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Unburdening expectation and operating between: Architecture in support of palliative care

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Unburdening expectation and operating *between*: Architecture in support of palliative care

The role of design and materials in the enactment and experience of healthcare has gained increasing attention across the fields of evidence-based design, architecture, anthropology, sociology, and cultural geography. Evidence-based design, specifically, seeks to understand the ways in which the built environment can support the healing process. In the context of palliative care, however, the very measure of healing differs vastly. Physicians Mount and Kearney suggest that “it is possible to die healed,” and that such healing can be facilitated through the provision of “a secure environment grounded in a sense of connectedness” (2003: 657). Acknowledging this critical difference raises important questions around the various ways through which the built environment might support healing, but also about the potential of architecture to impart care. This paper reports on fifteen interviews with architects, experienced in the design of palliative care settings, from the UK, US, and Australia, to provide a deeper understanding of the questions being asked within the briefing processes for these facilities, the intentions embedded in the ways that architects respond, and the kinds of compromises deemed allowable (by various stakeholders) within the procurement process. Our findings suggest that palliative care architects often respond to two briefs, one explicit and the other unspoken. Design responses in relation to the first include: formally expressing a differentiation in the philosophy of care (signalling difference), attention to quality, extending comfort and providing “moments.” The second relates to the unburdening of palliative care facilities from their associative baggage and responding to the tension between the physical and imaginative inhabitation of space. In revealing the presence of this hidden brief, and the relationship between the two, this paper invites a broader discussion regarding the capacity of architecture to support palliative care patients, their families, and staff.

Introduction

Healthcare facilities present a challenging design problem. They require the accommodation of large groups of people with varying and highly specific needs, the careful organisation of complex systems and services, and adherence to strict standards of hygiene and safety. Aside from these manifold pragmatic concerns, many architects involved with healthcare design aspire to fulfil a performative agenda: that of affecting a sense of care. Sociologists Martin, Nettleton and Buse have argued that buildings *affect care* because they shape the caring practices that are performed within them, and the way those practices are anticipated; engendered “through the orchestration of architectural atmospheres” that elicit affect (2019: 1). The architectural brief initially developed for the Maggie’s Centres—a series of domestically scaled, non-clinical buildings, located on the grounds of acute

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3 hospitals across the UK, that offer support services to oncology patients and their families—provides
4 one of the most explicit examples of the faith placed in the capacity of designers to elicit affect. These
5 buildings were the brainchild of the late Maggie Keswick Jencks, landscape designer and oncology
6 patient. The original brief asked architects to create a building that:
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9 feels safe and welcoming, that could succeed in promoting serenity, joy or
10 acceptance, that is able to raise spirits and bolster one's capacity to face a difficult
11 challenge – an architecture that 'rises to the occasion' in solidarity with those who
12 inhabit it (MKJCCCT, 2015: unpaginated).
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16 The design provocation above was issued in direct opposition to traditional hospital spaces that
17 Keswick Jencks, herself, found dispiriting (1995). Important to discern here is that Maggie's Centres
18 have no clinical spaces, no waiting rooms, no wards, no surgical suites. They are buildings less
19 hampered by constraint and complexity than an acute, or subacute, healthcare facility.
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23 Research regarding the design of contemporary healthcare settings typically focuses on how the built
24 environment can support the healing process. For example, single rooms can assist with infection
25 control, sleep quality can be supported through lighting design, and the spatial arrangement of ward
26 environments can improve co-worker proximity and communication, alongside patient visibility,
27 contributing to improved patient care (Ulrich et al, 2008; Maben et al, 2015). Much of this research
28 emerges from the field of evidence-based design, where benefits are measured in terms of improved
29 recovery times and reduced healthcare costs (see, for example, Sadler, 2011). Yet in the context of
30 palliative care, where there is no "recovery," at least not in the terms it is considered within an acute
31 setting, what it means to "heal" is conceptually very different. Physicians Mount and Kearney have
32 defined healing as "support[ing] optimal quality of life when medical science can no longer modify the
33 natural history of disease" (2003: 657). They suggest "it is possible to die healed" and that such
34 healing can be facilitated through the provision of "a secure environment grounded in a sense of
35 connectedness" (2003: 657). Acknowledging this critical difference raises important questions around
36 the various ways through which the built environment could support healing for palliative care patients,
37 their families and healthcare staff.
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46 As Martin, Nettleton and Buse observe, the way a building *feels* "is subtly entangled with the ways that
47 people feel *about* [that building] ... and their understanding of the feelings they have whilst *in* [that
48 building]" (2019: 1-2). A building's design is typically deemed to be successful if it provides evidence
49 that the architect developed a deep understanding of the needs of the people who will inhabit that
50 building; and translated that understanding into a physical environment that responds appropriately to
51 those needs (Behar et al, 2017). Architects undertake a range of research tasks to guide their
52 response to designing healthcare environments, including focus groups and end-user interviews, they
53 may also draw on personal experiences of illness, hospitalisation, or the loss of a loved one. When
54 asked to design for palliative care *patients*, however, design professionals must respond to
55 experiences that can be appreciated only theoretically at best. While literature can provide some
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3 insight into the experience of facing one's death (see, for example, Blain, 2007; Cody, 2011; Rophie
4 2016), the relationship of the built environment to this experience is seldom discussed within such
5 texts. Further, at present only a small number of studies have gathered patient views regarding their
6 needs and preferences relative to the built environment when nearing the end of life (Cohen et al.,
7 2001; Fleming, Kelly and Stillfried, 2015; Kayser-Jones et al, 2003; Rowlands and Noble, 2008; Tan,
8 Braunack-Mayer and Beilby, 2005). Further complicating the extent to which architects can rely on
9 these studies is research that suggests a person's needs and preferences can change markedly as
10 they more closely approach death (Bell, Somogyi and Masaki, 2010; MacArtney et al, 2015; Rowlands
11 and Noble, 2008). As architectural theorist Karen Bermann has so astutely observed:

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16 It's hard to speak through and about pain, and it is pain as well as anxiety, boredom, hope,
17 fatigue, and more, that need to be articulated, concretized, and made into the shape of a chair,
18 the location of a window, the depth of a sill, the interior of a toilet stall (2003: 513).
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22 Acknowledging that buildings embody cultural and social meaning, architectural theorists Markus and
23 Cameron have suggested that a building provides the answer to a question. They caution, however,
24 that, in our ability to inhabit and experience buildings "we are usually in the position of judging the
25 answer without knowing what the question was" (2002: 78). These theorists recommend looking to the
26 physical texts that precede buildings, particularly the written brief which documents a range of
27 functional needs and client aspirations in relation to a problem, to which a design solution must
28 respond. Following this approach, within this article, we look to the way that architects themselves
29 interpret and respond to the needs and aspirations that commonly shape palliative care facilities.
30 Interviews with fifteen architects provides a deeper understanding of the questions being asked within
31 the briefing processes for contemporary palliative care facilities; the intentions embedded in the ways
32 that architects respond through the medium of design; alongside the kinds of compromises deemed
33 permissible (by various stakeholders) within the procurement process. This knowledge contributes a
34 deeper understanding regarding the capacity of architecture to impart care, counter expectation, and
35 respond to the liminal nature of end-of-life experiences. In doing so, it invites a broader discussion of
36 the potential of the built environment to support palliative care patients, their families, and staff.
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47 Method

48 This paper reports on fifteen qualitative, semi-structured interviews with architects experienced in the
49 design of contemporary palliative care settings, nine were from Australia, five from the UK, and one
50 from the US. Following ethics approval, participants were identified for inclusion based on snowball
51 sampling of recommendations by palliative care physicians and healthcare architects known to the
52 researchers, and via an internet search to identify recently constructed palliative care facilities. Seven
53 of fifteen participants were experienced in designing large, government-funded acute hospitals,
54 alongside smaller facilities for private or charitable organisations. Semi-structured interviews were
55 conducted by author one, either face-to-face or via an online platform, lasted between 40 and 90
56 minutes, and were digitally audio recorded and transcribed verbatim. An interview guide informed by
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3 the literature and the authors' experience in the field was used; this sought to understand the design
4 rationale, end-user consultation, and procurement processes, as well as architect's perceptions of how
5 design contributed to patient, family, and staff experiences. This paper focuses on interview data
6 related to the communication of care within the design process. This data forms part of a larger, three-
7 year, multi-methods study of how the design of inpatient care facilities impacts the delivery, and
8 overall experience, of palliative care that will include views from patients and family members (ongoing
9 restrictions related to COVID-19 has delayed the completion of these interviews). Patients or the
10 public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.
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15 Data was thematically analysed using a framework approach, which included: (1) familiarisation – the
16 researchers reviewed the interview transcripts; (2) identification of framework – key themes and issues
17 identified around which the data was organised; (3) indexing – application of themes to text; (4)
18 charting – use of headings and subheadings to build a picture of the data as a whole; and (5) mapping
19 and interpretation – in which associations were clarified and explanations worked towards (Pope &
20 Mays, 2006). Independent coding of the data was provided initially by author one, and then cross-
21 checked by author two to facilitate the development of themes, advancing an overall interpretation.
22 Once themes had been established, both authors independently reviewed interview transcripts to
23 compare, check and improve consistency. Our reading of this data was further shaped by secondary
24 literatures, particularly those related to materialities of care, sociologies of health and illness,
25 architectural history, and evidence-based design.
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34 **Imparting care through the built environment: Design intent and desire within palliative care**

35 Across a range of palliative care settings created for children and adults, architects employed four
36 design strategies in response to the challenges faced by patients, their families, and staff. These
37 included (1) signalling difference – utilising architecture to communicate that this is a different kind of
38 space to a hospital; (2) attention to quality – of materials and workmanship; (3) extending comfort; and
39 (4) providing “moments” to reflect, connect and regroup. While our conversations with architects did
40 not focus specifically on spaces for end of life, the significance of this experience and the design
41 considerations related to that remained at the forefront for many of the architects interviewed.
42 Correspondingly, design responses created for inpatient care for symptom management or respite
43 care often did not vary markedly to those created for end of life, except within the case of children's
44 hospices.
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51 ***Signalling difference***

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53 How can we use a building to convey that this is not a typical hospital; how can we
54 show in the architecture that something different is going on here, and make it a place
55 where people feel welcome to come? (Participant 2).
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58 Underpinning the delivery of palliative care is the desire to provide patients and families with an
59 inpatient experience that is markedly different to that of general hospital care, reflecting the aims of
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3 this medical specialty to improve a patient's quality of life through the enhancement of physical,
4 psychosocial, and spiritual wellbeing (WHO, 2020). As such, palliative care staff regard their
5 responsibilities as extending beyond the patient, to the emotional needs of the wider family (Steele &
6 Davis, 2015). Ensuring that architectural responses reflected this differentiation emerged as a key
7 priority for clients and their architects. This is similarly reflected in the literature, which strongly
8 supports the architectural expression of this differentiation through an atmosphere of homeliness
9 (Fleming et al, 2015; Gardiner et al, 2011; Timmerman et al, 2015; Zadeh et al, 2018). Precisely what
10 constitutes the attainment of homeliness, however, or even the particular design strategies for
11 obtaining it, is nowhere explicitly defined (*ref. blinded for review*). Hence, we asked participants to
12 articulate what their clients desired when requesting homeliness:
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17 [homely] is one of those emotive things – easier to define by what it's not than what it
18 is.... it's where you'd choose over an acute setting (Participant 1).

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20 our client had this idea that [visiting the hospice] was as if you were a guest coming to
21 a house ... that led to the de-institutionalisation of the design (Participant 12).

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23 a sort of heightened domestic ... that obviously a lot of care has gone into (Participant
24 4).

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28 These comments confirmed what is intimated within the available literature; while homeliness eludes
29 straightforward definition or analogy – and can be seen as encompassing many tendencies – it might
30 be summarised as antithetical to “institutional” (also see McGann, 2013). This responds to research
31 that suggests, where healthcare environments *feel institutional* this can exacerbate feelings of anxiety,
32 discomfort, alienation, and vulnerability (Brereton et al, 2012; Edvardsson et al, 2006; Fleming, Kelly &
33 Stillfried, 2015; Keswick Jencks, 1995; Zadeh et al, 2018). As a design aspiration, homeliness is often
34 used interchangeably with comfort, appearing as a kind of shorthand specification for spaces that
35 engender comfort while providing an atmospheric antidote to anxiety. Accordingly, researchers from
36 evidence-based design have attempted to isolate correlations between the aesthetic appearance of a
37 waiting room and patient anxiety (Becker, Sweeny & Parsons, 2008; Leather et al, 2003).

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39 While this desire for domesticity repeatedly manifests in the use of architectural forms, most
40 commonly gable-form roofs, for the architects we spoke with, homeliness proved to be about more
41 than visual signifiers. Several participants confirmed that spatial experiences were curated to evoke
42 feelings of being within a domestic setting:
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45 the building has been set up with ideas about some of the habitual aspects of day-to-
46 day life. It's the same as when you arrive at someone's house ... We sort of go
47 through these rituals ... leaving your shoes at the front doorstep ... we wanted an
48 experience which is like standing on a veranda of someone's house, straight away,
49 the cues speak to a different experience (Participant 13).

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57 Here the architects recognised a subtlety that is little discussed within the literature emerging from
58 evidence-based design, it is, as healthcare researchers Hilli and Eriksson have pointed out, “even if
59 healthcare settings are homelike, they do not necessarily facilitate the experiences of being at home”
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3 (2019: 426). Homeliness, nonetheless, holds the promise of familiarity and comfort, which are key
4 themes the following sections will develop further.
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8 ***Communicating care through the quality of materials and workmanship***

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10 Research confirms that finishes and furnishings that *feel clinical*, alongside a general lack of care
11 shown toward the environment, can trigger negative emotions for patients and their family's (Gardiner
12 et al, 2011; Rasmussen & Edvardsson, 2007; Rowlands & Noble, 2008; Timmermann et al, 2015;
13 Zadeh et al, 2018). Such research should act to heighten questions around the selection and
14 maintenance of materials, imbuing them with concerns beyond those related to efficiencies of cleaning
15 and cost. So often, however, it is precisely these efficiencies that determine material selection. As one
16 architect explained, where palliative care units are located within acute facilities, entrenched cleaning
17 procedures can narrow the use of materials deemed acceptable by the hospital: "they've got the same
18 cleaners that they use for the whole hospital, they don't want to have an isolated system" (Participant
19 8). The prioritisation of cleanliness is, of course, related to concerns of infection control that presents
20 an ongoing challenge to the use of softer furnishings (Gardiner et al, 2011; Duque et al, 2019). All of
21 the architects we spoke with were frustrated by the various limitations imposed on their material
22 selections, a vexation that appeared to be felt more keenly for architects less experienced in the
23 healthcare sector. In the following excerpt, two architects discuss the specification of vinyl instead of
24 floor tiles within a bathroom:
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32 We had this ambition to have a very homely and domestic style bedroom and
33 bathroom that had to be compromised (Participant 14).
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36 Yeah, there were definitely times when it was just like, "you've got these three choices
37 and they're three terrible choices" ... [bathrooms are] personal spaces... they're
38 spaces where people are undressing – there's that level of intimacy attached to them
39 – and yet at the same time, we're being challenged by extremely onerous constraints
40 around what [materials] are deemed acceptable from a healthcare standpoint
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42 (Participant 13).
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46 Other participants detailed various strategies they'd used for negotiating the use of alternative
47 materials and furnishings. Often, this required the dedication of additional time, on the part of the
48 design team, to secure approvals for non-standard materials. As one architect explained:
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51 We really challenged the infection control thing ... There was a file that was made up,
52 absolutely massive [gestures to around 800mm above the floor], that just documented
53 everything... there had to be a very rigorous argument [for the building inspector]
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55 (Participant 1).
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57 Another took steps to engage a local furniture maker, with the capability of upgrading their upholstery
58 fabrics to meet infection control requirements, to avoid the standardised furniture available through
59 NHS supply chains. They worked closely with the furniture maker to source comfortable armchairs in
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3 lieu of the standard-issue furniture “which just looked really institutional” (Participant 6). These
4 examples highlight that architect’s efforts toward homeliness were not frustrated by limitations that
5 were necessarily practical in nature, but rather by *perceptions* of what was safe which acted to
6 reinforce a limited outlook regarding what materials were suitable within a healthcare setting. One
7 hospital administrator, for example, relayed that his staff believed carpeted floors were “dirty”,
8 overlooking contemporary material technologies like antimicrobial coatings (*ref. blinded for review*).
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13 For the architects we spoke with, material considerations went well beyond the ease of maintenance,
14 a capacity to communicate comfort, or to infer quality. Instead, material concerns were suggestive of a
15 desire for furnishing mental states by affecting emotional response:
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18 there is a difference walking on a solid timber floor, it’s not the same as walking on a
19 floor that looks like timber but is actually not ... it’s a haptic sort of visceral experience
20 (Participant 13).
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23 It’s the human connection with materials that’s important ... materials and finishes that
24 have got some craft in them ... that show a lot of care has gone into their creation
25 (Participant 4).
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28 Architects also recognised that family members might obtain the greatest benefit from this attention to
29 materiality. One participant spoke of how a higher quality environment has the potential to ease the
30 guilt felt by family members who may longer provide be able to provide care for their loved one at
31 home (Participant 8). This echoes an observation by architect and theorist Sarah McGann that dying
32 in a hospice can, albeit unfairly, be perceived as a kind of failure—of the family, or even of the
33 physical space of the house itself, to accommodate the pressures of dying at home (2013: 37).
34 Another architect we interviewed observed that certain materials might be jarring in the face of loss:
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38 What’s fine in the ICU, is maybe not what you want if you’re going to see your
39 grandmother for the last time (Participant 2).
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42 The approaches taken by these architects echo the findings of Nettleton, Martin and Buse (2020: 153)
43 who observed that architects are attached to materials with the “scope to enact care” and “nurture
44 atmosphere” (also see Bille, Bjerregaard, and Sorensen, 2015).
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48 ***Expanding definitions of comfort***

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50 While participants acknowledged the importance of soft furnishings, and of mitigating the appearance
51 of medical equipment, they also spoke of comfort in terms of sensory experience, accessibility,
52 recognising the need for individual choice, and alleviating situational unease. This suggests that what
53 is missing from much of the evidence-based design literature for palliative care is an expanded
54 definition of comfort; one that is more explicit about the fact that there is more to homeliness than soft
55 furnishings. The view of the patient from the bed; what they could see, and how that affected their
56 emotional state was a common theme. For some, this was an instinctive first response. One architect
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3 recounted how their design aspired to help patients feel “nested and safe” (Participant 3). For others,
4 this presented an evolution in their thinking across successive projects:

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6 We are now not so worried about what it looks like to look *at the bed* ... but what
7 patients look at *from the bed* ... and for the patients that have no family and friends,
8 how do we make the room not feel so full of empty furniture (Participant 8).
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12 Other important generators of sensory experience were lighting, access to fresh air, the presence of
13 water, and natural, outdoor spaces. One participant explained how they changed the feel of the
14 hospital room “dramatically” by installing warmer lighting. Akin to the process of challenging what was
15 possible in terms of material selection, this architect challenged the need for bright, white light for
16 inpatient rooms. Accepting the need for the observation light directly above the bed to provide a high
17 level of light, he argued that, beyond that, the room could have a more “restful” feel by deliberately
18 keeping light levels lower and warmer in colour, similar to a hotel room (Participant 3; also see: *ref.*
19 *blinded for review*). Another architect pointed to the soothing potential of feeling water on the skin, and
20 the design possibilities this might inspire:
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24 [patients have said to me] when you’re going through pain management, one of the
25 joys is having water sprayed on you ... So why can’t you have a nice [shower] area
26 within the room ... more of an open connection like you have in hotels, to give a
27 retreat sense (Participant 8).
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33 As the quote above foreshadows, discussions of sensory experience can lead to discussions of
34 access. Several architects spoke of the importance of providing palliative care patients with access to
35 fresh air—the pleasure of a gentle breeze on the skin—yet operable windows were a feature that
36 architects had to continually fight for. While some prevailed, others were thwarted by perceptions of
37 risk that included infection control, safety, and security (also see: *ref. blinded for peer review*). In the
38 case of a children’s hospice, ensuring universal access to sensory experience was imperative as one
39 architect explained:
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44 No matter what situation one of the [patients] was in, they can get outside ... the tree
45 house has a bed-accessible platform and there is a wheelchair accessible abseiling
46 point at the rock-climbing wall (Participant 12).
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50 Comfort also manifested as the provision of choice for patients and their families. Accommodating
51 choice was recognised relative to different preferences for socialisation, recreation, processing death,
52 and grieving. As one architect observed, “we do and don’t have open conversations around death and
53 what that means for people – and it needs to be many different things” (Participant 12). Likewise, the
54 space in which such conversations emerge can’t be singular:
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58 Something we realised with palliative care is that you can’t just have one family area,
59 and you shouldn’t have them near each other. Grief is unexpected. You never know
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3 what's going to happen ... people who are incredibly rational and reasonable can
4 suddenly change (Participant 8).
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7 Another participant described how a large cavity sliding door was used to enable an end-
8 of-life suite to remain connected to the rest of facility – enabling “noise to bounce down the
9 corridor” – or to obtain greater privacy depending on the family's needs and preferences
10 (Participant 12). Similarly, the decision was made to provide only a kitchenette within the
11 end-of-life suite instead of a full kitchen:
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14 because we wanted to make sure that if a family – and some of them spoke this way
15 – if they wanted to sort of step out of the room and have a sit-down, maybe have a
16 meal or a conversation with somebody else, they can go and do that in the dining
17 room (Participant 12).
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21 Architects also showed consideration for the needs of family members in terms of mitigating the
22 uncertainty that can accompany the hospitalisation of a loved one – through the appearance,
23 functionality, or spatial layout of the design response:
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25 [As a family member] you're not quite sure how long you're going to be [at the
26 hospice], and we like for people to feel like they can stay ... So there's more joinery
27 than you'd find in an acute setting, more places to store things – the person that's
28 going to spend the night needs space to put their own clothing and the things they'd
29 like to have with them (Participant 2).
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33 The staff wanted first-time visitors to be welcome, but at the same time didn't want to
34 completely expose them to everything; to all the paraphernalia and the intensity of all
35 the other [paediatric patients] and their situations... so the [day lounge] sits further
36 back ... you're not confronting it straight away as you arrive ... there's an unfolding
37 sequence (Participant 13).
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41 42 ***Moments to reflect, connect and regroup*** 43

44 The word “moment” is common parlance in architecture for describing both a design intervention itself,
45 and the experience it is intended to provoke. In this way, “moments” are interchangeably spatial and
46 temporal: they are design gestures and arrangements ascribed causation – sometimes hopefully so.
47 In the palliative care context, moments tend to affect a break from the normative – a punctuation in
48 one's day, or an interaction. For the architects interviewed, providing moments sought to enable
49 patients, family members and staff to reflect, connect socially, or simply to compose themselves. This
50 was typically in response to the difficulties architects had observed working in the palliative care space
51 over multiple projects:
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54 We put in little conversation starters. What happens is that people will appear, and
55 they may not have seen each other for twenty years, and they didn't get along very
56 well, and here they are brought together by this unhappy event... If you can have
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3 something – a view, a bench, a fountain, a window seat – you can sit and pause, and
4 find a reason to start a conversation (Participant 2).
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7 In the case of a children’s hospice, those moments were designed to deliver “magical kid experiences”
8 – which was a theme that emerged from focus groups with parents and stakeholders:
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10 Part of creating that ... was finding spots where people can pause and have
11 conversations, or just a moment to be away ... the doorway to the dining room has this
12 little secret viewing window down into the stair ... and there’s a [special room] that,
13 maybe on your first visit, you didn’t realize was there, or you might hear a whisper that
14 it exists (Participant 12).
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19 Creating moments also featured consistently in the ways that architects expressed care to staff and
20 volunteers:
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22 Say we’re told the [hospice has] volunteers in the laundry ... rather than just having a
23 vent in the wall, you might have a little area with a glazed bit so they can iron and look
24 onto the garden... it’s a bit more humane (Participant 4).
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28 The recognition of staff needs relative to wellbeing is an important point. The stresses associated with
29 working within this palliative care are well recognised (McNamara, Waddell, & Colvin, 1995; Parola et
30 al., 2018), as is the value of supporting the wellbeing and resilience of medical staff more broadly,
31 through the provision of restorative spaces and access to nature (Armstrong et al., 2004; Cooper
32 Marcus, & Barnes, 1995). Yet, given the patient-centered focus of much evidence-based design
33 research, the needs of staff are scarcely discussed within the literature on designing for palliative care.
34 Further, *** et al (*ref blinded for review*) have recently highlighted the risk that, precisely because staff
35 share this patient-centered focus, they are likely to elevate the needs of patients and families above
36 their own resulting in these needs being overlooked within architectural briefing processes. This risk
37 was echoed through the comments of one architect who recounted obtaining critical insight from
38 visiting an existing hospice where the only retreat space available for staff was a storage room:
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44 It was just so sad... [so we gave staff] a space where they could be connected to
45 nature and kind of download and be away from everywhere else (Participant 12).
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51 **Unburdening expectations and opportunities for escape: Palliative care, and its architects,**
52 **as operating *between***
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54 What was broadly implied but rarely stated within our conversations with architects was an awareness
55 of the need to respond, in some way, to the simultaneous physical and imaginative inhabitation of
56 space. The feeling of any space implies a continuous negotiation between a subjective interiority—of
57 thoughts, past experiences, emotions, and expectations—with an exterior milieu of qualities and
58 properties composed within a physical space. Architectural theorist David Littlefield has written that
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3 “buildings live most powerfully in the mind ... we constantly process them, assimilate them and digest
4 them ... We constantly invest buildings with meaning” (2007: 15). Hospital environments, and perhaps
5 more so those related to palliative care, are imbued with a sense of unease that architecture is
6 implicated in perpetuating. McGann, reflecting on her involvement in designing a hospice project in the
7 late 1980’s, recalled: “from the [project] outset ... there was an awareness of the importance of
8 creating a building that resisted incarceration and enclosure, feelings of entering a building and not
9 coming out again” (2013: 63). From the patient perspective, however, little is documented in terms of
10 the spaces and surfaces of this disquiet. One exception is a study by healthcare researchers
11 Edvardsson, Sandman and Rasmussen which gathered patient perceptions of visiting an oncology
12 centre. The following series of metaphors was used by patients to describe their experience of visiting
13 a radiotherapy unit located within the basement: “the tomb”, “the catacombs”, “the underworld.” The
14 experience of traversing “long corridors and laborious stairs” to get to the radiotherapy unit
15 represented both a “physical and mental descent” for patients (2016: 191). A second notable example
16 is Keswick Jencks’s now often cited meditation on waiting rooms. This similarly speaks the oscillation
17 between physical space and a patient’s mental state, but also to the way that hospital spaces
18 communicate:

26 neon lighting, interior spaces with no views out and miserable seating ... all contribute to
27 extreme mental and physical enervation. Patients who arrive relatively hopeful soon start to
28 wilt... most hospital environments say to the patient, in effect: “How you feel is unimportant...
29 Fit in with us, not us with you” (1995: 21).

32 Our final example comes from mental health but similarly speaks to the intimate relationship between
33 the physical and mental inhabitation of space. Architectural researcher Stephanie Liddicoat (2017), in
34 a series of interviews with patients, identified an emotional aversion to hospital furniture that appeared
35 worn or bore traces of past use. For the patients she spoke with, this heightened their awareness of
36 the suffering of others who had occupied the space before them. All three of these examples speak to
37 the tension between sensory and imaginative engagement, and to the need to unburden healthcare
38 facilities from the weight of expectation they carry.

44 Underpinning the design strategies that emerged from the interview data, of signalling difference,
45 attention to quality, extending comfort and providing moments, was a less acknowledged set of
46 concerns. The first speaks to the need to unburden palliative care facilities from their associative
47 baggage and, the second, to responding to the tension between physical and mental space—an
48 acknowledgement that these environments are perhaps never fully inhabited, but experienced as a
49 kind of *suspension between*. Within palliative care spaces, parallels might be drawn between the
50 physical room and the cognitive and emotional *space* of the patient; these spaces are analogous to
51 the world and a departure from it. Being *suspended between* that echoes through the work of
52 sociologists MacArtney et al, whose interviews with thirty patients regarding their transition from active
53 (or “curative”) treatment to palliative care, challenges the simplicity of author Susan Sontag’s (1978)
54 description of cancer in *Illness as Metaphor* as being like a passport to another world. MacArtney et al
55 argue instead that palliative care patients understand:

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3 their self as a source of continuity, contrasted to the flux of backdrops or future drops
4 that their life and illness brought ... we can now recognize not only the back-and-
5 forth character of those lived experiences of the transition but also the productive
6 possibilities of being in different states, in different ways, and at different times
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8 (2017: 631).
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11 The experience for these patients is thus one of “liminality ... of “concurrently living *and* dying” (2017:
12 631). While these researchers argue that this has significant implications for “how the self and
13 subjectivity might be conceptualized at the end of life” (2017: 623), we suggest these implications
14 should extend to how physical space is handled for patients occupying this liminal psychological
15 space. Considerations of unburdening and tending to physical and mental space were not spoken of
16 explicitly in the conversations we had with architects, yet they were ever present within the design
17 approaches expounded and can thus be considered a kind of unspoken brief.
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23 Unburdening was approached through the sequencing of spaces in ways that spoke to signalling
24 difference and to comfort, but also to familiarity. Perhaps owing to the more confronting nature of
25 paediatric palliative care, those architects who had designed children’s hospices understood that
26 architecture could foster inclusivity through the careful arrangement of spaces. All three participants
27 spoke of the need for a gentle introduction to these places, in ways that respect the visitors’ capacity
28 to cope with the emotional burden of what they might find there. Providing access to allied facilities,
29 such as hydrotherapy pools (that are on the hospice site but can be visited independently), arriving
30 through landscaped courts, and replicating the intimacies of domestic ritual were various strategies
31 employed. It is possible that the use of verandas and entrance halls, within palliative care settings,
32 may impart familiarity on a deeper sensory level than communicating ideas of domesticity through
33 gabled forms and soft furnishing could achieve, allowing reassurance to be drawn from encounters
34 that *feel* quotidian. One participant explained that their personal experience, as the close friend of an
35 adolescent with cancer, drew their attention to the importance of a more domestic entrance sequence:
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42 a hospital process is very anonymous for a lot of people when they when they go
43 in. Yes, there’s the nurse’s station and so on, but if you’ve been [visiting] for nine
44 months, you just walk all the way through. You go straight to someone’s bedroom ...
45 And you could walk in and out and, probably, no one would know any difference ...
46 there’s no personal connection (Participant 13).
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50 On the one hand, this architect lamented the lack of community within the hospital environment and
51 the fact that spaces could, instead, be arranged to foster more intimate personal connections. On the
52 other, this observation hinted at the way that domestic rituals of arrival are encoded with
53 considerations of dignity and respect that can too easily be neglected within healthcare settings. As
54 McGann has similarly observed: “visitors to a hospital are faced with the dilemma of which way to
55 look. In domestic space we would very reluctantly walk into a neighbour’s bedroom for a chat while
56 they lay there semi-clothed” (2013: 18).
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3 A crucial design approach in response to the simultaneous inhabitation of physical and mental space
4 was the extension of space beyond its limits, often physically by utilising views to spaces beyond, but
5 also tacitly mental. Read in this way, the relationship to nature within palliative care settings might
6 more closely related to an intuitive understanding of the “flux” that patients experience (MacArtney et
7 al., 2013:631) than to the simple affordances of landscape as “something to overlook ... something to
8 do [take a walk] ... or somewhere to sit” (McGann, 2013: 61). The architects we interviewed all
9 conveyed the importance of landscaped spaces as visual and physical distractions from one’s room.
10 These were consistently referred to as enabling “connection” – with others, and with nature – and
11 occasionally as having the capacity to hold wonder. The architect of a children’s hospice, for example,
12 explained how the central courtyard was designed to enable a net to be fixed over the top and “two
13 hundred butterflies” to be released into it (Participant 12). This can be seen to continue a long tradition
14 of employing landscape to soothe the flux of emotions that challenge a patient’s psychological
15 wellbeing that was similarly present within the design of nineteenth century asylums; views and
16 access to landscape was considered of the utmost importance in the process of reconnecting patients
17 with a prior sense of self—one that was more at ease within the world (Browne, 1847; Hickman 2009).
18 Landscape historian Clare Hickman (2009) has suggested the genesis for this exists in the work of
19 eighteenth-century writers on landscape, such as Joseph Addison, who wrote that delightful scenes in
20 nature have “kindly influence” on the mind “and not only serve to clear and brighten the imagination
21 but are able to disperse grief and melancholy” (Addison cited in Hickman, 2009: 426). W.A.F. Browne,
22 a leading advisor on nineteenth century asylum design, similarly observed that:

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32 To many... [the] country affords delight ... the changes of season... the living and
33 moving things which pass across the scene, form a strong and imperishable tie with
34 the world and the friends to which the heart still clings (1847: 182).
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38 The passage above speaks to the paradoxical experiences of presence and escape that landscaped
39 spaces simultaneously enable. Views to the exterior allow visual exploration of outdoor spaces that
40 are tantamount to mental or imaginative exploration. Nature can also reconnect us, according to
41 Browne, with the emotional ties that bind us to this world, and thus secure a desire to remain attentive
42 to, and active within, the present. McGann similarly intimates the importance of an “inside-outside
43 connection”—the consistent awareness of landscape from within the interior—in assisting this
44 reconnection:
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49 Long stays within hospital buildings can disconnect the occupier from the world outside,
50 leaving him or her completely unaware of the weather, time of day or even what day it is,
51 unconnected to his or her world, *dis-identified* (2013: 59, emphasis added).
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54 McGann’s use of the term “dis-identified” highlights how easily a patient’s self-identity can be
55 threatened in the face of terminal illness and hospitalisation. The extension of dignity to patients within
56 palliative care, as *** et al (*ref blinded for review*) have recently highlighted, is often reduced to
57 concerns of privacy, and conflated with the provision of single (as opposed to shared) rooms. Yet Guo
58 and Jacelon (2014: 935) offer a definition of dignity that includes, amongst its considerations, “being
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3 self”—that is “the continuity of the individual self, in spite of one’s advancing illness.” While nature can
4 be seen to play a significant role in *enlivening* the spaces of palliative care by ensuring a
5 consciousness of life and liveliness, it is equally significant for its revealing of, and relationship to,
6 time, self, and the wider world.
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10 The capacity for enabling the mind to wander was similarly encapsulated in the response of “creating
11 moments”: to gaze out of a window is to be distracted, to have a conversation with a loved one, or to
12 hear and watch a fountain is sensorially immersive. In the study by Edvardsson, Sandman and
13 Rasmussen, opportunities for distraction within the oncology care setting imparted a sense of
14 hopefulness: “If the environment contained objects that attracted attention and initiated thinking, then
15 suddenly the world of cancer could be escaped from, for however short a moment” (2016: 194). The
16 desire commonly expressed for palliative care environments to feel homely perhaps relates as much
17 to providing opportunities for mental escape as to supporting feelings of comfort and familiarity.
18 Indeed, it might be through comfort and familiarity that the mind is invited to wander. McGann has
19 conceptualised the idea of homeliness within palliative care settings as “an interpretation of the
20 hospice as a temporal dreaming space ... as a place in which to have the scope to dream” (2013: 56).
21 Here, she is drawing on Gaston Bachelard’s theorisation of the meaning of home in *The Poetics of*
22 *Space* as “a space for daydreaming [and] one that holds our memories” (Bachelard, 1969: 4-5). A
23 closer look at how healthcare researchers working beyond palliative care conceptualise homeliness
24 further supports McGann’s conception. Hilli and Ericksson have suggested that feelings of “at-
25 homeness” are about helping patients to feel:
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34 in connection with themselves and their belongings, places, activities, and significant
35 others, as well as having a transcendental capability. At-homeness is both a process
36 and a state that encompasses having a place where privacy, safety, and identity can
37 be preserved and protected (2019: 430).
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40 “At-homeness” thus suggests a feeling of comfort that goes far beyond the material environment;
41 whether a person can feel *like oneself* in an environment that is (psychologically) very far from home,
42 alongside a capacity to temporarily escape this reality, typically through sensory experience. To
43 engage with atmospherics and detail might constitute imaginative and emotional suspension.
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49 Conclusion

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51 Our conversations with architects working within the space of palliative care, designing for patients
52 within this liminal state, and for their loved ones, revealed many, varied methods to affect a sense of
53 care and to aid a patient’s *dying healed*. These ranged from acts of advocacy, to tweaking extant
54 systems, to imaginative and generous spatial gestures, spatial sequencing, cultivating comfort through
55 familiarity, the simple provisions of amenity, material and haptic consideration, and the curation of
56 sensorial experiences. Whether or not the corresponding buildings created by the architects
57 interviewed achieved this or not remains beyond the scope of this article and thus represents a
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3 limitation, one that future research will need to address by gathering views from the patients and
4 family members who have experienced these spaces. Further, it must be acknowledged that the
5 practical limits of architectural influence within the procurement of healthcare facilities will always
6 restrain the idealism to which they might otherwise aspire; this was nowhere more evident than within
7 discussions around materiality. Notwithstanding, our interest here was to understand the way that
8 architects perceived their obligations in designing spaces so heavily laden with emotion; how they
9 responded through the medium of design; and what further opportunities might be possible for
10 advancing design practice relative to the needs of palliative care.
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15 What we found beyond these conscious acts of design—signalling difference, attention to quality,
16 extending comfort and providing moments—was an implicit sensitivity to additional layers of liminality,
17 or between-ness. The first is the site of the word ‘space’ itself, and its tendency to drift between
18 physical and metaphysical constitution. As buildings that house people who are between life and
19 death, palliative care facilities are settings in which simultaneous encounters of physical and mental
20 space are prevalent and made more fluid by the availability, and limits, of time. The second is the
21 recognition that alongside addressing an explicit spatial brief, architects in general, and healthcare
22 architects in particular, are entangled in a far more complex and tacit brief: the cultivation and tending
23 of mental space – that is, an individual’s imaginative world. This relates both to the unburdening of
24 hospital spaces and to extending opportunities for imaginative escape. Architects operating in this
25 arena are (and aren’t) just making a building, and a highly pragmatic and technical building at that.
26 These facilities are not the jurisdiction of phenomenologists and poets: they are difficult buildings and
27 occasional battlegrounds. Yet, among the architects we spoke with, poetry and generosity were eked
28 out, sought within sidelong approaches to the primary concerns in response to a second, unspoken
29 brief; that of tending to the cognitive state of patients, and also their families, in the hopes of imparting
30 care through the extension of comfort and reprieve. These ideas are seldom acknowledged within the
31 contemporary literature on the design of palliative care environments. We suggest their incorporation,
32 though a broader discussion of what it means to design with the desire to impart care, counter
33 expectation and respond to the liminal nature of end-of-life experiences, could lead to richer physical
34 environments in support of patient and family wellbeing.
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47 Bibliography

- 48
49 Armstrong, D., M. Kane, D. Reid, M. McBurney and R. Aubrey-Rees. 2004. “The Role of Hospital
50 Design in the Recruitment, Retention, and Performance of NHS Nurses in England.”
51 <https://www.thenbs.com/PublicationIndex/documents/details?Pub=CABE&DocID=276261>
52
53 Bachelard, Gaston. 1969. *The Poetics of Space*, trans. M. Jolas. Boston: Beacon Press.
54
55 Becker, Franklin, Bridget Sweeney, and Kelley Parsons. 2008. "Ambulatory Facility Design and
56 Patients' Perceptions of Healthcare Quality." *HERD: Health Environments Research & Design Journal*
57 1, no. 4: 35-54.
58
59 Behar, Carrie, Fran Bradshaw, Louisa Bowles, Ben Croxford, Darryl Chen, John Davies, Marianne
60 Heaslip et al. 2017. *Building Knowledge: Pathways to Post Occupancy Evaluation*. Reading: RIBA
(Royal Institute of British Architects) and University of Reading.

- 1
2
3 Bell, Christina L., Emese Somogyi-Zalud, and Kamal H. Masaki. 2010. "Factors Associated with
4 Congruence Between Preferred and Actual Place of Death." *Journal of Pain and Symptom*
5 *Management* 39, no. 3: 591-604.
- 6 Bermann, Karen. 2003. Love and Space in the Nursing Home. *Theoretical Medicine* 24: 511-523.
- 7
8 Bille, Mikkel, Peter Bjerregaard, and Tim Flohr Sørensen. 2015. "Staging Atmospheres: Materiality,
9 Culture, and the Texture of the In-Between." *Emotion, Space and Society* 15: 31-38.
- 10 Blain, Georgia. 2017. *The Museum of Words: A Memoir of Language, Writing and Morality*.
11 Melbourne: Scribe.
- 12
13 Brereton, Louise, Clare Gardiner, Merryn Gott, Christine Ingleton, Sarah Barnes, and Christopher
14 Carroll. 2012. "The Hospital Environment for End of Life Care of Older Adults and their Families: An
15 Integrative Review." *Journal of Advanced Nursing* 68, no. 5: 981-993.
- 16 Browne, W.A.F. 1847. "What asylums were, are and ought to be." Reprinted in *The Asylum as Utopia:*
17 *W.A.F. Browne and the Mid-Nineteenth Century Consolidation of Psychiatry*, Andrew Scull, ed.
18 London & New York: Tavistock, 1991.
- 19 Cody, Joshua. 2011. *Sic: A Memoir*. London: Bloomsbury.
- 20
21 Cohen, S. Robin, Patricia Boston, Balfour M. Mount, and Pat Porterfield. 2001. "Changes in Quality of
22 Life Following Admission to Palliative Care Units." *Palliative Medicine* 15, no. 5: 363-371.
- 23
24 Cooper Marcus, Clare, and Marni Barnes. 1995. *Gardens in Healthcare Facilities: Uses, Therapeutic*
25 *Benefits, and Design Recommendations*. Concord, CA: Center for Health Design.
- 26
27 Didion, Joan. 2005. *The Year of Magical Thinking*. London: Fourth Estate.
- 28
29 Duque, Melisa, Sarah Pink, Shanti Sumartojo, and Laurene Vaughan. 2019. "Homeliness in Health
30 Care: The Role of Everyday Designing." *Home Cultures* 16, no.3: 213-232.
- 31
32 Edvardsson, David, P. O. Sandman, and Birgit Rasmussen. 2006. "Caring or Uncaring – Meanings of
33 Being in an Oncology Environment." *Journal of Advanced Nursing* 55, no.2: 188-197.
- 34
35 Fleming, Richard, Fiona Kelly, and Gillian Stillfried. 2015. "'I Want to Feel at Home': Establishing What
36 Aspects of Environmental Design are Important to People with Dementia Nearing the End of Life."
37 *BMC Palliative Care* 14, no. 1: 1-14.
- 38
39 Gardiner, Clare, Louise Brereton, Merryn Gott, Christine Ingleton, and Sarah Barnes. 2011. "Exploring
40 Health Professionals' Views Regarding the Optimum Physical Environment for Palliative and End of
41 Life Care in the Acute Hospital Setting: A Qualitative Study. *BMJ Support Palliative Care* 1, no. 2: 162-
42 166.
- 43
44 Guo, Qiaohong, and Cynthia S. Jacelon. 2014. "An Integrative Review of Dignity in End-of-life care."
45 *Palliative Medicine* 28, no. 7: 931-940.
- 46
47 Hickman, Clare. 2009. "Cheerful Prospects and Tranquil Restoration: The Visual Experience of
48 Landscape as Part of the Therapeutic Regime of the British Asylum, 1800—60. *History of Psychiatry*
49 20, no. 4: 425-441.
- 50
51 Hilli, Yvonne, and Katie Eriksson. 2019. "The Home as Ethos of Caring: A Concept Determination."
52 *Nursing Ethics*, 26, no. 2: 425-433
- 53
54 Kayser-Jones, Jeanie, Ellen Schell, William Lyons, Alison E. Kris, Joyce Chan, and Renee L. Beard.
55 2003. "Factors that Influence End-of-life Care in Nursing Homes: The Physical Environment,
56 Inadequate Staffing, and Lack of Supervision." *The Gerontologist* 43, no. 2: 76-84.
- 57
58 Keswick Jencks, Mary. 1995. *A View from the Front Line*. London: Maggie Keswick and Charles
59 Jencks.
- 60
61 Leather, Phil, Diane Beale, Angeli Santos, Janine Watts, and Laura Lee. 2003. "Outcomes of
62 Environmental Appraisal of Different Hospital Waiting Rooms." *Environment and Behavior*, 35, no. 6:
63 842–869.
- 64
65 Liddicoat, Stephanie, K. 2017. "Architecture and the Design of Therapeutic Environments." PhD
66 dissertation, University of Melbourne, Australia.

- 1
2
3 Littlefield, David. 2007. "Introduction." In *Architectural Voices: Listening to Old Buildings*, edited by
4 David Littlefield and Saskia Lewis, 1-18. West Sussex: Wiley-Academy.
- 5 Maben, Jill, Peter Griffiths, Clarissa Penfold, Michael Simon, Elena Pizzo, Janet Anderson, Glenn
6 Robert et al. 2015. "Evaluating a Major Innovation in Hospital Design: Workforce Implications and
7 Impact on Patient and Staff Experiences of All Single Room Hospital Accommodation." *Health
8 Services and Delivery Research* 3, no 3: 1-304.
- 9 MacArtney, John I., Alex Broom, Emma Kirby, Phillip Good, and Julia Wootton. 2017. "The Liminal
10 and the Parallax: Living and Dying at the End of Life." *Qualitative Health Research* 27, no. 5: 623-633.
- 11 MacArtney, John I., Alex Broom, Emma Kirby, Phillip Good, Julia Wootton, Patsy M. Yates, and Jon
12 Adams. 2015. "On Resilience and Acceptance in the Transition to Palliative Care at the End of Life."
13 *Health* 9, no. 3: 263-79.
- 14 Markus, Thomas A., and Deborah Cameron. 2002. *The Words Between the Spaces: Buildings and
15 language*. London: Routledge.
- 16 Martin, Daryl, Sarah Nettleton, and Christina Buse. 2019. "Affecting Care: Maggie's Centres and the
17 Orchestration of Architectural Atmospheres." *Social Science and Medicine* 240: 112563.
- 18 McGann, Sarah. 2013. *The Production of Hospice Space: Conceptualising the Space of Caring and
19 Dying*. Oxon: Routledge.
- 20 McNamara, Beverley, Charles Waddell, and Margaret Colvin. 1995. "Threats to the Good Death: The
21 Cultural Context of Stress and Coping among Hospice Nurses." *Sociology of Health & Illness* 17, no.
22 2: 222–241.
- 23 MKJCCCT (Maggie Keswick Jencks Caring Cancer Centres Trust). 2015. Architectural Brief.
24 [https://www.Maggie'scentres.org/media/uploads/file_upload_plugin/Maggie's-architectural-
25 brief/architectural_brief_Maggie's.pdf](https://www.Maggie'scentres.org/media/uploads/file_upload_plugin/Maggie's-architectural-brief/architectural_brief_Maggie's.pdf)
- 26 Mount, Balfour, and Michael Kearney. 2003. "Healing and Palliative Care: Charting our Way Forward."
27 *Palliative Medicine* 17: 657-658.
- 28 Nettleton, Sarah, Daryl Martin, Christina Buse, and Lindsay Prior. 2020. "Materializing Architecture for
29 Social Care: Brick Walls and Compromises in Design for Later Life." *The British Journal of Sociology*
30 71, no. 1: 153-167.
- 31 Parola, Vitor, Adriana Coelho, Anna Sandgren, Olga Fernandes, and João Apóstolo. 2018. "Caring in
32 Palliative Care." *Journal of Hospice and Palliative Nursing* 20, no. 2: 180–186.
- 33 Pope, Cathrine, and Nicholas Mays. 2006. *Qualitative Research in Health Care*. London: Blackwell.
- 34 Rasmussen, Birgit H., and David Edvardsson. 2007. "The Influence of Environment in Palliative Care:
35 Supporting or Hindering Experiences of 'At-Homeness'?" *Contemporary Nurse* 27, no. 1: 119–31.
- 36 Rophie, Katie. 2016. *The Violet Hour: Great Writers at the End*. London: Little, Brown Book Group.
- 37 Rowlands, Julie, and Simon Noble. "How does the Environment Impact on the Quality of Life of
38 Advanced Cancer Patients? A Qualitative Study with Implications for Ward Design." *Palliative
39 Medicine* 22, no. 6: 768-774.
- 40 Sadler, Blair L., Leonard L. Berry and Robin Guenther. 2011. Fable Hospital 2.0. *Healthcare design*.
41 <http://www.healthcaredesignmagazine.com/article/fable-hospital-20>
- 42 Sontag, Susan. 1978. *Illness as Metaphor*. New York: Farrar, Straus & Giroux.
- 43 Steele, Rose, and Betty Davies. 2015. "Supporting Families in Palliative Care. In *Oxford Textbook of
44 Palliative Nursing*, edited by Nessa Coyle and Betty R. Ferrell, 51-72. Oxford: Oxford University Press.
- 45 Tan, Heather M., Annette Braunack-Mayer, and Justin Beilby. 2005. "The Impact of the Hospice
46 Environment on Patient Spiritual Expression." 2005. *Oncology Nursing Forum* 32, no. 5, 1049-1055.
- 47 Timmermann, Connie, Lisbeth Uhrenfeldt, Mette Terp Høybye, and Regner Birkelund. 2015. "A
48 palliative environment: Caring for seriously ill hospitalized patients." *Palliative and Supportive Care* 13,
49 no. 2: 201-219.
- 50
51
52
53
54
55
56
57
58
59
60

1
2
3 Ulrich, Roger S., Craig Zimring, Xuemei Zhu, Jennifer DuBose, Hyun-Bo Seo, Young-Seon Choi,
4 Xiaobo Quan, and Anjali Joseph. 2008. "A Review of the Research Literature on Evidence-based
5 Healthcare Design." *HERD: Health Environments Research and Design Journal* 1, no. 3: 61–125.

6 WHO (World Health Organisation. 2020. Definition of Palliative Care.
7 www.who.int/cancer/palliative/definition/en
8

9 Zadeh, Rana Sagha, Paul Eshelman, Judith Setla, Laura Kennedy, Emily Hon, and Aleksa Basara.
10 2018. "Environmental Design for End-of-Life Care: An Integrative Review on Improving the Quality of
11 Life and Managing Symptoms for Patients in Institutional Settings." *Journal of Pain and Symptom*
12 *Management* 55, no. 3: 1018-1034.
13
14

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