



Beyond the visual and verbal: Using participant-produced photographs in research on the surroundings for care at the end-of-life



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ABSTRACT

The web of relationships between wellbeing and the environments in which people live has long been recognized. However, relatively little research has been conducted about end-of-life surroundings from the perspective of the dying person. In this study, we investigate which aspects of their surroundings are particularly meaningful for the people inhabiting them in the last phases of life, based on participant-produced photographs with follow-up interviews. Twenty-three people were purposefully recruited via specialized in-patient palliative care/hospice units, specialized palliative care home care teams, and residential care facilities for the elderly. Participants were given a digital camera, and asked to take pictures of that which was meaningful for them in their surroundings. The interviewer later viewed the photographs with the participant, asking: “what is this picture of?” and “why is it meaningful to you?” The database consists of 76 photographs with follow-up interviews, which were analyzed qualitatively in an iterative process. These empirical data demonstrate how a sense of being valued, and of being able to maintain contacts with one’s daily life and sense of identity appear supported or hindered by features of the care surroundings. These features include a positive aesthetic experience incorporating both sensory stimulation using one’s body as well as general ambiance; support appropriate for maintaining a sense of functional independence; and connections with one’s past, present and future as a person within a wider world. Corporeality appears crucial for understanding, negotiating and interacting in one’s surroundings, while maintaining both physical and social function. This data collection approach was found to offer alternative forms of expression as verbal ability decreases and symptom burden increases, making it useful in end-of-life research and practice development.

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1. Introduction and aim

As Rasmussen and Edvardsson (2007) remind us, the webs of relationships between people’s physical, psychological, emotional, and existential wellbeing and the environment in which they live

have long been recognized. Attention has more recently been paid to the surroundings in which people spend the end-of-their-life, as having important implications for “orchestrating” emotions (Worpole, 2009) and “integrating people and place in therapeutic environments” (Glenister, 2012). Parallel to the relief medical technologies and pharmacological treatment aim to provide for physical suffering, we argue that supportive surroundings at the end-of-life (EoL)—whether at home or in an institution—should facilitate well-being for the dying person, his/her significant others, and for staff.

Within a European Union 7th framework-financed project,

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OPCARE9 (Mason et al., 2012), Lindqvist et al. (2012) documented staff's self-reported efforts and activities related to creating an aesthetic, safe and pleasing environment in 16 specialized palliative, hospice and home care facilities in nine countries. Attention to sensory stimuli such as qualities of sound, sight, color and textures appeared particularly important in staff efforts in "maintaining connections to the individual's everyday life" (Lindqvist et al., 2012). While the researchers had not expected the extent to which non-pharmacological caregiving activities during the very last days of life would have this focus, nor the variety of activities carried out, their work explored staff self-reports only. Staff may have an idealized view of the value of their efforts, as patients may or may not perceive attempts to make person-based adjustments in caregiving settings, and will interpret both staff efforts and the settings themselves in a variety of ways. Further examination of the literature made it clear that relatively little is known about the experience of EoL surroundings from the perspectives of the dying person and even, as pointed out by e.g. Giesbrecht (2013) those spending time with them, often family members.

Recent literature on EoL care settings has focused strongly on location of EoL care (see e.g. Chen et al., 2016; Cohen et al., 2015; Gage et al., 2015; Gisquet et al., 2015; Hakanson et al., 2015; Kinoshita et al., 2015; Pivodic et al., 2016; Sasao et al., 2015). Another body of literature focuses on the architecture of these settings (see e.g. Worpole, 2009), that is "space" in line with Harrison and Doursih's definition (Hornecker, 2005; Lentini and Decortis, 2010), referring to the physical environment. Our interest in this study is however on qualities and experience of "places" for living at the end-of-life, that is place as involving "... the dimensions of lived experience, interaction and use of a space by its inhabitants" (Lentini and Decortis, 2010). We build further on a body of knowledge at the intersect of human geography (e.g. Andrews and Evans, 2008; Castleden et al., 2010; Evans et al., 2009; Gatrell and Payne, 2014; Giesbrecht, 2013) and empirical research, primarily nursing-based, on experiences of surroundings in the EoL (e.g. Edvardsson et al., 2005; Liaschenko et al., 2011; Moore et al., 2013; Rasmussen and Edvardsson, 2007; Lindqvist and Tishelman, 2015). In the study presented here, we aim to better understand which aspects of their surroundings are particularly meaningful for the people inhabiting them in the last phases of life, using an approach based on participant-produced photographs.

2. Methods

2.1. Data collection/procedures

We used participant-produced photographs with subsequent interviews to explore perspectives of people in five care settings in the capital city of Sweden and in a university town in the rural north of the country.

Participant-produced photographs are receiving increased attention as a strategy for generating research data with a variety of populations and agendas (Affleck et al., 2013; Balmer et al., 2015a, 2015b; Creighton et al., 2015; Han and Oliffe, 2016; Kantrowitz-Gordon and Vandermause, 2015; Morrison and Thomas, 2015; Oliffe et al., 2008). One reason for this relatively new popularity may be that this approach reaches beyond the constraints of verbal interviewing alone, and can as Sandhu et al. (2013) point out, be particularly effective in exploring issues that may be difficult to speak directly about. It has been utilized in health care research to this end, including studies related to palliative or EoL issues (Campbell, 2011; Campbell and Amin, 2012; Moore et al., 2013). While different terms, e.g. "photo-elicitation" or "photovoice" (e.g. McClymont Peace and Myers, 2012; Olausson et al., 2012, 2013) can be found for similar approaches, there is not always consistency in

how these terms are used; for example "photo-elicitation", the term most common in research contexts, is used to indicate both researcher-generated photographs used to stimulate discussion in interview situations as well as photographs produced by participants. We therefore use the more generic term, participant-produced photographs, for clarity here.

In line with the ethical review board permission for the study (Dnr Ö 29–2012), participants who were judged by staff to be cognitively aware and thus able to provide informed consent were purposefully recruited via staff referral at one specialized in-patient palliative care (PC) facility and two hospices (17 participants), specialized palliative home care teams (4 participants), and residential care facilities for the elderly (3 participants), as shown in Table 1, with 8 participants recruited from northern Sweden and the remainder from the Stockholm region. A total of 24 interviews were conducted with 23 people; one woman participated initially when in an in-patient facility as well as after her return home, enrolled in palliative home care.

It should be noted from the onset that our sampling was not intended to be representative of EoL settings in Sweden. Although Sweden is often reported to have high quality specialized palliative care (World Health Organization and Worldwide Palliative Care Alliance, 2014) and notably low out-of-pocket costs for all health care (Lindqvist and Tishelman, 2016), access remains geographically uneven and predominantly directed to people with cancer (Swedish Palliative Register, 2016). Most deaths still occur in residential home care facilities and acute care hospitals, with access to some form of specialized palliative care (inpatient, home care, or consultancy) at end-of-life varying between approx. 6–23% across the country (Swedish Palliative Register, 2016).

Participants were each lent a digital camera and asked to take three photographs of that which they found important or meaningful to them in their care surroundings. We suggested this number to avoid overburdening participants; however a few participants took and discussed four or five photographs instead. In a follow-up interview at a timepoint agreed upon with participants but generally conducted the next day, the participant and interviewer together looked at and discussed the photographs, after transferring them for viewing on a computer screen. Two questions were used to stimulate discussion: "What is this picture of?" and "Why is it meaningful to you?" with further questions and conversation dependent on the individual and what was told. Each interview was audio-recorded and transcribed verbatim, and along with the 76 photographs produced by the participants, constitutes the database for the analysis.

2.2. Data analysis

Data analysis was an inductive, iterative process, carried out in different team constellations. Initially the researchers (authors IG, CT, OLi, BHR) and interviewers (LGS, a RN research assistant and SH, a post-doc acting as both researcher and interviewer), all with backgrounds in nursing, met regularly, to examine the photographs and listen to interviews. This process generated sensitizing concepts of importance for continued interviewing and analysis and steered continued purposeful recruitment to add heterogeneity among participants, region, and type of setting.

More formal data analysis began while data collection was ongoing, through a series of research retreats with the research team. In a reflective process, we first jointly listened to two audio-taped interviews while simultaneously reading the written transcript and viewing the photographs. This stimulated discussion of content and potential salient categories and themes, and methods for continuing analysis. We then made an effort to categorize the photographs alone based on their manifest content as interpreted

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