

Architectural, interior architectural and industrial design in the last phases of life:

Design for wellbeing in palliative care

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Abstract:

The environment in which patients (need to) reside has a great influence on their wellbeing (Ulrich, 1991). That is why introducing ‘Design for Wellbeing’ is key in the design of palliative environments. People in the last phase of their life become more receptive to environmental stimuli. From our perspective, this triggers design to become even more relevant in such contexts. People’s search for subjective well-being (SWB) has promoted a change in vision in the design of new products, services and environments, with a focus not only on material properties, but also on the personal values that trigger actions that can contribute to people’s SWB. Such considerations contribute also to proposing answers to the question of how design can support people to have a meaningful life and ‘be well’ in the best possible way, according to the circumstances.

The purpose of this paper is firstly, *if* design for wellbeing can be performed in the context of palliative care, and secondly, *how* research could be set up in such a precious context. A thorough literature review will be performed to answer these questions. The value of this study lies in aiming to try to enable terminally ill patients and people from their immediate surroundings to cope with these events via design, and to stimulate people to be able to perform activities that they like (most) and which contribute to their SWB.

Keywords: design for wellbeing, palliative care, interior architecture, last phase of life.

Nowadays, palliative care promotes advanced care planning and aggressive symptom control in patients with severe illness (Dans & Sheldahl, 2015). In its beginnings, palliative care centers were established for terminal patients diagnosed with cancer, but now palliative care is open to any patient who is terminally ill (Rosenwax et al., 2005). Its goal is not to prolong or shorten life, but to improve the quality of life for both patients and families, for as long as possible. Palliative care integrates physical, psychosocial and spiritual aspects to help patients to live as actively as possible until their

death, and to help family members during illness and pain. Hospital care includes palliative and curative care, but mainly focuses on curing patients.

It is important to emphasize a palliative patient is mostly more open than any other patient to discuss emotional problems more deeply (Hui and Bruera, 2016) and to reflect consciously about actions, decisions and their potential repercussions. Unfortunately, although the need to implement palliative care in patients is necessary and urgent, not all patients who would 'profit' from palliative care receive it (Meffert et al., 2016).

That said, we intend to introduce the idea that the subjective well-being of palliative patients could be fostered by means of design for wellbeing and in understanding the role of the environment as a place and as a multi-layered need. We will specifically elaborate about the possible 'added value' that architecture, interior architecture and industrial design can have in this respect. In our view, introducing this perspective would allow to work on issues that a traditional palliative care center does not seem to cover, and provide guidance for new approaches.

Literature review

Design for wellbeing

Inspired by ideas based in positive psychology, Desmet and Pohlmeier (2013) aimed for positive design to be able to support human prosperity. Their approach promotes a change in vision in the design of new products, services and environments. The framework which they propose, takes into account three key components: (i) design for virtue (which encourages people to be a morally good person), (ii) design for personal significance (which supports people to pursue personal goals) and (iii) design for pleasure (intended to stimulate a pleasurable experience and diminish those who are not). Of these three components, the last is the one that is based on experiencing positive affect (positive emotions) when interacting, which means that a person having positive affective experiences will increase their perception of subjective well-being. Although it is not easy in practice, the ideal form of introducing these three aspects is to mix them together; yet, it is fundamental that at least one of these components is used to work on 'Human Flourishing'.

Interior architecture may also have another way of promoting the subjective well-being of people in particular places, that is, by implementing the concept of attachment to a place: the emotional bonds formed between people and their physical environment (Manzo & Devine-Wright, 2014). When people live in a particular environment, they try to make a particular space their place; 'a home'. In this line, Petermans and Pohlmeier (2014) studied if and how interiors can be feasible to provide subjective well-being to people. There is also literature that shows that there can be an emotional bond between an object and a person (Schifferstein & Zwartkruis-Pelgrim, 2008), so they experience positive emotions towards the object, or experiencing a loss if this object is lost.

Design for well-being in palliative care

In traditional medicine, the palliative care approach is primarily aimed at mitigating physical pain, and although psychological support is provided to the patient, the main efforts usually are not aimed at relieving anxiety (Saunders, 2001). However, in recent years the perspective on health services has changed, taking a holistic approach, and all the factors that produce well-being for patients have begun to be considered as more important; that is, the physical factor, the psychological and the spiritual (Meffert et al., 2016).

People who are in the conditions of a palliative patient become much more receptive to environmental stimuli, so design becomes even more relevant. However, adequately designing the environment for terminally ill patients is only possible through in-depth knowledge of the psychological processes they are experiencing, in order to recognize their needs and wants (Gola et al., 2016).

There are different examples of how design for wellbeing has been successfully applied in the lives of human beings: Ruijs et al. (2012) found a way to transform a negative emotion into a positive experience in children's hospitalization. Miller & Kälviäinen (2012) proposed ways to improve the quality of life of both staff and residents in care homes, considering both the physical design and the design of caregiver roles and responsibilities. Chapman et al. (2012) focused on the design of new services and technologies to help with the management of type 2 diabetes. Barrera et al. (2014) designed a patient-centered innovation that engages all stakeholders and empowers patients to manage chronic diseases. These studies demonstrate that it is possible to aspire to an improvement in human life through design for wellbeing, which inspired us to reflect on how architecture, interior architecture and industrial design in particular can contribute to the wellbeing of people residing in palliative care.

A palliative patient's experience from a general approach

There are currently qualitative studies that discuss the death experience in terminal patients, which explore what is a 'good death' for patients and / or caregivers, or approach the issue from the perspective of the quality of death (e.g., Yao et al., 2007; Miyashita et al., 2008; Choi et al., 2013; Darer et al., 2015). In this respect, the quality of dying has been found to be a multidimensional construct, which includes physical, psychological, social, and spiritual experiences, term of life, preparation for death and circumstances about death, as well as the characteristics of health care at the end of life.

To date, research has demonstrated that the quality of death and dying, as well as the issue of experiencing a 'good death' (according to studies carried out with caregivers, doctors and terminal patients) is composed of the following characteristics, factors and descriptions:

(i) being free of pain, not with pain or symptoms of stress (Gott et al., 2008; Zimmermann, 2012; Dans & Sheldahl, 2015; Witkamp et al., 2015; Kamal et al., 2015); (ii) being free of psychological symptoms; have a good family relationship; being able to die in a place or environment that has been favoured (Yao et al., 2007; Gott et al., 2008; Hales et al., 2014); (iii) maintaining good relationships with the medical team, being able to discuss treatment with the doctor, having a nurse with whom one feels comfortable (Miyashita et al., 2008); (iv)

not being a burden on others, not having financial worries (Dans & Sheldahl, 2015); (v) to always maintain dignity and feel that you are satisfied at the end of life (Hirai et al., 2005; Miyashita et al., 2008); (vi) maintaining a sense of control (Hirai et al., 2005; Miyashita et al., 2008); (vii) having fought against the disease to its ultimate consequences (Hirai et al., 2005; Miyashita et al., 2008); (viii) keep hope (i.e., have something to spend the last days and that is enjoyable, live positively) (Hirai et al., 2005; Miyashita et al., 2008); (ix) not prolong life (Hirai et al., 2005; Miyashita et al., 2008); (x) being able to contribute to others (i.e., maintaining a role in the family or in occupational circumstances, feeling that one's life is worthwhile) (Goldsteen et al., 2006); (xi) having planned what will happen after death (i.e., having funeral planned, the last will) (Goldsteen et al., 2006); (xii) not being aware of death (i.e., dying while sleeping, dying without being aware that one is dying) (Gott et al., 2008); (xiii) thank and acknowledge others, be grateful to people (Witkamp et al., 2015); (xiv) maintain pride and having faith (i.e., feeling that one is protected by someone with a power beyond oneself, having religious beliefs (Choi et al., 2013).

The fourteen factors mentioned above can be compressed into three: (i) Acceptance of death: accepting death and being calm, free of psychological symptoms such as stress or anxiety; (ii) Physical symptoms and being free of pain (iii) Place and environment: the power to die or spend one's last days in a favorite environment or place. It is in particular this third factor that opens opportunities to investigate the possible contribution that architecture, interior architecture and industrial design can have regarding the implementation of design for wellbeing in palliative care.

How to improve a palliative patient's experience via design

After having investigated *if* design for wellbeing can be performed in the context of palliative care, in this section, we discuss *how* design can contribute to improving people's experiences in palliative care. The three factors mentioned above are our guidelines in this respect.

(i) Acceptance of death

The fear of death in palliative patients may trigger a series of emotions that result in great anxiety, which in turn negatively impacts on their physical, psychological and social wellbeing. Anxiety is a fear that can take multiple forms. Generally, human beings face anxiety before death using the resources offered by our culture, although the reality is that most will spend much of their energies in denying the fact, in an effort to regain that control they have lost (Furer & Walker, 2008). The main problem of denial is that, no matter how much fear is attempted, anxiety will end up manifesting itself in a variety of symptoms such as worry, stress, depression and conflict (Yalom, 2008). Yet, positive oriented individuals who are motivated by their desire of having a meaningful life tend to cope better with denial of death (Wong & Tomer, 2011).

(ii) Physical symptoms and being free of pain

Pain is another key component to consider in the treatment given to patients in palliative care, since while pain is still present, it is very difficult for patients to feel comfortable. It is precisely here where design can generate support in a multidisciplinary field, since design can enable people to mitigate anxiety and pain (Jakob & Collier, 2016) which may generate the appropriate conditions for a holistic treatment (Ramadan et al., 2013), in physical,

psychological and spiritual realms. For that, design uses tools that can directly impact emotions, reducing the degree of anxiety and even mitigating pain.

In the domain of health, multiple studies have shown that exposure to a natural environment by means of biophilic design can provide relief from pain, and accelerate patient recovery. Biophilic design exploits the human need for nature and aims to provide a satisfying natural experience providing health and well-being (Kellert, 2008). In addition, it can also increase the morale of medical personnel (Kellert & Calabrese, 2015). Also, the use of windows that allow the contemplation of natural scenarios directly impacts the amount of analgesic medication needed by patients (Grinde, 2009). Such design not only impacts favorably on the health of the patient; it can also have repercussions on the relatives and medical personnel. According to studies, direct contact with plants in the workplace reduces the stress of medical personnel, while increasing their perception of satisfaction in the work environment (Ramadan & Heat, 2013). Dilani (2001) tells us that appropriate control of the environment through design generates a conducive means of directing energies towards social interactions; this helps to generate a low level of stress and strengthens the abilities of the individual to handle difficult situations.

Walch et al. (2005) conducted a study where the impact of sunlight on pain was determined in patients with spine surgery. According to the study, patients who were exposed to sunlight needed 22% less analgesic drugs, in addition to reporting a significant decrease in stress. Another finding was that patients exposed to sunlight have a shorter hospital stay. Diette et al. (2003) tested the effect of combining natural sounds and images in patients while undergoing bronchoscopy; these patients reported a significant increase in pain control. Another resource that showed its effectiveness, although difficult to use in the hospital environment, is water. It was demonstrated that using water as an element in design or even just integrating the sound of water, increased patient satisfaction levels (Grinde & Patil, 2009). Tse et al. (2002) induced pain to healthy patients who were exposed to a video of natural scenes, resulting in an increase in their tolerance to pain. These results indicate that the patients' environment can be modified to influence the perception of pain, thus reducing the use of medications and their side effects. In the same way, an 'improperly designed environment' can be a source of stress, frustration and therefore affect health (Theorell & Arnetz, 2000). It is clear however that designers operate according to an 'holistic' approach of a particular environment, while taking into account different kinds of stimuli which can impact on the eventual 'experience' of a particular place.

Golembiewski (2016) argues that aesthetic changes in the design of an environment can improve patients' health. Architecture can influence psychologically to improve or worsen their conditions, as it can have an effect on the neuroendocrine system of people. So, the use of design can have a significant impact on health care in general and palliative care in particular. In the case of palliative patients, who are exposed to very high levels of anxiety and pain, the use of biophilic design has proved to be an important adjuvant for the control of stress and pain, impacting not only on the patient, but also on their relatives and medical personnel.

(iii) Place and environment

Research shows that dying at home, where most patients want to die (Higginson & Sen-Gupta, 2000), brings higher quality of life (Wright et al., 2010). Therefore, dying in this place or a place that represents this quality within an environment may be associated with better

evaluations of the end-of-life experience than approaching one's end in a hospital.

The place where death is experienced is related to the age of the patient, the time since (s)he has been diagnosed as a palliative patient, type of illness, how well the caregiver adapts to his or her tasks as such, and the issue of not receiving or receiving little assistance in palliative care (Hales et al., 2014). Research by Yao et al. (2007) showed that patients who responded better to their disease and who were clearly conscious regarding their diagnosis were those who preferred to die at home.

Life experiences have such emotional quality that they create a league with the places where this experience occurs. Also, attachment to a place has the potential to provide predictability in a daily routine, a place to relax from the more formal roles of life and the opportunity to control various areas of life (Low and Altman, 1992). According to literature regarding place attachment, the highest quality environments are those that support a person's goals and activities (Stokols & Shumaker, 1982). Applying such considerations to palliative care, it is clear that a patient in this type of environment will feel supported by living in a place where he has had the possibility to create a bond. Taken into account these considerations, one can understand why a person in palliative care often prefers to die at home or in a home-like atmosphere. Knowing about these factors allows one to control or adapt places to enable them to become a place to which a person can attach, and where a person can feel 'at home'.

In summary, it is clear that a palliative care environment can be designed in such a way so that it allows patients to bring along objects they already know, as this can generate identity and place attachment. This enables people to experience a sense of belonging, control, self-esteem, meaning and security (Scannell & Gifford, 2016), so that the setting of the place where the palliative patient lives his last days can be composed of objects, artefacts and items, that refer to a place where they felt 'well'. In this way, making such home-like environments for people in palliative care can enable them to intensify their well-being through the emotional, social and psychological characteristics that attachment to a place triggers.

Discussion and Conclusion

Following the above, it is evident that the use of design in the field of palliative care aims to provide the patient with wellbeing which allows him to face his last days with the greatest possible serenity, generating, as far as possible, an environment that allows to spend the last moments in the 'best possible' way.

Considering the importance of palliative care in recent years, it is our belief that design for wellbeing can be an inspiring approach to work on conditions so that patients in their last moments can 'be well' and be supported by design. Working on the interior architecture of palliative facilities can also be a resource of great help, since it would provide the patient with an environment that is familiar and where he can feel safe and calm. However, understanding patients' experiences of death is difficult to achieve completely, so it is necessary to focus on gathering enough information to make the design of these environments as close as possible to what patients need and want. This is where the interest and creativity of a designer to find new ways, or adapt existing ones, is important. Finally, it should be noted that, although the concept of 'the pursuit of happiness' in terminal patients may seem rather strange or maybe even inappropriate at first sight, in the end, feeling 'well' until one's very end is what most people long for. From our perspective, it is notable that both design, architecture and interior

architecture are capable of providing wellbeing to patients in these circumstances. Beyond the medical care and physical care that these patients need, it is necessary to remember that striving for wellbeing is something that can only be reached in a multidisciplinary context, in which design has a preponderant role. Applying a holistic perspective, while considering a system as an interconnected whole that is part of something larger, is key in this respect.

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