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Tanqueray, Laetitia; Larsson, Stefan; Winkle, Katie

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PO Box 117
221 00 Lund
+46 46-222 00 00

In Search of Informal Caregivers in HRI: Situating and Disentangling Practices concerning Robots for Care within the HRI Conference

Laetitia Tanqueray^{1*}, Stefan Larsson¹ and Katie Winkle²

^{1*}Department of Technology and Society, Lund University, Lund, Sweden.

²Department of Information Technology, Uppsala University, Uppsala, Sweden.

*Corresponding author(s). E-mail(s): laetitia.tanqueray@lth.lu.se;
Contributing authors: stefan.larsson@lth.lu.se; katie.winkle@it.uu.se;

Abstract

Despite the acknowledged significance of informal caregivers in health care generally, it remains unclear whether and to what extent the HRI community accounts for informal caregivers. Accordingly, this article provides a systematic review of 52 articles, published within the ACM/IEEE International Conference on Human-Robot Interaction (2006-2023), to situate informal caregivers in health care within the Human-Robot Interaction (HRI) community. This study relies on a theoretical lens – deriving from Feminist HRI and Social Justice-Oriented Design – and qualitative methods to showcase four dimensions on how informal caregivers are, *or not*, being investigated in comparisons to other stakeholders within health care in HRI. These dimensions focus on (1) how the study is motivated, (2) who the study includes, (3) the methods used in order to answer this aim, and (4) how much caregivers are accounted for. The results point to informal caregivers only being participants in eight studies, yet are not mentioned in 15 studies, which does not echo their societal importance and our reliance in HRI on that group. We discuss our findings and provide five high-level recommendations based to account more for informal caregivers in HRI.

Keywords: HRI, Health Care, Informal Caregivers, Critical Systematic Literature Review, Social Justice, Feminist HRI

1 Introduction: Informal Care and HRI

Informal caregivers have been named by the United Nations as “co-producers of care services” [1], 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” [1, p.2]. In practice, this means that it is estimated that 80% of all care within the European Union (EU) is provided by informal caregivers [2], and although the exact number is not known around the world, it is most often informal caregivers providing the bulk of the care [3]. This can be explained in part by Western nations “shifting responsibility of care from the state to the voluntary and informal sectors” [4, p.2], meaning that care is being deinstitutionalised and informal caregivers are being more and more relied on. Looking more closely at the figures, in the USA, it was estimated that around 21% of the population were informal caregivers (with around 5.7% of those caregivers being under 18 years of age) [5], a similar number to the EU [6], Israel and Canada [7]. This number is slightly lower in places such as India and New Zealand (around 10%), and 5% in Japan, possibly due to varying definitions of what an informal caregiver is/does [7]. Carers UK estimates that two out of three people in the UK provide informal care at some point in their life [8]. Evidently, informal caregivers are crucial to real-world care delivery, and ought hence be considered within human-robot interaction (HRI) research relating to care. With this review, we seek to situate informal caregivers in HRI studies and disentangle them from other key stakeholders within health care, namely: care receivers, formal caregivers, control groups, and other experts. We mostly focus on providing comparisons between informal caregivers and formal caregivers.

We take our working definition for “informal caregiver” from that of Royal College of General Practitioners [9, p.1] 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 [5, 10, 11]. Furthermore, our definition of health care goes beyond that of institutions, such as hospitals or care homes and formal diagnoses of particular diseases or medical (in)capacity, which is why 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 aging and/or long term health issues. We exclude general childcare, but include situations of informal (health) care provided by parents/guardians in line with the definition given above (“parent carers” being a recognised group within the informal care literature [12]).

The main aim of this study is to identify and synthesise how informal caregivers are included and/or positioned, if at all, in HRI studies on health care. We do so by comparing and contrasting works which do and do not specifically target/include informal caregivers compared to formal caregivers and care recipients. We pursue this

by conducting a systematic literature review 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 practice [13–16], we suggest that the highly selective nature of the conference (acceptance rate typically 25% or less) suggests work published at the conference is considered high quality by the community. We would also suggest 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.

This comparison is led by a theoretical lens, namely from Social Justice-Orientated Design [17] and Feminist HRI [18]. This lens allows us to reflect and specifically focus on (1) how the study is motivated, (2) who the study includes, (3) the methods used in order to answer this aim, and (4) how much caregivers are accounted for. Our results indicate that informal caregivers are not often being considered in studies, and when they are considered, they frequently have secondary, or even tertiary, roles. Based on our results, and also drawing on additional literature beyond our article sample set, we reflect on the alignment between the role of informal caregivers in society, and those in HRI studies. This then allows us to provide high-level recommendations.

To create a foundation for the analysis, section 2 provides more insight on informal caregivers in general. The following section, section 3, introduces relevant literature; section 4 provides the theoretical lens relied on to conceptualise the study, then section 5 introduces the methodology followed to conduct the systematic literature review. The results section, section 6, showcases the four dimensions we analysed. These findings are then discussed and reflected on in section 7. This leads to five recommendations for why and how informal caregivers could be better included in HRI research, as well as a conclusion in section 8.

2 Background on Informal Caregivers

In this section, we present four key takeaways from the wider literature on informal caregivers to demonstrate the complexity and nuances of their situation, before we clarify what has, and has not, received attention in HRI with regards to informal caregiving.

Firstly, informal caregivers exist all over the world, there are issues in identifying informal caregivers. Carduff et al. [19] discuss informal caregivers’ difficulty in identifying as caregivers; these include (1) becoming a ‘carer’ is often a gradual process, and thus they prefer to see themselves in their relational role (i.e. spouse, child of, friend), (2) care roles can be all-encompassing, rendering the caregiver unable to access relevant services, and (3) who should be identifying them – should it be the medical institution for example.

Secondly, there is a considerable amount of research pointing to the negative impact of caring can have on the informal caregiver with respect to their own overall wellbeing [10]. That said, informal caregivers are not a homogeneous group and all have different lived experiences in this regard. Hegelaar et al. [20] undertook a scoping review to demonstrate how utilising an intersectional perspective in research on

informal caregivers would show the various factors which will influence informal caregivers experiences, such as age, sex, relation to care recipient for example, and would allow better tailored solutions for caregiving. For example, within the realm of autism, Papadopoulos et al. [21] demonstrate the role of stigma within autism, which has huge (often unspoken) impacts on informal caregivers' own mental health. Another example is young carers – children caring for a relative – whose own needs are often overlooked by society despite their vital role in the family [22].

Thirdly, even if the care receiver moves into a care facility, informal caregivers will still be providing “considerable front-line work” [23, p.105]. These findings the invisible work informal caregivers often carry out. This becomes especially important when considering covid-19. Indeed, it was found that informal caregivers who were already struggling with their care responsibilities experienced the greatest difficulties during the covid-19 restrictions [24]. Furthermore, social isolation, loneliness and care burden increased for informal caregivers during covid-19 [3].

Finally, informal caregivers have been reported to be overloaded by information even as their own informational needs go unmet. For example, they may get a lot of information at a time of diagnosis, but this often omits specific information that they would like to have [25].

3 Relevant Literature

3.1 Human-Machine Interaction and Informal Caregivers

Robots are not the first digital technologies to be posited for and/or utilised by informal caregivers. LaValley et al. [26] 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 carer 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. [27] 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 shows that the internet is being used as a platform by informal caregivers for their role as carers. Additionally, Messina et al. [28] 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” [28]. 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.

Within HCI, these issues have already received some attention. In 2014, Schinkinger and Tellioglu [29] 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 Tellioglu point out that this technology can directly help informal caregivers in order to communicate with professional care services, be part of self-help groups or also monitor among other applications [29, p.349]. Since 2023, there is an increasing focus from the HCI community on informal caregivers: Smriti [30] published an extended abstract to show how they will bring informal caregivers forth into the design of artificial intelligence (AI) systems that are best suited to help them in their care role; and there is an ongoing scoping review underway to evaluate IT applications for informal caregivers [31].

3.2 Human-Robot Interaction in Care

On a general level, current HRI research for care points to health professionals (including doctors, nurses, carers) perceiving the usefulness of social robots (see e.g. [32]), as well as elderly people (see e.g. [33]), children (see e.g. [34]) and even pets [35]. Some HRI studies specifically invite domain experts and potential users to identify how exactly robots could be helpful in the care context, with participants often able to identify possibilities that they might be enthusiastic about [36].

Literature reviews in this field have focused on, for example, what types of robotics were being researched and for what care applications, which includes social robots [37], as well as how social robots are used to help end-users within elderly care [38] or within children's mental health care [39]. Literature reviews from critical perspectives have focused on elderly care [40–42], to showcase 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.

3.2.1 HRI and Informal Caregivers

Since this article only reports on selected articles (sampling only from those published at the ACM/IEEE International Conference on Human-Robot Interaction), it is relevant to mention other HRI studies which have included informal caregivers. Amabili et al. [43] looked at the use of eWare, composed of a lifestyle-monitoring technology and a social robot with the aim of reducing stress and improving quality of life for both informal caregivers as well as people living with dementia. They report that "the impact of the system in reducing the caregivers' burden needs to be deeply investigated" [43, p.1]. With their CARESSES project, Papadopoulous et al. [21, 44] test and evaluate culturally competent socially assistive robots among older adults, describing in one study how they involved informal caregivers [44], although the findings on their involvement are unclear. Laban et al. [45] 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.

3.3 Critical Perspectives within Human-Robot Interaction

Researchers within HRI have identified that the demand for robots in care is seemingly not bottom-up [40, 46]. 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 [40, 41]. 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 in skilled workers in care (for example [47, 48]), issues which indeed 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 [49], or the policies framing the “need” for robots in care [42], nor do they fully acknowledge informal caregivers. As a consequence, this usually results in technologies benefiting only a certain type of user – this can be within care for example, where elderly care is often the object of literature reviews within HRI (for eg [33], critical (for eg [40, 41]) and medical (for eg [38, 50]) articles. A number of recent studies have called attention to the ways in which HRI research can reproduce a (sometimes harmful) status quo, e.g. with respect to gender stereotypes [51, 52], including within care [53], and call for the HRI community to consider not only how we, the HRI community, might *avoid* this, but actually the role it might/ought to have in *challenging* the status quo.

Building on from this, 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 [16]. This is somewhat echoed in another literature review at the demographic looked at in HRI studies [54], 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.

4 Theoretical Lens: Social Justice and Feminist HRI

The scope of this paper is to understand how researchers are including informal caregivers in comparison to other groups within HRI health care research at the HRI Conference. Accordingly, we map out various aspects that we believe to be key considerations regarding how various stakeholders are included within HRI health care studies. Ultimately this is where the technology has the potential to preserve or challenge current practices. Said differently, what knowledge is produced about how to use technology might overlook stakeholders which are already omitted. Accordingly, we borrow the concepts “designing for recognition” and “designing for accountability” from HCI scholars, Dombrowski, Harmon and Fox [17]’s Social Justice-Oriented Design, and mould them to our research. We also draw on the concepts of power and subject-positioning relations from Feminist HRI, by Winkle et al. [18].

Dombrowski, Harmon and Fox [17] use their starting point to demonstrate the need for social justice in HCI by pointing out that research projects examine or intervene in large scale issues – such as health care – which require scholars to engage in (or

against) state and/or personal level politics. Therefore, although design is ultimately, they argue, about creating change, those designs will create "new technological objects [which will] afford new practices, social habits, and ways of living and interacting" [17, p.1]. Thus, by explicitly engaging in social justice, researchers and designers can facilitate more equitable change.

Turning to the definition of social justice-orientated design, Dombrowski, Harmon and Fox [17] rely on Lötter's conceptualisation of social justice as a multi-dimensional concept, whereby "at its core, Lötter's conception of social justice centers on the social concerns, obligations, and ethical commitments created through social interactions" (p.3). Therefore the very notion of social justice is a continuously evolving concept, and offers, based off Lötter's conceptualisation, six dimensions: *transformation, recognition, reciprocity, enablement, distribution, and accountability*. These dimensions demonstrate design strategies to create an engagement with difficult, often political, questions that designers should confront. This should be achieved from a systemic perspective rather than an individual level. For the purpose of this literature review, we borrow two dimensions: recognition and accountability.

Recognition is a notion that focuses on identifying practices as well as identifying people impacted by a certain phenomenon [17, p.6] – here HRI for health care. To do so, we analyse collected articles within specific parameters to understand how HRI researchers articulate and frame research problems within HRI for health care, and who is included when answering the research question. By explicitly and systematically recognising research practices, we address social– and in turn research– challenges that might have previously been under-recognised. Therefore recognition is about focusing and identifying (possibly unjust, according to [17]) practices, whilst also showing the complexities of one phenomena – here stakeholders in health care.

The next dimension is *accountability*, which includes holding responsible, but unlike the rest of their definition of this dimension we do not sanction. Accountability in this review is not veering the analysis, but a consequence, as we are holding up a mirror to the HRI community on how research is conducted in HRI for health care. Although it is limited to the HRI Conference, we are reflecting and confronting current practices. Our hope here is that by holding HRI community accountable, we allow a reflection of our own practices, so that as researchers we can leverage on our power to decide who is part of our studies and how it could be possible to create more holistic research designs within HRI in health care.

Finally, those dimensions, and generally social justice, have to also account for power. Here, we use Winkle et al.'s [18] conceptualisation from a feminist HRI perspective. A HRI feminist perspective, as Winkle et al. point out, means being sensitive to power structures [18]; this can be at an institutional level (ie 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. The 'HRI' part is also important here, as robots through their embodiment, bring their own challenges. Consequently we, as researchers and designers, need to consider the context in which the robot is used in as well as how people (for eg researchers in our study) position robots in a setting.

Overall, we summarise our theoretical lens, a motivating start-point but also the lens through which we analyse and discuss our results, as Social Justice-Oriented Design and Feminist HRI. This uses the concepts of *recognition* of stakeholders and practices as well as *accountability* of HRI research for health care, within *power* structures which will position robots in certain settings and impact various stakeholders in health care.

5 Method

5.1 Research Questions

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

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 caregivers included in health care HRI studies?

5.2 Choice of Literature Corpus

Influenced by previous studies that have done so (for example, [13–16, 54]), this study is limited to the ACM/IEEE HRI conference. The nature of the conference is to showcase the latest pioneering research within HRI, operationalised via e.g. limited acceptance rate, therefore we think it is reasonable to assume 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, namely thematic analysis (explained in subsection 5.4), requires significant time and resources, resulting in setting some upper bounds on the amount of literature we can include. As can be seen below, the terms used to collect the literature were very broad, leading to a relatively large number of hits which required manual assessment. This was intentional, in order to 'catch' papers that might have somehow included informal caregivers without mentioning them as such, and to demonstrate which stakeholders are key in health care HRI research. Finally, we note that there is not one clear obvious alternative venue or venues that might be more or less relevant. For example, the CARESSES project published in the International Journal of Social Robotics but do not once mention informal caregivers [55], however they also published in Archives of Public Health where they explicitly mention how they recruited informal caregivers [44]. Consequently, we assumed that using our sample following the PRISMA method (explained below) within the ACM/IEEE HRI conference would lay groundwork on the relevant stakeholders and focusing especially on how the HRI community is accounting for informal caregivers within health care.

5.3 Delimiting the Search and Screening

To complete this systematic literature, we relied on the PRISMA method (see Figure 1), whereby based on keywords, we identified, scanned and included articles according to our inclusion and exclusion criteria [56]. Using the ACM Digital Library, we searched for 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*"). Each keyword choice was decided between authors, which includes engineers and scientists, all of whom are critical scholars.

We used boolean operators in order to group terms, those include the use of "OR" in the same bracket to have similar terms searched for, and in between brackets we used "AND" to combine layers. The first set of brackets, ("health care" OR "healthcare" OR "assistive" OR "impairment"), were decided to saturate the field of health care, where we combined different terms that are similar to care within HRI literature; The "AND": due to the amount of results from this first layer, we used the "AND" operator to bring an additional layer; The second set of brackets: ("care" OR "assist*"): this bracket was specifically to ensure that the robot was deemed to either care or assist in some way. The asterisk (*) was used in order to also get results which used the stem word 'assist', including terms such as "assistance" and "assist".

The results were deemed broad enough, with a total of 187 hits. All the literature from the results were then exported onto EndNote 20 to be able to screen the documents easily. Figure 1 shows the screening process, which totalled to 52 studies to be reviewed and analysed.

We had clear inclusion/exclusion criteria. The inclusion criteria consisted of academic literature which were within our health care definitions and referred to care robots. More specifically, the study was about bringing a robot into a certain care setting; care was defined as health care, meaning that the study either looked at improving current care practices, improving quality of care, bring some independence to the user or loneliness and companionship, supporting or motivating the user or/and reduce workload within healthcare settings. Furthermore, studies must have used a robot, this can mean anything from a robot which aims to assist with exercises and rehabilitation to a robot that monitors the care receiver, or aid the caregiver. The use of the robot in the study can be a hypothetical robot; videos/images of robots; and an actual physical robot. Finally, the study must have participants.

The exclusion criteria were studies not within health care, for example the study contained our keywords in a different context but in educational settings; literature reviews; studies which evaluate the use of robots but do not consider technical aspects to do (eg ethnographies); and abstracts.

5.4 Reviewing and Analysing the Literature using Thematic Analysis

To achieve our aim, we used a thematic analysis approach to review and analyse our collected literature, in accordance with Braun and Clarke [57]'s five steps (Familiarisation, Initial Coding, Theme Search, Theme Review, Naming and Definition). The first step was familiarising ourselves with the data. This allowed us to create initial

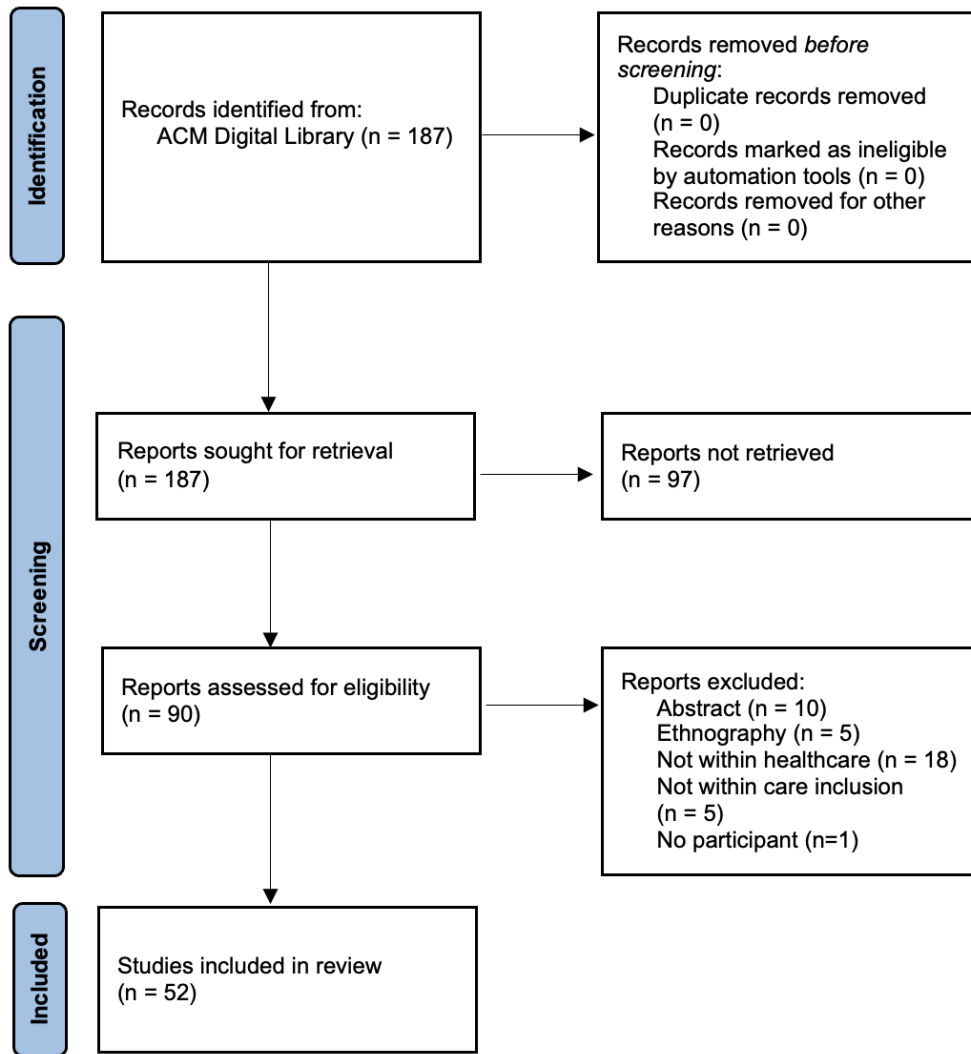


Fig. 1 PRISMA Flowchart Diagram of Selected Studies [56]

themes and create a codebook for the second step. A codebook defines codes as well as delimits them, and thus creates a deductive approach to coding. As the third step (theme search), we transferred the articles onto NVivo, a software used to qualitatively code data (herein academic articles) and used the codebook to code themes within the articles. This was an iterative process to ensure our codebook reflected the literature reviewed (theme review and naming and definition).

The use of NVivo yielded qualitative and quantitative data that was easily reviewable. This allowed for one author (LT) to review and code all articles following iterative development of the codebook with a supervising author (KW). Together, LT

(sociolegal scholar) and KW (HRI scholar) bring a combination of critical and HRI perspectives. The codebook was continuously re-iterated between these two authors until saturation was reached for the purpose of our literature review.

Since the data was coded on NVivo, it was possible to go beyond the binary and add the papers into various categories within the same overall code (who was investigated in the research: care receivers, formal caregivers and other experts for example). All the results from the coding were quantified in an Excel Spreadsheet after having done all of the qualitative coding, which is available in the additional materials.

6 Results

In our results, we focus on the four following themes – representing each subsection – that shed light on how stakeholders are positioned within HRI studies, with a specific focus on informal caregivers:

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.

6.1 Overview of Reviewed Articles

This subsection sets the scene on the article that were reviewed, and how the articles themselves set the scene for their study.

6.1.1 Background of Reviewed Articles

The articles within the health care domain started getting published in 2008 within the HRI Conference, as can be seen in Figure 2, which is two years after the beginning of the HRI Conference. Out of the 52 articles reviewed, eight studies included informal caregiver (totalling to 15% of the time) and 20 studies included formal caregiver (totalling to 38% of the time).

The first appearance of formal caregivers were in 2010 – which is also the only publication on health care that year. After that, they are sporadically included as participants, and from 2017 formal caregivers have been constantly included in health care studies. The first publication to include informal caregivers was in 2014. However, the next time informal caregivers are investigated is in 2020, six years later, where there is also seemingly an exponential growth of HRI studies in health care. Overall, informal caregivers are included at a much lower rate in comparison the amount of HRI publications in health care.

Furthermore, articles either looked at care for: older people, over 65s (35%), adults (12%), children (13%), all age groups (42%), and staff (12%). For studies that investigated informal caregivers, the figures are the following: 35% for older people, 0% for adults, 25% for children, 25% for all age groups, and 0% for staff. Whilst for studies

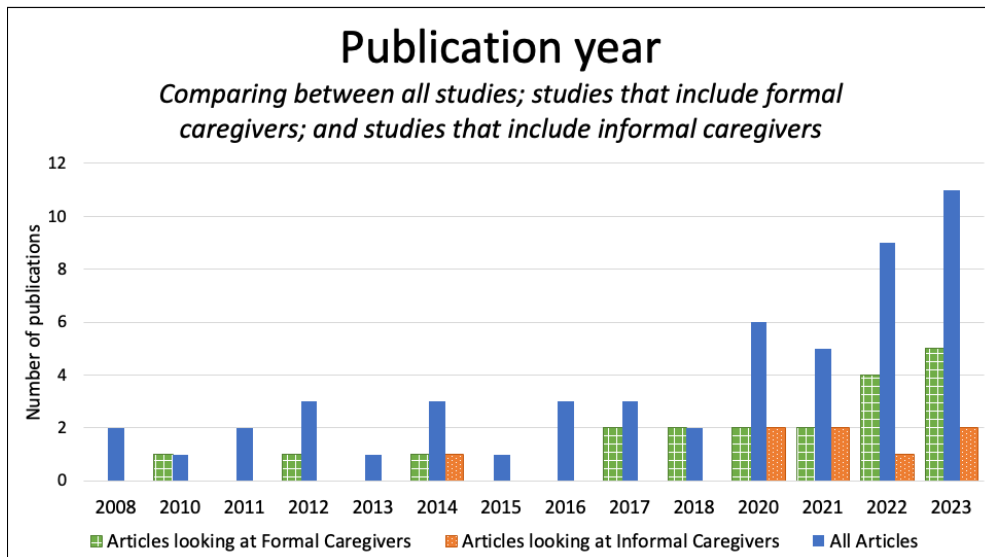


Fig. 2 Graph showing the number of publications between 2008 and 2023

that investigated formal caregivers: 50% for older people, 15% for adult, 5% for children, 15% for all age groups, and 25% for staff (representing all the articles which look at how to support staff, except for one which also aims to support formal staff but does not investigate formal caregivers [58]). All informal caregivers investigated were over the age of 18.

6.1.2 Motivation behind Reviewed Articles

Motivation as a theme is used here to pinpoint how authors motivate their research within their opening paragraphs. We identified *alarming narratives*, *lived experiences*, and *further(ing) current robotic research*. *Alarming narratives* refers to the use of statistic (such as the change in demographic for example), 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” [59, p.243]. *Lived experience*, refers to helping the reader understand either the technology or the context from a care role perspective, without necessarily using academic referencing nor being specific to HRI. A good example of this is by Nanavati et al. [60, p.24]: “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”. The final category showcased here is *further current robotic research*, which is where the justification refers to previous (HRI or related)

articles looking at a similar issue within the domain, positing the current work as developing on/responding to those previous works.

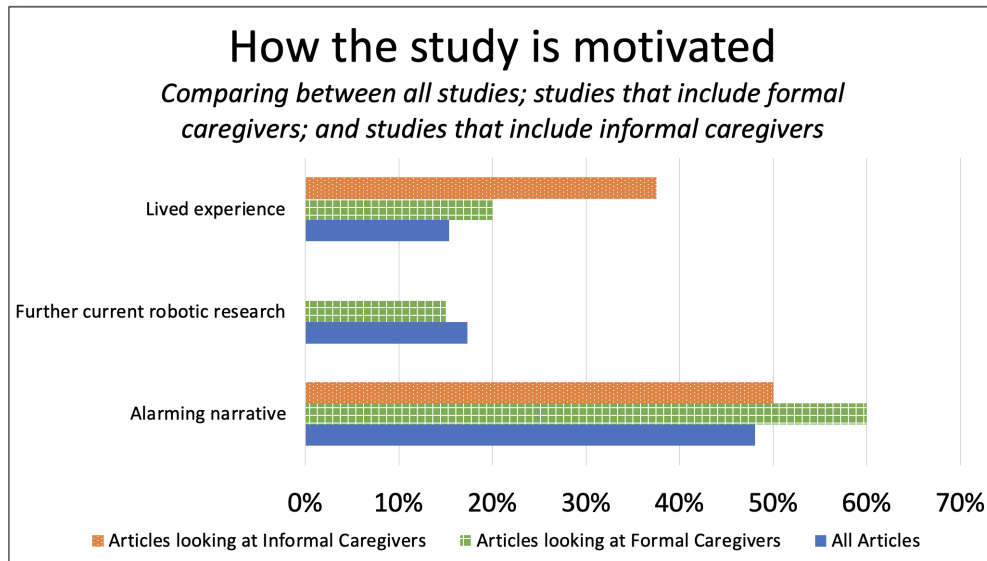


Fig. 3 Chart comparing motivation(s) relied on by the studies to set the scene

Figure 3 illustrates the three categories spoken above. *Alarming narrative* is used by most articles, nearing 50% of the time (n= 25 of all studies rely on this), although it is used more often when the studies include caregivers than care receivers, especially when formal caregivers are participants (60% of the time). With regards to studies involving informal caregivers as participants, it is used 50% of the time ([61–64]). The use of alarming narrative for studies including informal caregivers represents some recognition of their importance in healthcare, as Lee et al. [64, p.475] show in their opening paragraph: “10% of older adults in the US live with dementia. Dementia requires substantial amounts of care; often, this is largely informal care provided by the patient’s family members. About 85% of the dementia patients reside in their own homes rather than in nursing facilities. Unpaid family members are the most common carers for persons with dementia; this continues even after persons with dementia move to residential care settings”. *Lived experience* is also used relatively frequently (38% of the time – n= three out of eight studies) specifically by studies including informal caregivers. In contrast, lived experience is referred to in around only 15% (n= eight out of 52 studies) of the overall articles reviewed.

Finally, motivations based on *furthering current robotic research*, were not seen so often, at least within the opening paragraphs. Approximately 17% of all studies (n= nine out of 52 studies) included some such motivation, **none of which** included studies relating to informal caregivers. This already perhaps points to a lack of previous work specifically considering informal caregivers in HRI research.

6.2 Who is included

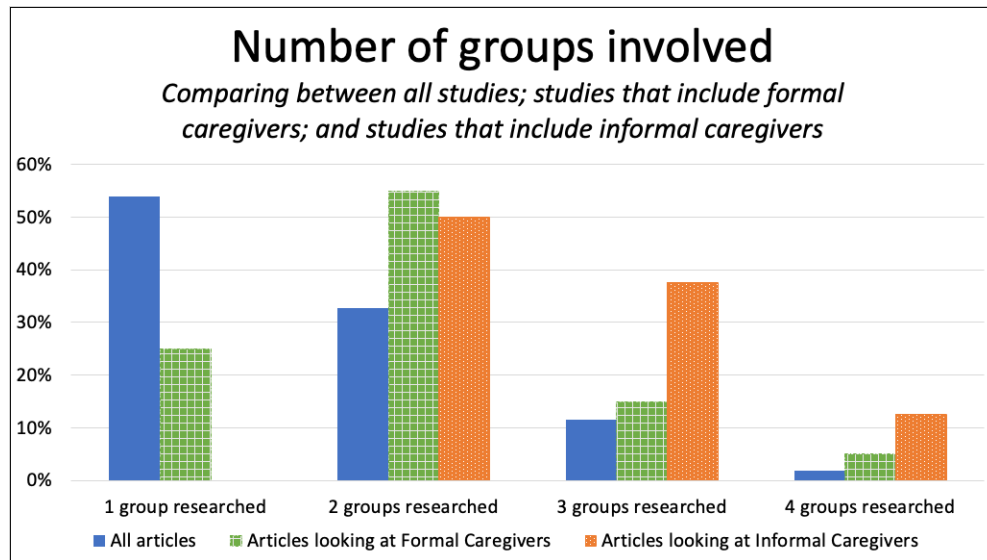


Fig. 4 Graph showing and comparing how many groups are included

Across all articles reviewed, 71% of studies included care receivers as participants ($n= 37$ studies out of 52 include care receivers as participants). Formal caregivers were included in 38% of articles ($n= 20$ out of 52 studies), and informal caregiver were investigated in 15% of articles ($n= nine$ out of 52).

6.2.1 Studies Investigating One Stakeholder

Different groups are mapped out in this part to showcase who is investigated in the study itself, which is illustrated by Figure 4. Over half of all articles reviewed (54%) solely investigated one stakeholder group, with care receivers being the most common [36, 58, 60, 65–89]. Specifically, out of the 54% investigating a single group of participants (equating to 28 studies out of 52). Out of those 28 studies, 61% investigated care receivers, 21% investigated control groups, and 18% investigated formal caregivers. When looking solely at the articles that investigate formal caregivers, those studies will investigate formal caregivers as a sole group 25% of the time ($n=$ studies out of 20 studies). In contrast, **no studies** investigated informal caregivers only.

6.2.2 Studies Investigating Two or More Stakeholders

33% of the articles reviewed investigate two groups (equating to 17 studies out of 52), and here the dynamic slightly changes [62, 64, 90–104]. 55% of all studies investigating formal caregivers also studied another group of participants [90–99, 104]. Similarly,

50% of studies which included informal caregivers also included one other group of participants [62, 64, 101, 104].

Finally, 14% of studies investigated three groups or more, equating to seven studies out of the 52 studies. Interestingly, only one such study does not include caregivers [105], all others do. Regarding formal caregivers specifically, 20% of studies (n= four out of 20 studies) additionally investigate two or more other groups of participants [59, 61, 106]; and four groups [107]. Turning to informal caregiver, this number increases substantially to 50% (n= four out of eight studies), as this group tends to be investigated in addition to two or more groups of stakeholders within studies (included in three groups: [61, 63, 108]; included in four groups: [107]).

6.3 Methods Used

6.3.1 Types of Methods Used

Methods here refers to approaches HRI researchers relied on to answer their research question(s). We show results for studies which did their data collection (1) in the wild, (2) through interviews or focus groups, (3) in labs or lab-like settings; and (4) through workshops. We group interviews and focus groups together on the basis that both typically target relatively homogeneous participant groups (e.g. “therapists”), unlike workshops – hence they are separated. As an example, focus groups were held in two different eldercare institutions with professional caregivers to inform robot design within that setting [82]. In contrast, an example of workshops is one where children and their parents were brought together by HRI researchers to co-design socially assistive robots to mitigate distress and pain in pediatric care and understand their perceptions [62]. Figure 5 showcases the four methods and how they are used in comparison to all studies, studies including informal caregivers and studies including formal caregivers.

Looking at studies conducted in the wild, this method was used 19% out of all the articles reviewed (n= 10 out of 52 articles). Six out of those ten studies (60%) included formal caregivers in their studies; five of the 10 studies (50%) are conducted in elderly care (50% of studies conducted in wild); one study (10%) is conducted in hospitality settings [95]. None of the studies conducted in elderly care facilities and hospital settings include informal caregivers. Only two studies (20% of studies conducted in the wild), are in a setting where the robot is left to use in a domestic setting for some time [76, 101], of which one study is for older people. Informal caregivers were only directly investigated in one of the in the wild studies [101], whilst for studies investigating formal caregivers, in the wild was a method used in 30% of the time.

Regarding interviews and focus groups, these methods were used in 42% of all articles reviewed (n= 22 out of 52 studies). It is the most popular method again when formal caregivers are being investigated, used 70% of the time within articles studying formal caregivers (n= 14 out of 20). However, it is only used 25% of the time when informal caregivers are being investigated (n= two out of eight). Methods using lab/lab-like are used over 52% of the time in all articles reviewed. These methods are not as popular for studies investigating formal caregivers (used 25% of the time), but used more when informal caregivers are investigated (38% of the time, n= three out of eight studies). Finally, workshops are the least typical method for most studies, as

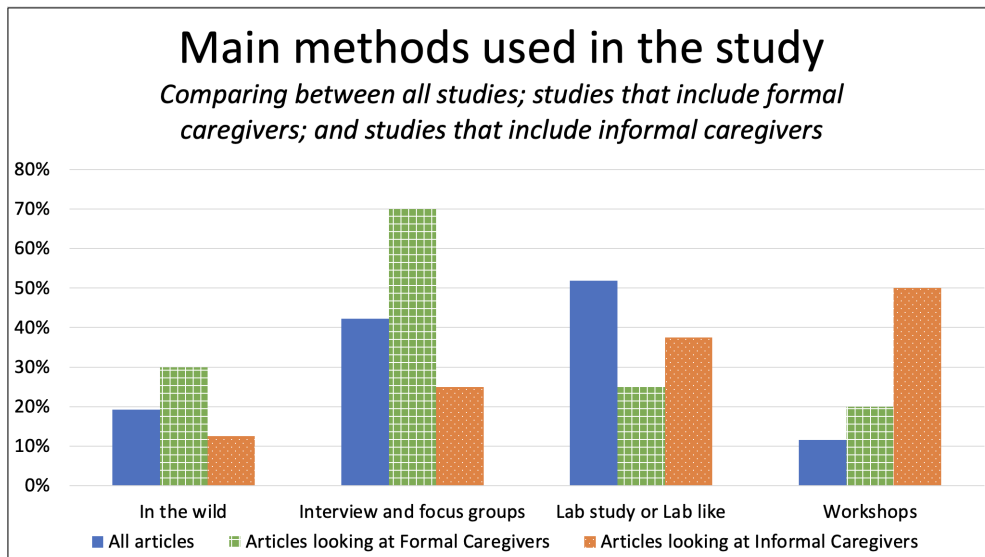


Fig. 5 Chart comparing various methods relied on depending on who is included

it is only used 12% of the time in all reviewed articles. In articles investigating formal caregivers, it is used 20% of the time. However, it is the most popular format for studies investigating informal caregivers, used 50% of the time.

6.3.2 Number of Methods Used

It is worth noting that 58% of all studies use at least two different methods (n= 30 out of 52 articles), thus cross-pollinate. For example, no study conducted in the wild, or studies using surveys solely relied on that method. Studies relying on one method mostly tend to use interviews (45% out of all the studies using one method). Looking at trends with formal caregivers, 60% of studies use at least two methods (n= 12 out of 20 articles). With informal caregivers 62,5% of the time at least two methods are used (n= five out of eight). Turning to formal caregivers, they are involved in most studies which use three methods – out of the 10% of all articles using three methods or more, 75% of them look only at care receivers and formal caregivers. Two of those reflect on long term deployment of robots, either for older adults with dementia [98], or for rehabilitation for post-stroke patients [95] and one, which is outside of the medical institution, to bring well-being robots into the workplace [92].

6.4 Caregivers' Involvement in Studies

Here we want to zoom in directly on caregivers, demonstrating also how we have defined informal caregivers in studies –even if researchers did not call them as such– whilst also showing a comparison between how much attention has thus far been paid to formal caregivers and informal caregivers.

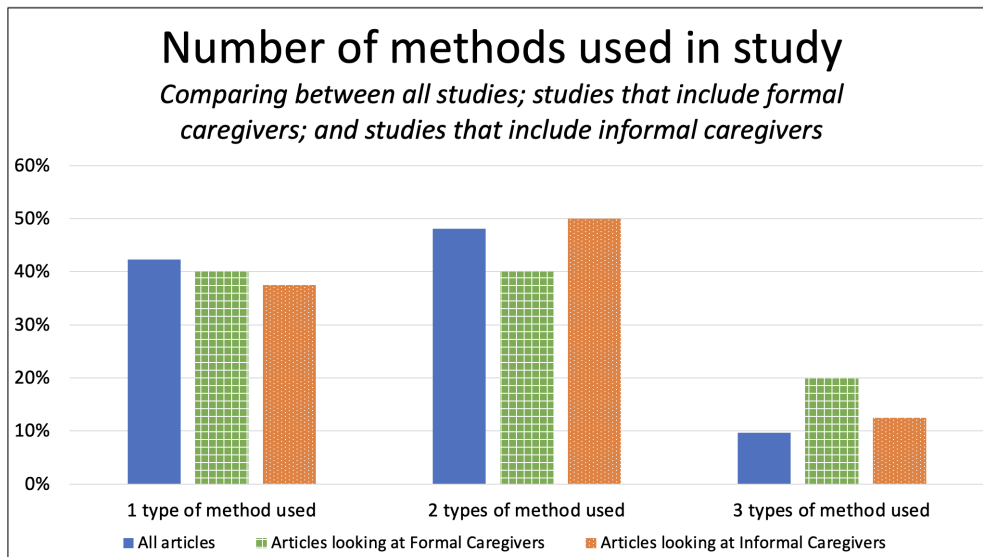


Fig. 6 Graph showing how many different methods are used

6.4.1 Identifying Informal Caregivers

As a reminder, we define informal caregivers 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" [9, p.1]. Put differently, a member of the family or a friend can be viewed as an informal caregivers if the support that they bring allows the care receiver better overall well-being and health. We do not include parenting as a general rule, however, parent-carers are an important – often overlooked – group, denoted by situations where the child would not be able to manage their condition without the help of their parent. These definitions are important to highlight, since out of the eight studies which include informal caregivers directly in their study, summed up in table 1, three of them (38%) do not actually refer to them as informal caregivers. Therefore it seems fitting to explain why we categorised them as such.

Out of the five studies that identified and explicitly named informal caregivers [61, 64, 104, 107, 108], three of them work with a robot application targeting users of all ages, whilst the other two consider elderly care specifically; furthermore, two use alarming narrative to situate their study [61, 64] and two others use lived experiences [107, 108]. Regarding the three which did not identify informal caregivers as such, two of them consider a robot application for children and one for all ages. Only one study used lived-experiences to situate the study [101]. This study, by Tsoi et al. [101], deployed robots to children during the Covid-19 pandemic, and opens by speaking of the social isolation that occurred due to restrictions imposed to limit social contact.

Title of Publication	Year	How informal caregivers are included
A mixed-method approach to evoke creative and holistic thinking about robots in a home environment [107]	2014	Scenario-focused workshops with different stakeholders, which included informal caregivers.
Robots for joy, robots for sorrow: community based robot design for dementia caregivers [104]	2020	Co-designed robots through workshops on caring for people living with dementia, which included informal caregivers and geriatric nursing students.
Transfer depends on acquisition: analyzing manipulation strategies for robotic feeding [63]	2020	Study included people who had experience feeding other people to test out the technology.
Co-designing Socially Assistive Sidekicks for Motion-based AAC [108]	2021	Informal caregivers were included in workshops to co-design assistive conversation technology.
Challenges Deploying Robots During a Pandemic: An Effort to Fight Social Isolation Among Children [101]	2021	Toy robot was brought into homes to help with child isolation during covid, parents provided information needed.
Understanding Design Preferences for Robots for Pain Management: A Co-Design Study [62]	2022	Informal caregivers co-designed to understand features both child and parent would want for pain management robot application.
Impacts of Robot Learning on User Attitude and Behavior [61]	2023	Compares perceptions from general population to caregivers of robot applications in the home for health care purposes.
Reimagining Robots for Dementia: From Robots for Care-receivers/giver to Robots for Carepartners [64]	2023	Explores the varying views of persons living with dementia and their informal caregivers and the importance of taking both into account for the robot design.

Table 1 The role of informal caregivers in studies that do include them

The reason we categorised Tsoi et al. [101]’s study as directly including informal caregivers is because the parents were the ones that assessed if their child felt lonely and how this could be improved, whilst also being the ones to set up the device, and fill out various surveys. The unusual circumstance, namely the pandemic, is what made their role go from being a parent to also taking on a more caregiving role as they became the ones that had to create the adjustments needed for children to live a healthy everyday life away from peers, activities and school, to name a few.

The other two studies relied on alarming narrative to set the scene [62, 63]. One of the studies, by Gallenberger et al. [63] investigated feeding strategies for robotic feeding. To achieve this, they recruited 25 people, of which eight, the paper specifically points out, had experience feeding others. It is somewhat unclear if the participants were informal caregivers, however, the fact that the researchers pointed it out demonstrates that the researchers suspected that the participants relied on their previous

experience to understand if this robotic tool would be useful. There is no clear way for us to know what capacity these people were feeding others, but as it is usually specified in other studies if the participants have formal qualifications which was not the case here, we therefore decided to categorise them as informal caregivers. Another study, by Zhang et al. [62] undertook a co-design study which includes parents and their child to understand design preferences for robots for pain management. This study directly looks at parents to help understand how to manage pain (for example, for surgical recovery) for children. The parents are not identified as informal caregivers, however, since this study is 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.

The definition of informal caregivers also allowed us to reflect on how robots were sometimes defined in studies, which aligned with the role of informal caregivers. For e.g.: *”Robotic systems may assist older adults in maintaining their independence, reducing healthcare needs, providing everyday assistance, and promoting social interaction”* [72, p.19], or *”Furthermore, they [children with diabetes] greatly enjoyed working with the robot and came to see it as a helpful and supportive friend”* [66, p.463], or *”[subsection: Intended Roles: Friend/Partner]: Robots can accompany older adults during PA [physical activity] (e.g., walking, creative hobbies) to counter loneliness and augment the PA as a social activity that may not be otherwise possible due to an inability to keep up with a partner or group in a meaningful way.”* [106, p.510].

6.4.2 Identifying Formal Caregivers

In stark contrast, identifying formal caregivers demanded a lot less reflection on whether we should define that group as formal caregiver or not. Indeed, that group was named according to their profession, this allowed us to categorise and differentiate between *”formal caregivers”* and *”other experts”*. For example, [109] included formal caregivers as they interviewed medical professionals that practiced medicine within the medical institution, as well as other experts, gender scholars who looked at and reflected on medical practices. Whereas [36] hosted focus groups and interviews with physiotherapists, occupational therapists, speech therapists and sports rehabilitation therapists, all of which fall under formal caregivers as they practiced within the healthcare institution and required certification.

With this understanding, we can now spotlight different levels of involvement between caregivers.

6.4.3 Level of Involvement of Caregivers in Studies

Up until this section 6.4, we have solely mentioned and reflected on stakeholders that are expressly investigated in the study. However, there are also interesting nuances on how the caregivers are involved and identified, we therefore used four different categories: *”no mention of caregiver”*; *”acknowledgement of caregiver”*; *”low level of involvement”*; and *”high level of involvement”*, to show at what level caregivers are mentioned (as depicted in Figure 7).

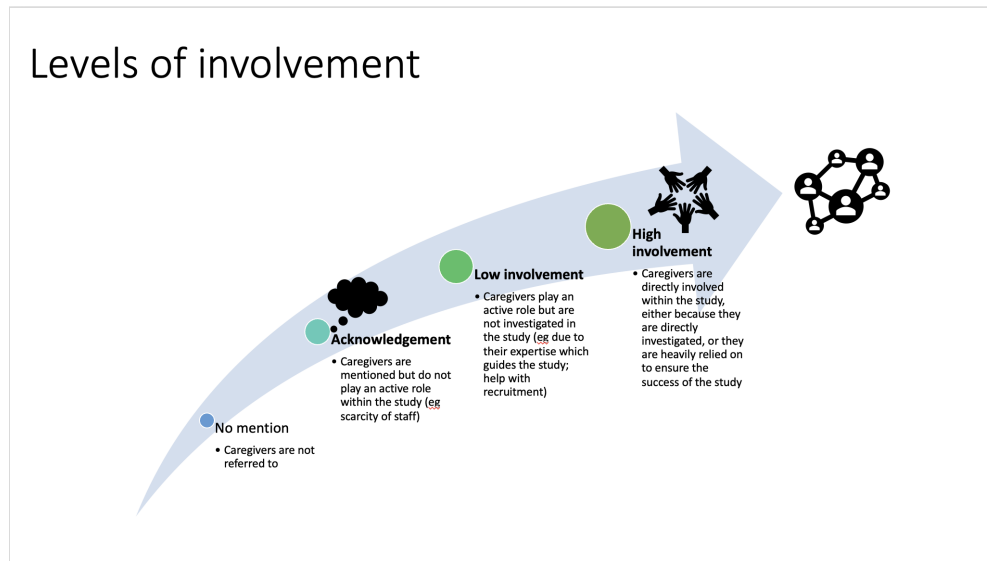


Fig. 7 Different levels of involvement of various stakeholders within HRI studies

No mention of Caregivers

10% of articles do not mention formal caregivers at all (n= 5 out of 52), whilst 29% of articles (n= 15 out of 52) – nearly one third of papers collected – do not mention informal caregivers.

Since there is such a high proportion of studies that do not mention informal caregivers, we quantify those that exclude them fully from their study. Four studies (27%) are situated in elderly care [71, 78, 82, 89]; one application is situated for children [67]; eight studies are targeted for all ages [65, 69, 70, 73, 84, 96, 100, 102]; and, three (20%) looking at robotic application for staff [82, 89, 99] — of which two are directly for medical staff. Turning to groups involved, 10 studies out of the 15 studies look at one group of participants. Within those 10 studies, seven studies look at care receivers; two studies look at formal caregivers; and one at control groups. The other five studies include two groups, two of which look at formal caregivers and care receiver; two studies investigate care receivers and control groups; and, one investigating formal caregivers and control groups.

Acknowledgement of Caregivers

Acknowledgement of caregivers is quite high for both formal caregivers (29%, n=15 studies) and informal caregivers (46%, n=24 studies). This means that the caregivers are not involved in the studies, however they are mentioned in some way. With regards to formal caregivers, this is done either through responses within interviews which name them [36, 60, 62, 105], or researchers mention that they hope the robot will help healthcare professionals [88], or the researchers want to imitate the medical setting, ie

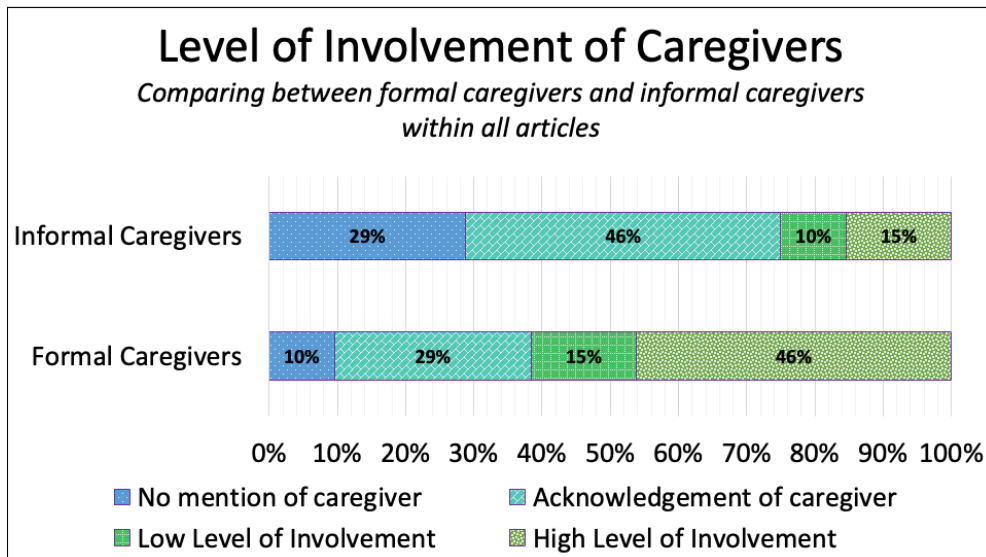


Fig. 8 A comparison between caregivers regarding how either (1) involved they are in the study, (2) acknowledged, and (3) not mentioned in the collected studies

a therapy session or physio [63, 65, 73, 85, 87, 102], or they are identified in previous relevant work [72].

There were studies that were unclear about whether they targeted informal caregivers or formal caregivers, but acknowledged that it would help support caregiving responsibilities [74, 79, 86]. We therefore categorised them as both types of caregivers in our analysis.

Within the 24 studies that do acknowledge informal caregivers within our definition, 15 studies (62,5%) refer to them in terms of their relation to the care receiver (eg ‘family’ or ‘friend’) rather than as informal caregivers. Within those studies, some take for granted how they would create informal caregivers, or create more workload to informal caregivers. An example is with regards to setting up the study: ”[section ”inclusion criteria]; Background: *At least one friend/family contact who is willing to connect by video-call; time to spend on GenieConnect, not too busy; has good WiFi coverage*” [76, p.1096]. Another example is to play a rehabilitative game ”*Another possibility would be to have one patient use a robot while another patient (or a therapist, or even a healthy friend of the patient) uses a simpler haptic interface*” [85, p.453].

Furthermore, regarding informal caregivers, their acknowledgment is summarised as: families helping set realistic goals to support the use of social robots for the care receiver [91, 93] or plays along [85] or can view and monitor progress [36]; family members could help set up the system [76, 107]; feedback from parents at the site the research is conducted – that is further elaborated on in a different paper [88]; recognising families as tertiary users of robots for its application in pediatric hospital setting [59]; needing to also account for robot interactions with family members [81]; recognising that potential caregivers are not accounted for [90]; responses from interviews

with care receivers [97, 105] or interview questions to care receivers include level of support they get from friends and family [77]; speaking of caregivers on a general level [80, 87, 98, 103]; referring to past literature which acknowledges families providing care [58, 72, 83, 95]. Finally, one study specifically speaks of how they tried recruiting informal caregivers, but were unable to do so [106].

Low Level of Involvement

Turning to low level of involvement, the difference between low and high, is that the caregiver is not relied on but has a more passive role to help with the running of the study. This low involvement occurred 15% of the time for formal caregiver (n= eight out of 52 articles). Whilst for informal caregivers, they are involved at a low level 10% of the time (five out of 52 articles).

Within low involvement, we included practices within the healthcare institutions which would require healthcare expertise in order to design it into the robot, as this demonstrates how expertise transpires into studies even if those experts are not directly participants. One study does so by automating Confusion Assessment Method for Intensive Care Units (CAM-ICU) used to detect delirium into a robotic system [83], whilst another 'induced' anxiety, through the Trier Social Stress Test for children, to demonstrate that robots can help improve children's mental health [103]. Low involvement also included health care workers that were not directly involved in the study, but were at the heart of the study in order to ensure that the tool could be used for them, an example is a study investigating how to use teleoperated robots in highly infectious hospital environments in order to allow health care workers to perform some of their duties at a safe distance [58]. A further two studies asked formal caregivers to propose participants who could take part in the study [66, 76].

We flagged a couple of studies that did not make it clear if the involvement was about informal or formal caregivers. One such study asked participants to plan a surprise party for their caregiver, and the participants were asked to think of who this caregiver should be and that chosen caregiver would be allowed to monitor the participant through the technology the participant had been assigned in this experiment [68]. Another study mentioned that caregivers accompanied the care receiver, herein the participant, in order to (1) go through the consent form, (2) go through the study protocol, and (3) attend the trial in order to engage in normal conversation with the participant [75].

Within studies that somewhat involved informal caregivers, two out of the five studies have been explained above. The three other studies, one study directly points out the involvement of the parent's participant in order to sometimes help clarify what the participant said during the interview [60]. Another speaks of an introductory meeting with the primary caregivers and family members of the prospect participants ahead of the study [94] (note that formal caregivers were part of this study, but not the potential informal caregivers). Finally, one study which investigated the use of a social robot to motivate and support children with diabetes keeping a diary, they speak of the important role parents play but also that some parents supervised the children whilst they were writing up their diary entry for the study [66].

High Level of Involvement

High level of involvement is the highest category that can be achieved in our classification, as it means that the caregiver is either (i) a participant or (ii) heavily relied on to directly mould the study in some shape or form. The analysis of all articles showed that although 38% directly investigate formal caregivers, four more studies directly rely on formal caregivers to ensure that the study is successful, meaning that 46% of studies overall highly include formal caregivers (equating to 24 studies out of 52 articles). Out of the studies that do not include formal caregivers as participants, one speaks of direct collaboration between roboticists and occupational therapists to create a flexible interface for a wheelchair mounted robotic arm [70], another was relying on a formal caregiver to interview some of the study participants in order to compare to a robot that asked the same questions [77], another study relied on caregivers in the facilities for children with autism to help design tasks for the robot [67], and finally one study relied on the executive director, who had also been a social worker, who directly helped with the question formulation, what questions should be included as well as collecting feedback from participants [64]. In contrast, no other informal caregivers were highly included in the studies, except for the ones that have already been mentioned (15%, equating to eight out of 52 articles).

This means over 60% of all studies collected, formal caregivers play a vital role in health care HRI either through high level involvement or low level involvement, whilst for the same level of involvement that number is 25% for informal caregivers.

7 Discussion

7.1 Applying the Theoretical Lens to the Findings

Our theoretical lens, deriving from Social Justice-Oriented Design and Feminist HRI, allows to map out different characteristics for stakeholder(s), context, and/or institution(s). This framework has enabled us to recognise various stakeholders, highlighting informal caregivers in particular, within different health care contexts; whilst also adding notions of accountability and being attentive to power structures. As can be seen from the results, our analysis dissected 52 research papers, where we set out to understand how the researchers set the scene, who they involved, what method they used, and how/if caregivers are mentioned. We were also candid about the complexity of categorising caregivers, which at times lead to subjective categorisations. Overall, this was an exercise of disentanglement in order to answer our overall research question, *How do HRI researchers position informal caregivers within studies relating to HRI in/for health care?*, and show a complex and nuanced understanding of informal caregivers within HRI.

The Who in HRI Health Care Studies

Our results show a trend in HRI work focusing on health care, with the majority of articles (71% of all articles reviewed) considering the care receivers' needs and perspectives. This is of course a positive trend, and should not be viewed as a critique. However, the results point at the complexity of who else is involved and how, especially

when looking at informal caregivers. Overall, informal caregivers are on the periphery of HRI health care research. If comparing to formal caregivers, formal caregivers are investigated 38% of the time, as opposed to 15% of the time for informal caregivers. Whilst 75% of the time, informal caregivers are either acknowledged in studies or not mentioned, in comparison to 40% of formal caregivers are either acknowledged or not mentioned. This is a significant difference, especially when considering the vital role informal caregivers play as co-providers of care [1].

Setting the Scene in HRI Health Care Studies

Mapping the opening paragraphs of the reviewed articles demonstrates how the studies motivated their study to grasp people’s attention. Out of all the studies which investigated informal caregivers, none relied on previous robotics research that they wanted to further – a practice that was somewhat used in other articles reviewed. Instead alarming narratives and lived experiences were used. It is worth emphasising that the use of lived experiences in studies investigating informal caregivers was a lot more than the average, see Figure 3. The use of alarming narrative has already been observed by other researchers, such as Maibaum et al. [40], Wright [42] and Pedersen, Reid and Aspevig [41], as it allows roboticists to show that there is a need for the robots to enter the field and find solutions. However, the use of lived experiences is not something that has previously been captured. Typically, the use of this type of practice is part of feminist approaches (see [110]), as it allows to show more individual perspectives. Put differently, lived experiences allows to show that there are other perspectives that could (and probably should) be taken into account, which could be explained by the fact that informal caregivers lie outside healthcare institutions but are still part of it from the sidelines. However, if this practice is relied on more than usually done in HRI studies, this could diminish the importance of informal caregivers to the HRI community.

Methods Used for answering HRI in/for Health Care

In relation to methods, we demonstrate how the studies were being conducted when certain stakeholders were involved. With regards to informal caregivers, the most popular methods used were either (1) lab or lab-like studies, or (2) workshops. In contrast to this, studies investigating formal caregivers were mostly using interviews or focus groups, closely followed by in the wild studies, see Figure 5.

The findings on the methods used, although a lot cross-pollinated, still show important trends. For example, when studies were conducted in the wild, 60% of such studies included formal caregivers. Within those, the studies tended to ask formal caregivers their reflection on the use of robots. Harrison and Johnson [111] point that in the wild studies allow levels of variation participant responses, with regards for example, to robot encounters they enjoyed and did not. However, informal caregivers – but not named as such – were part of in the wild studies once. Instead, it was much more likely that informal caregivers were involved in lab or lab-like studies and workshops (workshops being the most popular approach to investigate informal caregivers). Though, Harrison and Johnson [111] point out, lab studies tend to recruit participants who are more positive towards robots; and we add that this is likely to extend to workshops.

How were Caregivers Included in HRI Health Care Studies

Regarding who was investigated, we showed how many groups per study were investigated. When looking at solely one group of stakeholders being investigated in HRI health care studies, it was found that 21% of the time it was care receivers; 18% of the time it was formal caregivers; but informal caregivers were never investigated as one group. Instead, informal caregivers were part of studies which included two groups or more; meaning that they were part of studies which investigated more stakeholders than the average, see Figure 4.

Moreover, when informal caregivers were included, see Table 1, some of them had quite passive roles. This might not be so surprising, especially as literature reviews (including critical ones: [40–42]) do not tend to put much emphasis on informal caregivers' role within the HRI-health care eco-system. However, within health care research generally, the role of informal caregiver is unquestioningly necessary to the sustainability of healthcare institutions [1, 3, 10, 11], with many studies solely looking at them, for example: [2, 3, 10, 11, 21–23, 25].

7.2 The Complex Role of Informal Caregivers: Vital but Under-Recognised

Informal caregivers are part of the HRI health care eco-system. By showcasing level of involvement of caregivers in our results we pinpoint how informal caregivers play a role, even if passive. Regarding 'low level involvement', we pinpoint that they help from a recruitment perspective, or allowing the care receiver (participant) to take part in the study, or supporting the research process generally. This low level involvement occurred 10% of the time for informal caregivers in all of the articles, which is similar to formal caregivers (15% of the time). This reliance also shows that there may be an expectation on caregivers to be around, without necessarily being investigated. This is further evidenced when the informal caregivers are acknowledged in studies: they are acknowledged 46% of the time in all the studies collected, and within those times, they are sometimes either expected to be available for the study or they are expected to help with the set up of the robotic software once it is available. Although this is also the case some of the time for formal caregivers, formal caregivers will be monetarily rewarded for their time spent, since it is/will be part of their job role. Furthermore, studies conducted in the wild within institutional settings, have not included informal caregivers. Yet, when formal caregivers are included in these studies, it is to reflect on their experience of this robot on their everyday work life. This demonstrates that robotic applications for formal caregivers are being much more proactive in getting their view alongside the creation of the robot application; yet, methods used when informal caregivers (workshop being the most popular) were more about trying to understand how to account for them at design stage. This is also echoed by the number of groups involved, where informal caregivers are never investigated as a sole group, unlike care receivers and formal caregivers.

Relating this to previous work, informal caregivers are viewed as co-providers of care [1], as they will be the ones doing the bulk of the care outside of institutional care,

and still provide support within institutional settings [23]. This insinuates that, actually, HRI studies should and need to account for informal caregivers when they are also looking at formal caregivers. This is key as HRI Feminism and Social Justice-Oriented design point out, that there is a whole eco-system behind every HRI research, and it becomes the HRI community’s task to ensure a more diverse pool of participants is being included and to engage in the political structure of our research [16–18]. Furthermore, as it stands, the HRI community could potentially further burden informal caregivers, with issues such as information overload [25], difficulty accessing services, and at times care receivers, due to a global pandemic [24] – or in reverse, more care responsibilities are on the informal caregiver, as the care receiver cannot access professional services. In line with Winkle et al. [18] and Dombrowski, Harmon and Fox [17], we add that the HRI community should attempt to align with societal challenges beyond that of statistical narratives which tend to overlook some voices. Said differently, although there might be an ageing population and a decrease in health-care professionals available, this is likely to create – as well as put more pressure on – informal caregivers and we have a duty to account for it.

7.3 Recommendations: Including Informal Caregivers to Better HRI in 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.

Firstly, it is key to involve informal caregivers more in studies, either through high level involvement or low level. High level involvement would mean either recruiting informal caregivers as participants, or directly collaborating with them in some way to help steer the study in health care. We do understand that informal caregivers are difficult to identify and/or recruit. Accordingly, we suggest for low level involvement, researchers could disclose if they have any experience as informal caregivers, and say how this influenced their choice on how to account for informal caregivers in their robot application. This would be in similar style to low level involvement of formal caregivers, where researchers used their expertise as formal caregivers to steer their own health care research (for example, inducing anxiety in children). Although this has not been done (yet) by researchers looking at informal caregivers, it is likely that some of us have experience with such a role, and using that expertise explicitly in research studies could be a way to involve more openly informal caregivers.

Secondly, as researchers, we need to acknowledge the impact our potential use-cases will have on informal caregivers. Clearly, informal caregivers play a significant role in the health care eco-system, and will continue to do so in HRI health care applications. As pointed out in the results, we expect them to be able to help either (1) set up the device, and/or (2) set goals, and/or (3) play a game with the care receiver, and/or (4) give feedback. And likely, in the future, repair the robot – such as re-boot the robot – if needed. However, they will be expected to do so without necessarily being monetarily compensated for their time and effort. This is in contrast to formal caregivers, who are, and will be, employed to be trained on how to use the robot as well as paid to do it. Therefore we need to be aware of this as a community and explicitly acknowledge

the potential added – or new – workload onto informal caregivers, and how we can do so in a mindful way for all stakeholders involved, which has to include informal caregivers.

Thirdly, we recommend ensuring that bringing tech solutions to care receivers, which will likely impact friends and families, need to be recognised in policies and guidelines. The definition of caregivers offered in this paper did not refer to technology in any way, yet, as pointed out in the paragraph above, it will increasingly be required that informal caregivers help with the set up and use of tech solutions. Although we do not map out exactly how the robots were used for care receivers, the way both formal and informal caregivers were framed in our findings demonstrates that they will play a pivotal role in the deployment of robotic solutions. Whilst formal caregivers are being looked at (for eg [112]), the same needs to be done for informal caregivers to advise on necessary policies and guidelines recognising informal caregivers in this realm as well as ensure that this technology is suited to their needs.

Fourthly, from the dataset collected to do this research as well as from the relevant literature in this field, informal caregivers are seemingly an overlooked group in HRI and thus present a research gap. As the HRI community, we can leverage on our own power – that is who we decide to include and how. This will likely require to start thinking about including informal caregivers from the moment that the research in health care is being designed, in order to ensure that they are included in ethics applications and the recruitment process. Regarding recruitment, one possible way of doing so would be to ask care receivers to also ask their caregiver to take part in the study with them. And/or conduct the study in a way that would be least demanding on informal caregivers, for example, ringing informal caregivers to ask for their feedback on a certain application rather than asking them to fill out a survey or come to a location on a certain time and date. The latter would be well suited for in the wild studies, where informal caregivers might have interacted with the robot at various points during their visits. In turn this would allow for HRI research to respond to more bottom-up demands, rather than institutional ones [40, 46].

Finally, echoing the points above, there is a potential to use more technology in real life context for informal caregivers themselves. As more HCI applications try to cater specifically for informal caregivers [28–30], this shows the possibility for HRI to also look at application-specific for informal caregivers. HCI justifies this research as informal caregivers use technology in any case to help with their care role, thus there is a possible demand for this [27]. In alignment with this, research has demonstrated that if the technology is not well adapted then care receivers and informal caregivers will steer away from it [28]. This leaves the possibility for HRI to find ways to support informal caregivers’ well-being, and in turn improve quality of care for care receivers.

8 Conclusion

This study has aimed to disentangle HRI researchers’ practices within health care through a systematic literature review, using a qualitative analysis method, on 52 health care HRI studies in the ACM/IEEE International Conference on Human-Robot Interaction. The process of disentanglement lead to dissecting research papers

to showcase a narrative on four different facets: 1) *how the researchers capture people’s attention to demonstrate the need* for this application as well as for 2) *who the robot application is targeted for* and also mapping out *how many groups tend to be investigated*. Furthermore, we demonstrated 4) *how and to what extent caregivers are mentioned and involved* in the studies. These four points have been driven by our theoretical lens, namely Social Justice-Oriented Design – with a specific focus on the concepts called ”designing for recognition” and ”designing for accountability” – and Feminist HRI – focusing on power and subject-positioning relations. This framework allowed us to demonstrate the nuances and complexity within this growing field and which stakeholders have been looked at and, ultimately, overlooked.

From those four dimensions, our results indicate that, first and foremost, informal caregivers are not considered key stakeholders within health care in HRI – they were only investigated eight times out of the 52 studies. Yet, this group is still acknowledged as a stakeholder that could ensure the use of robots for the care receivers (they were acknowledged in 24 studies and involved at a low level in five studies). Although, we the authors, refer to this group as informal caregivers, studies do not tend to explicitly identify them as such – including the ones we consider to have investigated informal caregivers. This shows a difficulty in articulating who informal caregivers are in HRI, but the importance of challenging this notion in order to account for them. Furthermore, unlike with formal caregivers 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 formal caregivers were not participants, their knowledge was relied on to create relevant robots for care receivers, but this was not the case for informal caregivers. Finally, regarding methods, the least used methods when investigating informal caregivers were those conducted in the wild, interviews and focus groups – which was practically the opposite for studies investigating formal caregivers. In line with this, here are our summarised high-level recommendations:

1. **Involve informal caregivers more in studies, and this does not necessitate active recruitment:** The HRI community should involve informal caregivers at a higher level. This could either be by directly investigating them, or asking informal caregivers for expertise to use in studies, or acknowledging, within the research team, own experiences as informal caregivers to steer studies in health care.
2. **Recognise the vital role of informal caregivers in HRI, and its possible negative impact:** Informal caregivers play a vital role in society, and will also do so in robotic health care applications. Whilst formal caregivers also play such a vital role, they are compensated for it, and 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. As it is a difficult stakeholder to involve, we suggest in the wild studies are probably best suited to get their feedback.
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.

9 Limitations and Further Work

This work was limited to the ACM/IEEE International Conference on Human-Robot Interaction, which only accepts a number of papers only. Ideally this review should include journals to see if there are similar trends. A further limitation is the use of "informal caregiver", these individuals are not solely carers, and who they are caregiving for will also care for them – as the article asking care receivers to throw a birthday party for their caregiver reminds us. 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.

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Appendix A Section title of first appendix

An appendix contains supplementary information that is not an essential part of the text itself but which may be helpful in providing a more comprehensive understanding of the research problem or it is information that is too cumbersome to be included in the body of the paper.

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