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Ethics in Evaluating a Sociotechnical Intervention With Socially Isolated Older Adults

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Abstract

The purpose of this article is to consider how ethical principles can inform the effective design and implementation of technology-based interventions that aim to promote the wellbeing of socially isolated older adults. We evaluated a new iPad application with small groups of older adults. In this article, we reflect on the ethical issues encountered at each stage of the research process. Drawing on the ethical principles of beneficence, research merit and integrity, justice, and respect, we identify key issues to consider in the future design and implementation of social isolation interventions that use new technologies. Key issues include: (a) providing sufficient support to facilitate ongoing social interactions, (b) managing older adults' expectations, (c) providing encouragement without coercion, and (d) responding to individual needs. We conclude that it is important to report on ethical challenges incurred when evaluating social isolation interventions to inform future research in this important area.

Keywords

ethics / moral perspectives; older people; participation, social; technology; vulnerable populations

Social isolation occurs when a person has limited opportunities to see and interact with other people. It has been linked to several negative health outcomes, including depression and early mortality (Giles, Glonek, Luszcz, & Andrews, 2005; Steptoe, Shankar, Demakakos, & Wardle, 2013). For older people, the experience of illness or frailty can limit opportunities to engage with others. This is particularly problematic for those who live alone. In some Western countries, close to one-third of all people aged 65 and above live alone, making older people especially vulnerable to social isolation (Administration on Aging, 2012; Australian Bureau of Statistics, 2013).

Researchers have evaluated the outcomes of numerous social isolation interventions (see Dickens, Richards, Greaves, & Campbell, 2011) but limited attention has been given to the ethical issues that arise when intervening in the social lives of vulnerable older people. Social isolation interventions include diverse approaches, such as group activities, educational programs, and one-to-one befriending schemes. Emerging technologies now provide new opportunities to extend these approaches, but they also introduce concerns about privacy and autonomy (Sorell & Draper, 2014). Although there has been some discussion in the literature about the ethical issues associated with the use of assistive and monitoring technologies for older adults (e.g., McLean, 2011; Sorell & Draper, 2014; Zwijsen, Niemeijer, & Hertogh, 2011), there has been little consideration of ethics in the context of using communication technologies to enhance the social lives of older adults. Assistive devices and communication technologies have vastly different purposes and uses. The latter requires older adults to fully participate in using the technology to engage in communication with others, while the former can sometimes require a passive role from older adults as recipients of care, service, and surveillance. It is necessary, then, to consider the ethical issues that arise in the context of technology-based social isolation

interventions separate to the ethics of using assistive and monitoring devices. Reflecting on the ethical issues that occur when evaluating new social isolation programs can help to inform the design of future interventions to ensure they truly support the social engagement of this vulnerable population.

In this article, we examine key ethical challenges encountered during qualitative research that evaluated a *sociotechnical* intervention used to address social isolation in older people. Sociotechnical systems are those that use technology in defined social settings. Our intervention consisted of a specially designed software application (i.e., the "technical") and a protocol for regular face-to-face gatherings, visits from researchers, and communication with a care organization (i.e., the "social"). The technology was a prototype iPad application, *Enmesh* (Engagement through Media Sharing), designed specifically to be used by older adults to create, share, and view photographs and messages within a closed social network. The application featured an interactive shared display: using a touch-screen interface, participants could move photographs or messages around the screen, alter their size, or remove them from the display. These interactions were visible to the other people connected to them on Enmesh, to enable isolated older adults to form a sense of the presence of others in the network. The underlying aim of this project was to identify how new technologies can be used to enhance the connectivity and, consequently, the wellbeing of older adults who are socially isolated.

We have previously evaluated the degree to which this sociotechnical system enriched the lives of older adults who were predominantly housebound and socially isolated (Vetere et al., 2012; Waycott et al., 2014; Waycott, Vetere, Pedell, et al., 2013). Our aim in this article is to identify the ethical issues concerning the design, implementation, and evaluation of technology-based social interventions for older adults. We firstly review the principles and practices of

research ethics and outline the issues that are common in qualitative research conducted with older adults. We then describe our research process in more detail and discuss the specific issues and challenges encountered at each stage of the process. Finally, we draw on our experiences and underlying ethical principles to identify key considerations for the future ethical design and implementation of technology-based social isolation interventions.

Ethical Research With Older Adults

Research studies that involve human participation, regardless of methodology, must be designed to adhere to ethical principles. The Australian National Statement on Ethical Conduct in Human Research identifies four core principles: *beneficence*, *research merit and integrity*, *justice*, and *respect* (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors' Committee, 2013). These principles broadly align with international standards of ethical research (e.g., Council for International Organizations of Medical Sciences, 2002). Adhering to the principle of *beneficence* requires ensuring there are clear research benefits for participants and the broader community and that the benefits outweigh any risks or potential harm that participants might experience. The principle of *research merit and integrity* highlights the need to consider the value of the research and the integrity of its design. This includes, for example, selecting appropriate data collection methods and ensuring researchers have the ability to conduct the research with integrity. The principle of *justice* refers to the fair treatment of research participants and assurance that participants are not unfairly burdened by their involvement in the research. Finally, *respect* is central to all human interactions, including research. This principle means having respect for participants' autonomy and displaying a commitment to protecting participants from physical or emotional harm. These

four principles underpin ethical research practices, such as gaining informed consent, ensuring participants' confidentiality, and minimising any risks participants might encounter.

Formal governance procedures ensure human research can only proceed if the design of the research is ethically sound. By submitting proposals to institutional ethics committees or review boards for approval, researchers adhere to the formal requirements for ethical research. Guillemin and Gillam (2004) made a useful distinction between these procedural ethics requirements and more specific and emergent "ethics in practice," which they described as the "day-to-day ethical issues that arise in the doing of research" (p. 264). It is important for researchers to consider ethical principles throughout the research process, not just when planning the research, particularly when the research involves ongoing interactions with participants. Social interactions are unpredictable. This requires researchers to adopt a reflexive awareness of the ethical issues that occur during the research process, to consider their implications for the research, and to plan an appropriate course of action (Allmark et al., 2009; Guillemin & Gillam, 2004; Hewitt, 2007). This course of action might deviate substantially from what was originally planned; in some cases, adopting a reflexive stance involves reconceptualising the meaning and aims of the research (e.g., Russell, 1999). Furthermore, at the point of research completion there is an opportunity to reflect on how specific ethical issues can be mitigated when translating the research into practice.

Ethical and methodological challenges occur in all research, but they are often amplified when the research involves vulnerable participants or sensitive topics. Aging itself is not a vulnerability. Individual experiences of aging vary greatly, and older adults have diverse levels of independence, cognitive capabilities, and financial security (Schroder-Butterfill & Marianti, 2006). For those who are frail and housebound or dependent on care, however, vulnerability

imposes barriers for the ethical conduct of research and raises challenges regarding the role of the researcher, appropriate recruitment strategies (e.g., through service providers) and the location of the research, which often takes place in the participant's home (Allmark et al., 2009; Jokinen, Lappalainen, Merilainen, & Pelkonen, 2002; Locher, Bronstein, Robinson, Williams, & Ritchie, 2006; Quine & Browning, 2007; Russell, 1999).

Locher and colleagues identified two key ethical concerns in research conducted with housebound older adults. First, because such participants often receive health and community care from service providers, they can be prone to "therapeutic misconception," where they mistake the research process for formal care or service provision (Lidz & Appelbaum, 2002). Second, researchers who interview older adults in their homes can experience "role conflict". That is, they might have difficulty maintaining and setting boundaries around their role and knowing when to step outside the role of researcher. Role conflict is more likely to occur in research that takes place in the home. In private domestic spaces researchers become privy to the sort of information that would normally be kept hidden. For example, researchers might observe risks to participants' physical safety at home, or discover evidence of elder abuse (Locher et al., 2006).

When the research addresses a sensitive topic, such as older adults' experiences of isolation, the participants' vulnerability can be further accentuated by the research process itself, thereby challenging the ethical principles of respect and beneficence. Russell (1999) reported the procedures followed during a qualitative study of older adults' experience of social isolation. The sensitive topic made it difficult both to recruit participants and to conduct interviews. Service providers were reluctant to nominate their clients for participation because they believed this would challenge clients' "identities as independent people" (p. 405). The researchers therefore

changed the interview guide to avoid asking participants direct questions about their isolation. They found some participants were nevertheless willing to share intimate details about their experience of isolation and appeared to find this disclosure cathartic. Others, in contrast, went to great lengths to avoid any discussion of such topics during the interview. For these participants, giving voice to vulnerability was threatening. There appeared to be a tension, then, between the principles of respect and beneficence.

The ethical principle of justice is embodied in the right to participate. Providing older adults with an opportunity to share their stories and voice their concerns can clearly be a positive experience for participants (Higgins, 1998). Standard recruitment practices and procedural ethics requirements, however, can preclude older adults from participating in research, particularly those who have cognitive or sensory impairments which can impact informed consent and standard data collection methods (Quine & Browning, 2007). This means they are either not invited to participate or are limited in their ability to engage fully in the research process, denying them the opportunity to share their stories. This exclusion can contribute to the marginalization of older people in society. As Quine and Browning argued, excluding older adults from research because of "paternalistic views" can be a form of discrimination (p. 135).

The ethical issues discussed in this section primarily relate to interview research, but ethics in practice issues are emergent and diverse, so that each research project will encounter a unique set of challenges (Allmark et al., 2009; Guillemin & Gillam, 2004). Research that employs multiple and innovative methods, that takes place over an extended period of time, or involves interactions other than those between participants and researchers (e.g., between participants and health practitioners), will encounter additional challenges. Furthermore, the emergent, or unanticipated, nature of ethics in practice is amplified when research involves the

use of new technologies with vulnerable participants. In our study, implementing and evaluating a novel social technology with older adults presented unique ethical challenges.

The Study

Our research comprised three separate field studies. Each study was approved by the University's Human Research Ethics Committee. During each study we evaluated a new iteration of the iPad application (Enmesh) with a new group of socially isolated older adults. Each study involved slight modifications to the social component of the program, but the research process remained largely similar across all studies. Here, we describe the research process before reflecting on the "ethics in practice" issues encountered at each stage of the process.

Participants

The research was conducted in collaboration with an aged care service provider. Participants were all clients of the care provider and were living independently in their own homes but were frail, with limited mobility and complex needs, which made them eligible for home-based care and support services. Each client had a care manager who was responsible for assessing, organizing, and overseeing their care and support services. In this role, care managers developed a thorough knowledge of the clients' care needs and maintained a supportive relationship with them, which involved regular home visits (usually once a month) and telephone calls.

At the start of each field study, care managers identified clients who were suitable to participate in the study. Clients were deemed to be suitable if they were: a) identified by their care manager as being (or at risk of being) socially isolated; b) receiving a community home care package, which meant they were over 65 years of age and had significant health and/or mobility problems; c) living in their own home (i.e., not those in residential care); d) willing to participate

and had the physical and cognitive capacity to do so (as assessed by care managers). There was no expectation about familiarity with or access to particular technologies. As the project progressed we refined our criteria for identifying clients who were socially isolated. Clients were considered to be isolated if they scored highly on one or more of three checklists that measured: a) how much support clients had from family members and friends, b) how often clients participated in group or community activities, and c) how connected clients felt to the world around them. This checklist was developed by the project team based on items selected from established measures (Hawthorne, 2006; Lubben et al., 2006).

Although participants were recruited through the care organization, we took care to ensure clients understood that participation was voluntary and any decision not to participate, or to withdraw from the project, would have no impact on the care they received. The project plain language statement included a clause stating that:

> **Participation is voluntary:** You may withdraw your consent to participate and discontinue participation at any time. You may also withdraw any unprocessed data previously provided. As your care provider, the [care] organization does not require or expect you to participate. If you choose not to participate or to withdraw your participation at any time, this will not affect your relationship with your care manager or the service you receive from [the care organization].

Procedure

For each field study, the research protocol began with a visit to participants in their homes. We introduced the technology and conducted interviews that explored participants' experiences of social isolation. Throughout each field study, participants used Enmesh to create photographs

and write captions or messages. Enmesh is a closed social networking tool. Participants could see each other's photographs and messages on a shared display, but only if they were connected as "friends" on Enmesh. Initially, participants shared photographs and messages with the researcher and their care manager only. The researcher and care managers also created photographs and messages, which they shared with participants to provoke interest, encourage use of the technology, and model the sort of communication that could be facilitated using this tool. After using Enmesh for a few weeks, participants had the opportunity to meet each other in person at a social event. These events were held in a central location and took place during morning or afternoon tea. The care organization arranged transport for clients; care managers also attended the events. The events were very successful and helped participants to build friendships and develop a sense of community. Following the first social event, participants were able to connect to the other participants via Enmesh. For the remainder of the study they shared photographs and messages with each other using Enmesh. At the end of each field study we conducted final interviews with the participants and their care managers to evaluate how well the intervention had worked for them. In addition, we analysed the content that participants created and shared on Enmesh (Waycott et al., 2014; Waycott, Vetere, Pedell, et al., 2013).

Ethical Issues Encountered in This Research

In this section, we reflect on the ethical issues encountered at each stage of the research process. For the purposes of this discussion, we have divided the research into five stages: a) recruiting participants, b) introducing the technology, c) using Enmesh to communicate, d) hosting social events, and e) ending the field studies.

Recruiting Participants

We recruited participants through the care provider. Care managers spoke to the selected clients to find out if they would be interested in learning more about the project and to gain permission to pass on contact details to the researchers. If permission was given, researchers contacted the selected clients and met with them to explain the purposes of the project and to formally invite them to participate in the study. Care managers usually attended these meetings, which took place in the client's home. Our participants were often vulnerable, and it was important they were introduced to researchers in the presence of a familiar and supportive person. In some cases this was not necessary and we met participants on their own. We were guided throughout by the care managers, who knew their clients well and could advise us on the approach that would make their clients feel most comfortable. The care managers' role in obtaining consent, however, was only to identify suitable clients and to gain permission for researchers to contact the clients. Care managers did not explain the project in detail to clients and did not ask clients to sign consent forms.

Recruiting through the care organization enabled us to identify and target the people that this project aimed to support, but it created two opportunities for reflection about ethical issues that can be problematic in this research setting. First, there was a risk that participants might have experienced stigma knowing their care managers had identified them as socially isolated (this issue has been discussed previously by Russell, 1999). In our studies, we did not explicitly inform clients that they had been identified as suitable to take part because they were considered to be socially isolated. However, during the process of informed consent, the purpose of the study was made clear. At this stage, some participants clarified that they did not consider themselves to be isolated or lonely, but were happy to take part in the project. One client chose to

withdraw from the project because she found the focus on social isolation to be confronting (Waycott, Vetere, & Pedell, 2013); in this case, we offered follow-up support to the client through the care manager. Other clients typically viewed the project as an opportunity to try something new. They were pleased their care manager had considered them to be capable of learning to use an iPad and were keen to explore new opportunities to connect with other people.

Second, this method of recruitment led us to reflect on the dependent relationship between clients and care providers. Although care managers did not recruit participants themselves, caution was required to ensure that clients did not feel any coercion or obligation to take part in the study, or experience therapeutic misconception (Lidz & Appelbaum, 2002). There is always a power imbalance when research involves recruiting participants through healthcare services, but this was mitigated in our case by care managers seeking consent for contact only. In addition, care managers took part in the study as co-participants, using Enmesh to communicate with their clients in a social way, outside of the care relationship. Care managers played an important role in reassuring clients about their capacity to participate as the technology aspects of this project were extremely foreign to most participants. We acknowledge there is a fine line between encouragement and coercion. We mitigated this risk by emphasising that participation was voluntary, that not participating would have no effect on the care participants received from the organization, and that they were free to withdraw at any time. This process was effective, with clients deciding to withdraw at various points in the research process. Nevertheless, there remains a risk that participants might have felt obliged to participate, and obliged to report back that they enjoyed the study, because their care managers had suggested it would be “good for them”.

One participant was clearly motivated to continue taking part in the project because she wanted to please her care manager. This client, aged in her 90s, was particularly frail and dependent on others for support. At several points during the study she expressed disinterest in the iPad, but then exclaimed "Don't tell her [care manager]! She'll put me into a home, she will." Although said with some jest, this statement reveals an underlying motivation to impress the care manager. The client wanted to portray a particular image of herself as an independent person to reassure the care manager that she was still capable of looking after herself. Being seen to disengage from the project because she did not want to use the iPad (primarily due to her deteriorating eyesight) would have compromised this image. This is the only case we encountered where the client's relationship with the care provider created an ethical challenge, but it highlights the need for clear guidelines on encouragement and coercion when managing the implementation of similar sociotechnical interventions via care providers in the future.

Introducing the Technology

We faced two ethical challenges when introducing the technology: a) managing participants' expectations about the technology and, by extension, the project; and b) reassuring participants that they were capable of using the technology without coercing them to participate.

During the introductory meetings we explained to participants that they would be using a new iPad application, Enmesh, to communicate with each other. The iPad is a popular technology. Participants, family members, and care managers all had preconceptions about what it could, or should, be used for, particularly as a tool for communicating with family members and friends. Participants were free to explore other uses of the iPad, but we were unable to provide substantial support in helping them learn these other features. We clearly explained the goals and scope of the project, through plain language statements that had been evaluated and

approved by the university's ethics committee. The plain language statement explained that if clients chose to participate they would be using Enmesh to share information with other aged care clients in order to foster new social connections. This focus on sharing information within a newly created group was part of our research protocol and allowed us to include older adults who did not have any existing family members and friends with whom to communicate. Although we made this clear during the introductory phase, participants sometimes anticipated the project would help them learn to use the iPad for divergent purposes, such as communicating with grandchildren. As this was outside the scope of the project, we were unable to ensure these expectations were met. The innate qualities of the iPad as a multi-function consumer device created unanticipated consequences for managing participants' expectations about the project.

The second challenge we faced is that some participants were fearful that they would struggle to learn to use this new technology. These participants were initially hesitant to participate because of a lack of confidence in using the technology, rather than a lack of desire to be involved. Some participants agreed to take part following encouragement and assurance from the research team that they would do a "good job". In one case a participant wanted to withdraw because she thought she was failing the research team by not contributing enough. The researcher explained that there were no set expectations regarding her contribution to the project and that she had not "failed" the project. In the end she decided to continue and said she was grateful she had been given a "second chance".

Using Enmesh to Communicate

In this research we introduced a new technology to older adults, while also facilitating new social connections via the technology. This created three new ethical challenges: a) managing participants' misunderstandings about the technology, b) ensuring the expected social benefits

were realized, and c) supporting communications between people who did not already know each other.

In response to the first challenge, we found there was a need to carefully manage and respond to participants' understandings about the technology. Although we provided scaffolding and support in using the technology, there were times when misunderstandings about the technology were difficult to overcome. Participants were quick to blame themselves or lose confidence if anything went wrong. One participant accidentally put the iPad into "airplane" mode. Not knowing what this meant, she was worried her iPad was now interfering with air traffic control and even turned the television on to check if there had been any air disasters. During one field study we discovered another participant, who had struggled to understand how to use the iPad, had been writing messages using the *Notes* application on the iPad. These were memos that had not in fact been sent to anybody, but the participant believed he had sent them to the researcher and clearly expected a response, as these extracts from his notes show: "Have you got my messages, my good lady?" and "I put on twice a message to you . . . Hopefully this one will come to you. This is the third time I tried to respond to your nice wishes." This was a significant ethical issue. The participant, who lived alone and had no family nearby, was waiting for the researcher to reply to messages that had never been sent or received. This misunderstanding was not due to a lack of information about the system; it was an unintended result of using a consumer product which contained numerous applications in addition to the software we were evaluating. In future evaluations it could be useful to limit or control the external applications a participant can use or to provide more extensive support and training that covers the full range of software that can be accessed using the selected device.

A second related issue is that it was difficult to ensure the anticipated social benefits of the project would be realized. There was sometimes sporadic activity on Enmesh, causing frustration for participants who wanted more frequent communication. Each field study involved a small group of participants. A range of factors impacted participation levels, leaving other members of the group wondering why nobody was communicating with them. One participant sent a message that asked: "Is anybody out there? I feel like I'm talking to myself. Please help me by answering me. I hate talking to myself." Over the next few minutes he sent several similar messages, culminating in: "That's it. I knew I was just talking to a plastic thing. I feel silly." His messages could be viewed as somewhat playful ("I feel silly"), but they also suggest an underlying loneliness and an expectation that this feeling would be alleviated by immediate responses from others in the group. In the future design and implementation of similar systems designers need to consider how the technology can support immediate communication and how expectations regarding communication and connection will be managed.

A third issue is that we were connecting a group of strangers and there was no guarantee that participants would enjoy communicating with each other. One of the important findings from this research is that participants found it difficult at times to find common interests (Waycott, Vetere, Pedell, et al., 2013). We experienced one incident in which a participant was clearly unpopular with other members the group: during a social event, he dominated group discussions and talked over other people. The other participants requested not to be connected to him on Enmesh. This raises an interesting ethical dilemma about how to ensure the benefits of social isolation interventions are open to all, while also respecting individual participants' rights to choose who they want to communicate with.

Hosting Social Events

Although many participants spoke highly of the social events and suggested that more gatherings like these would have improved the project, the social events highlighted to us the various forms of frailty, mobility constraints, and other individual needs that affected our participants. For example, one bedbound participant required support from his family to attend the social events. At one event, his daughter took part in the group conversation and offered feedback about the impact the iPad had had on her father's life. Her insights were valuable, but her participation raised ethical challenges. It was unclear how we should use the information she provided, given that she was not officially a consenting participant in the study. The challenge of involving non-participants in the research process is common in research conducted "in the wild" of real-world settings (e.g., Munteanu, Molyneaux, & O'Donnell, 2014).

We came to realize that inviting participants to attend face-to-face events could have created undue stress and discomfort for those whose health problems made it difficult to interact with others in social settings. One participant was clearly upset when he described his hearing loss, which made it very difficult to enjoy any social outings and left him feeling disconnected from group conversations. Another participant described the anxiety he experienced when travelling to and from the social events. Chronic pain and incontinence meant that leaving the house for any length of time was fraught with challenges. He said he was hesitant to accept a drink while at the morning tea because "if you don't take anything in you don't need to lose it somewhere." These examples highlight the importance of using inclusive methodologies and responding to individual needs when developing sociotechnical systems for isolated older adults. They also emphasize the potential benefits of technology-based social isolation interventions for older people who are housebound because of medical conditions. Technology can provide an

opportunity to connect with others without experiencing the pain, discomfort or embarrassment that social gatherings might induce.

Ending the Field Studies

As is common in qualitative research with vulnerable participants, care was required to ensure we ended the field studies in an ethical manner. There were two particular challenges we faced: a) ending the relationship between participants and researchers, and b) removing access to Enmesh.

Other researchers have noted that one of the key challenges of conducting research with older adults, particularly when the research involves building rapport over time with participants who normally have limited contact with other people, is ending the relationship between participants and researchers (e.g., Higgins, 1998; Russell, 1999). In our project, the field studies ranged in length from three months to more than six months. During that time researchers communicated with participants in multiple ways: we visited participants in their homes, attended social gatherings, and shared photographs and messages on Enmesh. In addition, because our participants were frail and needed support, we were sometimes asked to assist with minor tasks during the home visits. These multiple forms of contact can inadvertently raise participants' expectations of friendship and support beyond the life of the project. We tried to manage this by making it clear that the project would be coming to an end at a particular time. Nevertheless, one participant was explicit about her expectation of ongoing friendship. When asked how she had benefited from the study, she replied: "I've enjoyed the contact I've had with you and I would like that to be maintained".

A second challenge we faced was removing access to Enmesh without causing harm or distress. At the start of each study we explained to participants that the iPads were on loan from

the university and they would be obliged to return the iPads at the end of the study. When the time came, this was quite difficult because some participants had benefited from using the iPad extensively for a range of purposes. To resolve this ethical challenge, the aged care provider agreed to provide each participating client with a new iPad. Access to Enmesh could not be maintained, however, because it was a prototype that was not supported outside the project. Many community-based interventions eventually come to closure due to limited resources or project funding. It is therefore important when designing and implementing sociotechnical interventions to consider how those interventions will be supported beyond the project to ensure that the benefits are long-ranging, rather than temporary. Similar concerns have been raised by researchers who have developed and implemented new technologies in neighbourhood community settings (Taylor, Cheverst, Wright, & Olivier, 2013). In our project, at the conclusion of each field study care managers organised alternative social activities for their clients as needed. One of the outcomes from the project is that care managers became more aware of the social needs of particular clients and were able to recognise and respond to those needs through ongoing support and provision of services. Therefore, although ending the field studies did involve ending communication with other clients via Enmesh, it also led to further opportunities for other forms of social contact. In addition, we provided participants with the option to continue communicating with each other; for example, through email or telephone contact or through attendance at joint social events organised by the care provider.

Ethical Principles for Implementing Sociotechnical Interventions

In this section we work within the framework of the four principles of ethical research to reflect on the key lessons learned from the challenges we encountered during our research. In doing

this, we provide recommendations for ethical considerations in the design and implementation of technology-based social isolation interventions for older adults.

Beneficence

The principle of beneficence means that the benefits of the study for the individual or group outweigh the risks of participation. Our project resulted in a number of benefits. The participants enjoyed using Enmesh. It facilitated social engagement, provided new opportunities for creative self-expression, and enhanced the relationship between clients and care managers (Vetere et al., 2012; Waycott et al., 2014; Waycott, Vetere, Pedell, et al., 2013). The project was an evidence-based intervention: it was designed based on the likelihood of success, drawing on a review of the literature on social isolation interventions (Cattan, White, Bond, & Learmouth, 2005), feedback from care managers, and the close involvement of the aged care partner organization. Adapting evidence to a real-world setting, however, is not always seamless or precise. Some of the challenges we encountered highlight opportunities to improve beneficence in future implementations of technology-based social interventions.

Our experiences suggest that it is not enough to simply enable isolated older adults to use technology to connect to other people. To ensure anticipated benefits are realized, it is crucial to attend to the social aspects of the intervention. Being mindful of our participants' vulnerability and their limited experience using technology, we introduced the technology to participants in a staged process, scaffolded their use with encouragement and support from care managers, and provided opportunities for participants to communicate in person (Waycott et al., 2012). Although these strategies supported participants' technology-based interactions and helped them to gain enjoyment from using the technology, it was difficult to ensure they experienced ongoing benefits. A key lesson here is that significant effort is required when designing an intervention to

ensure that socially isolated older adults have the opportunity to get to know each other and to build common interests. Consideration also needs to be given to how the social benefits can be maintained beyond the life of a project, when support from practitioners and researchers is no longer available. We recommend that future technology-based social isolation interventions need to be designed to include an "exit strategy" where improvements in social inclusion are supported in an ongoing way. In addition, to ensure the sustainability of a project such as this, consideration needs to be given to ownership of the technology; it is better to provide technologies that are fully owned by participants and can be used beyond the life of the project.

Research Merit and Integrity

The principle of research merit and integrity promotes the careful design of research to ensure that the outcome is worth pursuing and the research is conducted with sufficient rigour. In adhering to this principle, a key challenge we encountered was managing participants' expectations about the project. Both clients and care managers had preconceptions about how the technology should be used, which sometimes interfered with their comprehension of the purpose of the project. In addition, participants saw their involvement in the study as an extension of their role as clients of the care organization (Waycott et al., 2012). This was helpful for ensuring they felt comfortable contributing to the research, but also raised questions about the ethics of recruiting through a care provider. When conducting research in collaboration with care providers there is always a risk of therapeutic misconception (Lidz & Appelbaum, 2002). This can threaten the merit and integrity of the research because participants might modify their contributions according to what they believe is expected of them. Conversely, if participants' expectations about the project are not met, they might withdraw and stop contributing to the research, which also has implications for the integrity of the research outcomes.

Social isolation interventions are often implemented and evaluated by care organizations or community groups (Bartlett, Warburton, Lui, Peach, & Carroll, 2013). During the introduction of a social isolation intervention, care is required to ensure that participants have clear expectations about the intervention, separate from their expectation of service received from the care provider. In addition, when the intervention involves using new technology, it is important to clearly communicate expectations about how that technology will be used, particularly if it is an established and popular consumer device.

Justice

The principle of justice is reflected in inclusive research design that promotes equity. This involves not only giving people a voice by ensuring they have the opportunity to participate, but also safeguarding participants' right to withdraw or not participate. When the research is conducted in collaboration with service providers and involves considerable investment of time from participants, as our research did, it is especially important that participants have the ability and autonomy to choose not to participate or to withdraw from the study. Our experience shows the delicate balance required in respecting the principle of justice while also responding to participants' vulnerability. When older adults lack confidence in their ability to participate, gentle encouragement might be helpful – but care needs to be taken to ensure that researchers also respect participants' autonomy and right to withdraw or to choose not to participate. This can be particularly challenging when implementing social isolation interventions in a community setting. Care providers might want to encourage clients to participate in a program because they can see the benefits that clients would experience if they took part, but these benefits might not be immediately apparent to the clients themselves. Researchers and practitioners implementing

social isolation interventions will need to carefully tread this pathway and remain focused on the wellbeing of the participant as a priority.

Respect

Closely related to the principle of justice, respect is reflected in research practices that promote autonomy and adopt methods that allow for individuals to express themselves, gain benefit from the research, and feel valued for their contribution. In our research, adhering to this principle involved recognizing and responding to individual needs, understanding different experiences of vulnerability, and adapting our approaches accordingly. As discussed above, some participants required additional support to ensure they did not feel overwhelmed or confused when learning to use the technology and there were times when particular research practices, such as face-to-face meetings, inadvertently enhanced participants' vulnerability and might have risked psychological distress. However, as we have detailed in other articles about this research, participants experienced benefits from exploring new ways of socialising with others, which involved, on some occasions, stepping outside of their comfort zones. Participants' involvement in the research was well supported and their suitability for inclusion was guided at all times by their care managers.

One lesson we can draw from this is that it might not be possible or beneficial to design a social isolation intervention that adopts a "one-size-fits-all" approach. Older adults who are socially isolated comprise a diverse group. Respecting their individual needs and preferences requires careful and considered approaches. This can make it difficult to systematically evaluate a specific intervention. We recommend a combination of qualitative methods that can be adapted to be respectful of participants' individual needs and allow researchers and practitioners to

develop an in-depth understanding of the impact that the social and technical components of an intervention have on different participants' wellbeing.

Conclusion

In this article, we have reflected on our experiences of ethics in practice in research that evaluated a technology-based social isolation intervention for older adults. In health and social research, there is growing interest in the use of emerging technologies to promote the wellbeing of older adults who are socially isolated (Biordi & Nicholson, 2013). However, published reports describing the design and evaluation of these innovations rarely include discussions of ethical issues. By bringing ethical considerations into the foreground, our article contributes to current understandings about how new technologies can be best used to support older people who are socially isolated. Reflecting on the four core principles that underlie ethical research, we have identified key considerations for the ethical design of future sociotechnical interventions for socially isolated older people:

1. Promoting beneficence involves attending to the social aspects of a technology-based intervention and providing support to facilitate ongoing interactions;
2. Ensuring the merit and integrity of evaluation research involves clearly communicating project aims and considering how participants' diverse expectations about the technology and the program affect their participation and responses;
3. Adhering to the principle of justice involves providing encouragement to ensure that those lacking in confidence have the opportunity to participate, without coercing people who genuinely do not want to take part;
4. The underlying principle of respect involves recognizing and responding to participants' individual needs, and designing the intervention accordingly.

Although specifically targeting technology-based social research, these lessons have relevance to all qualitative research involving older adults. When designing research with older adults it is important to consider each participant's communication needs and preferences, to design methods to ensure participation is equitable, to carefully communicate what the research involves and what the outcomes might be, and to provide support as needed to ensure participants feel comfortable contributing to the project.

Our experiences support the argument that it is important to consider ethical principles not only when planning a project, but throughout the research process. This key lesson is central to all research, and particularly qualitative research involving vulnerable participants. Ethical issues evolve over time, highlighting the need for researchers to monitor their occurrence and reflect on the ethical challenges that emerge during each study. This applies not only to research, but also when health practitioners and organizations implement social isolation interventions in the community. The use of new technologies to help alleviate older adults' experiences of social isolation is an emerging research area. Evaluations of technology-based social isolation interventions need to go beyond reporting outcomes, to also consider the ethical challenges that such interventions can involve. Reflecting on these ethical issues can help to inform future research and development in this important field.

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References

Administration on Aging. (2012). A Profile of Older Americans: 2012: U.S. Department of Health and Human Services.

Allmark, P., Boote, J., Chambers, E., Clarke, A., McDonnell, A., Thompson, A., & Tod, A. M. (2009). Ethical issues in the use of in-depth interviews: Literature review and discussion. *Research Ethics, 5*(2), 48-54.

Australian Bureau of Statistics. (2013). Reflecting a Nation: Stories from the 2011 Census. Canberra: Commonwealth of Australia.

Bartlett, H., Warburton, J., Lui, C.-W., Peach, L., & Carroll, M. (2013). Preventing social isolation in later life: findings and insights from a pilot Queensland intervention study. *Ageing and Society, 33*(7), 1167-1189.

Biordi, D. L., & Nicholson, N. R. (2013). Social isolation. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic Illness: Impact and Intervention* (pp. 97 - 132). Burlington, MA: Jones & Bartlett Learning.

Cattan, M., White, M., Bond, J., & Learmouth, A. (2005). Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing & Society, 25*(01), 41-67. doi: doi:10.1017/S0144686X04002594

Council for International Organizations of Medical Sciences. (2002). International Ethical Guidelines for Biomedical Research Involving Human Subjects. Geneva: World Health Organization.

Dickens, A. P., Richards, S. H., Greaves, C. J., & Campbell, J. L. (2011). Interventions targeting social isolation in older people: A systematic review. *BMC Public Health, 11*(647).

Giles, L. C., Glonek, G. F. V., Luszcz, M. A., & Andrews, G. R. (2005). Effect of social networks on 10 year survival in very old Australians: the Australian longitudinal study of aging. *Journal of Epidemiology and Community Health, 59*(7), 574-579.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261-280.

Hawthorne, G. (2006). Measuring social isolation in older adults: Development and initial validation of the friendship scale. *Social Indicators Research, 77*, 521 - 548. doi: 10.1007/s11205-005-7746-y

Hewitt, J. (2007). Ethical components of researcher-researched relationships in qualitative interviewing. *Qualitative Health Research, 17*(8), 1149 - 1159.

Higgins, I. (1998). Reflections on conducting qualitative research with elderly people. *Qualitative Health Research, 8*(6), 858-866.

Jokinen, P., Lappalainen, M., Merilainen, P., & Pelkonen, M. (2002). Ethical issues in ethnographic nursing research with children and elderly people. *Scandinavian Journal of Caring Sciences, 16*(2), 165-170.

Lidz, C. W., & Appelbaum, P. S. (2002). The therapeutic misconception: Problems and solutions. *Medical Care, 40*(9, Supplement), V-55 - V-63.

Locher, J. L., Bronstein, J., Robinson, C. O., Williams, C., & Ritchie, C. S. (2006). Ethical issues involving research conducted with homebound older adults. *The Gerontologist, 46*(2), 160-164.

Lubben, J., Blozik, E., Gillman, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale

among three European community-dwelling older adult populations. *The Gerontologist, 46*(4), 503 - 513.

McLean, A. (2011). Ethical frontiers of ICT and older users: cultural, pragmatic and ethical issues. *Ethics and Information Technology, 13*(4), 313 - 326.

Munteanu, C., Molyneaux, H., & O'Donnell, S. (2014). Fieldwork with vulnerable populations: Ethical implications for human-computer interaction research. *Interactions, 2014*(January-February), 51-53.

National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors' Committee. (2013). National Statement on Ethical Conduct in Human Research. Canberra: Commonwealth of Australia.

Quine, S., & Browning, C. (2007). Methodological and ethical issues in conducting research with older people. In M. Pitts & A. Smith (Eds.), *Researching the Margins: Strategies for Ethical and Rigorous Research with Marginalised Communities* (pp. 130-142). Basingstoke: Palgrave Macmillan.

Russell, C. (1999). Interviewing vulnerable old people: Ethical and methodological implications of imagining our subjects. *Journal of Ageing Studies, 13*(4), 403-417.

Schroder-Butterfill, E., & Marianti, R. (2006). A framework for understanding old-age vulnerabilities. *Ageing and Society, 26*(1), 9-35.

Sorell, T., & Draper, H. (2014). Robot carers, ethics, and older people. *Ethics and Information Technology, 16*(3), 183-195.

Steptoe, A., Shankar, A., Demakakos, P., & Wardle, J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Science*.

Taylor, N., Cheverst, K., Wright, P., & Olivier, P. (2013). Leaving the wild: Lessons from community technology handover *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1549-1558): ACM Press.

Vetere, F., Kulik, L., Pedell, S., Ozanne, E., Gruner, A., Lillywhite, B., & Naufal, R. (2012). Mobile and broadband technologies for ameliorating social isolation in older people. Melbourne: Institute for a Broadband-Enabled Society.

Waycott, J., Davis, H., Vetere, F., Morgans, A., Gruner, A., Ozanne, E., & Kulik, L. (2014). Captioned photographs in psychosocial aged care: Relationship building and boundary work *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 4167 - 4176): ACM Press.

Waycott, J., Pedell, S., Vetere, F., Ozanne, E., Kulik, L., Gruner, A., & Downs, J. (2012). Actively engaging older adults in the development and evaluation of tablet technology *OzCHI '12: Proceedings of the 24th Australian Computer-Human Interaction Conference* (pp. 643-652): ACM Press.

Waycott, J., Vetere, F., & Pedell, S. (2013). *Designing communication technologies for socially isolated older people: Fieldwork reflections*. Paper presented at the CHI Workshop on Designing for - and with - Vulnerable People, Paris.

Waycott, J., Vetere, F., Pedell, S., Kulik, L., Ozanne, E., Gruner, A., & Downs, J. (2013). Older adults as digital content producers *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 39-48). Paris: ACM Press.

Zwijsen, S., Niemeijer, A. R., & Hertogh, C. M. P. M. (2011). Ethics of using assistive technology in the care of community-dwelling elderly people: An oveview of the literature. *Aging & Mental Health, 15*(4), 419 - 427.

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