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Kachur, Oksana, Sellen, Kate, Rodin, Gary and Rutgers, Job

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Challenging Contexts: Hearing the Voice of Residents and Families in Hospice Care Design Research

Oksana Kachur

OCAD University
Toronto, Ontario, Canada
ok09ic@student.ocadu.ca

Katherine Sellen

OCAD University
Toronto, Ontario, Canada
ksellen@faculty.ocadu.ca

Gary Rodin

Princess Margaret Hospital
University Health Network
Toronto, Ontario, Canada
gary.rodin@uhn.ca

Job Rutgers

Ambient Experience Lab
OCAD University
Toronto, Ontario, Canada
jrutgers@faculty.ocadu.ca

Abstract

It is commonly believed that the sensory environment influences the experience of end of life care for patients and families in this circumstance. However, there has been relatively little empirical evidence in this area. As part of a program of experience research and design in palliative care, we are surveying patients, families, professional caregivers and volunteers in a newly renovated residential hospice regarding their experience of the sensory environment. Hearing the unique perspectives of these individuals provides information that can lead to improvements in the sensory experience of patients who are approaching the end of life in hospice settings.

Author Keywords

End of life; palliative care; behavioural research; sensory perceptions; ambient technologies; research methods; research context

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms

Design, Human Factors

Introduction

Residential hospices are an important component in the continuum of end of life care. The hospice atmosphere emerges at the intercept of the psychosocial and physical environment and multidisciplinary care [1,2].

The purpose of the residential hospice environment is to deliver compassionate care and comfort for terminally ill residents. Comfort in this setting may be linked to sensorial perceptions and may be enhanced by ambient technologies for residents and their families. Such technologies may facilitate difficult transitions and enhance experience in this treatment setting.

Ambient and sensory design is defined as the orchestration of spatial stimuli in built environments, arranged to lift the quality of experience for the occupants [3]. Few studies have addressed ambient/sensory experiences in palliative care environments. This extended abstract reports the challenges and preliminary findings from an exploratory research study of sensory experiences in a hospice environment.

Study Design

Kensington Hospice operates through a partnership between the Kensington Health Center and the Princess Margaret Hospital/University Health Network in Toronto, Canada. Qualitative research on sensory experiences in the hospice connects the Kensington Health Center and Princess Margaret Hospital with OCAD University's Ambient Experience Lab and the masters program in Strategic Foresight and Innovation at OCAD University. The intent is to develop insights for the design of sensory/ambient technologies in palliative care.

To date, 4 groups of participants have been recruited to take part in the research study. These include the Hospice residents, their caregivers, professional caregiving staff and Hospice volunteers. Semi-structured qualitative interviews along with observations have been selected as research methods for this study. The data collected will be analyzed and collated to identify common themes and differing perspectives of patients, family members, professional caregivers and volunteers. Each of these perspectives are important and valid in their own right, and there must be sensitivity in the conduct of the interviews to the potential burden of the study for patients and to the needs of family members at this difficult time of transition.



Figure 1. A resident's room before personalization and decoration.

Discussion

The challenge of obtaining the perspectives and the opinions of the Hospice residents has begun to redefine the research approach, since these voices that are most critical are often those that are less accessible due to constraints of rapid (physical and cognitive) decline. The context of the Hospice as the site for research and design also presents the challenge of exploring the

perspectives of the Hospice residents and distinguishing them from those of family caregivers who may be more able to communicate. The views of family caregivers, patients and staff are all necessary in order to define the landscape of varied perceptions, and the data collection and analyses will need to take these differing perceptions into account in order to understand design qualities of this space .



Kensington Hospice was retrofitted from a former church. Many of the features of the church still remain.

Smells from the kitchen contribute to sensory experiences.

Family members decorate the Hospice with holiday ornaments

Residents might not be able to leave their private room to experience communal areas

Figure 2. The great room, with its historic hammer and beam ceiling, is a gathering area for the Hospice and includes a sitting area, dining area and community kitchen.

Care must be taken to include the perspectives of both more and less vocal participants in the study. There may be challenges in accessing the perspectives of patients who are seriously ill. There may also be tensions between the needs and perspectives of living and the dying participants and those in bereavement.

Uncovering tensions

The experiences of the Hospice residents may be intertwined with those of the family members. Both parties may have changing and different needs. For instance, family members may be inclined to initiate tangible projects in the environment (such as decoration the private and public space in the Hospice, bringing in supplies, initiating busy-ness through frequent visits) that are meaningful for their own transition into the difficult context of a hospice. These activities, however, may not necessarily be of interest to the residents who may be more confined to their private rooms.

Conclusion

The exploration of sensory/ambient qualities of the Hospice interior that are important to hospice residents and their families can inform and lead to enhancements in the experience of residential palliative care. It is important to be sensitive to the needs of patients and families while conducting this research in user-centered design and recruitment of adequate numbers of physically ill patients may take longer than anticipated. The perspectives of patients, family members,

professional staff and volunteers who inhabit the space of the Hospice are all important considerations in the design of this living and working space.

A recently developed philosophy on technology design-Thanatosensitive design- is a process which engages with end of life issues as part of the design concept [4]. The development of interactive artifacts that would help the hospice residents and their families through difficult transition points is an interesting research consideration as we move forward.

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