Thanatosensitive Research and Design
Ethics for Social VR at End of Life

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ABSTRACT
The emergence of Social Virtual Reality (VR) as an accessible, consumer-friendly technology is creating further opportunities to improve the quality of life of older adults who suffer from loneliness and/or a life-limiting illness, by mediating meaningful social interaction with their family members and loved ones. However, research and design with vulnerable populations presents ethical challenges that are unique to the intersection of the Social VR and palliative care contexts. We explore opportunities for Social VR in the palliative care space and describe our approach to conducting thanatosensitive research in practice.
INTRODUCTION
The loss of regular social contact puts older adults at significant physical and psychological risk, especially for those adults who are isolated and live alone at home. Social isolation can become even more pronounced when major life events (e.g., contracting a progressive illness) challenge someone’s sense of self and sense of place. Unfortunately, people experiencing the end of life are frequently confronted with severe existential symptoms and spiritual distress that challenge families and care providers and is exacerbated by isolation and loneliness [1].

The focus of palliative care is to ease the suffering experienced by people living with life-limiting illnesses and to bring dignity and self-esteem to patients and their loved ones. It provides support to those requiring treatment but is typically not involved in actual curative treatment itself. While technologies are currently serving many other caregiving and care support fields, the domain of palliative care has been relatively underserved and overlooked by the HCI field. This may be due to several factors, amongst which the lack of suitable technologies to address this complex space. Consequently, much of even rudimentary social computing technologies, such as video calling, have yet to be widely disseminated within the caregiving practice. Whether they are issues with technology adoption, training of staff, or a combination of confounding factors, these issues fall well within the bounds of HCI research. The emergence of Virtual Reality as both a robust consumer-friendly tech and a social-enabling tech is creating further opportunities that may help overcome HCI research’s collective reluctance to engage with the field of palliative care. Yet, this is not without challenges, especially on the ethical side, which we discuss later in this position paper.

BACKGROUND
In HCI research and design for older adults, we have recently come to apply the concept of ‘thanatosensitivity’ to describe the accounting for complicated matters of end of life into the research and design process. In short, this paper answers the question: How can Social VR research and design be conducted ethically and thanatosensitively? Working within the guiding framework of the Canadian Tri-Council policy statement on Ethical Conduct for Research Involving Humans (TCPS2, 2018) [6], we will explore different applications of social VR in the palliative care use context, and the unique ethical challenges posed by each. While TCPS2 is a Canadian-based ethical framework, its principles are universal, and it is considered to be one of the most comprehensive such frameworks, grounded in extensive and ongoing inter-disciplinary consultations [5].
Despite 92% of people stating that talking with their loved ones about end-of-life care is important, only 32% have actually done so [4]. Furthermore, 80% of people say that if seriously ill, they would like to talk to their doctor about wishes for medical treatment toward the end of their life. Despite this, only 18% actually report having this conversation with their doctor.

These gaps highlight a pressing need for all forms of solutions to address the loss of meaningful social participation by older adults, particularly for those who are living with life-limiting illnesses. In Canada, about one-quarter (24.6%) of the population aged 65 and over lives alone [3]. As the ageing population continues to grow, these existing issues that are facing our society may become exacerbated. Social VR presents a very promising avenue of approach to these problems, however, the vulnerabilities of the population in this context highlight important ethical considerations that must be accounted for before the design process can proceed responsibly.

This position paper will outline the opportunities for Social VR in the Palliative Care space, grounded in this, we discuss the ethical challenges that we anticipate arising from engaging with these research opportunities.

SOCIAL VR TECHNOLOGIES FOR PALLIATIVE CARE

In our own research we are currently exploring the implementation of three different approaches to Social VR for palliative care, by improving the social-participation of older adults. First, the VRchat style of social VR, where two or more users are synchronously situated within a shared virtual space, embodied with avatars. Second is interactive, live telepresence using a 360º video feed, for example from an important social gathering. Third, while only tangentially grounded in Social VR, is the use of VR video recordings of participant interviews in qualitative research. VR provides a new opportunity for qualitative research to re-experience an ethnographic touchpoint from an embodied, first-person experience.

As designers of Social VR, who are not all being subject matter experts in palliative care, we need to exercise caution to prevent existing misconceptions, biases and stigmas surrounding end-of-life from being perpetuated. To ensure a commitment to the projects’ primary care objectives, we are embarking upon a highly engaged, participatory design process.

THANATOSENSITIVE SOCIAL VR RESEARCH ETHICS

Our formative work so far has necessitated serious reflection upon the challenges associated with engage in palliative care research, and thus we will describe a range of anticipated ethical issues, that we are grounding in TCPS2. TCPS2, despite being one of the most comprehensive ethics frameworks, provides limited direct guidance for handling the intersection of novel technologies
with extremely sensitive populations. In this position paper we are not aiming to provide solutions or conduct a critical analysis but ask questions that we have identified as pertinent during our preliminary ground work and through consultation sessions we have had with our project partners (palliative care experts). We thus include these questions as the main contribution of our position paper, in the hope that these will start a discussion about the ethical challenges that we anticipate arising from engaging in VR research in sensitive settings such as palliative care. Through this, we invite the HCI community to contribute knowledge and practice to this emerging challenge, and to proactively shape this research from an ethical perspective before the field has advanced past the point where ethics can no longer be intimately embedded in our practice.

**Duty of Care**

How do we interpret the ethical duties of care, as defined by TCPS2, for the palliative care and social VR context? We understand the duty of care to be our obligation as investigators to act in the best interests of our participants in the context of our research, and while concerned with the welfare of individual participants, also focused on the generation of new knowledge that may or may not confer direct benefits on the participants [6]. How do we ensure that the foreseeable risks to individuals in their participation of social VR Research is justified by the potential benefits that may be incurred? Nevertheless, researchers must ensure that the foreseeable risks of engaging participants in Social VR are justified by the potential benefits.

**Harm**

We are also interpreting ethics pertaining to harm, as outlined in the TCPS2, to relate to both the physical and psycho-emotional wellbeing of our participants. Compared to other digital technologies, immersive VR may expose vulnerable users to a heightened risk of physical harm. For example, harm caused by motion sickness after prolonged VR may lead to nausea. However, the use of VR in palliative care research may still be justified. The harm caused by falling in VR, on the other hand, would be catastrophic and/or deadly to the user, and in the case of our research, could not justified by the benefits that it would comparatively provide.

We understand the cognitive wellbeing of palliative-care based participants to be determined by their emotional, psychosocial, and spiritual states, which could be highly influenceable by Social VR.
While our intentions are to design favorable conditions for our participants, we anticipate a high chance that some VR experiences may be subjectively perceived as negative for some users. There are currently no empirical guidelines defining what constitutes a potentially distressing Social VR experience, only sensibilities that are grounded in our assumptions. How might users of different cultural backgrounds or genders react differently to the same Social VR experience? What social situations should be universally avoided altogether?

**Respect for Persons**

In many cases the illness takes a greater psychological and emotional toll on loved ones and caregivers, than it does on the person who is dying. Thanatosensitivity provides us with a relevant theoretical lens from which to approach the ethical problem of respect for persons, in the palliative care context, includes bereaving families. In our work, we anticipate an ethical responsibility to respect the consent of bereaving families in regard to the handling of their loved ones’ digital artifacts. In our research, we may deem it necessary to reacquire consent from the families after the participant has died, to continue using digital artifacts derived from their participation as part of our projects. Alternatively, collected information objects can be modified as to be respectful towards the wishes of the participant and their families.

Looking broadly at digital technology as a whole, little research to date has addressed problems associated with the mortality and death of a social technology users and their information, with respect to the privacy and wishes of the individual and their family. What becomes of their virtual bodies after they have died? How might we want to approach the notion of handling the digital embodiment of a person who has died? How should digital artifacts left behind in Social VR by a deceased person be treated? On Facebook, the ‘virtual body’ of a deceased person, their profile, is converted into a funerary memorial page. To mismatch the affordance of user profiles being alive, with the knowledge that a person is deceased, creates a profoundly creepy experience for the user. In the case of Social VR, we can anticipate situations where users are suddenly confronted with the lifelike avatar of a person who is recently deceased. Applying these thanatosensitivities to Social VR may be wise, not only due to the palliative care context, where the death of the user is expected, but also due to the physically embodied nature of VR potentially exacerbating creepy experiences.

**CONCLUSION**

To sum, we explore current opportunities for Social VR in the Palliative Care space and discuss ethical challenges that are expected to arise in conducting research with vulnerable populations in this space. Thanatosensitive approaches to the research process can help realize HCI work that takes a responsible, ethical approach to VR design that actively integrates conceptions of death, dying, and mortality into practice.
REFERENCES


