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How can architecture redefine the spaces of palliative care for adolescents, balancing care needs with necessary requirements for individuality and intimacy?

Behind closed doors: Rethinking adolescent privacy in palliative care

Sara Nourmusavi Nasab, Chris. L. Smith, Rebecca McLaughlan

The hospice sits quietly on the edge of town, surrounded by gardens and tall trees. Just past the main entrance, a short corridor leads to the patient zone, which is divided into eight private ensuite rooms. A smaller, secondary entrance divides the patient zone, with six rooms for younger patients and two for older adolescents at the far end. Entering one of the rooms, the space is a simple rectangle, about 15 square metres, with a single bed at the centre. The bed is slightly higher off the ground than a domestic bed. It's framed by wooden laminate shelves and closets on either side, offering storage for personal belongings. The layout of the rooms mirrors that of a typical single hospital room, with functionality at the forefront. While this arrangement facilitates caregiving and ensures accessibility to medical equipment, it positions the bed directly in line with the doorway. This openness could leave patients feeling exposed, as there are no visual barriers to shield the sleeping area from the view of anyone passing by, or entering, the room.

Ensuite bathrooms provide a degree of privacy, offering a space where patients who are independently mobile may retreat momentarily. However, such moments seem insufficient given patients find themselves in an open environment, always visible for staff observation, always on display. This might contribute to a sense of vulnerability, particularly for adolescents who are navigating both the challenges of illness and the developmental need for autonomy and personal space. The prioritisation of clinical efficiency over privacy reflects a common tension in healthcare design. Yet, supporting the delivery of care through visibility and ease of access, comes at the cost of the patient's emotional comfort and sense of control. In a setting where children and adolescents face the most challenging moments of their lives, this lack of privacy and control over their environment is a barrier to comfort – a critical element missing in what should be a sanctuary for care. On this basis, we argue it deserves greater interrogation.

Adolescent palliative care patients face distinct emotional and personal needs[1] that render the need for privacy all the more pressing.[2] In this article we examine privacy as a key feature in paediatric hospice design, investigating how it is conceptualised in both medical literature and architectural case studies. While seven contemporary paediatric, adolescent, and young adult hospices were analysed for this study, the passage above makes specific reference to the Very Special Kids (VSK) hospice in Victoria, Australia. Our focus on VSK is not to position this as better or worse (architecturally) than the other examples. Worthy of acknowledgement, however, is that we could have chosen to write the passage above in relation to any of the seven hospices analysed, as the bedroom layouts are comparable. In focusing on how existing designs facilitate or hinder privacy – particularly within bedroom spaces as the most intimate of spaces for patients – we hope to encourage a deeper conversation about how privacy is provided for adolescents nearing the end of life; and about what opportunities are being missed to extend privacy in a more comprehensive way. To better understand adolescent palliative care needs, the literature review in this study includes studies on adolescent cancer experiences, helping to address gaps since few focus on adolescents nearing end of life.

To better understand the specific needs of this age group, it is important to first define who is considered an adolescent. The World Health Organisation traditionally defines adolescence as the period between ages ten and nineteen.[3] However, this definition has been increasingly challenged by researchers and clinicians who point to the shifting biological, cognitive, and social markers of development. In their influential article 'The Age of Adolescence', Susan M. Sawyer and her colleagues argue for an expanded definition of adolescence extending to age twenty-four, to reflect the prolonged transition to adult roles in contemporary society.[4] This broader framing is particularly relevant in palliative care, where patients between the ages of ten

and twenty-four may experience distinct emotional, social, and existential concerns that differ from both younger children and older adults.[5] Despite this, adolescents are frequently underrepresented in palliative and end-of-life care literature, with most studies focusing on either younger children or the general category of 'paediatric' patients.[6] To help address this gap, this study draws on research into adolescent cancer experiences and hospital environments to better understand the spatial and psychosocial needs of this age group.

The continuous disruption to a patient's daily routine owing to ongoing medical treatments and extended hospital stays can leave adolescent patients feeling socially isolated.[7] As psychologists Jennifer Shroff Pendley, Lynnda M. Dahlquist, and ZoAnn Dreyer point out, in the face of complex medical needs the need for emotional connection and meaningful social interaction can easily be overlooked.[8] This oversight may leave patients feeling disconnected from the normal experiences they cherish, such as spending time with friends or engaging in activities typical for their age group.[9] Adolescents may also struggle with a lack of control over their environment.[10] In a study by Faith Gibson and others, the ability to have control over one's environment was identified as an important need, particularly among older children, who expressed a desire for more privacy and personal space while in hospital.[11] The routines and restrictions imposed during hospitalisation can feel particularly limiting for adolescents as they strive for greater independence.[12] Alison Hutton, a nursing researcher who focuses on the privacy needs of young patients in hospitals, highlights that restrictions on privacy can lead to feelings of discomfort and embarrassment for adolescent patients.[13] This observation was reflected in our own conversations with medical specialists. A paediatric palliative care specialist recounted the experience of an adolescent patient during their hospice stay, who 'expressed a strong reluctance to spend time in their designated bedroom […]. The patient shared that being in the bedroom felt too reminiscent of their hospital stays, where they were often confined to bed due to their illness.'[14] This comment speaks to a layering of complexity in the way that hospice spaces are experienced by adolescent patients that is seldom acknowledged in the literature. This participant further observed the spatial implications of the fact that adolescent patients often find solace in areas where they can listen to music or play games, away from rooms or spaces that have a more medical atmosphere. Such reactions prompt us to consider the spatial capacity and arrangement of environments in palliative care facilities, highlighting the critical role architects can play in designing spaces that empower patients, particularly adolescents, to reclaim their personal space.

Research design and methods

This article reviews medical literature and conducts a comparative (desktop) analysis of seven exemplary hospice case studies in Australia, the United Kingdom and Japan, all constructed since 2001. These cases were selected both for their reputation in illustrating best design practices for end-of-life care and for practical considerations, such as the availability of detailed architectural documentation, including floor plans and site maps, which enabled thorough desktop analysis. The hospices include Bear Cottage in Sydney, Australia (2001); Very Special Kids Hospice in Melbourne, Australia (2021); Hummingbird House in Brisbane, Australia (2016); Manly Adolescent Hospice in Sydney, Australia (2023); Robin House Children's Hospice in Balloch, Scotland (2005); Noah's Ark Children's Hospice in London, UK (2021); and Tsurumi Children's Hospice in Osaka, Japan (2015). The inclusion of four Australian hospices reflects the country's internationally recognised leadership in paediatric hospice design, with Bear Cottage serving as a pioneering model that established a strong tradition in this field.[15] This tradition continues with the recent completion of Manly Adolescent and Young Adult Hospice, believed (by those who briefed it) to be the first of its kind internationally. This analysis is enriched by an understanding of the functional and lived experiences of these spaces, obtained via interviews with fourteen medical experts regarding their professional experiences of interacting closely with patients and their families; and eight architects experienced in the design of paediatric or/and adolescent palliative care spaces.[16]

The fourteen medical experts interviewed were professionals with extensive experience working directly in or closely alongside the paediatric palliative care including paediatric palliative care specialists, nurses, a social worker, a psychologist, and other allied health staff, ensuring that insights reflect their knowledge of patient and family interactions within these settings. The interviews were transcribed and analysed thematically. In this study, we focus on their views regarding the privacy needs of patients. These findings are presented together to highlight the perspectives of both those who work within these environments and those who design them. This approach allows readers to see the different but overlapping viewpoints and the ways in which actual design responds or fails to respond to identified needs. While the study acknowledges the critical importance of including children's and young people's own perspectives, practical and ethical constraints associated with conducting research in hospice environments limited direct patient participation in this phase of the research. While the absence of direct patient perspectives inevitably limits the ability to capture the lived, subjective experiences of privacy, the study attempts to address this gap through the combination of medical and architectural expertise. Medical professionals provide insight into patterns of interaction, care routines, and observed patient responses, while architects contribute an interpretive understanding of how spatial design can shape and mediate such experiences. In bringing these perspectives together, the analysis seeks to balance clinical observations with spatial interpretation, allowing architectural knowledge to extend the discussion beyond care practices towards how the built environment itself

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	Robin House Children's Hospice	Noah's Ark Children's Hospice	Hummingbird House	Very Special Kids Hospice	Bear Cottage Children's Hospice	Manly Adolescent Hospice	Tsurumi Children's Hospice
General information							
Building scale (size and number of floors)	3 levels (Basement, Ground, First); Approx. 2,691 m^2	2 levels (Basement, Ground); Approx. 2,199.9 m^2	3 levels (Basement, Ground, First); Approx. 1,990 m^2	3 levels (Basement, Ground, First); Approx. 1,650 m^2 (without family units)	2 levels (Ground, First); Approx. 1,740 m^2 (with carpark)	2 levels (Ground, First); maps unavailable	2 levels (Ground, First); Approx. 979 m^2
Number of inpatient beds and room size (excluding bath/balcony)	10 beds; room size $3.5 \times 6 = 21$ m^2	8 beds; varied 15–33 m^2	8 beds; $3.5 \times 5 = 17.5$ m^2	8 beds; $3 \times 5 = 15$ m^2	10 beds; approx. 17 m^2	8 beds; maps unavailable	8 beds; 14–15 m^2
Bedroom setup and monitoring							
Room type (single vs shared)	8 single bedrooms with shared baths; 2 ensuites	Single bedrooms sharing bathroom facilities	Individual ensuite bedrooms	Individual ensuite bedrooms	Individual ensuite bedrooms	Individual ensuite bedrooms	Shared rooms and bathrooms
Bed type (single vs double)	Single beds (sizes vary by age)	Single beds (sizes vary by age)	Single beds	Single beds (sizes vary by age)	Single beds	Mix of single and few double beds	Single beds
Bathroom access (private vs shared)	Shared baths	Shared facilities	Private bathrooms	Private bathrooms	Private bathrooms	Private bathrooms	Shared facilities
Age-responsive spatial zoning							
Age-based zoning (children vs adolescents)	Separate zones for younger and older patients	One zone, varied room types	L-shaped zone: one side for younger, one for older	Split into two sections with a central lobby	No distinct zoning	Entirely adolescent-focused facility	No age-based zoning
Dedicated communal/ activity areas by age	Teenager den	Tech-equipped teenage bedrooms and den	Dedicated teenage retreat	Multisensory and music therapy rooms near adolescent section	Teen activity room	Entire facility designed for adolescents	No dedicated adolescent space
Protected spaces for the family							
Dedicated family areas	Family units with small kitchens, toilets, and bathrooms (suite style)	Dedicated family suites without bedrooms	Separate family accommodation with bedrooms, bathroom, kitchen and carparks	Separate family units with bedrooms, bathrooms, and kitchen in a different building	Family rooms/units connected to patient spaces for proximity and separation	Two-bedroom family units with bath and kitchen	Shared family accommodation options
Private retreats for reflection and loss							
Secluded spaces for solitude	Circular quiet room and remembrance garden	N/A	Rooftop garden for reflection, connected to nature	N/A	Quiet "treehouse"-like room and remembrance garden	Private family lounge	N/A
Location of bereavement room	Lower level with private exit	Different level to patient zone	Ground floor, separate from patient rooms	First floor (patients reside on ground floor)	Central part of the ground floor, close to patient rooms	Ground floor with separate exit	None
Surveillance							
Control of patient view / visibility	Glazed door panels for visibility	Cameras to observe patients	N/A	N/A	Glazed door panels for visibility	Large nurse station near rooms with cameras	N/A

Table 1. Comparative analysis of privacy-related design elements in paediatric and adolescent hospices (authors).

may enable or restrict adolescents' sense of privacy and control.

To conduct the comparative analysis of the seven hospice case studies, each facility was examined through the lens of environmental privacy, with attention to how spatial design influences the experience of privacy for patients and families. The analysis began with general architectural characteristics – such as the overall scale of the building (including the number of floors and total floor area) and the number and size of inpatient bedrooms. Key room-level features were analysed, including whether rooms were single or shared occupancy, the type of beds provided (single or double), and whether bathrooms were private or shared. Visibility and monitoring were also considered, particularly how spatial layout (e.g. glazed doors, partitions, or open sightlines) affects staff supervision and the patient's sense of privacy. In addition to room configuration, the analysis examined age-responsive spatial zoning: whether facilities created separate zones or communal areas

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for children and adolescents, reflecting their differing developmental needs. The availability of dedicated family spaces, such as family units, lounges, or adjacent accommodations was assessed to understand how privacy was extended to caregivers and relatives. Finally, the study explored the presence of private retreat areas, including secluded spaces for solitude and the spatial placement of bereavement rooms. These features were considered for their role in offering emotional refuge and protecting dignity during moments of grief or reflection.

These spatial features were systematically compared across the seven case studies and summarised in structured tables to support critical evaluation and identify recurring design strategies, contrasts, and potential gaps in supporting privacy in paediatric and adolescent hospice environments. The comparative findings are summarised in *[*Table 1*]*, which outlines privacy-related features across the seven hospice case studies.

Together, the comparative analysis and interviews establish the foundation for examining how privacy is conceptualised and manifested within hospice environments. The findings from this stage inform the subsequent sections of the article, which consider how medical and architectural approaches align or diverge in their understanding of privacy and how built environments might better support adolescents' need for dignity, autonomy, and control at the end of life.

Medical and architectural approaches to paediatric palliative care design

A review of the literature reveals a distinct divergence between the perspectives of medical professionals and architects in addressing the needs of individuals in end-of-life care environments. Medical professionals, including clinicians and researchers, primarily focus on operational, psychological, and spiritual aspects, emphasising how spatial design can optimise care delivery efficiency and address patients' psychological needs. The medical literature underscores the importance of seamless access to medical services through effective patient monitoring systems,[17] and highlights the role of patients' psychological state in optimising quality of life.[18] These operational and psychological aspects are further emphasised in environmental design, which integrates specialised spaces for therapies to support quality of life in paediatric palliative care,[19] recreational areas to enhance emotional well-being,[20] family accommodations to facilitate essential support systems,[21] and outdoor areas to provide therapeutic benefits through access to nature.[22] Interviews with medical experts conducted for this study, echo the care priorities and approaches set out within the literature, highlighting the importance of creating controlled environments that align with the functional demands of patients, families, and medical staff. Despite the ethos of palliative care to address patient needs holistically, including psychosocial well-being, this operational focus nonetheless reveals an underlying assumption that meeting the physical and logistical needs of patients equates to addressing their overall well-being.

The dominance of systems-driven design, which prioritises efficiency and medical functionality, often overshadows the emotional, psychological, and social dimensions of patient experience. This article argues that achieving a balance between clinical requirements and the creation of supportive, emotionally responsive environments is a critical challenge in end-of-life care particularly for adolescents, whose needs extend far beyond the clinical. This raises a critical question; do end-of-life care spaces sufficiently meet the needs of young patients beyond the clinical? Despite the growing recognition of the importance of the environment in palliative care, most research has focused on adult settings, with far less attention given to children's palliative care, especially environments tailored to adolescents.[23] This gap in research highlights a pressing need to understand the distinct spatial, emotional, and psychological needs of younger patients at the end of life.

On the other hand, architectural literature (which mostly engages case study analysis and interviews with architects) reveals a complex interplay between medical functionality and conceptual design, emphasising the evolving discourse on how healthcare environments can effectively serve patients. While architects often prioritise the integration of practical medical needs, such as patient rooms, therapy spaces, activity areas, family accommodation, and medical support services, their designs are increasingly shaped by conceptual frameworks that emphasise homelike environments and domestic familiarity,[24] engaging children through play,[25] and concerns related to cultural diversity and sensitivity.[26] To achieve these aims, architects employ a range of spatial strategies and design elements, including form, colour, materials, furniture, and lighting to enhance both functionality and therapeutic quality.

Yet despite this more nuanced understanding, much of the current architectural literature, encompassing both conceptual and practice-based works, as outlined in earlier research,[27] still tends to overlook subtle, lived aspects of the patient experience that are especially critical to young people. For example, the design of palliative care environments seldom accommodates the wide spectrum of developmental stages present in paediatric settings, where patients range from infants to adolescents.[28] Research relative to adolescent experiences of cancer highlights the different ways this illness is experienced relative to age, and the ways that needs for privacy and autonomy similarly change with age. Early adolescents, typically described as spanning ten to fourteen years, seek personal space amid the insecurities associated with navigating early adolescence, while for middle adolescents, typically described as spanning fifteen to seventeen years, social interactions and relationships play a larger role in relation to privacy and autonomy, suggesting that any threats to this may be perceived as greater.[29]

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1 **Hummingbird House bedroom, Queensland, Australia. Hospice suite for children and families, designed by Thomson Adsett.**

2 **Manly Adolescent and Young Adult Hospice bedroom, New South Wales, Australia. Private inpatient room, designed by Team 2 Architects.**

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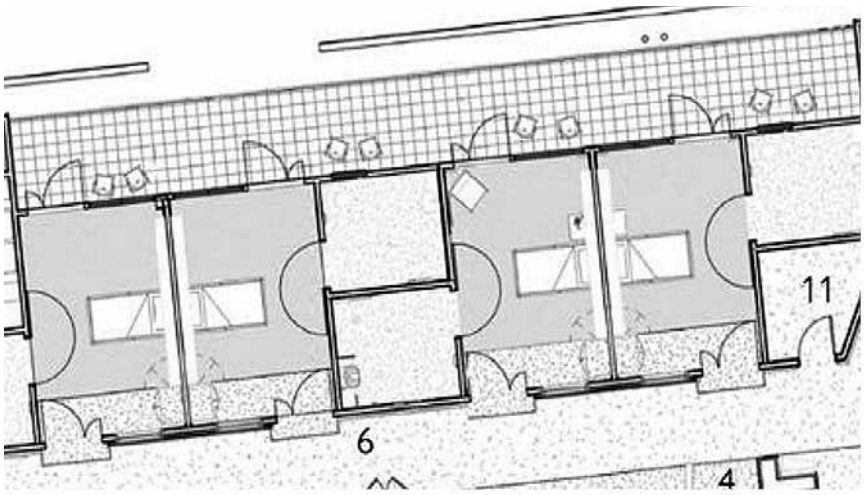
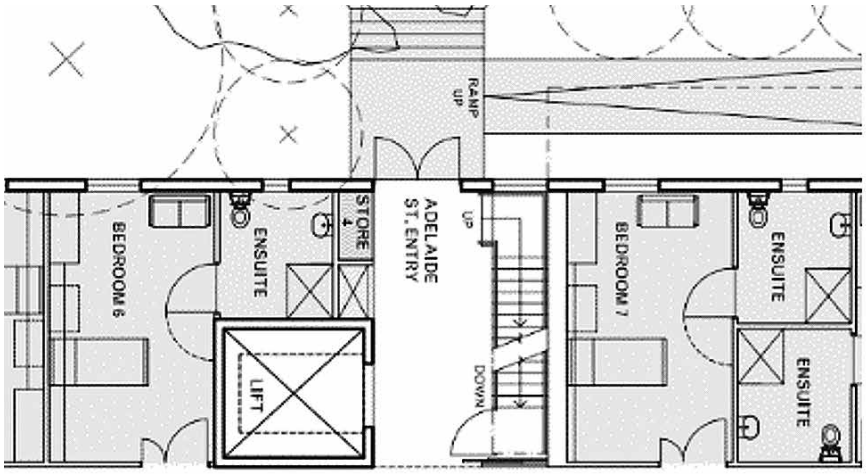


3 Hummingbird House bedroom plan, Queensland, Australia. Floor plan illustrating spatial arrangement of patient zone, designed by Thomson Adsett.



4 Very Special Kids Hospice bedroom plan, Victoria, Australia. Architectural layout showing patient rooms, designed by Bamford Architect Group.

This oversight is particularly critical in the context of end-of-life care, where the emotional stakes are heightened, and the need for personalised,[30] flexible spaces[31] (which may be better described as 'adaptable') becomes paramount. Such gaps in understanding may, in part, stem from how architects imagine, and often mis-imagine the users of their buildings. As Rob Imrie, a sociologist of urban and architectural space, and Jos Boys, an architectural theorist whose work in feminist and disability studies critiques architecture's assumption of a 'normal' or 'universal' body, observe, architects frequently rely on reductive or self-referential conceptions of the human body, often defaulting to normative or abstracted ideals that fail to capture bodily diversity.[32] Similarly, Christina Buse and her colleagues argue that architects' anticipations of building occupants are shaped by 'imagined bodies' constructed through professional assumptions, limited consultation, and prevailing ideologies of care.[33] These imagined users may obscure the complex, age-specific experiences of adolescent patients, ultimately reinforcing design solutions that privilege generalised functionality over developmental sensitivity. Privacy, in particular, is often overlooked as a result of these design assumptions, which is a concern in medical settings,[34] particularly for adolescent patients,[35] whose needs differ significantly from younger children often sharing the same spaces.[36] Privacy, then, emerges as a critical but under-theorised dimension of adolescent palliative care environments.

Framing privacy in context

The need for privacy can be understood through various theoretical perspectives that span psychology, communication, and environmental design. Legal scholar Alan Westin highlights the importance of individual control over information, suggesting that having control over personal details enhances feelings of safety and comfort.[37] Communication theorist Sandra Petronio focuses on the communication processes that shape privacy management, pointing out that how we share and protect personal information plays a significant role in our sense of privacy.[38] In this study, we particularly emphasise environmental psychologist Irwin Altman's theory, which explores the interaction between individuals and their environments more than the focus on information.[39] Altman proposes that the physical spaces we occupy can significantly influence our ability to achieve privacy. He defines privacy as 'the selective control of access to the self' and places emphasis on the interaction between individuals and their environments.[40] Rather than

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viewing privacy as a fixed condition, Altman sees it as a dynamic boundary-regulation process mediated through environmental mechanisms such as personal space, territoriality, and crowding. His approach is particularly valuable in contexts where the built environment plays a critical role in shaping human experiences, such as in palliative and hospice settings. Public health and psychology scholar Carl Anderson Johnson similarly explains, 'privacy is defined here as those behaviours which enhance and maintain one's control over outcomes indirectly by controlling interactions with others', highlighting how privacy is fundamentally tied to the sense of control people can exercise in a place.[41]

Altman's theory of privacy has been further developed by other scholars who examined how architectural and physical features influence privacy in organisational and spatial settings. Within this environmental framework, privacy is understood less as an abstract notion of control and more as a condition shaped by how physical design enables or constrains that control.[42] This perspective highlights the importance of visual access and visual exposure, showing that the ability to manage how and when one is seen by others is largely determined by the spatial configuration of the environment.[43] The arrangement of physical environments directly shapes the flow of visual information and, consequently, the degree of privacy achievable in everyday life. Privacy, then, is not only about withholding information but also about managing spatial and visual boundaries. This perspective is especially relevant when designing environments for paediatric and adolescent patients at the end of life, prompting us to consider how built environments can better support their privacy needs through thoughtful spatial organisation and control over visibility. In this study, privacy is therefore understood not merely as physical separation, but as a condition of negotiated control over one's exposure to others; emotionally, socially, and spatially.

Adolescent privacy as a distinct spatial concern in hospice design

Patients with life-limiting illnesses and those at the end-of-life frequently experience a profound loss of agency, as medical routines, procedures, and constant staff presence dictate much of their daily lives.[44] This issue is closely intertwined with the need for privacy, which has been discussed extensively in medical literature.[45] However, as our analysis of seven hospices shows, architectural responses to privacy needs often lack depth and fail to address the nuanced requirements effectively specifically for adolescent age group. The responses typically include the provision of single-patient rooms and dedicated quiet rooms (sometimes referred to as 'secret' rooms) that are provided for use by everyone, not just patients but also their families. The single bedrooms, usually sized around 15–18 m^2, feature a centrally positioned hospital bed, overhead shelves, surrounding closets, a TV, a desk, a sofa, and a window facing outside. Some rooms include a balcony, while others do not *[1–4]*. Some rooms have glazed panels in their entrance doors *[5]*, and some have cameras installed for patient monitoring *[6–7]*. While these amenities address basic functional requirements, they might fail to engage with the deeper, more nuanced aspects of privacy and the need for control area and context.

5

5 Glazed windows on patient bedroom door, Robin House Hospice, Scotland, United Kingdom. Designed by Hoskins Architects.

According to one of the architects who worked on the design of Bear Cottage Hospice, privacy was a key priority. The architect highlighted the use of a domestic scale to create a sense of intimacy and comfort for adolescent patients and their families. As the architect explained, 'using a domestic scale helps to mitigate the impersonal nature of traditional hospitals, enabling patients and families to experience moments of privacy that support their emotional well-being.'[46] However, this approach raises questions about whether the presence of clinical necessities, such as hospital beds, medical equipment, and standardised layouts might inadvertently disrupt the sense of privacy that the domestic scale is intended to create. While these rooms may appear private and homely, could the coexistence of domestic aesthetics and clinical functionality create a tension that undermines the very privacy and comfort it seeks to foster? Another architect, involved in designing Hummingbird House paediatric hospice, recounted:

> *There is a designated quiet room within the hospice itself. It functions like a library or study area, so it's quite private. You can open or close the windows as you wish. There are a couch and a library shelf in there. If someone wants to go in and have a bit of time alone, they can do so, especially if they're having a particularly tough day or just need a place to cry.*[47]

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6–7 **Camera positioning in patient bedrooms, Noah's Ark Children's Hospice, London, United Kingdom. Designed by Squire and Partners.**

While spaces such as quiet rooms can be valuable owing to their communal nature, there are practical limitations relative to the capacity of these spaces to extend privacy to all of those who wish to use it *[8–9]*.

Our interviews with medical experts make clear that the privacy needs of adolescent patients often differ significantly from other age groups, and this may impact the ways they want their families to be close to them (or not). As an adolescent psychologist noted; 'Sometimes they [adolescents] need to break away from their families, particularly their parents.'[48] Similarly, a paediatrician observed that, compared to younger children, adolescent patients might not want to be reliant on their families, desiring more control over their situation and their environment relative to who can stay with them in hospital.[49] On this topic, a social worker mentioned the role of family culture and dynamics, explaining that, 'the relationships among family members, cultural backgrounds, and individual personalities can all influence how privacy is perceived and valued.'[50] Speaking with a nurse revealed the ways that adolescents' privacy requirements diverge from those of younger patients:

> *Adolescents don't want to be in an environment with young children like that where it's loud and noisy and active. Often when adolescents are going through puberty, and particularly if they've got a chronic illness, sometimes they just want to, you know, sit in the dark with the duvet over their head. They want more privacy and need more privacy.*[51]

Adolescents with life-limiting illnesses find themselves at an age where paediatric environments often seem unsuitable, while adult hospices, designed primarily for older patients, also fail to provide an appropriate atmosphere for younger individuals.[52] As discussed by Jo Croft, a literary scholar whose research explored psychoanalysis, adolescence, and the meanings of everyday spaces such as teenagers' bedrooms, the adolescent bedroom is seen as a space for exploration and identity formation, where the uncertainties and liminality of adolescence are played out.[53] In this context, it contrasts with the childhood bedroom, which reaffirms domestic order and the control of parents over the space. Traditionally, this disconnect has created a significant gap in care for this age group, who require spaces that address their unique developmental, emotional, and social needs. Most hospices accommodate both paediatric and adolescent patients within the same facility. The Manly Adolescent Hospice, recently opened in Australia, is notable for being the only palliative care facility in the country specifically designed for the adolescent and young adult age group. The hospice adopts a holistic and youth-oriented approach, accepting patients aged between sixteen and thirty years, and combines medical, psychological, and social support within a home-like, non-clinical atmosphere. It offers private bedrooms with ensuites, family accommodation, recreational

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8 Quiet room, Robin House Children's Hospice, Balloch, Scotland. Designed by Hoskins Architect.

9 Quiet room, Bear Cottage Children's Hospice, New South Wales, Australia. Designed by Architectus.

areas, and direct access to landscaped outdoor spaces overlooking the beach.[54] While this represents a significant advancement in palliative care, further research is crucial for understanding the specific experiences of adolescents with chronic illnesses in the Australian context and how their privacy needs are addressed within this new architectural typology.

These insights suggest that privacy for adolescents extends beyond the provision of a private room; it can involve managing visibility, choice, and boundaries within a setting where care and surveillance coexist. The following sections explore these dimensions through two main themes. The first examines the sense of control, focusing on how monitoring occurs within the built environment and the potential for creating dedicated zones for adolescents in paediatric hospices. The second considers autonomy and intimacy, addressing how adolescents' developing identities and relationships intersect with their privacy needs within palliative care environments.

The sense of control through spaces

The medical literature notes that there might be differences in patients' preferences for controlling their environment based on age.[55] As mentioned above, the architectural response to providing control over the environment is often through single-patient rooms with private bathrooms. Seldom are specific zones for different age groups provided, and where this does occur, it is often through the simple designation of some spaces for younger patients and others for older patients. The way this is typically reflected in terms of the design is through the size of the single beds or the use of different colours for different age groups *[10–13]*. But the idea that having one's own room is somehow synonymous with having control over the environment can be flawed. Privacy and a sense of control over one's environment are not merely the result of physical separation. They are also influenced by spatial attributes and layout,[56] by hierarchy[57] – meaning the way places are

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organised into broader (superordinate) and more specific (subordinate) categories that affect how people perceive distance, direction, and relationships[58] – and by the quality of transitions between public and private spaces.[59]

Rebecca McLaughlan and others conducted research with palliative care staff and emphasised that privacy concerns extend beyond just bedrooms and bathrooms within adult palliative care settings.[60] They highlighted the importance of incorporating private spaces beyond the bedside, particularly green spaces that offer patients and families a peaceful retreat for reflection or moments of solitude. Additionally, they stressed the need for thoughtfully designed nursing stations and circulation areas that minimise noise, maintain confidentiality, and reduce unnecessary exposure to patient activities, thereby supporting dignity and creating a more respectful and calming environment. While single bedrooms are often seen as the solution to privacy and control, they are not a comprehensive response; a more nuanced approach is needed that considers the diverse emotional, social, and age-related needs of patients, ensuring that all aspects of their environment – both physical and relational – are thoughtfully designed to support their dignity and well-being.

The relationship between privacy, control, and visibility

For adolescents in medical care settings, privacy may involve having control over their visibility, including who can enter or view their space.[61] Interviews with medical professionals in this study emphasised the importance of privacy in relation to patient visibility. Many participants highlighted that patients expressed a preference not to be easily seen by passers-by or those looking through the glazed panels of their room's door. One paediatric palliative care expert noted, 'All of these groups [adolescents] should have single rooms; they shouldn't initially be in shared spaces [living spaces]. Ideally, these rooms should be located at the quieter end of the space, so not everyone is passing by and looking in the window.'[62] However, the architectural design of many hospice facilities often fails to fully reflect the complexity of privacy needs. Architects interviewed about the privacy of patients often highlighted the fact that all rooms are single rooms with ensuites, allowing patients to have personal space and time. Despite the provision of single rooms, the necessity of constant monitoring, often through glazing in doors or unscheduled staff entries, can undermine the intended privacy. One participant involved in the design of VSK hospice recounted that, 'the important thing was having individual ensuites and individual bedrooms for every single child.'[63] She also emphasised the need for a dedicated adolescent space, noting the requirement to ensure visibility to that space from the dining area, allowing staff to hear and have a clear view into the adolescent rooms without making them feel constantly surveyed. She stressed that while monitoring is important, it should be done subtly, so children do not feel like they are being watched at every moment. Another participant, a paediatrician working in the Very Special Kids Hospice, viewed monitoring more positively, believing it allows staff to avoid unnecessary room entry. This speaks to the complexity of balancing privacy and medical monitoring. This participant explained, 'I know this hospice […] has windows that look into the room […] so the nurses can just visualize the comfort of the young person without having to physically enter the space.'[64]

Constant observation, however necessary, still acts to diminish a patient's sense of control, reducing the room to a clinical holding space rather than a personal sanctuary. Another medical staff member emphasised the need to strike a balance in ensuring that teenagers have enough privacy to feel comfortable and respected, while also making sure that nurses are always easily accessible; this participant mentioned; 'For patients in general, finding that balance so that the staff are always nearby should the young person need their assistance […] for teenagers, privacy is a really important concept, and they demand it.'[65] This suggests that differing approaches to nursing and supervision practices can impact how privacy is experienced, independent of the built environment. Of interest here, however, is how the built environment itself can positively assist in the provision of privacy? This is an important question given the continued practice of positioning the bed in the centre of the room, exactly where the door opens to face the patient. How can we provide adolescent patients with a sense of control when the architecture itself places them on continuous display?

One medical expert mentioned the use of cameras for monitoring, explaining that these can be installed in patient rooms to ensure the safety and security of both patients and staff. In this expert's view, this approach allows for monitoring without the need for constant staff presence, potentially preserving a sense of privacy for patients.[66] However, how might patients feel knowing they are being watched at all times? Surely the knowledge of constant surveillance also compromises one's sense of control over the environment. In considering these questions, a parallel may be drawn between the surveillance in paediatric hospices and panopticisim.[67] Michel Foucault's account of Jeremy Bentham's panopticon highlights how design can be engaged for the purposes of surveillance. Although Bentham was primarily interested in prisoner monitoring, Foucault himself related this concept to the spaces of healthcare, primarily mental health but with boarder implications for the ways that people are monitored, watched, and surveyed in hospital spaces. He argued that surveillance is a form of power that disciplines individuals by making them internalise the feeling of being watched.[68] Considering this in relation to adolescent palliative care raises concerns about the ways that constant observation might negatively

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10 Children's bedroom, Noah's Ark Children's Hospice, North London, United Kingdom. Designed by Squire and Partners.

11 Teenager bedroom, Noah's Ark Children's Hospice, North London, United Kingdom. Designed by Squire and Partners.

12 Teenager bedroom, Very Special Kids Hospice, Victoria, Australia. Designed by Bamford Architect Group.

13 Children's bedroom, Very Special Kids Hospice, Victoria, Australia. Designed by Bamford Architect Group.

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impact a patient's sense of dignity and autonomy. The challenge long acknowledged in healthcare design, of how to balance safety with privacy,[69] becomes even more critical in this context, to avoid creating a disempowering environment for adolescent patients.

A sense of control as experienced via social engagement and the recognition of difference

Another important consideration relative to enabling a sense of control within palliative care environments is zoning for various age groups, particularly, how the built environment can both recognise and respond to the differences between younger patients and adolescents. The architectural design of paediatric palliative care spaces often overlooks the specific zoning needs required for different age groups. As observed in the case analysis, hospices frequently house patients of varying ages, with minimal environmental distinctions, either functionally or aesthetically. The distinctions were in the form of different colours used in the design of the rooms and variations in bed sizes. Among the cases analysed, only Robin House Hospice provided dedicated zones for different age groups, with specific spaces for younger and older patients. This hospice features a central recreation area and two dedicated rectangular zones: one with five bedrooms and the other with four bedrooms for patient stays. Within the zone allocated to teenagers (the four-bedroom zone), there is a designated 'teenager's den,' while the younger children's zone (the five-bedroom zone) includes a library. In contrast, most facilities accommodate all paediatric patients within a single zone, with bedrooms for younger and older children located next to each other *[10–13]*. In some cases, a small distance was created between rooms for different age groups, such as placing an assisted bath between them or providing an entrance from outside in the form of a small lobby. In principle these buffer spaces could afford a greater sense of separation and privacy, but in practice they were too small to be perceived. In other words, while rooms may be designated for younger or older patients within a hospice setting, these are often located too close to one another, resulting in little differentiation in the atmosphere created for each. This lack of separation raises concerns about whether the shared arrangement sufficiently addresses the psychological needs of older patients, who may require a greater sense of

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control and independence in their environment.

An architect involved in the design of a hospice currently under construction in Australia explained that since their facility will be expected to serve a patient cohort of diverse needs and ages ranging from infants to adolescents, it would not be practical to design separate zones for specific age groups. The different zoning was not feasible given the size of the facility. Instead, they chose to design all rooms in one zone to be similar yet customisable, allowing them to be personalised relative to the varying preferences of different patients while maintaining a cohesive aesthetic throughout the space. The options for personalisation were 'incorporated into the design of the joinery, along with some of the finishes and fixtures […] allowing children to customize their space.'[70] Despite the value of opportunities for customisation, this does not speak to deeper needs of privacy for adolescent patients, or their desire to be seen as no longer being children. As such, the approach of zoning hospice environments may support adolescent patients to feel more empowered, independent, and seen. Other research also has emphasised the importance of providing separate units for different age groups in paediatric and adolescent medical settings. Wendy Mitchell and others emphasised this for cancer patients,[71] and Gibson and others underscored the importance of addressing adolescents' distinct needs. For instance, a seven-year-old patient expressed frustration about being in a ward with younger children saying, 'They [babies] cry a lot, and it makes you feel nervous.'[72] In paediatric palliative care, Janet Barling and others noted challenges in meeting the unique needs of adolescents and young adults. Families in her study expressed dissatisfaction with the lack of dedicated teenage spaces stating, 'We had to come back to the children's hospital because there was nowhere else to go […] there was nothing for teenage children.'[73] Implementing zoning for different age groups might enhance young patients' ability to exert control over their immediate surroundings, potentially improving their emotional well-being. However, there remains a lack of clarity regarding how patients perceive these spatial arrangements and whether they feel their need for control is adequately addressed.

Need for autonomy and independence for adolescent patients

The psychosocial issues faced by adolescent patients with life-limiting illnesses makes more necessary the need to create spaces that respect their autonomy and independence[74] as they navigate the challenges associated with isolation from peers,[75] negative body image,[76] and concerns about sexuality.[77] These factors underscore the importance of providing private spaces where adolescent patients can feel safe and secure, allowing them to explore their identities and emotions without inadvertently increasing the perception of external pressure or judgment. Our interviews with medical experts have highlighted something seldom discussed within in the existing literature; the importance of privacy in relation to adolescent sexual desires and the need to exert autonomy within their environment. The following section explores how the design of physical spaces can either enhance or hinder young patients' experiences of autonomy, privacy, and dignity during their care.

Adolescent privacy, intimacy, and sexuality in palliative care

Oncologists Dirk Schrijvers and Paul Meijnders have made the argument that adolescents deserve a level of privacy and autonomy comparable to that of adults.[78] Patients often stay for extended periods in medical settings, which can create a desire for intimacy and connection with peers, or through romantic relationships, that might not be met in a clinical environment. Medical staff spoken to for this study acknowledge the importance of allowing young adults to explore their sexuality and have private moments, emphasising the need to respect boundaries. A psychologist specialising in end-of-life care for adolescents observed, 'When teenagers have a life-threatening illness or are approaching end-of-life care, their sexual needs become quite significant.' The psychologist further explained that many adolescent patients with chronic illness experience relationship breakups, as their illness introduces new challenges in their lives, and they may be left alone by their partners during this stage.[79] However, this is not the case for all patients. She mentioned that staff are trained to engage in open conversations about sexuality, recognising it as a normal part of development. Another participant with experience working with adolescent patients mentioned, 'I think their [adolescent patients'] sexuality needs become quite big in their mind […] they want to make the most of the life they have got.'[80] He noted that fathers often discreetly inquire about options regarding their children's sexual health and experiences, saying, 'I want my son to have sex before he dies.'[81] Interviews also revealed that many facilities operate under health policies that may restrict certain sexual activities, and staff are encouraged to discuss these limitations with patients. For example, they remind patients about rules around internet use for pornography while still acknowledging the need for privacy and sexual exploration. This raises an important question: how can monitoring practices, such as using cameras or having glazed panels on doors, coexist with the need for privacy and autonomy in patients' sexual exploration?

Interviews with medical experts have also revealed the extent to which many teenagers prefer having their partners stay with them. This preference highlights their desire for autonomy and a sense of normalcy in their relationships, even amid medical challenges. However, staff have pointed out significant limitations in the design of these care environments, noting that current arrangements often fail to provide adequate privacy. For instance, one paediatrician remarked,

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'In the hospital, you know, they have a single bed, and adolescents […] always want a bigger bed.'[82] Another suggested, 'I think there should be an option to have a bed that can be set up beside them if they have a partner.'[83] Unfortunately, the design of most hospice environments does not accommodate these needs. The prevalence of single beds, small rooms, frequent staff entry, and visual monitoring makes it challenging for adolescents to achieve the level of privacy they desire.

Conclusion

Privacy in adolescent palliative care emerges as a negotiated and relational condition shaped by architectural, social, and clinical factors. The findings indicate that privacy and control are mediated through the interaction of design, care routines, and social dynamics, rather than determined by any single spatial feature. Across literature and interviews, medical perspectives tend to emphasise observation, safety, and functionality, while architectural approaches focus on domesticity and comfort. Both, however, often overlook the developmental and psychosocial dimensions of adolescence, where privacy is closely tied to autonomy, identity, and interpersonal relationships.

The findings of this study demonstrate that adolescent privacy extends beyond the walls of individual rooms. The position of doors, glazing, and circulation spaces can either enable or erode a young person's capacity to manage exposure and achieve a sense of control. A sense of control is shaped by how spatial organisation, including zoning for different age groups, visibility, and monitoring practices, is configured. When zoning is absent or minimal, and visibility and surveillance remain constant, the environment can reinforce feelings of dependency and reduce opportunities for autonomy. The study also reveals that autonomy and intimacy such as the ability to manage social connections and private relationships remain insufficiently supported, constrained by spatial layouts and institutional policies that privilege surveillance over trust.

This study reaffirms that privacy in adolescent palliative care is not a fixed spatial condition, but a dynamic and negotiated process shaped by relationships, routines, and design. This relational view challenges conventional models that prioritise protection and observation, calling instead for environments that support participation, choice, and self-expression. Designing for privacy thus becomes an act of designing for participation, an approach that values autonomy and mutual trust as core components of care. Future research should build on this relational understanding by incorporating users' perspectives and exploring how spatial strategies can cultivate environments of dignity, autonomy, and emotional safety.

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Competing interests
The authors declare none.

Authors' biographies
Sara Nourmusavi Nasab is a PhD candidate at the University of Sydney, focusing on the design of paediatric palliative care environments. Her research employs qualitative empirical methods to investigate how architectural design can be optimised to support the well-being of children, adolescents, and their families in these sensitive care settings.

Chris L. Smith is a Professor of Architectural Theory in the Sydney School of Architecture, Design, and Planning at the University of Sydney. His research, over the last eighteen years, has focused on the nexus of architecture and the body, and he has lectured internationally on this theme.

Rebecca McLaughlan is a Senior Lecturer in the Sydney School of Architecture, Design, and Planning at the University of Sydney and a Registered Architect. Her research explores how architecture embodies care by examining lived experiences and perceptions of care environments, and the processes through which architects create architectures of care.

Authors' addresses
Sara Nourmusavi Nasab
sara.nourmusavinasab@sydney.edu.au

Chris L. Smith
chris.l.smith@sydney.edu.au

Rebecca McLaughlan
rebecca.mclaughlan@sydney.edu.au

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