



Room for Death – International museum-visitors' preferences regarding the end of their life



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ABSTRACT

Just as pain medications aim to relieve physical suffering, supportive surrounding for death and dying may facilitate well-being and comfort. However, little has been written of the experience of or preferences for the surroundings in which death and dying take place. In this study, we aim to complement our research from perspectives of patients, family members and staff, with perspectives from an international sample of the general public.

Data derives from a project teaming artists and craftspeople together to create prototypes of space for difficult conversations in end-of-life (EoL) settings. These prototypes were presented in a museum exhibition, "Room for Death", in Stockholm in 2012. As project consultants, palliative care researchers contributed a question to the public viewing the exhibition, to explore their reflections: "How would you like it to be around you when you are dying?"

Five-hundred and twelve responses were obtained from visitors from 46 countries. While preliminary analysis pointed to many similarities in responses across countries, continued analysis with a phenomenographic approach allowed us to distinguish different foci related to how preferences for surroundings for EoL were conceptualized. Responses were categorized in the following inductively-derived categories: The familiar death, The 'larger-than life' death, The lone death, The mediated death, The calm and peaceful death, The sensuous death, The 'green' death, and The distanced death.

The responses could relate to a single category or be composites uniting different categories in individual combinations, and provide insight into different facets of contemporary reflections about death and dying. Despite the selective sample, these data give reason to consider how underlying assumptions and care provision in established forms for end-of-life care may differ from people's preferences. This project can be seen as an example of innovative endeavors to promote public awareness of issues related to death and dying, within the framework of health-promoting palliative care.

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1. Introduction and aim

Death, dying and mourning are universal parts of life, inextricably interwoven with underlying cultural norms. At the same time they are extraordinary, memorable and often difficult experiences for individuals and their families. Just as medical technology and pain medications aim to relieve physical suffering, professionals in end-of-life (EoL) care have ambitions to facilitate well-being, safety

and comfort through supportive surroundings for dying—in home or institutional care. Based on empirical findings from our previous research from 16 specialized palliative care (PC) facilities in 9 countries (Lindqvist et al., 2012), the importance of what was called an "esthetic, safe and pleasing environment" at the EoL became apparent, as was the limited research on this in EoL settings.

Recent literature on EoL care settings focuses strongly on choice of care setting in terms of location (see e.g. Badrakalimuthu and Barclay, 2014; Calanzani et al., 2014; Campbell et al., 2014; Chen et al., 2014; De Roo et al., 2014; Fleet et al., 2014; Gomes et al., 2012; Hedinger et al., 2014; Hunt et al., 2014; Ko et al., 2014; Lee et al., 2014; McHugh et al., 2014; Reyniers et al., 2014; Venkatasalu et al., 2014); this is a rapidly expanding area of

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interest. However, surprisingly little has been written about the experience of the surroundings in which dying and death take place. This is the case particularly, as pointed out by Moore et al. (2013), from a place-centered perspective, i.e. in terms of lived experience and use of a place, rather than as a physical space in itself (Harrison and Dourish, 1996; Hornecker, 2005). Even less attention has been paid to how the surroundings might support death and dying being understood as a meaningful experience, in line with one's own life and history. While the literature on these issues in EoL care remains limited, recent reviews and research on health care design more generally (Andritsch et al., 2013; Browall et al., 2013; Drahota et al., 2012; Salonen et al., 2013; Ulrich, 2013; Ulrich et al., 2008) found a growing body of robust studies indicating that the physical care environment can promote improved outcomes for patients (e.g. reducing stress, diminishing use of analgesics, facilitating coping, and promoting well-being), as well as staff. Despite these findings, little has been published about the characteristics that constitute a supportive environment when dying (for exceptions, see e.g. Tofie et al., 2004; Edvardsson, 2008; Liaschenko et al., 2011; Rasmussen and Edvardsson, 2007). The literature found on EoL settings tends to focus on physical aspects, e.g. architecture (Worpole, 2009), which may not be readily susceptible to change, rather than on aspects of place in an existing care setting, and how they can be experienced and adapted. For the most part, the design principles informing modern care facilities remain largely functional, with efficient delivery of medical and technical services given priority over the well-being and lived experience of involved users, although the importance of design is increasingly recognized (see e.g. Bleken, 2012; Habell, 2013 on facilities for people with dementia).

Our initial research findings, combined with the lack of other data and literature in the field, has led us to initiate a research program to investigate experiences of space and place in EoL care from the perspectives of users, generally seen as the dying person, family members, and staff. In this article, we complement these perspectives with data generated from the general public attending an exhibition entitled "Room for Death" at the Architecture and Design Center in Stockholm. In this study, we aimed to investigate variation in public conceptions of desirable surroundings for death and dying.

2. Method

2.1. Background to the project

In 2009, the Stockholm County Council commissioned a project "Art and Handicraft in Care Environments" in which five pairs of conceptual artists and craftspeople who had not previously worked together were asked to create room for private talks in EoL care. One specialized PC facility, which primarily provided care for people with cancer in the last weeks and days of life, functioned as a 'laboratory' environment for developing prototypes with the artists/craftspeople working in collaboration with both PC staff and researchers. The project was presented in a book (Rosengren, 2013) and exhibition, which ran from June through mid-September 2012 at the Architecture and Design Center in Stockholm, located in the same building as the Museum of Modern Art (*Arkitektur-och Designcentrum*, 2014). The exhibition highlighted not only the prototypes developed, but also had Swedish and English audio- and written text with involved participants' reflections on the surroundings for death and dying and the process of creating the prototypes. The museum's objective was to demonstrate new ways of working beyond traditional borders between art, craft and design. The exhibition was also designed to shed light on how different forms of artistically-oriented approaches can inspire to

broader views of how one can work with designing milieus and objects, and stimulate thinking beyond set parameters when considering design for EoL contexts. The prototypes themselves dealt with different aspects of the care environment, ranging from the importance of personal presence and activity on site to examining the importance of materials and textures, and the creation of objects for new rituals. They included diverse objects, for example, a room with screens and a rug for difficult conversations, dioramas to stimulate storytelling and a wooden log stump to sit on.

One of the prototypes represented a chest, in which memories might be enclosed and sealed. To both illustrate how this might work and to have a means of receiving feedback from the exhibition visitors, the authors, both PC researchers, were asked to generate a question for visitors, in collaboration with the artist/craftsperson team responsible for the chest. A paper with the open-ended question: "How would you like it to be around you when you are dying?" in Swedish and English was therefore placed in a central place at the exhibition, for documenting reflections if so desired. The English question was followed with a question about country of residence. The visitor could place their response in a small chest, similar to the prototype shown in the exhibition. While formal approval from the research ethics committee was not necessary in Sweden, the paper with the question also included the information: "Your response may be included in a research project" with names, titles and contact information to both authors.

Five-hundred and twelve responses to this open-ended question were obtained from visitors from 46 countries on all populated continents but Africa. Most responses came from Sweden ($n = 96$) followed by the US ($n = 66$), France ($n = 28$), Germany ($n = 27$) and Italy ($n = 25$), with 122 missing responses to this question (see Appendix 1 for further detail). Responses were given a code number, scanned and transcribed verbatim into a qualitative analysis software program (NVivo 10). Each response was then examined, and those not in Swedish, English or other Nordic languages translated with help of bilingual consultants.

Fifty-three responses were initially omitted; after further analysis an additional 26 were omitted. Reasons for omitting responses included illegibility, as well as text and/or drawings not deemed meaningful responses to the question posed, and those which were not able to be interpreted with a reasonable degree of certainty. As one example, a response in the form of a drawing of a cross composed of two simple lines, with the text "M.D.N.A" was omitted. The letters might be an abbreviation for the name of the singer Madonna, as on the DVD with the same name, or might indicate a religious symbol, or some other abbreviation. Other excluded responses have the character of graffiti, with curses, coarse language, or pictures which were difficult to interpret as a serious response to the question posed, e.g. a drawing with the single word "penis" or those that contain only a ☺, a heart or a picture of a coffin. As general praxis, we chose to exclude responses rather than infer interpretations without firm basis.

2.2. Data analysis

Our initial impression prior to analysis was that there were notable similarities in the manners in which the visitors to the exhibition described their desires, despite the variety in countries represented. As we became more familiar with the data, we also became increasingly aware of differences in descriptions, which led us to choose a modified phenomenographic approach for continued analysis. Phenomenography is based on the assumption that there are a limited number of qualitatively different ways of understanding or experiencing phenomena which are shared by different people in similar situations at a particular point in time (Marton and Booth, 1997). While originally derived from the field of

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