

A CRITICAL CONSIDERATION OF THE POTENTIAL OF DESIGN AND TECHNOLOGY FOR THE CARE AND SUPPORT OFFERED TO PEOPLE WITH DEMENTIA AND DISCUSSION ON HOW THIS MIGHT IMPACT WELLNESS

“To honor life, affirm life, and transcend the suffering of life, one needs to reconnect, both intellectually and emotionally, with the sacredness of life”.

(Chaudhury, 2008, P4)

ABSTRACT

Florence Nightingale gives some of the first words of advice on design in her “Notes on Nursing” - “But the fewer passages there are in a hospital the better”, referring to the fact that hospital design can impact the need for fresh air, that in her opinion is essential to the healing process (Nightingale, F. 1860). In 1943 Maslow developed his hierarchy of needs, starting with the physical need to be safe and secure, above which is the need to be loved, connected and belong, followed by the higher needs of understanding, knowing and self-actualization. The relationship between the physical buildings/environment and the impact on quality of life of the people living with dementia is the focus of this assignment.

The World Health Organization Quality of Life Assessment Group (1998) includes the physical environment as one of the dimensions of the quality of life. The quality of life of people living with dementia has been in the spotlight over the past years, and Ready and Ott (2003) did a review of the measurement tools, pointing out the differences and complexities of trying to determine exactly what constitutes quality of life for people living with dementia. The transactional interaction between people living with dementia, their care partners (both formal and informal), the new role of technology and the design of buildings and cities are explored in terms of the role it plays in constructing a new discourse for improvements in the quality of life of people living with dementia.

INTRODUCTION

Quality of life is a complex issue. Lawton (1994) had a strong influence on the way quality of life of people with dementia is perceived, especially his view that both the subjective and objective perspectives should be taken into consideration (Ready and Ott, 2003). This is an important shift away from the purely biomedical approach where the opinions of people living with dementia were seldom considered, and takes into consideration not only wellness (or sickness), but also the more comprehensive domains of well-being (Power, 2010). Lawton (1994) argued that quality of life is made up of four domains, being psychological well-being, behavioral competence, objective environment and perceived quality of life.

Within “The Eden Alternative” philosophy, Fox et al. (2005) identified seven domains of well-being, namely identity, growth, autonomy, security, connectedness, meaning and joy. Measuring the outcomes of these domains when verbal communication is not possible, is about as complex as providing for all these domains to be actively present in everyday life in especially an institutional setting.

“Quality of life, then, is a multidimensional collection of objective and subjective areas of life, the parts of which can affect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experiences and the process of ageing”. (Bowling & Gabriel, 2004 P3) Would the same be true or relevant to people living with dementia? If we consider dementia as just another “life experience” and very much part of “the process of ageing”, quality of life would be defined in the same way for all human beings.

However, the complexity of preserving and enhancing the quality of life of people living with dementia, especially in the later stages when verbal communication might not be possible, is a major challenge, especially in the world of long-term care. Sabat and Harre (2008) show that people living with dementia, even in the last years, do not lose their sense of self. It is often as a result of the environmental factors, what Kitwood (1997) called the “malignant psychology”, that the world still entertains the perceptions that people living with dementia do not have a sense of self or experience valid emotions, and are thus not able to experience all the so-called normal domains of well-being. Kelly (2010) also points out that through honouring the sense of self of the person living with dementia, their well-being will be enhanced. This can be as a result of interactions with both people and the physical environment. Chaudhury (2008) says that “(T)he self that exists must be acknowledged, appreciated, and responded to at multiple levels” (P2).

Based on the above, one can safely assume that people living with dementia will experience all the emotions and feelings that contribute to or detract from quality of life and well-being, whether these are internal processes or triggered by external stimuli. This is underlined by Lawton (2001) in his statement: “Too often, people with dementia are viewed as being without the ability to react emotionally to the aspects of life that typically evoke feelings of pleasure, interest, sadness, anxiety and anger” (PS57).

The Eden Alternative™:

The brainchild of Dr. William Thomas, a specialist geriatrician, The Eden Alternative philosophy holds that loneliness, helplessness and boredom account for the bulk of suffering among Elders. The antidote to this lies in creating a human habitat, where life revolves around close and continuing contact with plants, animals and children (Thomas, 1999). This is often as a result of the fact that institutional settings mostly focus on the physical needs only, while the lack of true companionship, support and help with memory problems, and a lack of involving people in meaningful activities or providing

opportunities for meaningful engagement do not exist (Popham & Orrell, 2012), hence the feelings of loneliness, helplessness and boredom.

The human habitat is that place where the domains of well-being are alive, where the hierarchy of needs is fulfilled and where life experiences can flourish. The physical design, as mentioned earlier, is one of the contributing factors to quality of life.

In March 2012 I was part of a team who designed and opened a small home for 17 people living with dementia, in Paarl, South Africa. The physical layout of this home is that of a large family house, with some bedrooms being shared by two people. Not having the rigorous health and safety regulations of developed countries, this house is simply a normal living space, where residents have access to the kitchen, laundry, open gardens, communal and private spaces and options to choose to be in any part of the house in which they wished to be. Residents have the option to help with cooking, washing-up, doing laundry, ironing, setting the table for meals and/or working on the garden – as they feel fit to do. There is also a formal program of activities organized by the Occupational Therapist manager, but mostly life revolves around the activities of normal daily living.

Mr. M. was already in his 90's and living with advanced dementia for many years when his family decided that he should move to this new home. Having lived in the so-called "frail care" of a more institutional nursing home, Mr. M. stopped verbally communicating, had lost a lot of weight, and was generally living in bed, having his meals served on a tray. The first day that he moved in his lunch was served with three other (female) residents at the kitchen table with a proper table setting. Mr. M., new to the house, unfamiliar with the new people at the table, not communicating, looked at his plate of food, put out his hands to the other residents and said in a clear voice: "let us pray". He said a perfect prayer (grace) before starting his meal. From there on, Mr. M. not only improved in terms of his general health, but started communicating again and became the one telling jokes and being quite witty. The move from "hospital" to "home" changed the way in which Mr. M. not only perceived himself (becoming the head of the home again saying grace before the meal) but also in his engaging with the environment (he loved sitting out in the garden). He became far more functional and engaging as a result of being in an environment that was home. Chaudhury (2008) explains that people try to hold on to their identities that they have known of held for years. If the physical environment does not encourage this, quality of life will be compromised.

The design dilemma: designed by whom for whom:

Popham and Orrell (2012) take an important step in asking the question "What matters for people with dementia in care homes?" Davis et al (2009) made a very important transition in looking at dementia not as a condition, but as an experience. It is proposed that if person centred care is the primary focus, the design of buildings and environments cannot be based purely on health and safety checklists. It is a living space for people with dementia, and

as such should reflect their needs. This study clearly indicates that residents want to go out, go for walks, go to the shops and spend their time doing meaningful things like helping with housework, whilst staff has as their primary focus the health and safety of residents, resulting in residents sitting around being bored (Torrington 2007). Person centred care could easily be misinterpreted as seen in the diagram below (fig. 1), where all the attention is focused on providing care *for* the individual living with dementia, without finding out what it is that the person would like to do or how they would wish to be. Instead, it becomes more and more clear that relationship centred care (fig. 2) might be more conducive to well-being (Nolan et al. 2006, Torrington 2007).

There is often conflict between what authorities envisage and what people living with dementia want – the latter being relationships, privacy, autonomy, meaningful occupation, choice, control and identity (feeling known in a space where one can also be useful) (Popham and Orrell, 2012). As much as design is important, it is not necessarily where the focus lies for people living with dementia or staff. As demonstrated in fig. 2 above, meaningful, authentic relationships matter. Building design should encourage opportunities for family to visit and have spaces for children to play (Davis et al. 2009) which will enhance the creation of a human habitat and create opportunities to foster such relationships.

Chalfont (2008) puts it bluntly: “Too much house design ignores the people it is designed to house” (P9).

Home as an expression of Self:

Chaudhury (2008) says that “as we live, work, and play, we do so in places around us, and through this process we give meaning to those places” (P7). This again is an important paradigm shift, in that meaning is not given by the environment, but by the individual being able to express him/herself within that environment. In our daily living we give meaning to our physical environment as much as we can get meaning from it. He carries on quoting Jung: “the innate need of the self to express itself in the surrounding, to be part of others, and to make others part of oneself” (P23) is what really makes a place home. It is where we can give expression to who we are. In designing the physical space, the most important feature should therefore be an environment that allows and encourages individual expression and presentation of the self through living memories, meaningful engagement, authentic relationships and autonomy (Davis et al. 2009).

Power (2010) points at the biomedical dilemma where “an unfamiliar environment creates unmet needs that are a prominent factor in the genesis of behavioral expressions” (P129). So often do we see people with dementia walking (wandering) around aimlessly. Within the South African context people living with dementia are often restrained physically or chemically (or both). In a physical environment that is familiar, that represents memories and familiar icons, people will engage with their environment in a constructive manner and not wander seemingly aimlessly. Torrington (2006), as quoted in

Innes et al (2011) states that successful spaces are those that carry unambiguous meaning.

The Eden Alternative proposes that a life worth living is enhanced through loving companionship, the opportunity to give as well as receive care, and being in an environment where life is not ruled by routines and timetables, but where spontaneous interactions and happenings can occur. Davis et al (2009) point out “The physical environment can be designed or modified to encourage spontaneous personal enjoyment” (P191). This will mean different things for different people. In the home that I referred to earlier, it is interesting to see what people will do when they are free to choose from an environment that presents with a host of opportunities and very few restrictions. For some, it might mean pottering in the garden, for others it would be making their own cup of tea, and yet for others it would be sitting with their dog in the garden, looking at life happening. Davis et al (2009) also refers to ‘social death’ (P197) – in an environment where there is no room for meaningful and authentic relationships, whether with family, staff, animals, friends or the community, people living with dementia will close off and others will react to them as if they are dead. In her video recording demonstrating Validation Therapy, Naomi Feil refers to this as “people becoming living dead people”. Davis et al (2009) again emphasizes the way in which people living with dementia experience themselves and their environment as indeed becoming their experience of the dementia. An environment that enhances the domains of well-being will provide a better experience for people of their own dementia reality.

Outdoor spaces as an extension of the living space:

Outdoor spaces and gardens play an important role in enhancing quality of life and providing a sense of well-being (Duggan et al. 2008). Considering how small the worlds of institutionalized Elders can become, providing outdoor spaces will broaden the horizons and take the attention away from the immediate reality of being institutionalized. The study by Guisset-Martinez et al (2013) provides great evidence based on observations and interviews with people living with dementia and their care partners of the importance and necessity of garden spaces in improving the quality of life of people who live in institutional care settings. In this study of 21 gardens and facilities, it is shown that through proper design, gardens can be multi-faceted facilities providing a space where almost all the domains of well-being are satisfied. Again it stands out that residents were involved in the planning and maintaining of gardens with staff, management and community members. Being in the garden provides opportunities for spontaneity, creativity, engage in a pleasant and different context from the ‘medical and sickness’, enhance socialization and give access to all life forms. It creates a space for children to play, animals and birds to live and a live activity canvas for those people who are severely disabled by their dementia to simply watch the world at play. The transactional and relational opportunities of a garden are considered a benefit to staff and residents, as well as the broader community who can use the space and engage with people living with dementia in a setting that does not only highlight or focus on their deficits.

Creating age friendly (which will include dementia friendly) cities and neighborhoods will address the marginalization and stigmatization of people living with dementia, and promote the deserved citizenship (Keady et al. 2010). People living with dementia need to stay connected in order for them to live meaningful lives. By being part of a community their sense of identity will be enhanced and preserved much longer than when they are 'removed' from the community and institutionalized. In October 2007 the World Health Organization launched the "Age Friendly Cities" initiative. The last and most important aim of this effort is to create "a civic culture that respects and includes older persons" (www.who.int). In a country like South Africa where residential care only caters for about 2% of the older population (Mba 2005), the focus on design in communities - to enable people of all ages to be active citizens in these communities - should receive much more attention.

Technology:

The use of technology in care has developed from being used purely for safety, security and monitoring (Miskelly 2001, Orpwood et al 2007) to being used to improve well-being and compensate for deficits as a result of dementia (Rosenberg & Nygard 2011). In South Africa, technology in aged care is used mostly as a surveillance method. It has become the custom to install closed circuit television cameras in most homes, with almost no regard for the ethical issues around privacy. The very high crime statistics and remnants of apartheid make this a very contentious and complex issue for care providers.

In my work practice, this issue is often debated, especially around the fact that violent crimes of abuse still happen, in spite of having cameras in place. There is the argument that cameras will then help to convict the perpetrators. Nurses argue that they use the cameras as a 'training tool', in that they will look at the way that staff deal with residents on camera and show it to them afterwards as an example of good or bad practice. However, again there is no regard for privacy or even consent from the resident in whose room cameras are installed.

Hagen (2007) makes mention of the fact that thanks to the work of Prof. Mary Marshall, the use of technology for safety and monitoring purposes has changed. In spite of this change occurring in 2000 already after the ASTRID project, thirteen years later cameras are still used for that purpose only in South Africa. There is much debate at present in South Africa around importing technology to help with safety and security, i.e. fall detectors, movement monitors, electronic sensors, bed alarms etc. The lack of staff training for the care industry and the poor wage structure are not addressed on a governmental level, with the result that operators hope that this type of technology would improve levels of care.

Cellular technology in South Africa has recently produced an application to advance primary health care services, which is not readily accessible to most people living in rural and remote areas. "Vodacom mHealth Solutions aim to lower the cost of delivering health care services, while increasing service

efficiency and accessibility. They empower patients and health care providers, reduce market fragmentation and remove complexity” (Vodacom website 2013). This could possibly help care givers of people living with dementia in the community in future.

The “Technology, Ethics and Dementia” guidebook (1999) created a different discourse around the use of technology and the possibilities of what technology can offer. Instead of using technology ‘on’ people with dementia, a new focus was created where people with dementia were given the opportunity to engage ‘with’ technology not only for reminiscence and pleasure, but also to help with remembering, socializing and engaging (Hagen 2007). The well-being of the person with dementia is now at the center of the discussion, and the development of technology based on their views and needs.

“It’s never too late” is one of the many computer-based programs using the latest touch-screen technology to create life story profiles, provide entertainment based on the individual’s preferences, cognitive stimulation, spiritual engagement and opportunities to engage in physical activities through simulation programs. Sugihara et al (2013) confirm that technology can enhance relationships between individuals with dementia and their care partners, bringing about stronger feelings of being part of and interacting with society.

Facebook experiment:

In an experiment in the house in Paarl referred to earlier, Facebook was introduced to the residents in order to connect them through photographs and stories with family and friends. The Cornell Depression Scale was used before and after sessions on Facebook to determine if the interactions would have an impact on levels of depression. There was no significant change in levels of depression. However, the enthusiasm with which families started to engage with residents brought about a much stronger connection between them. Families could now see on a daily basis how engaged and involved the residents were, and it gave a new insight into the care relationships between staff and residents. The Facebook page is now very active, with very positive feedback from relatives to staff on their care efforts.

Transactions between people and places:

Rosenberg and Nygard (2012, 2013) refer to ‘transaction’, based on the work of John Dewey. When taking into consideration the impact of the environment as discussed, the reality that the experience of each individual living with dementia is unique and the role that technology can play in compensating for resultant deficits as well as enhancing positive well-being experiences, it would seem that the transactional nature of the care relationship deserves more attention. Our environment, consisting of the physical building/room/garden/living space can help us or detract us from creating and recreating our identity. In order for our identity and sense of self to stay dynamic, our physical environment with all and everyone in it should

constantly be engaging people living with dementia as the experts in their own lives, and not perpetuate the institutional stripping away of meaning (Peace et al. 2006).

The important role that staff plays in the creation of authentic relationships in care environments does not seem to get the priority that it deserves. On a recent visit to a top care facility in Switzerland with the latest technology, best design features and state of the art equipment, it was striking that residents were sitting in their rooms looking very lonely and bored. In South Africa, there are a number of homes where The Eden Alternative principles have been embedded through staff engagement and training. Some of these buildings are old and falling apart, do not have even the basic equipment nor any technology (some do not even have email facilities) and yet residents living with dementia are living meaningful lives, integrated socially, have a strong sense of their cultural identity and are valued for the role that they play as Elders who can participate in and contribute to everyday life in their community.

CONCLUSION:

Being in a space that comforts and nurtures through the memories associated with familiar objects, feeling safe and secure in navigating the physical space, being meaningfully occupied and participating in normal daily activities and having access to technology to compensate for deficits as well as enhance social interactions, will go a long way towards improving the well-being and quality of life of people living with dementia. The philosophy of person centred care should be reconsidered to encapsulate the relational and transactional dynamic of the human living experience, engaging people living with dementia as social beings who can determine and express their own needs if living in an environment that is ultimately a human habitat. Even the most sophisticated design will however never replace the need for authentic human relationships.

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