

**Not just things:  
The roles of objects at the end of life**

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*Disclosure Statement*

The authors of this article declare no competing interests such as financial interest or any benefits arising from the direct applications of the research.

## **Abstract**

While the study of objects in care contexts is an emerging research field, it is largely overlooked in end of life (EoL) care. In this study, we empirically and inductively explore the roles of objects at the EoL from the perspective of bereaved family members.

Open individual interviews were conducted with 25 family members recruited from palliative in-patient and homecare units, as well as residential care facilities. After verbatim transcription, the interviews were analysed thematically.

Based on these interviews, we conceptualise the roles of objects thematically as relating to temporality, transformations of the everyday, and care. Through analysis we offer two main insights, the first relating to interdependency between objects and people, and the second to the recognition of objects as simultaneously flexible and stable in this interdependent relationship. The capacity and challenge of objects as part of EoL care lies in their ability to encompass various viewpoints and relationships simultaneously. This might provide valuable insights for staff caring for dying persons and their families. We propose that staff's ability to navigate objects in care practices could be meaningful in supporting the relationships between individuals in EoL situations.

(188 words)

**Word count of the main body of the paper: 8176 (including bibliography and figures)**

### **Keywords:**

Death and dying; End-of-life care; Family members; Objects; Relationships;

## **Introduction and aim**

Dying inevitably impacts everyday life for both dying persons and family members (Wallin et al., 2014, Carlander et al., 2011, Broom and Kirby, 2013). Objects, here used to denote physical non-human entities that can be felt, perceived, and seen, are inescapably part of everyday life and interwoven with its social practices (Shove et al., 2012). Calvino (1988) likens objects to "...the pole of a magnetic field, a knot in the network of invisible relationships" (p.33), underlining their importance. In healthcare, the study of objects is an emerging field with researchers suggesting that objects can support relationships in care as well as facilitate understandings of experiences through illness trajectories (Buse et al., 2015, Chapman, 2006).

Studies that explore objects in relation to dying and death vary in scope, intent, and often focus on particular types of objects. Whereas some studies in design, art, and architecture are concerned with creating new objects to improve EoL care (Nordström, 2016a, Petersson et al., 2016, Scott, 2013), other studies investigate existing objects. Among the latter are empirical nursing studies that only briefly touch on how objects may contribute to how EoL environments are perceived (Edvardsson et al., 2005, Lowton, 2009, Morris et al., 2015, Timmermann et al., 2015). However, few studies specifically explore existing objects in relation to dying and death. Those we have seen investigate personal objects as a way to re-create a sense of home in an institutional setting (Kellehear et al., 2009), identify the transformed value of personal objects after a death (Gibson, 2010, Gibson, 2004), or explore symbolic objects in grief rituals (Sas, 2016). Although research on objects in EoL care is limited, the study of objects in the context of care is evolving with researchers drawing attention to how various objects are essential and integrated into care practices (Hout et al.,

2015, Barnard and Sandelowski, 2001, Mol, 2008). The diversity among studies concerned with objects in care contexts (Buse and Twigg, 2015, Gibson, 2004, Kellehear et al., 2009, Mol, 2008, Nordström, 2016, Gibson, 2010) illustrates how this research area intersects different disciplines. Additionally, Barad (2003), Brown (2001), and Chapman (2006), argue that people and objects reciprocally shape one another, and Star and Griesemer (1989) illustrate how an object can act as a bridge between individuals and contexts, encompassing different understandings. Barad (2003) also emphasises how attributes and roles of people and objects are not fixed, but rather emerge through their relationships with one another.

Our research group, which includes both designers and palliative care researchers designed this study as part of a comprehensive interdisciplinary project investigating experiences of EoL environments from the perspectives of dying persons, family members and staff, with the ambition to improve these settings. In this article, we aim to explore the roles of objects at the EoL from the perspective of bereaved family members. Although we did not set out to specifically explore objects from the onset, we engage with a range of relevant theoretical literature to discuss our empirical findings.

## **Methods**

We conducted 25 interviews with individuals who had witnessed the dying and death of a close relative or friend, following approval from the Central Ethical Review Board in Stockholm, Sweden (# 29-2012). Purposive sampling was used to obtain variation in the types of EoL settings participants had experienced. We recruited participants through specialised palliative in-patient or homecare units as well as

through residential care facilities for the elderly. Staffs at the different units were asked to help identify family members who were over 18 years of age, who they thought would be able and interested in participating and who had been present throughout the care trajectory of someone close to them. Our sample consisted of 17 women and 8 men, aged 31 to 84. The time span from the death of the family member until interview varied from 1.5 - 8 months. The interviewee chose time and place for the interview, which lasted between 30 minutes and 2.5 hours. Most often, the interview took place in the interviewee's home or at the facility where the family member had received care. Participants were informed about the study both verbally and in writing before giving written informed consent.

The interviews began with a prompting question along the lines of "can you tell me about the time around the dying and death of X" and participants were encouraged to talk about what was salient to them. All interviews were audio-recorded and transcribed verbatim.

### ***Data analysis and interpretation***

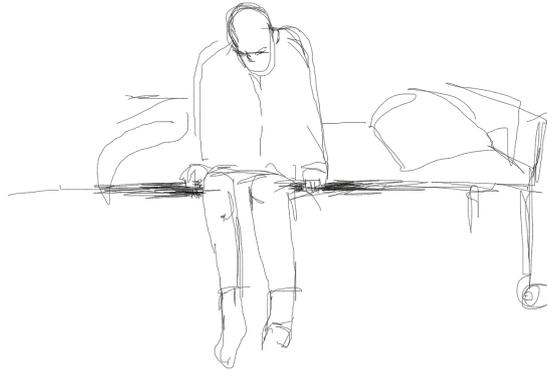
Our data analysis draws on inductive thematic analysis as described by Braun and Clarke (2006). The first author, HC, led the analysis in continuous discussion with the co-authors. HC began by repeatedly listening to the audio-recordings, while making written and sketched memos about their content. We noted that family members spontaneously mentioned everyday objects, (such as socks, hearing aids, beds), parts of objects (e.g. the edge of a bed) and objects that delineate space (e.g. floors), throughout the interviews. This triggered our interest in the roles that objects have in EoL contexts, which became the focus for continued analysis. Extracts including

objects were marked in the transcripts and these were preliminarily coded. To make sense of these extracts, HC developed the sketched memos into drawings (see Figures 2 and 3). The drawings remained close to the situations described, and complemented textual memos. Drawings are not typically used in thematic analysis but as Ingold (2011) notes, drawing is a useful tool which, “combines observation and description in a single gestural movement” (p.303). In our analytical work, the drawings facilitated multiple interpretations.

We constructed initial themes by organising extracts and their codes in relation to the research aim. The software program NVivo 10.2.1 was used as complement to the manual coding process. To check for alternative interpretations and to ascertain confirmability of themes, we moved back and forth between the transcripts, the coded extracts and tentative themes, and the full data set. Final refinements to names and descriptions of themes were made during the writing process as well as a final thematic map (Figure 1). In presenting the findings, we use exemplifying quotes with pseudonyms applied. Pauses are indicated by “...”, omitted phrases indicated by “(..)” and “[ ]” indicate authors’ comments.

## **Findings**

The results of this thematic analysis are presented in terms of three separate but not mutually exclusive roles that objects appear to play in relation to dying and death in these interviews: “Making Temporality Tangible” “Transforming the Everyday” and “Signs of Care”, as seen in Figure 1.



“...he fought, and I don’t know how he mustered the energy but he fought his way up to sit on the edge of the bed and I remember that I was almost angry with him, like “what the heck, do you really think you can stand up now or what...?” ...and then he grabbed ahold of one of his best friends and said “I want to get out of here” he said. And I said, “but you can’t, where are you going? What do you mean?” ... And it wasn’t as if he was confused and thought that he could leave, but it really was him signaling that he didn’t want to be a part of it anymore. But then he said “Take me out of here”

**Figure 1. Illustrated quote: Sarah talks about her dying husband John**

### ***Making Temporality Tangible***

In these interviews, objects had roles in making temporality tangible, often as markers of transitions along a dying trajectory. Objects also played roles in how family members oriented themselves in the dying process. This temporal focus reflects Adam’s (1990) argument that time is central to human social life as we organise and regulate life by it. It also resonates with Riessman’s (2015) account of her own cancer experience in which she found that temporality had become ambiguous without clear beginnings or endings. Riessman describes how the illness ruptured her everyday life making it necessary for her to actively reconstruct her sense of time. Our analysis thus adds to this, delineating how objects appear central in navigating temporality.

### ***Marking transitions***

Golan (1981) describes transitions as “period[s] of moving from one state of certainty to another, with an interval of uncertainty and change in between” (p.12). This resonates with our data as many family members mentioned arranging objects at various transitions, which may be interpreted as attempting to establish temporal markers along the dying trajectory. These arrangements appeared to be part of adapting to life with impending death and included bringing assistive devices into the home and rearranging furniture, or as seen in Emma’s example, introducing personal objects into an institutional setting:

*...It mostly felt okay anyway. I mean, it didn’t feel like a hospital room so...and it...it was...well, it was sort of warm. There were armchairs and there were other chairs and it was...yes (...) we had hung up pictures that the children had drawn and that kind of thing. And some photos and the like. So it was, it felt completely okay...*

Emma’s description suggests that objects such as pictures contributed warmth, and may act as reminders of other places and times. Hoskins (1998) notes that objects become entangled in life events and that they can function as vehicles for selfhood. It has been argued that a loss of objects as a result of care transitions can disrupt embodied connections to memories and identity (Buse and Twigg, 2014a). This implies that enabling arrangements with objects might support individuals through transitions. Implicitly Emma compared the overall atmosphere to other facilities, and spoke of it with a sense of acceptance. This is reminiscent of Davies and Nolan’s (2003) findings about relatives approaching nursing home placements “making the best of things” (p. 437). Objects as temporal markers can thus be understood as enabling individuals to actively *do* something when facing transitions largely beyond their control.

Family members generally talked about putting things in order after a death by e.g. dressing the dead person, lighting a candle, and arranging flowers. Some participants described clearing the room of medical equipment and assistive devices so as to remove reminders of sickness and dying. These types of configurations were mentioned in nearly all interviews, with some people explicitly saying this was a part of acknowledging the death of a person. The arrangements were either done by family members themselves or with help from staff. Eva described this in relation to her mother's death:

*So we took some favourite clothes and things out, and then we left [the room] and then they made her look nice and we had...we had roses in the room that I had bought a few days earlier and they used them to make it look nice at the bedside table, put it out there and had one of those small pretend candles that was lit and then they put a very beautiful quilt on...*

Eva outlined how several objects were arranged immediately after her mother's death, which together visually marked her death. The state of her mother's body was mirrored by the state of the surroundings – the clothes, the quilt, and the bedside table. This reflects arguments about atmospheres being actively shaped and supported by organizing objects and bodies and that arranging these become a way to share a social reality (Sloterdijk, 2011, Bille et al., 2015). While atmospheres can mirror ideals, they can also explicitly work towards reflecting discontinuities in experiences of the world. The latter might occur with disruptions in everyday life, and a need to construct new perspectives. This allows us to understand Eva's account and the described arrangements as part of a larger social pattern.

Several interviewees mentioned opening windows or closing doors after a death occurred, as to mark this event. Mats spoke of this when his mother died:

*I locked the door when I went in because I wanted to be alone, because otherwise it could happen that other people, demented people who lived there went into the wrong apartment and I didn't want anyone to walk in there (...) so I sat there with her and talked with her a bit.*

Mats indicated that a sense of privacy was important and by locking the door, he physically separated his mother's room from the rest of the facility. This separation may be interpreted as marking an existential boundary, comparable to how wrapping cloths have been described as offering physical separation, or boundary, between life and death (Nordström, 2016a). A wrapping cloth, paradoxically, covers the dead person so that the death of someone becomes visible and understandable (Nordström, 2016a). The closing of a door, or opening of a window allows for similar comprehension of death. The arrangements described by Emma, Eva, and Mats deal with transitions in different ways and irrespective of whether the transitions related to altering settings or if the transitions were existential, objects had roles in enabling and temporally marking these transitions. Thus, objects are not simply markers of EoL transitions, but crucial to mediating, and comprehending such transitions.

### ***Orienting on a dying trajectory***

In addition, family members spoke about the uncertainty of not knowing how much time was left and what that time would be like. Again, this reflects Riessman's (2015) account of how serious illnesses may disrupt life, underscoring the uncertainty of the

future. To illustrate this temporal rupture, Riessman describes how everyday routines, previously taken for granted, became increasingly important yet difficult when she was ill.

Similarly, several family members talked about how they observed the dying person's changing relationship to objects as a way to note changes along the dying trajectory.

Nina's reflection about her mother exemplifies this:

*My partner, he made a wonderful fish soup that she loved, and towards the end she wanted us to put it in the blender so that it would kind of be liquidy. And she could eat it with a spoon and could swallow it. And that was the last, like, real food she ate, on Friday.*

Nina's description of her mother's deteriorating ability to swallow includes three objects (soup, blender, and spoon) that become temporal markers of her mother's death. It seems that these interactions with objects allowed Nina to understand her mother's progress along a sickness trajectory.

In addition, several accounts of interactions with objects can be interpreted as demonstrations of the dying person's state of mind, for instance in Sarah's recollection of her husband John's dying, as drawn in Figure 2. At first, the situation might appear trivial, yet it depicts John's struggle to sit up on the bed, interpreted by Sarah as a way for him to communicate that he no longer had the will to live. Thus, it was not only bodily changes that allowed for family members to orient themselves, but the dying person's state of mind seemed to also be communicated through interaction with objects.



“We almost had a month at home, and we made that workspace into a bedroom. So we brought down the beds and then Anna and I slept there, and then at the end of the bed we placed the dining table and then next to it, a desk. I worked partly from home and we ate dinner there and...spent time together. It was cocooning in that room. And it was kind of fantastic. We were really together. We have two kids, and to be able to be so concentrated and intensely gathered at this time is something I think we live on now - in the long perspective - that we didn't ever have to be separated.”

**Figure 2. Illustrated quote: Erik talks about his dying wife Anna**

To summarize, temporality appeared complex yet central at the EoL. Objects had roles in marking beginnings and endings as well as allowing for orientation along a dying trajectory. Geismar (2011) offers insight into this:

*“...meaning cannot exist outside of human sociality. Objects, however, can, and do. It is the ability to both be defined by and transcend context that makes objects so interesting within our discussion of meaning, interpretation and translation” (p. 215).*

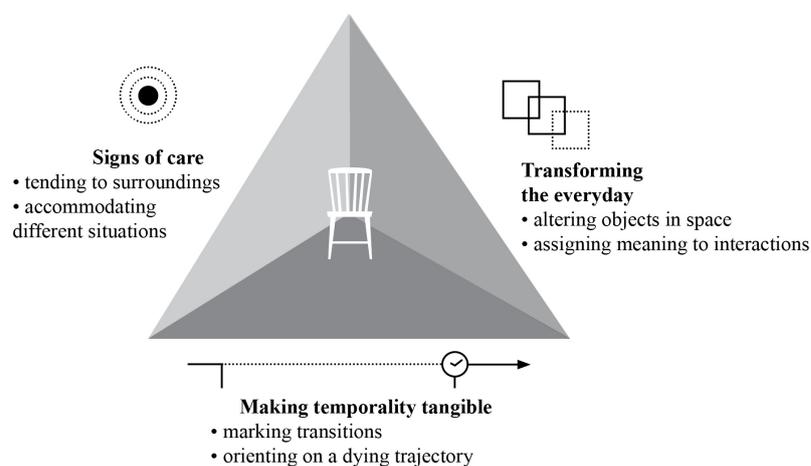
Geismar identifies how objects, because of their materiality, can go beyond their contextual meaning and bridge different situations and times. In our study, objects were stable enough to act as points of reference for family members. As such, objects allowed participants in the study to temporally concretize complex courses of events, making them comprehensible, a type of ‘hook’ that family members could ‘hang’ their experiences on to make sense of them.

## ***Transforming the Everyday***

While the role of objects as temporal markers demonstrates stability, objects can simultaneously offer flexibility. A number of scholars (Brown, 2001, Chapman, 2006, Komter, 2001, Latour, 2004, Mccracken, 1986) have addressed the reciprocity between objects and people. Our interviews revealed something of this and objects played roles in transforming everyday life as well as they were transformed by the interactions they were a part of.

### ***Altering objects in spaces***

Family members described transformations of ordinary and everyday spaces at the EoL. This is exemplified in Erik's description of how his wife died at home, depicted in Figure 3.



**Figure 3. Thematic map: the roles of objects at the end of life**

The quote and drawing hint at the transformation of a workspace into a bedroom. The bedroom was beyond the ordinary in that the whole family seemed to spend most of

their time there and it supported their continued life – working, eating and resting together even as one of them was dying. The bed appeared central, and even in other interviews the bed was described as a social focal point that enabled individuals to be together. A similar finding can be noted in Kellehear's (2009) study of bedside objects in a hospice. While Kellehear's study is not explicitly focused on beds, his analysis concerning objects placed on or around beds inevitably hints at their centrality, essential to various daily activities including eating, working, grooming and entertaining. Van der Geest and Mommersteeg (2006) suggest that beds are intrinsic to our lives, accommodating crucial moments such as giving birth, making love, and dying, yet beds have received little attention from social scientists. Our data suggests that beds not only may transform the relationships within a family but also that beds themselves are transformed by these interactions.

Implicit transformation of objects can also be noted in the above quote by Eva about arranging the room after her mother's death using ordinary things, already at hand. Eva explained that the roses on the bedside table were bought while her dying mother was still alive. However, these roses played a different role when placed on the bedside table next to her mother after death, demonstrating the flexibility of objects, in addition to their previously mentioned stability as markers. From Eva's description we can decipher a change in atmosphere. Atmospheres can be understood as interaction between subject, object, and space, an "in-betweenness" as Bille et al. (2015) term this, in which relationships are transformative rather than stable. This resonates with Barad's (2003) proposition that boundaries of things (human and non-human alike) are not predefined but that it is through interaction around a phenomenon that the roles of people and objects are determined and become

meaningful. This can be noted in the arrangements described by Eva, in which the objects were transformed from everyday objects for a living person to objects to commemorate a dead person. Thus, it was not only the person's body that was altered through a death, but even the roles of surrounding objects changed.

### *Assigning meaning to interactions*

Seemingly small and everyday actions were described as significant when they were a part of the EoL context. Chapman (2006) argues that the understanding of a person and an object is dependent on understanding the interaction between them, implying that an inquiry about objects inevitably involves interest in people and vice versa. Our findings similarly suggest that family members made sense of the dying person in part through their relationship to objects, and in this way seemingly mundane interactions were assigned with meaning. If we return to Sarah's story, depicted in Figure 2, the seemingly mundane act of observing John sitting on the edge of the bed became meaningful, amplifying what John verbalised. The situation (Figure 2) can thus be understood both as marking a certain point in time where Sarah understood that John's death was imminent as well as it illuminates how the roles of both the edge of the bed and John were determined through their interaction with one another. Jasmine, who talked about how she cared for her dying husband, provided another example about how interactions between a person and object could acquire new meaning:

*I could really see how he got worse and worse every day (...) for example...he didn't have the energy to take a shower because he would lose his balance and I used to tell him that we should take a bath instead. We have a Jacuzzi and I used to help him bathe*

*properly and sometimes I cried when I did it (...) because suddenly  
he was like a little, like a little old man who couldn't move anymore.*

Jasmine described crying when using the Jacuzzi as it signified that her husband could no longer shower – a stark contrast to how able he had previously been. In both examples, the mentioning of objects is subtle, yet they underscore the dying person's altered state, transforming everyday interactions.

There were also descriptions of how even seemingly insignificant objects could enable meaningful interactions, exemplified here by Gudrun's account:

*Both the doctor and Lars, my husband, were AIK fans [a soccer team] and they had so much to talk about which was also really good (...) And she [the doctor] could show him that she was wearing AIK socks so you know, so it was a bit like...it kind of wasn't only talk about sickness here.*

Socks are one of few personal clothing items that Swedish healthcare staffs wear when on duty, and these became a means for Lars and his doctor to talk about a common interest. In contrast to the descriptions above, this interaction includes a positive element, however it is similar to other accounts it carried a heightened significance since the socks, trivial as they might seem, enabled these individuals to meet beyond their established roles as doctor and patient.

The above examples illustrate how meanings of interactions with objects are transformed throughout the dying trajectory and that seemingly trivial interactions might become significant at the EoL. This challenge the coding of objects, referring to how we tend to share an understanding of what e.g. a house or a chair is (Brown,

2001, Chapman, 2006). When something fits comfortably in a code, we tend to take that object for granted, not thinking about its materiality (Chapman, 2006). However, Brown (2001) points out that objects are not understood as codes when they break. In these instances, we have to confront objects anew, because the deterioration of an object alters the relationship between the person and the object. Our study points to how relationships with objects may be similarly altered through the deterioration of a person's abilities or changes in their state of mind.

### ***Signs of Care***

Clothing and appearance have been noted to be visible indicators of the quality of care (Ward et al., 2008), and we made similar observations. Objects were interpreted as signs of care as family members related care both to how objects were tended to, and how objects themselves were perceived as accommodating. We use the term "accommodating" to refer to a reciprocal process of fitting into a situation, which can be seen in interactions between people and objects.

### ***Tending to surroundings***

When objects and surroundings were not adequately tended to, family members described experiencing distress and anxiety and that the dying person was not being well cared for. This could be seen when Karin described her dying mother's room:

*She came to the acute care hospital. And there she was really badly, terribly treated once again in [X] department. Filthy room and like, dark and drab, and it was, the floor was so dirty that I mean I had to wash it because, well mama's [colostomy] bags had leaked and*

*run out on the floor. I don't think that, as a visitor, I should have to be the one who takes care of that...*

Karin explained her mother being treated badly with the example of the floor and room not being tended to. The dirty floor seems to have been perceived as a lack of care, with its' importance emphasised by Karin's decision to clean the floor herself. This incident, along with Eva's description about arranging her dead mother's room, illustrate how care for a person and care for objects are not separate but rather integrated. While previous research has mainly made this point in relation to the personal and bodily care of the ill person (Ward et al., 2008, Reed-Danahay, 2001), our findings suggest that this includes surrounding objects too.

Another aspect of this is seen in previous descriptions of how family members arranged objects, e.g. in Emma's description of bringing pictures to the institutional setting. It seems as if such gestures with objects became ways in which family members' care for the ill person could be communicated, similarly to Van Der Horst and Messing's (2006) description of residents arranging plants, porcelain figures and vases to create a cosy atmosphere. In our interviews, family members also expressed concern about how objects were dealt with, such as hearing aids, or as Carl explained, clothing:

*And then quite a lot of clothes disappeared. Not because someone stole them, but I will never forget, it was because they were supposed to take care of laundry and then when you asked where the laundry was, pretty much all her clothes, like nicer pants and things, everything was gone.*

Carl's account makes clear that he viewed this as a consequence of neglect or organizational failure, rather than malice. However, it troubled him that no one seemed to care for his mother's clothes. Pols (2017) argues that in care practices, staff actively need to "take care" of objects when implementing new technologies. Our data suggest that this could also include everyday objects.

When procedures such as changing the bed sheets were experienced as being done with respect, they were described as genuinely caring. Another example of this can be seen in Sarah's story as she proceeded to talk about John:

*John's nurse, he brought a hammer and nails so that we could put up paintings that we had brought and you know (...) and we didn't even ask for it but he just saw that (...) It was very, it felt very personal, (...) they really came across as if they truly understood how important it was for us that this was John's room and not someone else's or a hospital room or something.*

Chapman (2006) suggests that relationships between objects and people are especially profound and fragile in relation to old age and death. While Sarah appeared taken by the nurse's gesture and recognition that this was important for them, this understanding is nonetheless potentially fragile in that offering a hammer and nail could be considered insignificant in a care situation. Yet this exemplifies the value of staff's ability to empathically navigate objects as part of EoL care.

### ***Accommodating different situations***

In EoL settings objects played a role in how family members described how they were able to accommodate to and be accommodated in different situations and settings, including different institutions. Rebecca described this, saying:

*Right outside her [mother's] room there was a group of sofas, a corner with sofas (...), and that was great because you often needed to go out [from her mother's room] for a while (...). Because you were sad, you had to go out and cry for a little while in that sofa or you would talk on your cell phone, and that sort of thing. So you were close but still a bit out of the way.*

Norman (2002) explains the properties of an object, which invite for certain understandings or functions as “affordance”. The sofas afforded Rebecca to rest, and made her feel like she had her own space in the facility. Scarry (1985) notes that there is inherent compassion within objects, explaining that chairs exist because people know of the pain of standing and their shape is “...the shape perceived-pain-wished-gone [...] the materialized structure of a perception: it is the sentient awareness materialized into a freestanding design” (p. 290). She adds: “distribution of material objects [...] means that a certain minimum level of objectified human compassion is built into the revised structure of the external world” (p. 291). The corner with sofas could thus be understood as materialized compassion of what it is like to be a family member in an EoL setting.

Still, there were instances when interactions with objects became problematic along the dying trajectory, as seen in Sandra’s description of the phone in her mother’s room; “...it [the telephone] rang and she had trouble handling that phone, and it was annoying for her when the telephone rang like that”. As Sandra’s dying mother’s

capabilities deteriorated, the phone, designed to be a means of communication, became a source of frustration. The phone remained intact but her mother's relationship with the phone had shifted as a result of *her* altered abilities. This indicates that peoples' relationships with objects are not static at the EoL but subject to continuous change. This is in line with Mol (2008), who argues that care is a process where objects as well as people need to be continuously attuned to one another, underlining how objects in care require ongoing engagement to be navigated.

While the above examples illustrate relationships between individuals and objects, family members also described objects as mediators between people. Gudrun's account about the socks in the previous section is one example. This mediating quality in objects is also manifested in Nordström's (2016) work on weaving wrapping cloths for stillborn children. The cloths were Nordström's response to a neonatal physician's comment: "What if there was a small cloth, to give to the parent who lost their child? Words are never enough" (2016b). Objects are, as Nordström (2016a) writes, "a tactile language" offering interpersonal connections.

Descriptions also included engaging with settings in other ways than those for which they were originally intended, as seen in Erik's story of how their family altered the workspace in their home (see Figure 3). Thus, it was not simply a matter of objects being designed with intended flexibility, but family or staff could sometimes adapt their interaction with objects depending on the circumstances. In these instances, individuals adapted the objects. This adaptation can be likened to the making of an object, which might strengthen the inherent compassion of objects. As Scarry (1985) suggests: "...the object's material attributes themselves record and memorialize the

intensely personal, extraordinary because exclusive, interior feelings of the maker for just this person – This is for you” (p.292).

To summarize, objects appeared to be tangible extensions of care, with the potential to demonstrate consideration for the family member’s or the dying person’s situation. Many examples concern changing relationships between a dying person and objects, which may not have been readily apparent to staff. In Karin’s account of the dirty floor and Carl’s description about his mother’s clothes going missing, it is possible that staff considered the floor and clothing subordinate and separate from the wellbeing of the dying persons. Yet these objects appeared to carry heightened meaning and importance for the dying person and their families. Thus, there are challenges in that one object can reflect various viewpoints. Differing understandings of objects, along with different sets of expectations, have been noted as a source of conflict between people (Komter, 2001). While Sarah’s story about being handed a hammer and nails attests to strengthening the relationship between the dying person, family and staff, not recognizing differing viewpoints as was the case in the situations described by Karin and Carl, indicates a potential threat and source of disruption to similar relationships in EoL care.

## **Discussion**

A variety of objects figure in the interviews with family members about the dying and death of someone close to them. The roles of objects at the EoL can be viewed separately, but also as interrelated facets (see Figure 1). Our analysis indicates that objects carry significant roles at the EoL relating to temporality, transformations of the everyday, and care. Through analysis we offer two main insights: the first relating

to interdependency between people and objects at the EoL, and the second to the recognition of objects as simultaneously flexible and stable in this interdependent relationship. Interdependency is seen in how objects in the interviews appeared to intimately accompany the processes of dying and death. In addition, objects seemed plastic enough to take on various meanings yet stable enough to act as points of reference for family members at the EoL. This combination of plasticity and stability offer both challenges and possibilities for further research and care practices.

The stability of objects relates to their ability to be "... both be defined by and transcend contexts" p.215 (Geismar, 2011). Objects can thereby become points of reference, bridging different times and environment, elucidating reflections. The study of objects in relation to health and illness is receiving increasing attention, as indicated by Buse et al.'s (2015) call for papers about "materialities of care" in which they note that while attention has been paid to "medical technologies, experimental materials and instrumentation (...) more mundane aspects of material culture have received less conceptual attention" (p.1394). The value of exploring everyday objects in relation to care is seen in Buse and Twigg's (2014b) study where handbags appear to support the identity of women suffering from dementia. Additionally, Buse and Twigg (2015) have studied clothing as a way to understand and access experiences of the illness trajectory and everyday life among people with dementia. Chapman (2006) proposes that all people have "special things" in their lives, and that these can be utilised to explore aging and how people make sense of the transitions that are inherent to this period in life. Buse and Twigg's (2014a; 2014b, 2015) and Chapman's (2006) studies focus on specific objects, and the objects become keys to access reflections about experiences of aging and illness. In contrast, we explore the roles of

objects based on data from open interviews about the EoL. On the one hand, our lack of direct questions about objects that could have steered the interviews supports the notion that objects are important at the EoL, and that these data are not artefacts of our probing. This inductive approach also meant that we remained open about which objects were of interest and how. On the other hand, this meant that we did not explore particular objects in-depth, which could have allowed for more, nuanced insights.

As mentioned above, we recognize challenges as well as possibilities in objects' simultaneous stability and plasticity. One possibility concerns how objects may act as lenses to study phenomena (such as temporality, the everyday and care at the EoL) using trans- and multidisciplinary approaches. This corresponds to Star and Griesemer's theory about boundary objects derived from their 1989 empirical study, in which they discuss how objects such as specimens, notes and maps were appropriated and understood by various groups in the development of the Museum of Vertebrate Zoology. They state that boundary objects "act as anchors or bridges, however temporary" (1989) (p.414) between different perspectives and point to how for instance a specimen becomes accessible and important for museum visitors, as well as for different scientists and theorists. In this way, a boundary object is at the nexus of multiple fields, practices and experiences. Objects in EoL care may be seen as boundary objects, positioned between different disciplines (e.g. health care professions, architecture, sociology, and design) and individuals (e.g. sick and dying people, family members, staff) in terms of how these objects are designed, used, and studied. Woodward (2016) notes that different disciplines can offer complementary perspectives that unsettles established ways to view a phenomenon. We found the

different backgrounds of the members of our research group enriching. Drawings (Figures 2 and 3) helped to shed light on subtle roles of objects in the analytical process. The drawings offer visual interpretations, explicating what was often difficult to verbalize. Also, we found the process of contextualizing our study using theories from several disciplines valuable. This study adds empirical depth to further develop theories about the relationships between people and objects. Simultaneously, this contextualisation enables our findings to be elucidated and situated in relevant frameworks, not divorced from practice. We thus suggest that there is potential in continued focus on objects to explore various phenomena at the EoL, and that this may bridge and bring together different disciplines.

We also suggest that our analysis might have implications for EoL care practices. Here, we emphasise how plasticity of objects involve challenges because the meaning, or altered meanings of objects may not always be obvious to staff. While it appeared as if staff's recognition of an object's meaning in a situation had the potential to strengthen staff's relationships with family members or the dying person, the lack of such recognition seemed to have potential to disrupt relationships. We therefore argue that staff's ability to be attentive to and navigate objects in care practices at the EoL is important. The understanding of relationships between objects and people at the EoL is an under-researched area. Studies are often focused on either the time before or after death (Gibson, 2010, Kellehear et al., 2009, Nordström, 2016). Our study adds a perspective largely lacking in the literature, as it is based on interviews linking the time before and after the death of a family member. Still, our study, as well as Gibson's (2010) investigation of how personal objects gain new value after a person's death, is based on retrospective accounts, which are naturally

affected by subsequent events in the participant's lives. It would therefore be relevant to complement this study with other research approaches, e.g. prospective longitudinal studies, direct observations or audits, as well as exploring how roles of objects are dependent on cultural perspectives. Different perspectives should also be explored further since it might well be that family members' accounts do not reflect the dying persons' or staffs' understandings. In addition, most participants in our study predominately described experiences from specialised palliative care, which is a relatively exclusive form of care in Sweden. Thus, it would be valuable to study objects in other forms of care such as acute care hospitals.

In line with Mol (2008), we argue that relationships with objects cannot be assumed or simply operationalized in care, but require continuous engagement to be navigated. To remain open towards what role an object might play in the EoL context appears important since our findings suggest that this can differ between individuals, contexts, and over time. In the words of Barad (2003); "...to figure matter as merely an end product rather than an active factor in further materialisations, is to cheat matter out of the fullness of its capacity" (p.10). The capacity and challenge of objects at the EoL lies in their ability to encompass various viewpoints and relationships simultaneously. Objects may make tangible that which is otherwise intangible and hint at concrete ways to navigate relationships. In this way, if objects are considered to be knots in invisible relationships (Calvino, 1988), these knots carry the potential to either reinforce or obstruct relationships. An understanding of such processes can be meaningful in care and we suggest that continued exploration of these issues is worthwhile.

## References

- Adam, B. (1990) *Time and Social Theory*, Philadelphia, Temple University Press.
- Barad, K. (2003) Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter. The University of Chicago Press.
- Barnard, A. & Sandelowski, M. (2001) Technology and humane nursing care: (ir)reconcilable or invented difference? *Journal of Advanced Nursing*, 34, 367-375.
- Bille, M., Bjerregaard, P. & Sørensen, T. F. (2015) Staging atmospheres: Materiality, culture, and the texture of the in-between. *Emotion, Space and Society*, 15, 31-38.
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Broom, A. & Kirby, E. (2013) The end of life and the family: hospice patients' views on dying as relational *Sociology of health & illness*, 35, 499-513.
- Brown, B. (2001) Thing Theory. *Critical Inquiry*, 28, 1-22.
- Buse, C., Martin, D. & Nettleton, S. (2015). 24(th) Sociology of Health and Illness Monograph: Materialities of care: encountering health and illness through artefacts and architecture. *Sociology of health & illness*, 37, 1394.
- Buse, C. & Twigg, J. (2014a) Looking "out of place": analysing the spatial and symbolic meanings of dementia care settings through dress. *International Journal of Ageing and Later Life*, 9, 69-95.
- Buse, C. & Twigg, J. (2014b) Women with dementia and their handbags: Negotiating identity, privacy and 'home' through material culture. *Journal of Aging Studies*, 30, 14-22.
- Buse, C. & Twigg, J. (2015) Materialising memories : exploring the stories of people with dementia through dress. *Ageing and Society*, 36, 1115-1135.
- Calvino, I. (1988) *Six memos for the next millenium*, United States of America, Estate of Italo Calvino.
- Carlander, I., Ternstedt, B.-M., Sahlberg-Blom, E., Hellström, I. & Sandberg, J. (2011) Being me and being us in a family living close to death at home. *Qualitative Health Research*, 21, 683.
- Chapman, S. A. (2006) A 'new materialist' lens on aging well: Special things in later life. *Journal of Aging Studies*, 20, 207-16.
- Davies, S. U. E. & Nolan, M. (2003) Making the best of things: relatives experiences of decisions about care-home entry. *Ageing and Society*, 23, 429-50.
- Edvardsson, J. D., Sandman, P. O. & Rasmussen, B. H. (2005) Sensing an atmosphere of ease: a tentative theory of supportive care settings. *Scandinavian Journal of Caring Sciences*, 19, 344-53.
- Geismar, H. (2011) "Material culture studies" and other ways to theorize objects: a primer to a regional debate. *Comparative Studies in Society and History*, 53, 210-8.
- Gibson, M. (2004) Melancholy objects. *Mortality*, 9, 285-99.
- Gibson, M. (2010) Death and the Transformation of Objects and Their Value. *Thesis Eleven*, 103, 54-64.
- Golan, N. (1981) *Passing through transitions: a guide for practitioners*, New York, The Free Press: A Division of Macmillan Publishing Co., Inc.
- Hoskins, J. (1998) *Biographical Objects: how things tell the stories of people's lives*, New York and London, Routledge.

- Hout, A., Pols, J. & Willems, D. (2015) Shining trinkets and unkempt gardens: on the materiality of care. *Sociology of health & illness*, 37, 1206-17.
- Ingold, T. (2011) Drawing together: materials, gestures, lines. In: Otto, T. & Bubandt, N. (eds.) *Experiments in Holism: theory and practice in contemporary anthropology*. Wiley-Blackwell.
- Kellehear, A., Pugh, E. & Atter, L. (2009) Home away from home? A case study of bedside objects in a hospice. *International Journal of Palliative Nursing*, 15, 148-52.
- Komter, A. (2001) Heirlooms, Nikes and Bribes: Towards a Sociology of Things. *Sociology*, 35, 59-75.
- Latour, B. (2004) *Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern*. The University of Chicago Press.
- Lowton, K. (2009) 'A bed in the middle of nowhere': parents' meanings of place of death for adults with cystic fibrosis. *Social Science and Medicine*, 69, 1056-62.
- McCracken, G. (1986) Culture and Consumption: A Theoretical Account of the Structure: A Theoretical Account of the Structure and Movement of the Cultural Meaning of Consumer Goods. *Journal of Consumer Research*, 13, 71-84.
- Mol, A. (2008) *The logic of care: health and the problem of patient choice*, Abingdon, Oxon: Routledge, 2008.
- Morris, S. M., King, C., Turner, M. & Payne, S. (2015) Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative Medicine*, 29, 487-95.
- Nordström, B. (2016a) *I ritens rum - om mötet mellan tyg och människa [In a room of rites - cloth meeting human]*. Licentiate Thesis, University of Gothenburg.
- Nordström, B (2016b) *I sin linda* [Online]. Available: <http://birgittanordstrom.se/i-sin-linda/> [Accessed 2017].
- Norman, D. A. (2002) *The Design of Everyday Things*, United States, Basic Books.
- Pettersson, A., Sandin, G. & Liljas, M. (2016) Room of silence: an explorative investigation of design students' redesign of an arena for reflection and existential meaning-making. *Mortality*, 21, 130-48.
- Pols, J. (2017) Good relations with technology: Empirical ethics and aesthetics in care. *Nursing Philosophy*, 18.
- Reed-Danahay, D. (2001) 'This is your home now!': conceptualizing location and dislocation in a dementia unit. *Qualitative Research*, 1, 47-63.
- Riessman, C. K. (2015) Ruptures and sutures: time, audience and identity in an illness narrative[Considerab]. *Sociology of health & illness*, 37, 1055-71.
- Sas, C. (2016) Designing Personal Grief Rituals: An Analysis of Symbolic Objects and Actions in Grief Therapy. *Death Studies*, 40, 558-569.
- Scarry, E. (1985) *The Body in Pain: the Making and the Unmaking of the World*, Oxford University Press.
- Scott, C. (2013) The sheltering sky. *Frame*, 192-5.
- Shove, E., Pantzar, M. & Watson, M. (2012) *The dynamics of social practice : everyday life and how it changes*, Thousand Oaks, CA: Sage Publications, 2012. 1st ed.
- Sloterdijk, P. (2011) *Neither Sun nor Death*, Los Angeles, Semiotext(e).
- Star, S. L. & Griesemer, J. R. (1989) Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science*, 19, 387-420.

- Timmermann, C., Uhrenfeldt, L., Hoybye, M. T. & Birkelund, R. (2015) A palliative environment: Caring for seriously ill hospitalized patients. *Palliative & Supportive Care*, 13, 201-9.
- Van der Geest, M. & Mommersteeg, G. (2006) Beds and culture: introduction. *Medische Antropologie*, 18, 7-17.
- Van Der Horst, H. & Messing, J. (2006) "It's not Dutch to close the curtains": visual struggles on the threshold between public and private in a multi-ethnic Dutch neighborhood.(Report). *Home Cultures*, 3, 21.
- Wallin, V., Carlander, I., Sandman, P. O., Ternestedt, B. M. & Håkanson, C. (2014) Maintaining ordinariness around food: partners' experiences of everyday life with a dying person. *Journal of Clinical Nursing*, 23, 2748-56.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C. & Cybyk, B. (2008) A different story: exploring patterns of communication in residential dementia care. *Ageing and Society*, 28, 629-51.
- Woodward, S. (2016) Object interviews, material imaginings and 'unsettling' methods: interdisciplinary approaches to understanding materials and material culture. *Qualitative Research*, 16, 359-74.