge. Care is contextual, and care means researchers reflecting on their own contribution. STS as a discipline has allowed me to kindly confront my own community by attending to practices in HRI (Paper I and Paper IV especially). This has meant turning to theories that are adjacent to STS, such as social justice-oriented interaction design (2016) and feminist HRI (2023) (Paper I). I do not use them in my theory here, since STS speaks directly to what those terms encapsulate. In other words: how to challenge power dynamics and confront the status quo to make room for less obvious stakeholders.

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[1] I am aware that foundation models challenge this to some extent, since it is expected that those models will be a lot more adaptable in real life applications. Though, this expectation is still under research, and likely to still rely on an expected set of predictable (planned) actions.

3.3 Activating the Socio-Legal STS Theoretical Framework

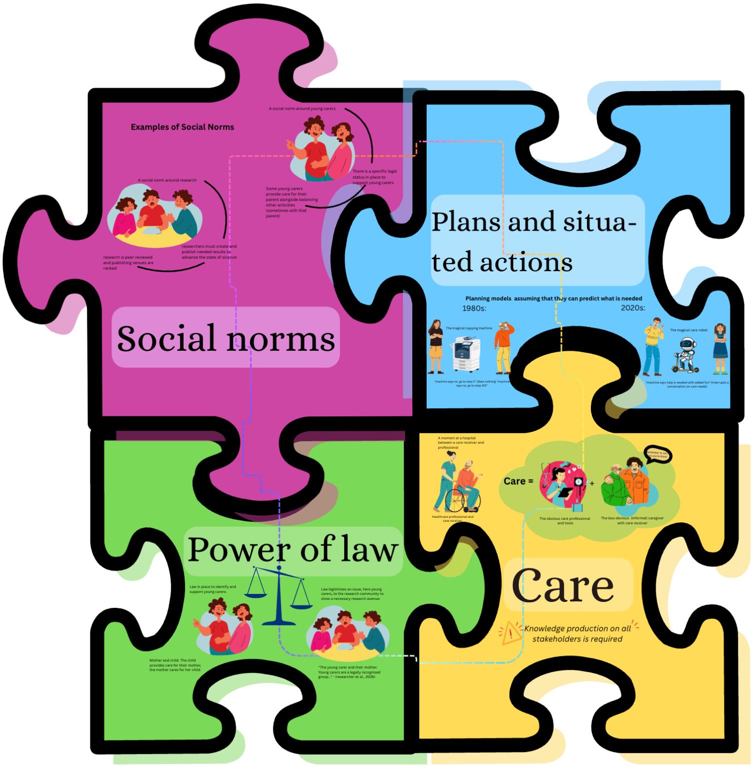

Figure 3.7: An illustration of four puzzle pieces fitting together marking the four theoretical concepts used in this thesis, namely: social norms, power of law, plans and situated action, and care. All four spill over to others pieces to make up a socio-legal STS framework.

And so the puzzle is now complete, as Fig. 3.7 illustrates, creating a socio-legal STS framework. Each puzzle piece has its own important theoretical concept, yet together they bring a fuller picture, demonstrating that there is a need to go beyond obvious end-users whilst respecting human relationships. Through SoL, I zoom in on the human aspect, where I depend on laws and norms and well reported societal issues in academic work on informal caregivers to represent their experiences. Through STS, I zoom in on the interaction between technology and humans, to showcase that technology must be situated and the task that technology is supposed to help with must be critically reflected upon and contextual.

The *power of law* allows me to legitimise the role of young carers in England in Wales. *Social norms* attends to (1) everyday realities of informal caregivers, especially young carers, and (2) research practices among researchers. Meaning that on the one hand, SoL showcases the deficiency of laws in the context of young carers, whilst also reflecting on the research practices in HRI on the development of AI-driven technologies and offering another possibility. *Plans and situated actions* attends to the translation of everyday practices in technology. This theory demonstrates that humans cannot be reduced to predictable actions, consequently for machines to be useful tools, they must consider for the available resources of anticipated users and how the technology can bring value. Finally, *care* is conceptualised to bring to light the role of knowledge production, and how researchers themselves must reflect on who will be impacted by technologies–including less obvious ones–as well as be critical towards potential applications and ensure that they remain situated. Altogether they create a bigger picture which ultimately demonstrates the need to go beyond the envisioned end-users and legal instruments in place to ensure that the development of AI-driven technology is adapted to its context.

I provide a table to demonstrate the theories used in the papers, and the influence of SoL and STS in the papers. These are not necessarily explicitly acknowledged in the papers themselves, but situate the reader on why I put particular significance to those theories for my thesis:

Table 3.1: Understanding the influence of SoL and STS theories in framing my research.

Papers	**Theories in Papers**	**SoL's Purpose**	**STS's purpose**
Paper I	Feminist HRI and Social Justice-Oriented Design	Understand social norms within research groups	Uncover stakeholders involved in HRI for health care (situated actions) and HRI researchers' care practices
Paper II	SoL and Gender Studies	Pinpoint the importance of legal and social norms in technology	Showcase the importance of context (contextual norms) and challenge current knowledge production in the HRI community
Paper III	Socio-Legal Robotics	Illustrate various legal and social norms on young carers and new technologies	Demonstrate contextual norms, the possible situated actions and avenues for AI researchers to care for as well as represent young carers
Paper IV	No explicit theoretical framing	Steer the legitimacy of young carers through law as well as recognise difficulties they face which HRI could attend to	Showcase young carers' situated actions by attending to them directly to present practical applications roboticists can use for their own work in health care

From Table 3.1, what is most important for the reader to understand is my own role:

during my academic journey, I have presented myself as a social scientist in HRI. I have not attended an STS Conference and have little involvement in the SoL community. Instead, those disciplines have shaped who I am as a researcher; how I ask questions and how I perform among academics and among my participants. Put differently, my academic community is HRI, where I publish and often co-host workshops in major robotic venues, such as HAI Conference, RoMan Conference, CoRL Conference, HRI Conference and Humanoids Conference. My role has time and again been to help roboticists do more cross-disciplinary work to better HRI research. My goal has not been to scrutinise HRI for SoL or STS purposes. That makes me an outsider to both these disciplines. Therefore, whilst I use them as my theoretical framework, their role is to aid me in understanding how I can advance HRI research and challenge the status quo of the development of AI-driven technologies currently to accommodate for informal caregivers.

This socio-legal STS theoretical lens marks the foundation of this research endeavour. As a researcher, I have been aware of my privilege to produce knowledge on the future applications of AI-driven technologies. As with most research endeavours, this research plays a very small part, though my hope has been to advance research in a way that encapsulates the realities of caregiving. Consequently, this theoretical lens legitimises the need to do so.

Chapter 4

Methods

Empirically, this thesis has for objective to bring forth (1) research practices regarding health care in HRI and their inclusion of informal caregivers as well as (2) include young carers into the HRI knowledge production. Accordingly, this chapter provides insights into (1) a critical narrative review and (2) focus groups with young carers.

In a sense, this thesis marks a linear journey regarding its research design, illustrated in Fig. 4.1. The starting point was to identify who and how roboticists included stakeholders in their studies (Paper I). From there, it was blatant that there was an overlook of a very important group, namely informal caregivers. This led to theoretically focused work to demonstrate the consequences of this invisibilisation of certain stakeholders (Paper II), and how to account for those, here being young carers (Paper III). To finally empirically bring in those neglected voices, namely young carers, and get their perspective on the development of AI-driven technologies, especially robots (Paper IV).

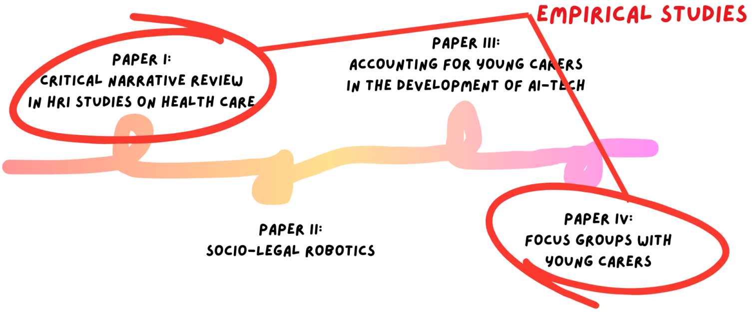

Figure 4.1: An illustration of the four papers, showcasing Paper I and Paper IV as empirical studies.

Accordingly, in this chapter, I showcase the research process, along with methodological and ethical considerations on the empirical studies. Overall, the thesis moves from an initial top-down approach (what experts say; how roboticists are positioning HRI in health care) to a bottom-up approach (asking young carers directly for potential HRI applications), to be able to attend to overlooked invisible care practices that the HRI community, and beyond, should and needs to acknowledge.

This chapter responds to the aims by empirically situating informal caregivers within AI-driven technologies, especially in HRI. It does so through (1) conducting critical social scientific interdisciplinary research on informal caregivers in HRI research on health care, whilst acknowledging HCI; and, (2) shedding light on current societal challenges on care regarding informal caregivers, especially young carers, to the development of AI-driven technologies. HCI will play a role in steering my analysis in Paper I and help conceptualise robot scenarios in Paper IV. It is important to note that throughout this empirical work, I critically utilised AI-driven technologies as artefacts–here being robots–whereby these artefacts seem possible solutions to care, but are still under development with an *appearance* of intelligence. Put differently, robot as an artefact under development is used to show how care is currently framed in HRI research, and how to reframe it to respond to informal caregivers' needs.

4.1 Overview of Studies

This thesis comprises of four articles, of which two are empirical studies. Paper I marks a critical narrative review on stakeholders and methods used in HRI literature concerning health care and Paper IV provides empirical insights from focus groups with young carers in England and Wales. A brief overview of these studies is provided in the table below:

Table 4.1: Overview of Paper I and Paper IV's empirical research design

Papers that include studies	**Sample/Participants**	**Methods**	**Analysis**
Paper I: In Search of Informal Caregivers in HRI	52 articles related to health care published at the ACM/IEEE International Conference on Human-Robot Interaction (2006-2023)	Critical narrative review	Thematic data analysis
Paper IV: Young Carers on Social Robots	13 young carers (aged between 13 to 18 years old) and 3 team leaders	Focus groups, including: vignettes, diaries, video-based robot demos	Thematic data analysis

4.2 Critical Narrative Review (Paper I)

The starting point of this thesis is a critical narrative review as it marks the beginning of my PhD journey–even if it is not reflected in the publication date. Interestingly, this narrative review started as a systematic review to pinpoint the framing of the user in HRI studies, as iterated in our extended abstract (Tanqueray, Castellano, et al., 2022). The systematic literature review, in other words, was not to investigate informal caregivers but to compare stakeholders. Yet, the analysis showed such staggering trends that as researchers–and as someone who was used to staying silent about being an informal caregiver and its impact on me–we had to point it out. This marked an entry point into combining my own interests: HRI and informal caregivers. Ultimately, this turned into a critical narrative review to demonstrate that informal caregivers are absent from studies, even though they are expected to be part of the deployment. This marks a strong case for why this should be my own project and thus is the very foundation of this thesis.

This review took the form of a critical narrative review. A narrative review refers to a specific type of literature review, it does not follow any established protocols and is flexible with regards to predetermined research question or specified search strategy. This type of review demonstrates gaps as well as interconnections in the literature, which in turn allows for theory building (Baumeister & Leary, 1997; Frennert et al., 2024). This resulted in having broad search terms for the study in order to capture as many studies as possible in HRI research concerning health care. Whilst the critical aspect was to critically interrogate research practices and holding the research community accountable.

4.2.1 Choice of Literature

All reviewed studies were published at the ACM/IEEE International Conference on Human-Robot Interaction. The keyword search was: ("health care" OR "healthcare" OR "assistive" OR "impairment") AND ("care" OR "assist*"). This led to 187 hits. Second, according to our inclusion/exclusion criteria, I went through all 187 articles collected to do an initial screening of titles and abstracts, which led to 90 articles being assessed for eligibility. Finally, 52 articles were analysed and included in the review, as illustrated in Fig. 4.2.

Our inclusion criteria were that studies had to (i) be empirical studies, (ii) include participants, (iii) include a robot (e.g. physical or video-based or hypothetical, mechanical or social), (iv) be within the scope of health care (e.g. improving quality of care, bringing some independence to the user or loneliness and companionship,

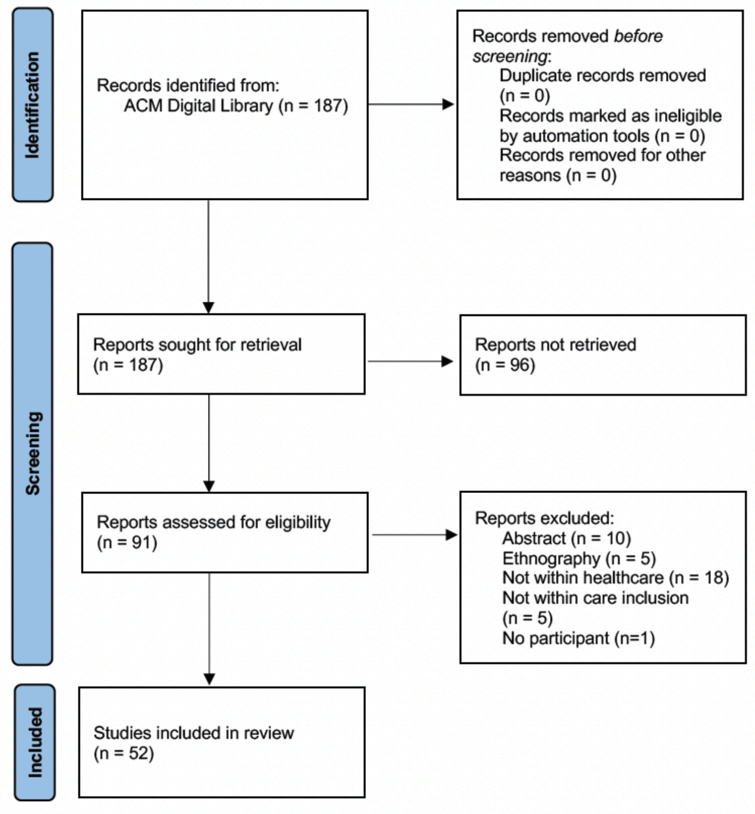

Figure 4.2: A depiction of the screening process for the critical literature review (Paper I)

supporting or motivating the user or/and reduce workload of caregiving), (v) using the robot to help or assist (e.g. with exercises and rehabilitation, monitors the care receiver, or aid the caregiver).

It is worth noting that we had tried different databases to collect relevant literature. However, we were concerned that those databases would not show the most relevant research nor be published in journals and/or proceedings that would demonstrate that these research practices were well established or deemed excellent (this was based on feedback from the extended abstract presented (Tanqueray, Castellano, et al., 2022)). Accordingly, we solely reviewed proceedings published at the ACM/IEEE International Conference on Human-Robot Interaction, as this Conference venue is viewed as highly selective (acceptance rate typically 25% or less) and is considered high quality by the HRI community.

4.2.2 Analysis of Literature

Once the screening stage was complete, the thematic analysis began. This followed Braun and Clarke's five steps to conduct a thematic review (Braun & Clarke, 2006), namely: Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition. We employed an inductive approach–meaning that there were no predefined themes ahead of the analysis. Accordingly, after the familiarisation stage, a pilot test was conducted between myself and Dr. Winkle using the same articles to find initial codes of interest and discuss them into themes and sub-themes. We relied partly on Dr. Winkle's expertise as a roboticist to decide what would be most useful to the HRI community. This created an initial codebook, which defines themes as well as delimits them, and thus creates a systematic approach to coding. I then analysed the rest of the articles on Nvivo, a qualitative analysis software. Since this was an iterative process, I would find new interesting themes, which would be discussed amongst authors.

Ultimately, all authors agreed to specifically report on the following four themes:

1. *How works were justified* within the opening paragraph, i.e. how authors motivated bringing a robot into the care context,
2. *Who* (in terms of role within care) was specifically investigated within the study,
3. *How* studies were conducted and if/how this varied when investigating different stakeholders,
4. *To what extent* (in)formal caregivers are considered in the reviewed articles overall.

The first three themes were based on particular parts of the collected research papers. Regarding (1), this was covered in opening paragraphs; (2 & 3) were mostly covered in methods and findings sections. However (4) was anywhere in the paper, to showcase how healthcare professionals and informal caregivers were still somewhat present in studies even if they were not directly investigated in the study.

The conceptualisation of the last theme is what renders the narrative review especially critical. Indeed, whilst we were identifying a gap, in theme (4) we were problematising it and contextualising why this was problematic (in similar vein to Frennert, Persson and Skavron (2024)'s critical narrative review on assistive robotic technologies). In other words, it went beyond describing and reflecting on trends regarding research practices by investigating informal caregivers' role and adding complexity to their (expected) involvement. To achieve that aim, we relied on Feminist HRI's conceptualisation of power and subject-positioning within HRI (Winkle et al., 2023) as well as Social Justice-oriented Design which is aimed at the HCI community (Dombrowski et al., 2016) only utilising "designing for recognition" and "designing for accountability" to hold the HRI community accountable for how research has been conducted, and who they chose to include within their own studies. Those conceptualisations enabled a nuanced coding, varying from "no acknowledgement" of healthcare professionals and/or informal caregivers to "highly involved" (see Fig. 4.3 for an illustration).

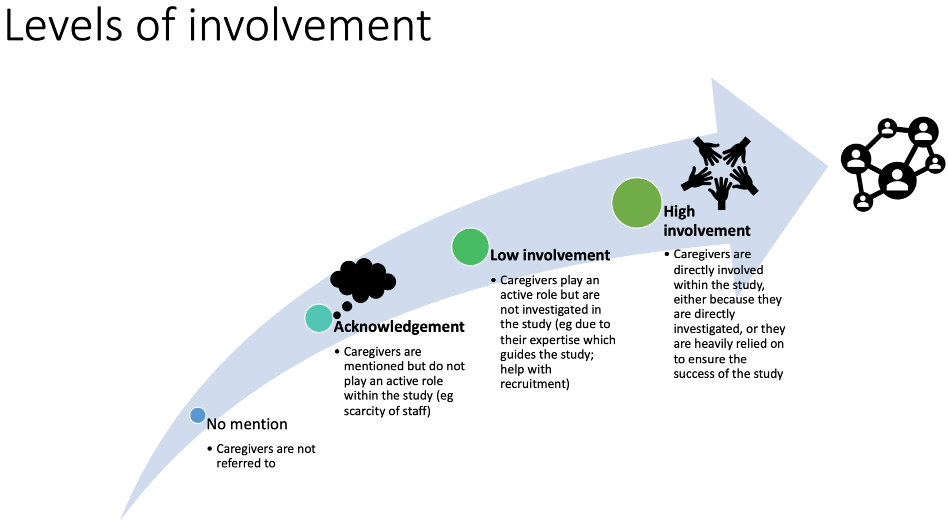

Figure 4.3: A scale illustrating different levels of involvement of caregivers (here encompassing informal caregivers and healthcare professionals) within HRI studies for health care reviewed

The systematic analysis of every article on NVivo allowed for the qualitative data to generate quantitative results. For example, regarding theme 1, all opening paragraphs were analysed and categorised. This allowed us to see trends among all reviewed papers and report this in terms of percentages. This allowed for the translation of a social scientific endeavour into engineering style of reporting to demonstrate the need for critical inquiries in HRI for health care research practices.

The basis of the analysis was grounded within the concept of robots being AI-driven artefacts, as defined in this thesis. Meaning that these robots *appeared* intelligent, but were still at research stage to anticipate how robot capabilities could help in envisioned care settings. Hence the analysis could be critical, as we aimed to hold to account HRI researchers in health care to showcase the necessity to include informal caregivers within this care discourse during development stages.

4.3 Focus Groups with Young Carers (Paper IV)

The critical narrative review showcased the latest research which uncovered the lack of informal caregivers' inclusion. As a side effect of conducting this review, I became highly aware of the anticipated capabilities and usability of robots as well as roboticists' expectations on robots for care. This second study thus represents a building block on top of the first, as I was able to map out potential use-cases for young carers and get direct feedback from them, whilst ensuring that the demands were aligned with HRI publishing norms.

The second study is comprised of focus groups with teenagers (aged 13 to 18 years old) who take care of a parent in England and Wales. Each participant would (in theory) attend two focus groups. The first focused on their experiences, their use of digital technologies and introducing robots, whilst the second showed video-based robot demos of possible applications for young carers and get their feedback.

Focus groups were deemed the best and most fitting method for various reasons. Focus groups provide a space for thoughts and ideas to be shared in a group who share similar characteristics (Krueger, 2014; Peterson-Sweeney, 2005; Stewart & Shamdasani, 2014). In this instance, the participants were young carers–close in age and lived in the same area–I was the one conducting the focus groups, and there was a team leader present at each focus groups. Younger participants may have felt intimidated or uncomfortable speaking to adult interviewers on their own; thus the group setting allowed for the participants to feel safe to share their ideas and foster a more natural flowing conversation between researcher and participants (Peterson-Sweeney, 2005). Put differently, focus groups redresses issues of power as participants feel that they are sharing experiences with their peers and not solely the researcher (Greene & Hill, 2005), whilst also building upon what others have said that they may not have previously considered (McDonagh & Bateman, 2012; Richardson et al., 2009). Another strong reason for focus groups was based on my own experience working with young carers: as a young carer, you tend to keep your care responsibilities quiet to friends and family, but in a setting where it is known that everyone is a young carer, you can be a lot more open about your care experiences. To me, it was important to normalise everyday experiences and show participants that they are not alone–their unusual experience are somewhat usual for young carers. This feeds into another vital reason: I could position myself as a previous young carer and I have the communication skills to be able to be a good facilitator/researcher whilst validating or giving advice based on what young carers told me–key to conducting successful focus groups (Gibson, 2007).

4.3.1 Uncharted Territory: an Overview of the Journey

Young carers had never been researched in HRI before, and in AI research generally. This study thus marked the beginning of a new research avenue. Consequently, even at the point of considering if this study should take place, we did not know if a PhD student conducting this research independently would be the best fit. Put differently, if it were part of an already established research project, there would be more funding and expertise readily available. However, someone needed to pave the way. I decided to do it, on two premises. Firstly, teenagers needed to be easily identifiable as young carers–England and Wales' legislation on young carers allowed for this as the person has to be assessed to get that legal status. Secondly, that I would do it in my own context, meaning that it would have to be in the UK where I was a young carer and had worked alongside young carers also.

To do such a research, I had to be located in the UK. Dr. Papadopoulos, a public health scholar based at the University of Bedfordshire (UK), specialised in informal caregivers and had been part of a much acclaimed project on the use of HRI for healthcare (CARESSES, an EU horizon funded project), accepted to host me. Dr. Papadopoulos ultimately became an essential mentor to this project.

Once the idea of this study was established, the project had to be conceptualised. This required merging (1) the latest research on young carers, and (2) how robots would be able to help. To attend to (1), the literature on young carers has not included the use of AI-driven technologies, though two studies explored smartphone applications for young carers (Hanson et al., 2022; Masterson-Algar et al., 2022). An extensive review of young carer research generally by Joseph et al. (2020) argued that there has been a saturation regarding issues young carers faced, instead, the authors called for more participatory research to directly engage with young carers' needs (pp.9-10). Pointing to a need for this type of research in the young carer scholarly community. Finally, attending to (2), this was achieved through my critical literature review. This allowed for a concrete research plan, and of course, protocols on how to conduct these focus groups ethically.

This study required two ethics applications: one from Sweden and one from the UK. This demanded that both applications had the same content and were legally aligned. An example of clashes in laws between English and Welsh and Swedish laws was the age of consent: in England and Wales, a child can consent from the age of 16, but in Sweden it is 15 years old. We therefore used the "gillick competence" principle to allow children from 15 years of age to consent in the UK. In accordance with UK law, the guardian(s) and/or charities decide if the child/teenager fulfils the "gillick competence", to ensure that the young person is mature enough to consent for themselves. Once this was agreed, the 15-year-old participant could sign the consent form. Since these children were young carers, it was very probable that they would fulfil the competence, so in practice it was not a hurdle. For children under the age of 15, their guardian had to sign the consent form for them. We also had to strictly adhere to the GDPR, such as data storage of sensitive data, where it was decided to use two highly-secure encrypted hard drives, which would be in two different locations, in case one was lost/stolen at any point. This also meant minimising paper traces, thus as soon as the paper form (including consent forms) was on the hard drive, the document could be destroyed. The transcriptions were also done offline so that the audio files were not at risk of being uploaded to servers.

I also had to conceptualise the promotion of the study during the ethics applications. I knew we did not want to have the words "robots" or "AI" appearing anywhere, including at the time of recruiting charities. We therefore resorted to "new digital technologies" throughout the recruitment process and in the informed consent form. The decision for this was the imaginary that comes with those terms, which might result in charities only being able to recruit participants who were interested in robots and AI. Though when speaking directly with charities, I would be transparent that my project was on AI-driven technologies, with a specific interest on robots. However, I would ask them not to tell the young carers at the time of recruitment.

The recruitment process was two-fold. I would first approach a charity from my own network, then they would recruit the participants. I first approached three charities that I had direct experience with. Two of them were very keen and one was unsure why they should take part in this project. I tried emailing various young carer charities across England and Wales. Only one in Wales responded and specifically stated that they replied as they recognised my name from when I used to be a young carer in their sister charity. By this point, three charities agreed to do the focus groups. However, one charity dropped out at the very last minute. This led me to reach out to Andy McGowan, a Policy and Practice Manager at the Carers Trust in the UK, who promoted my study to his network, and another charity came forward. In the end, I worked alongside three charities for these focus groups.

Finally, the focus groups were ready to take place. From the conceptualisation of the study to the first focus group there was exactly one year. Scheduling focus groups required a lot of flexibility. Originally the focus groups should have taken place whilst I was on my research visit in the UK, though this ended up not being the case for most of it.

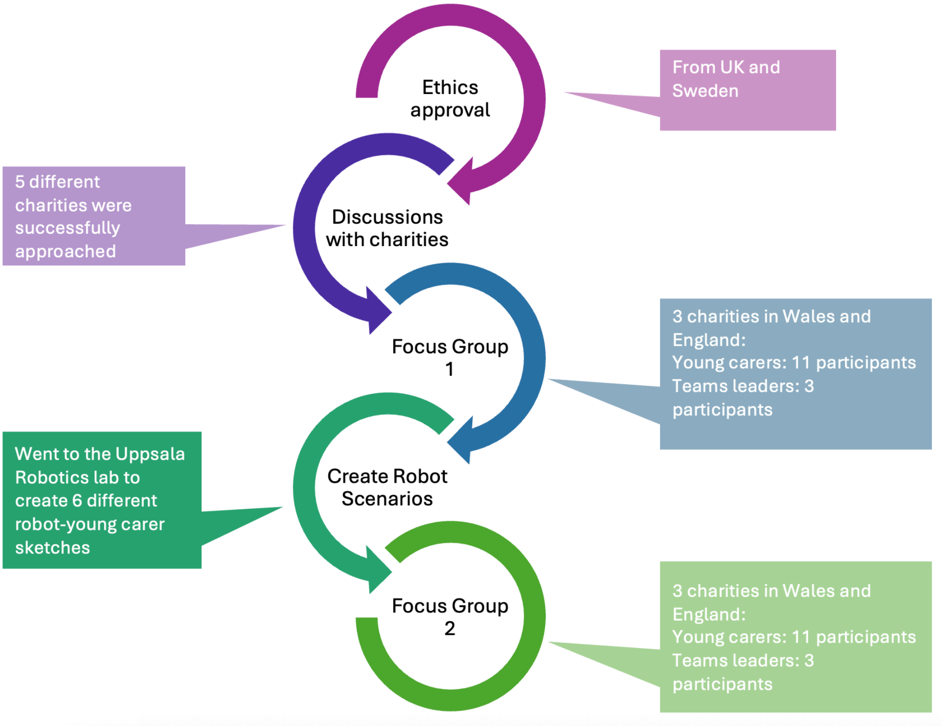

Figure 4.4: Visualisation of the stages leading up to the Focus Groups

Figure 4.4 demonstrates the steps towards the focus groups and the focus groups themselves. For each participant there were two focus groups (in theory). In-between focus group 1 and 2, I created robotic scenarios based on the input from young carers' responses generally and feedback on promotional robot videos.

4.3.2 Participatory Design with Young Carers

Participatory design at its root is about participant empowerment (Vines et al., 2013). This means that as researchers, we must provide the necessary knowledge for participants to articulate and elicit their views as well as design artefacts to either challenge their perception or elicit discussion on the said technology (Vines et al., 2013). Participatory design method is often advocated in HRI as best practice to include participants, especially stakeholders that are viewed as directly impacted by the potential robot application, see for e.g. (Alves-Oliveira et al., 2022; Axelsson et al., 2021; Lee et al., 2017; Nanavati et al., 2023; Olatunji et al., 2024; Winkle et al., 2020). The opposite of participatory design is relying on specialist expert knowledge, whereby experts provide answers to set questions, and those impacted by the answers are not part of the discussion (Schuler & Namioka, 1993). Accordingly, participatory design contextualises and situates a potential application to gain direct insights from a specific community that will be impacted by potential research developments.

Participatory design was an obvious choice to introduce young carers to the HRI community: their voice needed to be empowered and reported on. The findings from participatory design methods would complexify and nuance the social context in which developers envisage the robot to be deployed in for care purposes. This was all the more vital when teenagers have been time and again overlooked in HRI research generally (Cagiltay & Mutlu, 2024). Bringing young carers into HRI was thus not solely about bringing awareness on young carers, but also about how the HRI community can start to account for them and help their everyday life; rather than the roboticists proposing what informal caregivers will have to conform to using.

Within participatory design there is an undertone that there will be mutual learning between the researcher and the participants. Meaning that whilst I introduced participants to robots, participants shared their realities and how or why robots might (not) fit into certain aspects of their lives. There was a continuous reciprocal learning between the researcher and participants during the focus groups. Though as the researcher, I still needed to moderate the discussion to ensure that their responses were helping me create an understanding on what the robots could be able to help with.

The participatory design aspect took different forms in the two focus groups. This was mostly related to our familiarity, especially theirs towards me. In the first focus group, I needed to create a safe space and give more prompts to my questions to the shyer participants. In the second focus groups, they knew me and as a group felt a lot more comfortable with sharing stories. My role became one of a stricter moderator to keep the conversation from going in different directions.

As part of the ethos of participatory design, I was very transparent from the beginning that I used to be a young carer, and when the participants shared difficult stories, I would validate their experience and give them some encouragement. Though it is important to point out that a team leader was present throughout and was the one to intervene if participants shared stories that needed to be investigated, and then I would not transcribe those nor put them as part of my analysis.

4.3.3 The Key Role of Charities

Young carer charities played a central role in my study. During the conceptualisation of the study, I had set up a meeting with a young carer charity to advise me on what I needed to be aware of. For example, according to that charity, they heavily advised me to include children between 13-15 years old as well as 16-18 years old. Contacting charities also enabled me to know if they would be able to support such a project.

Once I had received the two ethics approvals, I set up meetings with each charity to discuss the focus groups arrangements and who could be included. After this debrief and sending them informed consent forms, they were then the ones to (i) recruit young carers, (ii) ensure consent before the focus groups, (iii) book the premises for the focus groups, and (iv) make sure that participants could attend. The charities were represented by team leaders. They were the ones to choose the location; some focus groups were held in schools or premises that charities were based in. Team leaders also chose the dates of the focus groups; some would directly contact young carers on availabilities and/or they would try and time it with exams and other (more fun) activities the charities offered.

Team leaders went above and beyond to ensure that the focus groups could take place. Two team leaders collected some of the participants themselves, either by car or public transport, to get them safely to the premises. The other charity booked taxis for the participants to the place the focus groups were held. If the participants were delayed, the teams leaders would be the ones following up on this.

The team leaders attended the focus groups, in theory this was mostly for safeguarding purposes in case one of the participants became distressed or something was said that needed to be chased up. There were instances where I needed to flag up safeguarding issues, and the team leaders immediately took action. Though in practice, they also took part in the focus groups and answered from their standpoint as professionals in the field; the team leaders were also able to promote events that young carers could participate in or available resources.

It is worth noting that all the participants knew the team leaders.[1] Team leaders are very much the cool adults who are clearly experienced at making young carers feel seen and at ease, often through jokes and banter with young carers. This created a sense of ease immediately at the start of the focus groups. The team leaders were also explicit in their trust towards me and were excited to be there, which allowed participants to feel safe. They acted as my co-facilitators to some extent as well as the safeguarding figure.

A note on the consequence of working with charities. The charities' involvement can be viewed as a delimitation of the potential pool of participants, as in practice it means that those young people have been assessed and identified as young carers by local authorities. This is as opposed to self-identification of a young person who sees

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[1] If the participants did not know that team leader in particular, the team leader would introduce themself and point out that they worked with the participant's assigned team member.

themselves as a young carer. As this was the first time for young carers to be involved in such studies, it was deemed a necessity–as explained in the theory chapter regarding the power of law.

4.3.4 Overview of Focus Groups

Each participant ideally would attend two focus groups, and send a photo diary (no participant did the latter). The attendance of focus groups was very unpredictable. Charities were not sure of numbers ahead of the focus groups, and often participants dropped out by sending a text message to the team leaders last minute (see Table 4.2 for a clear breakdown of attendance).

Table 4.2: Breakdown of attendance for each focus groups

Focus Groups (FG)	**Attendance**
Wales, FG1	young carers: 3; team leader: 1
South West England, FG1	young carers: 3; team leader: 1
West England, FG1	young carers: 5; team leader: 1
Wales, FG2	young carers: 3 (1 new; 1 unable to attend from FG1); team leader: 1
South West England, FG2	young carers: 1 (1 from FG1; 2 others unable to attend from FG1); team leader: 1
West England, FG2	young carers: 7 (same 5 from FG1; 2 new participants); team leader: 1

Though the unpredictable attendance was a limitation of the study itself, it also demonstrated the unpredictability of young carers' role. In the focus group held in south west England, only one young carer and a team leader were able to attend–with the two others not being able to attend last minute to focus group 2. However, this allowed for much more elaborate answers, as well as more time for the team leader to discuss some safeguarding issues flagged from the previous focus group (this was not recorded or analysed). For the second focus group in Wales, one participant had to drop out, but another one was able to attend. In the second focus group in West England, all participants that attended focus group 1 were able to attend focus group 2, though we had two new participants attend focus group 2 as they were unable to attend focus group 1. We attempted to hold zoom focus groups with the ones that missed the second focus group, however this was not possible due to team leaders not being able to allocate more of their resources on this project.

4.3.5 Conducting Focus Groups with Teenagers

At the beginning of each focus groups, I introduced myself as a researcher and previous young carer. I then introduced the project in more depth and all the equipment: a microphone to record the conversation, pen and paper for them to doodle whilst we chatted, a blank letter for them to fill out at the end as a form of diary entry, and my computer as I presented robots on the screen at some point in each focus groups. At the second focus groups, they also had printed-out background stories in case they had issues listening to the vignette. Throughout, I reiterated the informed consent, especially that they were able to leave whenever or decide to withdraw from the study at any point. I also gave them a rough plan with clear times for breaks. Each focus groups lasted at least two hours, with 30 minute breaks overall.

4.3.5.1 Focus Groups 1

I followed Ketell (2019)'s structure for conducting the first focus groups, as it was specific to young carers. Accordingly, once the introductions were made, to warm up the participants, I asked them to describe what being a young carer meant to them (in line with Kettell's opening). Instead of answering out loud, they wrote the words down on their papers then shared those with the group. Once everyone had written something down, each participant had to say what they wrote. This enabled everyone to participate equally, whereby quieter participants had to voice their thoughts and the more confident participants would encourage the others to share. Put differently, it set the tone that everyone's voice mattered and I wanted to hear everyone's individual viewpoint. It also allowed people to feel comfortable using paper to doodle or to write down their answers pre-emptively. Furthermore, it began the flow of the focus groups and allowed me to more seamlessly bridge the discussion based on my questions from the focus group guide and their answer.

Each focus groups were split into three parts (see the focus group guide in the Appendix to see a thorough breakdown). Focus group 1 was divided into three parts:

Part 1: Specifically targeted at looking at social norms, legal norms and stigma.
The aim was to get to know to know my participants and get a glimpse into their everyday lives as young carers.

Part 2: Understanding the use of digital technologies and how those helped with care responsibilities.
The aim was to understand if and what technology my participants were using, and for what purpose.

Part 3: Focusing on robots specifically.
The aim was to introduce my participants to various robots and get their initial feedback.

In this last part, I showed robot commercials available on YouTube. This allowed for feedback on robots generally, for me to keep in mind when creating robot scenarios. This coupled with their answers on their lived experiences allowed me to create scenarios that were closer to what could potentially help the participants. The second focus groups accordingly showed videos of these scenarios which reflected their feedback.

4.3.5.2 Creating Robot Scenarios

Based on the first focus groups, I had some understanding on how HRI applications could help young carers directly. It is important to note that there was a lack of representation in the promotional videos of robots. For example, young carers had difficulty understanding how the robot applications could help them but they could imagine how it could help the person they care for. This amplified a known issue, with countless literature reporting that young carers will put the needs of the person they care for ahead of their own (cf. APPG (2023)). This had been anticipated for, by first asking them about their everyday lives and care role generally (part 1) as well as what technology they use generally (part 2). This allowed me to do some translation work between what the participants had said they struggled with, how they used various technologies, their initial views of the robots and what I knew robotic applications could do in order to create robot scenarios that they would find useful. Put differently, I tried representing my participants' everyday lives into robot scenarios that could help alleviate some of their responsibilities. This resulted in six robot scenarios, filmed at Uppsala Robotics Lab, which showcased various ways robots could help young carers, sometimes beyond their care responsibilities.

4.3.5.3 Focus Groups 2

The aim of the second focus groups was to give feedback on the scenarios and their potential applications. As mentioned above, most of the participants knew me, allowing us to dive into robot scenarios. If there were new participants, I would take five minutes to introduce robots following part 3 from my focus group 1 guide. Focus group 2 was split in three parts:

Part 1: Reflections on the use of robots in care for young carers.
The aim here was to see if the participants had thought about robots since last time and what reflections they had in-between focus groups.

Part 2: Show scenarios of robots for young carers and reflect personally first then in group.
The aim was to show them the robot scenarios I had created and get direct feedback.

Part 3: Understanding at what point the young carers could be involved in the technical process of having personalised robots.
The aim was to move beyond the scenarios and for the participants to tell me how they would envision the robots being designed and deployed in their home.

4.3.5.4 Reflection on Conducting Focus Groups

Overall, conducting focus groups with teenagers was extremely fun. My participants were realistic about the usage of robots for care, and were optimistic though realistic about the future. I have had a lot of work experience with teenagers, including teaching and leading activities. These experiences meant that I was able to adapt to my participants and keep the focus groups playful. This was vital, especially during the second focus groups where the robot scenarios would reflect their reality back to them, which they might not have thought of in those ways.

To ensure that the participants were brought back to the present moment and gave feedback on the focus groups, each focus group ended with a postcard exercise where they could draw and write whatever came to mind. Often they would thank me as the researcher and draw something robot related.

4.3.6 Description of Robot Scenarios

During the first focus group, I first set the scene for digital innovation by asking about what technology they use as well as the applications they use for their own care role. Then the participants were introduced to four different types of robots, through promotional videos (see Figure 4.5). Each represented scenarios related to health in some way: double robot showed a medical professional communicating via a teleoperated robot to the patient[2]; Pepper robot showed how it could be useful to an older person[3]; Joy for All robot was of a cat robot purring seemingly bringing companionship[4]; and Furhat robot was in a public space offering some health advice based on symptoms to a woman[5]. This method was directly taken from previous HRI studies by Lee et al. (2017) and Winkle et al. (2020) that introduced robots to

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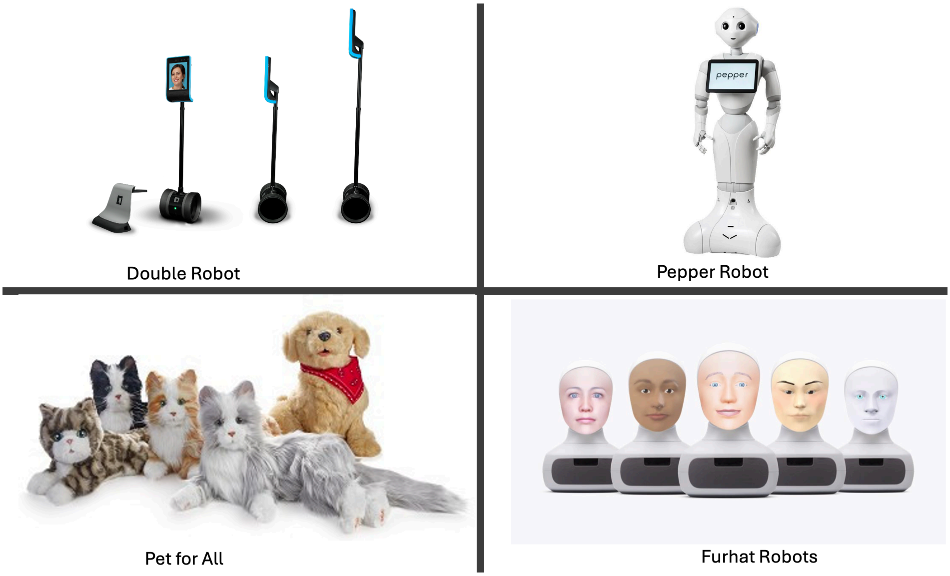
[2] Click here to access the YouTube link to Double Robot

[3] Click here to access the YouTube link to Pepper robot

[4] Click here to access the YouTube link to Pet for All

[5] Click here to access the YouTube link to Furhat robot


Double Robot

Pepper Robot

Pet for All

Furhat Robots

Figure 4.5: Four different robots exhibited through promotional videos to the participants in Focus Group 1

participants through videos clips before bringing in more hands-on demonstration of robots in their participatory design research.

In-between the focus groups, I went to the Uppsala Robotic Lab to write and bring to life robot scenarios. These scenarios were either (1) directly for young carers, or (2) aware of the young carer but the application was for the care receiver, or (3) a family robot who knew the young person cared for a parent. The robot scenarios themselves were based predominantly on HRI research applications, whilst the content attempted to reflect participants' answers from focus group 1.

Creating a safe space was paramount as we were reflecting a reality to young carers. First, regarding the identity or the depicted young carer and robot, I was influenced by Miranda et al. (2023)'s work on robot diversity. This led to special attention being accorded to names, pronouns, appearances of robots and young carers, as well at times sexuality of the young carer. Second, regarding the health condition of the parent. The depicted parent receiving care had physical and/or emotional/mental health needs that required support from the young carer. This was important as participants who cared for a parent with physical disabilities voluntarily shared about their parents' condition; in contrast, participants who seemingly cared for a parent with a mental health condition would only hint towards it. Third, coping strategies were offered. This was in part to give them a tangible outcome from participating in the focus groups–since they will not be receiving a robot for themselves. These strategies included advice on time management, mindfulness exercises and seeking support.

Introducing the robot scenarios was first contextualised through vignettes to then show the video. Vignettes are used across HRI studies to showcase a hypothetical scenario in a real life situation (see for e.g. (Haresamudram et al., 2024; Tanqueray, Paulsson, et al., 2022)). In practice, I called the vignettes "backstories" (see Appendix), and each backstory was attached to a particular robot scenario. I printed the backstories out for the participants to read and/or listen to me read them out loud. There was purposely space left between each backstory so that participants could write down their reaction at the end of each videos. Thus, after each scenario, they would jot down ideas but not speak to one another. Only after viewing all the scenarios could the participants speak about their opinions out loud. This meant that they did not condition each other–this proved key for the participatory approach, as it ensured that each had an equal voice and there were written opinions even if some participants did not want to share them to the wider group. I also made clear that these were initial designs based on their previous feedback, and robot applications could be rethought or changed entirely.

Six scenarios were created and are briefly recapped here. Four videos were created, readily available on YouTube (click here, or scan the QR-code) along with two storyboards (available in the Appendix). Only Furhat robot was used in the scenarios. Turning first to the videos:

1. **Babs (Furhat; she/they) and Hannah (young carer; she/her)** presents a snapshot of a conversation about Hannah disclosing to Babs her feelings of distress. This was triggered by her friends speaking of their half-term which was different to hers. This was influenced by Laban et al. (2022)'s study which created a social robotic application to elicit self-disclosure for informal caregivers.

2. **Elsi (Furhat; she/they) and Danielle (young carer; she/her)** presents Elsi creating a comprehensive to-do list for Danielle. This ensured that Danielle can spend time with friends, her girlfriend, and have some down-time alone. I did not use previous HRI research here, instead it was directly echoing stresses around time management and young carers not prioritising their own needs spoken of in the focus groups and recognised in an array of young carer literature (e.g. the APPG report (2023)).

3. **Moe (Furhat; he/they) and Lucy (young carer; she/her)** presents a dialogue between Moe and Lucy whereby Moe will monitor Lucy's mum whilst Lucy is out with her friends. Moe will alert Lucy if there is cause for concern. This is something roboticists have attempted for formal caregivers so that they are able to monitor patients without being in close proximity, such as (Cascone et al., 2021; Kraft & Smart, 2016).

4. **Furhat (Furhat; she/he/they) and Harry (young carer; he/they)** presents a dialogue where Harry asks information about his mum's new diagnosis to Furhat which is personalised to his situation and in accessible language. This was influenced by informal caregivers being overburdened with information and not necessarily understanding it (Crotty et al., 2020). The HCI community is attempting to understand how to create easily accessible apps designed for informal caregivers, part of which is accessing relevant information to them in their care role (Premanandan et al., 2023). It also mirrored the promotional video Furhat helped screening for a potential health issue the user was describing.

There are also two storyboards (available in the Appendix):

1. **Furhat (she/he/they), Axel (young carer; they/them) and Mum (she/her)** showcases a short story about Axel's mum falling. Axel is very distressed and is not sure how to go about lifting their mum. Furhat is able to talk through each step to ensure that the mum can be lifted as well as to describe how Axel can lift her in a safe way. Once Axel has lifted their mum, Furhat checks on the mum, and once the mum has left, Furhat then checks on the young carer. This scenario was based on focus group 1, and literature on young carers, where young carers tend to overlook their needs and emotions to ensure that they prioritise the person they care for (APPG, 2023). As well as the self-elicit robotic application (Laban et al., 2022).
2. **Berty (Furhat; she/he/they), Clara (young carer; she/her) and Dad (he/him)** is set at the General Practitioner's surgery. The dad and Clara are greeted by Berty, and Berty directly acknowledges Clara and flags Clara to the GP to make sure that Clara is identified and/or registered in the system as a young carer. This is influenced directly by how AI is aimed to help (aimed at formal caregivers), such as with medical systems being interconnected to other databases (for e.g. social services) for more efficient workflow (Topol, 2019).

The scenarios are all expressions of AI-driven technology as artefacts, since they represent anticipated applications regarding robots for care. In all these scenarios, the robot *appears* intelligent, but it is fully scripted, with one roboticist coding the robot to wait long enough for me (the actor) to give an answer. The scenarios thus seemed futuristic, especially to the participants, though most are under research, but not directed as applications at/for young carers. Thus, these

QR code to Robot Scenarios

scenarios help situate informal caregivers within
AI-driven technologies, here especially for HRI. The only scenario that was not based on previous HRI/HCI research was the robot organising Danielle's day and week for her. However, with increasing smart digital calendars applications available, this was still an anticipated used-case.

Furthermore, there were quite a few scenarios to go through. To ensure I kept their concentration and focus, there were jokes and ironies sprinkled throughout the videos. For example, the participants in the first focus groups showed fear and/or dislike for Furhat robot, so I directly addressed that with Hannah calling Babs "creepy" and Babs still being positive, to which Hannah responds with "you're such a live, laugh, love robot" (a topical ironic joke in the UK). Or when Danielle is choosing what to do for her down-time, she decides to learn the TikTok choreography to "yes, and?" by Ariana Grande.

All scenarios depicted the robot as a Furhat robot and the young carer as myself. 'My mum' was Dr. Katie Winkle, my supervisor, 'my dad' and 'the doctor' were Dr. James White and Dr. Charlotte Högberg, my colleagues. Participants were initially surprised that I was the actor, and were quick to be supportive of my acting skills (though I won't be quitting my day job!).

4.3.7 Data Processing and Analysis

All the data was transcribed locally on a computer disconnected from Wi-Fi using Whisper Transcription. Whisper is an automatic speech recognition system that is installed on the computer through python coding in the computer's terminal, deemed extremely secure regarding data privacy. Once the transcription was done through Whisper, I would manually check entirely and pseudo-anonymise immediately any confidential information, such as their name or places they live in/visit that they mention. The data was then kept on two hard drives and accessed only to work on NVivo. NVivo is a qualitative coding software. Through NVivo I was able to conduct a reflexive thematic analysis on the entirety of the data, which includes the focus groups and the written feedback written on the robot videos.

Reflexive thematic analysis (RTA) was used to do the analysis. This includes the usual five steps for thematic analysis: Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition (Braun & Clarke, 2006, 2019). I familiarised myself with the data and created memos for the rest of the team to review; this enabled initial coding on NVivo by tagging sections of texts representing key ideas/concepts throughout the data. Through these steps, clear patterns began to emerge across focus groups, and be discussed between authors (my supervisors and Dr. Chris Papadopoulos–my co-authors on Paper IV). This enabled closer investigation within themes, as well as an operative codebook for transparency and validity of the process. With Dr. Katie Winkle, we collaboratively reviewed the analysed data, and re-calibrated if needed, to finalise the themes relevant to Paper IV.

The reflexive part of RTA was deemed vital as it represents a constant recognition around my own positionality. Reflexivity was part of the process before the analysis itself–a key step to RTA (Braun & Clarke, 2019). It took place after the focus groups directly, through journaling and reflexive debriefs with the co-authors, especially supervisors, to navigate potential biases. In practice, this meant that I would email my supervisors with my initial thoughts and feelings. Additionally, this process served to protect my own psychological well-being, as collecting and analysing such emotive data–particularly given my own experience as a young carer–could have a deep impact on me. Secondly for the analysis, through reflecting on my positionality, my co-authors and I reflected on potential biases (1) to avoid one's own biases from negatively affecting the precision of the analysis and (2) to leverage on the personal insights I had to boost the critical depth of the analysis. In other words, I was transparent about how the focus groups had impacted me, but also what links I could see that I viewed as essential for the HRI community to move forward with this information, whilst ensuring the utmost respect to young carers and what they shared during the focus groups.

4.4 Methodological Considerations

There are many methodological considerations when undertaking research on informal caregivers and report their realities. We must circle back to my theoretical lens (Chap. 3) regarding care, the positionality of the researcher and its impact on knowledge production; it becomes a matter of what knowledge I choose to report on. Puig de la Bellacasa (2011, p.92) draws attention to Harding's standpoint theory (2004) when speaking of care. A person's social position (here as a researcher) and experiences (here as a young carer and researcher) shape their knowledge and perspective. The standpoint of a researcher therefore matters as it will directly influence what they research and in turn publish. This is an important part in this project, as I was attentive to how informal caregivers tended to be part of research projects and/or discussions. Furthermore, my position as a PhD student allowed me to directly produce knowledge on informal caregivers, whilst my experience as a young carer allowed me to directly access other young carers. This position of power meant that I needed to take care of this research project, by ensuring my project was ethical both from a research perspective and also to my participants.

The first methodological consideration was my own positioning. It became apparent very quickly about the need to position myself as an informal caregiver. The negative impact of being an informal caregiver is well reported across both adult and children providing care, see Chap. 2, and examples in (Bom et al., 2019; Deeken et al., 2003; Leu et al., 2023; Liu et al., 2020). However, it has been time and again overlooked in HRI research, including by myself at first. When I was assisting on a project regarding the use of robots to screen for peripartum depression, we had not included people that could be informal caregivers within our study. Yet, during an interview for that study, a particular moment stood out to me, which we report as follows:

> [O]ne [participant] was very critical of such a practice [robot screening application] since it tries to reduce the patient to an individual; this does not account for the other people involved in her pregnancy, such as her partner/family/friend who support or hinder her health. (Tanqueray, Paulsson, et al., 2022, p.604)

This demonstrated to me just how much we tend to put emphasis on the experience of care receivers and healthcare professionals, yet so little room is given to the people surrounding the care receiver who will mark a monumental role in their lives (and vice versa). This was ultimately demonstrated in the critical narrative review (Paper I), which unearthed the need to situate informal caregivers in robotic solutions.

The second methodological consideration was the (lack of) involvement of young carers in research. Anecdotally, when I spoke to the HRI (and HCI) research community about young carers, scholars tended to be flabbergasted that such a *thing* would be happening. In contrast, when I took part in outreach events outside of academia and spoke to people from industry, they were often aware of young carers and would tell me about ongoing projects. For example, Liverpool City Council in the UK has began aggregating data "from schools (on factors such as attendance, exclusions and special educational needs), youth offending, police arrest records and intelligence, health information, historic education data, early help status and social care" (Sentinel Partners, 2024). These data points very likely contain information on young carers, held by tech companies, which can have a huge impact on young carers. Yet researchers have not been part of investigating the impact of these technological advances on this group. Put differently, even if researchers do not acknowledge young carers, young carers are still vulnerable to AI-driven technology solutions and this must be studied and reported on. From these experiences, it seemed necessary that I initiate a research avenue on young carers in AI-driven technologies, by entering it through HRI and including young carers directly (Paper IV).

The third methodological consideration was the allocation of resources. There were limitations regarding available funding and how to best use resources. For the critical narrative review (Paper I), we decided to only review published articles at the ACM/IEEE International Conference on Human-Robot Interaction, as we wanted to ensure a fair representation of best practices–which would be well represented at such a venue–as well as ensure that we could do an in-depth analysis to find interesting trends. For the focus groups with young carers, the study took nearly a year and a half to conduct–from the time of conceptualisation to the final focus group. This was in part because it felt important to me that I include young carers as much as possible, by being the one to adapt to their availabilities and location, as well as conduct it in a context I was a young carer in (the UK). This resulted in hours of travelling and overnight stays to hold each focus groups–I was very fortunate that my supervisors agreed that this was a good use of my resources. However, and most importantly, it took resources from charities, as they would be the ones to host me, and of course, the young carers, who would be taking time out of their many responsibilities. It became an ethical consideration discussed below.

The fourth methodological consideration was how I reported on these studies. Both Paper I and Paper IV are published in engineering venues. Such venues require a positivist lens, for example "X% show that...". Both papers adhere to this format, though we tried to push back as much as possible. In Paper I, whilst appearing positivist, by the fourth theme, we become candid about the difficulty we faced in identifying and categorising informal caregivers in the reviewed articles. Paper IV showcased a catalogue of possible design solutions, by reporting on specific robot scenarios that were reviewed and approved by participants. However, we reported very explicitly on how my positionality was paramount to access young carers, as well as how my own experience was relied on throughout the duration of the study. Finally, it was also part of the methodological consideration that my thesis would go into a lot more depth on the behind-the-scenes of the focus groups, which Paper IV did not have the room for, to give clear insights on how such a study was feasible.

The final methodological consideration I share here concerns the generalisability of this thesis. Paper I's findings showcased trends in articles that are published in a reputable Conference. Therefore, the findings may not be generalisable, but showcase current best practices. Such a paper provides the foundation for more scalable work. Paper IV's findings are also not generalisable, but they provided initial insights into an overlooked stakeholder. Instead, the Paper IV presents a good starting point for other researchers to reference our work in their ethics applications to showcase why young carers must be included. These findings can in part help engineers develop HRI solutions for health care by either (1) (re-)use of our robot scenarios as a baseline for their own robot application and/or (2) use our results to develop user personas to reflect on the robot design/deployment, before going directly to young carers. Whilst reporting on our findings, we also show similarities between young carers and adult informal caregivers, as well as the differences. Therefore, this also allows for this paper to be part of the discourse on informal caregivers more generally, and how robotic applications can attend to and support their needs.

4.5 Ethical Considerations & Critical Reflexivity

The critical narrative review did not require ethics approval. The focus groups required ethics approval from the Swedish Ethics Board as well as the University of Bedfordshire's Ethics Board, both of which were granted. We relied on the support and gatekeeping of young carer charities to ensure that this study was conducted in a way that could advance research and empower young carers. Before or during the focus groups, each participant (or guardian) signed an informed consent and kept information on the study itself. Furthermore, we had protocols in place during the focus groups in case of any potential distress or emergency. Participants could freely choose to take part in the study and discontinue at any point.

The PhD position had not been defined in terms of what project it should deliver. I was therefore very fortunate to be the one to choose the direction of the project. I am aware that this resulted in my PhD project being more personal than a 'usual' one, which requires an explicit reflection. In feminist literature there is a clear discourse on the lack of boundaries between private and public sphere, and I think I put that lack of boundary to the test and can attest that it is correct. Relying on my own experience allowed me to investigate a sub-group of informal caregiver without attempting to be an *objective knower*, as Patricia Hill Collins (1991) names it. Objective knower assumes that knowledge can be separate from the knower and devoid of values or emotion, which I do not claim to do. Nevertheless, having my own experience as a young carer and informal caregiver generally, meant that the literature directly resonated with me, and the consequences researchers wrote about were experiences I had faced and knew the challenges and opportunities of those. There were also parts of the literature which showed me why I had faced a different outcome to many others, for example, how I am in a position to write a PhD thesis when many young carers tend to have difficulty attending higher education (The Carers Trust, 2024). Recognising those privileges made me more attuned to the potential in AI-driven technologies, and how those could attend to young carers so that they get adequate and accessible support in time. It also allowed me to know that I am not here to *save* young carers, and AI-driven technologies cannot *save* them either (forming the justification of Paper III); rather I see my role as demonstrating how to acknowledge and show how AI-driven technologies can assist informal caregivers, especially young carers.

Conducting the focus groups in the UK over Sweden meant that it was in my own context–although it is worth pointing out that the legal status afforded to young carers in the UK also played a key role (explained in Chap. 2, and theorised on in Chap. 3). By sharing a similar context to my participants, I could directly use my own experience when speaking to them and somewhat normalise their experience (and mine to some extent), whilst also collecting data relevant to various research disciplines. Being a young carer is often "othering", however, as Canales points out, being othered does not have to be necessarily negative (Canales, 2000). Instead, it can be used for inclusivity, which she coins as *inclusionary othering*. Inclusionary othering attempts to use the power within relations for transformation and coalition building–here the researcher can directly empower participants' experiences (Canales, 2000). In practice, I would not have felt comfortable undertaking research on young carers in Sweden as I could negatively "other" them, and be "othered" by them as I potentially misunderstand their context. Consequently, in every focus groups, we were all part of the "other" category, as young carers in England and Wales, which resulted in us partaking in *inclusionary othering*.

Turning to arguably the most important ethical considerations: undertaking a study with teenagers on a technology we do not know will make it into their homes anytime soon. In line with the review undertaken by Joseph et al. (2020), there is a saturation of results on challenges faced by young carers, thus doing such work would be unnecessary, and thus unethical. Yet, little participatory design work has been conducted with young carers, including in the realm of young carer research (Joseph et al., 2020), making research within AI necessary, as well as young carer literature. This therefore became a question of proportionality: how to produce much needed knowledge, whilst knowing that my participants would not have access to such technologies in the near future. This led to me ensuring that during the focus groups I also (1) educated team leaders and young carers on the development of AI-driven technologies, especially robots, during the focus groups, (2) gave tangible coping strategies that participants could implement now and (3) hosted the focus groups in a way that participants would be able to get to know each other better and hopefully make or strengthen their friendships.

I was very fortunate to have Dr. Chris Papadopoulos as a mentor and host. Dr. Papadopoulos has conducted many studies with vulnerable populations that he is part of, and is open about his own positionality when orally reporting on those studies. He was also part of the Ethics Board at the University of Bedfordshire, meaning that he was well versed on the ethics of the participants and the researcher. Whilst we have already mapped out the ones pertaining to the participants, it is worth noting the one on the researcher. Dr. Papadopoulos ensured that we include and explicitly reflect on the ethical considerations of this study on myself. This was a preventative measure, which allowed for a clear understanding of the potential impact these focus groups could have on me, and how to alleviate negative impacts as much as possible. Part of this ensured my own emotional wellbeing through clear protocols; for example, by sending a summary of how each focus group went to my supervisors and my supervisors replying to them and acknowledging what I wrote and supporting me through it, or another, by taking time out of work to process the information. This part is usually skimmed over, however, to me those protocols meant that I could be present in my research project, ensured that I did not burn out from it, and gave myself grace when the focus groups did feel emotionally heavy.

Chapter 5

Research Findings

This chapter presents the findings from the four papers that constitute the foundation of this thesis. The papers are arranged to tell a story. This means that it does not follow a chronological order as to when they were published, but rather their contribution. Paper I sets out who is included in HRI studies for health care; this is followed by Paper II which creates a theoretical framework to capture norms that impact AI-driven technologies; followed by Paper III which utilises parts of that theoretical framework from Paper II to place young carers into the AI research discourse; and finally Paper IV which presents results from focus groups with young carers on robots for care.

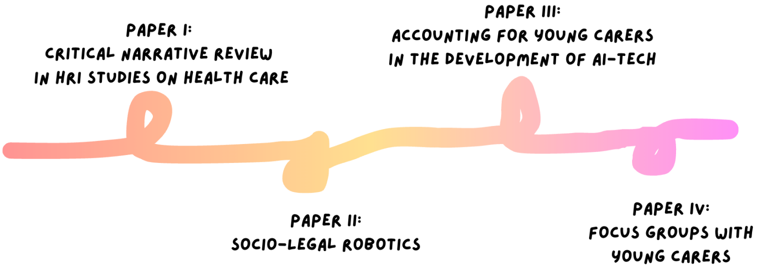


Figure 5.1: An illustration of the four papers founding this thesis.

The story begins by showing a lack of involvement of informal caregivers, it then unfolds by trying to empower researchers on how they can involve more stakeholders, and finally (spoiler alert) the story ends by showing that it is possible to represent young carers and empower their voices. This responds to the two-fold aims of situating informal caregivers through (1) conducting interdisciplinary research and (2) bringing forth societal issues to empower that stakeholder.

5.1 Paper I: In Search of Informal Caregivers in HRI: A Critical Narrative Review of HRI Conference Papers

Tanqueray, L., Larsson, S., & Winkle, K. (2026). International Journal of Social Robotics, 18(1).

The starting point with this paper was to understand which stakeholders are involved in HRI for health care and to what extent, with a particular interest on informal caregivers. After the first round of analysis, it became clear that a little more digging needed to be done on informal caregivers. To demonstrate this necessity, we conceptualised the study as a comparison between stakeholders to bring awareness to the HRI community and reflect on current practices.

The paper is a critical narrative review firmly rooted in critical social sciences, with the theoretical framework stemming from HCI and HRI, namely Social Justice-Oriented Design (Dombrowski et al., 2016) and Feminist HRI (Winkle et al., 2023). The articles were collected using keywords that were beyond healthcare institutions and inclusive of any type of stakeholders within studies published at the ACM/IEEE International Conference on Human-Robot Interaction. We prioritised doing a thorough analysis of the articles, rather than the quantity (as explained in Chap. 4).

The findings were split according to four main themes: (1) how the study was motivated, (2) who the study included, (3) the methods used in order to answer this aim, and (4) how much informal caregivers and healthcare professionals were involved in study (the latter depicted in Figure 4.3). Overall, from the retrieved sample from 2008 to 2023, there is seemingly an exponential growth in HRI in health care studies. From the 52 articles reviewed, 36 investigated care receivers, 20 investigated healthcare professionals and eight investigated informal caregivers. 16 articles investigated applications for older adults, seven articles investigated robotic applications for children, and six for staff.

The main findings from each category were: theme (1), studies that directly included informal caregivers tended to grasp the reader's attention by speaking of lived experiences–something unusual in comparison to the other articles that did not involve informal caregivers. Usually, alarming narrative was used to situate the study, especially for care receivers and healthcare professionals. Regarding theme (2), studies mostly investigated care receivers (n=36 out of 52) whereas informal caregivers were only directly involved in eight out of the 52 studies. Furthermore, informal caregivers were only investigated alongside other stakeholder groups. Turning to theme (3), studies tended to hold more focus groups and interviews with healthcare professionals, in contrast, informal caregivers tended to be part of workshops. Studies also usually included healthcare professionals' reflections on studies conducted in-the-wild (robots deployed outside of labs), which happened rarely for informal caregivers. Finally theme (4), informal caregivers were mostly acknowledged in HRI studies for health care, but usually referred to in terms of their relation to the care receiver, without reflection that these individuals were or will act as informal caregivers. In comparison, healthcare professionals tended to be involved in studies, even if they were not participants–which we refer to as low involvement, such as co-authoring. Quantitatively, out of the 52 studies, 38 studies either did not mention or only acknowledged informal caregivers, in contrast to 18 studies either that did not mention or acknowledge healthcare professionals (see Fig 5.2 to see an illustration of the results in those categories). We hypothesise that this is due to a lack of awareness on informal caregivers.

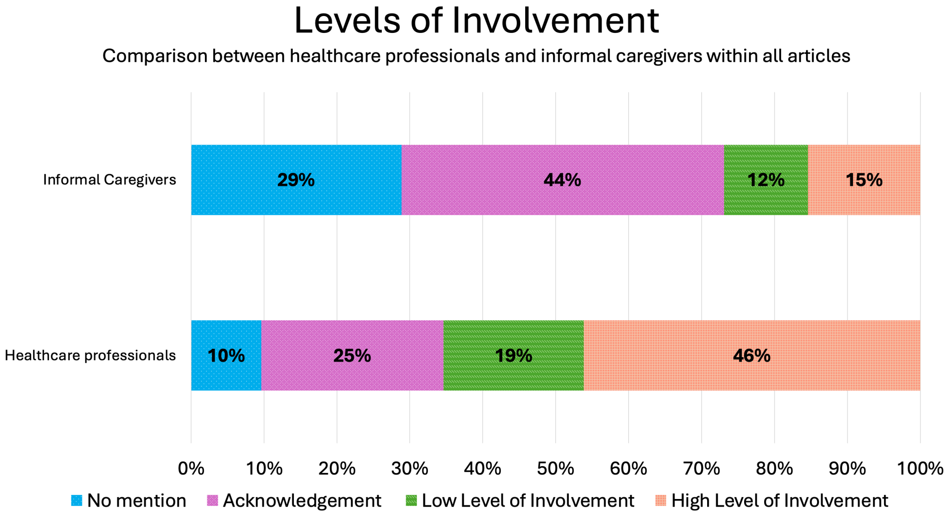


Figure 5.2: A comparison between informal caregivers and healthcare professionals in all reviewed articles regarding whether they were either (1) not mentioned, (2) acknowledged, and (3) involved at a low level or (4) highly involved

In theme (4), we directly apply Social Justice-oriented Design, rooted in HCI by Dombrowski, Harmon and Fox (2016) and Feminist HRI by Winkle et al. (2023). This was to hold to account the HRI community for its research practices, which required more in-depth investigations of the retrieved papers. As discussed in Chap. 4, for this theme the analysis was conducted throughout the reviewed articles. It became apparent that healthcare professionals' expertise has been heavily relied on and/or accounted for in the development of HRI for health care. Resulting in robotic applications directly accounting to their workload. However, regarding informal caregivers, this was not the case. Firstly, there were issues regarding identification. We had to be explicit in how we defined informal caregivers in studies, as many–including studies that we claimed investigated informal caregivers–did not identify them as such.

Secondly, whilst robotic applications did not account for informal caregivers in their development, there was still an implicit expectation from the research community on family members and friends to ensure the successful deployment of robots for care. This included (i) setting goals, (ii) taking part in multiplayer rehab applications, (iii) monitoring progress, or (iv) helping set up. Showing some acknowledgement of informal caregivers, but not being accounted for in the development of robotic applications for health care. By holding research practices to account with a Social Justice-oriented Design and Feminist HRI lens, we showcased the power researchers actually hold: who to exclude and who to include. We therefore concluded this paper with concrete ways to include informal caregivers moving forward; this included using researchers' own experience as informal caregivers if they are comfortable to do so.

5.2 Paper II: Towards a Socio-Legal Robotics: A Theoretical Framework on Norms and Adaptive Technologies

Larsson, S., Liinason, M., Tanqueray, L., & Castellano, G. (2023). International Journal of Social Robotics, 15(11), 1755-1768.

This paper marks an interdisciplinary research endeavour on how to bridge critical social sciences and engineering disciplines, through SoL, gender studies and HRI, which was published in a HRI journal. This paper therefore situates itself in reflecting on the development of AI-driven technologies, which will inevitably be part of social robots–such as large language models–to create more adaptable robots in society. Hence, the paper proposes a theoretical framework, namely *socio-legal robotics*, to capture the social aspects that are/will be interwoven in adaptive technologies.

The paper presents the foundations of SoL and gender studies, to show how those disciplines provide useful groundings for the field(s) of AI. This is reported by coining *socio-legal robotics*, and calling out issues of biases and stereotypes within society which can be reproduced and amplified in adaptive technologies, such as racist, homophobic, sexist and/or ableist biases. Here, stereotypes is defined as a way for how a particular set of social norms can be expressed. For example, gender stereotypes within voice assistants, not only sounding woman-like but also acting submissive, polite and patient. These demonstrate a mirroring effect within adaptive technologies, which we call out as *normative mirroring*, established in Larsson's earlier work (Larsson, 2019).

We therefore call for increased awareness around norms that can include problematic stereotypes. We do not call for specific sets of norms as we recognise the need that those are situated and contextual. Instead, we provide an illustration of socio-legal robotics through *norms-in-the-loop*. *Norms-in-the-loop*, illustrated in Fig. 5.3, conceptualises and reflects on (1) norms, namely legal, social, and contextual on the one hand, which will impact and be impacted by, (2) adaptive technologies, namely design, datasets, and in situ personalisation.

Figure 5.3: Norms-in-the-loop: The Mirroring of Norms (Larsson et al., 2023)

From Figure 5.3, there is an emphasis on three types of norms that are part of society generally: legal, contextual and social. *Legal norms* refer to formalised rules and principles codified in laws, regulations, and/or policies. *Social norms* are informal, shared expectations about appropriate behaviour within a community or culture. Finally, *contextual norms* are specific to a certain setting–which clearly points out that any adaptive technologies will be entering a specific social context, such as robots in homes or hospitals. All these norms point to the necessity of situatedness and the need to challenge the notion of universal norms that can be embedded in AI-driven technologies. Especially since, even if designers and developers do not account for these norms, these norms will still be intermeshed with the development of AI-driven technology.

Briefly turning to the adaptive technologies part, these refer to design-based, algorithmic or machine learning methodologies that will be incorporated in social robots. Adaptive technologies are will be trained on and learn to adapt through design features, datasets and personalisation features. These will directly be influenced by norms, and in turn influence norms. *Design* refers to the material, embodied, physical, and aesthetic choices in robots (including the appearance, gendering, role, etc.). *Datasets* refer to the collection of data used to train, test, or guide the learning behaviour of adaptive technologies such as social robots. The datasets are key to AI-driven technologies, and who is accounted for in the dataset will ensure they are represented. On the flip side this means that who is not accounted for will be de-contextualised, and likely stereotypes will play a bigger role. Finally, *in situ* personalisation refers to the adaptation of the robot in real-time or over time in interaction with humans (learning from user behaviour and context).

Through this framework, we provide recommendations with a particular emphasis on the need to be aware of social unfairness and challenge it when innovating AI-driven technologies. The hope of this paper is therefore to challenge the hype around advances in adaptive technologies, by attempting to bring reflections on how these technologies embed and reproduce norms.

5.3 Paper III: Accounting for the Unaccounted in Care: Bringing Young Carers into the AI Realm

Tanqueray, L. & Papadopoulos, C. (Submitted).

This paper was conceptualised once Paper I and II had been formalised. Meaning that we had the findings from Paper I which showed a clear trend of not accounting for informal caregivers in studies, and Paper II which warned about reproducing norms and relying on stereotypes. Since children as young carers had not ever been mentioned in this discourse, I was worried about what stereotypes there even would be if there was no representation whatsoever of young carers in research on AI-driven technologies. This was echoed by conversations I was having with AI researchers who did know about young carers. Thus to remedy this, Dr. Papadopoulos and I decided to write a position paper to address young carers in the development of AI-driven technologies. The aim was in part to warn of the possibility that these technologies might amplify biases young carers already face, and not help young carers in any way. Whilst we make a point throughout that young carers are people first, the paper is specifically positioned to empower these young people in their care role.

This paper marks another theoretical paper, in order to bridge the development of AI-driven technologies and young carers. This is novel in the sense that no literature from HCI or HRI have acknowledged young carers that we are aware of (except for Paper IV). Briefly, we use the notion of *norms-in-the-loop* described as part of *socio-legal robotics* in Paper II to showcase the alarming overlook of young carers in the development of AI-driven technologies. Put differently, if realities of young carers are not specifically acknowledged in technologies that are aimed to help alleviate societal issues, we must challenge how these conceptualisations of societal issues in the development of AI-driven technologies may be aggravating young carers' realities. The paper is therefore presenting contextual, legal and social norms on young carers in the UK and the development of AI-technologies in the first part. The second part offers practical uses of AI-driven technologies to attend to young carers. This may be through applications for young carers directly or applications that incorporate young carers in their design, datasets and/or in specific settings.

Importantly, this position paper provides a thorough review on the breadth of studies on young carers to showcase their everyday experiences as well as the systematic challenges they face. Demonstrating that a lot of studies have been conducted on young carers to understand their experiences–admittedly all outside AI research. The paper also offers insights into AI communities, shedding light on their innovations and legal instruments impacting them, to situate young carers in that discourse.

In the first part, we contextualised the reported realities of young carers in the UK from various disciplines. This included economists, calling out for the need to include young carers as a specific category, since they tend to be representative of the poorest households in the UK; as well as education, which demonstrated issues with school attendance and the difficulty of staying in higher education; as well as legal scholars explaining needs for clear regulations, to ensure children's care role is manageable. There is an array of issues that young carer researchers have already covered, which in turn means that AI researchers do not need to conduct those again but build on them. Young carer scholars have clearly stated that doing more research on already saturated findings has the possibility of becoming unethical since it is not required (Joseph et al., 2020). Instead, young carer scholars have called for more participatory methods to find more inclusive solutions for young carers. This is where a lot of HCI and HRI scholars tend to thrive, with clear ways of including stakeholders and having possible AI-driven technological solutions tested and challenged by participants.

The second part of the paper is supposed to be a lot more optimistic. There, we offer recommendations regarding strategies that could be used for developing AI-driven technologies to directly be catered to young carers. These strategies are at (1) an institutional level, (2) a care receiver level and, (3) a young carer level. We appreciate that AI-driven technologies do not need to be directed at young carers for them to be helpful for them as well. Though we recognise that creating such applications would demand resources to understand how those can help identify and support young carers; we are explicit that public services should still be available and accessible to young carers to get physical and emotional support that is beyond current AI-technological applications' capabilities.

We hope this entanglement of the development of AI-driven technologies and young carer research can be used as a justification for AI researchers to include young carers in their research. Put differently, one HCI study explicitly mentioned not being able to include siblings in their study to understand their role in the use of health care HCI application in domestic settings due to the ethics board not allowing it because of the siblings' age (Silva et al., 2024). Our paper provides a justification on the need to ethically involve children when looking at AI-driven technologies for care purposes, whilst also remaining critical that this should not impact access to availability of resources for young carers and their family.

5.4 Paper IV: Young Carers on Social Robots: Introducing Teenagers as Informal Caregivers to HRI

Tanqueray, L., Papadopoulos, C., Larsson, S., & Winkle, K. (2025). In 2025 20th ACM/IEEE International Conference on Human-Robot Interaction (HRI) (pp. 381-390). IEEE.

This final paper represents the grand finale of my PhD journey. This was a dream I was not certain could become reality: involving young carers directly into a HRI study. As explained in the methods chapter, this paper was years in the making, with a lot of uncertainty on how it would be received by the HRI community. We went for gold and tried to publish it at the biggest HRI venue: the HRI Conference. And lo and behold, it was accepted and recognised as a sustainable project by the conference–meaning that this study directly fulfils SDG requirements to create better robots for society as a whole.

This paper aims to introduce young carers specifically to the HRI community. The findings are first geared towards portraying the life of young carers along with their various constellations of experiences. Put differently, we try to show how there is not an archetypical young carer. Out of the 13 participants, each demonstrated being a young carer in a different way. For example, some young carers provided care alone, whilst others could rely on siblings or other relatives. Some cared for only a parent whilst others mentioned taking care of siblings as well. Most attended school, though some had to drop out. All participants used technologies to some extent, and some used technology specifically for their care role. All mentioned the importance of their parents in their parental role, meaning that their parents' support was essential to all–showcasing a reciprocity of care.

The next part of the findings presents initial reactions to promotional videos of robots. From the promotional videos presented to the participants, only adults were depicted and no children were represented. This resulted in participants having difficulties understanding how robots could help them. Instead they would come up with ideas on how it could help care receivers–albeit their parents or others.

Due to a lack of representation of young carers in the videos, we had to create new scenarios to demonstrate how robots could help young carers in the future. For this, and we mention it in the methods and results–as well as Chap. 4 herein–we had to rely on my expertise and experiences to create relatable scenarios. We refer to this as *translating* participants' everyday experiences they had reported to me in focus groups 1, as well as the literature available on young carers, into creating scenarios that were aligned with research developments in HRI. This led to participants reviewing six scenarios–five of which are reported in this paper.

The results on the robot scenarios pointed to all participants enjoying them and finding them relatable. Participants were able to give feedback–this time relating to themselves–on the potentials of these technologies. A lot of them pointed to the respite care robots could bring, as the robot would be able to monitor whilst young carers do other tasks. Though, participants were wary of having robots, voicing worries on privacy, resource redistribution which could render current services inaccessible, issues around the price of the robot as well as the range of the robot. The range of the robot here is about the robot's proximity to the young carer and/or care receiver when its assistance is needed, and the robot may be too far away to be alerted and/or help in real time. Every participant agreed that their families–including non-caregivers–needed to be part of the design process.

The positive feedback from the participants on the robot scenarios also resulted in us offering operational recommendations. Meaning that the robot scenarios we created could act as a starting point for researchers to include young carers in their envisioned robot application. This recommendation is essential, as getting access to young carers required a lot of resources, requiring not only high-level of expertise on young carers but also lived-experience being a young carer. Furthermore, we urge researchers that young carers' needs are different to those of children generally; for example our results demonstrate high level of responsibilities on young carers thus robots' level of authority and responsibility in comparison to a parent would differ from current research's position on this (L. Levinson et al., 2024). Therefore the scenarios can begin contextualising young carers' role in robot deployments, to then go directly to young carers with explicit representation of their role, and get appropriate feedback.

Chapter 6

Discussion

This chapter ties together the two aims of this thesis, which are grounded in visibilising and situating informal caregivers within the development of AI-driven technologies, by (1) conducting interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in HRI on health care as well at times HCI; and, (2) shedding light on current societal challenges on care regarding informal caregivers, especially young carers, to the development of AI-driven technologies. This chapter does so by answering the three research questions as well as including a reflexivity section. The three research questions are:

RQ1. How are informal caregivers currently framed in HRI studies for health care?

RQ2. How can critical social sciences assist in the development of AI-driven technologies to situate informal caregivers?

RQ3. How can AI-driven technologies, especially social robots, be developed to assist young carers directly?

There is a lot of knowledge production on both informal caregivers and the development of AI-driven technologies, however very little on how these two topics relate directly to one another. This chapter does so. To me, discussions are the fun part to any scholarly writing: it is the Mad Hatter moment showcasing why the reader had to read through everything to get to this point.

Follow me down the rabbit hole.

6.1 RQ1. Current Framing of Care: an Oversimplification of Care in HRI Research Practices

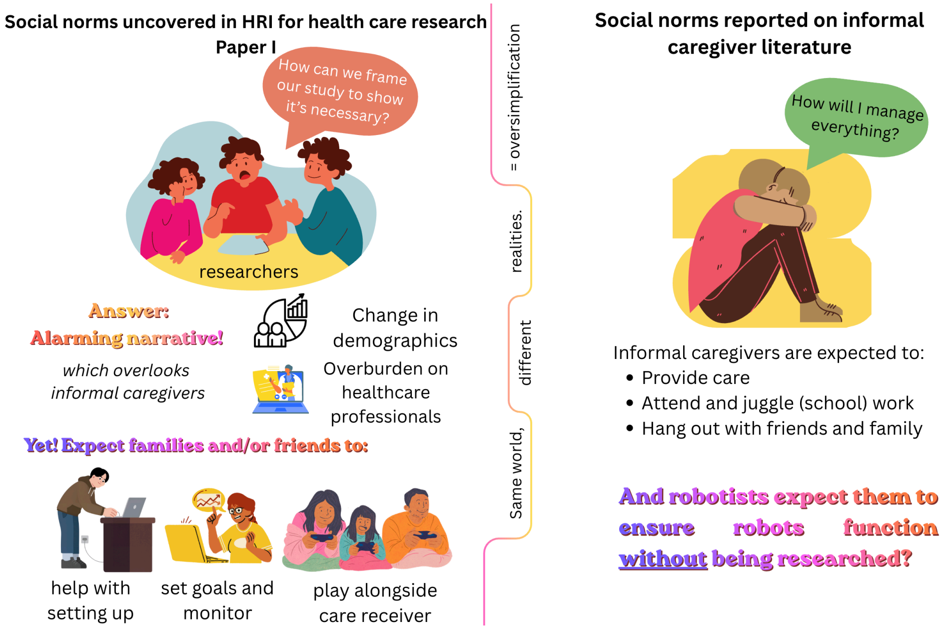


Figure 6.1: An illustration, on the left representing the oversimplification of care presented in HRI research, overlooking informal caregivers. On the right side, representing a typical reality for informal caregivers which is often overwhelming.

RQ1. *How are informal caregivers currently framed in HRI studies for health care?*

This first research question attends to the current framing of health care in HRI research, which is answered in Paper I and illustrated above in Fig. 6.1 on the left side. The findings in Paper I demonstrate that overall, robots are developed to serve and attenuate healthcare professionals' workload. The findings raise important questions regarding informal caregivers on how this framing neglects them and adds to their caregiving role (illustrated in Fig. 6.1 on the right side), which the socio-legal STS framework developed in this thesis attends to.

Reviewed HRI studies for health care tended to rely on an alarming narrative to justify the need for robotic solutions (Paper I). The sources often cited usually emanated from WHO (World Health Organization, 2006, 2015, 2022) to warn about an ageing population and lack of healthcare professionals to respond to increasing health issues. This also demonstrated that alarming narratives contribute to the publishing norms in engineering venues on robots for care: a lot of HRI scholars rely on showcasing an issue related to future predictions either regarding change in demographics and/or decrease in healthcare professionals to present robots as the *anticipated* solution to this. Social norms, as the theoretical chapter establishes, create a standard which in turn becomes important to that group–even if it is not legally binding. Meaning that this becomes a *living law*. Here, to publish in a highly regarded HRI venue, researchers usually adhere to reporting on doom and gloom narratives on obvious stakeholders in healthcare. Paper I thus holds accountable HRI researchers to question current practices, in line with Social Justice-Oriented Design (Dombrowski et al., 2016) and Feminist HRI (Winkle et al., 2023), and reflect on ways to achieve sustainable HRI practices in health care.

The use of alarming narrative becomes a guiding star on who is included in the studies. The vast majority of reviewed studies primarily investigated care receivers, and either investigated or relied on healthcare professionals' expertise. Very rarely were informal caregivers part of studies, being neither investigated nor relied on. Indeed, Paper I monitors this trend closely, and when informal caregivers are investigated in studies (which occurs eight studies out of 52), there is a slight deviation in publishing norms, whereby lived experiences become part of the introduction. This type of introduction situates a health condition to show the context of the robot's envisioned intervention. This could point to the involvement of scholars coming from social sciences that contextualise, and thus, justify the importance of including informal caregivers in studies, or researchers become aware of their key role. Nevertheless, this insinuates that a social norm among HRI scholars is to be able to rely on alarming narratives, which may not reflect the whole picture of the expected robot application. But, as Paper II warns, this will impact how AI-driven technologies adapt to various stakeholders. Hence, the title of this section, an *oversimplification* of care.

Lindén and Lydahl (2021)'s double vision of care demands researchers to engage in care practices that are *situated* and *critical* to showcase specificities while simultaneously interrogating them (p.8). This duality is present throughout Paper I: on the one hand, critically interrogating research practices themselves, whilst on the other, situating stakeholders–especially informal caregivers on their inclusion and exclusion–in reviewed articles. For example, studies conducted in-the-wild (robots deployed outside of labs into envisioned settings) usually included healthcare professionals' reflections, whilst very rarely included informal caregivers; one is quite obviously present, whilst the other is not. However, this overlooked the presence of informal caregivers and diminished their significance, especially as research has demonstrated that informal caregivers still ensure everyday wellbeing in residential care facilities for care receivers (Coe & Werner, 2022). This double vision of care also critically situates when informal caregivers are *implicitly* expected to take on key roles in robot deployments. In the envisioned future use of the robotic applications, researchers reported on the expected involvement of friends and families for the deployment of robotic applications. This did not include a reflection on those stakeholders likely being informal caregivers–people who are already expected to take on a lot of care responsibilities without the added inclusion of new technology (see Chap. 2 for a summary of informal caregivers' (usually apprehensive) perspectives on using digital technologies to help with their care responsibilities).

The inclusion of healthcare professionals, and lack of acknowledgement of informal caregivers (either by not naming them as such or not mentioning them) is also demonstrating the difficulty around informal caregivers more generally: an absence of standards (i.e. practices that must be adhered to). This absence of standards has been called out by Suchman more generally, whereby technology is advancing in selected areas of specialised knowledge (Suchman, 1987, p.43), probably since there is seemingly more standardised instructions regarding what actions to take in specific contexts. Hence Suchman's criticism of planning models being too reductive, as they do not account for the situatedness of the environment around envisioned technologies. For example, accounting for the situated resources the user has available to them in that moment. Furthermore, planning models expect an ideal situation where the outcome will be predictable. An instance of this is healthcare services having standardised protocols on what to do in various cases, though these plans might not be followed to the letter by the staff. This can be due to availability of staff or resources at hand, showcasing that planning models are an ideal that is ultimately an illusion.

Plans and situated actions therefore help capture the difficulty of predicting users and applications of robots. In part, because researchers put forward robots as artefacts that appear intelligent but are not yet deployed, meaning that it is not yet obvious which stakeholder will be present. And in another part, because stakeholders are not fully accounted for in their multi-faceted roles, albeit family relatives that are also informal caregivers that are also people with jobs. In Paper I, this erasure also included of children under 18 years old as caregivers. Put differently, HRI for health care research does not fully situate the setting robots are envisioned to be deployed in, and instead seemingly follows *standardisable* practices. This erasure results in their norms not being collected to support informal caregivers through adaptive technologies. As Paper II suggests, for adaptability and personalisation to occur in AI-driven technologies, it becomes a matter of who is accounted for in the collected norms as well as the setting. Meaning that by developing robots within healthcare settings with healthcare professionals, roboticists will be sensitive to deviations of plans, and attempt to develop robots that anticipate those and adapt accordingly. In other words, healthcare professionals' norms will become *norms-in-the-loop* through these research practices. Which is currently not the case for informal caregivers. Paper II warns of this, as these technologies rely on stereotypes. In this instance, it can be recognising young carers only as children, and not as caregivers also.

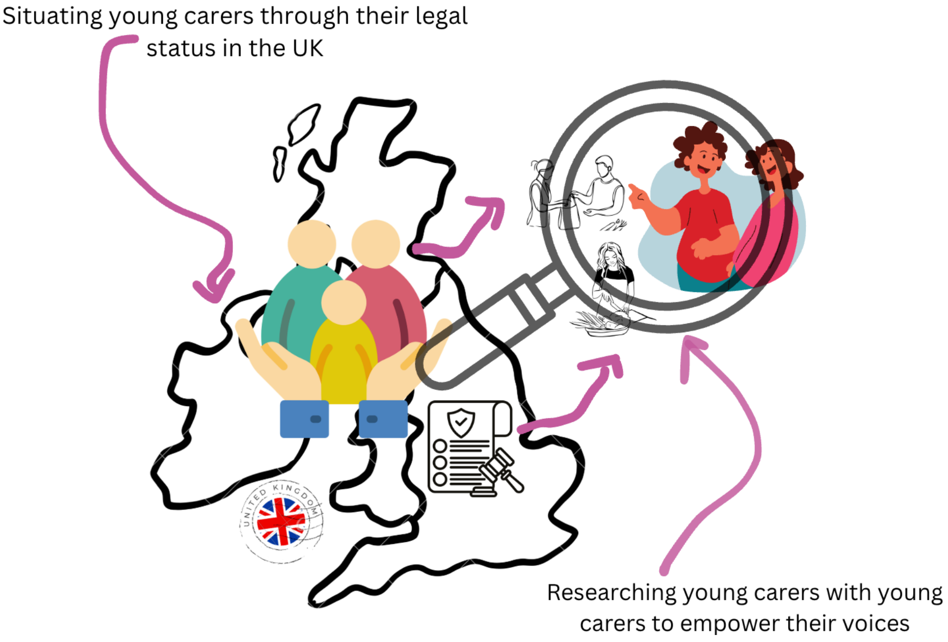
STS research has pointed to the fragmentation of care when attempting to bring robotic solutions (Arnelid et al., 2022; Vallès-Peris & Domènech, 2020). As well as the lack of recognition of the added labour of bringing robots into a care setting (Persson et al., 2023; Wright, 2021), and the displacement of human labour to ensure robots can be deployed in homes (Shin & Jeon, 2024). Furthermore, DeFalco speaks of the anthropomorphisation of care in robots, in that there is an assumption that humans all provide a gold standard of care (DeFalco, 2020). From the findings in Paper I, the fragmentation of care and human as gold standard of care remains mostly within the sphere of healthcare professionals: there is a disregard for care practices beyond them. In other words, care practices translated into HRI have been stuck in how healthcare professionals provide care. The fragmentation of care is consequently also a fragmentation of stakeholders.

This simplified translation of stakeholders involved in care practices points to Puig de la Bellacasa (2017)'s question: "what is included in 'our' world?" (p.4) when we talk of taking care of/for in HRI for health care constellation. As Paper I demonstrated, the ideal of 'our' research world is one where informal caregivers do not exist. Instead they are viewed as people in close proximity to the care receiver who will be able to help ensure successful robot deployment, albeit setting up or setting goals. Yet, in practice, this person will need to be aware of the care receiver's health condition(s) to ensure that the tech can be well adapted and know how to use the technologies–to me, this is quite obviously going to be an informal caregiver. Puig de la Bellacasa issued a warning about overlooking "voices [that] are less valued, as are their concerns and need for care" (2011, p.92). This warning should be taken seriously as informal caregivers are not only overlooked but also framed as helpers for the functioning of robots. Thus, the specific role of informal caregivers play in this constellation is simultaneously neglected yet implicitly added to.

The socio-legal STS framework ultimately points to (1) developers holding power to frame the development of AI-driven technologies for health care and (2) this involves the power to include informal caregivers. Informal caregivers need to be part of steering the development of AI-driven technologies for health care. Especially as their care responsibilities shape their social norms with regards to how they adapt their daily lives to include their care responsibilities–e.g. when they are expected to provide care and when they need to be available. To exemplify this further, a comparison between healthcare professionals and informal caregivers is useful. Healthcare professionals are trained and moulded to view caregiving as part of their role–a clear *plan*, albeit a doctor, a nurse, a caregiver. These plans include training on how to handle certain situation and access to support if decisions are unclear. However, informal caregivers' role is not clearcut, their exact role is not defined nor when other type of support can/should step in. This demonstrates that informal caregivers' actions are consequently *situated* to respond to care receivers needs (Suchman, 1987), and do not neatly fit into a standard protocol. Nevertheless, this must be accounted for in the development of AI-driven technologies for their successful deployment.

To answer RQ1 briefly, the current framing of care is on specific groups, namely care receivers and healthcare professionals, to usually alleviate pressure from healthcare services. This neglects informal caregivers in this framing. This brings forth Serholt et al. (2022)'s warning that stakeholders must be involved before deployment, otherwise "there is no space for them to reframe the problem or change the design idea" (p.420). The framing of health care in HRI thus has to be challenged to go beyond obvious stakeholders and publication expectations for knowledge production to include informal caregivers. Especially if HRI is to include a more complex understanding of caregiving practices for the successful deployment of such technologies.

6.2 RQ2. Situating Informal Caregivers: Challenging the Status Quo in the Development of AI-driven Technologies


Situating young carers through their legal status in the UK

Researching young carers with young carers to empower their voices

Figure 6.2: An illustration depicting the UK's legal recognition of young carers, which has allowed access to study this stakeholder group and report on their experiences.

RQ2. *How can critical social sciences assist in the development of AI-driven technologies to situate informal caregivers?*

Research question 2 aims to explore how critical social sciences assist in the development of AI-driven technologies, particularly in HRI though also in HCI, to situate informal caregivers. This section consequently zooms in on the necessity of attending to the identification of overlooked stakeholders–namely informal caregivers–during the development of AI-driven technologies so that we (AI researchers) are able to assist directly to these stakeholders and their needs. This PhD project did so by legitimising young carers through law as well as critically situating young carers through social norms and STS.

First, the power of law must be discussed, to then nuance the picture with discussing social norms (as attempted to be illustrated in Fig. 6.2). Following Paper I's findings of researchers' neglect of labelling informal caregivers as such, in Paper III and Paper IV the labelling of individuals as young carers was paramount. Labelling here is attached to the power of law (Smart, 1989): whether law acknowledges an individual to be categorised as an informal caregiver or not. This is contained within the UK legal system. The labelling of law is powerful, as it assumes rationality and recognises that there is an issue which needs to be attended to by State authorities (Smart, 1989). Though law refigures the actual event to format it into legal terms (Ewick & Silbey, 1998), meaning that even if informal caregivers prefer to identify themselves in terms of their relation to the care receiver (Carduff et al., 2014), for the law to come into force, the labelling of informal caregiver must be adhered to.

Fulfilling the legal requirements to be recognised as an informal caregiver has many consequences for anyone that is seeking support due to their informal caregiving duties. Part of fulfilling the requirements involves carrying out an assessment by the individual's local authority, where the individual has to demonstrate that the care receiver has caregiving needs that they attend to. Therefore, law's intervention is an indicator that an event is occurring and is deemed legitimate enough to require Sate intervention. As this thesis demonstrates, this can in part be leaned on to propel a discussion on what needs to be part of the development of AI-driven technologies, and directly challenge the current status quo of research practices. Furthermore, the labelling of law showcases that AI researchers need to be careful with how they label informal caregivers. Paper I showed that researchers tend to identify potential informal caregivers through their relation to the care receiver. This overlook in part could insinuate that many roboticists are not aware of the issue around informal caregivers, but consequently dismisses the opportunity to support informal caregivers. Paper III attends to this, by showcasing how law can assist directly by supporting informal caregivers–not 'just' family members–to get the relevant support according to their needs.

Paper III demonstrates the importance of the available legal status for young carers, and this very legal status was utilised in Paper IV to recruit participants that were recognised by the State as young carers. Put differently, I legitimised the role of young carers in AI research through law, to demonstrate that this problem is already addressed in society outside of engineering, and this must therefore be accounted for in AI-driven technologies. Paper III presents the available literature to bridge young carers and the development of AI-driven technologies, to demonstrate how the two can directly attend to the other. On the one hand, for example, AI-driven technologies can help identify young carers, whilst on the other, tools created for rehabilitation purposes can have two-player modes that can be adapted to young carers. This would help support one of their care responsibilities, by assisting young carers understand how to help with rehabilitation exercises. Put differently, AI-driven technologies can become tools to identify and support–a legal requirement in the UK–and young carers' daily lives become acknowledged and supported through technologies that help with care responsibilities in a way that is suitable for young carers.

However, though law helps challenge the status quo in the development of AI-driven technologies for health care, law does not challenge the status quo since *it is* the status quo in society. Young carer scholars have time and again published on the difficulties young carers face beyond the legal recognition of their role (see Chap. 2, for example the lack of available services for young carers (Brimblecombe et al., 2018; Burchardt et al., 2018) or young carers being more likely to live in poverty (Vizard et al., 2018)). Law is therefore not enough in and of itself, since it does not capture young carers' everyday realities.

Taking the power-of-law-rose-tinted-glasses off, there is a need to account for everyday realities–which SoL attends to. Paper II, Paper III and Paper IV attempt to do so, within and beyond health care. SoL thus becomes a key component of this thesis, since SoL engages with the tension of law and society, by attempting to uncover social norms beyond legal ones. In these Papers we attempted to showcase that law is one component that can be programmed into AI-driven technologies, though there will also be other norms, such as social norms. Social norms, due to their locality, are hard to pinpoint. They are local and contextual but those collected will inevitably impact design, datasets and personalisation of technologies. For those norms outside of those localities, technologies might create more issues, explained below.

Often, social norms mark an important steering component which can be overlooked by developers. Yet the prevalent social norms become more blatant once the technology is deployed, as Paper II argues. One example of social norms creating expectations is illustrated by Ruha Benjamin (2019) regarding the street ‘Malcolm X’ which the navigation system called out as ‘Malcolm Ten’ when giving directions. This demonstrated the expectation of Roman numbering for the letter ‘X’. Benjamin explained this as “the cultural norms and practices of programmers–who are drawn from a narrow racial, gender, and classed demographic–are coded into technical systems that, literally, tell people where to go” (Benjamin, 2019, p.78). The system thus reproduced certain commands, that here were racialised in Benjamin’s example, but could have been avoided with a more diverse group attuned to systematic societal issues. This is outside the legal realm–regulating such events would be hard to govern. Nevertheless, this example demonstrates an issue beyond racial norms and within social norms: norms are complex and require attending to, otherwise they reproduce a specific status quo that is harmful to most in AI-driven technologies. As Paper II suggests, norms will be collected nevertheless, but as Benjamin’s example demonstrates, may be misinterpreted by reproducing stereotypes (i.e. ‘Malcolm Ten’) or biases (i.e. erasing Macolm X as a historical figure). This exercise demonstrates that developers need to be attentive to what social norms should be expected–requiring an understanding of societal issues. This exercise is paramount to both HRI and HCI, and demands an investigation of specific stakeholders. This demands alternative research approaches that accommodate for different perspectives to create a fuller understanding of robots’ role in envisioned application–a warning already given by critical scholars within HRI (Ljungblad & Gamboa, 2024; Winkle et al., 2023). In this thesis, it has been to investigate informal caregivers through a socio-legal STS lens, especially young carers whose role has been erased during the development of AI-driven technologies, with little known consequences of this. STS has demonstrated the impact of technology beyond obvious stakeholders and beyond planned uses of technologies for envisioned end-users.

Paper III introduces young carers for researchers to become aware that they are likely collecting data on children that do provide care, but do not formally recognise nor identify them as such. The paper sets out what it means to be a young carer, for example the range in responsibilities and types of care receivers. The paper also demonstrates the various norms at play both within research communities and among young carers. Within the AI research communities, there is a lot of power held regarding who is included/excluded in study, and in turn what the dataset includes/excludes and how the application is designed to adapt to users. Put differently, who is seen and who is silenced/invisibilised. Yet, regarding young carers, they are excluded from HCI and HRI studies on health care–this can be due to ethics applications not allowing siblings to be part of studies (Silva et al., 2024), or a lack of awareness around young carers. Nonetheless, this dismisses their caregiving role, and issues around identifications and support–even with regulations in place. For now, since young carers are not viewed within that role, they are therefore likely labelled as children ‘only’, which overlooks their vital role as caregivers. This is turn reproduces norms which silence them as key caregivers within health care, and neglects their needs.

The role of Paper IV is to challenge the status quo in research by directly investigating young carers through a participatory design method–not solely as teenagers, but as teenagers that provide care to a parent and whose voice is necessary to the development of AI-driven technologies. The results at first point to participants using various types of technologies to support their care role, to then report on their views on the development of robots for health care. This leads to our findings not fully aligning with previous HRI studies conducted with teenagers generally–such as perspectives on parental responsibility (L. Levinson et al., 2024). We do not view this as surprising, but showcase why this group has different needs that researchers must account for. This repeats Paper II's warning, that relying on stereotypes in the development of adaptive technologies might result in creating more problematic technologies–which the participants were also quick to call out, such as robots not being developed to adapt to their families' unique needs.

The socio-legal STS framework in this thesis consequently demonstrates the necessity for situatedness that developers must attend to regarding informal caregivers. Both in terms of human relationships and caregiving responsibilities, but also technologies' impact on those. As the development of AI-driven technologies still does not account for children in their role as caregivers, this must be remedied so that AI-driven technologies' planned usages reflect realities of informal caregivers. The socio-legal STS framework also offers a possible way to undertake this type of research endeavour, which is aware of and sensitive to informal caregivers' complex context.

Briefly answering RQ2, knowledge production from AI researchers, through critical social sciences, can integrate more of informal caregivers' perspectives, especially as young carers have been neglected in research practices. Here, this was achieved firstly through labelling, and secondly, by attending to norms local to the surrounding environment of care receivers that will likely involve informal caregivers. This is all the more necessary as scholars outside of AI research have continuously pointed out the increasing expectation put on informal caregivers (Broese van Groenou & De Boer, 2016; Giesbrecht et al., 2012; Liu et al., 2020; Pavolini & Ranci, 2008)–explained in Chap. 2. Consequently, informal caregivers require additional safeguarding measures by researchers, so that we can attempt to support and validate their experiences as well as report on their realities. Critical social sciences is well equipped to do so to assist in the development of AI-driven technologies.

6.3 RQ3. Reframing Care: Empowering Informal Caregivers in AI-Driven Artefacts

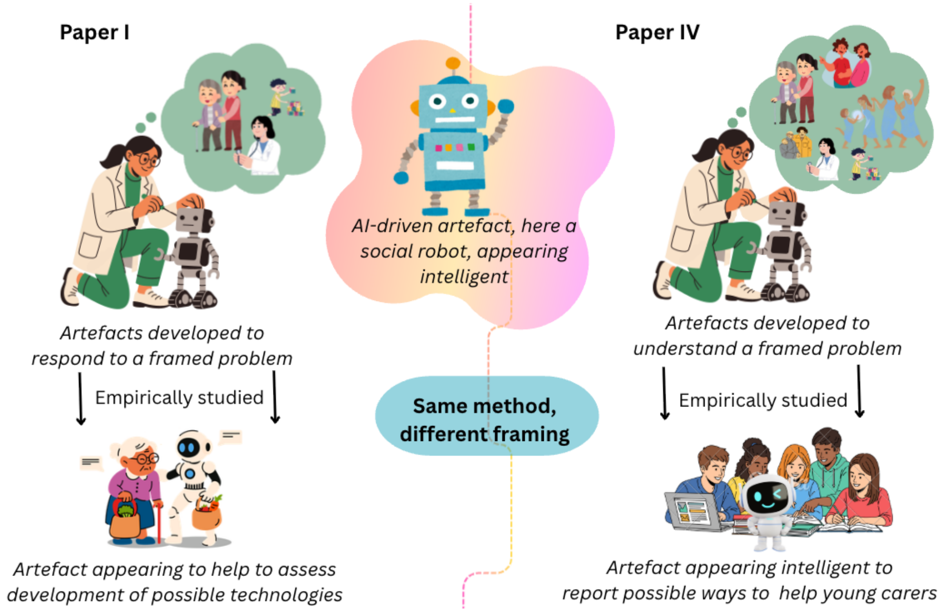


Figure 6.3: An illustration showcasing Paper I's framing and Paper IV's reframing of current HRI research practices on health care. This demonstrates that the development of AI-driven technologies are still not deployed and can still be reframed to incorporate more stakeholders.

RQ3. *How can AI-driven technologies, especially social robots, be developed to assist young carers directly?*

The third research question is about leaning into artefacts and their politics–as Winner called out (1980). The foundation of Feminist HRI is the significance of robots' embodiment: robots represent bodies as well as identities which will emanate from research projects (Winkle et al., 2023). These robots also materially embody the promises of AI-driven technologies: those robots are expected to rely on foundation models for more fluid conversations or to navigate in the space they are in. In other words, robots represent an embodiment of the promises of AI-driven technologies–even if those technologies have been overly hyped (Markelius et al., 2024).

The HRI community therefore often turns to the HCI community to understand the available technology and how this can be embodied into robots. Hence, the theoretical papers (Papers II & III) are grounded in more general AI-driven technologies. Since some AI-driven technologies are close(r) to deployment than robots, the theoretical stances in these papers offer warnings and opportunities that must be considered in adaptive technologies beyond robots. Such as the need to account for potential biases and stereotypes that are likely to occur (Paper II), as well as specifically introducing young carers into the development of AI-driven technologies to account for them in that role (Paper III).

Social robots at research stage present interesting artefacts, that can present alternative research approaches (Ljungblad & Gamboa, 2024). On the artefact of social robots generally, Ziemke states that "much of the 'social' nature of such [human-robot] interactions today is still largely in the eye of the beholder, who attributes intentional agency to the robot" (Ziemke, 2024, p.2). This is in the context of calling out the ironies of social robots, whereby as researchers we rely on the human-likeness people attribute to social robots to make that robot seemingly understand the situation. This is also echoed by Johnson on robots in a care setting specifically:

> This robot aerobics instructor is creating a stir [...] Stabilizing this disruption into a legible example of group exercise requires work; staging props, and captions to tell the viewer what they are seeing (Johnson, 2023, p.5).

These scholars demonstrate the very essence of this PhD project: (i) that the development of AI-driven technologies still being at research stage (ii) results in those artefacts appearing intelligent (iii) which researchers can leverage on to understand how to design and deploy useful technologies in the future. Since researchers attempt to understand robots in certain settings, these robots *imposter* on settings, as Johnson refers to (2023). Johnson's concept of *Pepper as Imposter* is very fitting, as the development of AI-driven technologies attempt to fulfil an imagined promise: curbing the care crisis due to demographic changes. Imposter here results in researchers having to use staging props and telling participants what this robot is expected to do, so that researchers can get appropriate feedback from participants. This shows the power these artefacts hold as we–participants and researchers–all have to adapt to them. In turn, this results in robots *impostering* on events, rather than providing the envisioned essential care.

Therefore robots being an artefact *appearing* intelligent that is not yet ready for deployment was viewed as an opportunity for this PhD project. Put differently, these artefacts that I am part of researching have politics and hold power that are still at predominantly at research stage. This results in a level of freedom to be able to reimagine current robotic applications trends (Paper IV), whilst using similar methods roboticists have used to evaluate potential robot applications in Paper I (as depicted in Fig. 6.3). However, and importantly, I was consequently inclined for these artefacts to be situated in young carer literature, which reflects current health care trends, such as budget cuts to public services resulting in children becoming young carers when the care receiver's health condition becomes more demanding. In other words, if the State cannot intervene with sufficient care services, informal caregivers–which include young carers–are expected to fill that necessary void regarding care receivers' health needs. It was therefore important to empower young carers' voices, and reflect their realities in these artefacts. The socio-legal STS lens was paramount to reframing these artefacts.

Reimagining robots for care was not solely about changing established HRI norms around research practices, but reframing the inclusion of stakeholders to go beyond care receivers and healthcare professionals (Paper I). As Fig. 6.3 illustrates, it is about including more stakeholders at this point. Suchman's theory of *plans and situated knowledge* attends to this, as she presents the importance of developers themselves for a machine to be deployed and used. Developers will need to project an imagined use of such machines–which concerns the *planning* aspect–whilst also retrospectively reconstructing the context of the action–which concerns the *situated* aspect (Suchman, 1987). This theory is not used to the fullest in this thesis, as I do not retrospectively reconstruct through my own user studies since robots are not deployed yet to do so. However, Suchman's theory is about uncovering symbolic representations as well as the unique and unrepresented circumstances when artefacts are in use (Suchman, 1987, p.189). Consequently, Suchman's theory in this thesis grounds developers' roles in creating artefacts that appear intelligent, whilst also attending to represent the unrepresented–here being young carers.

This is all the more important as robots do not merely reframe care practices, they reframe society. As Šabanović (2010) points out through *mutual shaping*, society shapes robot, but robots shape society. These artefacts can directly empower communities that have been silenced in society generally, if researchers are attentive to this. In Paper IV, the robot scenarios attended to care practices, but also challenged the lack of support in place for young carers. For example, the need for robotic solutions to not become substitutes for services currently available to care receivers and young carers. This knowledge production is important to create better policies that attend to young carers in society. Especially as Leu and Becker (2017) point out that the UK having support in place for young carers stems from (1) reliable national research and (2) contribution of national non-governmental organisations. There must therefore be knowledge production to bring forth challenges those communities face, which researchers in the development of AI-driven technologies should attend to; rather than mostly responding to top-down demands on care (Maibaum et al., 2022). In turn, by ensuring that robots respond to challenges within communities, these robots become more user-centred and thus more likely to be used in the future (Frennert et al., 2024). Which in turn creates changing norms that may create better support for young carers

(Leu & Becker, 2017)–showcasing the continuous *mutual shaping* (Šabanović, 2010).

An important caveat to reframing robots for care is that I could not simply create robot scenarios for young carers, I had to do so with care. I was presenting a mirror to my participants' daily realities and how those could be supported. This by default was *othering*, as I recognised that young carers needed support for something–even if it was normal to them. The care aspect was thus paramount for research purposes, (1) it was conducted in the UK, a context I know well; (2) the focus groups were based on participatory design methods, for participants to be empowered and share their contexts for me to learn (Vines et al., 2013); and (3), I took time to get to know my participants in focus groups 1 before showcasing robot scenarios to them in focus groups 2.

The first focus groups allowed me understand participants' realities, where I was discovering some important social norms that were present among most (if not all) of my participants. Part of this was to understand their commonality from an intersectional lens: all were under 18 years of age and (currently) educated at high school level–including those that had to drop out. Those norms became the equivalent of *living laws* for me to produce knowledge on as well as build robot scenarios from. It was therefore key to sensitively include those subjects, since, for example, one scoping review uses an intersectional lens on informal caregivers, which include age and education level (Hengelaar et al., 2023), showcasing different impacts based on those. Those can potentially result in AI-driven technologies overlooking important knowledge from young carers since they are under 18, still in education, and healthcare professionals are possibly less likely to recognise young carers' role and knowledge towards the care receivers (Wittenberg et al., 2018).

The second focus groups demanded another form of care, here it followed Puig de la Bellacasa's demand for attention to "voices that are less valued" (2011, p.92) in the assemblage of social robots–here being young carers. Focus group 2 was therefore presenting scenarios based on participants' experiences in focus groups 1, coupled with their neglect in current robotic applications, to alleviate the harm young carers could face by the deployment of social robots for care. For this to occur, there was in part a co-creation from focus groups 1, where participants situated their realities and their use of technologies as young carers in the UK. However due to the lack of representation of young carers in promotional videos of robots for care, participants had difficulties understanding how robots could help them, thus I also had to do some translation work to show how current developments of robots could attend to their care responsibilities, and beyond. Those robotic scenarios ultimately reframed envisioned applications to directly situate young carers in those, and pinpoint their necessary role to their parents' wellbeing despite their age. These showcased examples of planning, but to a huge extent, the findings showed the continuous need to situate those artefacts in the individual's unique context. The other care aspect was respecting my participants' time to attend these focus groups. Since those participants would not be getting their own robots, in the robotic scenarios, I offered various coping strategies based on their reported social norms that they had difficulties with.

Social norms were important in attending to my participants whilst reimagining robots for care. As a critical social scientist, I was trained to observe power dynamics, discomfort and tensions, as well as attend to those by reflecting on those practices. SoL researchers report on day-to-day realities to showcase norms outside of law that is followed by a certain group (Banakar, 2012; Ehrlich & Ziegert, 2017). Therefore, as previously noted throughout this thesis, SoL allowed for a duality between laws in place and young carers still facing adversity due to their care role. I did not try and find similarities between my participants, since none of them were caregivers in the same way: some had support at home, some had technologies already in place, some had to drop out of school. Instead, I concentrated on high-level themes, the equivalent of *living laws* at community level, that my participants discussed, some of which had been reported on elsewhere (see Chap. 2 on adversity young carers' face generally). The scenarios were therefore based on feedback alongside literature on young carers that point to a lack of free time, difficulty with school attendance, issues with who to speak to, care burdens, overload or not enough information on health condition(s), and time keeping–these are not new findings, though not in the context of technology. Those themes were coupled with various strategies participants could use in their own lives to help if they wanted to, such as reaching out to someone after a difficult event, or showing a squatting position to lift someone off the floor, or scheduling time for themselves to help with their daily lives.

Briefly answering RQ3, reframing requires interdisciplinary lenses to be attentive to societal trends. This requires resources to develop AI-artefacts that are sensitive to social norms and context, so that young carers can be directly accounted for in and supported by AI-driven technologies.

6.4 Reflexivity: Moving Towards Socially Aligned AI-driven Technologies for Care

This final section is reflecting back to be able to look forward. This was a highly personal PhD project, a project that empowered my own childhood experiences and my participants'. My role became multi-faceted, I was not merely a researcher in this project, I also became an advocate for young carers. I carefully navigated the norms around knowledge production to introduce young carers. Even in this thesis, only two of my papers are on young carers, as I needed to show the lack of inclusion of such a key group (Paper I) and the dangers of bias and stereotypes in adaptive technologies (Paper II).

A reflection on the decision to conduct the focus groups in the UK. Of course, my own positionality was key: a young carer in Wales and professional experience with young carers in England meant that I knew their context and had a network to help me. However, there were also legal aspects that played a vital role. In the UK, England and Wales have a specific legal status for young carers, which results in people being identified as young carers by local authorities and provide support often through young carer charities. This meant, as a researcher, I 'just' needed to ask charities to recruit teenagers that were recognised as young carers who cared for a parent. This would not have been possible in Sweden, where I am doing my PhD, or France where I have also lived in. Though Sweden has more in place for young carers than France, Sweden does not have legislation in place for young carers, with only some awareness and recognition of young carers among public, policy makers and professionals (Leu et al., 2023). This in practice would have meant that I would have needed to identify people as young carers myself, which felt too sensitive for a researcher to do, and there would not be the level of support that was available with young carer charities in the UK for me and my participants.

A reflection on being a critical social scientist in the HRI community. Being part of that community is very apparent, as I publish in HRI venues and attend mostly conferences catered to the HRI community. My contributions have been steered mostly towards the HRI community. However, in this thesis, I was able to bring my own social scientific background to the foreground and demonstrate how it has steered my PhD journey. Put differently, though I do not publish in STS and SoL venues, they have hugely contributed and shaped my thinking. I would hope that I have made some contributions to those two fields also, though ultimately, my goal has been to reframe research practices on the development of AI-driven technologies, to empower developers on the important repercussions on who they include in and exclude from studies.

A reflection on the type of papers I have published goes directly to the point above. For my papers to be published, papers had to follow expectations, which could be categorised as appearing somewhat positivistic. The papers are formulated to give some practical guidance. Paper I offers guidance on how to include informal caregivers, Paper II offers a socio-legal framework that is translated into an easy-to-follow *norms-in-the-loop* illustration, Paper III offers AI developers ways to include young carers in various types of applications, and Paper IV offers a catalogue of robot scenarios to envision supporting young carers as well as care receivers. I was able to contextualise those in this thesis, to demonstrate that these publications were to fill an evident gap: the lack of informal caregivers, and complete neglect of young carers, in the development of AI-driven technologies. Ultimately, I do not know if AI-driven technologies will offer help and support that young carers could benefit from, however, I do not think that this group should be neglected from this type of research.

A reflection on creating a new research avenue to bridge young carers and AI-driven technologies. My research in part has contributed to bringing attention to the lack of inclusion on informal caregivers overall in HRI. My research has also showcased how young carers have been entirely overlooked in the development of AI-driven technologies. I do not publish on the reasons why, however, from my own experience it seems that the HRI and HCI research communities overall are not aware of young carers. This lack of awareness coupled with the difficulties in young carers accessing further education could mean that people who were young carers do not tend to make it to a PhD level of education. Though, I doubt that I am such an exception. I was fortunate to have worked with young carer charities, known laws in place to identify young carers, and had an unwavering belief that young carers needed to be part of research agendas. Altogether, along with the support from my supervisors, and an undefined PhD project, allowed me to pursue a research project where I could frame young carers in.

Finally, on reframing care, research communities must centre human experiences and humour. Caregiving is part of being human, at some point, we will all attend to some form of caregiving, even if it is for a short moment. Caregiving, when done in conditions where the person is not overburdened or negatively impacted over long periods of time, can bring joy. Caregiving can show the amount of love and admiration friends and family have for one another. This thesis has only attended to the negative aspects by understanding how to alleviate care burdens through AI-driven technologies. However, AI-driven technologies may or may not be the solution, and they are definitely not the only solution. Nevertheless, knowledge production should not be about eradicating the joy and love that goes into providing care. Though admittedly, robots can be great artefacts to laugh at together–so let us lean into it as researchers.

This PhD has been years of training to mould me into a critical social scientist that can observe and report on the power struggles and tensions at play in the development of AI-driven technologies. I did not learn to programme, I learnt how to communicate with engineering communities. All in the hope that together, we can better innovations to make them more aligned with societal challenges communities face.

Chapter 7

Conclusion

The introduction began with two beginnings. On the one hand, rational and scalable AI-driven technologies that promise to bring solutions to the health care crisis, and on the other, the essential role of informal caregivers in society that is often overlooked. Throughout this thesis, the two have converged, to demonstrate their intricate entanglement: there is an implicit expectation that informal caregivers will enable the successful deployment of AI-driven technologies, and AI-driven technologies could directly account for informal caregivers to support their care role. Ultimately, converging informal caregivers and AI-driven technologies at development stage is complicated. This echoes Nelson (1974)'s remark, "[i]t may simply be enormously more difficult to design policies to equalize educational achievement or to eliminate prejudices, than to design a spacecraft to go to the moon". To reformulate Nelson for this project: it may simply be enormously more difficult to design AI-driven technologies to equalise care practices or to involve informal caregivers than to design a robot to go to the moon.

The thesis thus began with two beginnings and now marks an intersection: how researchers can include informal caregivers in the development of AI-driven technologies. The research aims of this thesis were two-fold: (1) to conduct interdisciplinary research on informal caregivers to bring forth the significance of critical social sciences in HRI on health care as well at times HCI; and, (2) to shed light on current societal challenges on care regarding informal caregivers, especially young carers, to the development of AI-driven technologies. The first aim was directed at the academic community, whilst the second aim was directed towards society by empowering specific stakeholders in envisioned AI-driven technologies as artefacts. The mixture of HRI and HCI was in part to bring young carers into the AI research field, whilst also acknowledging that HCI solutions are closer to deployment and would also benefit from this knowledge production. HRI was the testbed for empirical studies, whilst theoretical works were situated in both HRI and HCI literature.

The literature review chapter accentuated (1) the role of informal caregivers and their assumed role in society accentuated by States, with a focus on young carers; whilst also emphasising (2) research practices in health care in AI-driven technologies, and how researchers can attend as well as challenge them. The theory lens chapter introduced a socio-legal STS theoretical framework, to present the concepts of power of law, social norms, plans and situated knowledge as well as care. This framework provided a foundation to reframe current research practices concerning health care, and how to bring informal caregivers into the discourse of developing AI-driven technological solutions. The methods chapter sets out the empirical journey of this PhD project to situate informal caregivers in the development of AI-driven technologies, grounded in qualitative critical social scientific practices to an engineering audience. The results chapter provided insights from all four papers, showcasing a lack of involvement and acknowledgement of informal caregivers (Paper I), a theoretical framework to incorporate social and legal aspects within adaptive technologies (Paper II), a position paper explaining the socio-legal complexities around young carers in the UK and how to account for those within the development of AI-driven technologies (Paper III), and finally, an introduction to empirical work with young carers in HRI (Paper IV). These preceding chapters allowed to answer the three research questions in the discussion chapter, which showcased: (1) current oversimplification of care in research practices, (2) situating informal caregivers in the development of AI-driven technologies, (3) reframing care in AI-driven artefacts. Finally, the discussion chapter concludes with a reflection on my own journey to achieve the thesis' aims.

The contribution of this interdisciplinary thesis has ultimately been to *reframe robots for care*, by empirically uncovering research practices and responding to those theoretically and empirically. This was achieved by situating informal caregivers–especially young carers–in the development of AI-driven technologies through critical social scientific lenses.

7.1 Future work

Now that *Reframing Robots for Care* has been established, it is time to reframe care that robots attend to when they are deployed, which must be led by communities. Meaning that I would urge researchers to include informal caregivers in their ethics applications, to be able to have their voices included when evaluating possible AI-driven technologies.

What became more apparent about my research was the need for interdisciplinary researchers. I have positioned myself as a critical social scientist who attempts to problematise current societal issues around care in society and in engineering disciplines. For this, I relied on mentorship from a public health scholar as well as supervision from a socio-legal scholar and a critical engineer. This then shaped me to publish and present my research to engineers, for them to develop these possible applications into more tangible solutions. This showcases how I am part of a network: all researchers are interconnected through an intricate web of knowledge. I sincerely hope that engineers view my work as foundational work to deploying AI-driven technologies. I also hope that social scientists recognise their much needed skills to work alongside engineers, to critically conceptualise and evaluate possible AI-driven technologies.

This thesis, I hope, marks the beginning of incorporating young carers in AI-driven technology research for care. However, this was an exploratory project, where many more questions were found than answered. One question that particularly struck me is with regards to safeguarding. Levinson et al. (2024) have begun to question who should intervene when a child is disclosing sensitive information to a robot that poses risk to the child from experts' perspectives. In my own study, Paper IV showcased findings on who should be alerted when a child is asking sensitive questions to the robots on their parent's condition(s). It was voiced that young carers might ask about their parents' concerning health conditions, which would need a follow-up, such as questions on terminal illnesses or addictions. This needs to be further studied, especially if robots are expected to help with/monitor a certain condition, but are readily available in the household. This has to be teased out by researchers before deployment of AI-driven technologies in interdisciplinary teams, to ensure a situated and contextual framing of stakeholders in anticipated adaptive technologies.

Chapter 8

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Scientific publications

Paper I

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In Search of Informal Caregivers in HRI: A Critical Narrative Review of HRI Conference Papers

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Abstract

Background As the field of Human-Robot Interaction aims to develop and deploy robot applications for/in health care, it is important to disentangle research practices to understand who is (i) investigated, (ii) involved and (iii) how.

Objectives The principal aim is to identify and synthesise how articles in HRI for/in health care generally include various stakeholders in their studies. The secondary aim, evolving directly from the initial aim, is to shed a light on informal caregivers in contrast to healthcare professionals.

Method Using a critical narrative review method, we reviewed 52 articles related to health care published in the ACM/IEEE International Conference on Human-Robot Interaction (2006–2023). We specifically report on (1) how the studies are motivated, (2) who the studies include, (3) the methods used, and (4) how informal caregivers and healthcare professionals are accounted for.

Results Overall, there is seemingly an exponential growth in HRI in health care studies. From the 52 articles reviewed, 36 investigated care receivers, 20 investigated healthcare professionals and eight investigated informal caregivers. Using an alarming narrative to situate the study in opening paragraphs was commonly used, especially for care receivers and healthcare professionals. Care receivers were often investigated as a sole group, unlike other stakeholders. Healthcare professionals were often part of interview or focus group studies, whilst informal caregivers were often involved in workshops or laboratory studies. Finally, in 38 studies informal caregivers were either not mentioned or solely acknowledged, in contrast to 18 studies either not mentioning or acknowledging healthcare professionals.

Conclusion This critical narrative review demonstrates the importance that the HRI community gives to care receivers' feedback as well as the inclusion of healthcare professionals' expertise to deploy robots in health care. This review has also identified an important gap regarding the lack of identification and inclusion of informal caregivers in studies, despite their vital role. We therefore offer five recommendations on how to include informal caregivers more in study designs.

Keywords HRI · Health care · Informal caregiver · Care receiver · Healthcare professional · Critical narrative review · Social Justice · Feminist HRI

1 Introduction

Human-Robot Interaction (HRI) studies envisioning robotic health care applications often raise a narrative around alarming statistics, such as the expected change in demographics or the shortage of healthcare staff, to justify the need for such applications. Whilst these narratives point to a need to find societal solutions, there is also a need to pinpoint whether the use of such narratives impacts *who* HRI studies investigate, and *how* they include (or exclude) various stakeholders.

Health care marks an important pillar in society generally, albeit for diagnosing, treating, preventing diseases or

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injury to name a few. However, health care provisions by Western nations are moving away from State institutions (i.e. medical institutions, such as hospitals) to informal sectors, meaning that governments are shifting responsibility from the State to individuals [1]. This shift has a direct impact on who is expected to provide the vast majority of the care, namely informal caregivers. Informal caregivers have been named by the United Nations as "co-producers of care services" [2], as they are the ones to "help prevent or delay the need for institutionalisation of people in need of care or support and are enabling them to remain living at home" [2]. In practice, it currently is estimated that 80% of all care within the European Union (EU) is provided by informal caregivers [3], and although the exact number is not known around the world, it is most often informal caregivers that provide the bulk of the care [4]. Evidently, informal caregivers are crucial to care delivery, from in-home care to ensuring everyday wellbeing within residential care facilities for the person they support [5].

The objective of this narrative review is two-fold: the principal aim is to identify and synthesise how articles in HRI for/in health care generally include various stakeholders in their studies. The secondary aim, which evolved directly from the initial aim, is to shed a light on informal caregivers and healthcare professionals. The latter uses a critical lens deriving from Social Justice-Orientated Design [6] and Feminist HRI [7] to reflect on power structures and provide strategies to challenge current practices.

To achieve these objectives, we conduct this narrative review on articles published at the ACM/IEEE International Conference on Human-Robot Interaction (2006–2023) that are studies specific to health care. We disentangle the practices by analysing and reporting on four themes: (1) how the study is framed, (2) who the study includes, (3) what methods are used, and (4) how informal caregivers and healthcare professionals are accounted for throughout the articles reviewed. We are not aware of any HRI literature reviews that have conducted a literature review within this scope.

The definition of "health care" used here goes beyond that of institutions, such as hospitals or residential care facilities and formal diagnoses of particular diseases or medical (in)capacity. Hence we use a space between 'health' and 'care'. Instead, our definition encapsulates providing care for someone to support their healthy living. Such care might relate to overall well-being, preventative health care, temporary support following, for example, an injury or longer-term support associated with ageing and/or long term health issues. We exclude general childcare, but include situations of informal (health) care provided by parents/guardians in line with our definition ("parent carers" being a recognised group within the informal care literature [8]) as well as parenting during a global pandemic due to reduced capacity of services from institutions. The definition of "informal caregivers" used throughout this paper derives from the Royal College of General Practioners [9] as:

> A person of any age, adult or child, who provides unpaid support to a partner, child, relative, or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse.

We note that whilst informal carers are unpaid, the work they do is very demanding – both physically and emotionally [10–12]. We also note that there are barriers around identifying informal caregivers. Carduff et al. [13] point out possible reasons for this: (1) due to informal caregivers favouring to identify themselves by their relation to the care receiver (i.e. sibling or spouse) rather than their caregiving role, and (2) due to healthcare institutions being reactive rather than proactive to identify informal caregivers, meaning that healthcare professionals do not identify the person as an informal caregiver until a crisis occurs.

1.1 Research Questions

The overall research question (RQ) we explore can be summarised as: *how do HRI researchers position stakeholders within studies relating to HRI in/for health care, especially informal caregivers?*

We pose four sub-research questions that help us answer the main question:

1. How are researchers motivating studies in health care when including different stakeholders?
2. Which stakeholders are included in HRI studies for/in health care?
3. What methods are HRI researchers using when including participants for/in health care?
4. How and at what point are informal caregivers and healthcare professionals included in health care HRI studies?

This study is a critical narrative review based on articles published at the ACM/IEEE International Conference on Human-Robot Interaction. In line with previous reviews that have utilised the HRI conference proceeding as way of commenting on HRI practices [14–17], we suggest that the highly selective nature of the conference (acceptance rate typically 25% or less) indicates that work published at the conference is considered high quality by the community. We consider that methodologies and practices showcased at the conference are therefore likely to be seen as good practice and hence propagate through the field more broadly.

The remainder of this article is structured as followed: Sect. 2 presents relevant literature; Sect. 3 introduces the methodology followed to conduct the narrative review. The results section, Sect. 4, showcases the four dimensions analysed. These findings are then discussed and reflected on along with recommendations on how to include informal caregivers more in Sect. 5. This leads to a conclusion in Sect. 6.

2 Relevant Literature

2.1 Human-Robot Interaction in Health Care

Current HRI for care research points to social robots being perceived as useful by healthcare professionals, such as doctors, nurses, formal caregivers (see e.g. [18]), as well as older people (see e.g. [19]), children (see e.g. [20]) and even pets [21]. Moreover, HRI studies have specifically invited domain experts and potential users to identify how exactly robots could be helpful in the care context, resulting in participants often being able to identify possibilities that they might be enthusiastic about [22].

Literature reviews in this field have focused on (1) what types of robotics were being researched and for what care applications [23], (2) how social robots were used to help end-users within (a) residential care facilities for older adults [24] as well as (b) children's mental health care [25]. Literature reviews from critical perspectives have mostly focused on residential care facilities for older adults [26–28], which showcased the political nature of bringing robots into care: the power dynamic at play results in tech solutions being prioritised, rather than the societal challenges at hand. Finally, a critical narrative review reported on assistive robotics design, which investigated the low uptake of assistive robotics and ultimately concluded the necessity of technology being user-centred [29].

2.2 Critical Perspectives within Human-Robot Interaction

Researchers within HRI have identified that demand for robots in care is seemingly not bottom-up [26, 30]. In other words, care organisations or families may not be the ones asking for technological solutions to help. Rather, the demand is more from institutions, embedded within allegedly *neutral* discourse, emanating from governments and international organisations [26, 27]. This allegedly neutral discourse presents alarming narratives about seemingly "inevitable problems" regarding changing demographics, especially with regards to the increase in ageing population and shortage skilled workers in care (for example [31, 32]). Those issues of course require innovative approaches, yet those statistics do not include, for example, the rising struggles for care workers in part due to budget cuts in the sector [33], or the policies framing the "need" for robots in care [28], nor do they fully acknowledge informal caregivers. As a consequence, this usually results in technologies benefiting only a certain type of user – in the context of care for example, care for older people is most often the object of literature reviews within HRI (for e.g. [19]), critical HRI (for e.g. [26, 27]) and medical HRI (for e.g. [24, 34]) articles. Moreover, a number of recent studies have brought attention to the ways in which HRI research can reproduce problematic status quo in society, such as gender stereotypes generally [35, 36] and gender stereotypes within care [37]. These studies call for the HRI community to consider not only how we, the HRI community, might *avoid* this, but consider our role in *challenging* the status quo. Furthermore, a critical narrative review by Frennert, Persson and Skavron [29] was conducted on assistive robotics design, who demonstrated the need to look at underlying assumptions on the framing around disability and how to account for more user-centred – as well as the meso and macro systems at play – to ensure that these technologies will be used in the future.

Lastly, a previous literature review considering the HRI conference proceedings demonstrated that the 'H' in HRI often represents certain homogeneous groups, calling for increased efforts to diversify research participation and make studies more accessible to a broader range of participants [17]. This is echoed in another literature review investigating the demographics of participants looked at in HRI studies [38], where Seaborn, Barbareschi, and Chandra use the acronym "WEIRD" (acronym for Western, Educated, Industrial, Rich, and Democratic) to showcase the population primarily drawn on in HRI studies.

3 Method

This study is a critical narrative review of the HRI conference proceedings, aiming to identify stakeholders in HRI health care studies and synthesise the inclusions of specific stakeholders. Accordingly, we review articles in their entirety, this is in contrast with e.g. a systematic review, which would aim to assess the findings of those studies to understand the effects of those HRI interventions being investigated [39]. Put differently, narrative literature reviews focus more on the exploration by summarising and synthesising current research of a specific topic, which can in turn allow for a novel conceptualisation of the current trends [29, 40]. In this review, we systematically identify and map out how stakeholders —*with an emphasis on informal caregivers*— are considered within our sampled literature in order to offer critical reflections on their inclusion in HRI research (or lack thereof). Moreover, the critical part of this narrative review reflects and dives deeper into the findings to warn about the ongoing trends as well as provide constructive recommendations for the HRI community going forwards. Indeed, this narrative review also holds the HRI research in/for health care *accountable* within its *power* structures, for instance how HRI research brings and positions robots in certain settings to investigate particular stakeholders in health care (this reflection is influenced by Dombrowski et al. [6] and Winkle et al. [7]).

3.1 Choice of Literature Corpus

This study is limited to the ACM/IEEE HRI conference, as a premier venue of HRI research, in line with previous studies reviewing HRI practice (for example, [14–17, 38]). Since the nature of that conference is to showcase the best and latest research within HRI, operationalised via e.g. limited acceptance rate, we follow those aforementioned reviews in assuming that this research should be a sample of community-assessed good-practices within HRI in/for health care. Pragmatically, the nature of our explorative qualitative analysis (explained in subsection 3.3), also requires significant time and resources, resulting in setting some upper bounds on the amount of literature we can include, making the HRI conference proceedings a natural (and optimal) sub-selection of HRI research.

3.2 Delimiting the Search and Screening

The ACM Digital Library was the only database articles were extracted from. The search strategy and choice of keywords were decided unanimously between authors, which includes roboticists and social scientists, all of whom are critical scholars. The search strategy was restricted to research articles only within the HRI conference proceedings to find any abstracts containing the following keywords: (“health care” OR “healthcare” OR “assistive” OR “impairment”) AND (“care” OR “assist*”).

The use of boolean operators (“OR” and “AND” herein) were employed to group terms, either to have similar terms searched for or to combine layers. The first set of brackets, (“health care” OR “healthcare” OR “assistive” OR “impairment”), marks the *context*, which targets the saturation of the HRI in/for health care field through combining different terms that are similar to care within HRI literature. The second set of brackets, (“care” OR “assist*”), represents the *concept*, to delimit and target studies within the scope of care when researching the healthcare setting. The asterisk “*” was attached to the stem word ‘assist’, to provide search results which contain variations of that root word, such as“assistance” or “assistive”.

In order to delimit the papers included in this review, boundaries were set according to inclusion and exclusion criteria. The following inclusion criteria had to be met, the study must (i) be an empirical study, (ii) include participants, (iii) include a robot (e.g. physical or video-based or hypothetical, mechanical or social), (iv) be within the scope of health care (namely, improving quality of care, bring some independence to the user or loneliness and companionship, supporting or motivating the user or/and reduce workload of caregiving), (v) use the robot to help or assist (e.g. with exercises and rehabilitation, monitors the care receiver, or aid the caregiver). The exclusion criteria were: (i) studies aimed at education, (ii) literature reviews, (iii) empirical studies that conduct only observations (e.g. ethnographies or not about the robot design directly), and (iv) extended abstracts.

The final search was conducted in September 2023, with a total of 187 hits from 2008 to 2023. All the literature from the results were exported onto EndNote 20 to be able to initially screen the documents. Once the screening process was completed, articles were exported for analysis on NVivo to conduct a qualitative content analysis.

3.3 Reviewing and Analysing the Literature

We relied on Braun and Clarke’s five steps to conduct a thematic review method [41], namely: Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition. We employed an inductive approach – meaning that we did not have pre-defined themes ahead of the analysis. Accordingly, after familiarising ourselves with the retrieved articles, a pilot test was conducted between LT and KW using the same articles to find initial codes of interest and discuss them into themes and sub-themes. This created an initial codebook – a codebook defines themes as well as delimits them, and thus creates a systematic approach to coding. LT then coded the rest of the articles, and using an iterative process, would consult with KW if the theme needed to be reconceptualised or a new theme needed to be added, which in turn would revise the coding and codebook until saturation was reached for the narrative review.

The process of data extraction began inductively, meaning that we collected specific data of interest for this review through reading through articles. This led to clear research questions guiding the extraction process, particularly the location of the information for each question. The first three were based on particular parts of the papers. Regarding (RQ1), the data were extracted from the opening paragraphs; (RQ2 & RQ3) data were mostly extracted from methods and results sections. However (RQ4) data of interest were collected anywhere in the paper, as it was about demonstrating how healthcare professionals and informal caregivers were still somewhat present in studies even if they were not directly investigated in the study. The themes for RQ4 were shaped by Feminist HRI's conceptualisation of power and subject-positioning within HRI [7]; as well as Social Justice-oriented Design [6], borrowing the concepts of "designing for recognition" and "designing for accountability" to hold the HRI community accountable for how research is currently conducted, and who we choose to include within our own studies.

4 Results

The literature reviewed in this study was searched on and collected from the ACM Digital Library database, specific to the ACM/IEEE HRI conference. This initial search yielded a total of $n = 187$ records, as seen in Fig. 1.[1] Following title and abstract screening, 96 records were removed as they were not compliant with the stated inclusion selection criteria, resulting in 91 for full-text screening. Following the full-text screening an additional 39 records were excluded, leaving a total of 52 publications included in the present review.

4.1 Overview of Reviewed Articles

From our sample, articles in the health care domain begun to be published in 2008 at the HRI Conference, as can be

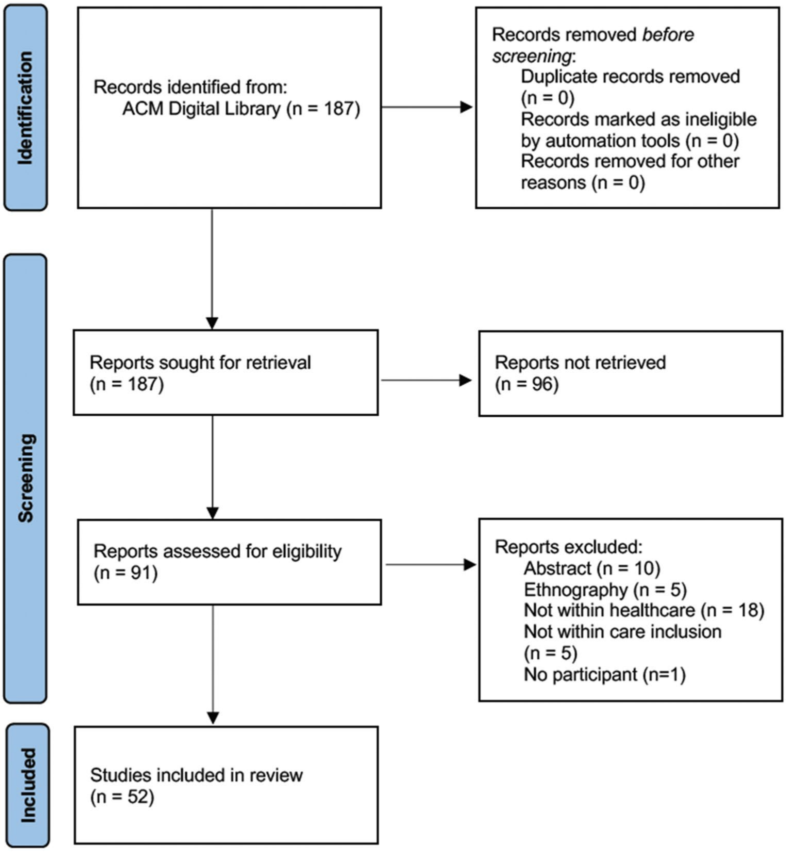

Fig. 1 PRISMA flowchart diagram of selected Studies [42]

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[1] Note that we use the PRISMA flowchart to illustrate the process, we do not use the PRISMA method for this review.

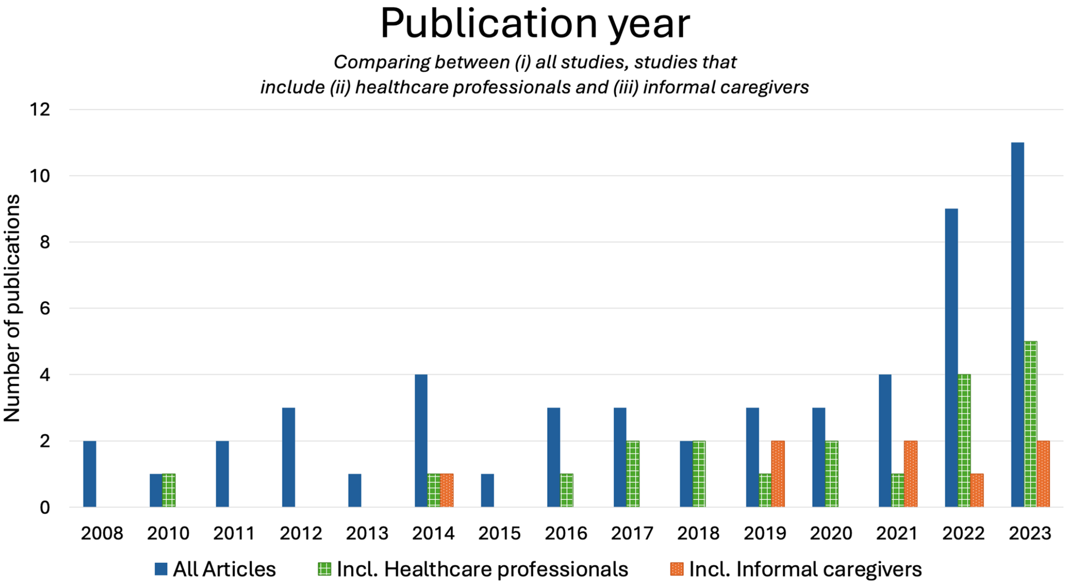

Fig. 2 Graph showing the number of publications between 2008 and 2023. The bars present a comparison between the percentage of (i) all articles (n=52), (ii) articles investigating healthcare professionals (n=20) and (iii) articles investigating informal caregivers (n = 8)

seen in Fig. 2. This is two years after the start of the HRI Conference in 2006. Seemingly there is an exponential growth of HRI studies in health care. Out of the 52 articles reviewed, 36 studies directly included the envisioned care receiver (totalling to 69% of the collected literature), eight studies included informal caregiver all of whom were adults (totalling to 15% of the collected literature) and 20 studies included healthcare professionals (totalling to 38% of the collected literature). For an overview of the in-depth analysis of articles see Table 2

4.1.1 Publication and Envisioned End-Users

As can be seen in Fig. 2, the first appearance of healthcare professionals was in 2010. After that, they were sporadically included as participants, and from 2016 healthcare professionals are consistently included in HRI health care studies. The first publication to include informal caregivers as participants was in 2014. From 2021, informal caregivers were continuously included in HRI health care studies as participants. Overall, informal caregivers are included at a much lower rate in comparison to the amount of HRI publications in health care.

The articles reviewed envisioned the care application either for: older adults (n=16 articles; 31%), adults (n=6 articles; 12%), children (n=7 articles; 13%), all age groups (n=22 articles; 42%), and staff (n=6 articles; 12%). For an overview of the articles along with their aims and participants, see Table 2.

4.1.2 Studies' Introduction

Introductions play a vital role in setting the context for studies: how authors choose to frame the introduction will ultimately set the tone for the justification of the study and how it was conducted. Accordingly, we analysed the two opening paragraphs (or if not applicable, up to one column of the introduction) of every introduction in order to pinpoint the motivation authors used. We identified several themes: *robot design*, *lived experiences*, *further(ing) current robotic research* and *alarming narratives*, as well as *automate task* and *augment task* (see Fig. 3 which illustrates the first four motivations). Note that the coding was not strictly restricted to one category, meaning that the opening paragraphs could include more than one motivation (see Table 2 for a detailed breakdown).

Robot design encapsulates the role of roboticists – within this theme, it assumes that the reader understands the role a roboticist plays within HRI without any clear referencing (thus more anecdotal). For example, Lee et al. [43] call out the role and design decision roboticists: "*The responsibility for making decisions about appropriate robot applications has so far been largely in the hands of robot designers; however, the societal significance and breadth of these*

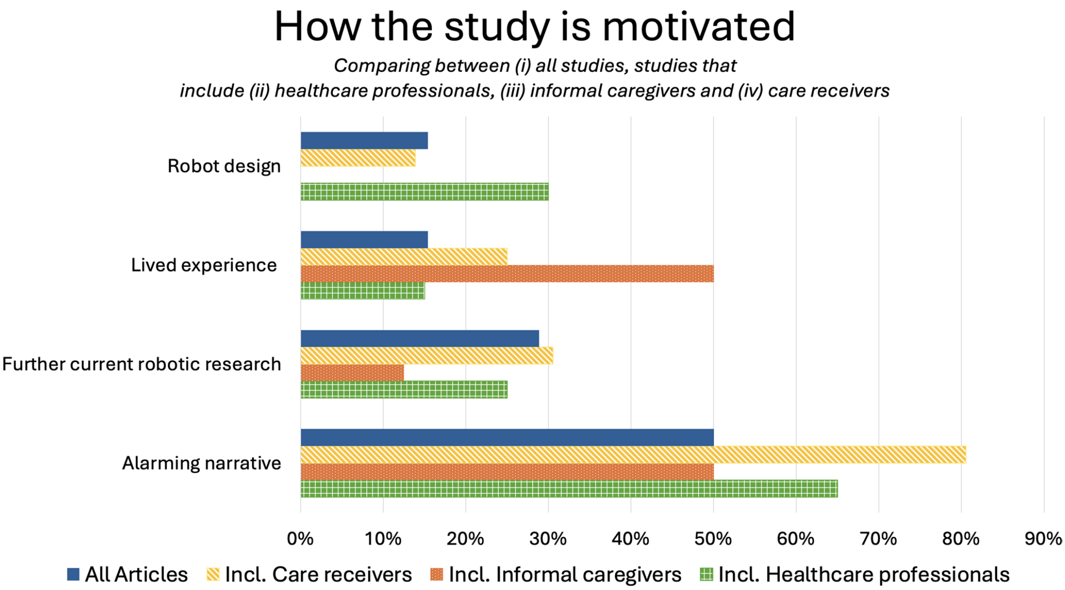

Fig. 3 A bar chart comparing motivation(s) relied on by the studies to set the scene. The bars present a comparison between the percentage of (i) all articles (nn=52), (ii) articles investigating healthcare professionals (nn=20), (iii) articles investigating informal caregivers (n = 8), and (iv) articles investigating care receivers (nn=36)

concerns suggests a more inclusive, participatory process is necessary". As seen in Fig. 3, this theme was more prevalent for healthcare professionals (n=13 studies) than other stakeholders, and not used in studies involving informal caregivers.

In comparison, *lived experience*, begins the research paper by setting the context of a certain medical condition without necessarily using academic referencing nor being specific to HRI. An example of this is by Nanavati et al. [44]: *"Take a moment to recall the last time you shared a meal. What made it meaningful? The company, the food, the ambiance? The stories that were told, relationships that were strengthened, milestones that were celebrated? If you were asked, 'How does it feel to eat socially?', you might say it is a pleasant experience"*. Fig. 3 shows that this theme is most prevalent with studies that included inform caregivers (with over 50% of studies investigating informal caregivers using it).

Alarming narratives refers to the use of statistics or the use of "doom and gloom" to demonstrate that there is a need for robots to enter that domain. An example of this: *"According to a recent report from the World Health Organisation (WHO), there is currently a global shortage of 7.2 million healthcare workers, and this number is expected to grow to 12.9 million by 2035"* [45]. This motivation is consistently used across all the reviewed literature for this narrative review, and as Fig. 3 shows, this is most used across all studies.

The final category showcased is *further(ing) current robotic research*, which is where the justification refers to previous HRI articles looking at a similar issue within the domain, positing the current work as developing on/responding to those previous works. This motivation was only used from 2014. As Fig. 3 demonstrates, it is the second most popular motivation to incorporate in introductions, though it was used in one study which investigated informal caregivers.

4.2 Inclusion and Investigation of Stakeholders

This subsection aims to demonstrate which stakeholders were directly included in studies as participants as well as which methods were used (see summary in Table 2). Data for these themes were extracted from the methods/results section of the sampled studies.

4.2.1 Group(s) of Stakeholders Investigated

At a glance, Fig. 4 shows that there is seemingly a trend in all articles that studies are much more likely to include only one or two stakeholder/user group(s) as part of the study.

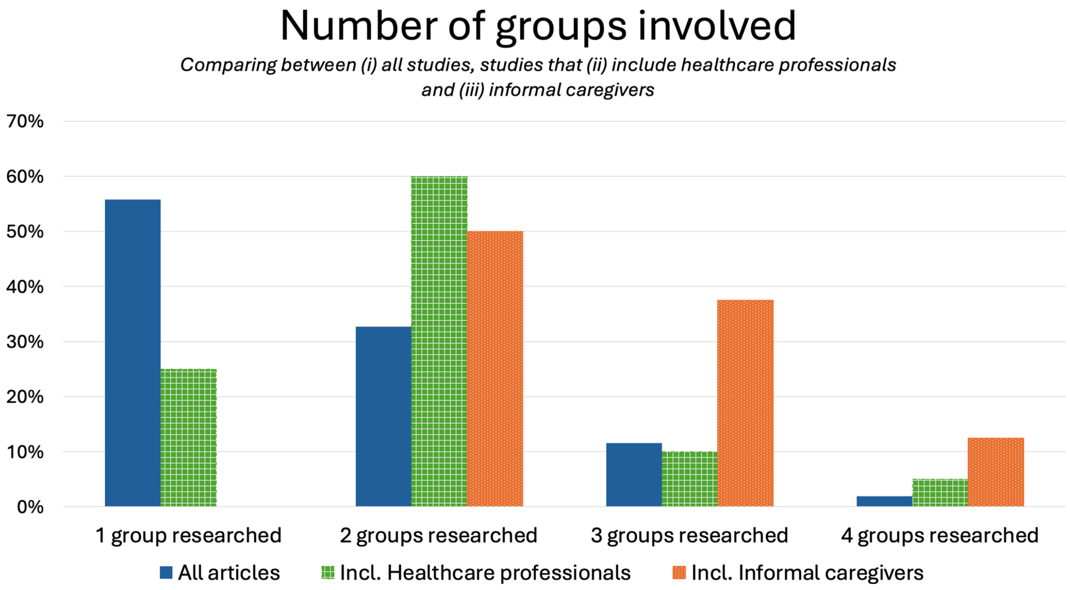

Fig. 4 A bar chart illustrating the number of groups involved. The bars represent the percentage of (ii) all articles ($n = 52$), (ii) articles investigating healthcare professionals ($n = 20$) and (iii) articles investigating informal caregivers ($n = 8$) to compare how many groups were included

Over half of the articles reviewed investigated only one stakeholder group ($n = 29$ articles), 18 articles of which investigated solely care receivers. In contrast, informal caregivers were never investigated as sole stakeholders.

Out of the 17 studies which included two different groups of stakeholders as their participants, 12 of those studies included healthcare professionals and four studies included informal caregivers. Finally, seven studies included more than three groups, demonstrating that this is quite uncommon in the collected studies. Four of those directly investigated informal caregivers (out of the eight studies that investigated them), one study investigated care receivers and three studies investigated healthcare professionals.

4.2.2 Methods Used

Methods here refers to the approaches researchers relied on to answer the collected articles' research question(s). Figure 5 depicts various methods studies used in our sampled literature's data collection. Importantly, interviews and focus groups are categorised together on the basis that both typically target relatively homogeneous participant groups (e.g. "therapists"), unlike workshops – hence they are separated.

Overall, administering surveys or questionnaires was the most common method in our sampled literature ($n = 32$ articles).[2] The second most common method was laboratory (or lab-like) studies ($n = 26$ articles) – which is not reflected in studies which investigated either healthcare professionals (used in four articles) or informal caregivers (used in two articles). The third most common method was interviews/focus groups. This method was the most widely used among healthcare professionals ($n = 14$ studies out of 20 use that method). On the other hand, interviews/focus groups were only employed in three studies when investigating informal caregivers.

In-the-wild studies refers to studies undertaken outside of laboratories where the robot is left to roam and interact for some time with people, which was performed in 10 of the studies collected. Healthcare professionals were participants in six of those studies, informal caregivers were participants in one of those studies, and care receivers were participants in eight of those studies. This method was mostly used in elderly care facilities or rehabilitation facilities ($n = 6$ articles); none of which included informal caregivers, and five of which included healthcare professionals as participants [46–50]. This method was also used in three studies taking part in the domestic setting, of which one article included informal caregivers [51].

The two final methods we report on were video-based and workshop-based studies. Video-based refers to researchers

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[2] Note that demographic surveys are not counted, only surveys or questionnaires that measured robot interactions/acceptance or feedback.

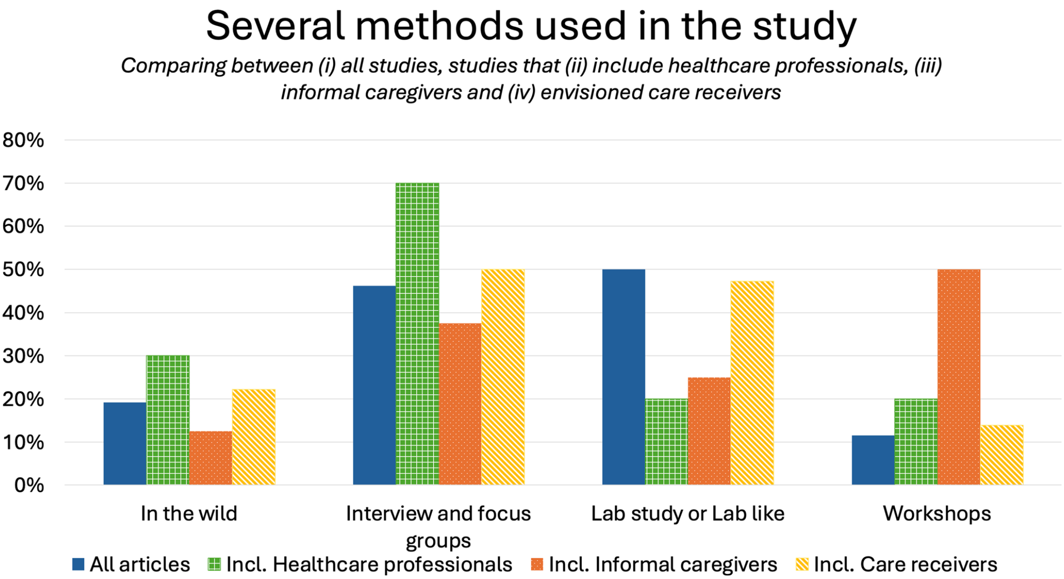


Fig. 5 A bar chart illustrating the methods used. The bars represent a comparison between stakeholders on methods used in the study according to the percentage of (ii) all articles (n=52), (ii) articles investigating healthcare professionals (n=20), (iii) articles investigating informal caregivers (n=8), and (iv) articles investigating care receivers (n=36)

showing video samples of robots, either commercially available or specific to the application that they are testing. This method was used in 13 studies, of which 10 included healthcare professionals, two included informal caregivers, and 10 included care receivers (see Table 2 for breakdown of studies). Workshops on the other hand are more creative and tend to design different robot applications in a more imaginative and hands-on way. This was the least common method amongst the sampled articles herein (n=6 articles), yet this was used in most studies which investigate informal caregivers (n=4 articles).

4.3 Involvement of Informal Caregivers and Healthcare Professionals

Up until this subsection, the results report on how HRI health care studies were motivated and conducted when published at the HRI Conference. However, these results made us authors aware of how little informal caregivers have been investigated. Using a feminist-HRI [7] and social justice-orientated design lens [8], we critically reviewed more in-depth to demonstrate (i) the difficulty of defining informal caregivers, especially in comparison to healthcare professionals, and (ii) how the HRI community involved and recognised these two stakeholder groups. Accordingly, we solely focused on those two groups to undertake a more critical analysis to hold the HRI community accountable and show the need to engage more with informal caregivers especially. Table 1 offers a full breakdown of every article and whether informal caregivers or health care professionals are mentioned, and if they are involved, how (the 'how' is only if they are involved at an either a low or high level).

4.3.1 Identifying Informal Caregivers and Healthcare Professionals

To identify informal caregivers, we relied on the definition from the Royal College of General Practioners [9], which recognises that a member of the family or a friend can be viewed as an informal caregiver if the support that they bring allows the care receiver better overall well-being and health. It is important to note that parenting as a general rule is not informal caregiving as such, however, we make two exceptions tho this: (1) parent-carers, denoted by situations where the child would not be able to manage their condition without the help of their parent, and (2) in time of world-wide health crisis, such as the COVID-19 pandemic, whereby more responsibilities were put on parents as services provided by institutions were shut down or extensively decreased.

The definitions of informal caregivers are important to highlight, as out of the eight studies which include informal caregivers directly in their study, only five refers to them as such – as summed up in Table 1. Put differently, three articles

Table 1 Involvement of informal caregivers and healthcare professionals in articles, sorted from informal caregivers being not mentioned to highly involved. A brief overview is offered regarding the involvement of informal caregivers and/or healthcare professionals if they are involved at a high or low level in the studies collected

Authors	Year	Involv. of Informal caregivers	Involv. of Healthcare of professionals	Level of involv. ofinformal caregivers and/or healthcare professionals (High & low)	Participants
Tsui et al. [52]	2008	Not mentioned	Highly involved	Occupational therapists (co-authors)	Wheel-chair users (intended care recipient; 17 to 60 yrs old)
Heerink et al. [46]	2008	Not mentioned	Low involvement	Study based directly within care facilities & recruited healthcare professionals	Older adults (intended care recipient; 65–94 yrs old)
Park et al. [52]	2012	Not mentioned	Not mentioned	-	Students with visual impairments (intended care receiver); control group (students without visual impairments)
Beer et al. [53]	2012	Not mentioned	Not mentioned	-	Older adults (intended care recipient; 65–93 yrs old)
Moosaie et al. [54]	2017	Not mentioned	Highly involved	Healthcare professionals are participants in the study; Try to understand, and improve, healthcare professionals perception of pain in patients	Control group (non-clinicians; Amazon Mechanical Turk); healthcare professionals (clinicians)
Chevalier et al. [55]	2017	Not mentioned	Highly involved	Study is based directly within care facilities, caregivers from those facilities helped design robot task	Children with ASD (intended care receiver; 8–17 yrs old)
Guneysu Ozgur et al. [56]	2018	Not mentioned	Highly involved	Healthcare professionals are participants in the study; study based directly within care facilities	Patients in need of upper limb rehab (3–68 yrs old; intended care receiver); healthcare professionals (neurologists, therapists)
Winkle et al. [57]	2019	Not mentioned	Acknowledged	-	Adults (potential care receiver; 18–74 yrs old)
Rea et al. [58]	2021	Not mentioned	Low involvement	Study is grounded in sports psychology scholarship	Adults (potential care receiver; average age 29 yrs old)
Lippi et al. [59]	2022	Not mentioned	Not mentioned	-	Control group (seemingly able-bodied – not reported)
Birmingham et al. [60]	2022	Not mentioned	Acknowledged	-	Adults (intended care receiver; recruited through Amazon Mechanical Turk)
Odabasi et al. [47]	2022	Not mentioned	Highly involved	Healthcare professionals are the participants of the study who also helped scope the initial study; study based directly within care facilities	Healthcare professionals (carers providing in-home care)
Camilleri et al. [61]	2022	Not mentioned	Highly involved	Healthcare professionals are the participants of the study; study based directly within care facilities	Healthcare professionals (nurse, physiotherapist, senior carer, carer, nursing home manage and occupational therapist)
Shi et al. [62]	2023	Not mentioned	Acknowledged	-	Intended care receiver (university students and Amazon Mechanical Turk)
Spitale et al. [63]	2023	Not mentioned	Highly involved	Healthcare professionals are participants in the study	Employees (intended care receiver; 18–55 yrs old); healthcare professional (well-being coaches)
Chen et al. [64]	2010	Acknowledged	Highly involved	Healthcare professionals are participants in the study	Healthcare professionals (intended care recipient; Nurses)
Beer et al. [65]	2011	Acknowledged	Acknowledged	-	Older adults (intended care recipient; 63–88 yrs old)
Chen et al. [66]	2011	Acknowledged	Low involvement	Study based on attempting to replicate nurse-patient relation	Control group(university students)
Prakash et al. [67]	2013	Acknowledged *(not identified as informal caregiver)*	Acknowledged	-	Older adults(intended care recipient; 68–79 yrs old)
Novak et al. [68]	2014	Acknowledged *(not identified as informal caregiver)*	Acknowledged	-	Control group (no arm impairment; 25 to 53 yrs old)

Table 1 (continued)

Authors	Year	Involv. of Informal caregivers	Involv. of Healthcare of professionals	Level of involv. ofinformal caregivers and/or healthcare professionals (High & low)	Participants
Hoffman et al. [69]	2014	Acknowledged *(not identified as informal caregiver)*	Acknowledged	-	Control group(university students)
Briggs et al. [70]	2015	Acknowledged *(not identified as informal caregiver)*	Highly involved	In control condition, the medical survey is administered by a healthcare professional	Adults (intended care receiver; average age 67 yrs old)
Herlant et al. [71]	2016	Acknowledged	Acknowledged	-	Users of robot arm (intended care receiver); control group (Amazon Mechanical Turk; local community – able-bodied); other expert (employees of robot manufacturer)
Hebesberger et al. [48]	2016	Acknowledged	Highly involved	Healthcare professionals are participants in the study; study took place in a healthcare setting	Older adults with progressed dementia (intended care receiver; 74–95); healthcare professionals (therapists)
Kraftet al. [72]	2016	Acknowledged	Low involvement	The study aims to understand how robot usage can protect hospital workers, so thee robot tries to mimic what the workers do.	Control group (people from surrounding community and campus)
Lee et al. [43]	2017	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals are participants in the study and co-authors	Older people (intended care receiver, no age mentioned) ; healthcare professionals (mental health therapists)
Winkle et al. [22]	2018	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals are participants in the study	Healthcare professionals (intended care recipient; therapists)
Feingold Polak et al. [49]	2020	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals are participants in the study; study based directly within care facilities; & physical therapist is facilitator and co-author	Post-stroke patients (intended care receiver, 51–75 yrs old); healthcare professionals (clinicians)
Fang et al. [73]	2022	Acknowledged	Low involvement	Expertise among research group to (ethically) scientifically provoke heightened anxiety in children	Children with mild anxiety traits (intended care receiver; 10–12 yrs old); control group (children without anxiety traits)
Kubota et al. [74]	2022	Acknowledged	Highly involved	Healthcare professionals are participants in the study	Older adults (intended care receiver; 73–75 yrs old); healthcare professionals (clinical researchers: neuropsychologists, psychiatry faculty member)
Wilson et al. [75]	2022	Acknowledged *(not identified as informal caregiver)*	Low involvement	Care providers helped with recruitment of participants. Study partly took part in care facilities.	Older adults (intended care receiver; 80–92 yrs old)
Tanqueray et al. [76]	2022	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals are participants in the study	healthcare professionals (medical expertise in peripartum depression); other experts (Gender Studies scholars)
Neerincx et al. [77]	2023	Acknowledged	Acknowledged	-	Children (intended care receiver; 8–10 yrs (& pilot: 9–17 yrs old))
Antony et al. [78]	2023	Acknowledged	Highly involved	Healthcare professionals are participants in the study	older adult (intended care receiver; 65–94 yrs old); healthcare professionals (physical therapists); other experts (engineering students)
Ranganeni et al. [79]	2023	Acknowledged *(not identified as informal caregiver)*	Acknowledged	-	People with high level of visual impairment (intended care receiver; 19–80 yrs old)

Table 1 (continued)

Authors	Year	Involv. of Informal caregivers	Involv. of Healthcare of professionals	Level of involv. ofinformal caregivers and/or healthcare professionals (High & low)	Participants
Jeffcock et al. [80]	2023	Acknowledged *(not identified as informal caregiver)*	Low involvement	Expertise in healthcare to integrate medical delirium detection implemented in robotic system	Control group (university researchers)
Kubota et al. [81]	2023	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals areparticipants in the study	Persons with mild cognitive impairment (intended care receiver; 65–80 yrs old); healthcare professionals (clinical neuropsychologists)
Matsumoto et al. [82]	2023	Acknowledged *(not identified as informal caregiver)*	Highly involved	Healthcare professionals are the participants of the study	Healthcare professional (in emergency medicine)
Caine et al. [83]	2012	Low involvement	Low involvement	Participants asked to give name of someone who could be their caregiver 'if the need emerged'	Older adults (intended care recipient; 69–88 yrs old)
Van der Drift et al. [84]	2014	Low involvement	Low involvement	Diabetes nurse recruited families for study; parents briefly mentioned (potential informal caregivers)	Children (intended care recipient; 9–12 yrs old)
Bhattacharjee et al. [85]	2020	Low involvement	Low involvement	Caregivers accompanied participants during feeding trials	Persons with mobility impairment (intended care receiver; 28–57 yrs old)
Cruz-Sandoval et al. [50]	2020	Low involvement	Highly involved	Study based directly within care facilities & recruited healthcare professionals	Older adults (intended care recipient; 74–86 yrs old) & healthcare professionals (caregivers)
O'Brien et al. [45]	2021	Low involvement*(not identified as informal caregiver)*	Highly involved	Healthcare professionals are participants in the study; informal conversation with children who had stayed in hospital, in presence of/along with their parents (seemingly researchers in group)	Control group (students & researchers from university; children in classrooms); healthcare professionals (paediatric doctor and senior child life specialists)
Nanavati et al. [44]	2023	Low involvement	Acknowledged	Parent is not a participant, but is mentioned as sometimes helping clarify what a participant is saying	People with motor impairments (intended care receiver; 18–58 yrs old)
Caleb-Solly et al. [86]	2014	Highly involved	Highly involved	Informal caregivers and healthcare professionals are participants in the workshop	Older adults (intended care receivers; 63–90 yrs old); healthcare professionals (dietician, doctor, home manager, carers); informal caregivers; control group (participants around 50 yrs old)
Moharana et al. [87]	2019	Highly involved	Highly involved	study recruited healthcare professionals and informal caregivers; study took part either in healthcare settings or in people's homes.	Informal caregivers (spouses and adult children); healthcare professionals (geriatric nurses & social workers)
Gallenberger et al. [88]	2019	Highly involved *(not identified as informal caregiver)*	Acknowledged	Though the role of feeding assistant was not defined, it is assumed that some participants were caregivers	Intended care receiver (had assistance with feeding as an adult), control group (no reported experiences with feeding assistance); informal caregiver (had provided feeding assistance experience)
Valencia et al. [51]	2021	Highly involved	Not mentioned	Parents (as parent-caregivers, though not defined as such in the study) are participants in the study	Augmented communicators (intended care receiver; 23–54 yrs old); parents (informal caregivers); professional puppeteers (other experts)
Tsoi et al. [89]	2021	Highly involved *(not identified as informal caregiver)*	Not mentioned	Study took place in the domestic setting to combat isolation, parents were the ones to report on effect of robot (seemingly the parents took on roles of caregivers)	Children (5–12 yrs old; intended care recipient) & parents (informal caregivers)

Table 1 (continued)

Authors	Year	Involv. of Informal caregivers	Involv. of Healthcare of professionals	Level of involv. ofinformal caregivers and/or healthcare professionals (High & low)	Participants
Zhang et al. [90]	2022	Highly involved *(not identified as informal caregiver)*	Acknowledged	Parents were participants in the workshops and interviews to give their perspective on children's pain management (as parent-caregivers, though not defined as such in the study)	Children (intended care receiver; 4–6 yrs old); parents (informal caregivers)
Moorman et al. [91]	2023	Highly involved	Highly involved	Caregivers included as participants in study	Control group (general population, represented by people on College campus); all types of caregivers (healthcare professional & informal caregivers)
Lee et al. [92]	2023	Highly involved	Highly involved	Social worker as co-author and another as collaborator to facilitate study. Informal caregivers and healthcare professionals directly participants in study	Person living with dementia (intended care receiver) & informal caregivers (named carepartners) all aged between 59–73 yrs old

that we claim to be investigating informal caregivers do not refer to them as informal caregivers [88–90]. Therefore it seems fitting to explain why we categorised them as such.

The first, by Tsoi et al. [89], involved parents for the deployment of domestic robots to help combat isolation among children during COVID-19. We argue that parents' role was beyond that of parenting, as they were the ones to assess their child's loneliness due to the pandemic and how this could be improved with a robot, whilst also being the ones to set up the device, and fill out various surveys to give feedback. Therefore the unusual circumstances the pandemic brought on meant that parents were taking on more responsibilities, which would usually be expected of educational (i.e. social interactions occur) and healthcare services (i.e. measuring impact of loneliness).

The second, by Gallenberger et al. [88], investigated feeding strategies for robotic feeding. From the recruitment, it is somewhat unclear if the participants were informal caregivers, however, the fact that the researchers pointed out that some of the participants had direct experience with assisted feeding adults (without mention of training) demonstrates that the researchers suspected that the participants relied on their previous experience to understand if this robotic tool would be useful.

Finally, Zhang et al. [90] undertook a co-design study which included parents and their child as participants to understand design preferences for robots for pain management. Since this study was to ensure a safe recovery from pain for children to be able to avoid long-term consequences due to the initial pain in childhood, it shows that parents in this context play a role that falls more in line with parent-carer, and thus, that of an informal caregiver.

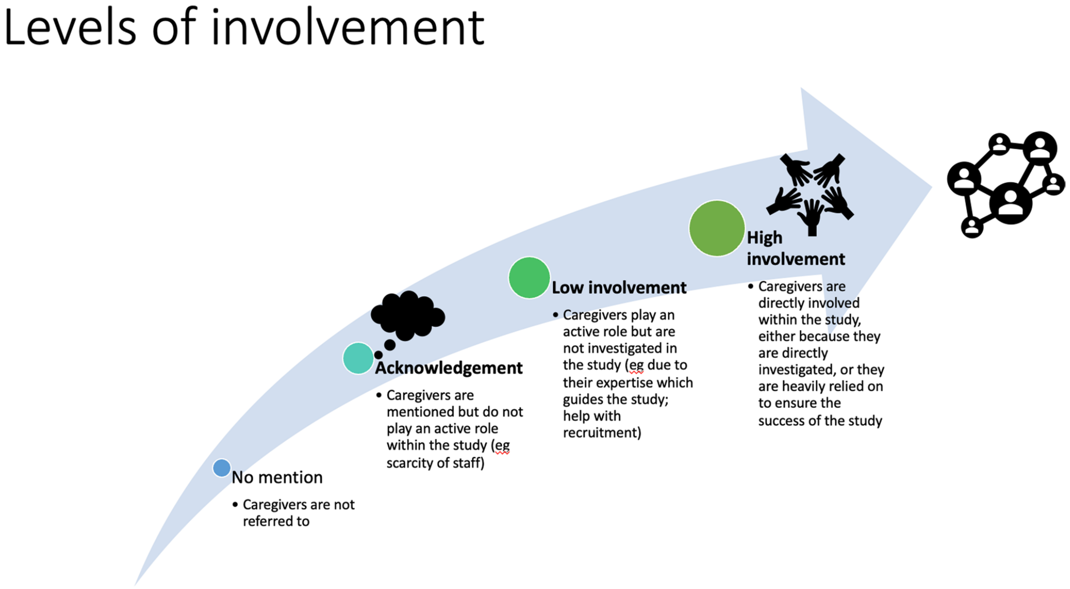
In stark contrast, identifying healthcare professionals did not demand a reflection on whether they fall under that category. Indeed, they were identified in reviewed articles by their qualifications and/or training.

4.3.2 Level of Involvement of Caregivers in Studies

Interesting nuances arose on how informal caregivers and healthcare professionals were involved in studies within our analysis. To illustrate this nuance, we identified four different categories to demonstrate the level of involvement of those two groups: (1) "*no mention*"; (2) "acknowledgement"; (3) "*low level of involvement*"; and (4) "*high level of involvement*" (as explained in Fig. 6, depicted in Fig. 7 and shown in Table 1). The data extraction was performed throughout the texts in the sampled articles. Importantly, if studies were unclear about whether they referred to informal caregivers or healthcare professionals, we categorised them as both.

No mentioned refers to articles that have not pointed to either informal caregivers or healthcare professionals anywhere in the article. Out of the 52 sampled articles in this review, fives studies do not mention healthcare professionals at all, and 15 articles do not mention informal caregivers.

Acknowledgement refers to articles that mention in some way informal caregivers or healthcare professionals. In the instance of healthcare professionals, they are acknowledged in 13 articles. Most commonly, healthcare professionals were mentioned in (i) interviews by participants [44, 57, 71, 90], or (ii) that researchers want to imitate their role in medical settings, for e.g. a therapy session or physio [60, 62, 68, 88], or (iii) that researchers hope that the envisioned robotic application will help healthcare professionals [77]. In the instance of informal caregivers, 23 articles acknowledged them, though 13 of those articles do not directly refer to them as such but in terms of their relationship to the care receiver (i.e. family member or friend, see Table 1). Most



Levels of involvement

No mention

- Caregivers are not referred to

Acknowledgement

- Caregivers are mentioned but do not play an active role within the study (eg scarcity of staff)

Low involvement

- Caregivers play an active role but are not investigated in the study (eg due to their expertise which guides the study; help with recruitment)

High involvement

- Caregivers are directly involved within the study, either because they are directly investigated, or they are heavily relied on to ensure the success of the study

Fig. 6 A scale illustrating different levels of involvement of informal caregivers and healthcare professionals (referred to as "caregivers" on the scale) within HRI studies for health care in all articles, investigating whether they are either (1) not mentioned, (2) acknowledged, and (3) involved at a low level or (4) highly involved

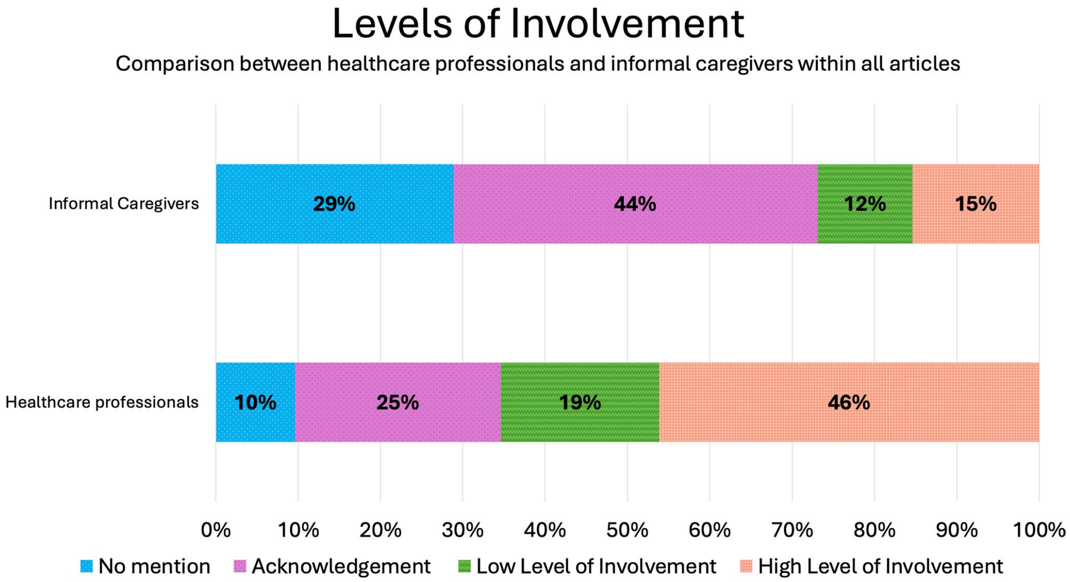


Fig. 7 A comparison between informal caregivers and healthcare professions in all articles reviews regarding their categorisation on (1) not mentioned, (2) acknowledged, and (3) involved at a low level or (4) highly involved

commonly, informal caregivers were acknowledged as a possible help for the deployment of the envisioned robotic application, through (i) setting goals [74, 81], (ii) take part in multiplayer rehab applications [68], (iii) monitor progress of the care receiver [22], or (iv) help set up the robot [75]. Informal caregivers were also acknowledged in interviews with other stakeholders [43, 70, 71, 76]. It is worth also noting that one article specifically points out that they tried recruiting informal caregivers, but were unable to do so [78].

Low level of involvement refers to informal caregivers or healthcare professionals not being participants in the studies, but still having a vital role overall to ensure that the study can take place (see Table 1). Regarding informal caregivers, six articles involved them, usually as facilitators to the study (see Table 1). O'Brien et al. [45] deviated from this trend by holding informal conversations (i.e. not part of the data analysis) with children and their parents who had stayed in hospital to gain their insights into their experience. Turning to healthcare professionals, they were involved at this level in 13 articles, usually to help with recruitment or their expertise is directly drawn on to design it into robots – for e.g., Jeffcock et al. [80] designed an assessment tool used to detect delirium into a robotic system.

High level of involvement refers to either informal caregivers or healthcare professionals as (i) participants or (ii) directly physically heavily relied on for the study. Informal caregivers were only participants in this category. In contrast, healthcare professionals were participants and also directly included in the study though not as participants in four articles. For example, in one study, a healthcare professional administered the screening interview in order to compare it to robot-administered screening interview [70].

5 Discussion

This critical narrative review was an exercise of disentanglement in order to answer our overarching research question, *How do HRI researchers position stakeholders within studies relating to HRI in/for health care, especially informal caregivers?*. Through analysing the literature from the ACM/IEEE International Conference on Human-Robot Interaction proceedings, we demonstrate a complex and nuanced understanding on research practices and inclusions of various stakeholders, especially on informal caregivers and healthcare professionals within HRI.

5.1 RQ1: Setting the Scene in HRI Health Care Studies

Mapping opening paragraphs of the reviewed articles help demonstrate the motivation behind researcher's studies and how to grab people's attention. Introductions are essential, as Tavakol and O'Brien write: "the introduction section is arguably one of the most critical elements of a written piece of research work, often setting the tone for the remainder of any dissertation or research article" [93]. Meaning that introductions are not neutral. How authors write their opening paragraphs will subsequently frame the relevance and need for this research – especially in competitive conferences such as the HRI Conference we review herein.

The use of *alarming narrative* may not come as such a surprise, as it clearly shows that there is an ongoing societal challenge that requires attention (which we illustrated in our own introduction). As Fig. 3 shows, this type of motivation is especially used when care receivers and healthcare professionals are participants in studies. Usually, as Table 2 showcases, it is to do with (i) the change in demographic, (ii) increase in specific conditions (i.e. dementia), or (iii) the shortage of healthcare staff – the latter especially used when articles investigate healthcare professionals. The use of alarming narrative has already been observed by other researchers, such as Maibaum et al. [26], Wright [28] and Pedersen, Reid and Aspevig [27], as it allows roboticists to illustrate a need for health care robotic applications to enter the field and find solutions. However, although the *alarming narrative* pinpoints that there is a narrative around an ageing population and a decrease in healthcare professionals available, this very narrative is likely to create – as well as put more pressure on – informal caregivers beyond robots; especially since robots are not ready for deployment but pressure on the healthcare system is already occurring and informal caregivers already help fill this shortage, which the HRI community should also account for and use to motivate why informal caregivers should be participants in studies.

The use of *robot design* is centred around roboticists' visions of their role: the decisions they need to make, how they envision the future of robots, or how to mould the correct human-robot interaction. This was used in nearly one third of papers which investigated healthcare professionals, possibly because roboticists want to try and imitate the healthcare setting which is envisioned to mean imitating healthcare professional. On the other hand, this is not as a framing used for articles investigating informal caregivers.

In contrast, the use of *lived experience* to frame introductions in our reviewed articles is used in half of the papers that investigate informal caregivers – a lot more than most other stakeholders. One reason for this could be that the researchers which investigated informal caregivers have more social scientific expertise within the research team and aim to demonstrate the experiences and difficulty of a certain condition from various perspectives – this type of introduction is more mainstream within the social sciences. Put differently, *lived experiences* allows to show that there are other perspectives from outside the discipline that could (and probably should) be taken into account, whereas *robot design* whilst also anecdotal, is more about achieving a "common goal" among roboticists.

It is also worth pointing out that while *further(ing) current robotic research* is somewhat used across the reviewed articles, it was only used once in articles looking at informal caregivers, in 2014 [86]. This suggests that there is a lack of previous work in HRI on informal caregivers.

5.2 RQ2: The Who in HRI Health Care Studies

Our results point to envisioned care receivers as the most investigated group of stakeholders ($n=36$ out of 52 articles). This is a positive trend, as it means that the HRI community considers their perspective and experiences very highly and (hopefully means) that we roboticists give them agency. The second most investigated group is healthcare professionals, with $n=20$ articles directly investigating them. This trend seemingly demonstrates a recognition by the HRI community to leverage on professional expertise for robots to be deployed within health care settings (see Table 2, specifically at aims and participants). The third highest group investigated are control groups, with $n=14$ articles doing so. This is sometimes due to accessibility issues, such as wanting to test out prototypes on a less vulnerable group (e.g. [45, 72]). Informal caregivers are the fourth most investigated group, with $n=$eight articles investigating them. This to us is an alarming result, as informal caregivers are identified as co-providers of care, and therefore have much expertise on how to provide care [2] – though admittedly on a much more individual level, and less scalable than healthcare professionals' expertise. The *who* therefore becomes reductive to individuals rather than the community that supports them.

Regarding how many groups were investigated per study, the trend seemingly suggests that one to two groups are the most common. The investigation of one group of stakeholders is especially used for participants which are care receivers or control groups. However, it is more likely for healthcare professionals to be included with at least another group of stakeholders. Informal caregivers are never a sole group being investigated, resulting in them being investigated with more stakeholders than the average, see Fig. 4. We want to briefly point out that research on informal caregivers from public health scholars have warned that, generally, informal caregivers' care burdens increased during the pandemic as healthcare institutions were unavailable [4]. Furthermore, informal caregivers' caring responsibilities can often be overlooked by society generally [94], and their role is stigmatised [95]. This was also pertinent in one of the reviewed article herein, which directly reported on the tensions between informal caregiver and care receivers [92]. This demonstrates the need to give informal caregivers' room to express their own experiences, as well as their expertise – which will likely be in tension with other stakeholders'.

5.3 RQ3: Methods Used for Answering HRI In/For Health Care

In relation to methods, we demonstrate how the studies were conducted when certain stakeholders were involved. Aside from surveys/questionnaires, the most popular methods to investigate informal caregivers used were either (1) laboratory or lab-like studies, (2) interviews/focus groups, or (3) workshops. In contrast to this, studies investigating healthcare professionals were mostly using (1) interviews/focus groups, or (2) video-based, or (3) in-the-wild studies, see Fig. 5.

The common use of laboratory or lab-like for informal caregivers is worth reflecting upon. Harrison and Johnson [96] point out that lab studies tend to recruit participants who are more positive towards robots; and we add that this is likely to extend to workshop-based studies. Put differently, the recruitment pool available would be people who are more inclined to find out about new technology and take part in this type of work. This is as opposed to in-the-wild studies, which allow levels of variation in participant pool and thus responses. For example, participants might not have thought to take part in a study, but have now encountered a robot and can provide reflections and feedback on that. Consequently, how we include informal caregivers might not be representative enough, and we are already not including them enough.

The popularity of interviews/focus groups and video-based studies with healthcare professionals follows the trend mentioned above of recognising and acknowledging the importance of expertise. Furthermore, within the studies conducted in-the-wild investigating healthcare professionals – usually in a healthcare setting – the studies tended to ask for their reflection on the use of robots. This is a positive trend since roboticists anticipate in those studies that the robots will alleviate the healthcare staff's workload. We would suggest that it is (very) likely that informal caregivers are also within those facilities and thus can also be included in studies. Indeed, a study demonstrated that even if the care receiver is admitted into a care facility, informal caregivers will still be providing "considerable front-line work" [5].

5.4 RQ4: The Inclusion of Informal Caregivers and Healthcare Professionals in HRI Health Care Studies

The analysis for this research question was based within Social Justice-Orientated Design [6] and Feminist HRI [7] theories. Throughout the results and discussion sections, we have ensured to give informal caregivers a predominant voice, as their voice has been overlooked. Literature from other disciplines warn about the essential role informal caregivers play in society [3–5, 10, 11, 94, 95, 97], which is likely increase as Western nations "shifting responsibility of care from the state to the voluntary and informal sectors" [1]. These warnings emanating from bottom-up research justifies our critical lens: the HRI community can leverage on its own power, as we can choose on who we include and how we include them in our studies. As HRI Feminism and Social Justice-Oriented design point out, there is a whole eco-system behind every HRI research, and it becomes the HRI community's responsibility to ensure a more diverse pool of participants and to engage in the political structure of our research [6, 7, 17]. Consequently, we compared informal caregiver and healthcare professionals, as both groups have expertise in providing care (for e.g., rehabilitation or administering medicine). The comparison showed a reluctance (or overlook) in concretely identifying informal caregivers in studies, unlike healthcare professionals.

To showcase the power of inclusion held by HRI researchers, we introduced a spectrum from *no mention* to *high level involvement* regarding healthcare professionals and informal caregivers. Nearly one third of the articles ($n=15$ articles) *do not mention* informal caregivers, whereas only five articles do not mention healthcare professionals (see Table 1). Furthermore, by combining *no mention* and *acknowledgement*, this amounts to nearly 75% of all articles reviewed regarding informal caregivers, whilst just over one third ($n=35\%$) of all articles reviewed regarding healthcare professionals either do not mention them or merely acknowledge them. This points to a lack of awareness around informal caregivers.

Unexpectedly, we found that a lot of articles which *acknowledge* informal caregivers (even if not identified as *informal caregiver*) was to illustrate their key role to deploy and use robots, such as (i) setting goals, or (ii) take part in multiplayer rehab applications, or (iii) monitor progress, or (iv) help set up. Though this is also somewhat expected of healthcare professionals within HRI too, there is an important difference to point out: healthcare professionals will be doing it as part of their paid job role, unlike informal caregivers. In addition, it is likely that healthcare professionals will have direct expertise in health care robotic application, unlike informal caregivers. This point should not be underestimated as informal caregivers have reported to be overloaded by information even as their own informational needs go unmet [97]. Thus, we should not simply expect informal caregivers to help out. Especially when the robotics application are unlikely (for now) to develop and evaluate robotic applications based on informal caregivers' perspectives — as well as care receivers and healthcare professionals, of course.

Turning to *low involvement* of informal caregivers and healthcare professionals, this only occurs once with informal caregivers. Here, we include how they help with recruitment as well as expertise within the research team. We want to bring to light to the one study which relies on informal caregivers' expertise without making them participants (though they do not identify the group as such). This study was conducted by O'Brien et al. [45], where they held informal conversations with children who stayed in hospital and their parents – this was achieved by turning to their own networks (i.e. friends or family members). This demonstrates that expertise is not necessarily about specific training, but also lived experience. This is especially pertinent for informal caregivers, where for example Carers UK estimates that two out of three people in the UK provide informal care at some point in their life [98], meaning that there is likely a lot of lived experiences among researchers and their network. Furthermore, *low involvement* also demonstrates that if there are issues with accessing stakeholders, then we can still leverage on informal caregivers' expertise in similar ways to healthcare professionals; that is by including them without investigating them as participants.

5.5 Recommendations: Including Informal Caregivers to Better HRI In/For Health Care

The findings section attempted to demonstrate an exhaustive set of results, which we rely on to be able to give high-level recommendations on informal caregivers within HRI in health care, and maybe beyond.

1. **Involve informal caregivers more in studies, and this does not necessitate being a participant**: The HRI community should involve informal caregivers at some level. This could either be by directly investigating them, or informally including their expertise in studies (for e.g. O'Brien et al. [45]), or acknowledging within the research team own experiences as informal caregivers to steer studies in health care (see for e.g. Tanqueray et al. [99]).
2. **Recognise the vital role of informal caregivers in HRI, and the possible negative impact(s)**: Informal caregivers play a vital role in society, and will also do so in robotic health care applications. Whilst healthcare professionals also play such a vital role, they are

compensated for it, and thus we should find ways to ensure that informal caregivers also benefit.

3. **Policies and guidelines need to recognise, conceptualise and evaluate informal caregivers in HRI**: Policies and guidelines regarding HRI in health care need to acknowledge the possible technological reliance on friends and families, and recognise it as a form of informal caregiving that extends across all health care – from rehabilitation, to companionship, to monitoring medication.
4. **Pro-actively leverage on our power within the HRI committee to respond to bottom-up challenges from informal caregivers**: The HRI community needs to pro-actively engage in ways to include informal caregivers in studies— and identify them as such. In practice this means accounting for informal caregivers within our ethics applications and funding applications to ensure we respond to their needs and not solely institutional needs.
5. **Create HRI applications specific to informal caregivers**: HRI applications should directly look at understanding how to help informal caregivers' well-being, which in turn can improve quality of care for care receivers.

6 Conclusion

This paper provides a critical narrative review on articles in/for health care published at the ACM/IEEE International Conference on Human-Robot Interaction (2006–2023). The review is structured around four key themes: (1) how the studies were motivated, (2) who the studies included, (3) the methods used, and (4) how informal caregivers and healthcare professionals were accounted for. Our principal aim was to report on how articles in HRI for/in health care generally included various stakeholders in their studies. The secondary aim, which evolved directly from the initial aim, demonstrated that informal caregivers had been given very little consideration, despite their important role in society generally. Including a critical lens to the latter aim, derived from Social Justice-Oriented Design and Feminist HRI, we focused and identified possibly unjust practices whilst also showing the nuances around the involvement of informal caregivers and healthcare professionals.

From the 52 articles reviewed, 36 investigated care receivers, 20 investigated healthcare professionals and eight investigated informal caregivers. Introductions usually used an *alarming* narrative to open the article, though the most used for informal caregivers was *lived experience*. Care receivers were often investigated as a sole group, unlike other stakeholders. Healthcare professionals were often investigated as part of interview/focus group studies, and involved in studies conducted in-the-wild. Whilst informal caregivers were often involved in workshops and laboratory or lab-like studies, and very rarely in-the-wild study. Finally, healthcare professionals were often directly *involved* in the reviewed articles, even if they were not participants. In contrast, it was more likely that informal caregivers were either *not mentioned* or were *acknowledged* in the reviewed articles.

From those four dimensions, our results identified an important gap regarding the lack of identification and inclusion of informal caregivers, despite this group being acknowledged as a stakeholder that could ensure the deployment and use of robots for the care receivers. Although, we, the authors, refer to this group as informal caregivers, studies did not tend to explicitly identify them as such – including the ones we considered to have investigated informal caregivers. This shows a difficulty in articulating who informal caregivers are in HRI, though this study has shown that this formal identification is required. Furthermore, unlike with healthcare professionals or care receivers, informal caregivers were never investigated as a sole group of participants in any study, reinforcing the notion of informal caregivers being ("only") secondary, or even tertiary robot users. This was also viewed within level of involvements of caregivers: even if healthcare professionals were not participants, their knowledge was leveraged on to create relevant robots for care receivers. Through the results of this narrative review, we posit that the HRI community must acknowledge and identify informal caregivers within their caregiving role – rather than solely their relation to the care receiver – as well as involve them more in our studies so that we can directly account for their needs in HRI design.

7 Limitations and Further Work

This work was limited to the ACM/IEEE International Conference on Human-Robot Interaction, which only accepts a small number of papers. Ideally this review should include journals to see if there are similar trends. Moreover, the term "informal caregiver" should be further refined to also consider characteristics of the informal caregivers (i.e. age, gender, occupancy) as well as map out the types of care that person is providing. This mapping will become key as the HRI community envisions informal caregivers to help with the deployment of the robots, we will also need to understand what responsibilities we have added on to informal caregivers through robot deployment, whilst also accounting for if/how we have helped with their caregiving responsibilities. Further work could be using this qualitative study and turn it into more quantitative work, to scale up this study to understand how informal caregivers are understood HRI health care studies across more HRI venues and beyond.

Appendix: Table of Overview of Analysis of All Sampled Articles

Table 2 Overview of all articles sorted by chronological order

Authors	Year	Aim	Setting the study	Targeted group/users	Participants	Methods used
Heerink et al. [46]	2008	Perceived enjoyment of conversational robots for older people (incl. assistive purposes)	Alarming: change in demographic, difficulties adapting to new tech, so must explore acceptance	Older adults	Older adults (intended care recipient; 65–94 yrs old)	In-the-wild & lab-like experiment
Tsui et al. [100]	2008	Development and evaluation of an interface for a wheelchair mounted robotic arm	Lived experience: describes difficulties of motor impairments and how to compensate for them.	All ages	Wheel-chair users (intended care recipient; 17 to 60 yrs old)	Lab study & questionnaire
Chen et al. [64]	2010	Evaluation of nursing assistant robots with different interfaces	Robot design: the importance of touch for human communication that robot likely need to recognise	Staff	Healthcare professionals (intended care recipient; Nurses)	Lab study & survey
Beer et al. [65]	2011	Understanding older adults' views on mobile remote presence robot systems to maintain independence	Robot design: importance of understanding robot acceptance by older adults	Older adults	Older adults (intended care recipient; 63–88 yrs old)	Lab/lab-like study & interview
Chen et al. [66]	2011	Investigating responses of robot-initiated touch by robot caregiver/nurse	Robot design & automate task: physical touch is key, also when iniated by robots especially in healthcare setting	All ages	Control group(university students)	Lab study, survey & questionnaire
Beer et al. [53]	2012	Investigate design implications for home assistive robots for older adults	Alarming: change in demographic with older people, many live independently, need to find ways to support ageing	Older adults	Older adults (intended care recipient; 65–93 yrs old)	Interviews & questionnaire & video-based
Caine et al. [83]	2012	Effect of monitoring older people in their homes through cameras and robots	Alarming: privacy issues around data collection required for robot functioning and becoming more readily available	Older adults	Older adults (intended care recipient; 69–88 yrs old)	Lab study, questionnaire & interviews
Park et al. [52]	2012	Investigating haptic exploration for teleoperation for people with visual impairment	Robot design: roboticists have advanced the potential used-cases of robots, SARs need to be multi-purpose	All ages	Students with visual impairments (intended care receiver); control group (students without visual impairments)	Lab study
Prakash et al. [67]	2013	Investigating robots assisting with medication management	Alarming: societal need for independent living, but difficulty with medication management contributing to hospital admissions	Older adults	Older adults(intended care recipient; 68–79 yrs old)	Interviews & questionnaire
Caleb-Solly et al. [86]	2014	Understanding older adults' views on domestic care service robots	Robot design & further robotics: need to have voice of older adults included for appropriate robots	Older adults	Older adults (intended care receivers; 63–90 yrs old); healthcare professionals (dietician, doctor, home manager, carers); informal caregivers; control group (participants around 50 yrs old)	Workshops, video-based & survey/questionnaire
Hoffman et al. [69]	2014	Investigating affects of robot responsiveness to disclosures	Automate: robots will likely be caregiving, communication between robots and humans are key to investigate	All ages	Control group(university students)	Lab study & questionnaire
Novak et al. [68]	2014	Investigating motivation of rehabilitation robots with two-player games	Automate task & further robotics research: Robots can provide good rehabilitation, already positive results on this	All ages	Control group (no arm impairment; 25 to 53 yrs old)	Lab study & questionnaire

Table 2 (continued)

Authors	Year	Aim	Setting the study	Targeted group/users	Participants	Methods used
Van der Drift et al. [84]	2014	Effect of robot motivating and supporting childrenwith diabetes keeping a diary	Alarming & augment task: number of children facing diabetes and the potential of digital tools	Children	Children (intended care recipient; 9–12 yrs old)	Lab study & questionnaire
Briggs et al. [70]	2015	Investigating robots administering health status survey with people with Parkinson's Disease	Alarming & augment task: statistics on & challenges people with Parkinson's Disease face and how robots can act facilitator or mediators	All ages/older adults	Adults (intended care receiver; average age 67 yrs old)	Lab/lab-like study & questionnaire
Hebesberger et al. [48]	2016	Exploring deployment of companion robots in therapy for older adults living with dementia	Alarming & Lived experience: increase in dementia cases & the difficulty of living with condition	Older adults	Older adults with progressed dementia (intended care receiver; 74–95); healthcare professionals (therapists)	In-the-wild & interviews
Herlant et al. [71]	2016	Investigating use assistive teleoperation of robot arms	Further robotics research: build on already positive results on the use of robotic arms for gaining independence	All ages	Users of robot arm (intended care receiver); control group (Amazon Mechanical Turk; local community – able-bodied); other expert (employees of robot manufacturer)	Lab/lab-like study, video-based & interviews
Kraftet al. [72]	2016	Investigating comfort and trust for teleoperated robots providing medical care to patients in infectious disease outbreaks	Augment task & Lived experience: how robot can alleviate the harsh impacts of infectious disease outbreaks on healthcare workers	All ages	Control group (people from surrounding community and campus)	Lab study, survey & questionnaire
Chevalier et al. [55]	2017	Understanding children with ASDs reaction to imitation task protocol using a robot	Lived experience & further robotics research: describing different Autism Spectrum Disorder (ASD) and already positive results for robot therapy	Children	Children with ASD (intended care receiver; 8–17 yrs old)	Lab-like study & questionnaire
Lee et al. [43]	2017	Developing participatory design of social robots with older adults with depression and therapists	Robot design & alarming: calls out the current trend of roboticists having to make important design decisions, but need for stakeholder involvement	Older adults	Older people (intended care receiver, no age mentioned) ; healthcare professionals (mental health therapists)	Interviews, workshops & video-based
Moosaie et al. [54]	2017	Exploring usage of facially expressive robots to calibrate clinical pain perception	Robot design & further robotics research: desire for roboticists to create more human-like robot non-verbal interactions	Adults/Staff	Control group (non-clinicians; Amazon Mechanical Turk); healthcare professionals (clinicians)	Lab-like study, questionnaire & video-based
Guneysu Ozgur et al. [56]	2018	Exploring designs for upper limb rehabilitation games with robots	Lived experience & automate task: explains the need upper limb rehabilitation that many do not do, thus robots may be able to help	All ages	Patients in need of upper limb rehab (3–68 yrs old; intended care receiver); healthcare professionals (neurologists, therapists)	Lab/lab-like study
Winkle et al. [22]	2018	Investigating design implications for robots in rehabilitative therapies	Augment task & further robotics research: rehabilitative therapy needs to be consistent, robots can help with engagement – already positive results	Staff	Healthcare professionals (intended care recipient; therapists)	Interviews, focus groups & questionnaire
Gallenberger et al. [88]	2019	Investigating manipulation strategies for robotic feeding	Alarming: statistics on people requiring feeding assistance, burden on caregivers; lack of tech assistance	All ages	Intended care receiver (had had assistance with feeding as an adult), control group (no reported experiences with feeding assistance); informal caregiver (had provided feeding assistance)	Lab study, survey & questionnaire

Table 2 (continued)

Authors	Year	Aim	Setting the study	Targeted group/users	Participants	Methods used
Moharana et al. [87]	2019	Exploring robot design implications from dementia caregivers' perspectives	Alarming: demographic change, growing pressure on finding solution, need caregiver involvement as they face majority of burden	Older adults	Informal caregivers (spouses and adult children); healthcare professionals (geriatric nurses & social workers)	Interviews & workshops
Winkle et al. [57]	2019	Investigating link between persuasiveness and assistance in SARs	Further robotics research: definition of SARs and research on persuasion to engage patient	All ages/adults	Adults (potential care receiver; 18–74 yrs old)	Lab study, interviews & questionnaire
Bhattacharjee et al. [85]	2020	Exploring preferences of users with mobility impairments in robot-assisted feeding	Alarming & further robotics research: statistics on mobility impairment and difficulties faced with this condition, already positive studies on this	All ages	Persons with mobility impairment (intended care receiver; 28–57 yrs old)	Lab study, video-based & questionnaire
Cruz-Sandoval et al. [50]	2020	Social robot as therapy facilitator for people living with dementia	Alarming: statistics on the increase in number of people living with dementia, possibly need technology to help	Older adults	Older adults (intended care recipient; 74–86 yrs old) & healthcare professionals (caregivers)	In-the-wild & interviews
Feingold Polak et al. [49]	2020	Exploring the use of social robots for stroke rehabilitation	Alarming & augment task: recurrent challenges post-stroke among patients, which could improve with rehab through SARs	All ages	Post-stroke patients (intended care receiver, 51–75 yrs old); healthcare professionals (clinicians)	In-the-wild, focus groups, video based & surveys/questionnaires
O'Brien et al. [45]	2021	Creating robot prototypes of therapeutic robot companions for children	Alarming & augment task: shortage of staff, need for robot assistance to ensure children are not isolated	Children	Control group (students & researchers from university; children in classrooms); healthcare professionals (pediatric doctor and senior child life specialists)	In-the-wild, interviews & focus groups
Rea et al. [58]	2021	Exploring implications of (im) politeness from robots during exercise	Robot design & Automate task: coaches might need to push athletes, roboticists design how robot says things so that positive attitudes remain	All ages/adults	Adults (potential care receiver; average age 29 yrs old)	Lab study
Tsoi et al. [89]	2021	Exploring deployment of robots to combat isolation among children during pandemic	Lived experience: need for social interaction but COVID-19 hugely impacted those	Children	Children (5–12 yrs old; intended care recipient) & informal caregivers (parents)	In-the-wild & survey
Valencia et al. [51]	2021	Exploring the use of SARs for motion-based communication	Lived experience: explaining type of augmentative and alternative communication devices and their issues for people using them	All ages	Augmented communicators (intended care receiver; 23–54 yrs old); informal caregiver (parent); other experts (professional puppeteers)	Survey & workshops
Birmingham et al. [60]	2022	Investigating perceptions towards SARs' cognitive or affective responses	Automate task: empathy is an important part of human interaction, which robot will need to assist	All ages/adults	Adults (intended care receiver; recruited through Amazon Mechanical Turk)	Video-based study & survey/questionnaires
Camilleri et al. [61]	2022	Exploring professional carers' expertise to inform design of SARs	Alarming, augment task & Robot design: shortage of staff; carers' continuous assessment to adapt to patient robots need to do	Staff in residential care facilities	Healthcare professionals (nurse, physiotherapist, senior carer, carer, nursing home manage and occupational therapist)	Focus groups

Table 2 (continued)

Authors	Year	Aim	Setting the study	Targeted group/users	Participants	Methods used
Fang et al. [73]	2022	Investigating role of SARs for reducing anxiety and preserving autonomy in children	Alarming & further robotics research: statistics on rise of mental health issues among children, SARs seem to provide timely and appropriate treatment	Children	Children with mild anxiety traits (intended care receiver; 10–12 yrs old); control group (children without anxiety traits)	Lab study & questionnaire
Kubota et al. [74]	2022	Exploring use of SARs for neurorehabilitation interventions in homes for people with mild cognitive impairment	Alarming, Robot design & further robotics research: COVID-19 showed health disparities, roboticists are trying to understand how to provide clinical delivery at home	Older adults	Older adults (intended care receiver; 73–75 yrs old); healthcare professionals (clinical researchers: neuropsychologists, psychiatry faculty member)	Interviews, focus groups & video-based
Lippi et al. [59]	2022	Benchmarking of lower limb exoskeletons performance	Further robotics research: commercial availability & improvement of usability of exoskeletons means that there is a need to benchmark	All ages	Control group (seemingly able-bodied – not reported)	Lab study
Odabasi et al. [47]	2022	Exploring the use of robots for refilling water bottles in care homes	Automate task & Robot design: robot can take on some responsibility to lesser workload on healthcare professionals	Staff in residential care facilities	Healthcare professionals (carers providing in-home care)	In-the-wild & questionnaire
Tanqueray et al. [76]	2022	Investigating the use of SARs to support diagnostic screening for peripartum depression	Alarming & augment task: statistics on women experiencing peripartum depression and how SARs can help with screening	Adults	healthcare professionals (medical expertise in PPD); other experts (Gender Studies scholars)	Interviews & video-based
Wilson et al. [75]	2022	Investigating affective responses of older adults to companion robot	Alarming & further robotics research: statistics on loneliness and impact of COVID-19 on loneliness, research suggests robots can help tackle this issue	Older adults	Older adults (intended care receiver; 80–92 yrs old)	In-the-wild, interviews
Zhang et al. [90]	2022	Exploring design of robots for pain management to mitigate distress in children	Lived experience: what pain is and its impact on children and how to mitigate pain	Children	Children (intended care receiver; 4–6 yrs old); parents (informal caregiver)	Workshops, interviews & survey
Antony et al. [78]	2023	Investigating robots to promote physical activity among older adults	Alarming: statistics and cost of physical inactivity, robots's efficiency to motivate is unclear so must account for needs and wants	Older adults	older adult (intended care receiver; 65–94 yrs old); healthcare professionals (physical therapists); other experts (engineering students)	Interviews & workshops
Jeffcock et al. [80]	2023	Investigating use of transformers in robots for delirium detection	Alarming: statistics and cost of delirium's impact on healthcare system	All ages	Control group (university researchers)	Lab study
Kubota et al. [81]	2023	Exploring use of cognitive assistive robots to support collaborative goal setting	Augment task: pandemic sparked transition from in-person to digital services, allowing for collab between clinician, robot and patient	Older adults	Persons with mild cognitive impairment (intended care receiver; 65–80 yrs old); healthcare professionals (clinical neuropsychologists)	Interviews & video-based
Lee et al. [92]	2023	Exploring robot design from family caregivers and person with dementia's perspectives	Alarming: statistics on dementia, burden of care. Though there are HRI studies, there is no acknowledgement of family members as care providers	Older adults	Person living with dementia (intended care receiver) & informal caregivers named carepartners) all aged 59–73 yrs old	Focus groups
Matsumoto et al. [82]	2023	Exploring telemedical Robots to mitigate care disruption	Alarming: difficulties of being in emergency medicine, staff have to make important high-stake decisions with disastrous effects	Staff	Healthcare professional (in emergency medicine)	Interviews & questionnaire

Table 2 (continued)

Authors	Year	Aim	Setting the study	Targeted group/users	Participants	Methods used
Moorman et al. [91]	2023	Investigating the impacts on end-users of in situ robot learning in assistive tasks	Alarming & automate task: change in demographic, shortage of healthcare professionals, robots will be needed and interact with end-user	All ages	Control group (general population, represented by people on College campus); all types of caregivers (healthcare professional & informal caregivers)	Lab study, video-based & questionnaire
Nanavati et al. [44]	2023	Exploring design principles for robot-assisted feeding in contexts of social dining	Lived experience: asks reader to imagine a scenario to showcase the importance of social dining	All ages	People with motor impairments (intended care receiver; 18–58 yrs old)	Interviews & video-based
Neerincx et al. [77]	2023	Exploring effect of SAR gesturing on children's engagement, anxiety, fear and trust	Augment task & further robotics research: SAR can mediate between healthcare professional and child through different engagement strategies	Children	Children (intended care receiver; 8–10 yrs (& pilot: 9–17 yrs old))	In-the-wild, interviews & surveys/questionnaires
Ranganeni et al. [79]	2023	Exploring levels of control for a navigating assistant for people with visual impairment	Alarming & augment task: statistics on blindness or having low vision, difficulties navigating causing dependence, robots can provide assistance	All ages	People with high level of visual impairment (intended care receiver; 19–80 yrs old)	Lab study & questionnaire
Shi et al. [62]	2023	Evaluating user-perceived quality of text-to-speech through different embodiments in therapy	Automate task & further robotics research: mindfulness practices are shown to be effective, using different embodiments may help with greater accessibility	All ages	Intended care receiver (university students and Amazon Mechanical Turk)	Lab study, video-based, survey & questionnaire
Spitale et al. [63]	2023	Investigating robotic mental well-being coaches for the workplace	Alarming, further robotics research & augment task: reference to WHO report on ensuring workplaces promote well-being, but lack of resources; already positive results on assistive robots	Adults	Employees (intended care receiver; 18–55 yrs old); healthcare professional (well-being coaches)	In-the-wild, interviews, focus groups & questionnaires

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Declarations

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Paper II

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Towards a Socio-Legal Robotics: A Theoretical Framework on Norms and Adaptive Technologies

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Abstract

While recent progress has been made in several fields of data-intense AI-research, many applications have been shown to be prone to unintendedly reproduce social biases, sexism and stereotyping, including but not exclusive to gender. As more of these design-based, algorithmic or machine learning methodologies, here called *adaptive technologies*, become embedded in robotics, we see a need for a developed understanding of what role social norms play in social robotics, particularly with regards to fairness. To this end, we (i) we propose a framework for a *socio-legal robotics*, primarily drawn from Sociology of Law and Gender Studies. This is then (ii) related to already established notions of acceptability and personalisation in social robotics, here with a particular focus on (iii) the interplay between adaptive technologies and social norms. In theorising this interplay for social robotics, we look not only to current statuses of social robots, but draw from identified AI-methods that can be seen to influence robotics in the near future. This theoretical framework, we argue, can help us point to concerns of relevance for questions of fairness in human–robot interaction.

Keywords Socio-legal robotics · Human-Robot Interaction · Social norms · Gender studies · Mirroring of norms · Adaptive technologies

1 Introduction: The Social in Social Robotics

In this study, we theorise on the implications of social norms for social robotics, informed by gender studies and socio-legal theory. We use recent AI-developments as an opportunity to demonstrate and emphasise the need for this, although our scope includes also non-learning algorithmic systems and robotic design as such.

Social robots are, most simply put, robots that can interact and communicate with humans (cf.[1]). Scholars within the realm of Human–Robot Interaction (HRI) define social robots as having distinctive personality and character traits, as well as perceive and express emotions; those enable social robots to communicate through the use of natural cues—such as gaze and gestures—and 'expected norms' within a given context (cf. [2–4]), and lead to a further need for addressing ethical and legal questions when empowered with AI and autonomy ([5]). Social robots hence take part in a social context, which has prompted studies on what social norms they reflect [6], including with regards to gender [7]. Interestingly, in a scrutiny of gender and robotics, it has been pointed out that actual practices of robotics at worst may serve to "re-entrench existing social stereotypes and hierarchies rather than to contest them" [8, p.360] (cf. [9]). A recent study however found evidence of that breaking gender norms boosts robot credibility regardless of gender or cultural context, and regardless of pretest gender biases [10]. In addition, while recent advancements in AI-research has enabled robots to recognise faces [11], synthesise speech to

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be more accepted [12], observe and learn from human movement [13] it has also stressed the need for ways to better ensure fairness in HRI. Regarding norms and gender, this need has for example been argued from the basis of how traditional housewife ideals still are reproduced in technological devices for the home [14] and can be seen in calls for *feminist HRI* [15]. That is, as data-dependent AI-systems and large language models further power robots—where the way we speak, write and behave in various contexts becomes training data—there is a continuous need to theoretically revisit the relationship between the social and the robot, also beyond design and "non-learning" systems. Particularly so as social robots make-up a part of a complex, and in some distinct ways problematic, data-driven, sociotechnical world.

Indeed, researchers have found that AI-systems frequently mirror and display existing prejudices and societal injustices [16–19]. There have been numerous awareness-raising scandals where the false universal of 'man' or 'whiteness', taken as coexistent with 'being human' itself, have interplayed with learning technologies. These include commercial facial-recognition systems with much less accuracy for female faces and dark skin [20], gender-discriminating job ads [21], and antifeminist and anti-Semitic sentiments expressed by adaptive conversational agents [22]. Consequently, as long as robotic design at large, including machine learning-based systems that learn from incomplete datasets, depend on biased and unfair social structures, we can expect them to not only reproduce but also amplify inequalities [23–25]. In parallel and despite the best of intentions, there is a risk that definitions of fairness may fail to consider how the social context intermesh with technology in different forms. We use the term *adaptive technologies* (see Fig. 1) to theorise on how robotic design, with or without AI-systems, adapt to or reproduce social norms in their design or via collected data.

In short, we see a need for more interdisciplinary work in social robotics *in relation to* social norms and stereotypes. We use theoretical findings in Sociology of Law (SoL) and Gender Studies to highlight the mirroring of norms in robotic learning and design. While law, as in formal norms, are of relevance for governing technologies, and also adapt in relation to technological development [26, 27], our study mainly focuses informal, social, norms. This focus is often found in socio-legal studies, hence the proposed terminology of *socio-legal robotics*. With regards to adaptiveness, we refer to technologies that purposefully are built to change, transform or develop the relation to social interaction, which social robotics falls into. This is also why we point to *normative mirroring*, a term suggested in the socio-legal literature with regards to the interplay between AI-systems and society [23, 28], as one way to conceptualise this space of scrutiny. Lastly, while we primarily draw from discourses on gender, it should here be seen in its wider intersectional approach. That is, gender is framed in a way that is not solely about the person's sex, but is also impacted by a person's race, age, (dis)ability, ethnicity and socio-economic status to name a few, which all play a role in how a person lives and experiences their everyday life [29–31].

1.1 Purpose and Aims

In this article, we propose a conceptual framework on *socio-legal robotics* through the interplay of SoL, Gender Studies and HRI. As disciplines, SoL and Gender Studies are both critical disciplines to understand the interplay of various norms and power structures in certain settings, often with contributions envisioning a more just society; whilst HRI is a discipline seeking to bring social robots into society. Combining all three disciplines accommodates for emerging concerns in social robotics. That is, to be able to theorise and understand how to deal with the fact that the underlying technologies are, and likely increasingly so, becoming adaptive of the social interplay that includes social norms and informal social structures, e.g. related to gender. Put differently, as robots adapt to and mirror gendered informal structures, a heightened awareness is necessary with regards to understanding the complexities of this interaction.

Under this aim, we seek to:

1. Propose a theoretical basis of socio-legal robotics, primarily drawn from the realms of social sciences that underpins both Sociology of Law and Gender Studies.
2. Relate the theoretical framework to already established notions of acceptability and personalisation found in social robotics as a field, in order to sketch three levels of adaptive technologies: design, datasets and in situ personalisation. That is, if a robot mirrors or adapts to and "learns" social norms, how may we better understand the implications of this mirroring?
3. Contribute to how we can think of fairness as a contextualised and situated practice, in light of robotic mirroring of social norms.

1.2 Developing the Argument: Acceptability and Personalisation

Robots' ability to learn from and adapt to humans is arguably a key aspect in the field of social robotics [32]. With the advent of learning technologies strengthened by data-dependent ML and automation, social robotics is moving beyond pre-programmed rule-based systems, and towards human-in-the-loop ML-based approaches for the generation of what can be called socially adaptive robot behaviours [33]. Correspondingly, official projections predict that in the course of the next two decades, societies will see pervasive use of robotic technology in all contexts of social interaction, public and private [34]. There is development in techniques for reinforcement learning in social robotics [35], adaptive robotic tutors [36] and various studies on personalisation in anything from learning scenarios to bartending (cf.[37, 38]). In addition, development in language modelling and generative AI like GPT generations—which has been found to be biased towards gender stereotypes [39]—is likely to an impact in HRI as well (cf. a "foundation agent" for robot manipulation, learning from human movements [40]). Despite its importance for social robotics applications, work on context-specific norm learning on robots has been limited [41]. However, research in social robotics has recently begun to take an interest in normative issues from an adaptive point of view. This, for example, concerns 'affective' robotics, arguing for the need for robots to be able to be attentive to moods and attitudes in HRI [42] or how robots may be able to reason about social norms in order to plan appropriate behaviour [43] or how robots may challenge gender norms [44]. This includes a critical perspective on robotics, that has been advocated for as a way to identify conflicting ideas about technologies, particularly with regards to understanding innovations in robotics and their potential social consequences [45].

1.2.1 Robotic Mirroring of Human Traits

Previous research has shown that mirroring human traits in the design of both a robot's appearance and behaviour may be beneficial for acceptability by humans users [7, 46–48]. What we do not know yet is exactly how much or what type of mirroring is necessary for acceptability, as well as how context (i.e. application, culture) dependent this mirroring should—or should not—be, and how it should be accounted for in ML-based approaches to endow robots with socially interactive skills.

More specifically, some research indicate that the more human-like a robot is in appearance, the more likely people are to empathise with it [46]. People's responses change, though, in presence of very human-like robots, such as androids and humanoids. Robotic agents that are very human-like in appearance, but robotic-like in their behaviour, may generate a violation of people's expectations, which evokes feelings of eeriness and unfamiliarity, according to the so called uncanny valley hypothesis [49, 50]. Moreover, researchers have investigated broader issues that relate to the mirroring of human traits in robots and that may be key for the acceptance of robots in society, for example cultural aspects. Šabanović shows this in a critical exploration of how Japan has introduced social robots in society [8]. She demonstrated that researchers are expected to reproduce conservative social values, an "assumed cultural homogeneity", in order for social robots to be accepted by consumers—which is problematic in and of itself [8, p.358].

1.2.2 Gendering Robots

Research on social robots and gender shows that there are still complex issues being tackled around whether and how social robots should be gendered, both in appearance and behaviour, as well as whether robots should mirror gender norms. These are still open questions, and important, especially as we discuss in relation to the mirroring of social norms. The interplay between technological design and gender is a wide field, with several highly problematic biases in both design, designers, and data, pointed to by works from for example Criado Perez [30] and D'Ignazio and Klein [51]. Therefore, on one hand, the lack of a gender-sensitive approach to the design of social robots in certain applications might lead to the phenomenon of gender data gap [30], where there is a lack of representative data for women.

On the other hand, there is a risk that the gendering of robots and thereby mirroring social norms may lead to the reproduction and perpetuation of gender biases. A recent UNESCO report, for example, has demonstrated that the gendering of voice assistants led to production and reproduction of gender stereotypes, especially the notion that women should be submissive, polite and patient [52]. In social robotics, studies have explored the relationship between robot gendering and gender and occupational stereotypes [53, 54], human likeness [55] and perception of robotic non-compliance [56]. Moreover, recent studies investigated how social robots could be designed to go against current digital assistants' gender norms and suggest that feminist robots can play a role in reducing gender biases and harmful stereotyping [44] (see also the mentioned calls for *feminist HRI* [15, 57]). Recent commentary have made compelling arguments on the need to develop the critical scrutiny of the detailed learning techniques in order to better understand discriminatory implications and thereby contribute to a more aware development of robots [58, 59]. Even within the same application scenario, a gender-sensitive approach to the design of social robots pointed to the fact that mirroring some gender aspects might be beneficial (e.g. a robot's appearance), while the mirroring of gendered norms might not [7].

Furthermore, research shows that non-representative datasets used to train ML algorithms for automatic face recognition might lead to disparities in recognition accuracy for under-represented groups [20]. Consequently, new investigations are needed on how gender should be accounted for in datasets used for training robot behaviours for social interactions. We posit that there is a need for more focus on how to handle questions of biases or harmful social norms picked up by robots' interactive skills, and learned via ML-based approaches, e.g. with datasets capturing different types of human interactions. It is currently unclear how the design of more inclusive datasets (e.g. in terms of gender, ethnicity) could lead to more inclusive robotics (cf. [7]), and how this, instead, might lead to social robots reproducing harmful human biases.

1.2.3 Adaptive Technologies and Norms

There is an increased awareness in the wider community of AI-research around the need to address ethical challenges and questions of norms. For example, an IEEE report on ethical issues linked to autonomous and intelligent systems acknowledges the possibility of "norm conflicts", where for example tension "may sometimes arise between a community's social and legal norms and the normative considerations of designers or manufacturers" [60, p.175]. This calls for a deeper understanding of the interplay between robots, or "adaptive technologies", and social norms, particularly in relation to questions of fairness. In Sect. 3 below, we propose a model for how this interplay can be understood, and in Sect. 4 we conclude by promoting distinct areas of focus in the path ahead.

In sum, it is reasonable to assume that a coming strand of research in social robotics will have to be rooted in an interdisciplinary theorising on what type of norms socially adaptive robots should and should not reproduce, and how this interaction can be better studied and understood from an applied, everyday perspective in relation to social structures and gender. In the following section, we primarily look to SoL and Gender Studies to contribute to a theoretical frame of socio-legal robotics that can guide the understanding of *the social* in social robotics.

2 Theoretical Development: Interdisciplinary Contributions

In this section, we draw from Sociology of Law (SoL) and Gender Studies to theorise on how social norms and stereotypes inform and are mirrored in robotic design, how design can be normative, and what importance situatedness and contextuality have for addressing questions of fairness in robotics.

2.1 Sociology of Law as a Study of Norms

SoL, as a discipline, theorises and empirically studies the relationship between law and society, including non-formal aspects of social control [61]. For many years, SoL scholars have studied legitimacy in terms of social norms (often based on the notion of "social facts" [62], as a set of informal expectations that can be compared or contrasted to law [63–66], and is of relevance to social control [67]. Early accounts point to *living law* [68] or *law in action* [69] to explain what regulates the social life of communities and societies.

Drawing from SoL, we use a definition of norms that are (i) shared (and thereby social), (ii) expectations on behaviour by (iii) groups. Our definition of social norms take on a problematising approach in that we stress what Bicchieri et al. [70] call "scripted" or group behaviour. We focus this particular aspect of social norms which relates to conformity to group norms in a stereotyping way, which has been studied in HRI in elderly care in the sense that stereotypes "set normative expectations about how a good group member should behave" [71, p. 2]. That is, we treat stereotypes as a way for how a particular set of social norms can be expressed. They can both be useful for design—as with the acceptability described above—but also be harmful and unjust. Social norms have been studied in relation to group dynamics and how, in the words of Bicchieri et al., "social identity is built around group characteristics and behavioral standards, and hence any perceived lack of conformity to group norms is seen as a threat to the legitimacy of the group" [70, p. 9]. This is pointing to a social mechanism that can include problematic aspects of how social control may be both stereotyping, harmful, or in other ways, toxic.

We link these "scripted" group behaviours to stereotypes, that reciprocates also in technology development, such as in robotic design [9], in the "smart wives" of the home [14], or in how the sampling of data for large datasets in some instances has been shown to contain misogyny and malignant stereotypes [72]. Traditional gendered stereotypes see traits such as ambition, power and competitiveness as inherent in men, and traits such as nurturing, empathy and concern for others as characteristics of women [73]. These stereotypes can be reproduced also in robotic design. Consequently, and as concluded in a study on recommendations systems, that gender bias issues in AI recommendations cannot fully be addressed without addressing the gender biases in humans [74].

This means—in light of conversational agents adapting to anti-feminist sentiment, being designed to passively accept sexual harassment [52], or employment of gender-biased hiring applications [75]—that we advocate for an increased awareness of the importance of *which social norms* are learnt, also for social robotics [59]. Thus, the challenges with AI-supported robotics, for example, are more nuanced than to be about any simpler form of "alignment" to "human values" (for an extensive account, see [76]). Exactly what values, or norms, that gets "aligned" are far from a consensual, democratic or neutral process. In terms of design, this could mean that whatever perceptions of gender or bodies that the designers have may poorly influence design for women [30] or persons with disabilities [77], for example.

2.1.1 The Robotic Mirroring of Social Norms

Hence, these insights on the mirroring of norms in adaptive technologies lead to a normative question of what social norms a social robot *ought* to or *ought not* to reproduce. In approaching this normative question, we stress the need for an awareness of that such a robotic mirroring of social norms is an important question in the first place. This approach on normativity indicates a scope that goes beyond formal law, as it poses issues which affect society and communities generally in ways which formal law might not account for [78]. This sensitivity for social norms includes many mundane everyday situations that, although clearly structured and guided by social cues and conventions, are not necessarily primarily governed by formal law. This could concern how we converse or communicate in various contexts, including social media, behave at a dinner table, or how different norms on gender affect anything from family structures, partnerships and professional expectations. The legislature admittedly has difficulty regulating human judgment in different life situations, albeit there may of course be legal frames or boundaries surrounding these contexts. But many social norms regarding gender, family, sexuality and relationships, for example, are informal and "unspoken". They are exercised through bodily acts and speech [65] in everyday public and private situations, at work, in school and in the family. The main argument here lies in the sometimes problematic relationship to robotic design and how adaptive technologies make use of data from these contexts.

These social norms may not only be seen as guiding communities in a multitude of non-formal normative issues, but also—of particular relevance here—perpetuate biases and unfair social structures. From a ML-perspective, this can be seen in what is expressed and captured in what images are included in the collection of facial features [20], what data that was used for prediction tools in human resources [79], or the human tagging of images in image-databases [80]. So, social norms expressed in texts in books, emails or on websites, but also organisational structures, gendered labour markets and purchase patterns, are used to train algorithmic models to detect, translate and predict. This is discussed by Larsson [23] with regards to "data-dependent AI that learns from real world examples derived from human activities may be understood as a mirror of social structures, leading to questions of accountability for those devising the mirror, its reproducing as well as amplifying abilities" [23, p. 589]. It is this type of mirroring we advocate needs further scrutiny in social robotics, and develop a model for below.

Pointing back to questions of acceptability, and to add a layer of complexity, there may indeed be useful and functional aspects of "personalised" robots, that can adapt to ways of talking or behaving in order to be accepted [38]. There are likely many non-problematic ways that personalised robotics can be used for developing HRI. However, one can also picture that for some communities or contexts it is stereotypical or even misogynistic expressions that could contribute to human acceptability—in that particular group—for robots, if they thereby mirror norms present in that community or context. Similar issues have been analysed from an ethical perspective in the case of gender-stereotyping in robotic eldercare [71]. This points to the normative complexity of meaning-making, acceptability and robotic mirroring of social norms. A first step, from a critical point of view, is however to acknowledge that this adaptivity may at worst pick up "a number of structural biases and imbalances that societies struggle with in general, such as inequality, unfairness, discrimination and racism" [23, pp.589–590].

In practice, for the adaptive aspects of social robots, it means that social robots may directly reflect society and its various contexts, some of which harmful, discriminatory or violent. Tanqueray et al. [7], for example, have demonstrated that socially assistive robots in the context of perinatal depression may mirror unwanted practices for the screening of peripartum depression, and perpetuate the narrative of the more powerful institutions at play. Furthermore, those who help develop such a technology may overlook gendered power relations and power structures [15, 18, 51]. Correspondingly, Tanqueray et al [7] show that the bridging of SoL and HRI is needed to critically develop social robots in a given context.

2.1.2 Code as Law, and the Materiality of Robotic Norms

Beyond law, norms can also—in a sense—be coded or designed into material objects. In debating how the early Internet met and related to normative structures, the legal scholar Lawrence Lessig argued for code—in terms of "cyberspace"—becoming "law" [81, 82]. For Lessig, this was a way to stress that another type of often overlooked regulator, that is, an entity that actually controls behaviour, in addition to formal legislation. Next to formal law, he also included markets, social norms and architecture as a governance structure (cf. [65, pp.589–590]). This notion of "code as law" has influenced much thought on how governance is played out for primarily digital environments, for example on digital platforms [83], digitally mediated property [84], but also governance of AI, for example in Japan [85], as well as in robotics [86]. This technologically designed side of norms may not be explicitly *intended* to be normative—not in the sense that formal law explicitly is intended to be normative—but may, just as well, be. Consequently, in the critical AI literature, as shown above, there is much critique found in *whom* is developing [17, 30, 51, 52] (see also the call for a feminist HRI [15, 57]) in the sense that this privilege also affects design normatively, often with blind-spots for those groups that are not heard or part of the development [6, 51]. This is also why we include *design* in the three levels of adaptive technologies below, shining a light also on risks of non-diverse sampling in HRI research [87] and what norms the actual designers may represent [6, 30].

Furthermore, moving on from this explicitly material design, by following Lessig's argument for "code" being law, we can argue that this normativity is not only expressed through the robots' embodied appearances—for example if they are gendered or not [71]—but also in how their abilities are following from programming in relation to training data. And, even more so, given the focus on adaptive technologies in this analysis, what normative aspects can be picked up in how a robot talks and positions itself in the social relation to the humans interacting with it. For example, what normative positioning do the virtual agents in the UNESCO report mentioned above perform? They are designed to be female, and to respond with a submissive tonality—"I'd blush if I could". In this case, it is not so much about physically *embodied* normative expression of gendered attributes—at least not in the same direct sense as with gendered social robots—but it is still an expression of a normative structure represented by code, and possibly, an adaptive approach enabled by the coding that may reproduce harmful stereotypes in its interaction with users. All of which stresses a need for an awareness in social robotics of what this mirroring means and may lead to.

2.1.3 Bridging Socio-Legal Studies and Gender Studies through Feminist Legal Theory

Before the next Sect. 2.2, it is worth highlighting the linkages between gender-related struggles and legal and social norms. The wave metaphor is a popular tool for telling the recent history of feminist struggles. The division brings attention to successful achievements in struggles for women's rights in predominantly Western contexts, yet the classification has been criticised by scholars for adhering to a logic of progress and fixing specific types of struggles or approaches to particular decades [88]. By stressing the links rather than the discontinuities between different theoretical frameworks, it is possible to situate the history of feminism in an understanding that brings attention to feminism's history as a series of ongoing contests and relationships, rather than discontinuities, within which feminism is characterised by heterogeneity, tension and critique [89]. While first-wave feminism was a movement recognised for its struggles to achieve legal recognition in relation to women's own personhood (e.g. not having the right to own property, or the right to vote), second-wave feminism, in turn, brought attention to the private sphere as a political arena, highlighting issues such as women's unpaid labor, in terms of domestic labor, birth control and economic empowerment [90].

While tensions and disagreements around questions of inclusion and exclusion in feminism and in society always have been a central part of struggles for gender rights, within third wave feminism, the notion of intersectionality established a conceptual framework for recognising multiple, interacting axes of power [91] and third wave feminism came to be known as the era in which the inclusivity of all women were recognised [92, 93]. The above discussion shows the importance of recognising the existence of asymmetric power relations in society, to grasp the impact of social norms on women's everyday lives and the possibilities and limitations of legal instruments for establishing justice. Overlooking these dynamics within the sphere of engineering could reproduce problematic discourses, such as issues of universalising rather than contextualizing data [94, p.8]. In the section below, we will concentrate more on the gender studies aspect within the realm of algorithms, fairness, the social, and the human.

2.2 Gender Studies

Broadly defined, gender is the social meaning ascribed to a body (ie a body identified as female or male or non-binary presenting)[30]. When distinguishing sex from gender, feminist scholars have rejected explanations of gender derived from sex [91, 95]. By illuminating how gendered identities are reproduced through social institutions, such as for example the family, education or media, feminist scholars have challenged the very idea of an essential sex [51, 94, 96, 97]. In addition, as black feminist theorists have demonstrated [29], dynamics of gender always intersect with other social categories such as processes of racialisation, sexuality and class.

2.2.1 Fairness and the Need for Situatedness

Today, efforts to achieve fairness in applied AI-systems have become popular (cf. [98]), and a debate about the limits and possibilities of such attempts has emerged among feminist, anti-racist and gender scholars of AI, who stress that inequality is reflected and amplified in algorithmic systems in ways that statistical methods only partially can address [18]. To take action against the building of devices, platforms and systems that serve to propagate sexism and racism, scholarly interventions from feminist and anti-racist traditions of knowledge highlight the need for a shift in existing theorisations of "algorithmic" fairness (which offers many definitions, but in general deals with questions of bias in relation to machine learning-based prediction, cf. [99]). With the notion 'the impossibility of fairness', scholars argue that, in an unequal society, decisions rooted in formal equality will still produce substantive inequality [100]. These ongoing debates challenge the focus on fairness as a property of the technology itself and opens a debate regarding AI systems and existing relations of domination and oppression [101, 102]. Within this debate, scholars have highlighted the problems that can appear with attempts at moving beyond classification. They have shown that such approaches can fail to account for the harms that surface in the design of the system itself. For example, automated gender recognition systems encode the notion that gender is a binary, immutable, physiological form of identity [103]. But the reproduction of such assumptions in larger systems can give in harmful experiences among the users of technology. For example, as Sasha Constanza-Chock describes their experience in airport security:

> As a non-binary trans* femme, I present a problem not easily resolved by the algorithm of the security protocol. Sometimes, the agent will assume I prefer to be searched by a female agent; sometimes, a male. Occasionally, they ask for my preference. Unfortunately, "neither" is an honest but unacceptable response. Today, I'm particularly unlucky: a nearby male-presenting agent, observing the interaction, loudly states "I'll do it!" and strides over to me. I say, "Aren't you going to ask me what I prefer?" He pauses, then begins to move toward me again, but the female-presenting agent who is operating the scanner stops him. She asks me what I prefer. Now I'm standing in public, flanked by two TSA agents, with a line of curious travelers watching the whole interaction. Ultimately, the male-presenting agent backs off and the female-presenting agent searches me, making a face as if she's as uncomfortable as I am, and I'm cleared to continue on to my gate. [104, p.4].

Using the notion of *algorithmic oppression* [17], researchers bring to light the multiple, mundane ways in which (what we call) adaptive technologies negatively affect the lives of women, trans people, people of colour and people with disabilities (for a list of selected examples, see Myers West [105]). Showing that the effects of "algorithmic oppression" are not evenly distributed, research highlights that women and gender minorities, people of colour, people of lower socioeconomic status and people with disabilities are more strongly affected by them, and especially those whose identities lie at the intersection between several of categories [20, 25, 106–108]. Recognising these problematic implications, Sarah Myers West [52] suggests that we should move from individualised notions of "algorithmic" fairness to approach, instead, algorithmic modeling as *situated practice*.

To approach algorithmic modeling as situated practice would involve an understanding of fairness (or what in this contexts sometimes is referred to as "social justice") that starts from real-world problems of domination and oppression, rather than abstract models or categorisations [109]. Such an approach understands fairness as a property of the social context within which the problem emerges, rather than approaching it as property of technical tools [110]. Such an understanding recognises issues of decision-making, division of labor, and culture, as having an impact on fairness, despite the fact that they often are ignored in philosophical as well as technical discussions [109].

2.2.2 Resituating HRI: Who Profits?

One key aspect highlighted by feminist technoscientists is the ambition not to attribute an exact human-like agency to the robotic other, but to make the more-than-human entity intelligible within human–robotic interaction. How is it possible to allow such new patterns to emerge? Here, studies which are already classics in the field have pointed at problems with the decontextualised nature of visions or promises of robotic interaction, for example within notions of the machine-worker, and argued that the technologies cannot be developed outside of the power relations that shape the different societal spheres of production, consumption and reproduction [111–113]. Yet, reflecting a shift that recently has taken place, from focusing on rational-cognitive processes and problem-solving, to emphasising socio-emotional interaction, today, scholars focus on two main issues: sociality and emotionality when they explore the capacities for developing mutual understanding in relationships between humans and robots, including both physical robots and virtual chatbots [114, 115]. Some HRI developers have taken the relationship between infant-caregiver as a rolemodel for such exploration, tying the design to a developmental trajectory and to existing forms of relationality between humans. Nonetheless, researchers problematise the fact that such rolemodels often lack the social and cultural meaning of the figure of both the child and the role of the caregiver [116, 117]. Typically female-marked modes of bonding may downplay the symbolic ordering of the social, and risk to naturalise feminine traits as necessary for giving care [34, 115, 118].

Importantly, while these debates focus on how certain design decisions determine capacities of the robot, they do so by stipulating what social interaction means. Thereby they also define human-to-human interaction. In this context, feminist technoscience scholars [119, 120] challenge the de-contextualisation within which much of these developments have taken place, and suggests to re-situate these processes within specific arrangements of power by asking Who profits?, bringing in questions of responsibility for such "engineering of the social" [121, p.37]. As they connect the discussion of human and robot relationships to the societal division of labor and to existing divides between production, consumption and reproduction, this scholarly debate contributes with a significant re-contextualisation of present and

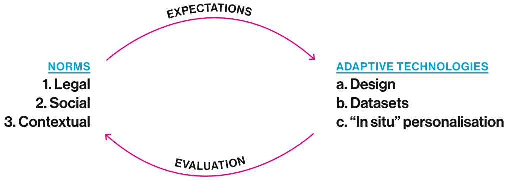

Fig. 1 Norms-in-the-loop: The Mirroring of Norms

future forms of work. Still, however, to a large extent today, the engineering of social and emotional robotic assistants are tied to notions of humanness based on certain gendered, racial, and occupational norms. One example here is the robot Nadine, assembled in 2013, created by Nadia Magnenat Thalmann (IMI Singapore) [122]. Moving from receptionist to social worker, Nadine is modelled after her creator, a White, college-educated, middle-class woman, and represents the fields of work that this robot will take over, in the realm of social work as well as the broader educational system. While such engineering of sociality involves both defining a problem in society—like the need of more workers in social work, teachers, health care workers—and delivering a possible technical solution to this, researchers have problematised the fact that the human labour forces that shape the basis for designing the robots, are coded as universal, despite the ways in which these labour forces are infused with gendered, racial and socio-economic power relations and stereotypes.

3 A Theoretical Framework

In this article, we outline a theoretical backdrop from SoL and Gender Studies in order to propose a conceptual framework on *socio-legal robotics*. Figure 1 describes a relationship between norms and adaptive technologies. Based on the presentations above, we divide norms into three categories:

1. *Legal norms*, that is, formalised normative claims. While there is a rich literature on both the relationship to technological innovation, as well as the relationship to social norms, we mainly focus the following category:
2. *Social norms*. While we acknowledge the vast literature on how to define norms, as well as the possible benefits in terms of acceptability that robots adapting to social norms may give, we focus problematic aspects of harmful social norms and stereotypes that risk being reproduced and amplified through adaptive technologies. Lastly, in lack of a more precise terminology, we include
3. *Contextual norms*, which means an emphasis on the need for contextuality and situatedness of how to study and understand adaptive technologies as played out and dependent on norms in various contexts.

When it comes to the normative mirroring, the *norms-in-the-loop*, so to speak, we roughly divide the adaptive technologies into

a. *Design*, pointing to both how robots can be embodied and e.g. gendered, and may reveal biases by the designers, and reproduce norms in a very material sense. Secondly, we point to
b. *Datasets*, which is acutely shown in recent debates on fairness in AI, where the sampling may either be biased in that it does not represent actual distributions in society, or biased in the sense that is represents an unfair society as such, which raises normative questions for those that automate and reproduce this unfairness in data-dependent design, algorithmic decision-making or AI-modelling. Lastly, we point to
c. *"In situ" personalisation*, in order to acknowledge normative questions for personalised robotics or other adaptive technologies that may learn from single individuals and individualise their feedback—perhaps well exemplified by a personalised chatbot used by an individual with self-harming behaviour. What is a fair position for the chatbot? Regardless, the position will be normative.

The interplay between norms and adaptive technologies are inspired by Iyad Rahwan's account on society-in-the-loop [28], clearly pointing to the societal expectations that evaluate and shape new technologies and methods like machine learning and AI-systems. For robots, this has been referred to as a sort of mutual shaping [123, 124], here framed as mirroring of norms.

3.1 Discussion

3.1.1 Norms

Firstly, and as outlined in Sect. 2.1 above, the interplay and friction between legal and social norms (see Fig. 1) has been studied in detail over a long time (cf. [61, 68, 69]). One the one hand, there are much regulation that firmly depends on supportive social informal norms [65] (as a social basis for law [61]). On the other, there are social structures and community norms that themselves may be expressing violent or harmful unfairness, such as discrimination, that law is set to try to come to terms with through regulation [23]. In Fig. 1 we also include contextuality, as a way to acknowledge the need pointed to in Sects. 2.2.1 and 2.2.2 above to regard context and situatedness when analysing social challenges in relation to adaptive technologies. This overlaps social norms to some extent, since many social expectations are triggered by or linked to certain contexts (cf. [125]), but is also a way to acknowledge domain specific norms, such as medical ethics or professional conduct (cf. [7]). For HRI developers to bring in social robots in certain settings, we argue, developers must understand the context in which they bring the robot [126, p.150], and what social implications this may have [45].

3.1.2 Adaptive Technologies

Secondly, bearing HRI in mind, we distinguish between three levels of adaptive technologies found to the right in Fig. 1. Of these, the overarching, on *design*, is of course very general, but a way to point to material aspects of robotic design, that we have pointed to as being normative in the sense of "code-as-law" in Sect. 2.1.2. Designs that gender robots are, for example, a clear example of the mirroring of norms, which at the same time may have many implications [10, 127]. The reason to include *datasets* as an adaptive technology in Fig. 1 is leaning on the recent and ongoing debates on bias and fairness in machine learning and AI, such as pointed to in the gender shades study [20]. However, there is an interesting duality in how to look at biased datasets pointed to by Larsson [26]. On the one hand, they may be biased in how they represent society, i.e. lacking training data for certain groups, cultures, regions or other phenomena—which may lead to a sort of algorithmic oppression [17]. The solution proposed to remedy this is often to collect more data, attempting to make the datasets more representative of society. On the other hand, which stresses the link to social norms further, one can also picture cases where the data may represent society fairly well, but society as such is skewed and unfair in how it distributes power, access to privileges such as work, education etc. In these cases, the data may actually be mirroring social structures or communities as such, but the challenge for adaptive technologies is found in that they reproduce or amplify violent, discriminatory, sexist or racist sentiment. For example, the datasets utilised for training ML-based prediction in image recognition or other classification algorithms can be heavily reliant on how and by whom the annotation is done. This has been problematised in terms of the construction of race and gender in an analysis of a large annotated database called ImageNet [80]. With regards to training data, this creates another type of challenge than non-representative datasets for AI-systems and robotic design, which is normative in relation to how to intervene or more actively scrutinise and engage in what it is a particular adaptive technology is supposed to do. At worst, and without awareness of how to deal with this set of problems, robots may merely reproduce also the types of social structures that would be harmful and unfair.

With the last category in Fig. 1, regarding the *in situ personalisation*, we point to individualised personalisation in the interaction of humans and robots (cf. [128]). By drawing from personalisation in other automated services like social media or artificial agents like the Replika chatbot [129], we see yet another type of interaction and adaptation to address with regards to adaptive technologies and norms (cf. [37, 38, 130, 131]).

3.1.3 On the Mirroring of Norms

By pointing to a theoretical framework that includes the notion of norms as measurable facts, we hope to provide with awareness of the role of informal social structures also in robotic design and HRI. To be clear, the existence of normative facts, that is, social norms, by no means mean that they are inherently fair and desirable for robotic "alignment". It only means that there is an existing structure linked to social expectations, that may explain certain behaviour. In fact, these social structures may be linked to behaviour that can be useful for understanding social interplay—and in some cases even increase acceptability of robots in some groups—but at the same time at worst also be harmful, divisive, misogynist and sexist. Social norms are not necessarily fair, so to speak.

The dynamics of "personalised" social robotics, set to adapt to an individual user, should therefore arguably not only be measured in terms of acceptability, as is common in HRI, but also stress a critical scrutiny of what norms are reproduced or amplified in this adaptive relationship. For example, robot design or learning techniques that aim to mimic human behavior are argued to not necessarily guarantee *fair* behavior [59]. Here, one may ask what it means to include aspects of social structures, for example what informal normative structures and human expressions related to gender, ethnicity, age, culture, language, as part in robotic learning. How should we detect and understand unfairness within this frame? To be able to contribute to this type of knowledge and its range of technological, methodological and theoretical dimensions, a research programme not only needs to include competence on the traditional strands in social robotics combined with aspects of the research fronts of computational AI-research, but also the theoretical underpinnings of disciplines that since-long have studied such social structures and their implications—for example SoL and Gender Studies.

We do not offer an answer to how to best handle or "solve" robotic mirroring of social norms, but stress a need for more awareness of this phenomenon. Informed by a socio-legal research paradigm, what values that are to be regarded as the achievable ones, in general and for various social contexts, is a core challenge of all communities and societies. In this context, feminist technoscientist scholars pointed to above intervenes into the techno-deterministic approaches which currently locates the robotic imaginary in an either-or position between a "utopian, welcoming position or a dystopian, resistant position", as they seek new approaches that could open up for the development of understandings of "socially-just kinds of human–robot co-habitation" [121, 132]. Further, within the fair-ML community, a key goal is to develop ML and automated systems that can achieve fairness in social and legal settings. However, scholars have shown that the concepts used to define notions of fairness and discrimination renders technical interventions "ineffective, inaccurate and sometimes dangerously misguided when they enter the societal context that surrounds decision-making systems" [110, p.59], mainly because such concepts fail to consider how the social context intermesh with technology in different forms. A change of focus of designs, some scholars argue, would mitigate the traps, for instance by refocusing AI designs in terms of processes instead of solutions, and by including social actors and different stakeholders into the abstraction boundaries, rather than being limited to purely technical dimensions [110].

Lastly, many of the examples given above relate to non-embodied examples of adaptive technologies—such as face-recognition, language-models or virtual agents. These do however arguably show what functionalities that are likely to become included in robotic, embodied, applications. This means that the social robotics field can learn from examples, mistakes and problematic cases from the non-embodied but adaptive AI-systems. It also means, following the material and coded architectures, that the social norms are not only to be learned in data-collection, but can also, obviously, be expressed in the materialities of design as such.

3.1.4 Recontextualising the Decontextualised

Social Robotics and HRI as a field is young [34, p.3], and research is continuously finding ways to bring social robots in society, as seen with the yearly HRI Conferences. Following the suggestions of feminist and anti-racist scholars, algorithmic modeling as a situated practice can provide a more robust way to hold the institutions creating and deploying AI-systems to account by affirming, rather than downplaying, difference [105, 110, 133, 134]. As Sarah Myers West highlights [105], some examples of such ambitions already exist, for instance in the Feminist Data Manifest-No [133], as well as in the calls of scholars upon technical designers to redraw their abstraction boundaries to include social actors [110]. Further, researchers push for ways in which a decolonial critical approach can be embedded in technical practice [134] to overcome the structural barriers that inhibit the development of a feminist "AI from below" [105]. For example, a systematic review of sampling in HRI research found it to be lacking diversity [87]. Another study explored the impact of overlooking gender and sex consideration in robot design on users [135]. This means that the "who" and "for whom" of HRI research are key factors to acknowledge since a lack of awareness risks propagating universalist claims for phenomena that are not universal. This is well in line with how we argue for a need for *recontextualising the decontextualised visions of technologies*, often presented as universal, despite the ways they may be gendered and infused with racial and socio-economic power relations and stereotypes.

Lastly, looking to the future, as social robotics becomes commonplace, it will not only be highly entangled with social norms and the complexities of interaction with humans, but also embedded in commercial strategies, datafied and shaped to fit business models of various sorts. Earlier shifts in technology-development can teach some of the implications of that transition. The early Internet that Lessig and others saw as a distributed and layered enabler of innovation has now morphed into a more *regionalised* and *platformised* sociotechnical construct, highly dependent on commodification of data, feeding the underlying business models (cf. [83, 136]). Often in the shape of ad-tech, or geopolitical struggles of dominion and control. As social robots increasingly become commonplace—and data-collecting, internet-connected entities—this field too will likely meet all sorts of similarly entangled issues relating to power, markets, business models and governmental control. This further calls for what feminist technoscience scholars [119, 120] suggest in terms of re-situating these processes within specific arrangements of power by asking: who profits? Any technodeterministic approach likely needs to be situated and challenged, stripped from universalistic attributes and scrutinised for what it actually is reproducing, for what reason and for whom.

4 Conclusions

In this article, we outline a theoretical backdrop from SoL and Gender Studies in order to propose a conceptual framework on *socio-legal robotics*. Here we seek to combine these disciplinary insights with HRI in an attempt to accommodate for what we see as emerging concerns in social robotics. That is, to be able to theorise and understand how to deal with the fact that the underlying technologies increasingly are becoming adaptive of the social interplay that includes social norms and stereotypes, here with a particular focus on gender. On the one hand, there are studies pointing to the usefulness of mirroring human traits in robots when striving for acceptability in human users [7, 46–48]. On the other, there are risks of mirroring social norms relating to for example gender—including stereotyping, sexism, and racism—pointed to in critical AI-research [17, 20, 25, 52, 75]. In short, we have:

- Proposed a theoretical basis of *socio-legal robotics*, primarily drawn from the realms of social sciences that underpins both Sociology of Law and Gender Studies. This focuses on social norms, relates to legal norms, while at the same time emphasises the need for the inclusion of context and situatedness.

- Proposed a framework that distinguishes between (i) design, (ii) datasets, and (iii) in situ personalisation as three distinct aspects of *adaptive technologies*. They adapt and mirror norms in different ways, which includes perceptions of the persons designing, issues of biased datasets as well as normative challenges inherent in technologies that adapt and personalise on an individual level.
- Related the theoretical framework to already established notions found in social robotics as a field, such as acceptability and personalisation; with particular focus on the adaptive interplay between AI-supported technologies and human social structures. If a robot adapts to and "learns" social norms, we point not only to potentially beneficial aspects of acceptability for certain users but problematise in terms of risks for reproducing or amplifying harmful, sexist, racist or otherwise deeply problematic stereotypes.
- Developed an account on fairness as a contextualised and situated practice in human–robot interaction, in order to be able to detect and avoid undesired or unfair aspects of robotic mirroring of social norms.

Lastly, the main argument depends on a theoretical understanding of societal unfairness. This opens for contributions from critical social sciences, to the already interdisciplinary domains of HRI, as advancements in adaptive technologies are incorporated into social robotics.

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Declarations

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Paper III

Laetitia Tanqueray, & Chris Papadopoulos
Accounting for the Unaccounted in AI & Care: Bringing Young Carers into the AI Realm
Under Review.

Accounting for the Unaccounted in AI & Care: Bringing Young Carers into the AI Realm

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Abstract

This position paper aims to introduce young carers as key stakeholders within the realm of informal caregiving and research on artificial intelligence which endeavours to assist within healthcare. This paper situates itself at the intersection of young people under the age of 18 providing care in the United Kingdom from a socio-legal and public health perspective. To do so, research on young carers and artificial intelligence is synthesised according to contextual, legal and social norms –in line with Larsson et al.'s norms-in-the-loop framework– as those have direct impact on adaptive digital technologies, even if the stakeholder is unaccounted for. The paper thus concludes by providing concrete on how to account for young carers, embedded within participatory design, to empower this important subgroup. We envision that this position paper provides evidence and justifications on why young carers need to be included as stakeholders in AI research. In other words, we present young carers so that AI researchers are aware of who they are, what to include in ethics applications on why young carers need to be included, and what practical steps can be taken into account.

Keywords: Young Carers, Artificial Intelligence, Informal Care, Socio-Legal

Introduction

"[Young carers] experience a lifetime of coming second (or third, or fourth) to the needs of another" [1, p.36]. This quote is from a submission by Sibs to the United Kingdom's All-Party Parliamentary Group (APPG) for Young carers, to indicate that some children who provide informal care have to choose between their future, or the future of the person that they care for. The APPG report represents the first ever Parliament inquiry into young carers– which was released in November 2023 – presenting evidence on the realities of being a young carer in the United Kingdom (UK) and identifying potential ways to alleviate care responsibilities and their impact on the young person [1]. Meanwhile, in the realm of artificial intelligence (AI), tech solutions are attempting to resolve issues ranging from education [2], to health [3], to everyday tasks [4]. These applications are also used by children, which must be taken into account. However, the issue should not be generalised to all children; instead, it should be approached with context and specificity. This paper, in particular, focuses on children who provide care. This is especially pertinent as, to the best of our knowledge, young carers have mostly been overlooked in AI research and applications. This is disconcerting, as they represent at least 6% to 8% of the child population and is usually a hidden form of care in society [1, 5, 6]; moreover, they are likely to be supporting the very care recipients that AI researchers are designing for. As such, this position paper directly situates itself at the intersection of young carers in the United Kingdom and AI, from a socio-legal and public health perspective, in order to highlight the challenges ahead and explore ways to transform them into opportunities for the AI community.

We use “AI community" here as an all-encompassing community varying from robotics, to large language models, to social robots, to personalised computer games, to smart assistants. Put differently, we categorise AI as a field of development and enquiry which takes the form of various tools, such as a smartphone app or robot. Following the definition provided by UNICEF, AI systems make predictions, recommendations, or decisions that influence real or virtual environments based on objectives set by humans [7, p.16]. Nevertheless, AI represents a huge opportunity to nations generally. In January 2025, the Secretary of State Science, Innovation and Technology in the UK presented a report to present how to leverage on AI so that the UK is an *AI maker* and not an *AI taker* [8]. Within this report, health care, social care and education are viewed as excellent uses of AI to improve people’s lives. However children are not mentioned as a specific stakeholder. Yet if AI systems are intended to alleviate current societal challenges, we must also account for stakeholders that are currently overlooked in AI research. Consequently, this position paper is a call to AI researchers to directly include young carers in studies so that the envisioned tools can empower and challenge current practices.

Beyond the research spheres of AI and technology generally, young carers have been well researched within law and social sciences. Though there is no clear definition of young carers, we use Becker’s [9] widely used definition by the young carer research community and practitioners to define young carers:

> Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has a chronic illness, mental health problem or other condition connected with a need for care, support or supervision. [9, p. 378]

This conceptualisation demonstrates that young carers are (a) under 18 years of age, (b) providing a form of care, (c) to someone that can be either (i) family: parent, grand-parent, sibling or (ii) friend; (d) care often happens on a regular basis. We add that (e) caregiving has positive and negative impacts on the young person [10], (f) young carers fall under the broader category of informal caregiving, meaning that despite the demands of their care role, it is unpaid and no training is provided, as well as (g) young carers are typically demographically very close to the person they care for, whereby the care receivers and young carer usually live in the same household.

In line with our aim, we use Larsson et al.'s framework 'norms-in-the-loop' [11] to demonstrate the socio-legal complexity of young carers in society and the challenges as well as the opportunities these bring to potential AI systems. *Norms-in-the-loop* [11], argues that norms – namely contextual, legal and social – must be considered, as they form the foundation of AI systems. Consequently, these norms become intertwined through systems' design, datasets and in situ personalisation (see Figure 1 for an illustration of this). Put differently, norms are at the core of AI innovations and those norms should be accounted for in order not to perpetuate problematic societal issues. Relating this to young carers, this group is already hidden in society generally, therefore AI systems would likely perpetuate this and not account for that key role in the child's life. In practice, data might be collected and utilised on children that are young carers, but the AI systems do not recognise the person's role as a carer and consequently overlooks potential avenues which could aid the young person with their care responsibilities. Accordingly, we adopt this framework to showcase the norms around young carers within each of these stages, to then illustrate adaptive technologies which could directly and indirectly account for young carers. We specifically leverage on the community's practice around participatory design to demonstrate why this is required in such a sensitive area.

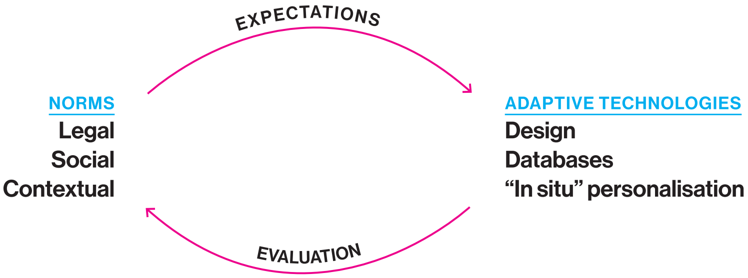


Fig. 1 Theoretical Framework 'Norms-in-the-loop': The Mirroring of Norms by Larsson et al. [11]

We must also highlight an important critique from a disability rights scholars around young carer service design, as these can undermine the parental role of the parent with a disability [12, 13]. AI research should not focus exclusively on young carers as carers but should instead adopt a more inclusive approach that considers the broader family dynamics. Therefore, while we fully support the need to ensure that care receivers receive adequate care, we aim to show why it is essential to research and design AI systems with both young carers and care receivers in mind. By taking a whole-family approach [14], we can ensure that these AI applications are beneficial and effective for everyone involved. Furthermore, whilst informal caregivers roles are usually essential to the person they are providing care for, *young carers are children and young people first* [15, p.1]. This position paper therefore serves to advocate that young carers should be recognised as a vital user-group, and AI systems should ensure that they are also designed for them as carers as well as young people, in addition to other stakeholders.

Accordingly, this paper first sets out relevant literature, demonstrating the contextual norms, legal norms, and social norms entangled in young carer and AI research. This will lead to a discussion section on (1) strategies designed for institutions that could be adapted to support the identification and support of young carers; (2) strategies for the care receiver to enable indirect support; and (3) strategies specifically directed for young carers.

1 Contextual Norms: Bringing Awareness around Young Carers

Larsson et al. [11] argue that questions of fairness need to be contextualised and situated when a practice becomes intertwined with technology. This is in direct contrast to universability (of care, in this instance). This is key in this paper as we try to situate a specific practice which has been mostly overlooked by the AI community and thus requires contextualising. Accordingly, this section aims to showcase the context of young carers in the UK, as well as a sample of AI research on informal caregivers.

1.1 The Realities of Being a Young Carer

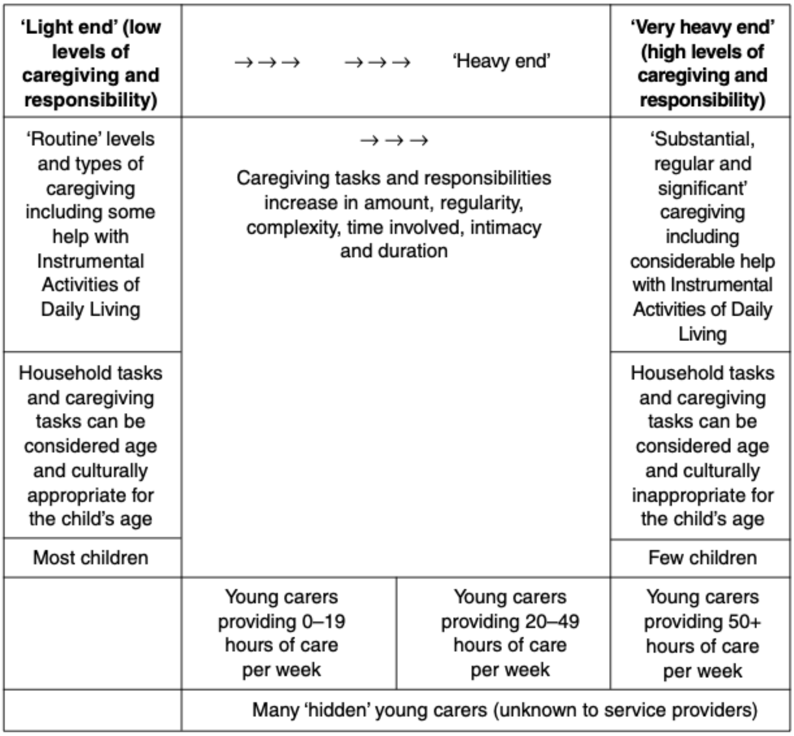
In 2021, it was estimated that 127,176 children and 229,690 young adults (over the age of 16) were young carers in the UK. However, as the APPG report suggests, these figures likely represent a significant underestimation [1, p.6]. Various studies consistently indicate that between six and eight percent of children in advanced industrialised capitalist societies, including the UK, are carers [5, 6]. However, these estimates are based on young carers known to authorities, meaning that the actual numbers are likely even higher [5, 6]. Nonetheless, it is estimated that young adult carers alone contribute over £3.5 billion (around 4.4 billion USD) of unpaid care each year [16], which demonstrates that young informal caregivers provide essential care within society.

As all other informal caregivers, young carers provide care and support for various conditions, which can range from siblings to parents to grandparents to friends. Young carers who take care of a parent represent the most extensively studied sub-group. Children might be caring for a parent due to substance abuse, chronic illness, disability or mental health issues, among other factors [17, 18]. Another subgroup of young carers have care responsibilities towards their sibling due to disability (e.g. autism) or chronic illness (e.g. cancer). This does not eliminate the role of the parent, though some evidence suggests that young carers providing care for siblings take on more care responsibilities than young carers taking care of a parent [19], yet there is a lack of awareness on how much responsibility they take on – including by their parents [20]. Other young carers might take care of a grandparent, due to a disability or chronic illness, such as dementia, though not as much research has been conducted on this area. A recent studies suggested that there is a lack of clear identification for this subgroup, in part due to their responsibilities being somewhat more occasional and that the young person is often not the primary caregiver [21, p.6]. Finally, there is a group of young carers emerging in research around young people providing care for their friends, due to disability, mental ill-health or chronic illness, the study showed that this segment of young carers reported more health problems – especially with regards to mental health [22].

Becker has suggested that it is useful to conceptualise care of young carers on a care giving continuum, ranging from "caring about" to "caring for", which can be gradual for the young person taking care of a care receiver [23]– we have included Becker's sketch, see Figure 2. This is important to note since young carer researcher include household chores as possibly part of caregiving, however it is also likely to be part of everyday life for a child who does not provide care for someone. It is thus the amount of responsibilities that is the important differentiator. Although there is not a one-size fits all description, young carers provide different types of care that usually span over more than one task of the following: general domestic tasks (such as cleaning), household management, finances, child/sibling care, acting as the translator for the care receiver, provide direct care such as emotional support and supervision, personal and intimate care, health and medical care, and self-care for the young person to ensure their own well-being (cf. [6, 24, 25]).

The impact of caring is also an important indicator to account for. Indeed, Aldridge highlighted that research suggests that the impact of providing care can be dependent on the duration of care, for example a young person caring for someone for longer than two years is more likely to experience mental health issues [10, p.159]. Said differently, if the impact of caregiving is major on the young person, the regularity on the care giving continuum might not be as useful. Nonetheless, caregiving can have a positive impact on the young person. Cassidy, Giles and McLaughlin demonstrated that there is increased resilience in young people who provide care, as long as it is not overly excessive *and* is socially recognised [26]. Leu et al. accentuate current research on the positive impacts of young people caregiving, which include increased maturity, closer relationships to parents, feeling more prepared for life, as well as being more empathetic and compassionate [5, p.3]. Though there are also negative impacts, such as higher absenteeism and drop-out rates from school [1], as well as anxiety [27], depression [28] and social exclusion [29].

The context of the UK is also pivotal as it marks a specific complex socio-economic setting. For example, a report by Vizard et al. intersectionally investigated child poverty in the UK [30], which includes a chapter on young carers. This chapter



<table>
<tr><td>'Light end' (low levels of caregiving and responsibility)</td><td colspan="2">→→→ →→→ 'Heavy end'</td><td>'Very heavy end' (high levels of caregiving and responsibility)</td></tr>
<tr><td>'Routine' levels and types of caregiving including some help with Instrumental Activities of Daily Living</td><td colspan="2" rowspan="3">→→→
Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration</td><td>'Substantial, regular and significant' caregiving including considerable help with Instrumental Activities of Daily Living</td></tr>
<tr><td>Household tasks and caregiving tasks can be considered age and culturally appropriate for the child's age</td><td>Household tasks and caregiving tasks can be considered age and culturally inappropriate for the child's age</td></tr>
<tr><td>Most children</td><td>Few children</td></tr>
<tr><td></td><td>Young carers providing 0–19 hours of care per week</td><td>Young carers providing 20–49 hours of care per week</td><td>Young carers providing 50+ hours of care per week</td></tr>
<tr><td></td><td colspan="3">Many 'hidden' young carers (unknown to service providers)</td></tr>
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Fig. 2 Becker's illustration of "A continuum of children's caregiving" [23, p.33]

highlights that while the key characteristics of young carers are recorded, they are often not separately analysed in public statistics, or they are under-represented due to small sample sizes. Despite this, Vizard et al. suggest, it is crucial to specifically account for young carers in data collection and analysis. Furthermore, Vizard et al. demonstrated that poverty rate among young carers is highest in comparison to other groups of children, and also found increasing rates of poverty in young carers' households. The report also points out that prior to the 2008 global financial crisis, young carers tended to be protected from poverty, demonstrating worsening welfare provisions [30, Chapter 4]. Moreover, studies suggest that families of young carers in need of care do not receive sufficient publicly provided care [31, 32]. This has been exacerbated by the covid-19 pandemic, with the lack of public services available leading to more care responsibilities to be performed by young carers [33, 34]. These insights demonstrate how young carers can become the *default* caregiver due to lack of support and services available for formal caregivers in the UK to take on care responsibilities.

1.2 Informal Caregivers and AI

Much AI research aims to relieve pressure or provide support for specific user groups. In this paper, we contextualise and present ongoing research on informal caregivers. This, in turn, highlights the capacity - and indeed the precedent - for the AI community to include young carers as a distinct user group, given that adult informal caregivers are already considered as such.

Human-Computer Interaction (HCI) as a field enquires about the interplay and communication between human(s) and computer– though the 'computer' part can take the form of an app on a smart phone or tablet for example. Schinkinger and Tellioğlu [35] published design implications specifically to support (adult) informal caregivers in their daily role. Through their ethnographic work with informal caregivers, they were able to show what qualities and features the technology should have to meet informal caregivers' requirements, which included communicating with professional care services, be part of self-help groups and monitor care receivers. Premanandan et al. [36] conducted a scoping review including 82 articles to outline what IT (information technology) applications were available for informal caregivers along with their use. Their findings point that informal caregivers can use IT applications to optimise their information access, such as relevant information related to caregiving, as well as access social support to feel less alone in their situation. Though there were also barriers, which relate in part to privacy concerns, lack of trust in application and lack of time to use the application to name a few. Another study specifically targeted understanding how tech can help and adapt to the experience of caregiving changing over time, whereby a child with cystic fibrosis (in this instance) is likely to gradually become more independent and require less care from parents [37]. One study looked at online intervention to provide support and self-learning tools specifically for informal caregivers who provided care for a person living with dementia, named 'iSupport' [38]. This platform has also consulted young carers directly so that the phone application is also accessible to them and is designed in a way that reflects their own reality (i.e. illustrations of children caring, not just adults) [39]. Though Messina et al. [38] found that there was a reluctance to use iSupport on behalf of (adult) informal caregivers as it created a level of burden; a sense of duty to use it; fear of being misunderstood by others; as well as difficulty in reaching relevant information. One study attempted to understand the co-regulation between the family with children who have ADHD, however the researchers specifically state that they were unable to recruit siblings due to ethical restraints [40]. Another study included young carers, was concerned in part with creating a phone application that met their needs, with the aim to provide psycho-social support to promote the mental health and well-being among adolescent young carers (though not through AI systems) [41].

Turning to Human-Robot Interaction (HRI), this field in comparison is specifically engaged in robotic applications, which requires the physical embodiment of an agent, i.e. a robot. In this field, there has been one study which specifically includes young carers by Tanqueray et al. [42]. This study aimed to introduce young carers to the HRI field as well as showcase potential scenarios which young carers could benefit from. This study was a direct result of a scoping review undertaken by Tanqueray, Larsson and Winkle [43] who found that only adult informal caregivers were included in HRI studies when looking at health care. Nonetheless, there have been studies which have demonstrated how robots may help informal caregivers. Laban et al. [44] investigated the deployment of a social robot to elicit self-disclosure for informal caregivers over five weeks. The preliminary findings were positive, and found that informal caregivers opened up more about their feelings over time, which helped alleviate some of their concerns in caregiving. Amabili et al. [45] investigated the use of eWare, lifestyle-monitoring technology within a social robot, in order to reduce stress and improve quality of life for both informal caregivers are well as people living with dementia. Within their findings they state that "the impact of the system in reducing the caregivers' burden needs to be deeply investigated" [45, p.1]. Lee et al. [46] explored the views of care receivers and their informal caregivers, to demonstrate their potential conflicting views and interest that would need to be taken into account for the design of socially assistive robots; these findings were also echoed by Winkle and Moradbakhti [47].

There are many other types of studies which consider the role of families as informal caregivers within the design of health technologies, however the studies pointed at herein demonstrate a general lack of consideration of the caring role of (grand) children of/siblings/friends of under the age of 18 to care receivers have when designing these technologies. This provides a new research avenue, that is much needed considering young carers' key role.

2 Legal Norms: Relevant Frameworks for Young Carers and AI

In this section, we outline various legal instruments, these in general establish normative shaping expectations in society, and in turn, AI systems [11]. Legal instruments serve as a foundation for the functionality of AI systems and also beyond, such as laws to identify and act on fraudulent behaviours or how personal data can be used and shared. Within AI systems, these normative expectations allow for specific types of applications help with legal obligations, for example detecting if someone is at risk and alerting the relevant authorities. By highlighting specific legal regulations and guidelines that directly affect young carers and/or uses of AI systems, we show how these can be explicitly incorporated when developing AI systems designed for, and in the best interest of, young carers.

2.1 Significance of Law for Young Carers

Leu et al. point out that there is an important question to be raised when a country decides to legislate on young carers: "[is it] acceptable for any country to have children in a caring role in the first place, and if so, to what degree?" [24, p.12]. This question points out the expectations of being a child in western societies, in that children are deemed to not be carers. However, Leu et al. highlight Nordenfors and Melander's criticism towards strong welfare States (such as Sweden), which do not formally recognise children as young carers –even when they do provide care– due to the belief that the welfare system eradicates children as carers; yet, paradoxically, this leaves children to care alone without support [48]. Put differently, ideally children would not be the person relied on to provide care and support to a care receiver, however legally recognising that this can occur allows for specific support to be in place. Consequently, legislation for young carers provides necessary welfare provisions to ensure essential assistance and wellbeing measures. The UK has specific legislation for young carers in place, which directly results in (1) young people being assessed, identified, supported, and protected from too much care responsibilities, and (2) prevent children from becoming young carers if other services or people are available [24].

The UK has been recognised by researchers as the only country with the most advanced legislation and policies in place for young carers [6, 49]. Indeed, in 2017, Leu and Becker created a classification to demonstrate country-level responses to young carers, the UK was the only country categorised as 'advanced' category as it (1) exhibited widespread awareness and recognition of young carers, (2) has laws in place and (3) good research base [6]. Though no country has achieved the highest category yet, namely 'incorporated/sustainable' [6]. This classification was updated in 2021 to show the changes within the past few years, however the UK remained as the only country in the 'advanced' category, and was still deemed not to have reached the highest level [49]. It is important to note that although the UK has this recognition, in practice there are gaps and inconsistencies of the implementation of such policies and accessing (often overburdened) services which resulting in the need to self-advocate– which can be particularly tough for young carers [1]. Nevertheless, Leu and Becker point out that there are two key factors that influence the extent and nature of policy responses: (1) reliable national research and (2) contribution of national non-governmental organisations [6]. This is well illustrated by the APPG report, which relies heavily on national research to evidence hardships young carers face, and the Carers Trust (a prominent UK charity) provided the Secretariat for the APPG on young carers [1].

The underpinning of UK legislation regarding young carers allows for AI researchers to consider and leverage on existing legal instruments in place. This would firstly enable new important knowledge on young carers and best practices to support them, and secondly, this can create better policies and support for children providing care for someone.

2.2 Applicable National Laws for Young Carers

The UK comprises of England, Wales, Scotland and Northern Ireland. Scotland, Northern Ireland and Wales, through devolution of power vested by specific Acts of Parliament for each, have different levels of power to govern their own nation. Devolution of powers directly delegates powers from central government to national governments, and in all four nations, social care is under national legislation and not UK legislation. In practice, this means that legislations around young carers are fragmented and regulated under slightly different national legislation which are not standardised [6, p.8], as it falls under social care provisions.

All legislations pertaining to young carers in the UK aim to prevent, identify, assess and support young carers. There are different tools to achieve this goal. In Wales, the Social Services and Well-being (Wales) Act 2014 [50] applies, meaning that young carers are regulated under the umbrella of informal caregivers. In England, the Children Act 1989 [51] (amended by the Children and Family Act 2014 [52]) and Children and Care Act 2014 [53], meaning that young carers are regulated under acts pertaining specifically to children. In Scotland, Carers (Scotland) Act 2016 [54] applies, meaning that young carers are part of a carer-specific legislation. Finally, in Northern Ireland, the Children (Northern Ireland) Order 1995 applies [55], which regulates young carers under law pertaining to children.

These regulations create a legal duty on local authorities to have appropriate services in place to identify, assess and support children that might be (or become) young carers. Through the assessment, the local authority can put in place various arrangements to alleviate or eradicate the care load from children taking care of a relative. This can take the form of respite for young carers, by attending support groups targeted at children that provide care. Furthermore, the legal recognition of young carers allows for some available State benefits in all four nations, namely the Carer's Allowance. However the material support is limited: the young person *must be over 16 years of age* and *left full-time education* to take care of the person they care for; the current rate is paid at a standard rate of £83.30 (2025/26) a week, and the person cannot earn more than £196 per week after tax from another employment [56, 57]. Only Scotland offers a Young Carer Grant– a lump sum of £390.25– meaning that any young carer between the ages of 16 to 18 who care for more than 16 hours a week in the last three months– can apply to the grant without it affecting their education or employment. The awarded grant is to be used for the young carer specifically, for “things like new clothes, driving lessons or a holiday" [58]. These limited forms of financial support have been widely criticised as inadequate, particularly given the significant responsibilities many young carers shoulder. Charities, advocacy groups and cross-party Members of Parliament have warned that the system is letting vulnerable children down. Recent cases – such as a young carer forced to repay over £2,000 after unknowingly breaching earnings rules – highlight systemic failures in monitoring and guidance [59]. Meanwhile, over 9,000 carers have faced severe debt from overpayment demands, prompting 108 charities, including Carers UK, to call on ministers to halt enforcement and write off existing debt [60]. These issues have sparked sustained government scrutiny and criticism.

2.3 International Legal Instruments on Children and AI

There are two key legal instruments which are useful to note when researching children and adolescents generally and for AI specifically: The United Nations Convention on the Rights of the Child (UNCRC) [61] and UNICEF (United Nations Children's Fund)'s policy guidance on AI and children [7]. Though those are not legally enforceable.

The UNCRC represents one of the most ratified Convention by States [62], which includes the UK and thus requires the UK to follow it in the principle of good faith [63]. The Convention is based on fundamental values represented by four articles: the right to non-discrimination (article 2), the best interest of the child (article 3), the right to life and development (article 6), and the right to be heard (article 12) [61]. This is applicable to anyone below the age of 18 years old. Within the context of young carers, applicable institutions accountable to the UN's Committee on the Rights of the Child have specifically undertaken work to empower young carers' voices directly through a survey filled out by over six-thousand young carers and present their needs [64].[1]

Regarding UNCRC's work on the growth of digital technologies, the UN's Committee on the Rights of the Child released a General Comment in March 2021 on the digital environment as a response to reports from State Parties mentioning issues regarding digital media and children [65]. Within the opening paragraphs, the Committee states: "if digital inclusion is not achieved, existing inequalities are likely to increase, and new ones may arise" [65, point 4]. The Committee's general comment iterates that (1) though the digital environment was not originally designed for children, it plays a significant role in children's lives and therefore children's best interest should be paramount (in line with article 3, UNCRC) [65, point 12]. In line with this, (2) children must be supported to participate as equally as adults within this environment, and thus their views need to be considered as well (in line with article 12, UNCRC) [65, point 16].

In November 2021, UNICEF released a policy guidance on AI and children [7], which references the general comment directly, and bases itself on the UNCRC to uphold children's humans rights. Accordingly, this guidance reflects key principles within the UNCRC, and directly calls out the lack of children's involvement in current technology design and national AI strategies.They further emphasise why this guidance is required by pointing out that one-third of internet users are in fact children [7, p.12]. Although this exclusion is general to all children, AI researchers should also consider sub-groups of children and how they might be impacted differently by AI innovations.

2.4 Data Protection in the UK

The UK has data protection regulations in place, which merges the UK's post-Brexit data protection law adapted from the EU GDPR [66] (this is referred to as the UK GDPR) as well as the the UK Data Protection Act 2018 (DPA) (section 3(10), [67]). Both laws' purpose is to provide a clear legal framework on how organisations collect, use, and protect personal data of individuals in the UK. The UK GDPR maintains the same core principles as the EU GDPR, such as lawfulness, fairness, transparency, and data minimisation. It also upholds the rights of individuals, including access to their data, the right to erasure, and protection not to be subjected to automated decision-making.

The UK GDPR makes special provisions regarding children. The UK GDPR lowers the age of consent to 13 years-old (Article 8(1)) – in comparison to 16 years-old

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[1] Article 43 of the UNCRC establishes the Committee on the Rights of the Child to examine the progress of the UNCRC, and review as well as comments on State Parties' reports, submitted every five years, to show how the UNCRC has been implemented. In accordance with its obligations, the UK has to have monitoring systems to promote and protect the UNCRC as well as ensure that policies and legislations regarding children align with the UNCRC. This is fulfilled through the Children's Commissioner, an independent children's human rights institution, established in Wales (under the Care Standards Act 2000) and England (under the Children's Act 2004). Both these institutions recognise young carers within their work.

in the EU GDPR (section 8(1)). Furthermore, article 123 of the UK DPA demands age-appropriate design of Information Society Services, such as social media, so that children can understand the privacy notices and give informed consent. This has direct consequences on how AI technologies can operate when capturing information, for example through sensors, direct input from users, data mining or third party data feed (i.e. smart watch sharing live updates to another monitoring platform). With regards to young carers specifically, this means that any AI technology collecting their data will need to explain its purpose in a child-friendly manner which also clearly defines the purpose of the application so that the child (and/or guardian) can make an informed decision on using it. The Information Commissioner's Office (ICO), an executive body in the UK specific to data privacy, has also released "The Age Appropriate Design Code" which explains that data sharing of children's data must be based on the UNCRC's child's best interest [68, pt.9]. This code is applicable to existing provisions in the UK for integrated systems specifically for children and young people, which has for objective to improve quality and efficiency of services by allowing better data sharing between healthcare and social care institutions. Put differently, the data collection cannot be simply to optimise the algorithm, but the collection of personal data must primarily account for the child's best interests and can allow for institutions to share data between one another.

3 Social Norms: The Gap between the Law and the Lived Experiences

Larsson et al. [11] define social norms as: “(i) shared (and thereby social), (ii) expectations on behaviour by (iii) groups" (p.4). Social norms indicate the expectations of society generally, this directly seeps into institutional expectations, which in turn steers who is included and excluded – which can be perpetuated in innovations. Though it does not necessarily apply to society generally, it can also apply to sub-groups, such as young carers and also the AI research community, as discussed in this subsection.

3.1 The Difficulties of Identifying Young Carers

Whilst the section on legal norms demonstrated that there are legal structures in place for young carers in the UK, the reality is that there are difficulties implementing the laws both on a systematic and individual level. This results in non-identified young carers to fall through the nets of identification, assessments, support and protection. Leu and Becker set out three reasons why the laws do not have the intended consequences [6]: (1) the complex landscape of laws in the UK and most professionals are not aware of specific legal requirements and responsibilities placed on them to identify and assess; (2) there is a gap between the ambition and the purpose of the law, with professionals within healthcare, education and social work not implementing the law, (3) there are insufficient resources to ensure professionals become aware of their legal responsibility (p.754). The APPG report further illustrated the latter by mentioning that despite the rise of awareness, there is not enough resources to be able to undertake those assessments, which leads to over six months waitlists for assessments [1, p.17]. This is further exacerbated by the term “young carer" not being well defined in law or research ([10, 69], which also results in barriers for young people to recognise themselves as young carers [5]. Law can thus only go so far. Nevertheless, researchers agree that while laws are essential to support young carers and can help alleviate some of their care-related responsibilities, they are unlikely to fully eliminate these responsibilities [69].

Self-identification is a common challenge faced by informal caregivers generally. Carduff et al. [70] pointed to three barriers to identifying informal caregivers: (1) taking care of one person is often a gradual process, and therefore carers do not identify as taking care of someone, but rather viewing it as part of their relationship to that person. This often leads to a health or social care professional who makes the person aware that they are a carer; (2) as the care receiver's condition deteriorates and their needs become more demanding, the informal carer may struggle to prioritise their own wellbeing. In practice, this can result in them not seeking support or assistance with their caregiving responsibilities, and instead continuing unsupported.; and, (3) there is a lack of clear pathways on when should the health institution begin to support carers. This often leads to healthcare professionals being reactive rather than proactive [70]. Teachers also play a key role since young people under 16 in the UK must attend school. Yet, a study involving 800 teachers in the UK, found that almost half of the teachers said that they would not feel confident that they could recognise a young carer; furthermore the study also found that 57% of those teachers said that young carers will hide their situation from figures of authority [71].

Though there are issues of identification stemming from institutions, identifying young people as carers might not have such an impact on their caring responsibilities. Indeed, Alexander found that laws in England helped shape young carers' emotional lives and the significance of the care work they provide, but did not alter the arrangement of care work that they undertake [72]. On the individual level, Aldridge et al. has pointed to the reluctance from families/children themselves disclosing that they are young carers, in part due to bullying and stigmatisation towards the young carer and in part to the potential involvement of social services taking away the young carer [73, p.17]. Stigma the young person feels due to being a young carer is often mentioned as a barrier (c.f. [74, p.23]). This 'otherness' (i.e. stigma) has been explored by researchers who found that this is either because of being carer or by association to the person they care for, which led to young carers withdrawing and cutting themselves off from their social world [75]. Furthermore, there might also be a normalisation of the care responsibilities the young person has [76]. Or there might simply not be enough services available to the person requiring care resulting in the young person filling that caring void [76].

This illustrates the complex social norms around the young person perceiving themselves as young carers, and professionals providing adequate support. Current social norms seemingly point to lack of clear support to provide young carers with their care responsibilities. This must be kept in mind ass AI applications can directly aim at alleviating some care responsibilities and challenge the current status quo.

3.2 Research Priorities in AI and Healthcare

Social norms also exist within research communities. By highlighting these norms within the AI and care sector, we can better understand the need to challenge current research practices. It is evident that within the context of AI, young carers are often overlooked and insufficiently included in the research focus (see subsection 1.2). This might not be surprising when looking at how AI research communities are understanding the challenges that lay ahead: a rapid change in the ageing population impacting demographics in the West [77, 78] and the shortage this will likely cause on healthcare staff [79]. This indicates a need in finding solutions to these issues, which AI researchers have found to be (unsurprisingly) tech solutions. Thus the responses from the AI community to healthcare have targeted mostly the care receivers' health which aid clinicians, from tools for early detection and diagnosis, to treatment, to prognosis evaluation (e.g. [80]). Or attempting to understand care for older people through AI applications (e.g. [81]). With some studies pointing out that families are key to ensure the implementation of the technology in elderly care (see for eg [46, 82, 83]).

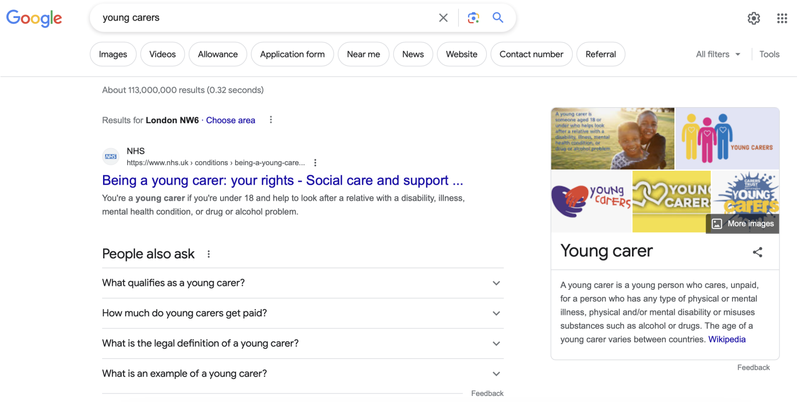
However, AI systems are *socio*technical, in that they are placed within a specific social context. Yet the application will be steered by the framing of societal issues – often iterated by funding opportunities [84, 85]. But those AI innovations will impact social structures and organisations of the setting. This exemplified by a study looking at clinicians uses of AI systems in a clinical setting, Zajac et al. [86] split between the technical as (i) the training data and machine learning model, (ii) system integration and data used, and (iii) user interface; and the social as (a) users and system use, (b) workflow and organisation, and (c) healthcare institution and political arenas. Though the authors note that the social and technical cannot be simply detached from one another and they are heavily dependent on the context, this will still have a significant impact on the workflow. This is also illustrated on robots for care settings: the current available technology is not currently fit for the purpose of caregiving fully autonomously, it requires setting up and monitoring by the care staff to function [87], and this burden will likely fall on informal caregivers too as independent living continues to gain traction [43].

These research norms show a direction that the AI community aims to head in, and also who is included and excluded in research. This should be understood as an indication on why this position paper is making a point out of it: there is very little research on young carers in these AI applications. In practice, this means that the technical aspect of AI applications do not integrate possible solutions aimed for/at young carers or aimed at the care receivers in order to alleviate some care responsibilities from young carers. Yet, it is likely that the social aspect of these technical tools, once the applications are commercial, will impact young carers. This may be setting up or supervising the tool to normalising its usage within the household. By not directly integrating views of young carers or data points specific to young carers, we are likely to reproduce and amplify their current realities – something that is pointed out by critical scholars repeatedly [84, 85, 88]. Accordingly, this position paper underscores that overlooking young carers is not just a missed opportunity but a serious concern. It is alarming that such a vital user group is entirely absent from AI research, particularly as the reliance on informal caregivers continues to grow due to the diminishing availability of formal support services. We subsequently demonstrate how the AI community can challenge the status quo and integrate young carers as specific users in AI systems.

4 Strategies: How to Account for the Unaccounted

Norms-in-the-loop which derive from contextual, legal and social norms, according to Larsson et al. [11], will directly impact the (1) design, (2) dataset, and (3) personalisation (which they refer to as “in situ"). We sum those three up as follow:

1. **Design**: the developers, those that decide who the application is for and how those will use it, might miss out on key stakeholders or overlook essential needs. This will likely result in the reproduction of unfair norms through design.
2. **Datasets**: how the dataset is collected might overlook the context in which it was collected in and might not fit the context it is used for. The dataset might collect complex social norms that are alleviating shortfalls of current legislations, or overlook discriminatory social structures, for example.
3. **In situ**: this encapsulates ideas of personalisation of a set application within a specific context (or situation). This notion may still rely on universalisation and stereotypes to develop rather than contextualising actual practices the system is attempting to assist with.



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NHS
https://www.nhs.uk › conditions › being-a-young-care...

Being a young carer: your rights - Social care and support ...

You're a **young carer** if you're under 18 and help to look after a relative with a disability, illness, mental health condition, or drug or alcohol problem.

People also ask

What qualifies as a young carer?

How much do young carers get paid?

What is the legal definition of a young carer?

What is an example of a young carer?

Young carer

A young carer is a young person who cares, unpaid, for a person who has any type of physical or mental illness, physical and/or mental disability or misuses substances such as alcohol or drugs. The age of a young carer varies between countries. Wikipedia

Fig. 3 Screenshot of a search engine results from typing “young carers" in Google in England in January 2024

We have attempted to exemplify this through a screenshot of a Google search on the term “young carer" (in London, England, in January 2024), see Figure 3. This search alone showcased various norms at play and how those pan out. This demonstrates how digital technologies can be of significant help (or hindrance) for young carers to understand their rights. When clicking the “people also ask" options, the top question was “what qualifies as a young carer". When opening that tab, the highlighted passage stated: “We define a ‘Young Carer’ as anyone aged between 5-17 that is significantly impacted by the diagnosed health condition, disability or substance misuse of a close relative". However, this is factually incorrect, there is no minimum age to be a young carer, and it is once the person is over the age of 18 years old that they do not fall under the scope of a “young carer" according to the applicable laws in the UK. Regarding the tab “how much do young carers get paid", the answer stated is the following: “The Young Carer Grant is a payment of £359.65 from Social Security Scotland. It’s paid once a year to carers aged 16 to 18 years, who do at least 16 hours of caring a week on average, but did not receive Carer’s Allowance or Carer Support Payment". This is something specific to Scotland, and will not apply to young carers in England (where the search was done from). Turning to the tab “what is the legal definition of a young carer?", the answer stated: “A young carer is a person under 18 who regularly provides emotional and/or practical support and assistance for a family member who is disabled, physically or mentally unwell or who misuses substances". This definition is sound and might be helpful to young carers based in England, though overlooks caregiving for a friend. Finally, “what is an example of a young carer", the answer is “He helps his mum with her personal and emotional care as well as doing regular household cleaning, washing up, helping with cooking and carrying heavy shopping bags. He worries a lot about his mum’s health and sits with her to keep her company and make sure she is okay". This is a good illustration of what being a young carer can be like.

From this Google search alone, the dataset was somewhat erroneous and overlooked important legal, contextual and social norms around being a young carer in England. The design may also lead to young people in England thinking that this is legitimate information that applies to them, which could in turn lead to further issues with regards to identification and assessments. This lack of correct norms-in-the-loop for young carers signals that more needs to be done, and more strategies can be devised for young carer to support and/or alleviate their care responsibilities. This can also account for more indirect applications ranging from the actual care to the care receiver to the well-being of other people in their family. Accordingly, we emphasise three different strategies whereby accounting for young carers in the design application and dataset will affect them. We posit that this can be achieved by including young carers directly through, for example, participatory methods. These strategies are possibilities and they may occasionally overlap: (1) strategies designed for institutions that could be adapted to support the identification and support of young carers; (2) strategies for the care receiver to enable AI assisted support; and (3) strategies specifically directed for young carers.

4.1 Strategies based in Participatory Design

AI researchers must include young carers’ own voices when designing and/or evaluating the deployment of AI technology that will affect them. This requires participation of young carers in research. Methods in *participatory* design within computer systems

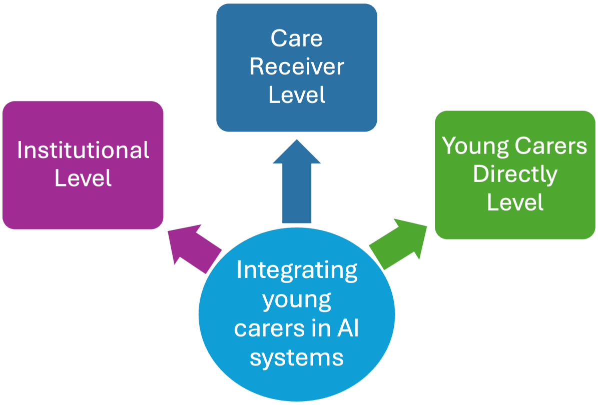

Fig. 4 Three possible ways to account for young carers in AI research

has been put in direct contrast to methods relying on *specialist* knowledge. As Schuler and Namioka explain [89], a specialist represents experts being sought out: the expert provides answers to set questions, and those impacted by the answers are not part of the discussion; whilst in contrast, for participatory design to work, expertise is part of a larger system of sought out information to form an active partnership on how to attempt to solve an issue that will affect that community directly [89, pp.xi-xii]. Participatory design method thus seeks to mitigate adverse applications of AI systems, through the inclusion of various stakeholders – especially from vulnerable populations in society [90].

It is worth pointing out that the young carer research community has identified participatory research as lacking [69, p.86]. Indeed, Joseph et al. in their overview of young carer literature and possible future directions are explicit that active engagement with young carers and their families are needed [69, p.86]. On the other hand, the AI community is already undertaking participatory design research to complexify social issues which AI applications are deemed suitable for. These include workshops with older people experiencing depression and how a robot might help [91]; or evaluating a conversational AI agent for a mental health app targeting stress management [92]; or focus groups with young carers about potential uses of social robots for them [42]. Thus, as a community, we are already equipped with methods which would help further young carer research, as well as ensure that the AI applications account for young carers directly. We should therefore leverage on this strength, and ensure to keep young carers in the loop throughout the research and deployment stage, along with other users/stakeholders This in turn provides safeguard that the technology is fit for purpose.

4.2 Strategies at Institutional Level

At the institutional level, we include educational, medical and social services institutions. All of these have a responsibility in the UK to screen for and identify potential young carers to then assess and decide how these young people can get the relevant help and support. Having responsive institutions to aid with identifying young carers allows for more prevention of (excessive) care responsibilities on young people, though this would need to be continuously reviewed to accommodate for children's change in circumstance which can occur at different points in their lives. This also requires special attention to privacy concerns, and how to address those sensitively. As pointed out previously, being a young carer can have a positive impact on the young person, though this requires the caring responsibilities to not be excessive and their care role to be socially recognised [26]. Disregarding children's care role leaves them unsupported and they fall through institutional gaps (a current issue pointed out by Nordenfors and Melander [48] when there are no regulations in place for young carers). However, over-focusing on young carers role which might undermine family dynamics or that young carers are children and young people first [1]. Accordingly, interdisciplinary research with a whole-family approach is necessary.

Institutions must abide to laws, such as the UK GDPR regarding the data collected on families and children, yet balance that with their duty to identify, assess and support potential young carers. AI systems could thus directly aim to help with identifying young carers. Identification within the educational setting could be achieved by directly accounting for a sub-group of young people who are young carers, either through monitoring attendance or to help staff in education navigate how likely a child is a young carer. This would in part support educational staff to recognise potential young carers and help identify the young person – which is an ongoing issue [71]. Or potentially using AI systems to flag students at risk of falling behind academically or socially due to hidden care roles (based on attendance, academic performance, behavioural patterns). These alerts could trigger pastoral follow-ups or support referrals. Medical institutions would likely come directly into contact with the care receiver more than with the informal carer, yet there would likely an informal carer present (even if virtual through texting)– which the AI tool could detect or directly ask who is accompanying the patient. This would align with current AI tool goals to provide comprehensive personalised healthcare (e.g. [93]). In turn this would result in potential young carers being directed to relevant authorities for assessments. Social services conducting assessments could benefit from AI systems to have a whole-family approach and understand different needs across families through more accessible and possibly wider participation in assessments of relatives and friends. This is especially pertinent as there is currently no standard assessment for young carers [74, 94]. To provide support, AI systems could be used within education to provide extra tutoring or help create smart timetables for young carers to manage their homework alongside their care responsibilities – as demonstrated by [42]; within the medical sector, AI systems could be used for relevant information to be given to young carers in a way that is suitable for young people and relevant to the care they provide. Finally, AI systems could provide resources or training for professionals on how to communicate with potential young carers effectively and ethically – this could be from direct input from young carers as well as various types of professionals.

4.3 Strategies for Care Receivers

Care receivers have an established relationship to the informal caregiver, regardless of the reason the person is now in need of care. Hence the critiques from the disability rights scholars on young carer services potentially undermining the role of the parent, even if the parent requires some assistance [12, 13]. Seemingly a lot of the AI healthcare research is being conducted on care receivers, meaning that AI researchers already acknowledge the agency of the person needing care; however, there is not as much acknowledgement of informal caregivers [43]. AI researchers thus need to be mindful of ongoing family and friendship dynamics and the broader cultural issues, in order to help the care receiver and indirectly help the informal caregiver. In practice, this can mean protecting the young person from excessive care responsibilities, but still acknowledging the young person (also as a carer) within AI applications. An illustration of this are rehabilitation games through robots or computer games for care receivers (see for e.g. [95–97]). These applications allow for games to be played between two people, which aid with rehabilitation whilst spending time together. By designing and understanding how to personalise applications directly with young people – the sibling, grandchild, friend or child of the care receiver– it would (1) allow for rehabilitation exercises to be fulfilled, and (2) allow for a close(r) connection beyond caregiving.

Another strategy may also be creating AI applications to help the care receiver manage some of their care needs alone – whereby the care receiver may gain more independence [37], or getting emotional and psychological support through AI systems [98] rather than potentially by young carers. Put differently, AI applications should ensure that they are continuously re-adapting to the individual needs, allowing the care receiver more independence and the ability to decide if they want an informal caregiver to be as present for caregiving purposes. This could support young people in their care role or even alleviate some care responsibilities, through for example, AI systems monitoring the care receiver and alerting if required– such as a fall or incorrect intake of medication. This part is paramount, as various scholars have explicitly studied potential tensions and challenges that arise between the caregiver and the care receiver regarding care responsibilities, which might be amplified through the use of technologies if we do not directly account for the tensions in the design [99, 100]. Consequently, the perspective of young carers would still need to be accounted for, to ensure that AI applications are suitable for the care receiver and informal carer(s).

4.4 Strategies specifically directed at/for Young Carers

The label of 'young carer' is a very all-encompassing category: it can range from children providing care to a sibling who has a terminal illness, to a parent who has an alcohol or substance use disorder for example. Nevertheless, it is unlikely that a young person providing care for a family member or a friend can be eradicated – especially with the ongoing difficulties accessing public services in the UK and the cost of living crisis. Therefore research must also be directed to the young persons that provide care, with a recognition that young carers represent a heterogeneous group. As this paper has set out, there are various difficulties and challenges young carers face, however there is only one study to date that maps out in practical ways how AI applications could directly help young carers [42]. Studies from young carer researchers suggest that young carers want assistance with their care role, but also want assistance so that they can go to school as well as be part of a community [42, 101]. There is another external factor that is worth pointing out, which is that young carers tend to come from poorer socio-economic backgrounds, with higher child poverty reported in that group [30], therefore AI systems should be designed so that they are accessible to all young carers.

The potential applications we provide here take inspiration from current research on adult informal caregivers. For example, Laban et al. [44] used a robot for five weeks with inform caregivers to elicit self-disclosure around emotions experienced, with positive feedback. Or Tixier and Lewkowicz [102] investigated social support older informal caregivers rely on to support them to then discuss how technologies could provide a platform to sustain (and possibly create) these key social relations. These mark potential avenues that are necessary to understand how to support young carers, so that they are/feel more equipped regarding their care responsibilities yet also have more time for themselves, and empower them to decide on what might be best for them.

Furthermore, AI systems can also support young carers in their life as children and teens. For example, the APPG report highlights challenges young carers face around attending school, with higher amount of absenteeism than average (on average a young carer will miss 27 of school days per academic year) as well as difficulties juggling care responsibilities with homework [1]. Accordingly, as AI in education continues to make headways [2], it is possible that there would be useful application for young carers, either for supplementary education through tutoring, or how to balance care responsibilities with schooling. Another use of AI systems could be to aid with social connectivity, beyond social media, to connect young people in similar situations to combat some of the more negative impacts of caring, such as anxiety [27], depression [28] and social exclusion [29].

5 Conclusion

This position paper has attempted to demonstrate the urgency of including an overlooked vital user group, that is young carers in AI research. Young carers represent a subgroup of informal caregivers who are under the age of 18. Through the frame of *norms-in-the-loop* by Larsson et al. [11] within the UK context, we showcased the importance of understanding the context, legal and social norms around being a young carer. We hope this has demonstrated to the wide AI community that we can directly account for the complexity of being a young carer in AI systems – rather than amplify and further current challenges they face. Indeed, rather than continuing to overlook this essential group, we can empower that community, which will require research applications and ethics applications as well as an acknowledgement of the vast and important work already undertaken by many young carer scholars. Young carer research has pointed that young carers, in contrast to other groups of informal caregivers, are likely to be in education, even if they are more likely to face higher absenteeism from school. In comparison to other children, young carers are more likely to live in poverty [30]. Young carers provide important care that, in the UK, has to be legally identified, assessed and supported. This must be recognised by the AI community so that we can design in a way that enables identification and/or support and/or protection from excessive caregiving responsibilities. Though by creating potential AI applications, this should not be used as justifications to cut public services for young carers – they still need physical and emotional support that is beyond current AI applications' capabilities. We have therefore provided research strategies that should be based within participatory design. Those strategies account for young carers either (1) at the institutional level to help with identifying and possibly assessing, (2) indirectly accounting for young carers when creating applications for care receivers, and (3) directly designing AI applications for young carers. This could enable prevention of excessive care responsibilities, but also assess and support young carers to ensure that they are able to put their own needs first.

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Paper IV

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Young Carers on Social Robots: Introducing Teenagers as Informal Caregivers to HRI
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Young Carers on Social Robots: Introducing Teenagers as Informal Caregivers to HRI

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***Abstract*—This paper presents a participatory, qualitative focus group study with 13 young carers – young people between 13 to 18 years old who take care of a parent due to either a chronic illness, mental health problem, or other condition connected with a need for care in Wales and England. We identify and assert young carers as an important, thus far unconsidered, user group in Human-Robot Interaction (HRI). As such, this study is the first to explore this group's unique perspectives, highlighting their lived experiences and perceptions of care robots in the domestic setting. Our findings reveal the heterogeneity of this group, particularly regarding support for their caregiving roles and their ongoing use of technology. While participants saw social robots as having potential, especially for (i) time management, (ii) emotional and (iii) informational support, and (iv) monitoring their parent's health; concerns were raised about issues such as (1) malfunction, (2) limited range, (3) privacy and (4) cost. We distil our findings into some reflections on how future HRI research might better consider this important user group, including some methodological reflections on the practical, ethical and emotional challenges of undertaking this type of work.**

***Index Terms*—Human-Robot Interaction; Informal Caregivers; Teenage-Robot Interaction; Young Carers; Focus Groups**

I. INTRODUCTION

Young carers represent around 6% to 8% of the child population in industrial countries [1], [2]. Young carers are a subgroup of informal caregivers, meaning that they help and/or support a person who is in need of care, which in turn prevents or delays medical intervention and enables that person to remain living at home [3]. Informal caregivers are estimated to provide 80% of all care within the European Union (EU) [4]. They are also deemed to represent an important group for Human-Robot Interaction (HRI) to ensure the successful deployment of robots in the domestic setting [5]. In this paper, we report on a qualitative study conducted in Wales and England with young carers, aged between 13 to 18, designed to gain their insights on how social robots could help (or hinder) them in their care role. We draw our working definition of young carers per the commonly used definition provided by Becker [6]:

> Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has a chronic illness, mental health problem or other condition connected with a need for care, support or supervision. [6, p. 378]

This definition demonstrates that there is some minimal criteria by which one is defined to be a young carer, that is often the *regular* provision of care, assistance or support. Arguably the *impact* of care is also necessary to consider [7]. This is important as the young person might not be the primary caregiver, but will still provide necessary care – For example, supporting a grandparent or parent with dementia [8], [9], or caring for a sibling [10], [11]. Providing care can have a negative impact on the young person, such as higher absenteeism and drop-out rates from school [12], as well as anxiety [13], depression [14] and social exclusion [9]. Research in the UK has also demonstrated a higher (and increasing) poverty rate among young carers in comparison to all other groups of children [15]. However, it is important to note that there can also be positive impacts, such as increased resilience, when care load is not overly excessive *and* is socially recognised [16], as well as increased maturity, closer relationships to parents and feeling more prepared for life (see for e.g. [1, p.3]).

The UK has been hailed as having the most advanced

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legislation and policy in place for young carers [2], [17], with laws for identification and support – which includes preventing such care from occurring (c.f. in Wales [18]; in England [19]–[21]). Yet, many States do not have specific legislation to identify and support young carers [2], [17]. Researchers have warned that this creates a paradox: by not recognising children as carers, it denies their existence and results in children left to care without support [22]. This demonstrates the importance of directly recognising such a group, hence we assert that young carers need to be directly acknowledged and recognised as potential stakeholders in/end-users of socially assistive robots (SARs) – even if we might wish the realities of who does what kind of (informal) care were different. This is especially pertinent as robots are posited for domestic settings (see e.g. [23]–[25]) – a household employing an assistive robot for independent living might also be home to a young carer.

The aim of this paper is therefore two-fold. First, we aim to shed a light on young carers as stakeholders in HRI, bringing their lived experiences, their needs and desires, in their own voices, to the HRI community. Secondly, we distill our results into some initial insights regarding the design of HRI *with and for* young carers, insights which can inform both existent and novel lines of research around HRI for care whilst also contributing to evolving notions of (more) family-centred (social/assistive) robotics [26]–[29].

To our knowledge, this is the first HRI work to specifically engage with and recognise young carers as stakeholders in HRI. The lack of previous research on this topic motivates our explorative approach, whereby we set out to answer the following high-level research questions:

1) Recognising young carers as stakeholders in HRI for care, what are the main points HRI researchers need to know about young carers to accommodate for their role?
2) How do young carers perceive SARs for care? Are they able to identify ways in which such robots might support (or hinder) them in their care role?
3) How can (and/or should) roboticists design social robots with and for young carers?

Working with young carers presents serious challenges both pragmatic and ethical in nature (see more in Section V-C). Accordingly, this study was led by a researcher who was herself a young carer in Wales and therefore has experience caring for a parent and direct contacts with young carer charities.

II. Related work

A. HRI for the Young

Teenagers, specifically, are an under-studied population within HRI studies [26]. Participatory research with teenagers on SARs for mental health offers valuable methodological insights for our work. It also highlights a key potential application of SARs in supporting young carers - specifically in managing their mental health [30]–[34]. Aside from this, previous work has demonstrated that teens' understanding around privacy ought be considered in the domestic setting [35], and that SAR behavioural design choices can influence e.g. user self-disclosure and trust [36].

B. HRI for the Informal Carers

Informal caregivers also represent an under-studied population within HRI studies [5]. In this review, Tanqueray et al. demonstrate that although informal caregivers are not often participants within studies, they are expected to help with the deployment of social robots, either during the study or once the robot is widely available. With exceptions such as [37], very few works specifically investigate how SARs might support informal carers. Those studies that consider both care givers and care receivers have demonstrated that there are conflicting views about how the robot can assist between the care receiver and caregiver [38], [39]. Methodologically, participatory design has been popular within HRI care research to demonstrate the need to complexify and nuance the social context in which developers envisage the robot to be deployed in [40], [41]. It also reflects a mutual shaping approach, that is one which acknowledges that robots will impact the users, and the users should, and will, also directly shape how the robot is designed and used [41], [42]).

Going beyond HRI, we identified two Human-Computer Interaction (HCI) studies relating to applications for young carers. One study investigates the use of a platform specifically for (adult) informal caregivers who provide care for a person living with dementia [43] and how it might be adapted to additionally meet the needs of young carers. Another study with young carers was, in part, concerned with creating a phone application that met their needs, with the aim to provide psycho-social support to promote the mental health and well-being among adolescent young carers [44].

III. Methodology

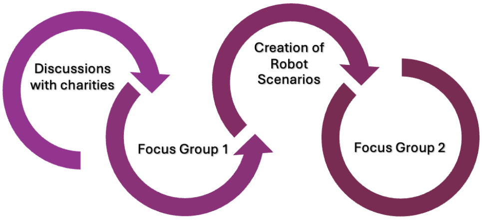

Fig. 1. Steps taken to conduct focus groups and create robot scenarios

We designed a participatory, qualitative focus group study per Figure 1. Participants were invited to take part in two focus group studies (approx. one month apart) which were co-organised with charities. In between focus groups, robot scenarios were created based on the feedback from focus group one, to be used as stimulus in focus group two (as depicted in Figure 1).

We conducted six focus groups in total, engaging 13 young carers and 3 team leaders (adult charity workers) across Wales and England, as detailed in Table I. Our study design was approved by Sweden's national ethics board in addition to the University of Bedfordshire's Institute for Health Research Ethics Committee in England.

TABLE I
BREAKDOWN OF ATTENDANCE OF EACH FOCUS GROUPS

Focus Groups in Wales & England	Attendance
Focus group 1 in Wales	young carers: 3; team leader: 1
Focus group 1 in South West England	young carers: 3; team leader: 1
Focus group 1 in West England	young carers: 5; team leader: 1
Focus group 2 in Wales	young carers: 3; team leader: 1
Focus group 2 in South West England	young carer: 1; team leader: 1
Focus group 2 in West England	young carers: 7; team leader: 1

A. *Study Design: Two-Part Focus Group*

We designed a two-part focus group based study with the idea that each participant would ideally attend both semi-structured focus groups. All focus groups were led by the first author following a topic guide, available in the supplementary material. The first focus group was designed to target the everyday experiences of young carers, whilst also "setting the scene" for discussions about robots by speaking more broadly about digital innovations and their current technology use. This included introducing the participants to four different types of robots using promotional videos available on YouTube: Furhat[1], Double Robot[2], Pepper[3] & Joy for pets[4]. These were chosen to demonstrate different forms (mechanical, animal/human-like) whilst indicating some possible uses and capabilities of SARs. This was based on established methodological approaches using video clips to familiarise participants with robots video clips ahead of more specific participatory design research [40], [41]. We specifically focus on SARs due to their wide range of potential applications in home settings and across various health conditions [37], [39], [45]–[47]. In between the first and second set of focus groups, we created a series of robot scenarios using the Furhat robot (see more under Section III-B). We identified Furhat as a representative SAR that suited the scenarios we wanted to record based on previous work (e.g. [48], [49]); but it was also a pragmatic choice in being the most suitable platform we had access to that supports diverse robot persona design, something we identified as important for our participant pool. The second focus group revolved around exploring these scenarios with the participants. Specifically, the researcher would read out the relevant backstory, show the scenario storyboard, then invite participants to individually write down self-reflections on the scenario. Then, the participants were invited to discuss the various scenarios altogether, with the researcher eventually asking how they would improve the robot and how they might envision the creation of such robots for their own home.

B. *Creation of Stimuli*

Our stimuli take the form of image-based story boards and videos depicting speculative robot-related scenarios, using Furhat robot, that broadly showcase robots: (i) designed directly for/to assist young carers (Scenarios A-B) or (ii) that were aware of the young carer, but primarily designed to assist their parent (Scenarios C-E). The storyboard images were captured in a HRI research lab staged to look like a domestic home environment, with members of the research team playing the role of young carers and their parents. A summary description of all stimuli is given in Table II, and the video clips are available on YouTube[5] whilst the backstories are available in supplementary material. The storyboard scenarios were grounded primarily in existent HRI for care studies, in addition to participant discussions in focus group one. However, given some (unsurprising) participant hesitancy to identify themselves as potential robot users "in need of help," the first author's own experience as a young carer was essential in interpreting and translating these perspectives (see Section V-C). We were cognisant that our scenarios depict potentially real-life scenarios for participants which could be triggering, c.f. a young carer needing to help up a parent who has fallen (Scenario E). We carefully considered how to engage with these situations in a way that minimised distress, for example using humour or demonstrating real-world useful ways/best practices regarding how young carers might cope in difficult situations. For example, results from focus group one indicated some participants found Furhat "creepy", therefore in one of the scenarios, the (depicted) young carer tells Furhat that she still finds it creepy and that it is such a "live, love, laugh" robot (a culturally relevant and contextual joke, meaning that the robot is attempting too hard to be positive and overly wholesome). Regarding the use of robots and potential users, we ensured that the (depicted) parents in the scenarios evidenced both mental and/or physical need for support from the young carer, in order to showcase the different forms informal care can take. Finally, we paid specific attention to the social identities of the robot(s) and the (depicted) young carer, as, influenced by recent works around both robot [50], [51] and user diversity [52]–[55] in HRI, we looked to showcase diversity in name, age, pronouns and appearance.

C. *Participant Recruitment & Collaboration with Charities*

Undertaking this study was only possible due to the willingness and openness of young carer charities to collaborate. These partnerships, established through the first author's network in Wales and England, were essential in facilitating access to participants, providing support throughout the research process, and ensuring the study's relevance and sensitivity to the needs of young carers. Once a charity agreed to be part of the study, clear instructions were given on who could be recruited to participate in the focus groups, such that the charities essentially acted as gatekeepers to participant

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[1] https://www.youtube.com/watch?v=u8u-DbZ1bRg
[2] https://www.youtube.com/watch?v=PtoG_pAX84k
[3] https://www.youtube.com/watch?v=2TcmjL6ZQzc
[4] https://www.youtube.com/watch?v=xHSlqO0F17s
[5] https://www.youtube.com/playlist?list=PLJXcaONWQwuAyblofaitiGURxAXHrhcW_

TABLE II
SUMMARY DESCRIPTION OF OUR STIMULI STORYBOARD SCENARIOS AND RATIONALE BEHIND THEIR DESIGN.

Scenarios	About	Purpose
A. Babs (furhat; she/they) and Hannah (young carer; she/her); video	a snapshot of a therapy-like conversation about Hannah feeling distressed after an interaction with her friends who spoke of their holidays.	A robot specifically for the young carer. Influenced by participants' overlooked emotional needs and Laban et al. [37]'s study of a SARs designed to elicit self-disclosure for informal caregivers.
B. Elsi (furhat; she/they) and Danielle (young carer; she/her); video	Elsi helps Danielle organise her to-do list as well as ensuring that she can spend time with friends, her girlfriend, and have some down time alone.	A robot to be used by the family, which among other things, can help the young carer organise their time. Influenced by the participants' issues around time management and current literature on young carers not having much down time (for e.g. [12]).
C. Moe (furhat; he/they) and Lucy (young carer; she/her); video	A collaboration between Lucy and Moe so that Lucy can go out with her friends whilst Moe monitors Lucy's mum and let's Lucy know if there are any cause for concerns.	A robot mainly targeted for the care receiver. Influenced by participants' worries about leaving parent when the parent is not very well, and roboticists attempt to support (formal) caregivers in monitoring patients without being in close proximity (e.g. [56], [57]) plus some initial HRI work showcasing similar for informal carers [39], [58].
D. Furhat (furhat; she/he/they) and Harry (young carer; he/they); video	Harry wants to have more information about his mum's new diagnosis. He asks furhat which is personalised to his situation and in a language he understands.	A robot that can be used by anyone in the household, though mostly targeted at the care receiver. Influenced by participants' need for knowledge on care receiver's condition as well as by research demonstrating informal caregivers being overburdened with information and not necessarily understanding it [59] and the HCI community's attempt at understanding how to relieve to create easily accessible apps designed for informal caregivers, part of which is accessing relevant information to them in their care role [60].
E. Furhat (she/he/they), Axel (young carer; they/them) and Mum (she/her); storyboard	Axel's mum had a fall. Axel is very distressed and is not sure how to go about lifting their mum. Furhat instructs Axel to ensure that the mum can and should be lifted safely by Axel. Once Axel has lifted their mum, Furhat checks in on the mum, and once the mum has left, Furhat checks in on Axel.	A robot that can be used by anyone in the household, though mostly targeted at the care receiver. Influenced by participants finding themselves in distressing situations and needing to act, as well as literature on young carers demonstrating how young carers tend to overlook their needs and emotions to ensure that they prioritise the person they care for [12], in addition to the previously mentioned robots for self-disclosure work [37].

recruitment. Our inclusion criteria required participants to be formally recognised (by law) as young carers who cared for a parent and were between 13 to 18 years old.

Once the young carers were recruited, participants or their guardian (depending on age) gave informed consent to participate. The study information given at this stage stated that the researcher herself had been a young carer, such that the participants and their guardians were aware of this ahead of time. Practicalities like focus group date, time and location were set by the charities, in order to align with their own events and ensure that someone from the charity would be able to attend. Charity representation in each focus group was essential to ensure ongoing support from a qualified professional if needed. This was particularly important in case the discussions triggered difficult emotions for the young carers, as they might not have felt comfortable seeking help from the researcher. The charity's presence ensured they were fully informed and available to provide appropriate support.

No data on gender, race or ethnicity were collected, for maximum participant comfort and to minimise concerns over confidentiality and align with regulations on data minimalisation. There were eight young carers and three team leaders that attended both focus groups, and five young carers that only attended one focus group (to see a full breakdown, see Table I). Team leaders played a vital role in maximising how many young carers could attend the focus groups, such as organising transport to/from venue. Snacks were provided by the researcher, and one charity provided food for a focus group; otherwise participants were not remunerated in any way.

D. Data Analysis

Regarding the analysis of the focus groups data, we followed a reflexive thematic analysis (RTA), using the five steps for thematic analysis (Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition) [61], [62]. The first author familiarised herself with the data and created memos for the rest of the team to review; this enabled initial coding on NVivo by tagging sections of texts representing key ideas/concepts throughout the data. Through these steps, clear patterns began to emerge across focus groups, and be discussed between authors. This enabled closer investigation within themes, as well as an operative codebook (available in the additional material). The first and fourth author then collaboratively reviewed the analysed data, and re-calibrated if needed, to finalise the themes relevant to this paper. The reflexive part of RTA [62], which was deemed essential, was the constant recognition around the first author's own positionality – which we make clear throughout the paper. This was achieved first after the focus groups directly, through journaling and reflective debriefs with co-authors to navigate potential biases. Additionally, this process served to protect the first author's psychological well-being, as analysing such emotive data - particularly given her own experience as a young carer - could be deeply affecting. To further safeguard her well-being, she also spaced out her analysis over time. Secondly for the analysis, through reflecting on the first author's positionality, authors reflected on potential biases (1) to avoid one's own biases from negatively affecting the precision of the analysis and (2) to leverage on the personal insights the first author had to boost the critical depth of the analysis.

IV. RESULTS

In alignment with the twofold aim of this study, the results are divided into (A) the young carers' lived experiences, and (B) initial insights regarding the design of HRI with and for young carers.

A. A Portrait of Young Carers

Here we try to offer an informative depiction of what being a young carer can look like, with emphasis on (1) family, (2) perception of caring, (3) available help, (4) school life, and (5) technology use. Whilst young carers mark a heterogeneous group, we propose that, given the difficulty of working (safely, ethically and practically) with this population, these depictions might be useful for developing realistic stakeholders personas [63] that can be considered during early stage research/development of HRI/robots for care in domestic settings.

1) Family Dynamics: Participants' family life varied. The majority of participants who spoke about having a sibling mentioned that they took care of that sibling as well as their parent. Few participants reported having a sibling who also engaged in care work. Participants spoke of parental figures and/or grandparents helping them directly with their care responsibilities (e.g. driving the parent to appointments as most participants were too young to be able to drive). We did not collect specific data regarding who lived with them, however, some participants openly spoke about having another (step-) parent or sibling living with them that could (though might not) help; if at-home help was not available, there was typically someone else (e.g. a grandparent) the participant could turn to. Though our participants take care of their parent, they also discussed more prototypical parent-child interactions through which their parent cared for them, e.g. their parent trying to protect them from harm, or being an important port of call when they were feeling overwhelmed.

2) Young Carers' View of Caring: On opening the focus groups, participants were asked to describe what caring meant to them. *Unpredictability*, *stress* and *responsibility* were recurrent words. All agreed that their care role was unpredictable, at times quite stressful as they worried a lot, and that they felt more responsible than their peers. They all viewed being a carer as nuanced, as described here:

> Well it's 50/50, like… it's stressful in some way, but it is rewarding in one way knowing that in the end, I know my family is okay and I know that they are taken care of.

Participants reported a lot of responsibilities, some of which included medication management, physically assisting their parent (either lifting after a fall or supporting a change in position) as well as emotional support and everyday chores (such as cleaning and grocery shopping); these responsibilities significantly reducing how much time participants have for themselves. Participants described ways in which they seemingly tried to make up for this by acting "more like teenagers", e.g. purposely going to bed later to try and do something for themselves, such as drawing or playing video games or scrolling on social media.

3) Availability of Help and Support: All the participants were formally recognised young carers, however some participants did not feel that the support associated with this recognition was necessarily helpful for them. Participants discussed the importance of charities (somewhat indirectly at times), mentioning social activities (including e.g. axe throwing and the annual Young Carer Festival) in addition to more targeted support like one-to-one emotional help. Some of the participants mentioned schools having dedicated young carer groups, although most participants did not attend such groups. The majority of participants felt that they could not turn to their non-young carer friends for support.

4) Young Carers' School Life: School was a very important aspect of the participants' lives alongside their caring responsibilities. Most of the participants still attended school (n=11); however two participants dropped out of school at the age of 16 due mostly to their care responsibilities. Five participants, all of whom were yet to sit national school exams, spoke about their low attendance at school due to caring responsibilities or worries about their parent's health. One of these participants specifically discussed missing half of the entire school year when she was 12-13 years old. Participants that had sat national exams did not mention issues with attendance but did discuss their difficulties engaging with school work and balancing it with their care load.

5) Young Carers' Use of Technology: All participants had a smartphone and a television that had access to streaming services; most had a laptop/tablet, some also had virtual reality glasses and game consoles and most (n=10) had Amazon's Alexa dotted around the house. Out of those that had Amazon's Alexa, a subset used it in some care capacity (n=4) mostly for checking in on their parent via Alexa's intercom function. One participant described how they have stopped using this as the Alexa did not seem to be broadcasting messages anymore, so they had reverted to using mobile phones in order to avoid incidents. Younger participants mentioned that their parents often check-in to know their whereabouts via smartphone applications, such as live 360 and Snapchat; and most participants mentioned staying in touch with their parents throughout the day via their phones. Participants described using Google, YouTube and TikTok to gain more information on their parent's (and sometimes sibling's) condition, typically trying to understand if the condition is getting worse, how best to help or how to calm the person down. One team leader asked if the participants knew of an app for young carers specifically, none did, and none of the other focus groups mentioned such an app. The participants also described using

Instagram, YouTube, TikTok, Netflix and Spotify in the context of having some "down time".

B. HRI With/For Young Carers

In line with our aim of demonstrating how HRI can directly cater to young carers' needs, we report on (1) initial ideas of possible tech for young carers, (2) initial reflections on robots (derived primarily from focus group one); then on (3) reactions to our scenarios; (4) roles for robots; and, (5) assistive robots for the home (derived primarily from focus group two).

1) Participants' Initial Ideas: Before any promotional videos of robots were shown, the researcher asked how future technology (of any kind) could possibly help with young carers' caring responsibilities, prompting participants that "*this can be very futuristic! It can range from a young carer influencer, to an automatic robot peeler if you think that would help!*". In every focus group, everyone agreed on influencers, all of them discussed that it would normalise young carers and give them representation they can look up to. Some participants identified the potential for a device with lots of up-to-date information. One young carer rebutted ideas of robots by saying "*A robot can't really do as good of a job as humans, no matter how much you program it*", and one team leader from another focus group announced "*Nobody wants robots!*". The other participant groups did not mention robots.

2) First Reflections on Robots: All but one of the promotional videos shown during focus group one demonstrated robots in some sort of care setting, but they did not include any depiction of young carers. When prompted to talk about whether these robots could be useful, some participants (n=4) discussed the benefits of having a robot cleaner. Most often however, these discussions of how robots might help ultimately always centered around the care receiver rather than the young carer themselves. Participants seemingly struggled to see how such a robot could help them specifically, as they perceived themselves as having the required skills to take care of their parent. Most participants raised and queried potentially negative consequences of robot deployment. Notable topics included (i) the potential for robot malfunction, which might result in the young carer needing to provide emotional support to their parent/sibling, as the robot would be "dead", (ii) a worry about robot omnipresence ("*probably should only be there when it [robot]'s needed. And if it's not needed, it's probably going to be like an annoying family member*") and (iii) a worry that a robot would only be available at the expense of other, much needed resources the care receiver requires/would benefit more from.

3) Participants' Reactions to Our Scenarios: Participants initially found Furhat to be 'creepy', yet from their individual written responses, the vast majority saw ways in which the robot might be useful to them:

> It looks very helpful, even though it's creepy it would definitely help out with things at home if we had a schedule fast like Elsi created for Danielle.

Only three participant responses included negative concerns at this stage, one discussing whether 'googling' might be faster (though he later crossed this out), one discussing whether search results coming from the robot might be distressing, and one questioning whether the robot might be too far (physically) from an incident to be able to provide help.

A number of participant responses also served to validate our scenarios, as participants suggested that they could directly relate to/would directly benefit from those depicted events. For example, regarding Scenario E (dealing with a fall), one participant wrote *"I'm not alone in that situation"*, and another wrote *"As I've been in a similar situation, I think it would be really nice, as trying to figure out what to do can be very stressful. It would be very useful having someone always able to help."*. Similarly, for Scenario A (the therapy-like robot-young carer session): *"Good to offload – no judgment, no interruption :); Nice to trust somebody/something*" and *"I would love this. There are some days where I just can't with things, so it'd be really nice to have a robot take care of it for me. and cheer me up."*.

On the other hand, team leaders expressed more concerns about robots in their written feedback. Two team leaders pointed to the robot-young carer interaction in Scenario D (giving information about parent's condition) as potentially problematic; they identified how some conditions might be a lot more traumatic, and question whether the robot should alert parents to let them know what the young carer was asking about, as one team leader wrote *"Know [young carers] worry about parent worrying about them so unlikely then to ask*". This raises issues of privacy, information access and safeguarding – an issue that one team leader also referred to in the context points out in scenario A.

4) Participant-Identified Roles for Robots: In focus group two, contrasting with focus group one, participants discussed the robot much more with respect to how it might help (or not) themselves or other young carers, rather than focusing so much on the risks/opportunities for care receivers. Participants often intertwined their ideas about the robot with their own experiences of those situations depicted in the scenarios:

> It just looks really good for stress relief while I'm out, because I could call her [parent] right now and she'd probably not answer because she's asleep, but I don't know that she wouldn't answer because she's asleep. It could be something much worse. So having someone else there to always check on her would be really nice. So it looks good!

Regarding scenarios that were more orientated towards the care-receivers, young carers pointed out that the information that the robot would give would be essential. In the example of explaining a condition (scenario D), some participants mentioned that searching on google about their parent's (or sibling's) condition(s) or symptoms often led to distressful results, therefore having a robot to explain in a way that is adapted to their level of understanding would allow them to know if there is cause for concern. Regarding scenarios that were more orientated towards the young carers, participants appreciated that it would help them in some way. For example, in scenario B, where the robot directly creates a timetable for the young carer, most participants mentioned how they would hugely benefit from such help. Some pointed out that it would take some stress away and allow them to spend more time with their parent, whilst others said it would help them better balance their care responsibilities with school work; though some were worried it would not work due to the unpredictability of their care role.

Overall, participants seemed to particularly appreciate the emotional support the robot brought throughout these scenarios – either directly, in providing a safe and supportive space to speak freely about their worries, or indirectly, e.g. where the robot was primarily supporting the care receiver, but kept the young carer in the loop, by supporting them in getting information and understanding better how to deal with the condition or/and situation. Here, one team leader pointed out the importance of ensuring that the parent keeps their role as parents. Thus, though our young carer participants viewed the robot as enabling more free time between themselves and their family, one team leader was sceptical that the robot might at times override decisions made by the parents – which should not be the case.

5) Helpful HRI for All in the Domestic Sphere: The final part of focus group two was designed to understand how participants might change our robot stimuli scenarios and who else should be considered. Something to note is that after engaging with these scenarios, the young carers were not as 'creeped out' by Furhat, and found it useful. This mirrors previous results regarding the way this form of participatory design work can positively influence robot acceptance [41]. Participants all voiced that they should be part of the design process, but so should be the rest of the family – including siblings that might not be involved in caregiving. They saw potential in the robot as a device that would listen, wait their turn, and give emotionally supportive and/or informational feedback. Some expressed concern that the robot might be too positive at times, so adaptability to the young carers needs would be crucial – sometimes they might not want/need to hear positivity. Furthermore, having the robot personalised to individuals in the household would allow for the robot to adapt its language to the user (including the spoken language itself). This was important as all participants found the voice to be, at times, too robotic, which could be jarring when the young carer is seeking emotional support.

Two focus groups raised concerns about the robot's range in terms of its physical abilities, sensing capabilities, and interaction potential, noting that Furhat is stationary and unable to move around. They expressed that pairing it to an Amazon Alexa speaker might help to ensure young carer can still get feedback from the robot in a different room and keep the price low of this technology. However, issues arose about recurrent power-cuts in their area, which would likely impact the robot's connectivity – this could potentially cause more distress to the young carer, especially if they have left the house. Issues were also raised about privacy and the amount of data the robot has access to, as well as what the robot does with the information that the young carer discloses, as sometimes it is just to get something off their chest and they would not want that information to go anywhere. But as a team leader points out, the robot should not be able to keep 'secrets' if the young carer is in danger. Additionally, there were worries around how much extra labour it might cause – e.g. around keeping the robot charged or needing to physically move it around the house.

V. DISCUSSION

A. RQ1: Young Carers are Stakeholders in HRI for Care

The participants were a heterogeneous group with differing needs, family dynamics, and experiences related to school and support. However, there were clear themes that directly echo young carer research, such as the young carers putting the needs of care receivers before theirs and constantly worrying about their parent's health [12], [64]. This should not be underestimated by the HRI community. As we attempt to deploy SARs into the home, we need to account for who else is in that setting, and how they are likely to be impacted by technology as well as how they could also be directly catered for within that technology – resonating with the concept of mutual shaping and participatory design as needed research methods for successful HRI [40]–[42]. Simply accounting for young people in the domestic setting is not enough. For example; Levinson et al. [35] found that there should be careful consideration between level of authority and responsibility a robot has versus for a parent – this does not apply in the same way to young carers. Indeed, as the results have pointed to, young carers are used to taking on responsibilities, and the robot's authority might help young carers make decisions that include their own well being as well as the care receiver's.

Young carers should be viewed as a specific stakeholder population with their own needs – they are neither prototypical young users nor prototypical informal carers. HRI researchers have already pointed out tensions between care receivers and (adult) informal caregivers [38], [39]. One of the biggest difference between young carers and their adult counterparts is that young carers are still in need of age appropriate parental support, something evidenced in our results where we saw discussions around the importance of recognising and maintaining parents' role as parents. SAR design and application would therefore need to reflect the fact that a child helps take care of that said parent but the child-parent relationship is essential to the development of the young person. This requires different conceptualisation of applications than adult informal caregivers. An example in this study, team leaders were cautioning against certain applications that young carers found useful – this already demonstrates that there would be tension on what should be available to young carers, who should be alerted, and how to ensure the parental role is at the full front (this might not be required for adult informal caregivers). This also mirrors ongoing young carer research that there must be a whole-family approach, in that we must account for everyone's need in the family ecosystem to ensure sustainable solutions [65]–[67].

B. RQ2: Young Carers' Perception of HRI for Households

An important finding for HRI was the digital literacy of the participants: all use technology to some extent. We might also speculate that it would be young carers who would end up using, programming and maintaining in-home SARs. Given the participants' positive responses to our stimuli, there is both a clear need and an opportunity for design and application advancements within the HRI field. Our participants felt that having a robot in the household would mean that is has to be adapted to their family – something which HRI is already promoting [26]. Participants viewed robots as a device that would allow personal emotional support and help with time management on one hand; and on the other support them in their care role through getting instructions and information from the robot about the person they care for – which in turn would provide emotional support as they better understand the situation. This demonstrates two important facets (1) robots helping the care receiver is useful for the young carer too, and (2) the robot's monitoring allows for respite for the young carer. This also indicates the necessity for SARs to be well adapted to care receivers, whilst also including informal caregivers, to ensure a successful deployment. If this is not taken into account, there is a high possibility that robot deployment would aggravate young carer's worries and stress about the care receiver's health. Although important concerns were raised, such as privacy and who should be able to access information – a point that was not aligned with team leaders' safeguarding views – there were also worries around malfunction, price and the proximity of the robot to incident (i.e. if the robot is too far, it cannot help) that ought be considered and subject to risk assessment/mitigation for in real-world deployments/studies.

C. RQ3: Methodological Reflections for HRI Design

Whilst we are excited to help the HRI community better see and understand young carers, we also want to note the difficulties of undertaking this kind of work. It required the researcher to be part of the community and work flexibly yet proactively with the young carer charities. Her explicit experience as a young carer was also key to gain trust from the participants over the two focus groups. This was indispensable to using the participatory design approach, as it meant that the participants felt comfortable sharing about their experiences of caring and how technology might be of help. Showing robots to this community could easily be received as being tone-deaf to their lived realities: they speak about real-life, at time difficult to navigate, everyday experiences, bringing in a robot at a prototype stage will not help solve those issues. Being aware of that, and seeing the participants' somewhat reluctance to think of how the robot could help them in focus group one, the researcher drew on her own experience and research knowledge when producing the stimuli for focus group two, acting as an intermediary between what young carers openly spoke to her about with their worries (e.g. lack of time to themselves) and possible HRI applications. This produced clear storyboard robotic applications that would relate to young carers in some way. This was highly appreciated by the participants, with some pointing out how relatable or helpful these applications could be for them.

A final methodological point concerns the significant resources required to conduct this research. To ensure the venues were accessible and participants could fully engage in HRI, the researcher travelled across England and Wales, incurring considerable costs and time commitments. Furthermore, there was an emotional cost, such as the researcher having been in many of the situations participants described, and using that experience to provide reassurance to the participants. Yet, these were difficult moments in her own life. To mitigate risk, clear procedures on taking care of herself were put in place ahead of the focus groups. It is for these reasons that, whilst we want to see more consideration of young carers in HRI, we might suggest e.g. (re-)use of our storyboards, available with this paper, and/or e.g. using our results to develop user personas to reflect on the robot design/deployment, before going directly to young carers.

VI. CONCLUSION

Young carers represent an important user-group, but have currently been overlooked within HRI research. We hope that this explorative participatory design study demonstrates both the need and opportunities that recognising young carers could bring to HRI research. Particularly, we call attention to considering a family-centred approach to (care) robots in the domestic setting, whilst also understanding how to help young carers in their care role and beyond. We also see positive design opportunities for robots which might help with participants' own time management and emotional support, whilst also helping with informational support, instructions and monitoring care receiver's health. However, we also highlight concerns around privacy and potential robot malfunction, cost, and range, in addition to the ethical and practical challenges of working with this important user-group.

A. Limitations and Future Research

Our sample size was relatively small, with unexpected drop outs last minute. This highlights the inherent unpredictability to young carers' care responsibilities. Only teenagers taking care of a parent were part of this study, which is not representative of all young carers. Furthermore, feedback was only provided on speculative scenarios on a specific SAR and from the young carers' perspective (for the most part). Future research should aim at multi-stakeholder design sessions to gain more insights into families' perspectives and the ways in which different family members might be in tension or agreement with regards to different care robots in the home.

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Appendix

Appendix A: Structure of Focus Groups with Young Carers

Structure of the Focus Group Study

The data collected for this study is primarily from focus groups, as well as (optional) photo diary with young carers.

The focus groups are semi-structured, this has two consequences: (1) it keeps a similar structure for all focus groups regardless of age groups, (2) it allows young carers to bring up other topics they feel is important for this study.

[Estimated time for each focus group will be around 90 minutes]

Focus group 1:

Introductions and Explanations:

Around 10 minutes

- Remind young people who I am and what the study is about
- Introduce the staff member and explain their role in the group
- Thank the young people for taking part
- Revisit information from assent/consent sheets, answer any questions and confirm ongoing assent/consent (consent from parent/legal guardian will have been checked prior to meeting)
- Explain that it is okay to take a break, not answer a question or leave the group if they want to
- Show them the audio-recorder and confirm their understanding of why I will be recording the meeting (Spend a few minutes talking about general things to help them settle and feel more at ease. Give out sticky labels and ask them to write their name on one. Explain ground rules, e.g. confidentiality, turn-taking etc)

PART 1: SPECIFICALLY TARGETED AT LOOKING AT SOCIAL NORMS, LEGAL NORMS AND STIGMA.

(Place large sheet of paper and lots of coloured pens on table/floor in centre of group)

Around 20 minutes

1. *(to be used for breaking ice purposes too*) Can you write down what words you would use to describe what being a young carer means to you, what words would you use?

(Prompts: if you were trying to explain to someone what a young carer is or does, what words would you say?)

(Take time to compare notes)

2. Has being recognised as a young carer helped you in any way?

(Prompts: since being assessed as a young carer, do have you had more support? Do you get more respite/time for yourself?)

3. How do you feel about being a young carer?

(Prompts: what comes to mind when you think about yourself as a young carer)

  a. What are the good things about being a young carer?

(Prompts: anything you enjoy? Feel good about?)

  b. And the not so good things?

(Prompts: anything you find difficult? Struggle with?)

4. How does being a carer affect your everyday life?

(Prompt: school, hobbies, friendships)

  a. Are there instances where being a young carer has had some impact?

(Prompts: can be good/bad, at school, home, at the shops, at the GP or hospital visits for eg)

Take a break! *If not before, or if another is needed.*

10 minute break.

PART 2: BRINGING IN DIGITAL TECHNOLOGIES AND THOSE HELP YOUNG CARERS

(Place new large sheet of paper and lots of coloured pens on table/floor in centre of group)
Around 20 minutes

5. What type of digital devices do you use in your everyday life?

(Prompt: can be smartphones, or smart TVs, smart anything! Or something that connects to the internet)

  a. Do you use any specifically for your care responsibilities?

(Take time to compare)

6. What type of app or websites do you use to help with your care responsibilities?

(Prompts: With regards to helping you in your own role as a young carer)

  a. Where do you look to learn how to do certain things for your caring role?

(Prompts: could be videos on how to lift, or watching videos on your parents' condition)

  b. Do you find ways to cope with being a young carer on certain apps or websites?

(Prompts: watching certain influencers, watching certain types of reels/TikTok or YouTube videos)

7. Can you think of ways technologies could help you more in your everyday life for your caring responsibilities?

(Prompt: this can be very futuristic! It can range from a young carer influencer to an automatic robot peeler if you think that would help!)

PART 3: FOCUSING ON SPECIFICALLY ON ROBOTS

(Introduce very briefly socially assistive robots in care, through a small presentation of the robots themselves and enacted scenarios of socially assistive robots in care). *This last part is to plant a seed and collect initial reactions.*
Around 15 minutes

8. Would you like such robots in your house?

(Prompt: if you could have any robot shown, would you like to have it?)

9. How do you all feel after seeing socially assistive robots?

(Prompts: from short video/images you just watched)

10. Do you think that it could be helpful for your own care role?

(Prompts: could it have a positive or negative impact for you as a young carer?)

11. What special features would you like a robot like this to have in the future to help you with your caring role?

(Prompts: should be friendly to you as well as your parents? Should help you and not just your parents? Should be a bright green colour?)

   a. Would you like the robot to do certain jobs or tasks?

(Prompts: in the videos the robot can help with monitoring everyday health or help with appointments, would that be useful?)

   b. Are there certain tasks you would not want the robot to help with?

(Prompts: so the other way around, maybe you wouldn't like the robot to monitor everyday health or help with appointments, any other?)

FINAL ACTIVITY:

Around 10 mins

Write a postcard that will be anonymous and write things that came to mind during the session, but you didn't want to share or share something about the focus group generally.

Ending focus group 1:

Around 5 minutes but ensuring that the photo diary is well understood and the participants have my phone number.

- Thank them for taking part and see them next time!
- Check each young person is okay (provide support organisation details as required)
- Explain the photo diary, and that it is optional
- Take time to write out my number for participants to send me their photo diary
- Show example of a photo diary if requested
- Explain the next focus group
- Explain what I will do with this information and create scenarios more adapted to young carers and what they have told me
- Spend a few minutes bringing the conversation back to general things – (e.g. what are you going to do now?)

Focus group 2:

For this focus group I expect a lot more natural discussion, partly because (a) we now know each other and (b) because it is about something quite novel. Therefore, this focus group has less questions but could mean that the participants take longer to answer these. Furthermore, answers from the previous focus group might create new questions.

Introductions and Explanations:

Around 5 minutes

- Remind young people who I am and what the study is about
- Introduce the staff member (if changed) and explain their role in the group
- Thank the young people for taking part again
- Revisit information from assent/consent sheets, answer any questions and confirm ongoing assent/consent (consent from parent/legal guardian will have been checked prior to meeting)
- Explain that it is okay to take a break, not answer a question or leave the group if they want to
- Show them the audio-recorder and confirm their understanding of why I will be recording the meeting (Spend a few minutes talking about general things to help them settle and feel more at ease. Give out sticky labels and ask them to write their name on one. Explain ground rules, e.g. confidentiality, turn-taking etc)
- Check in since last focus group
- Explain what has happened since last met.

Focus Group Questions:

(Place large sheet of paper and lots of coloured pens on table/floor in centre of group)

PART 1: REFLECT ON THE USE OF ROBOTS IN CARE FOR YOUNG CARERS

Around 20 mins

1. Since our last focus group, have you had more thoughts/ideas on whether having a robot could help you as a young carer in some way?

(Prompt: could it help you have different relationships to your parents, professionals, friends?)
As they have had time to reflect, take more time here

a. What do you think about using robots to support you?
b. How could a robot help you with your care responsibilities?

2. Do you think the robot could affect your role as a young carer?

(Prompt: could it challenge what it means to be a young carer? Would you think it could help you?)

PART 2: SHOW SCENARIOS OF ROBOTS FOR YOUNG CARERS AND REFLECT PERSONALLY FIRST THEN IN GROUP

Around 40 mins

(Present videos scenarios, allow young carers to write words on big piece of paper whilst watching)

After each video:

3. Can you write down what words you would use to describe what seeing a social robot adapted to young carers means to you, what words would you use?

(Prompts: any words that come to mind after watching the new scenarios)
(don't compare notes yet)

After watching all the videos:

4. How do you feel after seeing these scenarios?

(Prompt: own feelings about seeing social robots in your own environment)
(Now compare notes)

5. Generally, what do you think of these new scenarios for young carers?

(Prompt: would it benefit/be detrimental to young carers?)

Take a break! *If not before, or if another is needed.*
10-minute break.

PART 3: UNDERSTANDING AT WHAT POINT THE YOUNG CARERS COULD BE INVOLVED IN THE TECHNICAL PROCESS OF HAVING PERSONALISED ROBOTS

Around 20 mins

6. What improvements would make to this robot better?

(Prompts: how could you make it better for yourself as a young carer?)

a. Would you like to be part of creating the robot to help with your caregiving responsibilities? If so, how would you envision that?

(Prompts: what do you want see the robot helping you with? Would you like to help train the robot alongside your family? Or do it alone first and then all come together for example?)

b. Would you like the robot to help train you to do your caregiving responsibilities?

(Prompts: the robot could show exercises and describe them as you're trying to do them)

7. Would you change something about the robot to help you better with your care responsibilities?

(Prompt: monitor your parents health, support your parent emotionally)

FINAL ACTIVITY:

Around 10 minutes

Write a postcard that will be anonymous and write things that came to mind during the session, but you didn't want to share or share something about the focus group generally.

Ending focus group:

Around 5 mins

- Thank them for taking part!
- Check each young person is okay (provide support organisation details as required)
- Spend a few minutes bringing the conversation back to general things – (e.g. what are you going to do now?)

Appendix B: Vignettes/Backstories used for Focus Groups with Young Carers

QR code to Robot Scenarios

Backstory of the scenarios

[Each backstory is attached to a specific scenario. First read through the backstory then show video or storyboard. Then leave time for participants to write reflections in blank spaces.]

Elsi (she/they) & **Danielle** (she/her)

4 minute video

Danielle is currently in her first year of A-levels, has a job cleaning dishes on weekends according to her availability and cares for her mum. Her mum has physical and mental health related problems, so her caring role is quite unpredictable. Danielle finds herself paralysed at times by how much she has to get done and doesn't find time to ensure that she can meet with friends, her girlfriend and still find time for herself.

Elsi, the household Furhat, helps with admin for anyone that needs help at home. Danielle has decided to turn to Elsi to help her create timetables. Those vary from week to week but also keep tabs on upcoming important events. This allows Danielle to be aware of short-term plans, medium-term plans, and long-term plans. Although, she doesn't really get how at 17 she would have a clue about long-term plans, but for now, she just wants to find a way to put some order to things.

Furhat (she/he/they), **Axel** (they/them) & **Mum** (she/her)

Storyboard

Mum, the care receiver, has a Furhat for herself, although it has also been programmed for people who care for her, such as Axel the young carer. Furhat has mostly been used to help manage the mum's mental health. However, today, Axel's mum unexpectedly falls.
This is unusual, and Axel does not know what to do or how to go about it.

Moe (he/they) & Lucy (she/her)

2 minute video

Mum, the care receiver, has been having some bad few weeks. The new medication she has been prescribed has had an impact on her mental health as well as her physical health. The last couple of days, mum is starting to get better.

The young carer, Lucy, has been invited to go out with friends – after already having to cancel last minute due to needing to care for her mum – so she is not sure if she should go.

Lucy asks Furhat, named Moe, what the latest data on her mum's health might mean, and whether she could actually spend time with her friends today.

Furhat (she/he/they) & Harry (he/they)

1 minute 30 video

Harry's mum has recently been diagnosed with a new physical condition named asthma. Harry doesn't really understand what that would mean and if he should be worried. Although his mum just told him as a passing comment and she seems upbeat, he's guessing it's probably not much, but he doesn't really know. So he turns to Furhat to ask.

Babs (she/they) **& Hannah** (she/her)

3 minute 40 seconds video

Furhat has been programmed to help with self-disclosure for young carers, as a way to help speak through everything. This can vary from things happening in school, or at home, or anywhere!

Hannah has a dedicated Furhat she calls Babs – short for Barbara – as it acts as her 'wise older friend'. Hannah is still unsure if she can call Babs a friend, and she's still unsure if she should tell Babs anything. But on days it gets too hard to cope and Hannah doesn't have the energy to hear "oh your life must be so hard" or "but why do you have to do that", she turns to Babs. Today is one of those days.

Berty (she/he/they), **Clara** (she/her) **& Dad** (he/him)

Storyboard

Furhat, Berty, welcomes all the patients at the GP practice. They have been programmed to ask not only who the patient is, but if they are bringing anyone else in today and who that person is in connection to the patient. It happens that today, Clara is with her dad to go to his appointment, but she's not usually with him.

Appendix C: Storyboards used for Focus Groups with Young Carers

Axel’s mum fell, she calls out for Axel to come and help.

Axel tries to help, but feels too distressed, so they call out to Furhat to ask for help on what to do.

Furhat explains how to check whether it is safe for Axel’s mum to get up.

Furhat explains the position Axel needs to get their mother in, to then be able to lift her in a way that won’t hurt Axel’s back.

Axel and their mum are now sitting down, whilst Furhat assesses the mum to decide whether to schedule a visit to the doctor’s.

Furhat checks in on Axel once alone to ensure that Axel can speak about what happened and speak of the emotions they felt.

Berty asks who Clara is. After answering that she is her dad’s daughter, Berty asks if she helps care for her dad. Clara says yes.

During the consultation, the doctor is notified that Clara is with her dad and that she likely provides care.

When the doctor asks the dad to get on the examination bed, Clara instantly goes help him.

The doctor asks Clara how much care she provides and what help she gets.

The doctor makes a note to ask for Clara to be assessed as a young carer.

Artificial intelligence (AI) for health care is often framed as the solution to the care crisis that is fast approaching. With the boom of AI technologies, such as ChatGPT and DeepSeek, it seems likely. Yet, this projection overlooks an important stakeholder: informal caregivers.

Whilst on the one hand, AI-driven technologies are painted as the solution for care receivers' needs as well as healthcare professionals' duties to be fulfilled; on the other, there is an already increasing responsibility on informal caregivers to help alleviate responsibility from States. The two issues should not be separated--though they currently are for the most part. The two issues instead need to be studied together. This becomes a question of reframing the current discourse around AI-driven technologies in order to account for informal caregivers. This thesis stands at this intersection by investigating informal caregivers in AI research. Put differently, this thesis looks into the development of AI-driven technologies, by investigating the inclusion of informal caregivers.

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