

## Designing Palliative Care Facilities to Better Support Patient and Family Care: A Staff Perspective

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### ABSTRACT

**Objective:** To contribute staff perspectives on the design of palliative care facilities to better align with the philosophy of palliative care, in support of patient, family, and staff wellbeing.

**Background:** The receipt of palliative care differs from other inpatient experiences owing to its distinct philosophy of care, longer lengths of stay, a greater presence of family members, and more frequent end of life events. While research regarding the optimal design of palliative care environments recognises these differences, this knowledge has been slow to exert change on the guidelines and procurement processes that determine the design solutions possible within these settings. Sustained research attention is required.

**Methods:** An online survey, comprising a series of open-ended questions, elicited the perceptions of palliative care staff regarding the relationship between the physical environment and the distinct philosophy of palliative care.

**Results:** Responses from 89 Australian-based palliative care professionals confirmed the high value that staff place on environments that offer privacy, homeliness, safety, and access to gardens to assist the delivery of optimum care.

**Conclusions:** Our findings illustrate that the implications of privacy and homeliness extend far beyond the patient room, and that homeliness is about more than an aesthetic of comfort. This highlights a broader capacity for design to better support the philosophy of palliative care. Importantly, the data reveal a key relationship between staff wellbeing and the environments in which they work; environments that are unable to match the quality of care that staff aspire to deliver can engender frustration and distress.

# **Designing Palliative Care Facilities to Better Support Patient and Family Care: A Staff Perspective**

## **Introduction**

The receipt of palliative care differs from other inpatient experiences in important ways. Palliative care has a distinct philosophy of care, lengths of stay are often longer, there will typically be a greater presence of family and friends (outside of pandemic conditions), and end-of-life events will be more frequent, as will the difficult conversations that accompany those events (AIHW, 2020a; AIHW, 2020b; Bergenholtz et al., 2019). While evidence-based design aims to discern the various ways that the physical environment can support the healing process, the very measure of healing within palliative care is different from other inpatient settings. As physicians Mount and Kearney (2003) have written, “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.” *Healing* here intimates a broader conception of care within palliative care settings, which extends from the patient to include the wider family (Steele & Davies, 2015). It recognizes that end-of-life experiences are as momentous for family members as they are for patients, and that the ongoing psychological impacts of this experience can be long-lasting (Rosenzweig, 2012; Wright et al., 2010). While it is broadly accepted that the way a facility is designed can support the delivery and overall experience of palliative care (Gardiner et al., 2011; Hajradinovic et al., 2018; McLaughlan & Kirby, 2021; Rowlands & Noble, 2008; Zadeh et al., 2018), McGann (2016) has drawn attention to the need to prioritize the “philosophy of care” in the consideration of palliative care spaces, and recognize the true extent to which physical space undermines the achievement of these ideals.

This article reports on the perceptions of palliative care staff, specifically their understanding of this relationship between the physical environment and the philosophy of care. How staff perceive the capacity of an inpatient environment to support or obstruct their delivery of care has implications for the quality of care delivered to patients and families, but also to job satisfaction and staff wellbeing (Curtis & Northcote, 2016; Maben et al., 2015; McLaughlan & Pert, 2019; Novotná et al., 2011; Tyson et al., 2002). Perceptions of a space, or how a building *feels*, as Martin, Nettleton & Buse (2019) have observed, are “subtly entangled with the ways that people feel *about* [that building] ... and their understanding of the feelings they have whilst *in* [that building].” Staff perceptions can provide designers and decision makers with data that speaks to functional suitability, but also to the emotional experiences contained within these spaces (Edvardsson et al., 2006; Jencks, 1995; Irish Hospital Foundation, 2009). The reason this understanding is important is because, despite the broad acknowledgement that palliative care spaces should be designed *differently*, this understanding is more seldom reflected within the design guidelines and procurement practices that determine what design solutions are possible (McLaughlan & George, forthcoming; McLaughlan & Kirby, 2021).

A reliance on design evidence from other healthcare settings may be exacerbating this problem. A recent review identified only a dozen studies that expressly examined the design of palliative care settings (Wong et al., forthcoming). This limitation of available research means design evidence from other healthcare settings is often adopted for use (see, for example, Irish Hospice Foundation, 2009; Zadeh et al., 2018). Although there is value in translating research from other healthcare settings, doing so carries the risk of effacing the specificities of palliative care needs and transferring this erasure into future palliative care design outcomes. Inspired by Keeney’s (1992) theory of “value-focused thinking,” we asked staff to consider the facility in

which they deliver care relative to the philosophy of care (the value system) that guides their work (also refer McLaughlan & Pert, 2020). As McLaughlan et al (2020) have previously posited, highlighting the relationship between spaces and the values that underpin care can make clearer which spaces contribute most to supporting those values, usefully guiding where design attention should be focused. Whilst recognising the unique perspective that staff can offer regarding the environments in which they deliver care (Elf et al., 2015; McLaughlan & Kirby, 2021; McLaughlan & Pert, 2020), the data reported here forms part of an ongoing 3-year study that seeks to complement the knowledge obtained from staff with the views of patients and family members (ongoing COVID-19 related restrictions have delayed these interviews).

### **Participants, Method & Analysis**

The study reports responses to an online survey from 89 Australian-based healthcare professionals working in palliative care (Table 1). Ninety-one healthcare professionals submitted the survey, however, two were excluded as they were not based in Australia. The largest participant group was nurses (n = 45), followed by doctors (n = 34). While a variety of inpatient settings were represented, 43% worked within an acute hospital (n = 38), 18% within a sub-acute hospital (n = 16), 23% within a free-standing palliative care unit located on an acute hospital campus (n = 21), and 10% worked in a standalone palliative care facility (e.g. located “driving distance” to from the nearest hospital) (n = 9). Data were gathered between July 2020 and March 2021.

The survey included four open-ended questions, two photo-elicitation questions, and seven demographic questions (see Appendix 1); this study focusses on the responses to the open-ended questions (1, 2a, 2b, 3a, 3b, 3c, 3d, and 3e). The survey began by asking staff “what do you think is the most important part of your job,” with the intention of focusing participants on

the value of their contribution, as a care professional, to the experience of patients and/ or their families. The second asked about the physical environment in terms of how it *supported* or *obstructed* their delivery of care to focus staff on the relationship of their working environment to the broader value system that underpins their professional practice. Question three asked staff to reflect on how they felt their physical environment could be improved, whom such an improvement would *most benefit* (patients, families, staff, or a mix thereof), and *how*. The questions were designed in this way to obtain a deeper understanding of how staff perceived a connection between the philosophy of palliative care and how the physical environment supports the delivery of care in line with that philosophy, or not.

[insert table 1 about here]

In March 2020 six interviews were held to inform the survey design. Four were walk-through interviews, held onsite with clinicians at four different hospital facilities, two were held with Professors of Nursing via online platform; all had recent experience consulting on the design or refurbishment of hospital facilities. A preliminary version of the survey questions was then reviewed by five palliative care professionals in May 2020. Their recommendations prompted changes to the wording used within the drop-down selection menus for the “location” and “relationship to landscape” questions. The revised questions were then piloted with an additional five palliative care professionals. This determined that no further modification was required. Pilot responses were not included in the results. Question order was intentional (not randomized), and no adaptive or conditional questioning was used.

All healthcare professionals with palliative care experience within Australia were eligible to participate. A convenience sample was sought. To obtain a more representative sample, however, the survey was circulated to hospitals, professional healthcare organizations, healthcare

services, palliative care associations, and other professional bodies throughout Australia, who then shared the survey with their staff and members (see Appendix 2). Participation was voluntary and anonymous, and no incentives were offered.

Participants followed a website link to complete the survey on SurveyMonkey. Anyone with access to the website link could complete the survey. Some questions were compulsory (delineated by an asterisk in Appendix 1) and participants were unable to progress to the next question without completing them. Participants could not change their responses once they had exited the survey. Completion rate was 100% for all compulsory questions (1, 3a, 3b and 3c). For the non-compulsory questions, completion rate was 78% for question 2a, 84% for question 2b, 91% for question 3d, and 59% for question 3e. View rate, response rate, and participation rate could not be calculated because (a) instances where the survey link was accessed but nothing was submitted were not tracked, (b) the entire survey, including consent information, was viewed on one page, and (c) participants had to complete all compulsory questions before submitting the survey. Despite being completed during the COVID-19 pandemic (97% were completed between July- September 2020), only two responses made explicit reference to infection control, suggesting that, at the time of the survey, these concerns were not heightened for Australian-based staff. One respondent suggested “updating air conditioning ... [for] infection control”; another, that patient rooms might be accessible “via outdoor paths, so that in COVID times people can visit via the outside.” While COVID-19 cases increased steadily from mid-June, peaking on August 16, the highest number of national hospitalizations during the course of this survey was 694 (Australian Department of Health, 2021). IP addresses were monitored to identify duplicate entries; no duplicate entries were identified. The study received ethics approval from The University of Newcastle (HREC number H-2019-0056).

The survey responses were analyzed in NVivo using a ‘qualitative descriptive’ approach (Colorafi & Evans, 2016; Neergaard et al., 2009). Participant responses for questions 2a–3e were analysed together, given the interdependent nature of these responses. Question 1 was analyzed separately. Two authors, (XX, XX), independently coded the first 20 responses into meaning units with minimal abstraction (where meaning units refer to blocks of text conveying a single idea). Meaning units with thematic similarity were then grouped into themes. The two authors compared themes and a consensus was reached in consultation with a third author, (XX). These themes were then reviewed by two palliative care experts (XX & XX). The remainder of the responses were analyzed by one author (XX). Throughout analysis, all authors continued to discuss and review the emerging themes during meetings and via email, and all authors came to consensus on the final themes and subthemes.

## Results

When asked to describe the most important part of their job (Question 1), nearly half (n=39) of the responses included the provision of “comfort” or “support to patients and their families,” and a quarter (n=23) discussed providing care that was “holistic,” “individualized,” or in alignment “with the patient and family’s own therapeutic goals.” The following responses are illustrative of the way that **many participants expressed the provision of clinical care as being closely integrated with patient and family support:**

“Probably the communication with patients and support [is the most important part of my job]. The time we take to explain things, the shared decision making, the reflective listening... Symptom management probably sits second to that.”

“Providing holistic care to patients and families, on their terms, based on their priorities.”

“Being present for patients and family, communication and managing symptoms.”

While participants were asked to respond to Question 3a with “one change” they would make to their working environment, participants responded by listing between one and 14 changes; together the 89 participants suggested 151 changes in response to this question. Patients were identified as the primary beneficiaries of the changes suggested within 64% of responses (n = 57). Nineteen per cent (n = 17) of suggestions were for the primary benefit of family members, and 17% (n = 15) for staff. The responses to Question 3d, which asked if the same changes would benefit any other group, revealed the extent to which changes made for the benefit of one group also benefited others. Of the 57 patient-centered responses, 33% (n = 19) were believed to also benefit families, 17.5% (n = 10) were believed to also benefit staff, while a further 42% (n = 24) were believed to offer benefits to both family members *and* staff (this left only 8% of patient-centered responses (n = 4) that did not specify benefits beyond the patient group). Of equal importance, from the 15 staff-centered responses, 87% (n = 13) felt the changes recommended would contribute directly to a higher quality of care being extended to patients. Further, many of the suggestions made ostensibly for the benefit of staff did not appear to have staff at the heart of these suggestions, for example, one participant suggested that “more family meeting rooms” would most benefit staff by providing “optimal conditions for very challenging discussions.” This was clearly underpinned by a deep concern for the wellbeing of families.

Three distinct themes emerged from the analysis of Questions 2–3. The first two circumscribe the comfort of patients and family members, while the third relates to core medical functions, distinguished from the provision of emotional and psychosocial forms of support. Each of these categories and the types of qualities they implicate are first defined, the results are then presented according to prominent spatial divisions.



### ***Definition of themes.***

*Privacy.* For confidentiality, intimacy, being out of view of others, and freedom from disturbance caused by others, privacy was viewed as crucial to maintaining a quality of care aligned with staff values. Where privacy was lacking this was seen to compromise patient dignity; to negatively impact the relationship between staff and the patient or family; to obstruct the quality of time families could share; and to exacerbate patient, family, and staff distress, including making the grieving process more difficult. **Concerns of privacy extend beyond the consideration of bedrooms and bathrooms, highlighting the importance of providing private spaces beyond the bedside, particularly greenspaces, alongside the design of nursing stations and circulation spaces to support dignity.**

*Homeliness.* A desire for homeliness was expressed in the hopes of helping patients and families to feel “more settled, less stressed, and more likely to relax”; to minimize the restrictions and emotional discomfort associated with extended periods of hospitalization; even to assist with distraction from negative thoughts or feelings. Defined as such, homeliness encompasses a variety of spatial and interior design concerns: making hospitals feel less clinical, recognizing a patient’s individuality (including opportunities to personalize the hospital environment), and providing spaces that allow families to stay overnight but also to maintain the rituals of home.

*Safety.* The third theme emerging from the participant data was the need for safe and efficient care environments. Safety relates to minimizing the risk of injury to patients, families, and staff, while efficiency relates to minimizing the effort required to perform core medical functions and other routine tasks. Design considerations related to safety and efficiency included insufficient and inadequately designed spaces, often in relation to patient beds and bathrooms, storage, staff office, and meeting and break out spaces.

### *Spaces and spatial qualities.*

*Situating a palliative care facility.* Staff felt that locating palliative care facilities within acute wards “diluted the philosophy of palliative care,” as it often resulted in unpleasant levels of noise, embarrassingly public care, and an inability for patients and families to spend meaningful time together. Overcrowding, too close a proximity to high-traffic areas, and high noise levels were also associated with acute wards. This resulted in environments that feel “very stressful,” and where “communication [is made] difficult.” “Calm,” “quiet,” and “restful” were qualities commonly associated with free-standing facilities. Participants related low levels of noise to a sense of calm and control, and, ultimately, to an “improved quality of life” for patients.

Designated wards or freestanding facilities were seen, moreover, to “empower” the “family [to be] with the patient, and staff to deliver compassionate care.” Separating palliative from an acute care environment was also believed to support better patient outcomes, and to improve staff wellbeing: “staff would feel more satisfied as they would be providing care in a more appropriate environment.”

*Developing an atmosphere suited to palliative care.* Reducing the clinical feel of palliative care environments by increasing natural light, using warmer lighting, livelier color schemes, artworks and comfortable furnishings were prominent suggestions. Some participants also suggested decreasing the visibility of clinical aspects of care, such as sharps bins, signage, and other medical equipment. “Family members will... feel more comfortable,” one participant suggested, “in an environment that has more personality than blue walls and a linoleum floor.” Staff commented that “fluoro [fluorescent], cold lights are clinical, anonymous, and harsh, and remind me of cold, hard places like railway stations and public toilets ... [Whereas] warm lighting and lamps are softer and calmer and more relaxing and help people forget they are in a hospital.” It

was also suggested that achieving a different atmospheric quality could directly contribute to better patient care by “reminding [staff] that the hospice is different from other clinical environments and a special place where people leave this world... and grieve for loved ones.” An atmosphere suited to palliative care also extended to recognizing—and, indeed accommodating—individual preference. As one participant answered, in response to question 1, palliative care is about “making the model of care fit the [patient and family] needs”, not vice-versa. Children and adolescents, alongside patients of different cultural backgrounds, naturally experience ‘home’ in different ways, and catering to these experiences within palliative care environments was seen as a way to make patients feel more at home within these environments. The option of receiving care outdoors is another example of this, particularly within the Australian context, outdoor spaces provide an important means of recognizing sociocultural diversity, as many Australian Aboriginal and/or Torres Strait Islander patients prefer to receive “most or all of their care outdoors.”

*Patient rooms that are private, homely, and safe.* Private bedrooms, with accompanying bathrooms, were viewed by many participants as a necessary provision for good palliative care. Staff saw private rooms as helping to minimize or alleviate distress and to maximize dignity for patients, families, and staff. They also perceived long-term benefits for family members, in that private rooms “may help families in the bereavement phase if they feel they had adequate privacy and space to say their goodbyes.” Enabling patients to control and personalize their environment was seen to “increase the mood of patients” and to make palliative care environments “more appealing.” Strategies included providing space for personal objects and mementos, localized temperature and lighting controls, openable windows for fresh air, providing a wardrobe, or even space for a small fridge.

Providing adequate space for families to be present for extended periods, and to maintain rituals normally undertaken at home was an important contributor to patient comfort. Design provisions related to this included comfortable chairs and sufficient space for family around the bedside; alongside provisions for family members to sleep over, including larger beds for co-sleeping, fold-out beds within patient rooms, or boarding spaces elsewhere within the palliative care unit or hospital campus. Where in-person family visits aren't possible, support for internet-based communications (e.g., telehealth, Skype, etc.) was said to enable “those family [members] who can't be there [to] easily link to the patient/family in the room.” [While geographical distance or work commitments often prevent friends and family from being physically present, visitor restrictions related to COVID-19 have heightened the perceived necessity of communicating with loved ones via technology \(\\*\\*\\*\)](#).

Access to appropriate medical equipment in patient rooms, such as hoists and medical gasses, was said to make routine medical tasks both safer and more efficient, as did adequate storage for medical equipment and supplies. Patient rooms and bathrooms that are prohibitively small, or badly designed, make the safe and efficient performance of routine medical tasks more difficult, while causing unnecessary disturbance to patients and families in the process.

Bathrooms, in particular, when “poorly designed for [the] high-care needs of patients”—such as when the distance of bathrooms to patient rooms is too great; when basic safety features like handrails and non-slip surfaces aren't installed; when they are not wheelchair accessible; or when sinks, toilets, and doors are incorrectly positioned—can pose substantial safety risks to both patients and staff, while making core medical tasks more labor-intensive.

*Spaces away from the bedside.* Staff highlighted the importance of a variety of communal spaces, such as consultation rooms, private enclaves, communal areas for sharing meals, lounge areas,

and activities rooms, as a way of cultivating a homely atmosphere and offering privacy away from the bedside. Such spaces were said to allow staff “have sensitive conversations more privately,” and “to communicate bad news.” They were also seen as contributing to the welfare of family members. As one participant observed: “Families often spend extended periods of time ... in inpatient [palliative care] settings, [and] having different environments outside the patient room ... is important.”

Spaces that support privacy and sociability away from the bedside were seen as significant factors in the patient and family perception of care. One participant observed that these conversations “determine the future trust and engagement with the palliative care team,” and that the quality of the spaces in which they occur influences this relationship: “If I was in this situation, I would never forget how the news was delivered and where I was.”

*Versatile outdoor spaces.* Staff perceptions of garden spaces highlight the sheer versatility of outdoor spaces in palliative care contexts. Garden spaces were seen as “something to look at” other than “a [room] full of sick patients [and] four walls,” as making facilities care environments “less like a hospital,” and as providing a means of “escaping the ward environment.” They were also seen as spaces for privacy, and moments of quiet reflection, where “family members [could] gather with patients to have private conversations away from the bedside.” They were seen as places to accommodate everyday activities, like birthday parties, barbeques, or simply going outside for some fresh air, sunshine, and greenery. Gardens were seen as places for children to play, to receive care, and to accommodate large family visits. While balcony spaces, or gardens (where adjacent and level) with the patient room made it easier for staff wheel bedridden patients “outside into the fresh air,” whilst also enabling easier visitation by pets and family members (particularly during COVID-19).

Many staff saw natural settings, gardens, and outdoor areas as offering both something pleasant to look at *and* somewhere pleasant to be, as an outdoor extension of the care environment. Accessibility was crucial: a handful of participants (n = 9) mentioned the value of views to natural settings, but close to half of the participants (n = 36) commented on the accessibility of gardens and outdoor spaces, often in conjunction with internal access to fresh air as a preference to fully air-conditioned environments.

*Circulation spaces also contribute to care.* Circulation routes were seen as potentially contributing to privacy for patients and families. Staff observed that providing alternative ways to circulate through a palliative care facility, including via the outdoors or via secondary corridors, would help grieving families by preventing them from having “to move through the elevators with all [the other] visitors while distraught.” Alternate circulation routes also assisted in the transportation of deceased patients without distressing others.

Circulation spaces can also be seen to play a role in staff wellbeing, particularly where these appeared cluttered. Excessively cluttered environments, including and beyond hallway spaces, were the source of many complaints related to health and safety. Further, there were also perceived psychological benefits in maintaining an organized working environment. “A fresh uncluttered environment, instituted by a new nursing manager, has improved morale and team efficiency.”

*Spaces for staff.* Staff recognized that environments that supported the wellbeing of patients and families, also improved staff wellbeing, as one participant said, “We would like to care for patients whilst caring for our staff’s safety.”

Quiet office space was described as an optimal, “distraction-free” setting for note-taking, paperwork, and routine IT tasks. Without this, it was suggested, such tasks become safety

concerns, as they tend to be undertaken in thoroughfares or at nurse stations. Similarly, spaces for hosting staff meetings and training sessions would “increase collegiate behavior, improve interdisciplinary care [and] improve overall care for patients by staff.” Many responses suggested these types of spaces were either lacking or absent from the palliative care facility they worked in.

Spatial relationships that optimize the visual and physical proximity of patient rooms and nurses’ stations were said to “allow easier observation,” “minimize risk of falls,” and “allow earlier detection of patient distress,” while nurses stations that were “visible and open” were observed to make palliative care environments more welcoming for patients and family members.

Access to staff-only breakout spaces was raised as a provision for staff wellbeing that translated into better patient care. Adequate space for staff to take “an uninterrupted break”—to eat without disturbance, to rest, to unwind—would “improve staff ability to rest and then provide excellent care.” Another said, “we currently use a multipurpose space—photocopy room, come office, come tearoom/break space.”

## **Discussion**

That privacy, homeliness, access to the outdoors, and safety are highly valued within the design of palliative care environments does not present new knowledge (Fleming et al., 2015; Gardiner et al., 2011; Hajradinovic et al., 2018; Irish Hospice Foundation, 2009; Rowlands et al., 2008; Verderber & Refuerzo, 2006; Zadeh et al., 2018). However, **the frequency of responses related to privacy, homeliness and access to the outdoors suggests that many participants perceive that the environment in which they work could achieve more in supporting these values relative to delivering optimal palliative care.**

In a recent review, Wong et al. (forthcoming) highlight two limitations within the extant literature for the design of palliative care environments: the assumption that a private room is the best architectural solution to upholding patient dignity, and the risk of reducing homeliness to simple matters of interior design (also see McLaughlan & Kirby, 2021). Privacy, as the staff perceptions reported above make evident, is a design concern that reaches far beyond the bedroom and bathroom. The data reported above confirms that these spaces are important, but so too is the provision of spaces beyond the bedside for family to spend time together, or to take a moment for quiet reflection. Further, staff spaces, including nurses' stations, meeting rooms, and even circulation corridors, can all be designed to further the values of privacy and dignity. Homeliness, similarly, is about more than a comfortable armchair, or the opportunity to bring items from home. The data confirms that, more than a simple atmospheric aspiration, **homeliness can be supported through the provision of spaces where families can imitate the routines and rituals of home, as a way of facilitating familiarity and comfort.**

Outdoor spaces were also recognised by staff as playing a highly important role in supporting both privacy and homeliness, alongside staff wellbeing and, in some cases, also safety. While the importance of nature features heavily in the literature (Brereton et al., 2012; Fleming, 2015; Hajradinovic et al., 2018; Rowlands & Noble, 2008; Zadeh et al., 2018), this is often presented as a given; an acceptance that all hospitalised patients benefit from views to nature, particularly those who may be bedridden (Verderber, 1986; Ulrich, 1984). The data reported herein provide a more nuanced understanding of the importance of access to nature and outdoor spaces relative to the specific needs of palliative care; for families to spend time together, for individuals to reflect and/or grieve, and for staff to recharge. Recognition of the benefits of moving patients with limited mobility out into the fresh air, using balconies or garden



spaces at the same level as the patient room, was also important. The architect of a recent palliative care facility in Australia recalled that the advice given to them by a consulting physician was that “a person with slipping consciousness is still going to register [fresh air] as fundamental” (McLaughlan & Kirby, 2021). Given that 62% of participants said their facility provided easy access to a garden or balcony (n = 55), and a further 12% said a garden was accessible to patients via an elevator (n = 11), the importance of access to gardens and outdoor spaces likely reflects direct observations, by staff, regarding the various ways that outdoor spaces are inhabited during a patient and families experience of palliative care. The data thus elucidate that **access to nature supports and enhances palliative care experiences in significant ways that a simple view to nature could not.**

In the pursuit of environments that support care, a broader issue that recent research has highlighted is a discord between the desired and real-world design outcomes of palliative care facilities. Common challenges to homeliness, for example, include concerns of infection control, but also national procurement processes, and expectations around the application of uniform design standards across hospital sites (Brereton et al., 2012; Gardiner, 2011; McLaughlan & George, forthcoming; McLaughlan & Kirby, 2021). These all contribute to compromises that result in these facilities *feeling* more clinical than comfortable. A recent study that interviewed clinicians, architects, and hospital administrators from Australia, the United Kingdom, and the United States, revealed that particularly where palliative care wards exist within an acute hospital setting, procurement processes can impede the achievement of homeliness. As one architect told researchers:

you get handed the architectural finish standards that they’re using everywhere else on the [hospital] campus. So, you do sometimes get pushed to use materials that wouldn’t be

your first choice ... What's fine in an ICU, is maybe not what you want if you're going to see your grandmother for the last time (McLaughlan & Kirby, 2021).

Similarly, while the importance of accommodating family presence is widely acknowledged within the literature (Fleming et al., 2015; Gardiner et al., 2011; Hajradinovic et al., 2018; Kayser-Jones et al., 2003; Zadeh et al., 2018), this is not always reflected within the design guidelines that determine the size and character of palliative care facilities. In Australia and New Zealand, for example, the design parameters for new, government-funded hospitals are based on guidelines provided by the Australasian Health Infrastructure Alliance (2018). Within those guidelines, the only differentiation between a palliative care room and a standard hospital room is an additional 2 square meters of floor space in patient rooms to accommodate an “overnight fold-out chair.” Without discounting the capacity of a fold-out chair for making family members more comfortable at the bedside, this minimal provision pales in comparison to the concern expressed for the comfort and wellbeing of the wider family that is evident within the data reported here.

The palliative care professionals who participated in this survey displayed an acute awareness of how environmental compromises impact patient and family comfort, to the extent that, **where palliative care environments do not support the quality of care that staff aspire to deliver, this was said to engender frustration or even distress among staff.** Staff responses evoked the seminal work of Mount and Kearney (2003), which highlights the importance of caregiver presence and relations to one another in facilitating “healing” at the end of life (where healing is defined as “not dependant on the presence of, or the capacity for, physical wellbeing”). Where staff perceived the environment to impede the possibility of healing, and particularly where the environment was seen to unnecessarily exacerbate patient and family distress, staff

also found this distressing. Other studies have similarly observed that where the ability of staff to deliver an appropriate level of patient care is compromised by external and competing factors, both including and beyond those related to the built environment, this results in feelings of frustration (Bartlett & Clarke, 2012; McLaughlan & Pert, 2019).

That staff expressed such awareness, and indeed concern, for patient and family wellbeing suggests that **improving the built environment for the benefit of patient and family comfort might also positively impact staff wellbeing** (also see McLaughlan & Pert, 2019). It would be remiss of us, however, to make this observation without also acknowledging that this could compound an existing risk—the needs of palliative care staff could be easily overlooked within architectural briefing processes because staff are likely to prioritize the needs of patients and families above their own. Our survey asked participants to suggest an environmental change for the benefit for patients, families, *or* staff, yet only 17% (n = 15) responded (to Q. 3a) with a staff-centered suggestion, and many of those were underpinned by broader concerns for patient and family wellbeing. Notably, only 3% of participants asked for staff break out spaces (n = 3). Given the known stresses of working in palliative care (McNamara, Waddell, & Colvin, 1995; Parola et al., 2018), supporting staff wellbeing and resilience—particularly through the provision of spaces that would enable them to take a quiet moment on difficult days—should be a pressing concern. Previous research has emphasized the importance of such spaces for staff (Armstrong et al., 2004; Cooper Marcus, & Barnes, 1995). Designers have a responsibility, therefore, to advocate for the wellbeing of staff within the design process given that, as the data reported here suggests, they are unlikely to advocate strongly for themselves.

## **Conclusion**

This study adds to an increasing body of literature which confirms that both medical professionals, alongside many architects engaged in the design of these facilities, display an acute awareness of the importance of designing palliative care spaces differently to other inpatient facilities. This knowledge does not always appear to be present, however, within the guidelines and procurement processes that determine how palliative care facilities are constructed; these more often reinforce standardization over difference.

A more open acknowledgment of the emotions contained within palliative care spaces, specifically, how the philosophy of care responds to such challenging emotional experiences, may assist in advocating more successfully for *why* these design considerations are critical to better supporting patients, families, and staff. While the findings presented here can be used to inform the design of palliative care facilities, we hope they will also prove valuable in assisting those engaged in decision-making around the future funding of these facilities. Specifically, to encourage greater recognition that a different design response is required for palliative care and should be implemented more widely.

## **Limitations and Future Research**

The data reported here provide important insights from palliative care staff about how the built environment can contribute to better experiences of palliative care for patients and families. Future research needs to obtain views from patients and families themselves, who are currently underrepresented within the literature more broadly (Wong et al., forthcoming).

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		<b>Number of Respondents (n=89)</b> <b>% shown in brackets</b>
<i>Profession</i>	Nurse	45 (50.56)
	Doctor	34 (38.20)
	Allied health	3 (3.37)
	Other	7 (7.87)
<i>Years worked in palliative care</i>	0 to 5 years	28 (31.46)
	5 to 10 years	20 (22.47)
	10+ years	41 (46.07)
<i>Age</i>	18 to 34 years	9 (10.11)
	35 to 44 years	27 (30.34)
	45 to 54 years	28 (31.46)
	55+ years	24 (26.97)
	Not specified	1 (1.12)
<i>Gender</i>	Male	9 (10.11)
	Female	79 (88.76)
	Other or not specified	1 (1.12)
<i>Location of workplace (Australian state or territory)</i>	Australian Capital Territory	4 (4.49)
	New South Wales	51 (57.30)
	Northern Territory	1 (1.12)
	Queensland	4 (4.49)
	South Australia	0 (0)
	Tasmania	4 (4.49)
	Victoria	21 (23.60)
Western Australia	4 (4.49)	
<i>Type of facility worked in (defined in relation to the nearest hospital)</i>	Inside an acute hospital	38 (42.70)
	Inside a sub-acute hospital	16 (17.98)
	Freestanding on an acute hosp. campus	21 (23.60)
	Freestanding on sub-acute hosp. campus	0 (0)
	Stand-alone (e.g. driving distance to the nearest hosp.)	9 (10.11)
	None of the above	5 (5.62)
<i>Relationship of facility to the exterior</i>	Set within a garden	35 (39.33)
	Garden adjacent & on the same floor	15 (16.85)
	A garden is accessible by elevator	11 (12.36)
	No garden patients can access	14 (15.73)
	No garden; walking distance to a park	4 (4.49)
	None of the above	5 (5.62)
	Outdoor balcony (other; participant defined)	5 (5.62)

**Table 1.** Survey respondents

**\* 1. What do you think is the most important part of your job?**

*Please answer in 1-2 sentences.*

**2. The way spaces are designed can support or obstruct patient care making it easier, or harder, for staff to carry out their roles. Can you think of any way that your current physical work environment supports and/or obstructs your job and how?**

*You can leave this question blank if you can't think of anything.*

a. Supports:

b. Obstructs:

**\* 3a. If you could make one change to the physical environment you currently work in, to improve it for patients, family members and/or staff, what would you change?**

*Changes could include alterations to existing spaces or adding new spaces / architectural features.*

**\* b. Who would this change most benefit?**

Patients / Family members / Staff [survey accepted only one response]

**\* c. How would it benefit this group?**

**d. Would this change provide benefits for any other group? Please tell us which group and how?**

**e. Are there any additional changes to the physical environment you would like to make?**

**Table 1.** Questions (2) and (3) form the primary data set analysed herein. Both questions were open-ended. Questions shown with an asterisk were compulsory or the survey could not be submitted.

## Implications for practice

- Palliative care professionals displayed an acute awareness of how environmental compromises impact patient and family comfort. This understanding provided a stark contrast with the design guidelines and procurement processes that ultimately determine what design solutions are possible within palliative care environments.
- While privacy and homeliness remain critical to assisting the optimal delivery of palliative care, the focus on patient bedrooms and comfortable furnishings within the guidelines and the extant literature is suppressing recognition of the broader capacity of design to support these values.
- Gardens and outdoor spaces perform a greater role in the delivery of palliative care than is reflected within the current literature. Gardens provide vital spaces to spend precious last days with loved ones, for families to grieve, and offer a reprieve from long hours spent within the hospital.
- Environments that lack adequate provision for patient and family comfort can result in staff distress. This finding highlights the need for further research to better understand the relationship of patient and family comfort to staff wellbeing, and the role of the built environment in contributing to staff satisfaction.
- Within this survey, staff routinely prioritised the needs of patients and families above their own, highlighting the risk that staff wellbeing may be easily overlooked within architectural briefing processes for new palliative care facilities. Designers should remain aware of the need to advocate on behalf of the needs of staff.

## Appendix 1

The survey questions as they appeared on SurveyMonkey. Questions marked with an asterisk were compulsory. Respondents were given a prompt and were unable to progress to the next question if these compulsory questions were not completed.

### Survey Description: Designing for Inpatient Palliative Care in Australia

We'd like to understand your views on the physical environments in which inpatient palliative care is delivered in Australia.

Anyone who works in palliative care, or has previously worked in palliative care, in Australia, is eligible to answer this survey.

This survey will take **12-18 minutes**; it consists of 6 survey questions, plus 6 demographic questions.

**Your participation is voluntary.** By completing this survey you are consenting to the researchers using the information you provide within conference papers and journal articles. **No identifying information will be published.** All responses will be saved in a de-identified format, which means they will not be linked to any information that can identify you (name, email address, etc.). You will be given the option to provide your email address for further correspondence. If you chose to provide an email address, this will be stored separately from your survey responses once your responses are exported from surveymonkey.

If you have any questions about the project, please contact the chief investigator, Dr \*\*\*\*\*: [email removed]

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2019-0056. Contact: [details removed for peer review]*

#### \* What is your current role in palliative care?

*If you previously worked in palliative care, please tell us your most recent role.*

Nurse

Doctor

Allied health professional

Other (please specify)

#### \* 1. What do you think is the most important part of your job?

*Please answer in 1-2 sentences.*

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1  
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5  
6 **2. The way spaces are designed can support or obstruct patient care making it easier, or harder, for staff to carry**  
7 **out their roles. Can you think of any way that your current physical work environment supports and/or obstructs**  
8 **your job and how?**  
9

10 *You can leave this question blank if you can't think of anything.*

11  
12 (2a) Supports \_\_\_\_\_

13  
14 (2b) Obstructs \_\_\_\_\_

15  
16  
17 **\* 3a. If you could make one change to the physical environment you currently work in, to improve it for**  
18 **patients, family members and/or staff, what would you change?**

19 *Changes could include alterations to existing spaces or adding new spaces / architectural features.*

20  
21 \_\_\_\_\_

22  
23  
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25  
26 **\* 3b. Who would this change most benefit?**

27  
28 Patients

29  
30 Family members

31  
32 Staff

33  
34  
35  
36 **\* 3c. How would it benefit this group?**

37  
38 \_\_\_\_\_

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41  
42  
43 **3d. Would this change provide benefits for any other group? Please tell us which group and how.**

44  
45 \_\_\_\_\_

46  
47  
48  
49 **3e. Are there any additional changes to the physical environment you would like to make?**

50 *Please list changes or leave this question blank if you have no further changes to add.*

51  
52 \_\_\_\_\_

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56  
57 **\* 4a. The photographs below depict different palliative care settings. Which do you find the most appealing?**

58 *Click on the image to select.*



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24 \* 4b. What did you find appealing about this image?

25 \_\_\_\_\_

26  
27  
28 \* 5a. Which do you find the least appealing?



51 \* 5b. What did you find unappealing about this image?

52 \_\_\_\_\_

53  
54  
55  
56  
57 \* 6. Do patients bring personal belongings into the hospital to make it feel more like home?

58  
59 Yes

1  
2  
3 No

4  
5 If yes, please provide examples of the types of personal belongings that patients bring in:  
6  
7  
8 \_\_\_\_\_  
9  
10

11  
12 **\* How many years have you worked in palliative care?**  
13

14 Less than 1 year

15  
16 1 to 2 years

17  
18 3 to 5 years

19  
20 5 to 10 years

21  
22 10+ years  
23  
24  
25

26  
27 **\* Please select the answer that most closely describes the location of the palliative care facility you work in, or  
28 worked in:**  
29

30 Inside an acute hospital

31  
32 Inside a sub-acute hospital

33  
34 Beside an acute hospital (i.e. it is a free-standing building on a hospital site)

35  
36 Beside a sub-acute hospital (i.e. it is a free-standing building on a hospital site)

37  
38 Driving distance from the nearest hospital (i.e. it is a stand-alone hospice or palliative care facility)

39  
40 If you answered 'none of the above' - please briefly describe your work environment:  
41  
42  
43 \_\_\_\_\_  
44  
45  
46  
47

48  
49 **\* Please select the answer that most closely describes the relationship to landscape of the palliative care facility  
50 you work in, or worked in:**  
51

52 My facility sits within a garden setting (e.g. gardens are all around and easy for patients to access)

53  
54 It has a garden space adjacent to the building and on the same floor

55  
56 It has a garden but patients must travel by elevator to access it

57  
58 My facility has no garden space but there is a public park within walking distance  
59  
60



1  
2  
3 There is no garden space available for patients to access  
4

5 None of the above  
6  
7

8  
9 If you answered 'none of the above' - please provide a brief description:  
10

11 \_\_\_\_\_  
12

13  
14 **\* In which Australian state or territory is your workplace located?**  
15

16 ACT / NSW / NT / QLD / TAS / VIC / WA  
17  
18

19 **Which gender do you most identify with?**  
20

21 Female / Male / Non-binary / Prefer not to say  
22  
23

24 **What is your age?**  
25

26 18-24 / 25-34 / 35-44 / 45-54 / 55-64 / 65 and over  
27  
28  
29

30  
31 **Thank you for completing this survey.**  
32

33 Photographs were generously contributed by the following architects / photographers:

34 Bates Smart / Peter Clarke; Ryder Architecture / Keith Hunter; Perkins + Will / Jim Roof.  
35

36 For further information about this project please visit: [\[website address removed for peer review\]](#)  
37  
38

39 **Would you like a summary of the results once the project is completed? Yes/No**  
40

41 **Are you interested in being contacted to participate in future research about palliative care design? Yes/No**  
42  
43

44 **Your email address**  
45

46 If you answered 'yes' to either of the questions above, please provide your email address so that we can contact  
47 you (this will be stored separately from your survey responses).  
48

49 *If you would prefer not to provide your email address in this survey, but you would like a summary of the  
50 results and/or would like to be contacted for future research, please email \*\*\*: [email removed for peer review]*  
51  
52

53 \_\_\_\_\_  
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## Appendix 2

Wording of the emails circulated by the organisations and hospitals who were asked to promote the survey to their members and staff.

Organisations that were contacted included: The Australian & New Zealand Society of Palliative Medicine; Palliative Care Nurses Australia; Palliative Care associations of Victoria, Australian Capital Territory, South Australia, Tasmania, and the Northern Territory; alongside eight different hospitals within Victoria and New South Wales where the researchers had relationships with physicians who were willing to assist in circulating the survey to their colleagues.

Dear Members/staff,

[Our hospital/organisation] has received a request for voluntary member participation in a survey (approximately 12-15 minutes to complete) from \*\*\*\*, School of \*\*\*, University of \*\*\*.

This survey has been approved by the University of \*\*\* Human Research Ethics Committee and approved for distribution to [our hospital/organisation] members/staff by [our hospital/organisation].

### **Designing for Inpatient Palliative Care in Australia**

We are trying to understand how the spaces in which palliative care is delivered can be better designed to support patients, their families and healthcare teams through end of life experiences. Specifically, how the design of inpatient environments work (functionally) for each group - and what could improve them - alongside how the appearance of these environments make people feel.

If you work, or previously worked, within an inpatient setting for palliative care in Australia we would love to hear your views. Please click on the link to respond: <https://www.surveymonkey.com/r/FDLJR7S>

Please feel free to forward this invitation to colleagues at other hospitals who may be interested.

Data from this survey will contribute to a multi-method research study that will gather views from patients, family members and staff.

For more information about this project, please visit: <https://palliativecare.design/publications/introducing-designing-for-palliative-care/>

or contact Dr \*\*\*\* at [email removed for peer review]

Thank you for your participation.

## EXECUTIVE SUMMARY

This article reports an online survey that elicited the perceptions of 89 Australian-based palliative care professionals regarding the relationship between the physical environment and the distinct philosophy of palliative care. While it is broadly understood that palliative care differs from other inpatient experience—including the philosophy of care, lengths of stay, the presence of family members, and more frequent end-of-life events—this knowledge has been slow to exert change on the guidelines and procurement processes that determine the design solutions possible within these settings. Sustained research attention is required. Key findings include that (1) while privacy and homeliness remain critical to assisting the optimal delivery of palliative care, the focus on patient bedrooms and comfortable furnishings, within extant literature and design guidelines, suppresses recognition of the broader capacity of design to support these values; (2) gardens perform a greater role in the delivery of palliative care than is currently reflected within the literature; (3) environments that lack adequate provision for patient and family comfort can result in staff distress; (4) staff tend to prioritise the needs of patients and families above their own, highlighting the risk that staff wellbeing may be easily overlooked within architectural briefing processes for new palliative care facilities.