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Personhood-Based Dementia Care

Using the Familial Caregiver as a Bridging Model for Professional Caregivers

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Abstract

With biomedicine at the forefront of our culture's understanding of illness, personal healing is often neglected. It has become common practice to place elderly persons living with Alzheimer's disease in nursing homes or long-term care facilities that do not always regard their well-being as a top priority. This article draws from familial caregiving roles as a basis for understanding personhood, which I take to be a bridge between the world of a caregiver and the world of a person with Alzheimer's. Furthermore, through the modeling of professional caregiving in familial caregiving strategies, I show how one might form meaningful relationships in long-term facilities, and likewise provide the aging and afflicted person with forms of healing.

Keywords: *aging, personhood, caregiving, Alzheimer's, healing.*

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Introduction

The devastating effects of Alzheimer's disease are not limited to just the diagnosed. Family members witness the vigor and personality of their loved ones "fade away, leaving behind a shell" (Lock 2013:19) of the person they once were. Amidst the biomedical drive to discover the biological mechanism that will cure Alzheimer's disease and family members' search for their own explanations, the real needs of the person are often forgotten. The confusion, hopelessness, and loss of meaning which persons experience as a result of Alzheimer's must be accounted for. These persons need healing.

For clarity, my usage of the term "healer" is adapted from the definition in Curing and Healing: Medical Anthropology in Global Perspective (Strathern and Stewart 2010). For Strathern and Stewart, a healer is defined as one who "restore[s] wellness to the body or person as a whole" (2010: 32). This definition must not be limited to one who "treat[s] specific conditions" (Strathern and Stewart: 2010: 32) which would be described as one who "cures." The distinction is important for the argument of my paper. Many symptoms of Alzheimer's can be treated separately by modern medicine, yet the disease as a whole remains incurable.

As a result of the diminished ability to communicate, people with Alzheimer's are socially defined by their illness, rather than being a person with an illness. Due to the state of being that the disease incurs, they are commonly not able to intervene on their own accord, or so we're told, because it is thought that they cannot communicate effectively. Yet, further research (Basting 2001, Jenkins and Price 1996, Lock 2013, O'Connor, et al. 2007, Strathern and Stewart 1998) has shown that by turning to personhood, a guide to healing can be attained.

This paper is primarily concerned with two caregiving settings: professional, long-term, care facilities (nursing homes) and at-home or familial settings. Caregivers in a professional caregiving facility often experience high workload, low pay, and understaffing. Nearly 60% of nursing home caregivers in a study stated that they are understaffed, have too much to do at one time, and have too little time to spend with residents (Cocco, et al. 2003:82). Understaffing in particular has been found to be associated with "more quality of care deficiencies" (Harrington, et al. 2000:284). Some of the shortcomings are being remedied by the 'culture change movement' in nursing home care that "goes beyond superficial changes to an inevitable reexamination of attitudes and behavior" (Rahman and Schnelle 2008:142). Some examples of this movement are briefly mentioned below.

Susan Eaton's (2000) work explores the connection between economics, human resources, and the quality of care provided to the residents of nursing homes. She found that recent "regenerative community" initiatives such as the "The Eden Alternative" and "Sisters of Providence/ Mt. St Vincent Care Facility" are examples of care which oppose the conception that people who enter nursing homes are in a state of “permanent irreversible decline” (Eaton 2000: 608). Although the above mentioned examples constitute a fraction of the 16,000 nursing homes in the United States, these examples depict situations in which a simple change in “managerial philosophy [had] transform[ed] nursing homes from impersonal institutions into safe, caring communities” (Lopez 2006:55). Lopez describes this transition as “culture change management.” In her discussion of the Eden project, Eaton attributes the principle that, “people need to give care as well as receive care to feel valuable,” to the founders of the Eden Alternative (Eaton 2000:603). This principle is undoubtedly a very important aspect of eldercare that requires further research and implementation for caregivers and residents alike. This article is primarily concerned with quality of care and a route to provide individualized care in the current predicament of elderly caregiving and its institutional shortcomings.

As an undergraduate student of anthropology, my research fieldwork consisted of volunteering on an Alzheimer’s/ Dementia-care floor of a nursing home in the northeastern United States during the summer of 2014 in order to investigate personhood amidst the manifestation of Alzheimer’s. After just a short time at the nursing home, it became clear that I had not categorized the residents as the members of “the Alzheimer’s unit”; rather they were Frank, Maria, Rita, and Leroy. There was something about each person that separated their symptoms and illness experience from each other. This realization allowed me to focus on each person’s illness narrative with a discursive network of meanings and expressions. I examined how their personalities, desires, expressions, and thoughts were still resonant in their present actions despite the progression or state of their dementia.

Bereft of a personal history or a familial relationship to an individual with Alzheimer’s, a caregiver can still establish a sense of personhood with a sufferer of this disease. By encouraging an individual to express him or herself, and through a mindful-interpretation of his or her words and actions, one can relate to the person on a deeper level. This interpretation of a person with Alzheimer’s present state of being, in relation to our society and to themselves in the context of their own life course, is that individual’s personhood. “Personhood,” as defined by Tom Kitwood (1997), is “the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood 1997 in O’Connor, et al. 2007:1). Establishing personhood with individuals with Alzheimer’s can be the bridge to their world, the foundation for a caregiver-care receiver relationship, and an avenue to provide a sufferer with a sense of personalized healing.

The Frontiers of Healing Amidst Incurable Illness

Alzheimer’s disease remains an incurable illness that emphasizes the momentous importance for a focus on healing as opposed to biomedicine’s present infatuation with finding cures. Toombs (2008), a sufferer of Multiple Sclerosis (M.S.), and the primary caregiver for her husband in his final years (who ultimately died of oral cancer) provides the reader with vital insight into the struggle of healing from an insider’s perspective. Like Alzheimer’s, both illnesses were deemed incurable by modern biomedicine. In *Living at the Boundary: Healing and Incurable Illness*, Toombs describes healing as:

> Whole person care, to the preservation or restoration of a sense of personal well-being, dignity and integrity that is not dependent upon the physical integrity of the body. Even in the absence of a cure, it is possible to promote – and receive – healing (2008:2).

Toombs lays out the cultural implications of healing. Four themes that are most applicable to Alzheimer's disease are the sufferers' relationships with others, communication, connectedness, and culturally prescribed role of personhood.

Our society's need to "de-emphasize relationship[s], placing inordinate value on autonomy and self-reliance" (Toombs 2008:9) becomes particularly problematic for individuals with Alzheimer's whose existence hinges on the care provided to them by others. As a result, persons with Alzheimer's are stripped of their sense of self and status in a society; they are often referred to as "lost" and even hopeless causes. A distinction made by Toombs that is particularly applicable to those with Alzheimer's is the dichotomy between "'doing' [as opposed to] 'being'[…] A person's worth is judged according to the capacity to produce (to be useful) or the ability to achieve a professional status" (Toombs 2008:9). The culturally constructed sense of personhood assigned to those with Alzheimer's is not (and should not be) the only form of personhood that one is able to achieve in a lifetime. The recognition of this assertion can be especially fruitful in the attempt to provide them with healing. Toombs suggests that placing the emphasis on *being* instead of *doing* will encourage loved ones to "look beyond the disease to the person" (Toombs 2008:10). Toombs' ideas were largely developed from her interactions with her husband; they shared an interpersonal history spanning thirty-one years of marriage. The interaction between a caregiver and care receiver is confounded when one can no longer share this personal history, or learn about a one's history (in the case of a trained caregiver for an individual with Alzheimer's).

In a research study on caregiving for patients with Alzheimer's disease, Jenkins and Price assert, "Dementia poses a number of fundamental challenges, not least of which is the fact that the caregiver can no longer be sure whether the care he/she delivers is as the patient would have wished" (Jenkins and Price 1996: 84). This presents a troublesome and counter-productive interaction for both parties involved. Toombs' ideas of healing, however, can become relevant in the discussion of Alzheimer's if we can establish a link or bridge from the perspective of the caregiver to the world of the care receiver. This link is personhood.

For individuals who act as caregivers for their spouses or loved ones, there is a reciprocal sense of healing that motivates them to provide care. What motivates/ provides meaning for caregivers in long-term care facilities? Suhonen et al. (2012) state that caregivers "perceptions of work satisfaction are positively associated with perceptions of individualized care" (Suhonen 2012:486). Individualized care is the belief that "all patients are different and require potentially different interventions to meet their individual needs" (Radwin and Alster 2002 in Suhonen et al. 2012:481). In other words, in professional facilities which equip and encourage caregivers to provide individualized care, they experience a greater, more meaningful, and rewarding work satisfaction. Individuals such as Anne Basting, Dr. Bill Thomas and his wife (of the Eden Alternative) serve as models for the values and techniques that a professional caregiver should display.

Professional (Non-Familial) Caregiving

A relatively recent study assessed what "professional caregivers working in nursing homes consider to be a good life for residents suffering from dementia" (Kalis, et al. 2005:1). The research found that the majority of participants mentioned "peace and quiet" as the most important quality representing a "good life" for individuals with dementia. The authors note that this makes a caregiver's work "easier and more pleasant to do" (Kalis, et al. 2005:40). This seems to present a problem. Although 'peace and quiet' may be mutually beneficial for keeping agitation to a minimum and making the professional caregiver's role easier, it should not be the defining factor for what constitutes a "good life" for a resident.

The environment that managers shape for their workers produces the belief that 'peace and quiet' is the quintessential aspect of good nursing home care. Eaton found from interviews with nursing home managers that they "did not trust their workers" and classified caregivers as being part of a "low-wage, high turnover cycle" profession (Eaton 2000:597). By not placing value in quality of care, but rather in the ability to maintain sanitary and quiet environments, empathetic caregivers are often undervalued for their contributions.

The satisfaction, or lack thereof, which caregivers feel regarding their place in the care provider chain has been positively correlated to effect the "support of patient individuality, individuality in the care provided, and knowing the person" among other independent variables (Suhonen et al 2012:487). The establishment of a displeasing work environment may result in the hiring of unsuitable applicants. In a separate study which investigated nursing home staff members' view of residents with dementia, 85.1 percent viewed residents with dementia as "behaving in a completely aimless way" (Brodaty, Draper, and Low 2003:586). By judging the actions of dementia residents as "aimless", nursing home caregivers are denying the potential of extracting meaning from residents' actions. Without seeing meaning in the residents' actions, the prospect of individualized care is hindered.

Finding the Bridge: Fieldwork and First Impressions

I have chosen to write this article in an analytic autoethnographic style. A great deal of the literature on caregiving is survey or questionnaire-based analytic research. My writing and fieldwork benefit from the analytic autoethnographic style in that by bringing the reader into a moment of a sufferer's illness narrative, he or she is brought into conversation with my article. This allows the reader, just as I have, to interpret the scene as they see fit. Analytic autoethnography allows one to 'set the scene' and guide a reader to a conclusion, by using and introducing relevant literature to bound one's observations within a cultural context. In addition it is "made possible by being a part of a culture and/ or by possessing a particular cultural identity" (Ellis, Adams, Bochner 2011). Finally, I feel it is nearly impossible to encompass the vast diversity in personality, interaction, and response to care in a questionnaire or by more rigid forms of data collection.

Leon Anderson states that the five key features of analytic autoethnographic style are: "complete member researcher, analytic reflexivity, narrative visibility of the researcher's self, and commitment to theoretical analysis" (Anderson 2006:378). Although this type of data collection is "limited in its practical utility […] the social world under study gives the researcher an added vantage point for accessing certain kinds of data"(Anderson 2006: 389), kinds that may often be missed by survey.

My mode of gathering data consisted of participant-observation on an Alzheimer's/ dementia care floor of a nursing home in the Northeastern United States. As a volunteer at the unit, spending time with the residents was my only task. Other than occasionally wheeling residents to a common room, bathroom, or cafeteria for holidays (such as Thanksgiving), I had no other duties or responsibilities. It immediately became clear that there was a wealth of knowledge to be unearthed having been afforded the ability to interact without many restrictions, communicate with the residents (in an array of different ways), and to participate in their daily lives.

After each day that I spent on the floor and upon returning home, I wrote down everything I remembered in a journal. I wrote down things that seemed important (and conversely less important), things that impressed me, names, actions, ideas, short stories, interactions, impressions, etc. During my writing sessions and reflecting on my journal entries every night, I noticed that the residents' actions no matter how nuanced or subtle starting taking on a new light. This enabled me to explore patterns and micro-behaviors during my following visits.

The unit I volunteered at was a thirty-seven-bed floor of a nursing home. The home provided services such as: arts and crafts, pet therapy, religious services, music, sensory stimulation, and daily exercise. In the common room, where I spent most of my time, there was one caregiver who was responsible for ten to fifteen residents who were usually in the room, some were able to come and go as they pleased while others required more attention. If a resident's behavior became too unruly for the staff, they were placed into what was called the "cool down room." It was a somewhat dimly lit room with a recliner and a TV, adjacent to the common room. Directly outside the common room there was an elevator that could only be used after the input of a code. Intersecting the common room and elevator was a long hallway with residents (some in recliners, some in wheelchairs) scattered on either side of the hallway against the wall. The residents' bedrooms branched off of this main hallway on both sides.

On my first day on the Alzheimer's/ Dementia-care floor, my first impressions matched up to what I had expected. After getting off the elevator, one of the caregivers led me to the common room where I spent most of my time during my stay at the facility. The common room contained ten to fifteen people sitting around (and facing) a television. The television typically showed a man singing live in an easy-listening concert. Many of the residents ignored the television, while others seemed to be in a daze – looking out of the window or staring off into the distance. Yet, some stared at the television (although I got the feeling that they were not really watching it, but rather looking at the TV because it seemed like that was what they were supposed to be doing). Some residents seemed to be very uncomfortable in the room; they looked around constantly and usually kept to themselves. The mood of the room was very static; most residents were in wheelchairs or recliners and were advised by caregivers to "pick a chair" or would be asked if they were "in or out." On the wall, there was a large poster with the date, month, year, and the weather outside. The caregivers who were on duty spoke very loudly to the residents encouraging them to introduce themselves to me; some did, while most of them ignored the suggestion.

The range of severity of dementia from resident to resident varied. I have chosen to convey the stories of Leroy, Frank, Rita, and Maria because these individuals were those which I had the most interaction with over the course of my stay at the unit. These four were always in the common room where I volunteered, and this allowed me to observe and participate in their daily lives day by day, which led to a greater understanding of how their life narratives and personhood intertwined and materialized.

Leroy

The first resident that I came to interact with regularly was named Leroy. He was known around the home as Leroy "the Singer," and was introduced to me as such. Leroy sported a white five o'clock shadow and typically wore a plaid button down, grey sweatpants and white socks. Leroy was confined to a wheelchair but had no trouble using it to get around. Running into people with his wheelchair to get one's attention was not out of the ordinary for Leroy.

On my first day in the unit, one of the caregivers encouraged him to sing for me. After some time of hesitation he grabbed my arm with his shaking hand, looked me dead in the eye, and began to belt out a song. While never losing eye contact, he peered up at me as with a gaze that seemed to be waiting for approval of some sort from me. I had no idea how to react or what to say, so I just smiled and bobbed my head to his melody. After he concluded, the only words I could mutter were "that was amazing, do you know any Sinatra?" He nodded his bald head as if he understood my question, and then proceeded to sing the same song again. He sang with the same intensity and once again sang for the purpose of gaining my approval.

At this moment, while his hand was latched onto my arm, Leroy and I were engaging in what Toombs would describe as "healing communication." Although, this interaction contrasted to typical cultural and societal norms and roles, Leroy demonstrated his newfound personhood, and I as the listener, validated this personhood. Even for just that moment communication occurred on the basis of "touch, gesture, through facial and bodily expressions, through demeanor and attitude". (Toombs 2008: 8) Although Leroy was not demonstrating his culturally prescribed cultural role he connected with his surroundings and me in that moment, expressing himself in a way in which he felt most comfortable.

Leroy craved attention. Often times he demanded it, regardless if I were talking to another resident. He implored that I listen to him by tapping me or yelling "Hey!" He would become very agitated if I did not give him my full-undivided attention. One day, after demanding my attention several times, he began to repetitively ask me if I had heard an impersonation he knew. Regardless of my answer, over the course of about ten minutes he repeated the introduction to the Ed Sullivan Show. Each time he asked me about the impersonation, the same progression of events transpired. First was the demanding of attention, followed by asking whether I had heard his impersonation, and finally the Ed Sullivan introduction itself.

From time to time, I would explore a bit with my answer. I took note of how he would respond to each answer. It became clear that interaction with Leroy was very difficult. It was very one sided; he seemed to act for his audience, and he paid no attention to any response, other than praise. One really had to follow his lead; you could not change the direction of the interaction. It seemed as though he had a few scripted acts that he was confident in and would not veer off the path. I began to wonder if these types of communication were those, which received the most validation from caregivers in the facility, resulting in Leroy's comfort in performing them.

Another very interesting thing that I noticed about Leroy was that every so often, he would turn over his shoulder and yell "Alright!" in a very perturbed, aggressive tone. You could expect it to happen at least one time during every interaction that one would have with him. It was as if someone was nagging or reprimanding him, and he would respond with a curt, agitated, response. No one, however, was provoking him. I wondered if this was a subconscious window into Leroy's past. Obviously he had some very vivid memories, of the Ed Sullivan Show for example, yet this reflex could also possibly shed light on his background and personality. Not wanting to assume that this reflex was just a meaningless side effect of the disease, I took note of it and tried to interpret it later.

Upon further reflection, I explored the possible causes and nature of the reflex, as opposed to how it could be physiologically explained. Possibly, someone in Leroy's recent past had probed him to remember things, or had ridiculed him for his lack of memory. Is it possible that this was a residual response to that? Also, this type of response seemed to fit his personality a bit too well to be considered coincidental. His quick-tempered, impatient, and attention-demanding personality would seem to go hand in hand with a reflex such as his perturbed "Alright!"

In retrospect, I wish I had allowed myself to give Leroy more of a chance. I feel that I may have been somewhat reluctant to really form a relationship with him due to his irritable personality, but given more time I think he was definitely someone who could have shown me what healing means to him. In order to provide Leroy with day-to-day care and healing one must take the time to understand his enacted personhood and note the subtle clues of his reflexes, responses, and actions. Exploration into these subtleties, and recording and tracking them as the Alzheimer's progresses may prove to be very useful. Furthermore, they may lead to more individualized healing strategies and therapies.

Frank

The next resident I would like to introduce is Frank. Frank was a very lively man who was always smiling. He had a very warm and comforting smile; one of the caregivers called him the "mayor" of the unit. Frank typically wore grey sweatpants, a white t-shirt, white socks, had a full head of grey hair, and stayed in a reclined chair. He always struck me as very cramped in his reclined chair as he constantly moved around in a seemingly endless search for comfort. Beginning the first day I met Frank, he always greeted me as if he had known me forever. He was a very personable man who loved to talk. As with many of the residents, each had certain topics and words that they were confident talking about, which would allow them an opportunity to open up. In many cases, including Frank's, it was the name of one's hometown. Frank was from Anthracite, Pennsylvania and loved to talk about it. Even though many times he was not necessarily discussing about the town specifically, something about hearing its name triggered a familiarity for Frank, which allowed him to confidently jump into a story. In many cases, bringing up the name of his town would elicit, "You wanna hear a story?"

Frank's propensity to tell stories and interact is indicative of his inclination to perform. Furthermore, Frank was one of the most popular residents around the caregivers because of his outgoing and jovial nature. As a result, Frank received somewhat more attention from the caregivers. Frank's stories were many times referred to as "gibberish" by caregivers. His story would start off in a specific direction, then he would lose his spot or forget in which direction he was going, and implement an alternate progression of the story. For example, I was told by one of the caregivers that Frank was "quite the football player in his day." Once after asking Frank about his football playing days, he began to talk about football, and then just a few seconds later he was giving directions to a neighboring town, stating road names and giving distances on certain roads.

Often times, Frank would yell "C'mon Albert!" during a story without being prompted. I learned from the caregivers that Albert was the name of his son. Similar in nature to the "Alright!" of Leroy, this seemed to be reflex of some sort for this man. These reflex-like outbursts seem to be personalized and continuations of past conversations. Frank, just like Leroy, did not seem to pay the outburst much mind. I did notice it often marked a change in direction of his story (or segue into another impersonation in the Leroy's case).

I never quite knew how to respond to Frank's stories. I would often just rotate through affirming and reassuring responses from "yeah," to "I see," to "Ahhh," and to "interesting." Furthermore, I found two more subtle practices on my part that were important to encouraging Frank to continue his dialogue. First, was to always keep eye contact. As long as I kept eye contact, I found that Frank felt that I was following along with his stories. The second thing I would sometimes do would be to act confused and somewhat perplexed, and then a few seconds later act as though his story had provided me with understanding. He responded to this, and I believe it gave him confidence in his discourse, and conveyed to him that we were connecting. Frank would many times look down while telling a story and then trail off to see if you were still listening, but if I were to say something like "Oh of course!" his vigor would return. Perry offers a similar example in his research on spousal care, when he says, "some things, such as whistling a few notes of a hymn or laughing appropriately at a story or joke, were meaningful to spouses and regarded as competence" (Perry and O'Connor 2002: 58). By engaging myself in Frank's disconnected story, I "maintained continuity" and "supported his competencies", essential principles posed by Perry and O'Connor. Frank liked to tell stories. Although I do not know his personal history, I was able to deduce that even amidst his condition, his inclination to tell stories was his "medium used for creative expression" (Basting 2006:16) as well as an expression of his present-personhood.

Like many of the other individuals in the unit, the delusion of being able to leave the unit was a pretense that many of the caregivers would allow the residents to buy into as well as play along with. Frank would ask me as well as the other caregivers if we could give him a ride home. The common response among caregivers was usually "sure when I'm finished my shift, Frank," and I myself after sometime learned to play along with it. At times, however, the residents did have a notion that this was not a temporary stay for them. For example, one day Frank said to me, "Hey you, down the hall, and two rights, and that's my room, see my memory isn't so bad." This particular phrase struck me because it called a few things to my attention. First, I interpreted it as recognition of his state of mind. This phrase seemed infer that he understood his memory was fleeting. Secondly, if even just for that moment, since he knew he had a room at the home, he knew his residence there was not simply a short stay. Frank often displayed a conscious effort to prove himself and his memory capacity to others. At this moment, he was in the present, but he could lose touch with this reality within a matter of seconds.

Rita

Rita was a resident at the nursing home who was very personable and fairly easy to talk to. From day to day, the conversations that I had with Rita were very similar as a whole in content. Typically, the conversation would start off with her asking where I was from. I had found out that Rita was from a town adjacent to my hometown. But I discovered later that no matter where I said my hometown was she would say "Is that by Lavazza (the name of her hometown)?" Rita seemed to have a very good grasp of her childhood and adulthood. She described that her father worked in the coalmines but was an alcoholic. Her story was consistent from time to time, always reflecting the same elements. Then after talking about her past for sometime, she would ask "So where are you from?" And the conversation would begin again.

In addition to this, Rita always told me that I was good looking and then went on to state I was her boyfriend. I always assumed she intended this in a joking manner. However, if I were to talk to other female residents, she would often get jealous. Rita's awareness of the present confused me. She seemed to remember my presence there, and that she had met me, but it seemed as though when a conversation broke, asking where I was from was her way of leading us back to a somewhat scripted dialogue.

Similar to the reflexive outbursts of Frank and Leroy, Rita also had one. At times, during a conversation or when she was alone, she would yell "Ouch!" and then start rubbing her hand. If I were talking with her, while this happened and asked, "Are you okay?" she would sort of just ignore my question. It seemed like her outburst surprised her and her uncertainty to what happened and lack of control of her actions may have frightened her a bit.

Maria

One of the women at the unit, Maria, was a resident that I spent a lot of time interacting with. Maria was still able to communicate verbally however she could very easily get lost in conversation. She was a resident whose emotions could fluctuate very quickly. In seconds, she could transition from laughing to irritated, crying, and aggressive. To complicate matters, in the weeks before I arrived at the unit, Maria had fallen and broken her leg. Her leg was cast up and she was propped in a reclined chair at all times. She often forgot that she had broken her leg, and when she would become irritated she would try to get up to leave, resulting in greater stress and confusion. This presented a challenging obstacle for the caregivers of the unit. They had to find ways to divert her attention away from her current unease and tried to relieve her anxiety.

I interacted with Maria frequently while being at the unit. As a volunteer, and since she needed constant attention, I sat with her and kept her calm. By calm, I made an effort engage her and keep her in a manageable state where she was not at risk of further harming her leg. I felt anxious my first time being presented with this task. I did not think I was ready for the responsibility and I was nervous that I would say the wrong thing, or that she would try to get up and further injure her leg (because as a volunteer I was not able to be involved with helping restrain residents). When conversing with Maria I always tried to talk about things in the present, such as the weather, what was happening on the TV, or what she was wearing. I never wanted to frustrate or confuse her by asking her questions about her past. I found that keeping our discourse in the present was a very difficult task.

One day while I was talking with her, I said that I really liked her sweatshirt. It was a black sweatshirt with a black train on it. She responded saying, "See this train?" while pointing to the train, "My dad worked on this train." I remarked that it was interesting and said I wish I had a sweater like that; she then went on to say that she had "100 of the same one, and 100 pairs of black shoes to go with each sweater." When I said, "Wow, really?" she responded, "Well Yeah! They're in my closet at home." After saying this, she then casually tried to get out of her chair. I immediately became nervous knowing she had a broken leg and could not get up. I told her that she could not get up and asked her what she needed, and she said, "Well, I'm going home." As she struggled to get up, she became very frustrated and started crying. The chair she was in was locked in a reclined position and her leg was set which made getting up difficult. During her struggle I called over one of the caregivers to help. The caregiver asked her where she was going and Maria kept repeating "Home. I'm going home." What the caregiver said next surprised me. She said, "But Maria, the bus isn't here until three." After hearing this, along with the reassurance that the caregiver would let her know when the bus arrived, Maria calmed down. I was uneasy after the caregiver left, and did not know what to say so I said, "I like your sweatshirt, Maria" and she responded, "See this train, my dad worked on this train…"

The Reflexes of Personhood

Frank, Leroy, and Rita, all exhibited what I refer to as a seemingly involuntary "reflex". After getting to know each person better, their respective reflexes seemed to suit them and their personalities quite well. Clifford Geertz's (1994) notion of the duality of "meaning" behind a "wink" relates here. The reflexes that these individuals displayed varied and were enacted in group settings. Residents with Alzheimer's experience a different perception of the world around them, just as Geertz points out "Culture is public because meaning is" (Geertz 1994: 219). These public displays, whether "controlled" or not, had a deeper significance. It made sense that Leroy – an irritable, quick tempered and aggressive resident – would have a rapid, irritated reflex such as "Alright!" Whereas, Frank, a family oriented man who enjoyed talking about his hometown, would have a reflex pertaining to his family. Finally, Rita was a woman who seemed to be a rather emotional resident who enjoyed attention, pity, and often displayed signs of jealousy. A cry for attention or care, "Ouch!" seemed fitting for her. As I stated above, I do think each of the reflexes were involuntary, yet the specificity of each reflex and its correspondence to a personality was more than mere coincidence. None of these observations would have been immediately obvious to me without first getting to know each resident thoroughly beforehand. It is possible that my own interpretation of each may be askew, because I do not have the background/history and context, which could provide a deeper meaning and foundation for each reflex. This describes an instance in which familial care would be useful. A family member who has grown to know one's past and understanding one's nuances and idiosyncrasies, may have insight that a caregiver would not be able to attain. They may be able to describe and respond to such reflexes more productively. As a result family members could recognize agitation or other subtleties in discourse more easily and respond in sympathetic ways more quickly.

A second commonality among all the residents was the desire to go "home". It seemed to transcend all of their other desires. Although the mental states of the residents seemed to fluctuate, the constant feeling of being an outsider in an unfamiliar environment was ubiquitous. I noticed that the only residents who really never spoke of going home seemed, in my opinion, to be the most 'separated' from the group. This made me wonder whether a sense of acceptance has come over these residents, or have they experienced despair that they withdrew from their social environment. In particular, Maria's plea to go home was the one that hit me the strongest of all, because of the deep intense emotion with which she pleaded.

As described above, Maria's desire to go home was a frantic and very striking display of displeasure. Maria exhibited intense panic and confusion, which struck me as one of the most eye-opening and heartbreaking experiences of my time volunteering on the Alzheimer's floor. When I saw the exertion and urgency she put into her attempt to leave, it struck me, "Wow, this is real genuine pain and emotion." Her memory may be fleeting, she may be losing touch with her grip of reality, but the confusion, sadness, helplessness, and despair she felt in that moment was painfully real. Maria seemed to be more prone to these emotional fluctuations as compared to other residents. It took a very specific style and type of interaction to calm her to the point that she was not a danger to further harm herself. The caregiver at the time acted with such a clinical efficiency and resolve that it had made me realize that this probably happens fairly frequently. The immense emotion that hit Maria was more often than not a daily occurrence. How would this be different if she were at a place she called and knew as home, around individuals that know her and know how to comfort her? I can say with certainty that a great deal of pain would be avoided.

In contrast, Frank was very calm when he inquired about leaving. I think this calmness can be attributed to Frank's comfort with talking and being in social/group settings. He asked me multiple times, "Hey, can I get a ride home with you?" it did not seem to be a pressing matter for him. It appeared he understands his current situation, but the next moment he seemed to lose touch with the desire to leave. Frank's intermittent moments of clarity intrigued me. But if nothing else, they evoke the constant stress that this desire can play even on a typical jovial and upbeat person.

For Maria, there is no resolution to her illness. A doctor cannot cure the biological mechanism that accounts for her symptoms, however, there is an opportunity for healing for people like Maria. Anyone can provide healing. It is tough for family members to be able to interact with a person who is a shadow of the person they once knew. However, Maria did laugh, she could interact and feel happy. At first, I was a little bit appalled at the caregiver's white lie that a bus would be coming. This did, however, provide Maria with a much-needed peace of mind and calm in a distressed situation. I would refer to this type of work as healing.

Caregiver response to these interactions seems to take on a "weather the storm" mentality, which all things considered, makes sense. The caregivers of the unit, one being responsible for ten to fifteen, obviously form relationships with the residents and do get to know them in quite personal ways. The caregiver's primary concern, however, is to maintain order, to keep the residents calm, and prevent them from hurting themselves or others. When a caregiver's role is essentially to function as a babysitter, there seems to be something counterintuitive to any idea of healing. There is not much room for learning in an environment such as this. I was told that many of the residents' families either do not visit or have moved away.

The emotional stress of 'losing' a loved one to Alzheimer's also plays into one's ability to detach themselves from a sufferer. If one can no longer interact on an emotional level, it may be easier to withdraw from them. An option to remedy this situation may be to create a set of classes, as Singh et al. suggests regarding India, that a family member or loved one could attend to enlighten them on the progression of the disease, and instruct them as to ways in which they could relate throughout the progression of the illness. Ann Basting calls this the "emotional level". These classes would comprise of "behavioral management techniques, including problem solving, memory training, and reality orientation" (Singh et al. 2013:55). Mindful understanding and application of these themes would play an important role in maintaining and transitioning one's relationship along with the progression of the disease as opposed to having the relationship and person "fade".

Personhood-Based Caregiving

In American culture, how would one recognize, or on what basis, would one assert that a person is truly capable of partaking in personhood? Societal expectations in American culture may offer up the following: decision making ability, consciousness, or in light of Toombs work, the ability to "do" as possible responses. Yet, curiously all of these seem to infer a static definition of personhood, thereby allowing personhood to "fade" with age or declining health. There is no doubt that these social expectations dictate how care proceeds in professional care. Through analyzing the frames of interaction between caregiver and care receiver, the type of personhood, which exists in a certain settings, emerge and take shape.

Frames of interaction are "definitions, of what is going on, which give meaning to behavior" (Tannen 1985: 327). The frame of interaction that was established between caregivers and the residents in the nursing home was that the caregivers were the decision makers and residents were the passive receivers of a group-focused quality of care. The frame of interaction that caregivers created was focused on cultivating an environment that is beneficial for the group as opposed to the individual. Caregiving was shaped by: cleanliness, peace and quiet, and keeping the private, less desirable, traits of these persons out of the public eye. This "framing" was a " filtering process through which societal-level values and principles of conduct are transformed and refocused so as to apply to the situation at hand" (Gumberz 2001 in Park and Takanashi 2011:185). In this setting, caregiving is enacted in terms of providing an environment that seems to mold the residents into passive subjects.

In the familial caregiving model, there seems to be a more dynamic view of personhood. By the term dynamic, I refer to the tendency that with age or declining health, personhood can be founded or maintained on new principles as one ages or as one's capacities change. As mentioned above, this depends on the culture in which the caregiving is provided. Familial caregivers frame interaction with their loved ones somewhat differently than professional caregivers. Their frames of interaction invoke a sense of meaning because the interaction between family member and the individual with the illness exhibits a sense of personhood that is mutually intertwined in both the personhood of the familial caregiver and the individual with the illness. The investment and effort to establish new interactions of personhood is a mutually beneficial endeavor (i.e., personhood aides in the healing of the sufferer as well as maintains meaning for the caregiver). In this setting, nurtured personhood is allowed to evolve.

In an effort to provide a personhood-based caregiving model that establishes a more dynamic view of personhood for professional caregivers, I have adapted some of the most important tendencies of familial caregiving models into a flow chart in the next section. However, I feel it is important to note that there is a pre-requisite to the incorporation of this chart. Although I did notice how certain societal expectations dictated the macroscopic trends in caregiving in the nursing home that I volunteered, there were instances of sympathetic caregiving, which struck me as exemplifying "true care." These were the non-scripted behaviors between caregiver and care receiver, which provided healing to persons in moments of agitation. The white lie to Maria (about when the bus would arrive), the occasional rubbing of a shoulder of a resident, or always maintaining a smile regardless of how frustrating the caregiver's task may be, would be examples of these behaviors. These were the redeeming aspects of genuine sympathetic care that were evident in the facility that I volunteered, providing crucial aspects for a familial caregiving model.

Bridging the Gap

In instances of familial caregiving, the socially stigmatizing effects of Alzheimer's are often kept to a minimum. In such situations, the actions of the individual with Alzheimer's are understood and personhood is maintained (Perry and O'Connor 2002, Singh et al. 2013). Whereas in a culture where the illness has become hyper- medicalized, the afflicted are often placed in facilities which define them solely in terms of their disease. The loss of autonomy which accompanies the loss of familial and personalized care may be responsible for some of the socially stigmatizing effects that are often present among individual with Alzheimer's; one of the most notable being agitation. Agitation is common among Alzheimer's patients in long-term care facilities (Kalis, et al. 2005 and Wang and Herman 2006). Further research on the topic of whether personalized familial caregiving would decrease agitation would be beneficial. A possible avenue to explore this topic would be to observe the frequency of episodes of agitation and ranking the severity of the episodes on a consistent scale, among familial caregiving and professional caregiving environments. One would need to also take into account the progression of the illness in the subjects of each group, to maintain consistency and minimize the amount of potentially conflicting variables.

At its core, the disregard for the well-being of the elderly and dementia sufferers in conjunction with the lack of healing is one of the biggest problems facing our aging population. In America, medical rationalizations largely account for the increasing population of elderly individuals inhabiting nursing homes as opposed to home care settings. In contrast, the "culturally appropriate" search for healing of Alzheimer's in India is to: "design a program for family and kinship caregivers in the management of these diseases" (Singh et al. 2013: 62); a program that "has reduc[ed] the level of agitation and anxiety in patients with dementia" (Brodaty & Gresham, 1989; Haupt, Karger, & Janner, 2000, in Singh et al. 2013:62). In America, the majority of money for Alzheimer's and dementia research is geared toward "prevention by means of molecular manipulations" (Lock 2013:8). Lock asserts that this approach is also of "direct link to the interests of Big Pharm" (Lock 2013:8). These opposing approaches, beg one to consider whose real interests are at stake.

Despite the beneficial effects of familial caregiving, it is unrealistic to expect a shift in culture to occur in which the population will drastically increase the percentage of familial care cases. As mentioned by Toombs, much of American culture is centered on "doing" which decreases available time to deal with illnesses of loved ones. The duty to care give becomes burdensome and is placed in the realm of medicine, which delegate it to professional facilities such as nursing homes. Yet, valuable information for professional caregivers can be gained from settings in which individuals with the illness are cared for by loved ones. In situations of familial care in United States, they are treated as "an intact person who has a disease rather than just a source of stress and burden […meanwhile] the overall goal of preserving personhood appears to benefit both [caregiver and care receiver]" (Perry and O'Connor 2002: 60).

The point of this paper is not to devalue professional caregiving, but to call attention to some of the well-researched shortcomings of professional caregiving and propose an interim solution. To address the current problem of caring for the elderly, we must first consider the state of the caregiver. Job satisfaction, understaffing, and turnover rate of caregivers have been addressed and must be acted upon. Suhonen et al. (2012) believes that improving the work satisfaction of nursing home caregivers will ultimately lead to an increase in quality of care provided to the residents and allow caregivers to "stay committed" to their work (Suhonen et al. 2012:487). A parallel assessment from Castle et al. offers up the possibility of "care pairs" (permanent assignment of caregivers to residents) as well as more social activities (Castle et al.2006:9) as solutions. Ultimately, a greater sense of individualized care needs to be the goal of a nursing home. Eaton states that "the typical resident spends at least ninety-one of 112 waking hours a week doing nothing whatsoever in the traditional facility" (Eaton 2000:599), this needs to change. There are benefits to professional caregiving, if family members remain attentive and a part of their loved ones life.

Research has shown that some family members who admit loved ones into caregiving facilities are able to transition their efforts from aiding in their loved ones in tasks such as: "getting in and out of bed, dressing, getting to and from the toilet, bathing, [etc.]" (Ory et al. 1999:181) to relating to their loved ones on a more emotional level. (Alzheimer's Association 2014:33) Furthermore, "residents who receive monthly visits…[achieve] a higher life satisfaction" (Mitchell and Kemp 2000 in Port et al. 2005: 87). This is a very suitable and beneficial arrangement for one with Alzheimer's. However, this is not my target audience. I am primarily concerned with those who have minimal interaction with family members after being placed in a professional caregiving facility but still need the emotional relationship that family members can typically provide. Professional caregivers can develop methods to care for individuals with the illness in ways that transcend personal hygiene and bodily maintenance.

Conclusion

How does one provide healing for Alzheimer's sufferers, such as Leroy, Frank, Maria, or Rita, without having personal histories from which to contextualize their actions? I struggled with this question for some time because I had difficulty separating my understanding of healing from the heavy biomedical influence which has shaped it. Familial caregiving serves as my model for "ideal" caregiving. I suggest that by juxtaposing the literature with my fieldwork one arrives at a particular conclusion, that personhood is congruent to culture in an institutional setting. One must see the person in a historical context.

Figure 1 describes a flow chart that I propose will bridge the gap between caregiver and sufferer.

Figure 1. Non-Familial Caregiving Flowchart

Immersion refers to the initial contact with a sufferer of Alzheimer's. I learned very quickly at the Alzheimer's unit that the disease is a spectrum, and no two patients exhibit the same symptoms or have the same actions. One must immerse themselves in who the person is at that moment in time. One must eschew preconceptions of what they expect the person to do or act like; let the person establish the direction of the relationship. For example: listen to Leroy sing, focus attention on Frank's story, and allow Maria to guide the path of the conversation. In other words, by immersing yourself in the actions of the resident one can establish a sense of personhood in their terms. The discussion of frames of interaction again becomes appropriate here. Just as roles and expectations change from person to person, for example, between friend and parent, expectations of the residents differed from one resident to the next. Understanding frames of interaction, which will best suit the expectation of the resident, is crucial to providing healing communication.

After one arrives at a tentative understanding of how the resident acts and in which ways they prefer to establish a relationship, one can engage with them in different ways. One cannot simply passively sit and listen to residents. Communication is a two-way street, this principle holds for interaction with an individual with Alzheimer's as well. One must look for meaning in what they do; avoid treating everything as a symptom of the disease; analyze reflexes; try to understand personalities; and find competencies. For Leroy, it could be very easy to passively let him perform for you, but responding to his performances in different ways can unveil different avenues of communication. Similarly, although Frank and Rita's stories were difficult to follow, you must pay attention, affirm that you're listening, and ask questions. Rita could usually hold interaction as long as I was engaging her, but breaks in discourse usually signaled a tangential interaction or would seemingly "restart" the conversation. For Frank, his stories typically went in different directions, but the reassurance that you were listening was very important to him. Allow the resident to create and display their personhood with you and not for you.

Exploration, by definition, can lead to undesirable outcomes from time to time. It is important to remember things that agitated residents or gave them a feeling of uneasiness. Adapting your role in the interaction to one that caters to their personhood and wellbeing becomes very important. Here one must remember Perry and O'Connor's themes of "supporting competencies, protecting from incompetence, and strategizing encounters." It's the caregiver's responsibility to know and protect the resident from potentially harmful or distressing episodes. When Maria became distraught about going home, knowing how to calm her in a second's notice was critical. Arriving at a solution for this type of episode obviously required some significant exploration but proved to be invaluable for providing her with a sense of peace, as well as fostering healing communication. It is important not to expect a conversation to make logical sense, rather appreciate it for what it is, a form of interaction. These "expressions of physical affection, and mutual pleasure in appearance, provide an area of meaning for lay care" (Jenkins and Price 1996:89). I became aware of the subtleties of their personhood, just as family members would know them. By serving as this corporeal memory for each person, interaction with each of them every new day, was easier and much more fluid. The healing had become a discourse and the discrimination between the disease and the person began dissolving.

In the end, my limited research has provided basic awareness that non-familial caregivers can form relationships with individuals with Alzheimer's that mimic the care that can be provided from a family member or spouse. The 'non-familial caregiving flow chart' (Figure 1.) is a fusion of Toombs' principles of healing for incurable diseases (relationships with others, communication, connectedness, and culturally prescribed role of personhood) fused with the strategies presented by Perry and O'Connor in spousal caregiving scenarios (maintained continuity, supporting competencies, protecting from incompetence, and strategizing encounters), mixed with my own ethnographic findings (however brief). This flow chart is meant for caregivers who do not know the personal histories of their residents, but wish to establish a relationship focused on meaning and personhood with the sufferer of Alzheimer's.

Research has shown that being at home doesn't necessitate feeling "at home". Cutchin, Owen, and Chang have concluded, "meaningful activity in place is central to overcoming disruptions in the person- place relationship" (Cutchin, Owen, Chang 2003: 242). In other words, for an individual to feel at home in the care they receive, they don't need to be at their physical residence being cared for by a family member. It is meaningful caregiving that can establish this peace of mind. With the adoption of the methods mentioned above, I have no doubt that professional caregiving facilities can become true homes for these persons in need of healing.

References

Alzheimer's Association

2014 2014 Alzheimer's disease facts and figures.Alzheimer's & Dementia, 10(2), e47-e92.

Anderson, Leon

2006 Analytic autoethnography. Journal of Contemporary Ethnography 35(4):373-395.

Basting, Anne Davis

2001 "God Is a Talking Horse": Dementia and the Performance of Self. TDR/The Drama Review 45(3): 78-94.

2006 Arts in Dementia Care:'This is not the end... it's the end of this chapter'. Generations 30(1):16-20.

Brodaty, Henry, Brian Draper, and Lee-Fay Low

2003 Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. Journal of advanced nursing 44(6):583-590.

Castle, Nicholas G., Howard Degenholtz, and Jules Rosen

2006 Determinants of staff job satisfaction of caregivers in two nursing homes in Pennsylvania." BMC Health Services Research 6, (1): 60.

Cocco, Ennio, Monica Gatti, Carlos Augusto de Mendonça Lima, and Vincent Camus

2003 A comparative study of stress and burnout among staff caregivers in nursing homes and acute geriatric wards." International journal of geriatric psychiatry 18(1): 78-85.

Conklin, Beth A., and Lynn M. Morgan

1996 Babies, bodies, and the production of personhood in North America and a native Amazonian society. Ethos 24(4): 657-694.

Cutchin, Malcolm P., Steven V. Owen, and Pei-Fen J. Chang

2003 Becoming "at home" in assisted living residences: Exploring place integration processes. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences58, no. 4 (2003): S234-S243.

Eaton, Susan C.

2000 "Beyond ‛unloving care": Linking human resource management and patient care quality in nursing homes. International Journal of Human Resource Management 11, no. 3 (2000): 591-616.

Ellis, Carolyn, Tony E. Adams, and Arthur P. Bochner.

2011 Autoethnography: an overview. Historical Social Research/Historische Sozialforschung: 273-290.

Geertz, Clifford

1994 Thick description: Toward an interpretive theory of culture. Readings in the philosophy of social science Pp. 213-231.

Harrington, Charlene, David Zimmerman, Sarita L. Karon, James Robinson, and Patricia Beutel

2000 Nursing home staffing and its relationship to deficiencies. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences 55(5): S278-S287.

Jenkins, David, and Bob Price

1996 Dementia and personhood: a focus for care? Journal of Advanced Nursing 24(1):84-90.

Kalis, Annemarie, Maartje HN Schermer, and Johannes JM van Delden

2005 Ideals regarding a good life for nursing home residents with dementia: views of professional caregivers. Nursing ethics 12, (1): 30-42.

Lock, Margaret

2013 The Alzheimer conundrum: Entanglements of dementia and aging. Princeton University Press.

Lopez, Steven Henry

2006 Culture change management in long-term care: A shop-floor view." Politics & Society 34(1): 55-80.

O'Connor, Deborah, Alison Phinney, Andre Smith, Jeff Small, Barbara Purves, Joann Perry, Elisabeth Drance, Martha Donnelly, Habib Chaudhury, and Lynn Beattie

2007 "Personhood in dementia care Developing a research agenda for broadening the vision. Dementia 6(1): 121-142.

Ory, Marcia G., Richard R. Hoffman, Jennifer L. Yee, Sharon Tennstedt, and Richard Schulz

1999 Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist 39(2): 177-186.

Park, Joseph Sung-Yul, and Hiroko Takanashi

2012 Introduction-Reframing Framing: Interaction and the Constitution of Culture and Society. Pragmatics 21(2):185-190.

Perry, JoAnn, and Deborah O'Connor.

2002 Preserving personhood:(re) membering the spouse with dementia*." Family Relations 51(1): 55-62.

Port, Cynthia L., Sheryl Zimmerman, Christianna S. Williams, Debra Dobbs, John S. Preisser, and Sharon Wallace Williams

2005 Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia." The Gerontologist 45 (no. suppl 1): 87-95.

Rahman, Anna N., and John F. Schnelle

2008 The nursing home culture-change movement: Recent past, present, and future directions for research." The Gerontologist 48(2): 142-148.

Singh, Ravinder, Vibha Sharma, and Upmesh Kumar Talwar

2013 Patients with Dementia and Epilepsy: Does Family and Kinship Care Matters?." Advances in Anthropology 3, no. 02 (2013): 55.

Strathern, Andrew, and Pamela J. Stewart

2010 Seeking personhood: anthropological accounts and local concepts in Mount Hagen, Papua New Guinea." Oceania (1998): 170-188.

Strathern, Andrew, and Pamela J. Stewart

2010 Curing and healing: Medical anthropology in global perspective. Durham, NC: Carolina Academic Press, (2010).

Suhonen, Riitta, Andreas Charalambous, Minna Stolt, Jouko Katajisto, and Markku Puro

Caregivers' work satisfaction and individualised care in care settings for older people." Journal of clinical nursing 22(no. 3-4): 479-490.

Tannen, Deborah and Cynthia Wallat.

1987 Interactive frames and knowledge schemas in interaction: Examples from a medical examination/interview." Social Psychology Quarterly ??: 205-216.

Toombs, Kay

2008 Living at the Boundary: Healing and Incurable Illness. 2008 Medical Humanities Lecture. Baylor University, Texas. 15 Oct. 2008. Lecture.

Wang, Kris L., and Carol Hermann

2006 Pilot study to test the effectiveness of healing touch on agitation in people with dementia. Geriatric Nursing 27(1): 34-40.