



Development of A User-Centered Design Framework for Palliative and Hospice Care Patients for a Better Quality of Life Experience

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Abstract

Goal Three of the Sustainable Development Goals emphasizes the concept of “leaving no one behind”; a model for inclusivity and coherence. Amongst those that are often “left behind” are patients at the end stage of their life due to a terminal illness or a medical diagnosis. These are often left to die without thought to the quality of life that they receive before their demise, and many experience this stage at home due to fear of expenses, or in a best-case scenario at a hospital to help alleviate or manage pain. In many places worldwide, this is where palliative and hospice care come in and focus on the End-of-Life care provided to patients who fit the criteria.

The number of architecture and design related studies in this field are not numerous, and those that are there do not focus on the patient as a user with rights, but merely as a patient that is there. The concept of a user-centered design is forgotten in midst of all the pain and suffering of all concerned, namely, the patient, his beloved, and his caregivers. However, focusing on this nexus at the core of the design project may help promote this painful and stressful time in life and induce serenity and acceptance in a time that is often dark and ominous. This research aims to develop a design framework for places that deal with End-of-Life care and how to provide a better quality of End-of-Life experience for terminally ill patients.

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Keywords

End-of-Life care; user centred design; palliative and hospice; leave no one behind; tailored spaces; quality-of-life;

1. Introduction

The right to quality of life is a focus across many disciplines today, that happens to adhere to both the World Health Organization (WHO) recommendations as well as the Sustainable Development Goals (SDGs); for amongst the focus on beneficiaries addressed by Goal 3 of the SDGs: “leave no one behind”, are those in need of palliative care (Pettus, 2017). The WHO estimates that less than 14% of all people who deserve palliative care actually receive it (*Palliative Care*, 2020), and aims to ensure that individuals have the ability and provisions to live comfortably and happily in existing circumstances (World Health Organization, 2016).

Palliative and end of life care do not only fall under the objectives of the SDGs and the capacity of the WHO, but also as a human right argued by Brennan in 2007, the right to health and the right to life bereft of suffering (Brennan, 2007). Currently, there are almost 2,100 palliative care centers around the world, with more than a third stationed in the United States alone (*Global Directory of Palliative Care Institutions and Organizations*, n.d.), the WHO states that each year, almost 40 million individuals around the world become in need of some form of end of life care, with

more than 70% of that number in low to middle income countries, thus leading to insufficient access to this type of care (WHO & WHPCA, 2020).

The roots of palliative care stems from the modern hospice movement that focused on the sum of the effect of the different distress stressors; emotional, spiritual, social and physical, on the pain perceived by an individual or what is called “total pain”. The continuous care and support provided to patients in need of palliative care helps decrease frequent unwanted and mostly unbeneficial visits to the hospital and its related cost plus with the help of psychological care provided helps patients and loved ones accept the concept of dying. (Zadeh et al., 2018)

The existing literature amplifies both the psychological and social dimensions (Blakey & Abramowitz, 2017; Gerlach et al., 2021; Hearn & Higginson, 1998; Price et al., 2006), while not always being able to commit to the physical aspect. The physical component may consist of the right to health, the right to appropriate and comfortable housing, and ultimately housing alternatives, and the right to leisure and recreation, amongst other parameters that may not always be present or may not be up to the expected standard. The problem intensifies in individuals with life ending disease and terminal state illness, as well as old age frailty, and more often than not impacts the quality of life they are subjected to.

At the End of Life (EoL) stage, quality of life of both patients and caregivers is heavily impacted as patients with terminal illnesses’ health deteriorates and they suffer from stressors due to their physical state, these may include insomnia, or general sleep disturbance, anger, fear, fatigue, anorexia, nausea and depression, amongst other factors. The impact of the physical environment on these stressors may help diminish their impact as well as provide beneficiaries of palliative care a comfortable and aesthetic pleasing EoL experience.

1.1. Disparities between Hospice and Palliative care

The End-of-Life (EoL) care is an approach that helps alleviate potential suffering and trauma related to terminal disease. It was essentially advocated to help patients have a better quality of life during their last days as well as help families and caregivers cope with the prospect of dying and death of a loved one (Mularski et al., 2007). EoL care refers to two types of dealing with a terminally ill patient with a life expectancy of up to six months: palliative and hospice care, with hospice being the root for palliative. The main difference between the two types of care is the administration of medicine to cure the present ailment or disease, palliative care tends to take into consideration curing the patient as well as easing his suffering, as much as is possible given the side effects of the medicine used and the interaction between the limitation of specific types of interventions, while hospice care focuses on the patient leading a better quality of life regardless of the idea of curing the patient; having the patient lead a comfortable end-of-life experience through pain killers. Knowing the needs of each type is a tool to aid architects and designers in providing better solutions to facilitate and ease this stress inducing practice, not only for the patients, but also for both nurses and caregivers.

The role of the hospice team is to provide a pleasant end of life experience through relieving pain and stress through focusing on enhancing the social, psychological, and physiological aspects of the patient’s life. It helps celebrate life and provides the needs and measures needed for each specific individual to be able to do so. On the other hand, the main focus of palliative care is the alleviation of pain and suffering through administering appropriate medication while ensuing comfort and support. Hospice care, delves on providing help and care, (and even bereavement therapy upto one year post mortem), to patients and their families during the last period of the patient’s life, while palliative care does not deal with the aftermath of the process of dying. (Figure 1)

Both types of care may be administered at a hospital, in an assisted living facility or a nursing home or even at the patient’s residence. The place of care depends on several factors such as projected life expectancy, cost of care, presence of a caregiver, location, and proximity to place to the responsible physician and his team, and willingness of the patient or his first of kin.

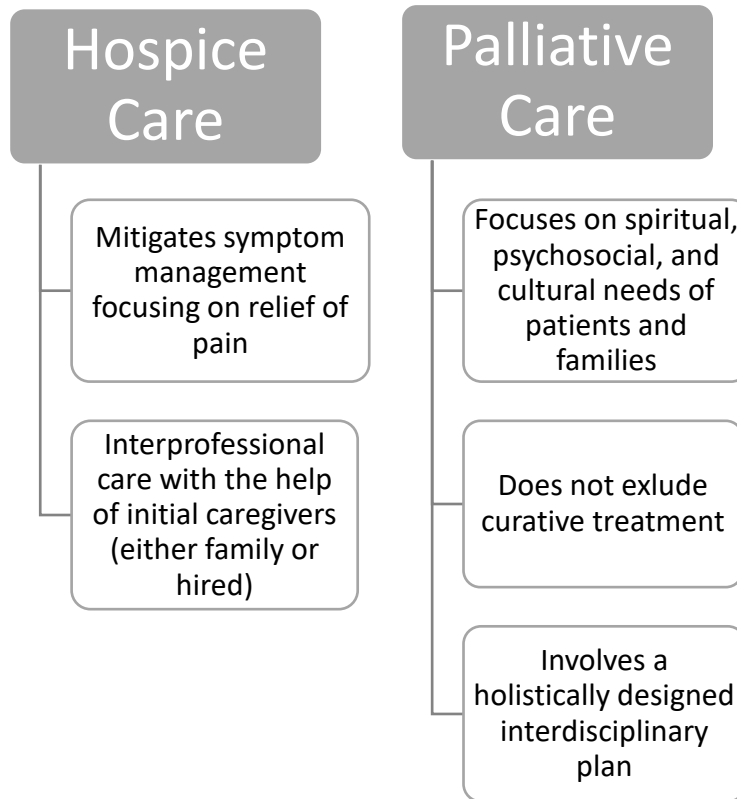


Figure 1: Main differences between Hospice and Palliative Care

Also, in opposition to hospice care and its numbered team, palliative care is administered through a palliative care therapy unit, consisting of physicians, therapists, physical therapists, and nurses, as the main professions, alongside them, creative therapists (music and art), psychologists, psychiatrists and spiritual healers are also involved, not to mention legal and financial advisors and occupational consultants. The literature does not provide that designers and architects should be incorporated into this unit nor the important role that they play amongst retailing the experience of quality of life to the end-of-life phase, although there is growing focus on the architecture of death and dying.

This research discusses the additional areas of design that may help make the end-of-life experience better as well as develop a user centred design experience tailored to each individual patient in opposition to a one size fits all approach to ensure a better quality of life experience. The study aims to develop a design framework to provide a better End-of-Life experience for terminally ill patients, it also examines structuring a detailed interview questionnaire for both patients and caregivers to give a better personal aspect to this dire time and provide quality time for all concerned to enhance their quality of life.

2. Methodology

To better understand the number and amount of relevant publications published with the keywords architectural design, user-centred, palliative and hospice care, the VOSviewer platform was used. VOSviewer is a map and infographic builder that correlates data from several academic search engine sites such as dimensions, Web of Science and Scopus. The format used to import the data into the VOSviewer is a .csv extension. The VOSviewer accepts metrics from four specific engines, namely, Scopus, web of science, dimensions and PubMed. The two engines used in this research are Dimensions and Scopus due to them being freely available for researchers. The dimensions.ai search engine searches existing academic articles for more than 13 major publishers including springer nature, PLOS, Wiley, IOP, frontiers, emerald publishers, and many others, was used to research the correlation between several keywords and their incidence. The keywords used initially was hospice design, which yielded 156 publications. The main categories of research were then filtered as is shown in (Figure 1), and 8 of the 11 categories were chosen, yielding 127 publications, as shown in Figure 2.

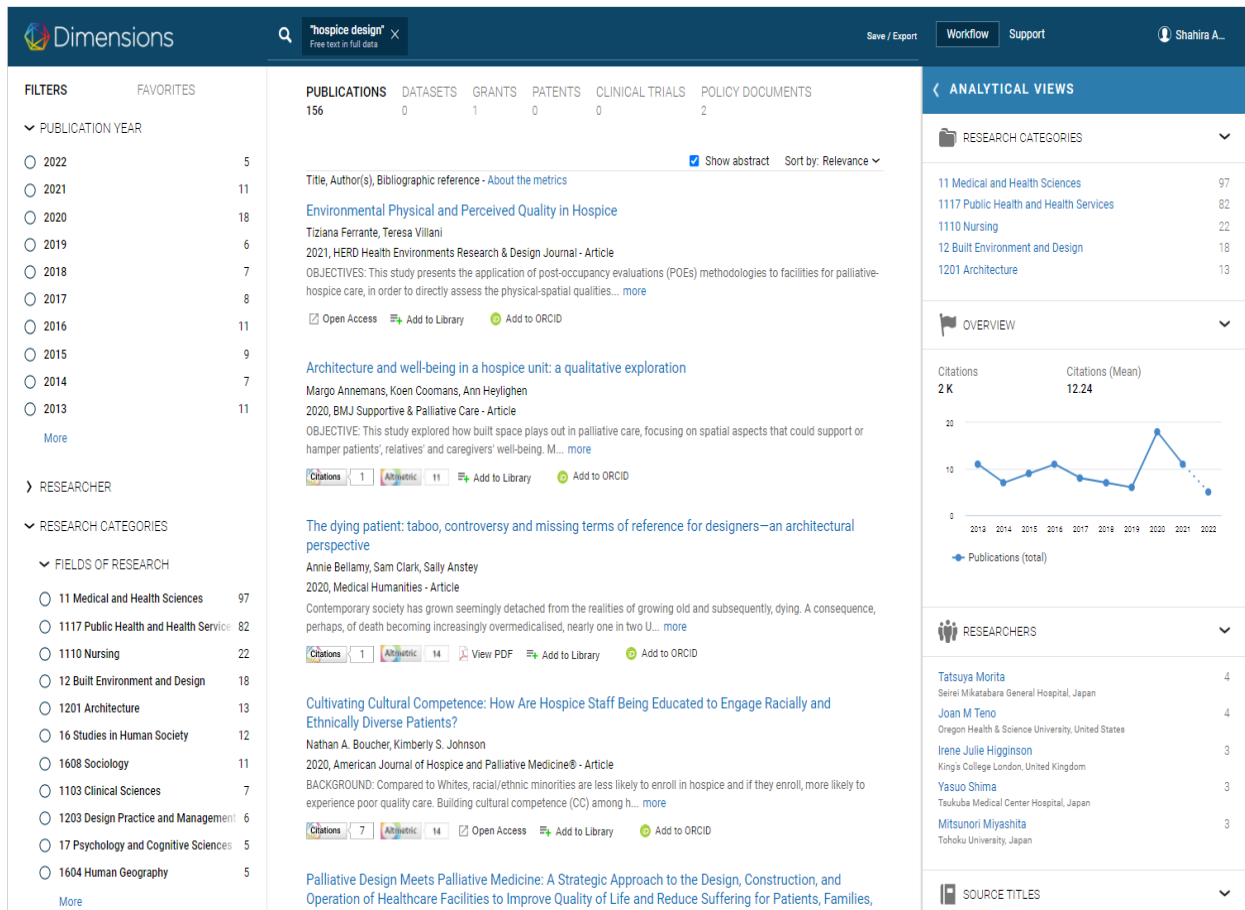


Figure 2: results from the dimensions.ai application showing the number of search items that resulted from the keywords While in Scopus database, the term “palliative care design” came up with 123 entries, and “hospice care design” came up with 28, (Figure 3 and 4 respectively).

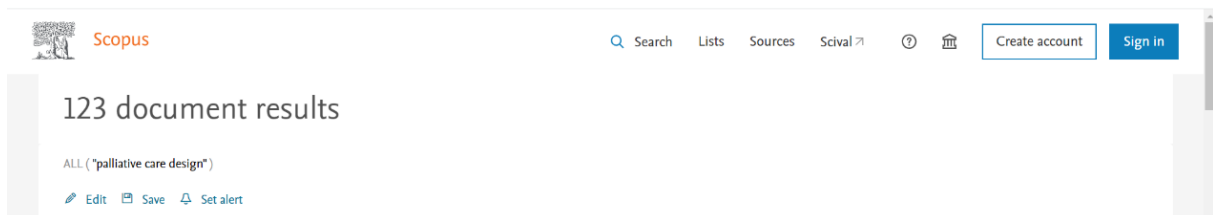


Figure 3: Results of the search query “Palliative care design” on the Scopus database

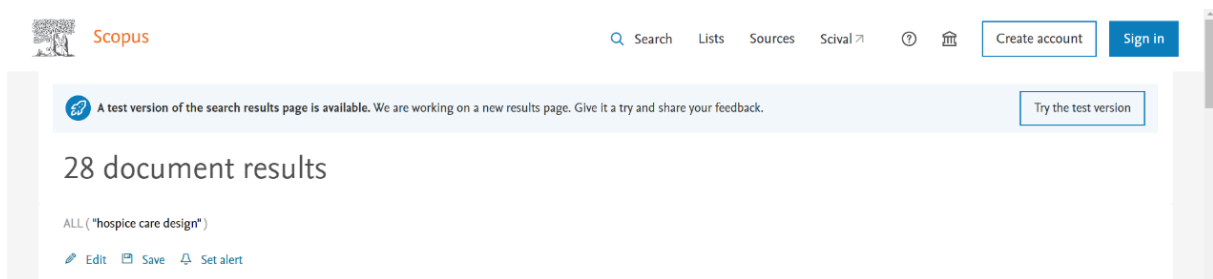


Figure 4: Results of the search query “hospice care design” on the Scopus database

The data was then exported from both dimensions.ai and Scopus database, downloaded and imported into VOSviewer and a VOSviewer bibliometric map was designed.. The keywords are then mapped and a filtration of unnecessary or ineffective words are screened manually, (words like chapter, book, article, proceedings, authors names, countries and other irrelevant data to the point of research) and removed. The resulting bibliometric data shows the incidence and correlation between certain keywords and the links occurring from their use. The program computes the words into clusters and a visual map result, as is seen in (Figure 5).

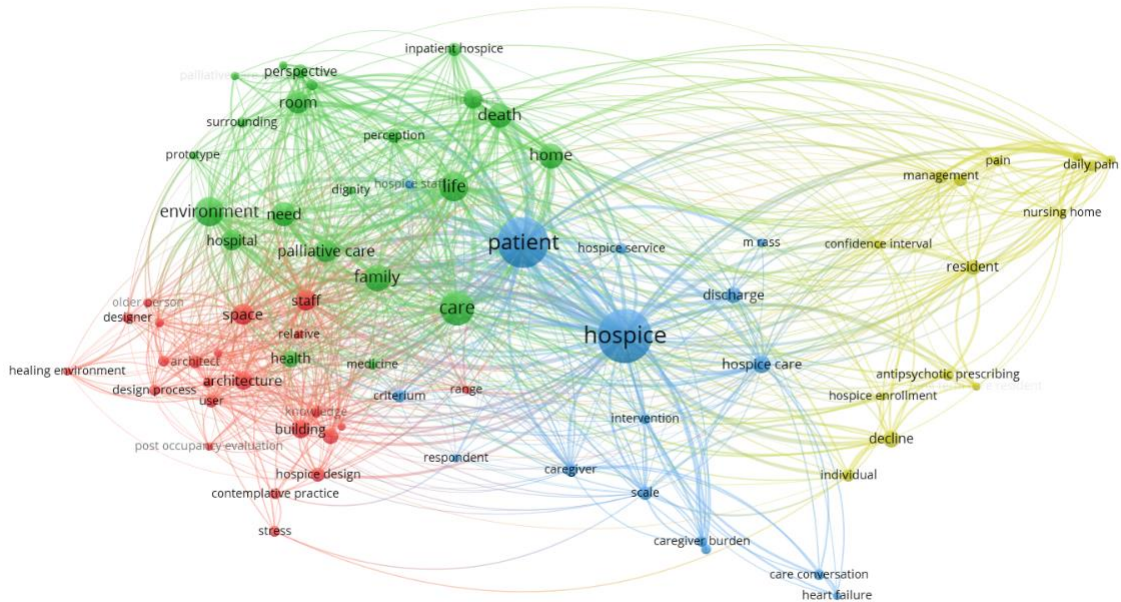


Figure 5: Visualization map resulting from the words selected showing incidences and links between keywords

It is evident that the repetitive and keywords in association with hospice is non design related and that the keywords are patients, caregivers, family and care, while those associated with design are few and with little to no links or connectors (**Figure 6**)

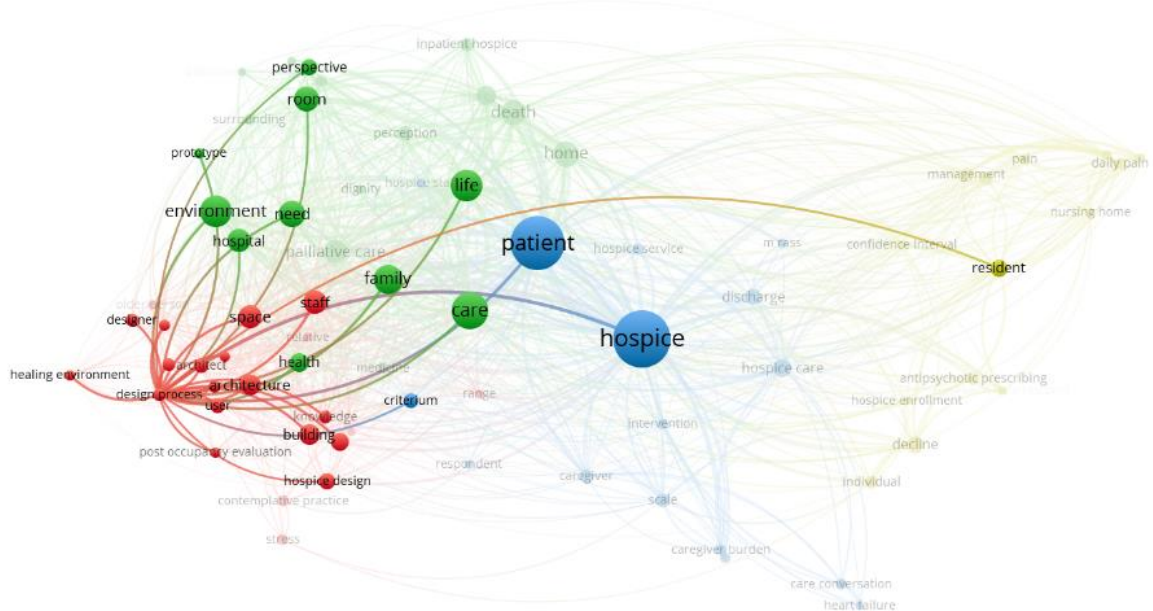


Figure 6: Map visualization showing weak links and incidence between keywords such as design process, healing environment and design in relation to hospice

A desktop literature review was then carried out to determine the design standards available for these types of institutions and to build upon the findings the criteria to be added in the development of the framework, taking into consideration the elements of personalization that may be added to devise a conceptual design for areas that may aid in achieving a better quality of life for terminally ill patients through a formulation of an interview questionnaire tailored for each individual.

3. Literature review

While related literature focuses on medical care and medication (Bain & Weschules, 2007) (Gawande, 2014; Goldenheim et al., 2014; Kohara et al., 2005; Russell et al., 2017), and to some extent their psychological care as well (El-Jawahri et al., 2011; Ferrante & Villani, 2021; Gola et al., 2016), little emphasis is placed on their surrounding environment (both built and natural) and their immediate wishes to live their last days. And while both hospice care centres and palliative units often focus on the physical comfort of the patient, it does so without tailoring a definitive setting to each individual, a point which affects their perception of care during their last days (Ferrante & Villani, 2021).

Architectural design focus on both types of care is not evident and only few researchers have ventured into this domain, as evident in the methodology section. Architectural and environmental design are inevitable in the provision of an overall integrated and holistic experience to ensure patient satisfaction and vitality. To better understand the qualitative research done in relation to architecture and either hospice or palliative care, academic search engines were utilized to research the number of publications across the years. The overall result showed that these design guidelines were missing and that was the sole driver of this current research.

Initially hospice and palliative care were designed to ease the suffering of terminally ill cancer patients, today with the adoption of Goal 3 of the sustainable development goals leave no one behind to palliative care, it has become broader to encompass other life-threatening debilitating illnesses, such as organ failure, dementia, extreme frailty due to old age, severe tuberculosis, HIV and anyone who's level of suffering is affecting his quality of life. Palliative care also differs according to the age of the patient, children are dealt with in a different manner than youth or geriatric patients and the expectations of family is different according to the age group.

Evidence based empirical research shows that palliative care does indeed improve quality of life of the patient as well as the end of life experience (El-Jawahri et al., 2011; Kane et al., 1984) research also showed that both patients and familial caregivers showed a higher satisfaction to the efforts administered through palliative care in opposition to usual hospital stays, however, the extent or mode of measurement of this satisfaction was not qualitative with no proper mode of measurement identified. (Dy et al., 2008; Higginson et al., 2003) another point worth mentioning in regards to satisfaction is that studies done in regards to palliative care cannot be taken as is; context, place, location and patient specifics are important factors that may affect heavily satisfaction outcome and the overall experience (Higginson & Evans, 2010; Mularski et al., 2007)

Amongst the parameters measured for satisfaction in the palliative care experience, the aspect of architecture and design is often overlooked, although it plays a vital role and deals with the overall quality of life and may help in enhancing the EoL quality experience. In one study, amongst 37 factors integrated into a questionnaire to measure satisfaction of patients and caregivers, none of the factors embedded in the questionnaire were related to the built environment or the physical surroundings of the patient. (Partinico et al., 2014), this may be due to the fact that at the EoL stage, aesthetics and architecture may not be important to some. However, architecture and aesthetics is embedded in the daily perception of individuals to any setting and studies have shown the psychological effect that spatial design has on users.

3.1. Barriers to End-of-Life Care

Religious, financial, and psychological aspects all contribute to lack of implementation of end-of-life care. Most religious beliefs view the time of death as a sacred and unknown instance that cannot be predetermined and as such may not believe the time life expectancy stated by the physician. Another point of consequence is a psychological one, where caregivers and immediate family would resist treating the patient as terminal as to not foretell his demise (or jinx), believing that it is ominous to think of a loved one as dead. The third aspect to refusing end of life care is often financial, the cost of care for a person, for up to six months in an assisted living facility is often a cost consuming one and many may not be able to afford it, not to mention the psychological synopsis associated with guilt of putting that person up to be cared by somebody else.

4. Results & Discussion

The idea of investing in an architecturally designed hospice may be a strange notion, not understandable to all, for the mere fact that most people who are on the throes of palliative or end of life care, won't have design and interior design on their mind and may not even realize its importance. Hospices, much like hospitals, come with a very high price tag, on their own without the added component of having them specifically designed and tailored to the individual case or setting. However, the psychological benefits that may arise from embedding design strategies into the EoL care setting may be the light at the end of the tunnel needed for families, patients, and caregivers.

4.1. History of Palliative and Hospice Care Design

The idea behind hospice care, started by Dame Cicely Saunders, in the late forties of the last century was a breakthrough in medical care. Saunders took it upon herself to divulge into the care of dying patients and to later open the first dying care home, which she named hospice; originating from hospitality. In 1969, Dr. Elisabeth Kubler-Ross wrote the book "On Death and Dying", a 500-interview log of dying patients aiming to set in stone the notion of patient involvement in his end of stage care (Newman, 2004).

The beginning of hospice care design standards came about after a study was done by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to assess the number of hospital programs that had a hospice unit, a dedicated nursing unit, or a detailed design compliment for terminally ill patients. Based on this empirical research, together with the construction of standalone hospices, certain design elements were embedded within the overall design of these structures; spaces that were uncommon before in the hospital setting came forward, multi-usage spaces were introduced to serve several purposes in the same area to allow ease of use and accessibility. Interior materials and finishings resembled homelike atmospheres and included residential and domestic elements.

New ideas such as places for grieving, spiritual areas, places of respite, therapeutic, restorative and healing gardens were also introduced. Places for family accommodations, spatial requirements for therapy and counselling were also made available and encompassed several types and stages (Verderber & Refuerzo, 2019) in essence, designing for grievance and hospice is designing with compassion, it needs to bear in mind the time of distress that accompanies families, loved ones and caregivers.

The idea of a one model fits all approach is not one that will work in terminally ill patients, with each having their own life expectations, experiences and mechanisms for coping, and while the hospice team and unit interview patients and their next of kin extensively to reach an optimum plan of care, it is most likely focused on the medication plan that helps relieve pain, an important factor which is directly related with the relieve of stress. Studies have shown that the higher the amount of pain, the worse the stress levels of both patients and caregivers (Abdallah & Geha, 2017; Feuerstein, 2007). However, pain and stress relieve are not the only sides of coping with a terminally ill situation nor will they ensure a better quality of life. This research focuses on devising design outlines that will be tailored to each individual user as per their explicit needs and wants. A detailed interview questionnaire should be structured to help understand the specific needs of each patient, and ultimately aid the design team to focus on how to embed these needs into the design framework to be able to fulfil them duly.

Optimally this is carried out in the assisted living unit or a nursing home, however it may also be used in the patient's residence (although it may incur additional costs and expenses). Hospitals are not always the preferred place of stay between the four accommodation types due to many reasons, the first being the idea of being surrounded of disease and death as well as the financial toll on governments and insurance bodies as hospitals tend to have a higher need of individualized beds to make way for other patients especially in the case of terminally ill ones. Most hospitals do not want to increase their mortality rate and have a terminally ill patient stay and die at their establishment, so even if the idea of costs and expenses are not the issue, the need to make way for other pressing patients with curable diseases is another point that is factored into the equation.

4.2. Personalization of interior spaces

Most end-of-life care design standards revolve around the accommodation's unit itself; (size, furniture, placement, floor area ratio, window placement and proximity of care). Little to no emphasis is placed on the life of the individual at the centre of care.

The main aspect of personalization comes from four main pillars physical, social, psychological, and physiological (Table 1), each of these components can be dealt with through design to help maximize or diminish its positive or negative effects.

Table 1: Aspects of personalization of spatial design based on user-centred design and tailored to each individual need

Pillar	Component	Design Criteria	Design needs
Physical	The physical surroundings of the patient including his lodging quarters, belongings and everyday activities and practices	Spatial design of the patients' surroundings to help in overall support	<ul style="list-style-type: none"> Fixtures installations Ambient temperature Ambient lighting Embedding an automated monitoring system for thermal comfort Changing the overall scenery inside the space Interaction with nature through the different senses Digitization of well-being devices such as curtain movement, heater start, sound system levels Accessibility
Social	Social interactions and connections and their incidence and frequency, whether with family members, friends, acquaintances or others	Close proximity design of needed social spaces	<ul style="list-style-type: none"> Allowing social interaction with peers for meaningful conversations that stay away from the subject of illness and death Engaging with therapists and other professionals help ease negative feelings Hired listeners Access to different age groups and scopes of people
Psychological	Deals with the different additives that may impact the patients state of mind and overall mental well-being, this may be due to cultural, genetic, social or religious mandates that may in turn affect the patient's responsiveness and state of mind	Design of stress relief areas to decrease the focus on pain, death, and stress	<ul style="list-style-type: none"> These are embedded strategies in the types of activities that the patient may be able to undergo, given his physical and health state, these may include accessibility to places of hobbies, music, art and other leisure activities, they should be formulated and designed in accordance with each individual need and to the level of activity that he is able to undergo. Religious areas (according to practice) to help regulate bouts of anxiety and psychological onsets Therapeutic gardens and places of general rumination which include birds, flowers, water elements, trees, and other relaxing elements to engage the senses
Physiological	The physiological state of the patient and the levels of medications needed to alleviate the pain, whether they affect any other organ and cause any side effects. They may even render the patient asleep the entire time thus not fulfilling the idea of quality-of-life measure	Parts of the detailed strategies may be brought to the patient in room to make for his lack of being able to experience these in their own settings	<ul style="list-style-type: none"> Scenic landscapes drawn, hologrammed, projected or glued to the interior of the room Biophilic design interventions Music played inside the room Placement of art and other visually appealing items Placement of flowers and other arrangements Accessibility aids that can be tailored to individual need, weight, and height Ease of use of close proximity equipment, like lighting, bell calls, thermal comfort monitors, regulators, and controllers.

Each point in **Table 1** is converted to one or more questions in the interview questionnaire for a more specific user-centred experience. The questions are designed to understand the preferences and taste of the patient as well as his caregiver or next of kin (caretaker not from the nursing staff) as is seen in the sample questions in (**Table 2**). Should the patient not be able to undergo these questions, his caregiver is to ask on his behalf and a temporary location may be administered until the patients needs are met and he is satisfied.

Table 2: Sample of interview questionnaire for personalization of personal space

Sample Questions	
Physical attributes	What is your preferred method of lighting? (Direct/Indirect)
	What is your preferred colour of light? {Warm (yellow)/Cold (white)}
	Is there a preferred colour of choice for the interiors colour of the walls?
	Would you like access to additional landscape scenery inside your room, or is the garden view enough?
	Would you like to have the sound of nature brought inside the room (birds chirping, rustle of leaves, sound of rain, sound of water)
	If so, would you like to be able to control it.
	Would you like to have the smell of nature brought inside the room (orange orchids, flowers, fresh grass, smell of the fields)

Not all terminally ill patients are frail (Eklund et al., 2013), some just want to be able to spend their last days in a pain free environment, with the people they love, in a setting they prefer. While homes and personal residences may be the ideal setting, they are often lacking in essential amenities, take their toll on the immediate family, not to mention may be out of reach of physicians and staff. Designing end-of-life care facilities to resembles personal homes or the idea of “homeliness” is often mentioned in the research, making the place of care resemble a home as much as possible, and initially, hospice care units were housed in residences donated by their owners as a last resting place. The idea of homeliness is further enhanced through concealing machines and devices. This was harder to adopt earlier due to both the size of the machine and the need to attach it to the patient, however, nowadays with the evolvement of technology and artificial intelligence tools and sensors, both these problems may be dealt with. In the instance of the size of the machinery, the size has diminished considerably and may be masked in either a moving cupboard that resembles a commode, or through placing it in an integrated setting facing the wall, to be turned around only when needed. The other point that has to do with machinery is the constant sound of monitors and other vital signs checks, sensors through small wrist attachments, help send signals and data directly to the nursing units that monitor the patients’ vitals through a monitor and an electronic management system, that may give out an alarm if a specific number is not in accordance with the overall finding. This electronic management system is embedded within the overall computing system of the facility and helps regulate the workload of nurses as well.

Personalization of the interior space includes personalized thermal comfort, in contrast to a central HVAC facility that may become an irritation rather than a convenience (Abdel-Razek et al., 2022). Patients with terminal illness are usually immuno-compromised and may thus be more sensitive to temperature than others, this is also affected by their metabolic rate, medication and type of illness. That is why a tailored experience for each of user is more befitting.

Proximity of nursing stations and other caregivers is another aspect that has been given vast recognition, not only as a form of function, but also to design spaces, where the caregivers may acquire enough rest to recharge to be able to continue their vocation without its dire negative effects. Evidence has shown that the side effects of dealing with a terminally ill loved one leads to stress, depression, mood swings, anxiety, panic attacks, high blood pressure and general misery(Boucher & Johnson, 2021; Connellan et al., 2013; Gawande, 2014; Petersen et al., 2020; Russell et al., 2017). That is where the design process comes in to provide relief to both caregivers and next of kin to be able to

meltdown; open air spaces, gardens, crying rooms, scenic landscape areas, music rooms, libraries, game rooms, activity areas, places for hobbies, general chatrooms, social areas, each according to their mode of stress reducing activity. Nursing stations as proposed in Figure 7, should be stationed in a place where they have close access to both patient rooms and social spaces, so as to decrease the amount of time spent back and forth between them. Social cultural leisure zones should be divided into clusters to decrease walking time and provide continuous access to all. Grievance areas should be placed in a farther away spot to restrain from becoming a place of bad omen to patients and caregivers alike, while places of worship should be coupled into the proximal space to promote spiritual accessibility. (Figure 8)

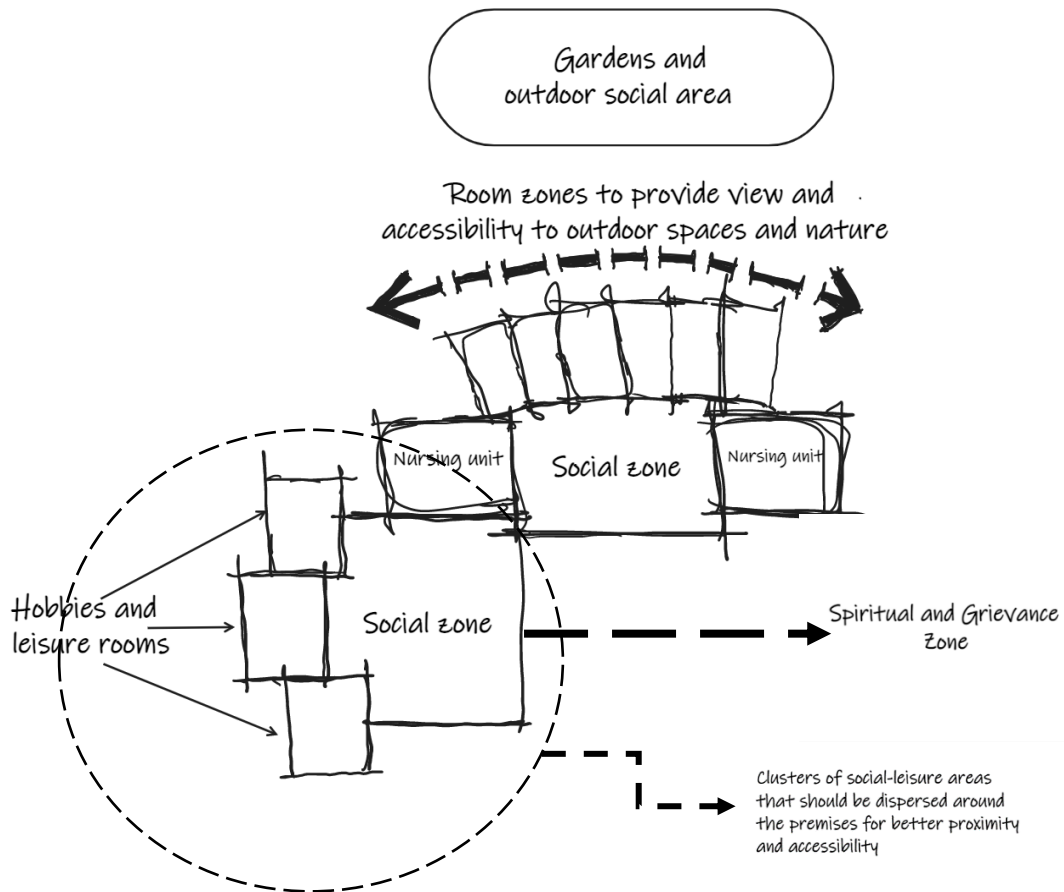


Figure 7: conceptual design of design relation between patient rooms, social areas, and nursing units and accessibility to the outside



Figure 8: Grievance areas should be secluded and kept at the back of the spiritual zone

Studies have shown that while some terminally ill patients preferred shared accommodations, some felt that it breached their privacy and was not ideal for familial conversations and medical assistance (Smith, 2014), the entry interview with patients and caregivers should ask about the preferred choice of accommodation type and work upon it without placing two medically incompatible patients in the same room (same diagnosis shared room is preferred). Empirical research has also shown that many inhabitants of assisted homes preferred open space dining in opposite to single room dining and en-suite kitchen services.

Large Windows with internal shading fixtures should be present in all patient rooms. According to one study done to understand what the most important design component of rooms in hospice care units, most patients emphasized the point of more light (Eaton, 2008). Dim rooms give a sense of foreboding that is often perceived as gloomy or depressing. The internal shades should be operable mechanically using handheld controllers provided to the patient to maximize benefit and facilitate use.

Another point of importance is the provision of a physical activity place,(not rigorous exercise), evidence-based research has shown that patients with accessibility to places for walking (Morris & Hardman, 1997; Ouf et al., 2021; Visvizi et al., 2021), meditation (Goyal et al., 2014; Innes et al., 2012; Scott, 2022), yoga (Maddux et al., 2018; Shohani et al., 2018; Woodyard, 2011), and mindfulness (Bartlett et al., 2021; Mohammed et al., 2018) are prone to lower stress levels, lower pain levels and overall general improvement, than ones not partaking in these types of activities. This entails that designers design easily accessible areas that fit these types of activities, both inside and outside to accommodate for weather changes. These spaces should be geriatric and child friendly and be fit for all levels of usage.

5. Conclusion

User-centred design is often forgotten in circumstances of extreme events, like dying. The end-of-life period, often a very stressful and exhausting one, especially to terminally ill patients and their beloved, is a time that should be invested in to provide solace and make memories, as well as help transition loved ones into the process of grief. Embedding systems and designing detailed places aimed at improving the overall mood and psyche of the patient-caregiver nexus is crucial to ensure a better end of life experience and help diminish adverse reactions and outbursts.

Providing a better quality of life to end of life terminally ill patients is a right that is often overlooked or discarded due to the dire circumstances. Often enough patients will want to live their last days in a serene place surrounded by friends and family with no pain or suffering, providing them with such is the least that designers and caregivers can do in this crucial and painful time. Moreover, loved ones and friends and families need to make memories and celebrate their life, as well as accept the notion of grievance and loss through spending quality time. Seeing a loved one in pain and suffering is a agitation inducing sight that many wish to not be subjected to. this research focuses on providing end stage terminally ill patients with a life expectancy a quality of life tailored to their specific need through an entry questionnaire designed to consider all aspects of their everyday life as well as their hobbies, interests, and preferences to come up with a user-centred design tailored to each individual separately

These measures can be taken on the physical, social, psychological, and physiological levels, each on its own or combined to give a better design experience. The proposed initial framework includes several introduced spaces to help ensure the patient is satisfied with his surroundings and has all his favorite pastimes available, it also features a personalization detailed questionnaire to help understand the patient's wishes and needs The embedded strategies are subtle homelike environments that are tailored to each patient individually, and may be achieved through things like embedding light and colour-changing sensors in the patient's personal space, including aesthetic placements of specific indoor environments, integrating the utilization of the different senses, all in an effort to help alleviate stress and reduce anxiety and overall pain, to provide a better quality of life during End-of-Life care.

6. Future research

Validation and implementation of the interview questionnaire for terminally ill patients as an evidence-based design approach

References

- Abdallah, C. G., & Geha, P. (2017). Chronic Pain and Chronic Stress: Two Sides of the Same Coin? Why Stress and Pain? *Chronic Stress*, 1, 1–10. <https://doi.org/10.1177/2470547017704763>
- Abdel-Razek, S. A., Marie, H. S., Alshehri, A., & Elzeki, O. M. (2022). Energy Efficiency through the Implementation of an AI Model to Predict Room Occupancy Based on Thermal Comfort Parameters. *Sustainability (Switzerland)*, 14(13). <https://doi.org/10.3390/su14137734>
- Bain, K. T., & Weschules, D. J. (2007). Medication Inappropriateness for Older Adults Receiving Hospice Care: A Pilot Survey. *The Consultant Pharmacist*, 22(11), 926–934. <https://doi.org/10.4140/tcp.n.2007.926>
- Bartlett, L., Buscot, M.-J., Bindoff, A., Chambers, R., & Hassed, C. (2021). Mindfulness Is Associated With Lower Stress and Higher Work Engagement in a Large Sample of MOOC Participants. *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.724126>
- Blakey, S. M., & Abramowitz, J. S. (2017). Psychological Predictors of Health Anxiety in Response to the Zika Virus. *Journal of Clinical Psychology in Medical Settings*, 24(3–4), 270–278. <https://doi.org/10.1007/s10880-017-9514-y>
- Boucher, N. A., & Johnson, K. S. (2021). Cultivating Cultural Competence: How Are Hospice Staff Being Educated to Engage Racially and Ethnically Diverse Patients? *American Journal of Hospice and Palliative Medicine®*, 38(2), 169–174. <https://doi.org/10.1177/1049909120946729>
- Brennan, F. (2007). Palliative Care as an International Human Right. *Journal of Pain and Symptom Management*, 33(5), 494–499. <https://doi.org/10.1016/j.jpainsymman.2007.02.022>
- Connellan, K., Gaardboe, M., Riggs, D., Due, C., Reinschmidt, A., & Mustillo, L. (2013). Stressed Spaces: Mental Health and Architecture. *HERD: Health Environments Research & Design Journal*, 6(4), 127–168. <https://doi.org/10.1177/193758671300600408>
- Dy, S. M., Shugarman, L. R., Lorenz, K. A., Mularski, R. A., & Lynn, J. (2008). A Systematic Review of Satisfaction with Care at the End of Life. *Journal of the American Geriatrics Society*, 56.
- Eaton, N. (2008). ‘I don’t know how we coped before’: a study of respite care for children in the home and hospice. *Journal of Clinical Nursing*, 17(23), 3196–3204. <https://doi.org/10.1111/j.1365-2702.2008.02630.x>
- Eklund, K., Wilhelmson, K., Gustafsson, H., Landahl, S., & Dahlin-Ivanoff, S. (2013). One-year outcome of frailty indicators and activities of daily living following the randomised controlled trial; “Continuum of care for frail older people.” *BMC Geriatrics*, 13(1), 76. <https://doi.org/10.1186/1471-2318-13-76>
- El-Jawahri, A., Greer, J. A., & Temel, J. S. (2011). Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. *The Journal of Supportive Oncology*, 9(3), 87–94. <https://doi.org/10.1016/j.suponc.2011.03.003>
- Ferrante, T., & Villani, T. (2021). Environmental Physical and Perceived Quality in Hospice. *HERD: Health Environments Research & Design Journal*, 14(4), 324–338. <https://doi.org/10.1177/19375867211028160>
- Feuerstein, M. (2007). *Encyclopedia of Pain*. Encyclopedia of Pain, October. <https://doi.org/10.1007/978-3-540-29805-2>
- Gawande, A. A. (2014). Being mortal : illness, medicine and what matters in the end.
- Gerlach, L. B., Fashaw, S., Strominger, J., Ogarek, J., Zullo, A. R., Daiello, L. A., Teno, J., Shireman, T. I., & Bynum, J. P. W. (2021). Trends in antipsychotic prescribing among long-term care residents receiving hospice care. *Journal of the American Geriatrics Society*, 69(8), 2152–2162. <https://doi.org/10.1111/jgs.17172>
- Global Directory of Palliative Care Institutions and Organizations. (n.d.). Retrieved June 10, 2022, from <https://hospicecare.com/global-directory-of-providers-organizations/>
- Gola, M., Francalanza, P. C., Galloni, G., Pagella, B., & Capolongo, S. (2016). Architectures for paediatric palliative care: how to improve quality of life and environmental well-being. *Annali Dell’Istituto Superiore Di Sanita*, 52(1), 48–55. https://doi.org/10.4415/ann_16_01_10
- Goldenheim, A., Oates, D., Parker, V., Russell, M., Winter, M., & Silliman, R. A. (2014). Rehospitalization of Older Adults Discharged to Home Hospice Care. *Journal of Palliative Medicine*, 17(7), 841–844. <https://doi.org/10.1089/jpm.2013.0224>
- Goyal, M., Singh, S., Sibinga, E. M. S., Gould, N. F., Rowland-Seymour, A., Sharma, R., Berger, Z., Sleicher, D., Maron, D. D., Shihab, H. M., Ranasinghe, P. D., Linn, S., Saha, S., Bass, E. B., & Haythornthwaite, J. A. (2014). Meditation Programs for Psychological Stress and Well-being: A Systematic Review and Meta-analysis. *JAMA Intern Med*, 174(3), 357–368. <https://doi.org/10.1001/jamainternmed.2013.13018>
- Hearn, J., & Higginson, I. J. (1998). Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine*, 12(5), 317–332. <https://doi.org/10.1191/026921698676226729>
- Higginson, I. J., & Evans, C. J. (2010). What Is the Evidence That Palliative Care Teams Improve Outcomes for Cancer Patients and Their Families? *The Cancer Journal*, 16, 423–435.
- Higginson, I. J., Finlay, I. G., Goodwin, D. M., Hood, K., Edwards, A. G. K., Cook, A., Douglas, H. R., & Normand, C. E. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management*, 25(2), 150–168. [https://doi.org/10.1016/s0885-3924\(02\)00599-7](https://doi.org/10.1016/s0885-3924(02)00599-7)
- Innes, K. E., Selfe, T. K., Brown, C. J., Rose, K. M., & Thompson-Heisterman, A. (2012). The Effects of Meditation on Perceived Stress and Related Indices of Psychological Status and Sympathetic Activation in Persons with Alzheimer’s Disease and Their Caregivers: A Pilot Study. 2012. <https://doi.org/10.1155/2012/927509>
- Kane, R. L., Wales, J., Bernstein, L., Leibowitz, A., & Kaplan, S. (1984). A randomised controlled trial of hospice care. *Lancet (London, England)*, 1(8382), 890–894. [https://doi.org/10.1016/s0140-6736\(84\)91349-7](https://doi.org/10.1016/s0140-6736(84)91349-7)
- Kohara, H., Ueoka, H., Takeyama, H., Murakami, T., & Morita, T. (2005). Sedation for Terminally Ill Patients with Cancer with Uncontrollable Physical Distress. *Journal of Palliative Medicine*, 8(1), 20–25. <https://doi.org/10.1089/jpm.2005.8.20>
- Maddux, R. E., Daukantaitė, D., & Tellhed, U. (2018). The effects of yoga on stress and psychological health among employees: an 8- and 16-week intervention study. *Anxiety, Stress and Coping*, 31(2), 121–134. <https://doi.org/10.1080/10615806.2017.1405261>

- Mohammed, W. A., Pappous, A., & Sharma, D. (2018). Effect of Mindfulness Based Stress Reduction (MBSR) in Increasing Pain Tolerance and Improving the Mental Health of Injured Athletes. *Frontiers in Psychology*, 9. <https://doi.org/10.3389/fpsyg.2018.00722>
- Morris, J. N., & Hardman, A. E. (1997). Walking to Health. In *Sports Med* (Vol. 23, Issue 5).
- Mularski, R. A., Dy, S. M., Shugarman, L. R., Wilkinson, A. M., Lynn, J., Shekelle, P. G., Morton, S. C., Sun, V. C., Hughes, R. G., Hilton, L. K., Maglione, M., Rhodes, S. L., Rolon, C., & Lorenz, K. A. (2007). A systematic review of measures of end-of-life care and its outcomes. *Health Services Research*, 42(5), 1848–1870. <https://doi.org/10.1111/j.1475-6773.2007.00721.x>
- Newman, L. (2004). Elisabeth Kübler-Ross. *BMJ: British Medical Journal*, 329(7466), 627. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC516672/>
- Ouf, T. A., Makram, A., & Abdel Razek, S. A. (2021). Design Indicators Based on Nature and Social Interactions to Enhance WellNess for Patients in Healthcare Facilities. In F. Trapani, N. Mohareb, F. Rosso, D. Kolokotsa, S. Maruthaveeran, & M. Ghoneem (Eds.), *Advanced Studies in Efficient Environmental Design and City Planning* (pp. 449–461). Springer International Publishing.
- Palliative Care. (2020). Fact Sheet. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
- Partinico, M., Corà, A., Ghisi, M., Ouimet, A. J., & Visentin, M. (2014). A new Italian questionnaire to assess caregivers of cancer patients' satisfaction with palliative care: Multicenter validation of the post mortem questionnaire-short form. *Journal of Pain and Symptom Management*, 47(2), 298–306. <https://doi.org/10.1016/j.jpainsymman.2013.03.018>
- Petersen, A., Munsie, M., Tanner, C., MacGregor, C., Brophy, J., Wathen, N., Harris, R., Wyatt, S., Pasveer, B., Synnes, O., & Moser, I. (2020). Section 3: Locus of Care. In *Health, Technology and Society* (pp. 135–180). https://doi.org/10.1007/978-981-15-4354-8_4
- Pettus, K. I. (2017). Leave no one (suffering) behind: Palliative Care and the SDGs. *Ehospice: Palliative Care News, Views and Inspiration around the World*. https://ehospice.com/international_posts/leave-no-one-suffering-behind-palliative-care-and-the-sdgs/
- Price, A., Hotopf, M., Higginson, I. J., Monroe, B., & Henderson, M. (2006). Psychological Services in Hospices in the UK and Republic of Ireland. *Journal of the Royal Society of Medicine*, 99(12), 637–639. <https://doi.org/10.1177/014107680609901213>
- Russell, D., Diamond, E. L., Lauder, B., Dignam, R. R., Dowding, D. W., Peng, T. R., Prigerson, H. G., & Bowles, K. H. (2017). Frequency and Risk Factors for Live Discharge from Hospice. *Journal of the American Geriatrics Society*, 65(8), 1726–1732. <https://doi.org/10.1111/jgs.14859>
- Scott, E. (2022). The benefits of Meditation for Stress Management. <https://www.verywellmind.com/meditation-4157199>
- Shohani, M., Badfar, G., Nasirkandy, M. P., Kaikhavani, S., Rahmati, S., Modmeli, Y., Soleymani, A., & Azami, M. (2018). The Effect of Yoga on Stress, Anxiety, and Depression in Women. *International Journal of Preventive Medicine*, 9, 21. https://doi.org/10.4103/ijpvm.IJPVM_242_16
- Smith, G. (2014). Evidence-Based design practices for the palliative care environment. <https://www.bdcnetwork.com/blog/evidence-based-design-practices-palliative-care-environment>
- Verderber, S., & Refuerzo, B. (2019). Innovations in Hospice Architecture. <https://doi.org/10.4324/9780429316104>
- Visvizi, A., Abdel-Razek, S. A., Wosiek, R., & Malik, R. (2021). Conceptualizing Walking and Walkability in the Smart City through a Model Composite w2 Smart City Utility Index. *Energies*, 14(23). <https://doi.org/10.3390/en14238193>
- WHO, & WHPCA. (2020). Global Atlas of Palliative Care 2nd Edition (Issue 2). <http://www.who.int/cancer/publications/palliative-care-atlas/en/>
- Woodyard, C. (2011). Exploring the therapeutic effects of yoga and its ability to increase quality of life. *International Journal of Yoga*, 4(2), 49. <https://doi.org/10.4103/0973-6131.85485>
- World Health Organization. (2016). Global report on urban health: equitable, healthier cities for sustainable development. http://www.who.int/about/licensing/copy-right_form/index.html
- Zadeh, R. S., Eshelman, P., Setla, J., Kennedy, L., Hon, E., & Basara, A. (2018). Environmental Design for End-of-Life Care: An Integrative Review on Improving the Quality of Life and Managing Symptoms for Patients in Institutional Settings. *Journal of Pain and Symptom Management*, 55(3), 1018–1034. <https://doi.org/10.1016/j.jpainsymman.2017.09.011>