

Robots and the Division of Healthcare Responsibilities in the Homes of Older People

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Abstract. This paper briefly describes the method of a qualitative study, which used focus groups to elicit the views of older people and formal and informal carers of older people on the ethical issues surrounding the introduction of social robots into the homes of older people. We then go on to sketch some of the tensions and conflicts that can arise between formal carers, informal carers, and older people when trying to negotiate the task of dividing care responsibilities, and describe how the introduction of robots may exacerbate, or ease, these tensions. Data from the qualitative study is used to indicate where participants acknowledged, identified and discussed these issues.

Keywords: Ethics, social robots, elderly, older people, care, responsibilities, duties, healthcare, control, autonomy, behavior change.

1 Introduction

According to Sharkey and Sharkey ‘[t]he three main ways in which robots might be used in elder care are: (1) to assist the elderly, and/or their carers in daily tasks; (2) to help monitor their behaviour and health; and (3) to provide companionship’ [1]. There is some overlap between these three uses. For example, monitoring may be instrumental for carers in helping older people [2], and as Sharkey and Sharkey and others [3] point out, assisting in daily tasks can lead to greater social isolation. Sharkey and Sharkey are concerned that older people’s ‘lack of control’ may reduce their quality of life as control is surrendered *to* the robot. There are clearly ethical issues surrounding control *of* the robot, too. Human carers of older people have responsibilities and interests to provide care (including that provided via a robot) in ways that may conflict with what the older person wants, but tensions between carers’ views of how best to deliver care may also be played out through the robot. Likewise, different kinds of carers may have different interests that may conflict with each other and/or the interests of the older person being cared for. Running together the assistance to older people and to carers with daily tasks may mask these tensions. Introducing care-robots may also have an effect on the dynamic between different kinds of human carers, which may raise further ethical issues.

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In this paper, we are concerned with two broad kinds of carer: formal carers – those who are paid to provide care and who may have differing levels of professional qualification and their own hierarchies of responsibility and accountability; and informal carers – relatives or friends of the older person who are unpaid and often unqualified. There are good reasons for ensuring that the older person has a significant say in how their care is organized (see, for instance, the recent political emphasis on ‘patient-led’ care [4], and the significance of householder autonomy in the introduction of robotic care [5]). Nonetheless, formal carers need to retain some control if they are to discharge their duties efficiently and ethically, and informal carers may be juggling the meeting of an older person’s care needs with the need to have some control over their own lives (including, in the case of older carers, meeting their own care needs), and also with other obligations in their lives. The introduction of a robot will be affected by, and have an effect on, the older person-informal carer-formal carer triad, and: ‘the division of tasks and responsibilities becoming care recipient, care provider (formal/informal), technology developer, system-provider (and others) respectively must be made clear’ [6].

This paper will report some of the findings from a qualitative study undertaken as part of the Acceptable robotiCs COMPAnions for AgeiNg Years (ACCOMPANY) project [7]. The findings presented here are incidental to the main aims of the study, which were to explore the potential tensions between values that had already been identified as potentially significant in the design of the ACCOMPANY robot¹ and to see whether additional values needed to be added. The findings outlined in this paper shed light on how the dynamics between members of the care triad, as described above, may be affected by the introduction of a robot; the main results of the study will be reported elsewhere.²

2 Method

21 focus groups were convened in France, the Netherlands, and the UK, with a total of 123 participants. There were three participant groups: older people (OP), informal carers of older people (IC), and formal carers of older people (FC). Four scenarios (Table 1) were designed to provoke discussion amongst the participants, and a topic guide was developed to ensure some consistency of discussion between the groups. They were conducted in native language, video and/or audio recorded, and transcribed verbatim. One representative transcript from each of the three kinds of group convened in the Netherlands and France was translated into English. All the English transcripts were then coded (by Draper) using a combination of directed analysis and Ritchie and Spencer’s Framework Analysis [8]. These codes were discussed with project collaborators at the University of Warwick (UW), the University of Hertfordshire (UH), the Centre Expert en Technologies et Services pour le Maintien en Autonomie à Domicile des Personnes Agées (MADoPA), and Hogeschool Zuyd (ZUYD),

¹ The values were autonomy, independence, enablement, safety, privacy, and social connectedness – see Sorell and Draper [5].

² All ACCOMPANY results are reported on the project website [7].

until agreement was reached. The remaining non-English transcripts from the Dutch and French groups were then coded according to this agreement, and quotations that were selected to represent these codes were translated into English. The report of all the data was then written and circulated to the research team for verification. The methodology informing the study was ‘empirical bioethics’ [9, 10]. Work combining the empirical data and the earlier philosophical work [5, 7] is currently underway and will be completed in September 2014. See Draper et al. [11] for a fuller account of the method and details of the participant characteristics.

Table 1. Brief Description of Scenarios

| Scenario | Brief description |
|----------|---|
| 1. Marie | Marie (78) resists the robot’s efforts to encourage movement that will help her ulcers to heal. She likes it reminding her to take her antibiotics but not its reminders to elevate her leg. She is not honest with her nurse about how much she is moving. |
| 2. Frank | Frank (89) is socially isolated. His daughter wants him to access an on-line fishing forum with the help of the robot. He isn’t keen to try. |
| 3. Nina | Nina (70) has recovered from a stroke. She is rude to her daughter and carers (causing them distress) but not her friends. The robot is programmed to encourage better social behavior by refusing to cooperate when she is rude. |
| 4. Louis | Louis (75) likes to play poker online using the robot. He uses its telehealth function to monitor/control his blood pressure. He doesn’t let the robot alert his informal carers when he falls (which he does regularly, usually righting himself). His informal carers want to re-program the robot so it will not let him play poker and to alert them when he falls. |

3 Findings

Findings are reported using conventional reporting methods for qualitative research. The data is not reported quantitatively, as reporting in quantities and proportions is not appropriate to this kind of data. Data interpretation is illustrated with representative quotations, selected to demonstrate the complete data set. The data has been grouped into themes that speak to the relationship between types of carer and the older person being cared for.

3.1 Responsibility for Older People’s Interests

In all of the scenarios the robot was capable of helping with the performance of some daily task but was also being used to encourage some behavior change in the older person to promote independence, enablement, or social connectedness. Here we will focus on behavior change insofar as it is relevant to the issue of the division of responsibility for caring for older people.

The fourth scenario involved a householder using the robot to facilitate his gambling. This elicited a range of attitudes about whether this use of the robot was permissible – these attitudes relate to the issue of responsibility. In the OP and IC groups, there were participants who viewed Louis as having responsibility for himself when it came to gambling:

Concerning the gambling he says he's in charge of his own money and I have to agree with him... (ZUYD OP1 E3)³

He can't live completely withdrawn into himself even if it's all he wants for now, at least that's how I feel (MADoPA IC1 P5)

The FC participants tended to support this, feeling that as long as the older person had mental capacity, (s)he could make decisions about such things by him/herself, and this perspective was noted by some of the IC participants:

P5: *It does not anywhere say he is mentally limited.*

P4: *Exactly, that is why*

P2: *He is not addicted to the gambling (ZUYD FC1)*

I think it's funny, because at the day of the informal carer at the house of my mother we had a discussion with the professional carers. And the care staff said: 'The client is the King. If the client refuses something we won't do it.' While the children, the informal carers, often have the tendency to say: 'Can't you do this or that with my mother, because that is better for her'. (ZUYD IC1 M5)

Some FC participants thought they may have a role in protecting older people from the over-protectiveness of family members:

Of course they love them, of course they don't want them to die in the immediate future, of course they don't want them to have any accidents, and yet at the same time, they don't realize that they are behaving – and please forgive the harshness of the word – like tyrants. (MADoPA FC P7)

Indeed, in the OP and IC groups, some participants expressed the view that it may be legitimate to restrict or prohibit behaviors like gambling in the interests of the older person:

Once they've added up the cost of his rent, his food, the people who care for him and everything, they can see how much he has left, can't they? (MADoPA OP1 O4)

³ Quotations will follow this format: the site name is reported first, then the focus group, and finally the individual participant code. This is with the exception of quotations with multiple speakers, in which case participants will be identified as they speak.

M1: *But when it comes to the debt repayment I would take action on playing poker before he got into debt.*

M3: *In my opinion sons can interfere with that. (ZUYD IC2)*

There was therefore disagreement between some of the OP and IC participants on the one hand, and FC participants on the other, about whose judgment about the interests of the older users was most authoritative when it came to deciding how the robot should be programmed.

The interests of the carers as a motivation for modifying the behavior of older users of the robot were also discussed. With regard to Louis's gambling, the FC groups tended to consider that familial intervention (re-programming the robot so as to block access to the gambling site) was not aimed at supporting Louis' interests, but was rather directed towards protecting the financial interests of the family members:

And you also have to take into account that there are children who will try and curb their parents' spending because it's part of their inheritance going out of the window! So, given the facts we have here, it's a difficult question (MADoPA FC1 P7)

The daughters also could think of their own benefits. If he spends all of his money his inheritance will not be as much (ZUYD FC2 P7)

The OP group participants also considered family members' financial interests insofar as relatives might inherit the older person's debts:

Everyone has to be considered, because the children are the ones who have to pick up the pieces afterwards, aren't they. (MADoPA OPFG P3)

[H]e could end up with a huge debt you know that's gonna cause problems in fact doesn't it. I don't know where he lives, let's assume that he is in his own house and he gets into a huge debt and the house has to be sold and he's got to go somewhere else. All these things follow on you know if you got drink problem you get into debt, drunk or you get into debt, he could lose thousands and thousands of pounds. I think then it does become a family problem. (UH OPFG P4)

In this instance, and especially in cases where the family are described as deliberately protecting their inheritances, the robot is perceived by the participants as a potential focal point of a power struggle, "a weapon" (UB OP2 P2) even. The presence of a robot whose programming can be changed may exacerbate tensions like these when it can facilitate activities that may otherwise be unavailable to the older person. This may be viewed as empowering for the older person, but it creates a dilemma for carers, who may be unsure what their responsibilities are regarding the new activities that the robot facilitates. For instance, some participants were concerned about the robot introducing older people to the internet in general:

I would have worries about being on an internet forum because Frank's vulnerable, like children are. I mean Frank might have very expensive fishing rods or antiques or something. And somebody on the forum can pretend they're anybody (UB OPFG2 P6)

In this respect, although it could appear, echoing Sharkey and Sharkey, that the robot is controlling the older person, our participants seemed concerned that the robot would be an extension of the existing controlling forces of family members or formal carers.

3.2 Responsibility and the 'Burden' of Care

Participants were also prompted by scenario four to discuss the extent to which Louis could determine when the robot reported his falls. Although Louis was usually able to get up himself with the aid of the robot, participants were told that he has recently lain for sometime unable to get up, and that this had resulted in a bladder infection and the need for more care input from his daughters-in-law. Some participants in the OP groups were sympathetic to the ways in which decisions made by older people could impact on the informal carers:

Well they're bringing him food, helping him, with his cleaning and doing his laundry so they're actually doing quite a bit and when he was in bed they took it in turns to stay with him during the day ...So I think they've got quite a lot invested in this and so to some extent I think there's a bit of a quid pro quo there (UB OPFG3 P7)

You can't make people do more than they can take (MADoPA OPFG1 P3)

Some of the FC participants were also sympathetic about the impact that the older person's decisions might have on informal carers, but they tended to be more sensitive to the effect on the FCs.

I also see it when people want to stay living at home then this has consequences. They do not want that, most often, but it does have those consequences. People sometimes do not want such a system with sensors and I say, but you want to remain living here, so we will have to ensure that it is safe, so there will be some changes to come. So in some ways I think you should expect this. You cannot force them, but that really has consequences. If he really does not want, what you can do as children is tell him. Then we also cannot take care of you. Because I think these children do a lot for him. Then it is allowed to expect a number of consequences of him. (ZUYD FC1 P3)

Some of the FC participants noted that sometimes older people were not sensitive to the fact that they had other clients, which meant that the timing of their visits did not suit everyone (calling during a favorite TV program was noted as an irritant). Personal robots may enable care to be better tailored to users' preferences.

IC and OP participants who had themselves been informal carers tended to be most concerned about increasing the care burden for family members.

In everyone's best interests actually; in his best interests and in the best interests of his family, who won't have to make unnecessary journeys. Who'll come round if he falls? (MADoPA IC1 P1)

All groups were concerned about the safety of older people. As we have already noted, some participants were more willing to accept risk as the price of autonomy, but the majority of participants in all groups tended to favor safety over autonomy or to feel torn between the two. Monitoring is one way of providing reassurance about safety, and is regarded as an advantage of assistive technology in general. Monitoring can reduce the “burden” of care by reducing anxiety, the number of visits required, and the amount of ongoing care required, by alerting carers to the need for early intervention. Falling is a good example here. Monitoring, however, also requires information to be shared, e.g. accessed from or transmitted by the robot to others. In spite of these privacy concerns, it may be in the interests of all three groups to use the robot in a way that will ensure the older person's safety.

3.3 Monitoring, “Policing” and Sharing Information

Our participants recognized the potential value of FCs being able to access health-related information from the robot. FC and OP participants were more concerned about such information being accessible to ICs. FC participants were also aware of the possibility that the care they provided could be monitored. We have reported these findings elsewhere [11].

In terms of ICs' access to information via the robot, of relevance to this paper is what this finding may suggest about the role of ICs in the care “team”. One interpretation is that restricting access to health information is an extension of the norms of medical confidentiality, as health information is not usually shared with family members without the consent of the patient. However, this might also be regarded as the playing out of power differences between ICs and FCs, where knowledge is a form of power and ICs are left to act on the instructions of the FCs who “know” best. Participants in all groups were concerned about ICs making decisions without consulting FCs:

I would have thought that should have been a medical decision, not for the daughters-in-law to decide whether he uses his sticks or his walking frame... I think it should be should be looked into if he is safe to have his sticks or if he needs a walking frame (UB OP2 P5)

No, should have discussed with the medical staff. (UH IC P2)

Obviously, this is not a new issue created by the use of robotics, but it could lead to a perception by ICs that they are below the robot in the care “hierarchy” as the robot has access to information that they do not. As one IC participant noted, ICs may already have the same information that the robot may collect more formally:

Yes, that the robot does something. That it notes things down, just like we do. For instance the number of times she got out of her chair. (ZUYD IC1 M6)

The latter might be regarded as a form of unwelcome “policing” of FCs by the robot. Furthermore, the robot may also be used to collect information on how well older users adhere to health advice (as opposed to just issuing reminders, e.g. to take medication) - participants were ambivalent about this.

They could look at the print out together, that wouldn't be quite as invasive as the robot saying: 'Actually she didn't do that when I told her three times and she didn't get up!' (UH FC PF)

They cannot cheat, right? ... That is the difference. The measures are taken and the robot sends them on to the physician. So there is no possibility to add a few degrees, or make it some degrees less. (ZUYD FC1 P2)

The robot could also be used to “police” whether ICs comply with FCs’ instructions about appropriate care, including where the two groups disagree about how best to discharge care or whether health advice must be followed. This could occur whether or not the older person objects. Many of the FC participants expressed views that were critical of ICs’ decisions, such as here where the ICs’ approach to caring for their relative is regarded as too forceful:

Sometimes, people's children want to force things upon their parents and in the end, instead of having an aid that perhaps was inadequate, they don't use anything at all (MADoPA FC1 P7)

Robotic surveillance may make it easier for ICs to coerce older people to comply with their view of what is best for them.

It seems legitimate for a robot to be used to “police” the care of older people. Older people should not be subjected to poor care or neglect from either ICs or FCs. Our OP participants did not seem to object to the robot being used to monitor health and pass information to FCs. But whether surveillance that lies between these two ends of the data-collection spectrum is policing or monitoring may be a matter of perspective that may reflect reasonable differences of opinion on what care to deliver and how. Ideally, differences of opinion and conflicts of interests in the care triad can be resolved by compromise and negotiation:

And how one gets to that end result, maybe a mix of you know, input from the nurse, further explanation, encouragement from other people might pop in, or I don't know. That's what I would be hoping for is this, you know, some[one] being able to understand the importance of what is needed (UH FC PB)

Disagreements may be magnified, however, if the robot shifts the balance of power by giving more control to one or other parties.

4 Limitations

Focus groups were conducted in different languages and meaning may have been inadvertently altered in translation. Some of the transcripts were analyzed in their original languages, which may have affected standardization in the analysis. The team attempted to mitigate these issues with discussion about the translation and coding.

5 Conclusion

In this paper we have presented and briefly discussed incidental findings from a qualitative study that shed light on how robots might impact on the division of care between FCs and ICs, and on how responsibilities for determining and providing care are perceived. We have considered some of the tensions that were discussed by the study participants between allowing older people to govern their own care, and carers taking some control over and responsibility for it. Notably, these tensions may be exacerbated with the introduction of a robot, particularly if it is used to monitor the older person's behavior. While monitoring may be seen by some as intrusive, it may often be justified by invoking both the interests of the older people in that it may help to ensure their safety, and the interests of both types of carer in that it may ease their burden of care.

We have highlighted the fact that existing divisions of responsibility may affect the interests of older people, but also those of the carers themselves. Furthermore, we have reflected on the added tensions that arise when different types of carer disagree about how to discharge care, when there can be suspicion or disapproval of the way that other carers do this. Use of the robot may therefore become a point of conflict between carers and the older people themselves, or between different groups of carers. This suggests that careful consideration must be given to the extent to which each care group, and the older people themselves, can control the robot. Our data may suggest that FCs should be given priority in their control of the robot over ICs, related to concerns that ICs may have financial motivations or other conflicts of interest. It may, however, be a mistake to imagine that FCs' motivations are so relatively undivided, as they must divide their care between multiple clients, and may, unlike ICs, perceive their obligations only to stretch as far as their professional role demands. Those designing robots for care purposes should be aware that these complex ethical issues exist, and should seek guidance from ethicists or ethics literature when considering how they are to be negotiated.

Acknowledgements. The work in this paper was partially funded by the European project ACCOMPANY (Acceptable robotiCs COMPAnions for AgeiNg Years). Grant agreement no.: 287624. This paper would not have been possible without the input of ACCOMPANY partners UW, ZUYD, UH, and MADoPA, especially Sandra Bedaf, Tom Sorell, Dag Sverre Syrdal, Carolina Gutierrez-Ruiz, Hagen Lehmann, Kerstin Dautenhahn, Gert-Jan Gelderblom, Hervé Michel and Helena Lee who were also involved in the data collection and the initial analysis of the data set. We are also grateful to all the participants who took part in our study.

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