Intimacy among the Socially Dead:
Examining Intimacy among Institutionalized Elders with Mid to Late Stage Dementia

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Abstract

This paper explores intimate relations between elders living with dementia in long-term care settings. By intimate relations, I am referring to holding hands, cuddling, touch, as well as loving relationships lasting months or years. With elderly populations expected to double over the next twenty years, the number of elders living with dementia and requiring the services of long-term care will also rise. The paper's theoretical framework contrasts views of dementing illness as a social death sentence with observational data suggesting evidence of rich, intimate relations between elders living with mid to late stage dementia in long-term care settings. The data suggests demented residents experience a simultaneous social death and life. While family and friends may distance as the disease progresses, peers living with similar cognitive challenges may engage in intimacy within the long-term care environment. The data challenges the loss of personhood, related to social death. Shorter time frames, lack of past recollection and limited use of language are unique traits of the intimacy examined in this paper. The data was collected through seven months of observation at a large-scale nursing institution and ten years of participant observation at a small, homelike facility.

Key Words: Dementia, Intimacy, Social Death, Personhood, Long-term Care

1. **Introduction**

According to the National Institute of Aging in America, "as many as 2.4 million to 4.5 million Americans have [Alzheimer's Disease]."[1] With estimates for the American elderly population to double over the next twenty years, and the risk of Alzheimer's disease increasing with age, the numbers of elders living with progressive, degenerative neurological diseases will also increase.[2] One effect of progressive neurological diseases is developing dementia. Dementia is a syndrome embodying multiple cognitive deficits, including memory problems and one or more cognitive challenges, such as aphasia or apraxia.[3] Due to the challenges associated with dementing illnesses, including physical, psychological and emotional

strains, institutionalization is not uncommon in the mid to late stages of the disease.[4] Since the numbers of elders with dementing illnesses are likely to increase, so too will the numbers of institutionalized elders.[5] What social reality exists for these institutionalized elders?

2. **Literature Review**

A. Social Death

Literature about the dementing process suggests that individuals with dementia, particularly middle to late stage dementia, experience a social death.[6] The term social death identifies an experience of social isolation and distancing by those considered no longer socially engaged. Glaser and Strauss' work describes this experience of "nonperson" treatment of comatose patients.[7] Sudnow's research explores patient treatment in American hospitals. He pays attention to the "point at which socially relevant attributes of the patient begin permanently to cease to be operative as conditions for treating him, and when he is essentially regarded as already dead."[8] Kastenbaum defines social death according to the lack of social exchange on both ends of the relation.[9] It is "a situation in which there is absence of those behaviors which we would expect to be directed towards a living person and the presence of behaviors we would expect when dealing with a deceased or non-existent person."[10]

An interesting commentary on social death comes from Mulkay, who argues that it is possible to be both socially dead to some and socially alive to others.[11] The simultaneous experience of social death and life resonates with my research among elders living with dementia. My experience in dementia research reveals regularity of simultaneous social death and life. Families often feel that their loved one no longer knows who they are; therefore, they choose to stop visiting. In other situations, demented individuals slowly lose friendships because of their inability to continue to engage in suitable cognitive functioning in activities, such as going out to eat. Preserving conversation and acting socially proper in social settings is often necessary to preserve friendships. In contrast to these engagements of discomfort and loss for both parties, my research suggests social intimacy between demented peers is often more engaged and sustainable.

Sweeting and Gilhooly describe three groups of people who likely experience social death: those in the final stages of a lengthy terminal illness, those who are old and those who experience a loss of essential "personhood."[12] Their argument suggests that individuals living with dementia fall into all three categories and therefore are likely to

experience an intense social death. In settings where demented individuals are living together, the potential for social death is challenged. In my research, I observe peers who are living with cognitive loss as less likely to ostracize others like themselves.

Defining “personhood” is challenging and open to different interpretations. Some definitions concentrate on an individual’s capacity to engage in relationships.[13] Other definitions concentrate on the individual’s capacity to engage in and enjoy life.[14] Kitwood’s work from the 1990s seeks to expand personhood by placing emphasis on the need for a social setting to support the individuals remaining capacities, thus fostering the continued presence of “personhood.”[15] Therefore, personhood relies on the presence of interaction, but may well depend on a supportive environment to exist. Kitwood’s idea of the “malignant social psychology” present for elders living with dementia is intimately connected to social death.[16]This topic is complex and deserves further exploration and research which cannot be accomplished within the limitations of this paper.

B. Intimacy

Research on sexuality among the elderly is limited, and it is generally believed that sex and desire are viewed as appropriate for the young, not the old.[17] The literature on dementia and intimacy is even sparser and can be grouped according to general areas. Some literature focuses on the effect dementia has on sexual behavior, both for the ill individual and their loved one.[18] Other research focuses on sexual behavior considered problematic within institutional settings.[19] Behavioral and pharmacological treatment of sexually inappropriate behavior in individuals with dementia comprises a part of the literature.[20] Yet, research suggests the percentage of the demented population engaged in sexually inappropriate behavior is limited, 1.8% to 7%.[21]Other research explores the effect sexuality and sexual expression of the demented has on the institutional functioning of residential care.[22]

In an attempt to help define intimacy among the demented, I turn to Moss and Schewebel’s articulation of five major relational components: commitment (feelings of closeness, cohesion, and positive regard), affective intimacy (a deep sense of caring, compassion, and positive regard), cognitive intimacy (thinking about and an awareness of another), physical intimacy (sharing physical encounters ranging from proximity to sexuality), and mutuality (a process of exchange).[23] These components will be applied to the findings on intimacy in order to gage the depth of the social exchange.

3. Settings and Method

The objective of the study was to compare data from two different dementia care facilities, specifically examining intimacy between residents.[24] Pine Tree Place existed in a Northeastern town of the United States. The observational unit, one of three in the facility, consisted of approximately thirty residents. The population was Caucasian and included a sex ratio of one male to three females. While the age, socio-economic status and diagnosis of each resident was confidential, most of the population was geriatric and living with diseases resulting in dementing disorders. The degree of dementia varied, but the unit provided care from mid to late stage dementia.

The design of the unit incorporated a continuous walking loop around the perimeter of the living and dining space. Because of the potential for wandering behaviors, the unit was locked. The center of the unit housed the kitchen. The living spaces included two dining areas with tables set family style. The living space incorporated an open area, flanked by two smaller TV rooms. Staff could see throughout the area because of half walls on the living and dining room areas. There was no room, outside bedrooms, offering privacy. The bedrooms were doubles and shared a bath between two rooms.

The second research site, Oceanside Vista, existed in a rural part of the Northeastern United States, ten miles from a town with a population of about twenty thousand. This facility was much smaller, with a maximum capacity of eight residents. The population was Caucasian, with ages ranging from sixty-three to ninety-five, and a male/female ratio ranging from 1:2 to 1:1. The design of the facility included bedrooms on the perimeter and a dining and living space in the central part of the house. One dining area looked out onto the ocean. The outdoors was accessible through a front door leading onto a deck. Oceanside Vista preserved walking areas which led to the ocean and up a wooded lane. The facility was not locked, but instead incorporated motion detectors for security of the residents.[25] Because of the traditional home build of the facility, intimate spaces existed. Residents could spend time on the porch or in the front hall without constant surveillance. Half walls did not exist in the facility.

Over seven months, I produced the Pine Tree Place observational data, resulting in field notes representing nearly four hundred hours of daytime observation. I integrated Atlas.ti in the line by line coding of the data, specific to themes of intimate engagement. The data collected at Oceanside Vista represented ten years of participant observation. My data

collection included informal and formal observations. I intermittently produced field notes, including situations suggesting rich data, which I recorded during or following incidents of intimacy between residents. In addition, I analyzed video data of intimacy among residents at Oceanside Vista. Oceanside Vista collected the data with consent from the residents' Power of Attorneys. The video data and field notes were entered into Atlas.ti for coding, memo generation, and analysis, specific to intimacy.

4. Findings

Residents in each setting engaged in intimacy with one another, disclosing a "continuum of communication"[26] among residents. Some individuals were able to use language and convey meaning, as well as interpret meaning. One touching engagement involved two elderly, demented women. They were friends for many years and lived on different units within the facility. On occasion, staff aided the more ambulatory resident to visit her debilitated friend. After a visit, the staff suggested the ambulatory woman should be getting back to her unit for dinner. The woman teetered over to her friend and gave her a kiss. She looked her friend, hunched over in a wheelchair, right in the eye and said, "I love you." Her friend smiled and replied, "Oh Dear, I love you too!" Both women held one another's hands for some time. This intimate exchange represented two individuals, living with mid to late stage dementia, who were able to use language and understand language. While the exchange may not have been complex, the use of language represents one end of the continuum of communication.

At another level of the continuum of communication, observed intimacy included holding hands. For many residents who were unable to use language as skillfully as the previous example, touch and holding hands represented a form of intimacy. Rather than speaking to another, residents would position themselves to take another person's hand. I witnessed many instances of residents walking or wheeling up to another resident and smiling and taking the person's hand to hold. In these situations, holding hands and touch acted as a means of greeting the other person and sharing an intimate moment. Individuals who may have been able to use language also held hands with individuals when walking or conversing. Intimacy viewed at Pine Tree Place ranged from verbal exchanges expressing love between friends to more progressed individuals relying on touch and hand-holding to engage in intimate exchange.

Data collected at the second site offered similar examples of intimacy between residents. Because of the extended period of data collection (ten years) and my role as participant observer, the depth of data

is greater and more longitudinal. Within this setting, examples of heavily debilitated individuals engaging in shard intimacy occurred regularly. Perhaps because the environment was smaller, relationships thrived.

A significant example of intimacy at Oceanside Vista included a love affair between a man and a woman, both living with middle stage dementia. They were ambulatory and physically healthy, but neither used complex language. Their memories were markedly impaired, resulting in neither individual understanding their full reality. Early in the relationship, the couple flirted with each other across the table, smiling and giggling at each other. As the relationship developed, each individual consciously sought out the other to spend time with. As the relationship continued, the couples desire to be sexually intimate also developed. To my knowledge, sexual intercourse never occurred, however, they often entered one of their bedrooms to undress to their underclothes and cuddle in bed.

The relationship appeared normal to the couple, but was much more alarming to staff and family. Staff expressed concern for the woman's safety, although never witnessing any aggressive behavior. The families tolerated the relationship, but drew the line when the couple wanted to share a bed at nighttime. It was not uncommon to find the two individuals sleeping together before lights out. Now, staff had to wake the gentleman and coax him into his own room until the morning. On many occasions, the couple resisted the staff's attempts to separate them for the night.

As in any intimate relationship, one could identify early flirtation, a lustful buildup, and then the slow normalization of the relationship and finally the decline. The decline occurred when the woman was admitted to a hospital for appendicitis and was absent for one week. Her partner never engaged with her as intimately again. As the two individuals became more compromised in their abilities, the relationship also waned. Until the death of the man, a flirtation and recognition of each other continued, with smiles across the meal table.

It is possible, that because of the dementia, the individuals believed their partner was someone from their past. Other examples of individuals developing relationships with residents whom they referred to as their husband or wife were common. At times, these individuals carried on as another identity. In other circumstances, the falsely identified husband of wife would not play along and these mistaken identities caused discontent for both parties.

Another example of intimacy at Oceanside Vista involved a gentleman who was living with an early onset case of probable Alzheimer's disease. He was in his late sixties and had retired just a few years before

showing signs of memory issues. When this man moved into Oceanside Vista, he had a very strong social network of family and friends. Many friends from his previous employment visited him, took him out for meals and called him on the phone. He had limited interactions with peers at Oceanside Vista. He isolated in his apartment and joined the residents for meals only.

As the disease progressed, his engagements with friends lessened. Outings for meals trailed off and some friends would just visit him at the facility for conversation. Eventually, over three years, because of his disease progression, his friends and family stopped visiting, except on holidays. People no longer called, because of his challenge communicating with language.

While a social death occurred in his life, his engagement with his peers increased. He began to spend more time socializing with his peers. He listened to music with a woman who also enjoyed singing along. This woman was about the same age as the gentleman and living with similar cognitive deficits. She used language more effectively, but lived with significant cognitive confusion. The two enjoyed one another's company. They engaged in a "show and tell" with each other, which amounted to each person showing the other an important personal item, such as a picture, book or music. They would tell each other about the item and the other would listen and then show their item. Their "show and tell" was an intimate exchange in that they concentrated on each other and found a way to express an interest and listen to the other's interest. It was not unusual for the couple to hold hands when sitting together. In addition, the woman would join the man in his sitting room for conversation, music or television.

5. **Discussion**

The continuum of intimate communication, from romantic love affairs to holding hands, touch and facial expression existed in both settings. These findings challenge the theoretical frameworks of social death and personhood. The intimate interactions suggest a different reality than social death. In accordance with Mulkay's definition of simultaneous social death and life, the research settings displayed examples of family members expressing grief and stress over their inability to connect with their loved one. At the same time, the resident carried on an intimate relation with another demented peer. The woman involved in the love affair offered an interesting example. While engaged with her boyfriend, family often commented on how difficult it was to relate to her. The social distancing by family and friends, resulting from the effects of the illness,

such as loss of the use of language, occurred alongside the intimate relationship fostered by peers living with dementia.

To display the significance of these relationships between demented elders, it is worth discussing the reactions of family members. In the love affair, the woman's children competed for her attention during visits. She was far more interested in spending time with her boyfriend, but staff would redirect the gentleman into another activity in order for the children to spend time alone with their mother. In another example, one of the woman's sons became protective and jealous. At a holiday party, the happy couple was dancing when the son arrived. The son walked to his mother to join her on the dance floor, and each man sized up the other, while the woman smiled and danced. The use of verbal language was nonexistent, but the body language was powerful. The son took his mother's hand to dance and the boyfriend began to take the other hand and walk away from the son with his girlfriend.

The relationships and intimacy shared between residents also challenge Sweeting and Gilhooly's third grouping of individuals who suffer the loss of an essential "personhood." Personhood among these individuals is complex and embodies Quinn's requirement for the capacity for relationships. While the residents' cognitive abilities were compromised in both settings, their ability to engage in intimacy was possible.

Whether engaged in a love affair, or just holding hands, both settings provided examples of intimacy. Moss and Schewebel's five major aspects exist in the examples presented. The romantic love affair displayed feelings of closeness, compassion, awareness of the other, physical connection and exchange. The early onset case also shared these elements of intimacy.

In relationship to the more debilitated individuals who held hands and were present with one another, aspects of intimacy presented. Hand-holding encompasses all of the relational components, including cohesion, compassion, an awareness of the other, proximity, and exchange.

In exploring some of the characteristics of these relationships, several unique standards apply. For example, in many of the more progressed cases, the individuals would engage in short interactions. Due perhaps to the neurological challenges to the communication, the interactions could be brief. Also, when the residents interacted with one another, there was generally no expectation of past recollection. The residents would pick up with their exchange and end it without any past context or future expectation. While an outsider may view this as lacking

depth, for the individuals engaged, it seemed appropriate. Living in the present may be a result of the weakening of the neurology, yet it does not deny intimacy among a cohort living with similar issues.

Related to a lack of past recollection, the usage of names was not present. The majority of observed interactions occurred without any name identification. Individuals, such as the couple who shared a love affair, never used names to communicate. Some individuals used endearing terms such as sweetheart and honey.

The final unique aspect of the interpersonal relationships was the limited use of language. In nearly every intimate relation observed at either facility, language was not a central component. Some individuals used language to express meaning, like the two old friends who spoke their love to each other. However, the couple who shared a love affair rarely spoke to one another beyond a few words. Their relationship required very limited language.

The gentleman with early onset Alzheimer's disease used language incompetently. He said words that were not the correct words, or he spoke sentences that made little sense. His woman friend would try to understand, then pick up and continue on with her end of the conversation. Neither party seemed disturbed by the challenges of language. Key to this exchange, and likely to the love affair, was a shared stage of debilitation. For individuals at different stages of the disease process, language barriers can be challenging.

The realm of intimacy among elders living with dementia deserves careful attention and exploration. Redefining how intimacy is perceived among a population living with progressive, neurological debilitation is necessary. The need for human closeness and support at a time when physiological challenges are immense should not seem strange. Yet, elders living with dementia are often viewed as not capable of initiating or maintaining a meaningful intimate relationship. The impact of environment on the development of intimacy among the demented is a necessary area for continued research.

[1] http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/GeneralInfo/#howmany

[2] ibid

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[8] D Sudnow, *Passing On: The Social Organization of Dying*. Prentice Hall, Englewood Cliffs, NJ, 1967, p. 74.

[9] RJ Kastenbaum, 'Psychological Death', In L Pearson (ed.) *Death and Dying*. Case Western Reserve University Press, Cleveland, Ohio, 1969.

[10] Kastenbaum, p. 15.

[11] op. cit.

[12] Sweeting and Gilhooly, pp. 95-99.

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[14] NK Rhoden, 'Litigating Life and Death', *Harvard Law Review*, vol. 102, 1988, pp. 375-446.
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[16] Ibid.
[17] D Aizenberg, et al., 'Attitudes Toward Sexuality Among Nursing Home Residents', *Sexuality and Disability*, vol. 20, no. 3, 2002, p. 188.
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[23] BF Moss and A.I. Schwebel, ' Defining Intimacy in Romantic Relationships', *Family Relations*, vol. 42, no. 1, 1993, pp. 31-37.
[24]This paper further develops research I conducted for a dissertation on "The Culture of Dementia." The research focused on the interpersonal engagements between the residents living with mid to late stage dementing illnesses.

[25] See Wigg (forthcoming), 2010.
[26] Wigg, 2007, p.114.

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