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Exploring photo-elicitation to elicit architecturally rich users' experiences with(in) palliative environments through a human-centred approach: a pilot study

Iris Beuls ^{1,*}, Ann Petermans ² and Jan Vanrie ³

¹ Hasselt University; iris.beuls@uhasselt.be; 0000-0002-8964-4157

² Hasselt University; ann.petermans@uhasselt.be; 0000-0001-7023-4628

³ Hasselt University; jan.vanrie@uhasselt.be; 0000-0003-2633-5194

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Abstract: The physical character of a palliative environment can (when well-designed) positively impact the wellbeing and experiences of its various users (residents, family, caregivers, and volunteers). However, it seems difficult for architects to translate quite abstract and subjective multi-user perspectives into more specific applicable design solutions, which is why the impact of palliative research in architectural practice seems little so far. To contribute to closing the loop between architects' design intent and actual users' experiences, conducting qualitative interviews with users of palliative environments seems a plausible approach to understand how they experience these environments. However, this concerns several ethical and practical challenges regarding the participants, the context, and the topic of this research. Hence, tension seems present between collecting more applicable architectural richer experiences and ensuring that this research does not unnecessarily burden participants. Therefore, this paper will focus on (1) how we can contribute to the participant-researcher dialogue in order to elicit more architecturally rich (subjective) experiences from various users of palliative environments, and (2) how we can adopt a human-centred approach when designing and conducting interviews of various users with(in) a palliative environment. For this purpose, a pilot study with three participants of a small-scaled palliative environment in Belgium was carried out to explore the potential and approach of photo-elicitation interviews. This paper reports on the pilot study and highlights methodological strengths and challenges from the lens of an architect-researcher with a strong focus on human-centredness. In this way, we hope to contribute to (re)designing more human-centred palliative environments.

Keywords: palliative environments; users' experiences; human-centred approach; photo-elicitation interviews; pilot study

1. Introduction

The physical character of a palliative environment, i.e., the building, the furnishings, the use of materials, and the immediate surroundings of the building, can (when well-designed) positively impact various users' experiences and wellbeing on multiple dimensions (i.e., physical, emotional, social, and spiritual) (Smith & Karol, 2019). Although not linked to a palliative environment, in 1984, Ulrich came to comparable insights by making a comparative study between patients' experiences in a hospital whose bed faced a window view with trees or whose bed looked out onto a wall. To date, almost four decades later, a growing global need for palliative care and increasing expectations from various users (i.e., residents, family, caregivers, and volunteers) regarding the provision of high-quality palliative care (Martens et al., 2020) has resulted in a growing palliative research scope and volume (Sivell et al., 2019). However, even though authors such as Gardiner et al. (2011)

and Verderber (2014) show that there has been some relevant research done in this specific area, the impact of palliative research in architectural practice seems little so far.

Several reasons can be considered why architects may be hampered in using evidence-based knowledge when designing palliative environments: for instance, the research is difficult to integrate into the design, it is rarely targeted at architects, etcetera (Van der Linden et al., 2016). On top of that, people in palliative care comprise various user groups (i.e., residents, family, caregivers, and volunteers) composed of individuals of different ages, conditions, needs, experiences, and consequently, different perspectives. Thus, to design human-centred palliative environments, palliative research should focus more on a multi-users perspective by considering synergy between different users' experiences. However, for architects, the difficulty often lies in translating these quite abstract and subjective multi-user perspectives and experiences into more specific applicable design solutions. When a situation arises in which research outcomes do not (easily) result in applicable design solutions, architects dare to use their relatively intuitive knowledge to make design decisions. However, since palliative environments are generally not commonplaces of which one has lived experiences, a possible discrepancy between architects' design intent and actual users' experiences could occur. Hence, it seems a plausible approach to ask users of palliative environments to clarify their experiences based on the circumstances in which they took place to elicit architecturally richer specifications.

However, conducting qualitative research interviews in palliative environments concerns several ethical and practical challenges regarding the participants, the context and the topic in which this research is situated (Sivell et al., 2019). For example, users of palliative environments can be considered a vulnerable group, particularly the residents, who have arguably limited opportunities to experience the benefits of this research in future practice (Addington-Hall, 2002). Furthermore, when approaching the end-of-life, taking part in research may also mean 'losing precious time with loved ones' (Casarett & Karlawish, 2000). These concerns often lead to an understandable protective attitude towards the participation of residents and (bereaved) families in research. On occasion, this may lead to decisions being made on their behalf that they would be perfectly capable of making themselves (Addington-Hall, 2002). Furthermore, the potential burden of participation in palliative research can be balanced by a study by Bloomer (2018). This study highlights the value that users of palliative environments place on having the opportunity to choose to participate in palliative research. In addition, there are also benefits related to participation in palliative research, such as helping others by contributing to society and future palliative care (Bloomer et al., 2018); and initiating an unintended therapeutic process for its participants (particularly with interviews) (Eide & Kahn, 2008). To meet these challenges, specific attention should be paid to issues such as trust, confidentiality, empathy, sensitivity, comfort, wellbeing etc., in the design and approach of the method.

In addition to a human-centred approach, getting an architecturally rich specification is an additional challenge. Even though providing a well-designed palliative environment positively impacts a person's wellbeing, interests in (interior) architecture do not usually play a primary role in the last phase of life. Apart from interest, most participants do not master the 'architectural language' and rarely share the same background and experiences with the researcher, making it sometimes difficult to express their experiences (that are affected by spatial aspects) using only words. As a result, there are two possible approaches to achieve this 'architecturally rich specification' in palliative research:

- When a participant shares a personal experience, the researcher can find out what circumstances influenced this experience and interpret the findings via the lens of an architect or designer. In this case, photographs and plans could help trigger the participant's memories and visualise the palliative environment where these experiences have taken place.
- Photographs and plans can also be used directly to express experiences that words alone might miss and to keep the conversation focused on spatial aspects (Church & Quilter, 2021). Using photographs when interviewing makes sense since, according to Harper (2002), visual processing information has existed longer in the human brain than processing verbal information. This approach also follows today's shift from privileged word-centred communication to more visual communication (Cleland & MacLeod, 2021), using images and photographs where words would have been used in the past to express experiences. Furthermore, engaging with photographs can explore issues that may be difficult to put into words (Balmer et al., 2015), especially among users of palliative environments (Tishelman et al., 2016). However, photographs in research do not always elicit more information, but this method can evoke a different kind of information (Harper, 2002).

There is a tension between ensuring that the research in this field meets its purpose and is applicable in architectural practice and ensuring that it does not place unnecessary burdens on the participants. To respond to these tendencies, we use a research method beyond the standard interview. A pilot study was carried out to explore the potential and approach of photo-elicitation interviews to derive personal experiences of multi-users with(in) a palliative environment in Belgium. This paper reports on the pilot study and highlights methodological strengths and challenges from the lens of an architect-researcher with a strong focus on human-centredness. In this way, we hope to contribute to closing the loop between the architect's design intent and the actual users' experiences so that informed architectural decisions can be made to (re)design human-centred palliative environments.

2. Theories and Methods

'Researcher introspection' is seen as a valid approach to study subjective experiences (Xue & Desmet, 2019), which can eventually lead to a human-centred experience-driven design. Therefore, the larger-scale study, which this paper is a part of, uses the introspective method of 'reflexivity within research' (Xue & Desmet, 2019). For this purpose, data will be collected in two palliative environments by the use of three data collection methods, namely by (1) participatory observations, (2) photo-elicitation interviews with residents, family, caregivers, and volunteers, and (3) reflexive fieldnotes of the researcher as being a participant in two palliative environments. This paper will only reflect on the methodological approach of the photo-elicitation interviews through a pilot study performed in one of the two palliative environments. This qualitative interview technique can explore participants' experiences using photographs or other images as stimuli or memorisation (Harper, 2002; Prosser & Schwartz, 1998), but also contributes to the participant-researcher dialogue by providing a focus on and visualisation of this physical palliative environment (Banks & Zeitlyn, 2015; Collier, 1995). In addition, participants' experiences can be related to both tangible and intangible spatial aspects; however, the latter cannot always be represented in a photograph. Therefore, photo-elicitation will not be used independently to obtain data but will be used in tandem with a semi-structured standard interview method. According to Padgett et al. (2013), this combination works the best for providing additional depth to participant responses. The context, sample, preparation, design, and procedure of these photo-elicitation interviews will be discussed in detail in the following sections.

2.1 Context

This study was conducted in a small-scale and freestanding palliative environment in Belgium. This building combines a hospice for eight residents and a day-care centre for groups of an average of five persons with palliative care needs. Here, professional caregivers and volunteers work together to provide high-quality palliative and bereavement care.

2.2 Sample

For this pilot study, three interviews were conducted with caregivers or staff members from the hospice and the day-care centre. Following this, the same interview guide will be used when conducting interviews with residents, family, caregivers, and volunteers in the hospice, the day-care centre, and a palliative care unit in a hospital. Including only caregivers or staff members for this pilot study has two reasons: (1) it was due to the obstacles caused by the COVID-19 pandemic at the time of the pilot study and (2) the aim was to obtain feedback on the approach, questions, duration, etc. of the interviews towards conducting interviews with other caregivers, volunteers, but especially with family members and residents.

2.3 Preparation

Before conducting this pilot study, the first author stayed as a participatory observer for one day in the hospice and one day in the day-care centre to better understand the location, the building, its organisation and people. Irrespective of the fact that these stays in themselves produced very interesting data, it also supported the design of the photo-elicitation interviews within this specific context. During these two days, important information on the actual use of the spaces in or around the building and structured photographs of all its interior and exterior spaces were collected. Then, for each space, an A3 collage of the photographs was made, with each photo collage providing the best

possible comprehensive representation of reality. For this study, researcher-generated photographs (preselected by the first author) were used instead of participant-generated photographs (taken by the participant). This decision was made to reduce the burden on participants in the first place, considering the precious time in the last stage of a person's life and the resident's (sometimes rapidly changing) conditions. Secondly, these photographs serve mainly to help participants visualise the entire building and its surroundings. This is important as it is clear that a walking interview or another related methodological approach requiring certain mobility of residents are often unfeasible given the circumstances. Moreover, to assist participants in the visualisation process, the architects' building plan was converted into a more universally readable A1 plan for people without an architectural background or with impaired vision. For this purpose, the plan was minimised to its essential information, different colours were used to indicate different functions, a larger font size was used, and architectural jargon to name the spaces was replaced by better-known vernacular. Furthermore, three different copies were made, either highlighting the hospice, the day-care centre, or both, so that the participant is not overloaded with information. Figure 1 shows an interview set-up where the plan and photo collages are used.

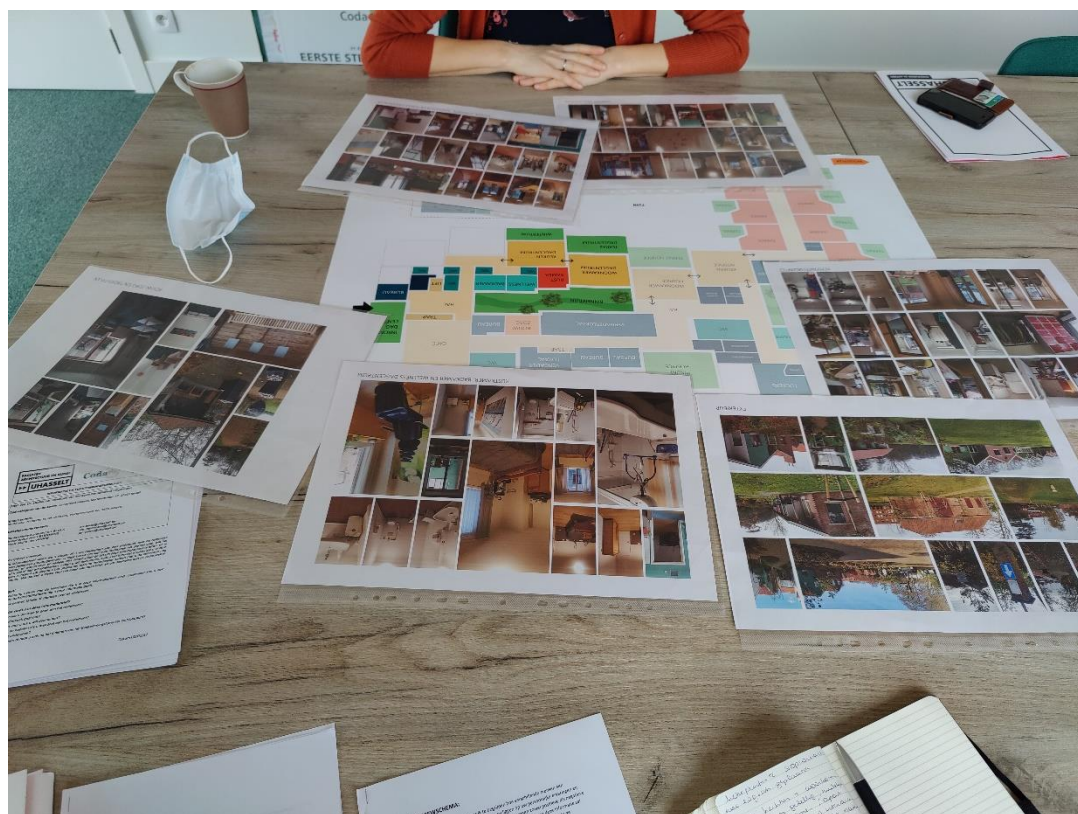


Figure 1. Photo-elicitation interview set-up.

2.4 Design

Since the aim was to design an interview guide applicable to all users of a palliative environment, we opted for a semi-structured interview form consisting of four main questions with a maximum duration of one hour. The interview guide starts with a question on relationship, expectations and first encounter with the palliative environment, but also allows the participant to indicate the daily activities and associated spaces using the converted plan. This question allows the researcher to determine which photo collages to include in the interview. The following two questions are intended to deepen understanding into participants' positive or negative experiences with(in) this palliative environment. In the final question, we looked at the participant's meaning of the concept 'homeliness' in general and in the context of this palliative environment since this was a frequently recurring concept during the participatory observations.

2.5 Procedure

In consultation with the caregivers of the hospice or the day-care centre, we will only ask potential participants meeting the inclusion criteria for this study. A few days before the interview, the informed consent is distributed among the potential participants to allow them time to read or in some cases discuss the study with someone close to them. Before the interview starts, this informed consent will be reviewed with the participant. The interview takes place in the palliative environment itself. The participants may choose a room in this building where they feel most comfortable conducting an interview, as long as there is a flat surface present to place the plan and photo collages on (e.g., table, desk, bed). The interviews are audio recorded, and the researcher takes notes during the interview to adjust the order of the questions or set probes where necessary.

3. Results and discussion

3.1 Methodological strengths

A human-centred approach is mainly achieved by adding a high level of flexibility to the study and enabling participants to make their own informed decisions about (1) participating; (2) the time, place, and duration of the interview; and (3) which personal experiences to share during the interview. By taking this into account, we try to reduce the burdens to a minimum and increase the will to participate. For this purpose, for example, it will be possible for bereaved family members to conduct the interview in their home environment. In addition, we use a semi-structured interview with open-ended questions. Answering all the questions does not take precedence, so the interview can be interrupted or stopped at any time on request of the participant. Furthermore, the researcher highlights that there are no right or wrong answers and that the participant's identity will remain confidential.

We used photo collages of each indoor or outdoor space and an easier-to-read plan to elicit architecturally richer specifications. Only the spaces used by the participant were added during the interview to avoid information overload. The researcher noted that the plan was used extensively by all three participants during the interview. They were often triggered by it and used it to guide the researcher through their experience. The aim was to use both the plan and the photographs only to support memorising, visualising and communicating. It struck the researcher that all participants answered the questions at first without really using the photographs. A possible explanation is that this palliative environment is their workplace where they (the 3 caregivers or staff members from the hospice and the day-care centre) spend much time and know the environment quite well. However, when their memories of experiences stopped, looking at the photographs helped them memorise other experiences. In addition, without using the correct architectural jargon, the participants marked particular architectural aspects on the photographs during the interview, reducing the language barrier between the researcher and the participant. Apart from the photographs and the plan, we noticed that the space in which the interview took place also helped to evoke experiences. One of the participants often looked out of the window during the interview because it looked out on other spaces of the palliative environment.

3.2 Methodological challenges

Even though we tried with the photo collages to provide the best possible comprehensive representation of reality, there will always be a potential bias in the choice and presentation of the photographs. In addition, photo collages were made per place, so that transition zones between (semi-)private and (semi-)public spaces could be overlooked. Furthermore, photographs are a snapshot of often tangible spatial aspects. Although during the interview, the researcher emphasises that these photographs probably do not contain intangible aspects (e.g., smells and sounds) and even not all tangible aspects, it can still be seen as a possible limitation of the design of the method. Moreover, the three participants in this pilot study (i.e., caregivers and staff member) use many spaces of the palliative environment, so there were many photo collages on the table during the interview. We noted that too many photographs could sometimes lead to an overload of information and consequently to less use of the photo collages. However, this problem is less likely to occur with residents and their families within the palliative environment since they use less spaces.

In addition, it should also be considered that these participants, especially in a work setting, may be more reluctant to offer criticism or negative experiences. Although theoretically, the informed consent could reduce this bias because it explains the benefits, confidentiality, anonymity, etc., of the research, in practice this document fostered some anxiety among the participants. Therefore, the researcher took the time to reassure them by clearly communicating the reasoning behind these ethical protocols before the interview began. However, when these informed consents are sent out in advance, it is not insurmountable that these forms' legalistic style and length can result in non-participation.

When the aim is to study multi-user perspectives, only including caregivers and staff members of the palliative environment in the sampling of this pilot study is certainly a limitation. As a result, no direct insight was conducted on how this methodological approach works on residents, family and volunteers in a palliative environment. However, the three interviewees' work and strong links with residents and families mean they have a wealth of experience and knowledge to provide considered and well-founded feedback. Hence, after each pilot study interview, the researcher requested feedback on the approach, questions, duration, etc., of the interviews to gain more insight for the subsequent interviews with other users of palliative environments. The participants of this pilot study unanimously agreed that an hour-long interview was too long for the hospice and the day-care centre residents. In addition, there are incapacitated people whose condition makes it difficult or even impossible for them to participate in an interview; however, it is essential for this research to study their experiences as well. It turned out that there is no one-fits-all solution for these challenges. As a result, even greater flexibility in the design of these photo-elicitation interview within a palliative environment will have to be considered in the future. By this, we mean shorter interview guides, interviews accompanied by a family member, maybe focus groups, etc. Even though we can increase flexibility in the design, a person's condition in palliative care can vary from day to day, so the planning often needs to be the most flexible.

A final challenge that may arise is when, during the analysis of data, we want to juxtapose different users' perspectives that come from different methodological approaches and have been carried out at different times. For example, the interviews for the pilot study were conducted during the COVID-19 pandemic, where there were restrictions on activities, visiting arrangements, and the use of space in Belgium's palliative environments. In the next round of interviews, these limitations may no longer apply, and the palliative environment may be experienced differently.

4. Conclusions

The intent behind using a pilot study of photo-elicitation interviews (on multi-user experiences with(in) palliative environments) was to capture the methodological strengths and challenges to support subsequent research in this field. Moreover, these results could also be helpful for research on other typologies to collect more architecturally rich (subjective) experiences from various (vulnerable) users by using a human-centred approach. However, we must emphasise that human-centredness often means that a tailor-made methodology is required. Nevertheless, the results of this pilot study can ultimately add value to (re)design more human-centred palliative environments by closing the loop between the architect's design intent and actual users' experiences.

Contributor statement

The corresponding author of the publication is responsible for any question regarding the Contributor Statement.

Conceptualisation: Iris Beuls, Ann Petermans and Jan Vanrie

Data curation: Iris Beuls

Methodology: Iris Beuls, Ann Petermans and Jan Vanrie

Project administration: Iris Beuls

Supervision: Ann Petermans and Jan Vanrie

Resources: Iris Beuls

Writing – Original Draft: Iris Beuls

Writing – Review & Editing: Ann Petermans and Jan Vanrie

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