**Wayfinding Difficulties Among Elders with Dementia in an Assisted Living Residence**

**Abstract**

The concerning phenomena of spatial disorientation and wayfinding difficulties among elders with Alzheimer's disease or a related dementia in assisted living residences is understudied. This qualitative study aimed to identify the types of wayfinding difficulties as experienced by residents with memory-loss in two special care units of an assisted living residence in Massachusetts. The data collection period included participant observation complemented by semi-structured interviews with care staff and managers and review of clinical records. A wide spectrum of wayfinding difficulties was identified as experienced by six residents. The residents experienced difficulties reaching several destinations on the units. The implications of the findings to practice and architectural design are discussed.

Keywords Alzheimer's disease; dementia; spatial disorientation; wayfinding; assisted living

**Introduction**

The ability of elder residents with Alzheimer's disease or a related dementia (ADRD) to reach desired destinations on a daily basis in the long-term care residences is considered a basic physical, psychological, and social human need, which directly affects their personal autonomy and quality of life (Passini, Pigot, Rainville, & Tetreault, 2000). Spatial memory or visuospatial processes were the focus of most studies that examined getting lost behavior in persons with ADRD (McShane et al., 1998; Tetewsky and Duffy, 1999, Mapstone, Steffenella, & Duffy, 2003). Specifically, more than one-third of persons with Alzheimer's disease (AD) were found in previous research to have disabling visuospatial disorientation (Cogan, 1985; Henderson, Mack, & Williams, 1989), which directly inhibits their ability to reach desired destinations (Mahoney, Volicer, & Hurley, 2000). For instance, persons with AD were found to experience difficulty finding their way even in a familiar environment (Passini et al., 2000; McShane et al., 1998).

Spatial disorientation is among the first signs to appear in AD, and often noted during the progression of the disease (Alexander & Geschwind, 1984; Liu et al., 1991). Spatial orientation is the person's ability of mentally imagining or representing a physical setting and of situating him or herself spatially within that representation (Passini, 1984). Spatial disorientation is defined as "misperceiving immediate surroundings, not being aware of one's setting, or not knowing where one is in relation to the environment" (Mahoney, Volicer, & Hurley, 2000, p. 125). These authors state that, "Even when the person can see clearly, space and location may be distorted, objects may be interpreted incorrectly, or directions may be misunderstood."

Wayfinding difficulties have also been reported as a problem of execution and attention (Chiu et al., 2004). For instance, Chiu and colleagues (2005) found that individuals require intact

executive functions in order to carry out wayfinding strategies in their daily lives. These executive functions, however, may be impaired among persons with dementia (Kennedy & Smyth, 2008).

Wayfinding is conceptualized as "spatial problem-solving abilities necessary in reaching destinations, when appropriate solutions are not available in memory" (Chiu et al., 2005, p. 761). As a problem-solving ability, wayfinding itself involves executive functions such as selection of a goal or destination; determination of a path or route; planning; execution of the plan; and application of strategies to follow the path and reach the desired end point (Lezak, 1982). According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR), executive function involves the ability to think abstractly and to plan, initiate, sequence, monitor, as well as stop complex behavior (Kennedy et al., 2008).

Passini and colleagues (2000) make the distinction between aimless wandering and wayfinding and state that in the former the person walks without having a destination in mind and without knowing where she or he is.

General wayfinding difficulties among persons with ADRD that were reported in the literature include the ability to remember what is needed to reach the aim (i.e., prospective memory) (Berg, 2006); pointing directions and keeping a sense of direction (Richard et al., 1979, 1981); being able to stay focused or concentrating on a task (i.e., attentional impairment) (Mahoney, Volicer, & Hurley, 2000); the ability to distinguish relevant from irrelevant information (Passini, Rainville, Marchand, & Joanette, 1998); the ability to process locational information (i.e., localizing target objects in space) (Nguyen, Chubb, & Huff, 2003); differentiating the object from the background (Mendez, Mendez, Martin, Smyth, & Whitehouse,

1990); the ability to recognize that an object has depth as well as height and width (i.e., depth perception) (Mahoney, Volicer, & Hurley, 2000); and the ability to remember mistakes or avoid producing the same errors trial after trial (Van der Linden, Juillerat, & Adam, 2003; Wilson, Baddeley, & Evans, 1994).

Specific day-to-day wayfinding difficulties include performing the procedural components of a route, such as hesitating when choosing a turn (Chiu et al., 2004) or going the wrong way at an intersection (Passini, Rainville, Marchand, Joanette, 1995); self-correcting difficulty or thinking one's way out of a situation by visualizing an alternative route (Mahoney, Volicer, & Hurley, 2000); difficulties in retracing one's steps (i.e., the person has to solve the problem of getting out of a destination zone as if it were a new problem) (Passini et al., 1998); difficulty finding one's room even if the name and the photo of the occupant are shown on the door; looking for one's room in the wrong corridor; and difficulty retaining one's room number (Passini et al., 2000).

Individual factors that contribute to wayfinding difficulties include the fact that impaired awareness of deficits or incapacities is a common feature in AD (Starkstein et al., 1997; Flaherty & Raia, 1994); the fact that persons with ADRD were found to overestimate their own wayfinding abilities in immediate familiar environments (Chiu et al., 2005); and the notion by which most persons with ADRD are not in a position to evaluate their own need for help and many would try to conceal their declining abilities (Berg, 2006). Compounding these factors are research findings showing that assessment regarding the wayfinding abilities of six residents with moderate to severe AD varied greatly among staff (Passini et al., 2000).

Physical environment features considered to aid in orientation among persons with ADRD include unit size, layout, room configurations, provision for protected wandering, presence or absence of noise, methods of exit control (Zeisel, Hyde, & Levkoff, 1994), small number of residents per living area, provision of only one living/dining room (Marquardt & Schmieg, 2009), signs, graphics, landmarks, color contrasts, and good lighting (Torgude, 2006).

Negative emotional consequences. According to Lynch (1960), spatial disorientation not only evokes feelings of insecurity but that a person's whole sense of well-being is deeply attached to his or her sense of space and time. Lynch (1960) observed that in our culture, the term "to be lost" also has an existential meaning and is associated with identity and autonomy. These views apply also to persons with ADRD whose emotional responses to getting lost may include distress (Liu, Gauthier, & Gauthier, 1996) anxiety and confusion (Passini et al., 2000), frustration, irritability, fear, panic, and (Passini, 1992). In accordance, Mahoney, Volicer, & Hurley (2000, p. 125) state that, "spatial disorientation may cause misunderstanding of the environment and lead to the development of fear, anxiety, suspicions, illusions, delusions, hallucinations, which in turn cause agitation and safety problems such as getting lost." As described by Orluv (2010), "The confidence of knowing where one is and anticipating where one is going – so fundamental to our existence – is suddenly fragile." According to Chiu and colleagues (2005), these strong negative feelings make the experience of getting lost devastating, and leads to reduction in wayfinding performance.

Potential consequences of not being able to reach a desired destination include diminishing activities of daily living (ADLs); wandering and becoming lost; and mistakenly going into the rooms of other residents or interference with other residents (Mahoney, Volicer, &

Hurley, 2000). In addition, being lost or fears of getting lost can contribute to a person's decision to avoid certain environments (Kaplan, Kaplan, & Ryan, 1998), which in turn may diminish daily independence, autonomy and the positive effect that comes from socializing with other residents. For example, Provencher and colleagues (2008) report on a person with early-stage AD (with Mini Mental State Examination (MMSE) score of 24/30) whose difficulty finding her way around her senior residence reduced her participation in social activities.

*Theoretical Framework*

The Competence-Environmental Press Model (Lawton & Nahemow, 1973) explores the interplay between elders' competence (e.g., whether they have the cognitive capabilities and skills required to perform a particular task) and the demands in their environment (i.e., environmental press). According to Rogers (1982), competence involves the effectiveness in which one interacts with her or his environment. Environmental press comprises proximity of services and ability to get around, predictability in the environment, and ease with which needs could be communicated. According to the model, the lower the level of functioning, the more dependent the individual upon the immediate environment and the more critical it is that the initial placement is such as to maximize person-environment fit and that changes in the individual's functioning are closely monitored over time (Nahemow, 2000). Since persons with Alzheimer's disease are likely to experience heightened sensitivity to influence from their immediate physical environment, which might contribute to maladaptive behaviors (Corcoran & Gitlin, 1991), the Competence-Environmental Press Model is particularly suitable to serve as a framework for understanding spatial disorientation and wayfinding difficulties among residents with dementia in long-term care residences.

Despite the far-reaching negative emotional, functional, and social consequences of spatial disorientation and wayfinding difficulties among persons with ADRD, these phenomena are relatively unexplored in research studies in long-term care residences in general (Orulv, 2010) and assisted living residences in particular. The importance of studying these phenomenon in assisted living residences stems from the fact that these care settings are the fastest residential care option for older adults in the United States (Kopetz et al., 2000).

*Research Question*

What is the spectrum of spatial disorientation and wayfinding difficulties experienced by residents with ADRD in two special care units of an Assisted Living Residence?

**Methods**

*Site Selection and Description*

I attempted to select a residence that provided a high level of quality of dementia care and sought the opinion of an expert from the Alzheimer's Association. I visited two ALRs and both seemed to be suitable. I selected the one where the managers were cooperative and was easily accessible.

The selected ALR was a non-profit organization designed solely for persons with ADRD. It had reputation of providing exceptionally good care and consisted of the following quality of care indicators: Alzheimer's-friendly environmental features; Habilitation Model of Care (Raia, 1999) as the guiding philosophy of care; extensive dementia-specific care staff training; extensive activity programming; strict staff hiring policy and low staff turnover. The ALR had a higher cognitive functioning unit (HFU) and a lower cognitive functioning unit (LFU). About 33 residents could live in each unit. The Floor Plan of the HFU (which is basically identical to that of the LFU) can be seen in Figure 1. The majority of the residents paid privately to live in the

residence while a few apartments were available for low-income residents under Program All-Inclusive Care for the Elderly (PACE).

*Sample Selection Process*

I selected 12 residents for in-depth study (seven from HFU and five from LFU). I chose this small number to allow me to document their daily experiences in detail. The inclusion criteria included experiencing negative emotional states and/or behavior difficulties on a continual basis; and having a diagnosis of ADRD. The exclusion criterion included expected discharge within three months. Using these criteria over a period of two months, I conducted extensive observations, 10 consultation meetings with 13 staff and managers (during which I sought their opinions regarding residents' suitable for the study), and family members of potential residents. An initial pool of 29 potential residents was re-evaluated and assigned a suitability score (i.e., high, somewhat high, medium, and low) based on the above criteria. To evaluate the behavioral difficulties and negative emotions of the candidate residents, I used, as a general/crude guide, the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, Marx, & Rosenthal, 1989) and the Observed Emotion Rating Scale (Lawton, Van Haitsma, and Klapper, 1999) to evaluate negative emotional states. This 2.5 months process led to select the final sample.

*Human Participants Protection*

The Institutional Review Board of the University of Massachusetts Boston approved the study. I received informed consents for participation in the study and access to the clinical records from the legally authorized representatives of the sample residents and from the ALR. Toward the end of the study, I deleted the entire de-identified data and destroyed all the interview tapes.

*Data Collection Procedures*

My ethnographic immersion occurred between August 1, 2007, and June 6, 2008. Typically I spent five days a week at the residence, an average of 9.5 hours per day. The bulk of my observations took place during the day and a few hours in the afternoon/evening.

In general, I observed the sample residents wherever they located themselves in the public areas of the unit, which mostly consisted of the three activity rooms, three dining rooms, and several hallways. I also observed residents during time periods when they were not participating in activities. As per suggestions for conducting fieldwork (Lofland, 1989), I typed my daily fieldnotes from my notebook to my laptop at the end of each day.

The data collection took place in two phases. Phase I lasted 2.5 months and included getting to know and building rapport with the staff and residents; familiarizing myself with the physical environment; selecting the sample residents; and seeking informed consents for participation. Phase II lasted close to eight months. I used participant observation as the primary data collection method, complemented by informal conversations primarily with staff and managers. I regularly observed care plan meetings and management meetings. In addition, I documented daily staff written reports from their communication log. In the last three weeks of Phase II, I conducted semi-structured interviews with staff and managers.

*Participant observations.* In a rotating manner, I spent one day in one SCU and the next in the other. I collected data only in the public areas of the SCUs. During my observations, I documented in detail those incidents in which residents experienced negative emotional states and/or behaviors when they were on their own. I attempted to strike a balance between positioning myself far enough from the occurrences/residents but not too far so that I would be

able to document the incidents in detail. While I mostly wrote notes visibly, at times I observed without writing, and, when the incident ended, I moved to a quiet place to write what I observed.

*Semi-structured interviews.* During the last three weeks of data collection, I conducted 13 semi-structured interviews with staff and managers. The interviewees included five certified nursing assistants (CNAs), two team leaders, two nurses, a recreation assistant, a music therapist, the director of recreation therapies, and director of ALR. I audiotaped the interviews and transcribed the tapes verbatim. One of the goals of the interviews was to capture the perceptions, insights, and opinions of the interviewees regarding the residents' wayfinding difficulties.

*Interview guides.* I conducted extensive data analyses at three times during the data collection, which provided solid grounding for the semi-structured interviews. Based on these reviews, I developed interview questions that I continued to modify until the beginning of the interviews and, as recommended by Belgrave, Zablotski, and Guadagno (2002), throughout the interviews time period as data emerged.

*Reactivity to Researcher Presence*

My presence appeared to have an effect on certain staff-resident interactions, though it is difficult to ascertain its scope. While certain staff put extra effort to attend to the needs of the sample residents, others seemed to continue to work as if I was not present. An example of the former is a resident's daughter who told me that her mother received better care because of her participation in the study. Since my interest was when residents were alone, while staff reactivity in this instance might have decreased the time a resident was alone, it did not adversely affect my observations. Examples of the latter included a staff member who asked me shortly before the end of data collection about a sample resident: "Is she in your study too?" Another example was

two lengthy verbal altercations between residents (lasting 27 and 39 minutes) that where taking

place in the dining room, which I openly documented when staff were present in the area but did

not attempt to defuse them. While this was distressing to witness, as a researcher I did not

intervene, as there was no immediate safety problem for either resident.

*Data Analysis*

I used Grounded Theory as outlined by Charmaz (1995) as the analytic framework of the study,

while being guided by Miles and Huberman's (1994) approach. I analyzed the data on an

ongoing basis from the beginning of the data collection until the study was completed and

followed the iterative analysis process described by Cobb and Forbes (2002).

Typing the daily notes from my notebook to my laptop allowed me to review the data and

add "on the go" reflective comments. This ongoing process assisted me in identifying incidents I

considered problematic. In addition, during the three aforementioned intensive data reviews, I

engaged in line-by-line review and reflection of the fieldnotes. While doing so, I highlighted

segments of text I considered relevant and meaningful to the study and made handwritten

comments in the margins. After the data collection, I transferred the entire data into N-Vivo 2.0

software where I managed and analyzed the data. I spent three months reviewing and analyzing

the data line-by-line as part of a detailed coding process.

*Validity*

Throughout the data collection and analysis of the study I used the following techniques as

recommended by Onwuegbuzie (2000) to strengthen the validity of the findings: Prolonged

engagement, persistent observation, triangulation, leaving an audit trail, member

checking/informant feedback, weighting the evidence, checking for representativeness of sources

of data, theoretical sampling, replicating a finding, rich and 'thick' description, and thorough documentation of methods used.

**Findings**

During the data collection, I documented a variety of spatial disorientation and wayfinding difficulties as experienced by six residents of the 12 who were in the sample of the study (three on the HFU and three on the LFU). As can be seen in Table 1 below, four of these residents were in the mid-stage of ADRD, while one was in the late-stage (there were no data to determine whether the other sample residents have experienced wayfinding difficulties).

**Table 1. Sample Characteristics for the Six Residents with Wayfinding Difficulties**

| Resident[1] | Age | Sex | Diagnosis | MMSE[2] | Dementia stage[3] |
|---|---|---|---|---|---|
| Mr. Green | 78 | Male | Frontal Temporal Dementia or Lewy Body Disease and Vascular dementia | 15/29 | Mid-stage |
| Mrs. Allen | 83 | Female | Alzheimer's disease | 20/30 | Mid-stage |
| Mrs. Edwards | 75 | Female | Vascular dementia and Alzheimer's disease | 16/30 | Mid-stage |
| Mrs. Harris | 79 | Female | Alzheimer's disease | 21/30 | Mid-stage |
| Mrs. Jones | 84 | Female | Alzheimer's disease | 7/30 | Late-stage |
| Mrs. Lewis | 83 | Female | Alzheimer's disease with a questionable vascular component. | Dementia Rating Scale 88/144 [Memory subset score 9/25] | Late-stage [Severely impaired cognitive functioning] |

[1]All the names in the table are fictitious.

[2]Mini-Mental State Examination.

[3]Stage of dementia at the outset of the study.

The different types of spatial disorientation and wayfinding difficulties as experienced by the six residents are presented in Table 2 (below).

**Table 2. Types of Spatial Disorientation and Wayfinding Difficulties**

| Types of wayfinding difficulties | Description |
|---|---|
| **Not recognizing the place** | Not knowing where one is (two residents) as reflected by statements such as: "I haven't been here before" and "Everything is mixed up. I don't know what to do. I don't know where I am." |
| **Difficulty finding one's apartment** | Experiencing difficulty or not being able to find one's apartment (five residents). Three residents were looking for their apartment in the opposite hallway. On one occasion, one resident was observed to be looking for her apartment for 12 minutes. Another resident did not leave her apartment in the morning because, as reported by the team leader, she was unable to find her way back to it. Context: To assist in navigating the unit, the walls of the opposite hallways were painted in different colors. In addition, shadow boxes filled with personal pictures and objects meaningful for residents were hung outside residents' doors to help them find their apartments. |
| **Mistakenly entering other residents' apartments** | Mistakenly walking into other residents' apartments (four residents). Occasionally, these entries interrupted and disturbed the residents whose apartments were invaded. On one occasion an aggressive incident developed between two residents after one resident was walking towards another's apartment. |
| **Forgetting one's apartment number** | Continuous difficulty remembering/retaining one's apartment number (one resident). This resident was observed to ask staff members to write her apartment number for her on a piece of paper and, on another occasion, she was also observed to have a bracelet on her hand with her apartment number written on it. |
| **Reading apartments' numbers incorrectly** | Reading apartments' numbers located next to one's apartment and another resident's apartment incorrectly (e.g., reading "G06" as "606" and "G20" as "620") (one resident). |
| **Difficulty finding bathrooms** | Not being able to find a public and private bathroom (two residents). |
| **Difficulty finding the right dining room, and dining room table** | Looking for one's dining table and designated seat in the wrong dining room during mealtime (one resident). In addition, this resident did not find his dining room table and seat even when he was in the dining room in which he usually eats. Context: name tags were placed by the staff prior to lunch and dinner on the dining room tables next to each resident seat. |
| **Not knowing where the unit's exit is** | Not knowing or remembering the location of the exit door of the unit (one resident). This resident asked: "Where are the exits?" Context: The exit door cannot be seen from the unit's main area due to a wall positioned intentionally nearby. |
| **Inability to understand/ retain route instructions** | Repeatedly experiencing extreme difficulty comprehending and executing route-related instructions (one resident). |
| **Difficulty locating the activity room** | Not knowing the location of an activity room (two residents) including difficulty finding one's way from one activity room to another. In addition, experiencing difficulty finding one's way back to the activity room after leaving it to go to the bathroom (one resident). This difficulty was observed on one occasion when the resident opened a closet's door when trying to find his way back to the activity room. It was also reported by a manager who stated: "He wanders out of groups more often and then he can't find his way back." |
| **Difficulty of group of residents in finding their way from one activity room to another** | Three staff members reported that on a continual basis groups of residents were experiencing difficulty staying on the route leading from one activity room to another. |

*Illustrative Examples*

Selected examples of spatial disorientation and wayfinding difficulties based on interview

excerpts, observation notes, and staff reports are presented below for illustration. All the names

used in this article are fictitious.

*Mr. Green*

Mr. Green was a 78-year old widower diagnosed with frontal temporal dementia or lewy body

disease, and vascular dementia. At the time of the study, he was at the mid-stage of his dementia.

On a continual basis Mr. Green experienced difficulty finding his way around the unit. The

following observation excerpt illustrates his difficulty finding his dining room, dining room

table, and seat during lunch time:

> 12:31 p.m. – An exercise activity ends in the main activity room. Group leader: "So
> everybody go and have a fantastic lunch and a wonderful day. Alright, time for lunch
> everyone." 12:33 p.m. – Mr. Green walks around the area of one of the dining rooms. He
> walks back and forth looking for a place to sit. He looks at residents' name tags placed on
> one of the dining room tables. [During lunch and dinner, the residents' seats are pre-
> designated with their name tags]. A CNA notices that Mr. Green is searching for his table
> in the wrong dining room and tells him: "Oh...the other side." [while pointing to the
> direction of the other dining room where Mr. Green usually has his lunch]. Mr. Green
> walks towards and enters his dining room. He stands by a table (not his) and looks at a
> name tag placed on it. His table, seat, and soup are located a few meters away from him.
> A second CNA notices Mr. Green and tells him: "It's lunch time. Right there." [while
> pointing to his seat]. 12:34 p.m. – Mr. Green walks in the general direction of his table.
> He walks by his table and continues to walk straight out of the dining room and across
> the hallway towards another resident's apartment. Mr. Green then stops, turns around,
> and walks in the hallway towards another resident's apartment. He notices a newspaper
> on the floor and picks it up. 12:35 p.m. – Mr. Green walks down the hall towards his
> apartment and enters it. 12:37 p.m. – Mr. Green enters his bathroom. A housekeeping
> staff member sees him and tells him: "Hi Mr. Green, what are you doing?" 12:38 p.m. –
> The second CNA who directed him to his seat notices him and tells him: "It's lunch time
> Mr. Green. Come with me." Mr. Green walks to his dining room. When he reaches it, he
> stands and does not know where to sit. Mr. Green leaves his dining room and walks to the
> other dining room (the one where he started his search for his table/seat). 12:40 p.m. –
> The CNA who saw Mr. Green there initially notices him again, gives him her hand, and
> tells him: "Let me show you your seat." The CNA walks with him to his dining room.

She walks with him while holding his hand until they reach his seat. The CNA does not leave Mr. Green until she sees that he sits down and starts to eat his soup.

On a continual basis, Mr. Green experienced extreme difficulties retaining, comprehending and executing route-related instructions of directions given to him by staff members (e.g., "Go bring your hearing aids from your room."). During a program meeting, the team leader reported: "You can't redirect him. He doesn't know where to go. He needs a lot of cueing." During a care plan meeting, the director of the ALR said about Mr. Green: "When you give him a direction you have to show him exactly where it is."

A neurological evaluation sheds light on Mr. Green difficulties: "He had great difficulties comprehending task instructions, and often needed instructions simplified and repeated. He often lost set (i.e., quickly forgetting instructions) and needed constant reminders to stay on task."

During an interview, I asked one of the managers what might happen if a staff member would ask Mr. Green to go from the dining room to his room to bring something. The manager replied: "He'll get lost. He'll walk into other people's rooms. He may know the first two steps, 'I am going there' but the third step, "what the hell am I doing?" The manager added: "It's scary how debilitating [the disease] it is."

One day the team leader reported about Mr. Green: "He wanders into anybody's room. I found his pants in one room, shirt in another, and shoes in another room."

A music therapist reported that Mr. Green "always does not find his apartment, and then finds it...reads his name label by the door and enters." She added that this is why he enters Mrs. Clark's apartment, which triggers her fears from him. Throughout the study, Mrs. Clark was observed to be highly anxious, distressed, and afraid of Mr. Green who, she claimed, entered her

apartment at night. A CNA confirmed that shortly after his move to the unit, Mr. Green

mistakenly walked into Mrs. Clark's apartment around 8:00 p.m. The CNA said, "It was

traumatizing for her and ever since she says that she is scared of him." One day Mrs. Clark

related to this problem when she talked about Mr. Green: "I know he is confused but this is too

much confusion for me to experience."

The subjective experience of Mr. Green related to his spatial disorientation and

wayfinding difficulties is illustrated in the following observation excerpt:

> 2:46 p.m. – Mr. Green and the team leader are in the care staff room. Mr. Green: "I don't
> know where I am going...but if the right person...[mentioned his daughter's name] or
> someone comes along...I will know where to...I'll be better off." Team leader: "Okay Mr.
> Green, let's go for a walk." Mr. Green: "Whatever you say I am at your disposal." Mr.
> Green: "I trust you." Team leader: "That's why we are friends. Okay, let's go." The two
> leave the room and walk together down the hallway.

*Mrs. Allen*

Mrs. Allen was an 83-year old widow. She was diagnosed with AD and had lived at the HFU for

11 months. Seven months after the data collection began, she moved to the LFU due to

deterioration in her cognitive function and agitated behaviors. At the outset of the study, she was

in the mid-stage of AD. Occasionally, Mrs. Allen expressed statements showing that she did not

know where she was, as the following observation excerpt illustrates:

2:13 p.m. – Mrs. Allen walks out of her apartment and asks: "Where am I now? Where am I

living in? What country am I in now? I want to know where the hell am I." On another day, at

10:47 a.m., Mrs. Allen told another resident: "I have to go home. I haven't been here before." At

that time, Mrs. Allen had lived in the unit for more then a year. In addition, one day I observed

the following conversation between Mrs. Allen and another resident: Mrs. Allen: "I don't know

where I am." Resident [surprised] responded: "You don't know where you are? Sometimes I get

mixed up as well." Mrs. Allen: [missed words]. Resident: "You never wanted to come here?"

Mr. Allen: "No." Mrs. Allen is walking away and the resident is saying quietly: "Oh gee."

On a continual basis, Mrs. Allen was observed to experience difficulties reaching desired destinations. The following observation excerpt illustrates her difficulty finding a bathroom:

> 3:33 p.m. – Mrs. Allen sits in the activity room and watches television. She stands up and says, "bathroom." Mrs. Allen exits the room, walks in the hallway by a public bathroom, passes it, and continues to walk down the hallway. She passes the care staff room and the emergency double door. She tries to open a door [which I never saw used before], located right after the emergency double door. The door is locked. 3:34 p.m. – Three CNAs are with two other residents in the dining room located next to the care staff room. Mrs. Allen turns around and walks back towards the direction she came from in the hallway. Mr. Allen looks into an apartment of another resident. [Mrs. Allen's apartment is located at the opposite hallway]. She turns around and walks back in the initial direction she took in the hallway. Then she turns around and walks back in the opposite direction in the hallway. Then she walks to the other hallway towards her apartment and enters.

Mrs. Allen also tended to mistakenly enter other residents' apartments, as reported by a manger to her daughter: "Your mom forgets where her room is and she goes into other residents' rooms which they don't like." For example, one day Mrs. Allen entered another resident's apartment and undressed in front of her. The resident whose apartment was invaded responded to the behavior by saying: "I have a big problem." On another day the following report was written in the staff communication log: "Mrs. Allen mistakenly entered an apartment of a male resident who was in his boxer shorts at that time." During a follow-up, a staff member reported that the entry resulted in a verbal altercation between the two residents.

*Mrs. Edwards*

Mrs. Edwards was a 75 years old woman who had vascular dementia and AD. At the outset of the study she was in the mid-stage of her dementia. This resident experienced continuous difficulties finding her apartment as the following observation excerpt illustrates:

> 2:43 p.m. – Ms. Edwards is walking by the care staff room. She comes close to the name-label placed by the door of an apartment of a resident who lives in the opposite hallway from her apartment. She looks inside the apartment for a second or two, and continues to walk in the hallway. 2:48 p.m. – Ms. Edwards is walking by the care staff room, looks at the name-plate by the apartment of the same resident she looked at earlier, and then

continues to walk. I asked Ms. Edwards: "Is there something you are looking for." Ms. Edwards said: "Actually I do. I've been looking for my room." I: "I can show you." Ms. Edwards smiled and said: "I run out of breath." We walked together towards her apartment. On our way, she told me: "I was completely on the wrong side."

*Mrs. Lewis*

The following observation excerpt describes an aggressive behavior between two residents that developed after a resident noticed another approaching her apartment:

> 2:35 p.m. Mrs. Lewis walks toward the direction of Mrs. Kendall's apartment [Mrs. Lewis's apartment is in the opposite hallway]. Mrs. Kendall shouts angrily: "Hey, don't open this door. This is my home." Mrs. Lewis turns around and starts to walk towards Mrs. Kendall who tells her: "No no, you do what you want." The two residents walk toward each other with a hand gesture as if they are about to hit each other. A CNA intervenes and separates them. While being separated, Mrs. Kendall tells Mrs. Lewis: "I'll kill you." Another CNA redirects Mrs. Kendall away from the area while Mrs. Lewis is leaving the dining room.

*A Group of Residents Moving From One Activity Room to Another*

Another type of wayfinding difficulty took place when a group of residents were walking from one activity room to another. As reported during an interview by one of the managers:

> "In the actual move...you can't just say, 'Okay everybody...we are going to the living room,' because I've done it before...and what happens is that everybody gets up, they go, and from point A in the main activity room, where there were 18 people, to point B in the living room you end up with 6 people...now how within 10 feet have you lost 12 people...it bothers my mind. If you are going from one group to a music group, if there is no assistance to help you...if you're by yourself...[quoting a staff member saying] 'I can't assist everybody,' you'll lose these people...they are going to go back to their rooms, they'll go to the bathroom, they'll go to the bathroom and come out and say that that's what they were supposed to do; they may just not want to go...and that's fine if they do not want to go...but again...if you lose the residents, you lose the group."

This report is consistent with the suggestion made by Volicer and colleagues (2006), who stated that, "For guiding/assisting folks as needed to the area of the event, a team of two works

best: one (at least) gathering participants and one 'anchor' to stay with those already assembled, greet newcomers, and arrange strategic seating. For one leader to gather an entire group of ambulatory individuals…is often like filling a bucket with a gaping hole in the bottom."

A music therapist commented during an interview on a problem that occurs when a group of residents is asked to go to an activity room:

> "If I was asking people to do things they couldn't do all the time, then I might get some negative behaviors…people might get frustrated…and I've seen people get frustrated in other situations before. When somebody is calling them into the other room to do something and they don't understand where they are supposed to go…that is very frustrating."

The music therapist described a difficulty that one resident experienced during her transitions between activity rooms located in different parts of the unit:

> "Mrs. Clark, often I found that the transitions are very difficult for her. She is happy reading in her room…but…if we are leaving the living room, where most of my music groups take place, to go to the main activity room, she'll start telling me [saying in an anxious tone of voice]: 'I'm okay, I'm okay' and being defensive about 'I don't need my walker to walk.'

The music therapist shared an approach she used with Mrs. Clark during transitions between one activity room and another:

> "If we leave the music group, in the living room, singing a song...like 'When the Saints Go Marching In' something upbeat that they can march down the hall to, often if we sing a song starting in the living room and ending at the main activity room, the transition is a lot smoother...because it's not like we're ending music [group], now we are walking, now we are sitting...we're trailing music out..."

I then asked the music therapist the question: What do you *not* see in those transitions in terms of Mrs. Clark's emotional states or behaviors...when you are doing those transitions while singing? The music therapist replied:

> "She isn't defensive about [quoting Mrs. Clark saying]: 'I can do this,' 'I'm okay,' 'Why do I have to be here? Why can't I go home?' She doesn't make any of those comments if we are singing because [laughs briefly] we are singing."

The director of the ALR reported during an interview about this approach:

> "One of the good things I like when I see with the staff here…sometimes there's more than one [staff] and they are singing as they go along from one area to the other or people are just directing them [saying] 'good job'…as they walk like a walking group…going down from one area to the other. It's *really* important because *anything* can happen…the person can just lose focus on what they were supposed to be doing or where they are going. So it is important that staff is really involved in directing them."

The "trailing music out" approach was used frequently and effectively especially by the music therapist and expressive therapist with many residents on both units when they led a group of residents to and from the activity room where they led music-related activities. This approach was described previously by Hanser (1999, p. 152), who suggested that after a music therapy group ends the group should be "marching (or wheeling) out of the room [which] may be done with musical or singing accompaniment to facilitate the movement of the group into another room or to prepare them for the next activity of the day."

*Effective Care Staff Strategies*

Several strategies were identified in the study as used or reported to be used by different care staff members when trying to address residents' spatial disorientation and wayfinding difficulties. These strategies included directing, guiding, leading residents to their desired destinations or walking hand in hand with a resident to her or his destination. In addition, throughout the study, as a matter of policy of the ALR, at least one CNA was consistently waiting near the living room (activity room) a few minutes before the activity was scheduled to end. Then, when the activity ended, the CNA would assist the group leader in guiding and leading the group participants to their next destination (e.g., other activity room; dining room). In addition, at least one staff member was required to be by the main activity room in case

resident's needs arise (e.g., need use the bathroom). Additional strategy suggested by a manager was that at least two staff members should lead a group of residents from one activity room to another. However, it may be challenging to implement this strategy during times when care staff are occupied with other care tasks. A further strategy that was used was giving positive feedback to residents while leading them as a group from one area to another (e.g., "good job"). Finally, the "trailing music out" approach (described above) proved to be effective in assisting a group of residents move from one activity room to another and preventing the frustration that might otherwise occur if these residents were trying to navigate this route on their own.

**Discussion**

*General Types of Wayfinding Difficulties*

Various wayfidning difficulties were identified in the current study as experienced on both units by six residents. The primary destinations that these residents had difficulty locating included their own apartments, public or private bathrooms, main activity room, dining rooms, and dining room table and seat. The difficulties in locating these destinations represents a disablement that, if not addressed effectively by the staff, may prevent residents from meeting some of their basic needs. For example, not finding the bathroom may prevent one from using the toilet, which could cause distress and incontinence; not finding one's apartment may prevent one from having private time, resting, or engaging in solitary activities such as reading or listening to music; not finding one's dining room may delay or prevent one from eating her or his meal and the companionship that is part of the dining experience; and not finding the activity room may prevent one from enjoying the benefits of cognitive stimulation or socializing with fellow residents.

Throughout the study, many staff members from different departments (especially CNAs, recreation assistants, music therapist, expressive therapist, but also nurses, managers, dietary and housekeeping assistants) regularly directed, guided, or physically led residents to their desired destinations on the units. The wayfinding difficulties I observed took place mostly when staff members were not in the area or were in the area but did not notice the resident's attempt to locate the desired destination.

The findings contribute to the body of knowledge on spatial disorientation and wayfinding difficulties among residents with ADRD who live in SCUs of an ALR. Specifically, it contributes to efforts to develop a typology of major destinations certain residents struggle to reach in order to meet their daily needs. By capturing residents' statements verbatim, the findings also provide a rare opportunity to better understand these residents' subjective experience and suffering caused by spatial disorientation and wayfidning difficulties.

*Practical Implications*

Inter-disciplinary teams in SCUs of ALRs should conduct ongoing structured documentation and assessment of the types of destinations certain residents are and are not able to reach. The term "mobility profile" was used by Passini and colleagues (2000) to describe the range of destinations a resident is able to reach (and will be used here also to include those destinations that the resident is unable to reach). The documentation and assessment aimed at determining the mobility profiles should be conducted as close as possible to the occurrence of the wayfinding difficulties (to capture them in detail). In addition, the mobility profiles should be updated regularly because the cognitive ability of the resident, her or his executive functioning, spatial orientation, and wayfinding ability is likely to change over time as the dementia progresses.

Furthermore, since the time available to care staff for supervision of residents is limited, the mobility profiles should be developed particularly for a selected group of residents who are considered to experience the highest level of difficulty reaching desired destinations.

The need to assess residents' mobility profiles is supported by the findings of the current study by which not all the six residents experienced difficulty in reaching all the reported destinations on their unit. With certain types of destinations, five residents experienced the same type of difficulty (such as finding one's apartment) while in others, only one resident was documented to experience the difficulty (such as looking for one's dining room in the wrong dining room). Still, certain residents seemed to have difficulties with reaching two or three types of other destinations (difficulty finding bathroom). Furthermore, the frequency of difficulties varied significantly among the six residents (i.e., certain residents experienced the difficulty on a daily basis while others experienced difficulty less frequently).

In short, identifying the specific types of difficulties that certain residents experience when trying to reach certain destinations on the SCU could inform staff efforts to provide cues, direct, guide, and lead those residents to these destinations. Every care staff member that comes in direct contact with the residents should be informed about the mobility profiles of each of the residents (and their updated versions, once a change in the wayfinding ability is noticed). It is reasonable to think that many staff members already know who these residents are and which types of wayfinding difficulties they experience. Therefore, one could argue that this suggestion would only add a care task to an already overworked staff. However, due to high staff turnover, inconsistent presence of per diem staff and volunteers, busy care staff schedules, changing residents' wayfinding abilities, change of staff across the three daily shifts as well as between

weekdays and weekends, it is also reasonable to assume that the "known" information regarding each of the resident's wayfinding disabilities would not reach all staff members in a unified and timely manner. Moreover, previous research found that staff assessment varied greatly regarding the wayfinding abilities of residents with AD (Passini et al., 2000). Effective evaluation and use of the mobility profiles could, therefore, assist in ensuring that changes in staffing would not lead to information slippage and missed opportunities to promote wayfinding.

Consistent utilization of the profiles across staff members, shifts, weekdays, and weekends could maximize the number of instances in which residents who need assistance in reaching their desired destination receive it. This approach is consistent with the "anticipatory care approach", which is defined as "actions taken before the usual time of onset of a particular need or problem in order to prevent or moderate the occurrence of the problem" (Kovach et al., 2005, p. 138). Anticipating resident's wayfinding difficulties and addressing them in a timely manner is a preferred care strategy to addressing the difficulties after they already developed and caused distress to the resident. An example of a problem that could be prevented by using this approach is "unplanned leakage" (Raia, as cited in Koenig-Coste, 2009) that may occur when a resident cannot find the bathroom and becomes incontinent (Mahoney, Volicer, & Hurley, 2000).

Furthermore, individuals with ADRD may have impaired awareness of their deficits (Starkstein et al., 1997), try to conceal their declining abilities (Berg, 2006), overestimate their wayfinding abilities (Chiu et al., 2005), not reliably evaluate their need for help (Berg, 2006) or not able to ask for help when they do recognize their need. Therefore, informed by the mobility profiles and proactively offering assistance to residents may assist in minimizing the number of

instances in which residents need to ask for these potentially embarrassing requests for help. This in turn could "save the face" (Goffman, 1967) and preserve the self-esteem of the residents.

*Avoiding Excess Disability*

Using the mobility profiles approach (Passini et al., 2000) could assist in compensating for and addressing the needs of residents who suffer from spatial disorientation and wayfinding disabilities. However, there is a fine line between assisting a resident to reach a desired destination in a way that addresses only her or his *actual* spatial and wayfinding impairments and contributing to excess wayfinding disability. Wayfinding difficulty among persons with ADRD can be caused by different cognitive reasons as well as by unique combination of these. In addition, a single route in the unit consists of multiple parts/segments and require different cognitive capabilities to complete each one of them. For example, 11 cognitive abilities may be required to complete almost any route on the unit. These include recognizing the need to move to a different location in the SCU, planning the route, initiating the walk, locating one's position relative to the physical environment while moving, retaining the purpose of the walk, filtering out irrelevant information on the way, not getting distracted by occurrences on the way, correcting oneself when going in a wrong direction, identifying the desired destination (including differentiating it from its background), deciding to stop at the destination, and recalling the initial purpose of reaching the destination.

Careful and ongoing assessment is the key in differentiating which of these specific spatial orientation and wayfinding abilities of an individual resident are intact (and should be encouraged to be used) and which are impaired (and should be compensated by staff assistance). For each resident who experiences wayfinding difficulties, a distinction between autonomous

and assisted wayfinding should be established within each of the cognitive abilities required to complete a particular wayfinding task (Passini et al., 2000).

The potential risk of excess disability in the context of wayfinding difficulties among residents with ADRD has been acknowledged previously. For instance, Passini and colleagues (2000, p. 696), who examined this phenomena in nursing home residents with advanced dementia, stated, "While it might be helpful and securing when the staff take the residents to their destinations, it may also lead to the residents not to use their remaining wayfinding abilities. The danger of an overly protective approach is to cause a possible atrophy of potential wayfinding abilities and a reduction of the residents' sense of achievement and autonomy."

*Architectural Implications*

The findings of the study support the need to continue to build small-scale care environments (designed for 7 to 10 residents in each household) such as the Green House Model of the Eden Alternative (Thomas, 2004). In this model, the communal space and hearth and the fully-equipped country kitchen are located at the center of the household and each elder's apartment opens onto this space (i.e., there are no long institutional corridors). In the first ever built Green House in Tupelo, Mississippi, the residents' rooms were no more than a few feet from the communal space (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). The Floor Plan of this Green House is presented in Figure 2. This layout can assist residents in their efforts to navigate their way around the unit and reach desired destinations more easily. These latter researchers found that many residents stopped using wheelchairs because they were able to navigate the short distances in the household. The small-scale layout also maximizes direct eye contact between staff and residents (Verbeek & Rossum, 2008), and therefore, improve staff supervision (Cohen-

Mansfield & Werner, 1998). In addition, small-scale units were found in previous research to be associated with reduced levels of anxiety and depression, increased mobility and self-care skills (Annerstedt, 1997; Skea & Lindeasy, 1996), and increased quality of life (Rabig, 2007).

*Limitations*

The findings of the study should be considered preliminary due to a few limitations. The study was conducted in a single residence and focused on a small group of residents. In addition, while dementia-friendly physical environmental features of SCUs can assist persons with ADRD in reaching their desired destinations (Mahoney, Volicer, & Hurley, 2000), this study did not examine the impact of such environmental features on the ability or inability of the residents to find their way around the units.

*Future Research*

Research is needed in other SCUs of ALRs to determine the scope of the phenomenon of spatial disorientation and wayfinding difficulties among residents with ADRD and characterize the full spectrum of their manifestations. Effective strategies used by care staff members to address the wayfinding difficulties should be examined in future research. These strategies should then be incorporated into care staff training programs. Future research should also examine the relationship between wayfinding difficulties and excess disability caused by overprotective care staff practices as well as lack of care staff assistance when such assistance is warranted. Results of these studies could inform efforts to develop mobility profiles, ones that reflect the true nature of the wayfinding impairment on an individual resident basis.

Future research on the phenomena of wayfinding difficulties should also utilize technological devices to enhance understanding of the nature, types, and temporal and spatial

patterns of these wayfinding difficulties, the emotional effects of these difficulties on the

residents, and the strategies used by staff to address them. The technological devices could

consist of a receptor that electronically monitors and records the exact location of residents in the

unit in a real time and in a continuous/sequential manner. The findings of such studies could

inform development of care staff interventions aimed at assisting residents in reaching their

desired destinations. Such technology, called "activity/behavior monitoring systems," already

exists and is used in long-term care residences (Kutzik et al., 2008). These devices gather

information about a person's routine behaviors and present the information to caregivers in a

way that can help them provide better care. As described by Kutzik et al., (2008, p. 237),

"Depending on the specific system, motion detectors, radio frequency identification, infrared

tags, vibration sensors, either worn or embedded in the environment, are used to collect the

data." Some of these systems such as Elite Care and QuietCare generate alarms calling for

immediate staff attention. These technologies are already used in the areas of falls, ADLs, sleep,

and to identify the location of individuals in real time. Researchers should also consider using

technologies such as Care-Media: Automated Video and Sensor Analysis for Geriatric Care

(NSF 0205219) (Bharucha et al., 2006). This technology enables recording and analyzing the

lives of residents continuously in real-time in the public areas of dementia units using automated

speech, image, and natural language processing, that is, detecting the trajectory of subtle changes

in affect, behaviors, and activity patterns as well as antecedents and consequences of incidents.

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# Figure 1. Floor Plan – Higher Functioning Unit
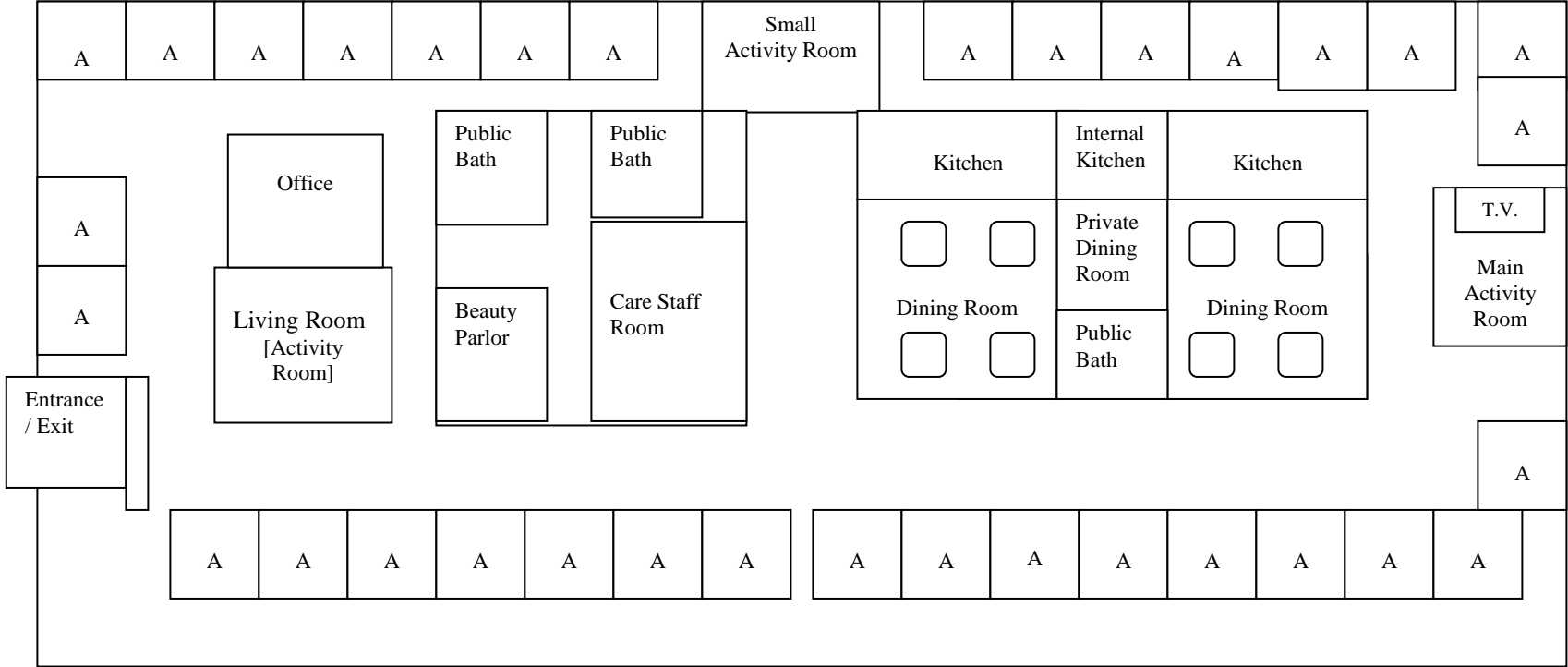


Notes: The letter "A" represents a resident's apartment; The four square shapes within each of the two dining rooms represent dining tables. The Floor Plan of the Higher Functioning Unit is basically identical to that of the Lower Functioning Unit.

**Figure 2. Floor Plan of First Green House in Tupelo Mississippi**

QuickTime™ and a
TIFF (Uncompressed) decompressor
are needed to see this picture.

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