The Alzheimer's patients' experience of the built environment: A Phenomenological approach

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ABSTRACT: Healthcare regularly uses phenomenology as a research perspective to improve medical care. This paper explores the opportunities for applying phenomenology to better understand how the built environment might impact the behavioral symptoms of patients with Alzheimer's disease. Alzheimer's disease is expected to be a major public health problem in the U.S. for the aging population. It is projected that by 2050, the number of patients diagnosed with Alzheimer's will triple. This projection raises the question of how we are prepared to provide care for this growing population who, in some stages of the disease, are no longer able to meaningfully communicate. This paper outlines a review of phenomenology as a tool for that planning. From its inception to modern applications, possibilities for applying phenomenology to the intersection of the built environment and Alzheimer's are reviewed. The ontology of phenomenology, including Husserl and others, is assessed, and standard methodologies are discussed. With this foundation, possibilities for the application of a phenomenological approach to better understand the built environment's role in the of the lived experience of Alzheimer's disease are explored, including discussions of quality standards. Rooted in interpretivism and seeking an in-depth understanding of contexts and personal interpretations, phenomenological studies typically gather data through surveys, interviews and observations, which may cause problems with patients that often have issue retaining their memories. As such, this paper walks through the development of phenomenology with an eye to its potential application to Alzheimer's. This is followed by suggestions for applying the phenomenological research paradigm towards the support - and potentially future cure process of Alzheimer's with a focus on the built environment.

KEYWORDS: phenomenology; Alzheimer's disease; aging; health; built environment

INTRODUCTION

Alzheimer's disease (AD) is expected to become a major public health problem in the U.S. for the aging population. It is projected that by 2050, about 65% of the aging population will die of Alzheimer's (Hebert et al. 2013). To put it differently, in about twenty-five years, the number of people diagnosed with AD in the United States will be three times larger than the current number of 5 million. This projection represents the fastest growing health risk for the elderly population. Since the definite cause of AD is not yet fully identified, medical researchers work toward solutions based only upon the hypotheses that speculate about causes. Because there is no identified cause, or cure, most current healthcare efforts to provide hope and support for this disease are directed at providing care solutions that alleviate the symptoms for patients.

The medical costs for supporting Alzheimer's patients is the largest segment of healthcare cost in the U.S., higher than heart diseases and cancers (Medicaid 2018). This suggests that there will be an associated increase in cost to provide care for the growing number of AD patients, many of whom will not be able to live alone or care for themselves. These projections raise the question of if - and how - we can establish an infrastructure to provide care for this growing population with such specific needs. Alzheimer's patients specific condition requires particular support in different stages of the disease progress. This condition is different in different person with different health background, age of involvement, and diagnosis, and therefore requires addressing a range of environmental design issues including, but not limited to, safety and security, special lighting design and exposure, night time care and supervision. The patients

would also need to be reminded and taught their daily routines and other specific tasks. With the ability to influence how patients are able to maneuver through their daily lives, and provide support for daily functioning, the built environment can play a crucial role in promoting both the care, and potentially the cure process, for the disease.

Given the projected increase in AD patients over the next decades, it follows that there will also be a high demand for patient care environments ranging in scale from individual units, family homes, and both public and private care facilities. This impending demand underscores the need for research to inform designers and policy makers about the built environment needs of AD patients in “care-oriented” settings. Research in this domain must develop a new understanding of how the built environment can - and must - better address and accommodate the needs of the patients in this growing population beyond doing no harm. Supporting AD patients through the built environment is particularly important because patients living with AD, as well as others showing signs of Mild Cognitive Impairment (MCI - a precursor to AD) spend most of their time in care facilities and homes (Constantine G. Lyketsos* 1999). Therefore, the built environment can be seen as both a factor to impact their symptoms and quality of care, but also as a potential support for future inventions in the cure process of AD.

Alzheimer’s is a cognitive functioning disorder that may impact the attention, concentration, language skills, memory, visual perception, perceptual ability, idea management, reasoning and intelligence of afflicted individuals (Boland 2015). Alzheimer’s disease symptoms are categorized in four different types: cognitive, behavioral, mood, and psychological (Boland 2015). Each type has its own subcategories of symptoms. For example, cognitive symptoms may consist of confusion in the evening hours, delusion, and disorientation. Behavioral symptoms might include aggression, agitation, difficulty with selfcare, and sleeping disturbances. Mood symptoms may appear as loneliness and mood swings. Psychological symptoms could be seen as depression, hallucinations, or paranoia. These complex symptoms become more complicated when overlaid with the variability of environmental factors in care facilities. As such, one important question becomes: how can researchers effectively design rigorous inquiries about environmental design considerations for AD patients? While the medical field is monitoring more in-depth physiological changes of AD patients and pathological signs of the disease, other disciplines such as design research should be rigorously investigating symptoms to suggest built environment scenarios not only for AD care, but also as a potential supplier of cure stimulus environments. The common point of these two disparate disciplines is that they both consider the experiences, even though they seem to have different agendas. Because of its emphasis on understanding the essence of the lived experience (Vagle 2014), the authors pose phenomenology as both a theoretical perspective and methodological approach that can provide valuable insight to inform design researchers about the experience of AD patients in care facilities. While a few studies have been done on phenomenology and symptoms of AD, such as depression (S.E. Starkstein 2008, Starkstein 2015), there is still much work that can be done in this arena. These types of studies would be helpful in informing researchers on medical care processes, continuing care providers, and design strategy selection and implementation.

1.0. BASICS OF PHENOMENOLOGY

Phenomenology is difficult to define since it can be viewed as both a theoretical perspective and a methodology (Creswell 2007); like similar general terms, phenomenology is routinely understood from widely different perspectives. Yet all observers agree that phenomenology concerns phenomena (Martyn Hammersley 2007).

The term “Phenomenology” was used in scientific context by Newton. In General Scholium, an essay added to his book of Philosophic Naturalis Principia Mathematica, Newton clearly claims that his understanding of his experimental philosophy in exploiting the laws of nature comes directly from the experience of the phenomena itself (T. Rockmore 2011). Here, Newton helps to define the role of phenomenology by testing experimental reasoning through the individual experience of the phenomena. This is very important that he defines phenomenology as trying

to know an experimental reasoning (theory) by exploring the experience of individuals on that theory.

Philosophers Kant and Hegel began using the term in the early 19th century, allowing it to gain popularity. Both were constructivists who desired to explain what it means to “construct” the “cognitive object” (Rockmore 2016). The strength of Hegel’s position on phenomenology lies in his ability to provide a logical explanation of what it means to “construct what one knows,” which leads to the construction and understanding of the phenomena. Hegel’s point of view, which describes phenomenology as constructing knowledge on what one knows about a phenomenon, presents a population who are involved in the phenomenon and/or have experienced it and can talk to a researcher about their experience. (Given 2008). Hegel differentiates between *what is* and what we *experience* in defining a pathway, addressing how we can reliably claim to know what is gained through experience (Redding 2017). His phenomenological approach bounds cognitive claims within the contents of awareness understood as phenomena, which do not refer beyond themselves either to noumena (the properties of perception), to the thing (by itself or things by themselves), or to the external world independent from mind. Kant, following Hegel, evaluates the preconditions of consciousness. Kant makes no claim to know what is outlined beyond the plane of consciousness (Redding 2017). This emphasis on the experience of the conscious condition shows how the Kantian phenomenology acquires information out of experience of people in a conscious condition; this does not necessarily happen in medical cases applying phenomenology. Particularly, because Alzheimer’s patients often have issues with clarity of thought, this approach could be a limitation towards applying phenomenology in the AD population.

2.0. HUSSERL’S PHENOMENOLOGY

Husserl became the father of the school of Phenomenology around the turn of the 20th century with the publication of his work *Logical Investigations*;(Given 2008). His books are the major references in most phenomenological studies. Husserl claims that “a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (Creswell 2007). Phenomenologists focus on describing what all participants have “in common” as they experience a certain phenomenon. For instance, we can look at grief as a phenomenon. Grief is experienced universally. The same could be said for pregnancy, and - it is likely - for Alzheimer’s disease. The main objective in phenomenology is to scale down individual experiences with a phenomenon to a more universal definition. The researcher then collects data from individuals who have experienced the phenomenon and outlines a composite description of the character of the experience for all of the persons. This description consists of "what" they experienced and "how" they experienced it (Creswell 2007). A deeper understanding of this type for those functioning daily with Alzheimer’s would be extremely helpful in designing built environments for their care.

2.1 Knowing

For analytical purposes, Husserl separated phenomena into two parts: the *noesis* and the *noema*. The *noesis* consists of the acts of consciousness, the *noema* is the properties of the perception. If there is, for instance, a bird in the garden, then it can be observed and be seen clearly. But if it is glimpsed, the perception of the bird remains vague and blurred. Different levels of attention constitute a different phenomenon every time the bird is seen – always a bird, but once with clarity and once with only vague contours. The *noema* in this case consists in the properties of the perceived. The bird is not a giraffe, and if it has an orange belly it does not have a blue belly, and if it is an old bird it is not a young bird. Whether any of these noematic characteristics are noticed depends on noetic attention. Therefore, both aspects, the noesis and the noema, creates the phenomenon. A phenomenon is always a noetic-noematic unity and includes “acts of consciousness as well as properties of their object” (J.Creswell 2018). We propose that with this noetic-noematic unity, different characteristics of disorders with similar symptoms can be distinguished and assessed. This type of approach could be helpful

in working toward a thorough understanding of the individual experience of an Alzheimer's patient by breaking down the conscious experiences and the perceived experiences.

3.0. THE OBJECT OF HUMAN EXPERIENCE

Phenomenological researchers identify a phenomenon as an "object" of human experience (Linda Groat 2013). Van Mannen defines phenomenology as "a grasp of the very nature of the thing" and phenomena as: an "object of human Experience" (J.Creswell 2018). Human experiences may be phenomena such as insomnia, blindness, being left out, anger, grief, pregnancy, or undergoing coronary artery bypass surgery. As noted, it is very possible that an experience as "object" could also be a diagnosis of Alzheimer's or being a caregiver for a loved one with Alzheimer's. Because Husserl had studied in fields such as philosophy, mathematics, physics and astronomy, his long experience working quantitatively with definitions and logic allowed him to outline the idea that philosophical analysis should change to "the things themselves". This was the birth of phenomenology, the 'science' of understanding phenomena. In this context, the question becomes: What are 'the things themselves' as it relates to the experience of Alzheimer's? How do humans perceive and conceive of this identified phenomenon?

Given this scientific shift in the field, what are "human experiences"? In this perspective, Descartes had seen the human's mind as a "subjective consciousness" that creates ideas corresponding to what was in the real world (Johnson 2016). As a general definition, phenomenology can be described as a theory perspective that focuses majorly on phenomena (defined as what we perceive) more than on the reality of things, such as what is directly observable. The approach and concentration of phenomenology is on the experiences of thinking and knowing: how phenomena was presented and occurred to consciousness (Havi 2011).

4.0. APPLYING PHENOMENOLOGY TO ALZHEIMER'S DISEASE

Alzheimer's disease is arguably one of the most serious challenges today, impacting millions of people around the world. Despite this, there is little research investigating what it is truly like to live with Alzheimer's from the patients' own perspectives; the essence of this experience is elusive. This gap in research may be somehow due to the shared idea, that people with dementia do not have clear understanding about their disease condition and are not able to describe their experiences precisely. Johnson, in her paper about exploring the lived experiences of AD patients, articulates that such beliefs are inaccurate and invalid in most cases, and shows a great opportunity in investigating AD patient's experiences in order to have better understanding of their particular situation (Johnson 2016).

No cure is found for Alzheimer's disease to this date. Also, the common treatment also is not noticeably impacting the disease progression (Johnson 2016). For treatment, the medical field is largely prescribing anti-psychotic drugs in an attempt to control symptoms (Johnson 2016, Eduardo Marques da Silva 2011); medical research has been very slow in finding any contributions to a cure for Alzheimer's disease. Specifically, some symptoms of the disease such as depression, anxiety and even simply sleeping disturbances are independently known and, in some cases, treatable. However, the holistic complexity of Alzheimer's is difficult to pin down. According to Brentano (as cited in Varela, E, and Rosch 1993), all states of mind (perception, memory, etc.) are *of* or *about* something; in his concept, mental states necessarily have "reference to a content" or "direction toward an object", which is not necessarily a thing in the real world. The clear use of the lived experiences or how Brentano named it intentionality, is the defining characteristic of the mind.

4.1. Addressing symptoms

One possibility is that major symptoms of AD, including depression, anxiety or sleeping disturbances and agitation, could be the result of external factors - including the built environment (Steenwinkel, Audenhove, and Heylighen 2017). Alzheimer's patients are left alone more frequently due to the significant difficulty communicating with others. Depressed

patients, on the other hand, who are not diagnosed with Alzheimer's are able to communicate more, which decreases loneliness, which can help the depression to be more treatable (Thorpe 2009).
There is little evidence to inform researchers and caregivers about the true experience. The above statements about Alzheimer's and its symptoms are from the generally accepted perspectives about patients living with Alzheimer's, which often results in increased alone time, impacting levels of loneliness. But is this situation truly the reality of their experience, or a perspective constructed by outsiders? One of the ways to illuminate understanding can be through the use of phenomenology in the field of Alzheimer's.

Medical diagnosis investigations cannot make us understand what the priority of the issues to Alzheimer's patients are and what are the constant challenges they are encountering in their daily routine. Understanding these factors which requires the researcher to seek an understanding of the experience of Alzheimer's patients of their everyday life difficulties, will enable her/him to enhance the AD patients living experiences. Therefore, Phenomenological approach in studying AD patients, brings valuable direction to the research and researchers and reduces inaccuracy (Johnson 2016).

4.2. Healthcare precedents

Phenomenology is a helpful and common methodology for investigating and expressing experiences. When phenomenology is applied in healthcare research, it seeks information about the experience of the disease, from the patient diagnosed with the disease to have a clearer understanding of the targeted experience. However, currently in medical research and practice the phenomenological approach is applied based on a predefined set of variables. Then, the experience of patients on these variables is investigated (Havi 2011).

In applied phenomenology, in an experiment conducted on patients who suffer from a disease, healthcare researchers try to carefully regenerate the process of how the patients experience the disease (Boland 2015). For example, in a cerebral hemorrhage case, researchers acquire precise explanations of each step of the trauma, beginning from the specific incident to the regained "sense-connections" after awakening from an artificial coma lasted 2–3 weeks (Flick 2014). Through this phenomenological approach, the lived-experience of patients was gathered through interviews, recorded and analyzed in order to reach an insight and understanding of the disease as the phenomenon of interest. In the cerebral hemorrhage case, the recovered patients could recall their experience and were able to share it with the phenomenological investigator. However, in Alzheimer's disease, particularly in progressed stages, patients have almost no mental or emotional connection to the surrounding environment and people. In this case, other individuals who share part of the phenomena's experience, such as caregivers or family, are asked for participation to express their experience of closely supporting people living with Alzheimer's disease.

Most research projects in the field of medicine are evidence-based. This approach focuses on the outcome which is carried out of the patients' experience of the health system including treatment approaches and the influences of them on the disease. Evidence-based approach is been applied in similar fields related to humans such as environmental design. Evidence-based design is an approach, design decisions are made based on the most reliable research evidence aiming for success in improving human's health condition and quality of living and monitoring the proceeding pathway of design outcomes (Malkin 2008).

4.3. Understanding alzheimer's

While phenomenology considers the distilled experiences of individuals and populations with the same experiences, it might be difficult with this depth of insight in mind to engage people who are not able to express themselves and their experiences in detail, such as Alzheimer's patients. However, Alzheimer's disease is a disease for a family, not just the individuals. This is because of the very unknown condition that involves the patient that needs special care and support as well as huge emotional load of these alterations due to the disease such as difficulty

in communication, speaking and hearing, fast pace progress of memory loss and orientation problem (Bergman et al. 2016). While this may be the case for the affected, the close family, friends, and caregivers would be able to share both their experiences as well as the experiences as communicated by the patient. For Alzheimer's and dementia, many different organizations are involved in trying to discover the causal factors to lead toward a cure. In a shift from this historical experimental approach, applying phenomenology as a research perspective focused on the lived experiences of AD patients would allow the focus to be on the patients' daily functioning in light of the disease. The resulting in-depth understanding might make a phenomenological approach one of the more useful frameworks implemented in medical research, working more toward patient-centered care than strictly the alleviation of symptoms without understanding experiences (R.M.Epstein and L.Street 2011).

The key element here is the patient's experience with the disease and their personal interpretations of these experiences, which would be recorded, interpreted and distilled by the researcher. For those living in progressive stages of Alzheimer's, the patient's experiences during the disease progress may seem unknowable yet may be the most important. When the subject has difficulty in describing his/her experiences, the researcher's interpretation of their journey may diminish the credibility of the phenomenological exploration of this disorder.

A study done by Rosenberg and Nygård (2016) explored the process of learning new technology as experienced by AD patients. The phenomenological approach investigated the way a new technology such as smart mobile phone or computer is learned by Alzheimer's patients in a daily routine, based on their individual experiences during the day and night. Few AD patients which were diagnosed of Alzheimer's were interviewed. The value in this type of information seeking is trying to understand such experiences not only to shed light on medical research but also to illuminate the way built environment designers research on designing supportive environment and product for this population.

5.0. CONNECTION TO THE BUILT ENVIRONMENT

The phenomenon of living with Alzheimer's disease can be broken down into micro phenomena that may be directly connected with design factors in the built environment. Medical teams still do not have a clear understanding of Alzheimer's patient experiences with their disease, daily living difficulties, and communication issues; it may be even more difficult for built environment teams to have a clear understanding of this population's needs to design meaningfully responsive environments. However, by taking a phenomenological approach to understanding the disease, some known symptoms are more likely to be treatable including, sleeping disturbances, agitation, depression and daily alertness. These may be addressed through design factors in the built environment (Aarts 2016).

While these symptoms are known as medical symptoms, they have connections to build environment factors. Research shows that some built environment factors, such as lighting design, can directly impact Alzheimer's neuro-biological and neuro-psychological symptoms (J. van Hoof 2009, konis 2018, White, Ancoli-Israel, and Wilson 2013). Van hoof research indicates that exposure to lighting with specific characteristics including intensity, wavelength, color temperature and exposure in a particular time of the day has shown significant impact on alleviating the symptoms of AD patients such as agitation, sleeping disturbances, and lack of alertness. These symptoms, and by association the lighting characteristics, have a direct impact on an AD patient's daily activity, and their family and caregivers as well.

Some research has focused on alleviating the symptoms of Alzheimer's disease. In the instance of lighting, the experienced phenomena of sleeping disturbances, daily naps and night-time agitation and hallucination for AD patients could easily be related to the lighting exposure, a direct impact of the design of the built environment. The lighting experiments conducted on the effect of light-therapy and bright light exposure on AD patients, although are yet to be investigated, show enhancement in resetting circadian rhythm and sleeping disturbances which can be applied as design retrofit plan for housing of seniors with memory disorders. Similarly, social engagement is linked to the design of social spaces in the physical

environment (Campbell 2014, Passini et al. 1998). Other literature indicates that certain wayfinding strategies may be able to work against memory and cognitive deficiencies in Alzheimer's disease patients (Passini et al. 1998), while design guidelines can address this issue to support wayfinding in memory care facilities (Passini et al. 2000).In addition to the aspects of Alzheimer's disease patients that is impacted by the design of the built environment, aesthetics and view is important as a factor of healing environment. In severe cases of AD patients who are not able to move easily during the day, the surrounding environment could change their experience in terms of light, color, pattern and view. According to the list of the symptoms of Alzheimer's disease, safety has higher value and priority. Many other factors can impact safety for Alzheimer's patients including their entrance and exit from the building. This opens up a vast chapter of AD patients' routine issues starting from wayfinding and orientation problem leading to the night wandering and agitation which is a serious threat for patients (McQuilkin 2016).

Sleeping disturbances and agitation have shown a connection to the light exposure by research. Phenomenology enables design researcher to investigate the different experiences of Alzheimer's patients in care facilities with various lighting design to reach a better understanding of this phenomena (Seamon 2000). Different care facility designs with admitted patients of different age and stage of the disease shape numerous scenarios with different lighting experiences to be studied. Similar approach applies on the differences we as designers need to consider in designing a care facility for patients with depression and Alzheimer's patients who have depression as a part of their disease symptoms. The way these two different groups experience daily living and function should be studied from a phenomenological perspective.

While evidence-based design is commenced as a medical research approach in the built environment design research in order to rely design decisions on humans' living experience in terms of different aspects of quality of life, it is still not covering the entire issue of humans' experience during life-time. Alzheimer's disease as discussed above, is one them which is increasing rapidly in number of people involved and not fully investigated and understood. One reason behind this delay is that evidence-based design is a general approach, which considers a series of variables for design research studies that are connected to humans' health and care support. In contrast, Alzheimer's is a partly unknown disease and consequently has different and undiscovered variables. The effect of environmental variables could vary not only among the patients of different diseases but also among the patients of the same disease with different stages (e.g., Alzheimer's has 4 stages with different symptoms and experiences). In summary, the conventional approaches to studying the impact of built environment on patient's well-being focus on a set of pre-defined well-being characteristics. We argue that, in addition to these general characteristics, each class of diseases (as specific phenomena) might need a set of characteristics that pertain to the differences in experiences of the patients. Phenomenology as both a research method and theory perspective can focus on specific population's experiences and derive and set the variables based on the experiences. Applying Phenomenology in investigating Alzheimer's patients' experiences which are influenced by the built environment, unites design researchers with AD caregivers for a more clear and purposeful support for patients.

6.0. DISCUSSION AND CONCLUSION

This study proposed phenomenology as a theoretical perspective and methodological approach that provides valuable insight to inform design researchers about the experience of AD patients in care facilities. The authors introduced the fundamental concepts of phenomenology by reviewing the definitions offered by the pioneers. The authors then discussed some precedents of applying phenomenology in healthcare research. In it's focus on AD, this paper reviewed the characteristics of this disease and its symptoms with a focus on environmental factors that can influence the experience of patients in their built environment. For instance, wayfinding, lighting design for AD patients, light-therapy, and safety assurance design.

Despite the advantages of phenomenology in understanding AD patients' experience in building and facilities, the authors acknowledge that phenomenology may have some limitation is certain cases, discussed as follows:

- Phenomenology may have limitations in explaining the experience of Alzheimer's patients in advanced stages because, in advanced stages, a loss of memory and disability in verbal communication may emerge. To mitigate this challenge, researchers must consider that a phenomenology of Alzheimer's patients experience in their care environment is not independent of their care giver's experience in the built environment. The care givers, families, and those who work in such environments can also provide relevant information that helps improve the experience of all occupants in such facilities.
- As relevant to the concerns about the memory of patients, the timeframe between the occurrence/emergence of certain phenomena and data collection may influence what the participants remember of the phenomena and their experience of it.
- Since Alzheimer has a range of stages and progressions, and patients even in the same stage may show different symptoms among the many possible symptoms, the lived experience of patients may vary greatly and therefore the attempts to validate an experience across all patients may be more challenging. Phenomenology gives the researchers some flexibility in addressing the variety of experiences the patients may have in care facilities.

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