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Résumé de l'article

Caring for persons living with dementia (PLWD) is challenging. Some of the most challenging aspects include managing behavioral and psychologic symptoms of dementia (BPSD). Many patients and families will consider dementia care facilities to better manage BPSD, which can contain design elements that use the physical environment to decrease BPSD by deceiving residents and controlling their behavior—all for their own benefit and safety. This immersive approach to behavior management represents a more holistic way to manage BPSD. Considering the especially vulnerable status of PLWD, these design elements should be thoughtfully implemented, researched post-implementation, and discussed with patients and their loved ones. The design-based approach to managing BPSD demonstrates the obligation healthcare providers and facility designers have to be more holistic in designing care environments for PLWD, especially for those living in dementia care facilities.

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WHEN DECEPTION PROMOTES DIGNITY: THE ETHICS OF USING ILLUSION TO CREATE SAFE SPACES FOR PERSONS LIVING WITH DEMENTIA

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ABSTRACT

Caring for persons living with dementia (PLWD) is challenging. Some of the most challenging aspects include managing behavioural and psychologic symptoms of dementia (BPSD). Many patients and families will consider dementia care facilities to better manage BPSD, which can contain design elements that use the physical environment to decrease BPSD by deceiving residents and controlling their behaviour—all for their own benefit and safety. This immersive approach to behaviour management represents a more holistic *way to manage BPSD. Considering the especially vulnerable status of PLWD, these design elements should be thoughtfully implemented, researched post-implementation, and discussed with patients and their loved ones. The design-based approach to managing BPSD demonstrates the obligation healthcare providers and facility designers have to be more holistic in designing care environments for PLWD, especially for those living in dementia care facilities.*

INTRODUCTION

At some point in life, most people will consider moving themselves or a loved one into an institutional care environment. For many, the reason will include a diagnosis of dementia, a progressive condition that increases in likelihood with age and impacts both cognitive function and essential activities of daily living (e.g.: bathing, toileting, eating, etc.). In addition, behavioural and psychological symptoms of dementia (BPSD) often cannot be readily managed at home (e.g.: agitation, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes, etc.).[1] Even in the institutional setting, managing these behaviours is both difficult and, some would say, undignified. To decrease agitation and minimize the subsequent use of restraints and/or psychotropic medications, memory care facilities over the past twenty to thirty years have turned to innovative behaviour management strategies, including strategies to control behaviour through the design of the physical environment. However, the concerns about dignity have not been solved, and these management strategies raise important ethical questions about deception, consent, and autonomy. The presence of dementia in this population further complicates the assessment of how best to resolve these questions.

BACKGROUND

Caring for persons living with dementia (PLWD) is challenging; some contend that those challenges may be managed more safely, and perhaps with more dignity, by using illusion and deception to control behavior than through traditional means of behavior management (i.e.: chemical and/or physical restraint). As a result, those considering institutional care environments for themselves or a family member with dementia are increasingly faced with novel choices about their living environment. Advances in medicine, architecture, and neuroscience have enabled the creation of physical environments intentionally designed to decrease BPSD by deceiving residents and controlling their behavior—all for their own benefit and safety.

The kind of immersive design techniques used to control behavior through environmental design matter. For example, a mural may be used to conceal a door to a medicine room thereby rendering it invisible to residents but not to the staff.[2] Concealment is not new: there can be good reasons to hide something that is unsafe and will invite conflict, particularly when one is responsible for the safety of others who cannot always make safe decisions for themselves. Another design-based intervention involves placing horizontal stripes on a floor before an exit doorway, which due to neurological changes and visual processing system changes seen with some types of dementia, can lead to the striped pattern being perceived as a barrier, perhaps as three-dimensional stairs, thus impeding the desire to exit a space.[3] Anecdotally, a black square in front of a door or an elevator can dissuade a person from approaching it, as the black square may be perceived as a hole in the floor.[4] These and other techniques are used to ‘steer’ PLWD away from areas that they perceive as unsafe or to promote safe wandering practices.

Some facilities utilize deeper and more immersive levels of illusion. Often PLWD will seek to ‘go home’ and become agitated if they are not allowed to leave or wander.[5] Some facilities utilize non-functional bus stops, where a resident can be taken to wait for a bus that never comes.[6] Due to short-term memory impairments, the resident eventually forgets what they were doing and can then be guided back to their room without feeling powerless or angry. Other facilities have shops with fake money that residents can use to buy real food.[7] Paths and walkways through the facility allow for “permissive wandering,” but there is no way out; residents are ultimately locked in.

DISCUSSION

The ability to avoid sedation and restraints to manage BPSD in PLWD has been a long-sought goal. However, how a laudable goal is achieved is important. While the precise mechanism by which these interventions function is not fully understood, and varying levels of evidence exist to support their use, there is a difference between concealing a door, so a resident overlooks it and inducing a fear response when the resident approaches something they perceive as unsafe.[8] A useful concept here is proportionality, which refers to the idea that avoiding one’s harm is not justified if doing so causes equal or greater harm, and by extension, an obligation to seek the least harmful means to achieve a goal. Just as with medical treatment, we should employ the least invasive or harmful means to achieve a given end.

This is not to say that design-based interventions are not appropriate. While it is deceptive to build an illusory environment that creates a false sense of freedom and autonomy, the alternative may be equally or more concerning. While dementia facilities have made great strides to move away from using medications and restraints to manage unsafe behavior, there are often few remaining options to de-escalate resident behaviors when non-pharmacologic interventions fail.[9]

The use of deception in medicine is subject to strict controls, both ethical and legal.[10] This oversight ensures patient's rights are observed, which generally means their autonomy and dignity are respected. Typical examples of nudging in medicine, for example, involve minor effects on a choice architecture that remains within the patient's control.[11] Placing a person in an immersive environment with broad and persisting deceptions from which they cannot exit presents a new dilemma in bioethics and for society at large. This is particularly concerning when we consider that most PLWD do not want to go to a long-term care facility to begin with, and once there, they frequently express their desire to go home.[12]

The goal of whole-person care promotes not just physical health, but emotional, social, and spiritual health. The choice of which to prioritize when not all can be achieved is a deeply personal one. The bioethical principle of Respect for Persons captures the idea that each person is an autonomous, unique, and free individual who has the right to make their own choices.[13] Some residents may prefer to bang on a locked door, knowing that it is locked, and remain aware that they are not being allowed to do what they seek to do. Others may prefer to be deceived if their anxiety and comfort are better maintained by doing so.

The implications of this in the care of PLWD are complicated by the lack of, or limited, medical decision-making capacity. To be legally respected, such decisions would have to be made before the onset of moderate or advanced dementia, which is not always possible because loss of capacity often occurs before functional impairments that necessitate assisted living. Thus, by the time a change in one's living situation is forced, the patient has often long since lost the level of capacity needed to evaluate the options and provide informed consent. Obtaining assent is one potential solution to this issue, but many PLWD express changing preferences. Assent at one point may not limit disruptive behaviors from emerging later based on the desire to go home but does little to relieve situations in which a patient insists on going home but cannot be managed there. There are few broad and straightforward approaches to determining how best to respect PLWD's expressed preferences, even when considering dementia-specific advance directives.[14]

In situations where a person cannot decide for themselves, there are two decision-making frameworks their surrogates may use: the Best Interests Standard and the Substituted Judgment Standard. The goal of the Best Interests Standard is to determine, as best as possible, what choice objectively maximizes the patient's interests, such as health, safety, comfort, and so on. The Substituted Judgment Standard is preferred because it asks what the person themselves—from their own subjective standpoint—would choose, were they able to do so.[15] However, the Substituted Judgment Standard is complicated even if the person's prior wishes are clear to their surrogates. In dementia care, Substituted Judgment has been framed as the "prior competent choice," but what someone thinks they want in the future may vary greatly from what they want when the future becomes their present.

Even if persons lack medical decision-making capacity, their ability to express a genuine, rational preference based on the impact of that living environment on their quality of life may remain intact. A person may consistently express a desire to go home, for example. While PLWD may lack a significant degree of autonomy, they often possess enough capacity to make at least some decisions for themselves at times. Utilizing or avoiding deceptive or illusory measures in this context can therefore be seen as a form of respect for these persons' preferences to live in a different environment.

While design-based interventions may offer a more ethically satisfying way of managing BPSD in PLWD, the current state of their implementation and effectiveness is largely unknown, calling into question any conclusions about their appropriateness. Many of these design techniques are currently implemented and utilized with insufficient or no research on efficacy or risks. By comparison, when medications, medical devices, or medical treatments demonstrate a similar ability to impact medical outcomes and behaviors, oversight is required. However, adequate oversight does not exist for built interventions to control the behavior of PLWD.[8] In a striking example, a recent proposal for a dementia care facility known to one of the authors, involved making every mirror in a facility digitally 'de-age' residents so they only saw a younger version of themselves, similar to the photographs in the award-winning photo series "Reflections of the Past" by photographer Thomas Hussey.[16] While this idea is based on a mirror's potential as a design-based intervention to make living spaces of PLWD more pleasant[17], it is an example of the new Wild West in long-term care: interventions are implemented without the consent of those most affected, without oversight into the decision-making process involved, and without research or follow-up to assess efficacy, risks, and benefits.

A whole-person care approach to managing BPSD in PLWD through facility design aims to enhance the physical, emotional, mental, and spiritual well-being and wholeness of each resident with dementia. While the physical expression of these values will differ with each implementation, we see three common aspects of including beneficence in facility design:

1. Design elements must enhance residents' quality of life. For example, designs that improve social connection and reduce isolation have the potential to decrease residents' morbidity and mortality.[18] PLWD, although often lacking in capacity, can still often express true and valid preferences about their quality of life worthy of respect.
2. Design elements must not influence behavior by generating a fear-based response or inducing other traumatic triggers. This would likely differ from patient to patient and could be confounded by the disease process of dementia itself but would entail eliminating design elements that appear to cause PLWD fear, distress, or agitation.

3. Design elements should aim to preserve functionally appropriate autonomy and control. Where physical harm would result, the principle of proportionality applies: the anticipated physical harm should outweigh the dignitary harm of taking the choice from the person. This reflects the principle of obtaining assent from residents unable to consent. It is respectful of one's human dignity to engage them in a discussion of any given treatment to convince them of the merits of the treatment path and gain their agreement, even if they are technically unable to legally consent. Even if one lacks ultimate control over their legal and practical affairs, this does not mean that they should be disbarred from the decision-making process.

CONCLUSION

Immersive design techniques that influence behavior to manage BPSD in PLWD have the potential to drastically improve on current management of BPSD. Utilizing the evidence above, immersive design techniques can offer a more dignified, less harmful way of managing the BPSD of PLWD, particularly for individuals who seek to practice a holistic approach to patient care. But to support their use and continued development, these design interventions must be thoughtfully implemented, researched post-implementation, and discussed with patients and their loved ones. A great deal of work remains to establish protections for these vulnerable members of our society. The obligation to be more intentional about our care for PLWD is an acute matter, especially for those living in institutional care environments.■

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Biographical note

Stowe Locke Teti, MA, HEC-C is a clinical ethicist, researcher, and author known for his work integrating empirical methods in bioethics. He has a current clinical appointment at Inova Health System where he oversees the Clinical Ethics Consult Service for the western region working with physicians, medical teams, patients, and families to resolve ethical issues in medical care and treatment decision-making. He teaches bioethics to medical students at the University of Virginia and Georgetown University medical students and is editor-in-chief of the pediatric bioethics journal *Pediatric Ethicscope*. He previously held an appointment at Harvard Medical School’s Center for Bioethics, where he was a member of the core teaching faculty, a lecturer in the Department of Global Health and Social Medicine, director of the writing support program, and executive editor of the *Harvard Bioethics Journal*. His research and writing have appeared in *The American Journal of Bioethics*, *The Journal of Clinical Ethics*, *Narrative Inquiry in Bioethics*, *The Hastings Center Report*, and the *Cambridge Quarterly of Healthcare Ethics*.

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Diana C. Anderson, MD, MArch, FACHA, OAQ is a board-certified healthcare architect, internist, and geriatrician. As a "dochitect," Diana combines educational and professional experience in both medicine and architecture. She has worked on hospital design projects globally and is widely published in both architectural and medical journals, books, and the popular press. She is a frequent speaker about the impacts of healthcare design on patient outcomes and care delivery. She is a past Fellow of the Harvard Medical School Center for Bioethics, an Assistant Professor of Neurology at Boston University, and a recipient of an Alzheimer's Association Clinical Scientist Fellowship award. As a Principal at Jacobs, Diana provides thought leadership at the intersection of design and health. Diana was recently elevated to Fellow of the American College of Healthcare Architects, one of less than 50 fellows globally, for her contributions to the profession.