**Letting Go of the Long Goodbye: Applying Disability Studies to Dementia**

Kate Welling Distinguished Scholar Lecture Series in Disability Studies

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*This presentation has accompanying slides, available to view on my website or here:* <http://hyperurl.co/oh9zji>

**[TITLE SLIDE]**

Hello, my name is Hailee Gibbons. I am a two-time Miami alumnae. I graduated in 2008 with a Bachelor’s of Philosophy in Interdisciplinary Studies with a Concentration in Gerontology, Psychology, and Family Studies. At the time, that was the Western College Program, which is now also referred to as Individualized Studies. I then worked for three years in Miami’s Office of Community Engagement and Service. Following that, I received a Master’s of Science in Student Affairs in Higher Education in 2013. I am currently a Doctoral Student in Disability Studies and University Fellow at University of Illinois at Chicago, and my research focuses on intersections of aging and disability and bridging the fields of disability studies and gerontology. My presentation today is titled, “Letting Go of the Long Goodbye: Applying Disability Studies to Dementia.”

#rethinkdementia

**[SLIDE 2]**

Before I begin, I want to honor Kate Welling, for whom this lecture series is named, and her friends Julie Turnbull, and Stephen Smith. I was actually a sophomore at Miami when these students lost their lives in a house fire. While I did not know these students personally, the entire campus was affected by this tragedy. I am very appreciative of the Welling Family continuing Kate’s legacy through their support of Miami’s Disability Studies program, which has given me the opportunity to talk to you today and also has exposed me and so many others to a wonderfully diverse array of scholars who have spoken at Miami over the years about disability studies.

**[SLIDE 3]**

I would like to start with a story.

*When I was 17 years old, I met an 85-year-old woman named Euteva who would profoundly shape the course of my life. As a high school student, I decided I wanted to volunteer. I ended up at Winchester Place Nursing Home in my small Ohio town. I say I ended up there because it was really more of a matter of circumstance than choice. I was a low-income teenager without a car, and the nursing home was one of the only places within walking distance. It was that or the Barbershop Museum. When I first met Euteva, I was told many things about her. I was told she was “demented.” I was told she was “crazy.” I was told she was in a locked ward “for her own good.” I was told I could not “believe” everything she said or “trust” her judgment. I was told her condition was “sad” and “tragic” and “a fate worse than death.” What I was not told was that she was a human being, with thoughts and feelings, worthy of respect and love. That is what Euteva – a supposedly demented, crazy old lady who could not be believed or trusted – taught me, in a way that no one else could.*

Dementia is undoubtedly one of the most feared and heavily stigmatized conditions in modern society. According to the Marist Institute for Public Opinion, “Americans fear developing Alzheimer’s disease more than any other major life-threatening disease, including cancer, stroke, heart disease, and diabetes.” However, fearing dementia is not without consequences, particularly as the number of people with dementia grows.

**[SLIDE 4]**

As Anne Basting noted, *“*We fear dementia. Some of that is natural…but ultimately the fear reflex is making the experience of dementia worse. We are living in the time of dementia. As we live longer than ever before, dementia touches the lives of more of us than ever before” (4). Alzheimer’s disease and other forms of dementia are terrifying to many aging adults, because dementia is depicted as a slow death marked by the progressive loss of mental and physical function, independence, and selfhood. As Gilliard, Means, Beattie, and Daker-White stated, dementia is seen as an illness “without hope and beyond help” (574).

**[SLIDE 5]**

These representations are rooted in a medical framework but have permeated various aspects of culture. Gerontology, as a discipline, has promoted ideas such as “successful aging,” “normal aging,” and “healthy aging” as ideals for which to strive. One of the core areas of research in gerontology has been trying to understand “normal aging.” To do this, researchers intended to prove that the experience of decline was age-related rather than age-caused, and thus, not an inevitable part of the aging process. To further the idea that disease and disability are not part of “normal aging,” older adults who did experience disease and disability had their aging processes classified in another category—“pathological aging” or “abnormal aging.” Due to the specific impairments associated with dementia, it is considered a prime example of pathological and abnormal aging, and the antithesis of successful aging.

Rowe and Kahn argued that gerontologists should focus less on dichotomies of “normal aging” and “abnormal aging,” and rather recognize the variability in aging and emphasize older adults “aging well.” This change in focus resulted in an idealized form of aging, termed “successful aging.” Rowe and Kahn defined successful aging as the ability to maintain: (1) “low risk of disease and disease-related disability;” (2) “high mental and physical function;” and (3) “active engagement in life” (38). Based on this definition, dementia does not fit the framework of successful aging, as it is regarded as a tragic disease that robs its victims of all function and results in complete disengagement from life. As Daffer posited, successful aging could be defined as “eluding the development of dementia” (1102).

**[SLIDE 6]**

More recently, in contemporary gerontology, there has been increased interest in what has been termed the third age. The third age generally refers to the period between the departure from the labor force and the onset of significant impairment, and as such, it has been marked as a time of health and vitality. Conversely, the fourth age is viewed as a time of increasing frailty and dependence, as the “onset of serious infirmity” marks the transition from the third age to the fourth. According to Gilleard and Higgs, “The fear of the fourth age is a fear of passing beyond any possibility of agency, human intimacy, or social exchange, of becoming impacted within the death of the social, a hyper-reality from which there is no reality to return”. Gilleard and Higgs asserted that this fear turns the fourth age into a “black hole,” in which one has passed beyond the social world (125). Given that dementia is already characterized as a living death, it is firmly rooted in societal fears of the fourth age and deep later life.

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In the light of these widespread cultural fears and aversions to aging and dementia, some gerontologists, aging studies scholars, and neurologists have called for individuals to change the way they view and act toward people with dementia. However, disability studies as a field has been largely uninvolved in this work. As Priestley observed, “Although…dementia is among the most common forms of impairment in older people, there has been relatively little research in this area from a disability studies or social model perspective.”

Disability studies lack of engagement with dementia is apparent when one considers that few disability studies theories consider old age, the process of aging, or life course perspectives. Much of the work in disability studies has been constructed within a “generational system” that favors and emphasizes youth and middle-aged adulthood and the roles associated with these stages of life, such as education and employment.

At the same time, few gerontologists or aging studies scholars have used disability studies perspectives. Despite scholars increasingly stressing the importance of interdisciplinary theory in gerontology and aging studies, current interdisciplinary work most frequently draws from traditional disciplines, such as biology, psychology, sociology, and political science, and while there has been an increase in the use of critical theory, feminist perspectives, and postmodernism, disability studies is noticeably absent. Exploring dementia through a disability studies lens bridges the fields of gerontology/aging studies and disability studies and, by doing so, opens up possibilities for how we view dementia and treat people with dementia.

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In this talk, I explore how applying a disability studies lens to dementia might open up new possibilities for the way people with dementia are conceptualized and treated. I first define dementia and discuss current discourse on dementia. Then, I examine dementia using four theories and frameworks in disability studies: the social model of disability, the political/relational model of disability, crip time, and rhetoricty. In order to substantiate the idea of theoretical integration, I support my analysis with gerontological theories, and also note when gerontological theories significantly differ from disability studies theories. Additionally, I intersperse my analysis with personal stories about dementia for several reasons. First, I am indebted to the many people with dementia I have known who have influenced me in my thinking and I hope sharing these stories will better illustrate my points. Second, lived experience intersects with and enhances theoretical understanding. This dynamic interplay between theory and practice highlights the ways in which praxis is enacted. Third, sharing these stories centers the lives of people with dementia, which contributes to their (re)humanization.

**[SLIDE 9]**

I will now briefly discuss the definitions and discourses surrounding dementia.

**[SLIDE 10]**

DEFINING DEMENTIA

 Despite its common usage in everyday life, dementia is difficult to define. As Zeilig observed, “Even in medical and scientific texts, dementia is conceptually slippery; it retreats from and resists definition…[Dementia] cannot be easily defined because [it has] been subject to subtly changing psychiatric, biomedical, and social/cultural stories”. In other words, although dementia typically has a medicalized definition, it is also subject to many social and cultural understandings. The term “dementia” is from the Latin “de mentis” which means “out of one’s mind.” Broadly speaking, dementia is an umbrella term for a range of neurocognitive conditions. Dementia is most frequently associated with memory loss, but also manifests in other ways, such as: experiencing confusion of time or place; struggling to complete familiar tasks at home or work; having difficulty planning or problem solving; having problems with speaking or writing; exhibiting poor judgment; withdrawing from social activities; and experiencing changes in mood or personality. The most common form of dementia is Alzheimer’s disease, and older adults are the most likely age group to experience dementia. Currently, more than 6.8 million people in the United States have some form of dementia (National Institute of Neurological Disorders and Stroke).

**[SLIDE 11]**

 The current discourse on dementia is highly medicalized. Although a detailed historical analysis is beyond the scope of this talk, it is important to note that dementia was not always viewed as a disease. Dementia used to be synonymous with the term “senility,” and dementia was viewed as a “normal” outcome of aging. Over time, various groups, including medical experts and gerontologists, engaged in efforts to separate “normal aging” from “pathological aging,” thereby furthering the medicalization of dementia. Dementia is now firmly rooted in a biomedical framework, and it is likely that the majority of people feel comfortable with its classification as a medical disease. After all, if dementia is a disease, then there is a possibility it can be treated and, by extension, eradicated. As Harding and Palfrey noted, “Society needs dementia to be medicalized, as, if it is classified as a disease, it holds out the prospect of a cure for aging and for death.”

In addition to current discourse on dementia being medicalized, it is also heavily militarized. The quest for a cure is likened to “waging a war” against a disease that “robs” and “ravages” the minds of its older “victims”. Individuals are constantly told one must “fight,” “beat,” and “end” dementia—and one can do this only by donating money to the medical industrial complex.

It is also worth noting that the assertion that “ending” dementia is a personal responsibility, furthered through the mandate to donate to non-profit and medical organizations, is an enactment of neoliberal ideology, or the privatizing of social issues and social identities. For instance, a recent article in *The* *Washington Post* covers how increasing numbers of people with dementia are speaking out in public spaces. However, the activism they are engaging in focuses predominately on increasing funding for treatments and cures. Hence, dementia is positioned as something that individuals need to "confront," "fight," "beat," and "end" – on their own, without state support.

 These medicalized, militarized, and privatized perspectives result in a focus on the disease and not the person, ultimately contributing to the dehumanization of people with dementia. This dehumanization is furthered by a cultural focus on suffering, pain, and despair. This critique is not to say that people with dementia do not experience suffering, pain, or despair. Rather, it is to point out that their experiences are not limited to these feelings.

**[SLIDE 12]**

People with dementia are also dehumanized because others often link dementia with a loss of personhood. This depersonalization of people with dementia is largely due to the memory loss that is characteristic of the condition. Basting explained:

Memory is how we store and retrieve our experiences, from the mundane to the profound. When we retrieve memory, we create story. We come to understand ourselves, others, and the world around us by listening to and telling stories. This process of storing and retrieving and retelling experiences enables us to respond to new experiences, apply what we know, and learn and grow from such encounters. It enables us to track our experiences across time, form a narrative about what those experiences mean, and create a sense of “self” in time, based on that narrative.

 Therefore, individuals strongly link identity and sense of self to memory. As a result, loss of memory equates to loss of self, which is why dementia is frequently depicted as a “living death.” Common misnomers for dementia include “the never-ending funeral,” “the long goodbye,” and “a slow unraveling of the self.” Dehumanization places the condition or “disease” of dementia at the center of discourse and society, and individuals with dementia at the margins.

**[SLIDE 13]**

However, disability studies offers new ways to rethink and challenge these dominant discourses.

**[SLIDE 14]**

THE SOCIAL MODEL OF DISABILITY

**[SLIDE 15]**

The social model of disability is considered one of the founding theories of Disability Studies, and has been the most frequently cited model in dialogues about using Disability Studies to conceptualize dementia. The social model “locates disability within society: in the *built environment* and the *values* and *social practices* which *discriminate* against people.” Crow defined disability under the social model as “the loss or limitation of opportunities resulting from direct and indirect discrimination,” and stated that social change (or the removal of disabling barriers) was the solution to disadvantages rather than treating or curing impairment. The social model dictates that the problem of disability rests not with the person, but with society, which has been empowering for individuals with disabilities and has contributed significantly to the Disability Rights Movement.

The social model of disability is similar to Lawton’s groundbreaking ecological model, which is a key framework in environmental gerontology. However, the ecological model focuses on changing the environment and, if possible, increasing the person’s capacities. Since we cannot cure dementia, the ecological model would not suggest increasing the person’s capacities, and focus on the environment. This is a practical approach, not rooted in a human rights and social justice perspective. Conversely, in the social model, the fact that one cannot “fix” or “cure” dementia is irrelevant. Regardless of a person with dementia’s capacities or prognosis, the scenario does not change: the problem is the inaccessible environment and attitudinal barriers, and the solution is to alter the environment and address oppressive attitudes.

**[SLIDE 16]**

Analyzing dementia through the social model challenges dominant societal views of identity, personhood, and quality of life. As society presently defines these concepts, it is unsurprising that dementia is sometimes described as a “fate worse than death.” Leaving this viewpoint unchallenged prevents individuals from reimagining the ways people with dementia can retain a sense of selfhood and experience satisfaction and happiness.

Furthermore, current dominant perspectives on dementia emphasize how the symptoms of dementia create challenges and problems for people with dementia. The social model offers a way to demonstrate how environmental and attitudinal barriers disable people with dementia. To underscore this point, I draw upon a personal experience about Maureen, a person with dementia with whom I worked.

*I’m sitting at a table in the dining room in Assisted Living when I notice Maureen is not there. “Where is Maureen, the Teenage Beauty Queen?” I ask, using Maureen’s favorite nickname. Edna looks down at her hands and does not respond. Angie quickly takes another bite of food. Muriel finally leans over and whispers, “She is gone.” She then dramatically adds, “They put her in the Memory Unit.” Toni says in a matter of fact tone, “It is about time.” Unsure of how to respond to Toni’s comment, I ask, “Has anyone gone to visit her since she moved?” “Heavens no, child!” Marge looks at me as though I should be put in the Memory Unit too. “You only go there if you have to!”*

This story demonstrates how one of the “symptoms” of dementia—withdrawing socially—is actually socially constructed, and not due to cognitive impairment alone. In other words, examining this phenomenon through the social model illustrates how people do not withdraw simply due to their impairment. While the impairment may be a factor, many people with dementia, their partners, and their caregivers describe how friends and family actually withdraw from them or create unwelcoming spaces. These spaces may be unwelcoming for people with dementia due to sensory reasons (e.g., large crowds, loud noises, over-stimulation) or due to prejudice and discrimination (e.g., judgment, lack of understanding, impatience, exclusion).

The social model can also help us reject the idea that people with dementia are “burdens” or “problems” by highlighting the lack of services and supports available to assist people with dementia living in the community. For example, there are many types of assistive technology that could allow a person with dementia to live in their own home for a longer period of time. These technologies range from low-tech (e.g., reminder devices, medication organizers) to high tech (e.g., a stove that turns off automatically after being left on for too long). However, many people are not educated about these options and some of the more high-tech technologies are often not readily available or affordable. Thus, the social model asks people to consider ways to change the environment and space in which a person with dementia lives.

Several scholars have advocated for using a Disability Studies lens to transform understandings of dementia, and have predominantly highlighted the social model as Disability Studies’ primary contribution. However, as these scholars recognized, the social model has several limitations. For example, it denies individual voice, rejects medical ways of thinking, and ignores that impairment can cause issues, pain, and suffering.

**[SLIDE 17]**

The political/relational model of disability offers ways to address some of these shortcomings.

**[SLIDE 18]**

Kafer advanced the political/relational model as a “hybrid” model, which “builds on social and minority model frameworks but reads them through feminist and queer critiques of identity.” The political/relational model views disability in a way that is similar to the social model, with a comparable focus on social change and political transformation. However, the social model distinguishes between impairment and disability. It claims that impairments are biological physical or mental limitations, whereas disability is socially constructed through inaccessible environments and attitudinal barriers. The political/relational model recognizes that both impairment and disability are social constructions. In other words, the political/relational model views impairment and disability as subject to the same social meanings, understandings, and contexts.

Additionally, while the social model is often viewed as the antithesis of the Medical Model, the political/relational model does not completely reject medical intervention. Instead, as Kafer stated:

it recognizes instead that medical representations, diagnoses, and treatments of bodily variation are imbued with ideological biases about what constitutes normalcy and deviance. In doing so, it recognizes the possibility of simultaneously desiring to be cured…and to be identified and allied with disabled people.

As a result, the political/relational model creates space to recognize, discuss, and even mourn impairment, pain, and loss of function. In doing so, the political/relational model seeks to include disabled people whom the social model has overlooked or marginalized.

**[SLIDE 19]**

An important aspect of the political/relational model for dementia is the focus on relationships, as “disability is experienced in and through relationships; it does not occur in isolation.” Dementia offers a unique way of illustrating this point. As previously mentioned, dementia is often depicted as a “living death” and “long goodbye.” Boss observed that caregivers frequently engage in “premature closure,” and often make claims such as “she is already dead to me.” Reverend Pat Robertson, a high profile religious leader in the United States, proclaimed that divorcing a spouse with Alzheimer’s is acceptable because dementia itself is “a kind of death.” On the dementia sub-group for the social news network site Reddit, people post about “mourning a husband who has not yet passed,” “shaking hands with death,” and “watching [loved ones] slip away.”

In all of these cases, people with dementia are being described as dead when they are still alive because people are grieving the loss of how they viewed or conceptualized that person, and consequently also grieving the loss of how they made meaning of that specific relationship. A person with dementia forgetting someone whom they recently met would likely be viewed and reacted to differently than a person with dementia forgetting a loved one they have known for many years. In my own personal experience as a volunteer in dementia units of nursing homes, I met many people with dementia, none of whom remembered me, and it never bothered me; however, I would likely have felt differently if one of them was my family member or close friend. This phenomenon supports Kafer’s notion that disability is highly relational, rather than simply a characteristic of a person or a result of the environment.

When one views disability as relational, one must also consider the “social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being”, and then, relatedly, how to overcome that exclusion and stigmatization. One way to do this is by reexamining how one views change in relationships. Individuals change throughout their life course, but changes brought by dementia may be more difficult to accept due to their seemingly radical nature. Some people say that friends and partners either “grow together” or “grow apart.” Similarly, how might one be able to think of ways to grow together with loved ones with dementia rather than growing apart due to the changes dementia may bring? How might one, in essence, perpetually (re)build relationships, taking into account the short-term and long-term changes people experience as a result of dementia? Even if a relationship with a person with dementia has changed completely, how can one still maintain their personhood and value their feelings and thoughts?

**[SLIDE 20]**

CRIP TIME

One possible way to reconceptualize our relationships with people with dementia is to focus on what that individual needs in that particular moment and time, and this is where crip time may inform our thinking.

**[SLIDE 21]**

Crip time is a part of disability culture that challenges normative views and constructions of time. According to Kafer:

Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of “how long things take” are based on very particular minds and bodies…Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.

For people with dementia, Kitwood named “five essential components to personal and social relationships: comfort, attachment, inclusion, occupation, and identity.” However, these needs may be constantly changing from moment to moment. Kafer discussed the temporal nature of disability, and articulated that in response to the temporal plasticity of disability, crip time is about, among other things, flexibility.

**[SLIDE 22]**

I offer a way of extending Kafer’s work on crip time by advocating for “dementia time,” which is about focusing on that particular moment in time and place and remaining flexible as moments pass and needs change. For instance, I met many people with dementia in nursing homes who forgot who I was as soon as I left the room. However, as I got to know them better, I would often reconnect with them over similar topics. Some people loved to talk about their careers, others liked to talk about their families, and others liked to talk about their interests and hobbies. As stories emerged (sometimes at unexpected times), I would remember them and use them to start conversations at later points in time. For example, Maureen loved talking about fashion. Every time I met her, I would talk to her about what she was wearing and her jewelry. Another woman, Rebecca, was a retired school teacher. I would often bring teaching up to her or talk about working with children. Even when Rebecca did not remember any stories about her days as a teacher, she would still express sentiments such as, “Children are wonderful,” and “I love children.” Doing this undoubtedly requires patience, as one may repeatedly engage in similar conversations. However, the important aspect of the interaction to focus on is the connection being built between oneself and an individual with dementia in that moment in time, and the happiness it brings that individual to talk about something they love. This is just one strategy for rebuilding relationships and living in dementia time.

Another possibility is to consider alternate realities as a part of dementia time. What makes one’s reality “true” and “objective?” If one can acknowledge the possibility of multiple or alternate realities, one can understand that people with dementia may be operating within their own reality that is just as meaningful. To demonstrate, I would like to share a story about an alternate reality that was incredibly significant for a woman with dementia and me.

*As I walk down the dimly lit hall with buzzing fluorescent lights, nervousness creeps up on me. I have never been down this ward before – the nurses at Winchester Place Nursing Home claim it is for “the most severe cases.” A woman wearing a long, white nightgown is shuffling slowly toward me. I weakly smile at her, still feeling very unsure. Suddenly she hugs me, tightly wrapping her arms around me. She whispers in my ear, “You came, you came! You are finally here!” I realize she is crying tears of joy. I wonder who she thinks I am, and almost as if on cue, she tells me. “I told everyone my daughter would come, and here you are!” She is still holding me, and I, a teenager with an unloving and abusive father, relish in how warm and tender it feels. She whispers to me, “I love you.” I look back at her and say, “I love you too.” Later, a friend chastises me for “lying” but I never saw it as a lie. In that moment, in that alternate reality, we both felt loved.*

Hence, trying to understand people with dementia’s reality in that moment and time and thus valuing what they think and say as part of that reality is another way to perpetually rebuild connections. However, in order to value what people with dementia think and say, it is important to consider why people often disregard and discredit people with dementia’s thoughts and statements in the first place.

**[SLIDE 23]**

Using a disability studies lens demonstrates that one primary reason is because people with dementia lack rhetoricity.

**[SLIDE 24]**

People with dementia are often dismissed, ignored, and avoided because they, like other people with mental disabilities, are denied rhetoricty. Price explained:

The failure to make sense, as measured against and by those with “normal” minds, means a loss of personhood…Prendergast marks this oppression with the term *rhetoricity* (202): that is, the ability to be received as a valid human subject. People with mental disabilities lack rhetoricity; we are rhetorically disabled. To lack rhetoricity is to lack all basic freedoms and rights, including the freedom to express ourselves and the right to be listened to.

People with dementia are primarily construed as severely lacking rhetoricity because of the defining characteristic of dementia—memory loss. To illustrate, I now share a story about Annette, a woman with dementia who repeatedly had her opinions and concerns ignored and denied due to her dementia.

*Annette, whom I visit with regularly at Winchester Place Nursing Home, complains to me for the third or fourth time that one of the orderlies has been taking things from her room. I report this to the head nurse, who looks at me like I am clueless, puts her hand on my shoulder, and says in a condescending tone, “Oh, honey – you can’t believe a thing any of these people say.” But when Annette tells me she is so happy to see me and spend time with me, I believe her.*

Thus, the general view is that people who are unable to remember cannot provide a “reliable” or “accurate” account. This belief often leads to the idea that people with dementia are incompetent, child-like, and clueless. A story that demonstrates this point involves a woman named Bettie.

*Bettie has been carrying around a baby doll for months, ever since she woke up in the hospital after falling and mistakenly thought she was there to give birth to her children, most of whom are in their 60s now. She almost always has the baby doll lovingly cradled in her arm. One day I notice she is not carrying it but say nothing. It is her choice after all, and I figure maybe today she just does not feel like it. But a nurse making her rounds notices and says to her in a high-pitched voice that one might use on a toddler, “Sweetheart! Where’s your baby?” Bettie glares up at her and says, “I know it’s a baby doll, I’m not stupid!” The nurse, taken aback, hurriedly leaves the room as I stifle a laugh.*

While the nurse in this story likely did not have ill intentions, the interaction suggestions that she infantilized Bettie, and assumed Bettie never knew what was going on around her due to her memory loss, rather than viewing Bettie as a person whose needs and ways of understanding the world changed moment-to-moment, as in dementia time.

Furthermore, in addition to often having issues with memory, people with dementia are also frequently diagnosed with aphasia. Aphasia is classified as a communication disorder that impedes people’s ability to use or understand words. Typically, people with aphasia do not realize they are not “making sense” to others, which makes communication frustrating for them.

Aphasia, in addition to memory loss, often furthers the perceived lack of rhetoricity. Being denied rhetoricity is not only isolating, but also dehumanizing. According to Price, “We speak from positions that are assumed to be subhuman, even non-human; and therefore, when we speak, our words go unheeded. In concrete terms…people with mental disabilities are presumed not to be competent, nor understandable, nor valuable, nor whole.” Macdougall argued that conversations with people with dementia make more sense than people realize, particularly if people attend to the idea of alternate realities. The important aspect of dialogue with people with dementia is not logic or rationality, but rather listening, engaging, and establishing connectivity. I exemplify this point with another story about Bettie.

*Bettie approaches me as soon as I enter the room and grabs my arm very tightly. Her eyes are wide and she looks very concerned. “Did you take the lamp to the doghouse?” she asks. I pause, trying to determine what she is feeling. She repeats the question, this time sounding even more anxious. “Did you take the lamp to the doghouse?” I do not know what she is attempting to communicate but I can tell from her tone and body language that it is really important to her and I feel it is wrong to ignore her question even though I cannot interpret her words. “Yes, I did,” I answer. Her eyes get even wider. “You did!” she cries. “No!” I quickly correct myself. “I did not take it.” She sighs with relief and smiles. “Oh good. Thank you so much dear.” She squeezes my hand and smiles up at me, and I smile back.*

Thus, it is essential to create moments and spaces in which the person with dementia’s rhetoricity is not denied. This act will not be simple, as it will call on people to suspend their judgment about what is “real,” “rational,” “logical,” and “correct.” But doing so will do more than allow people to connect on a deeper level with people with dementia, it will also help people remember that the voices, feelings, thoughts, and ideas of people with dementia are valid and meaningful.

**[SLIDE 25]**

CONCLUSION

In this lecture, I analyzed dementia through four theories and frameworks in disability studies—the social model of disability, the political/relational model of disability, crip time, and rhetoricity.

**[SLIDE 26]**

My goal in using a disability studies lens to reinterpret dementia is twofold. First, I want to consider ways to integrate gerontological theory and disability studies theory. Second, I want to explore new alternatives and build on existing alternatives for how we as a society conceptualize and treat people with dementia. Accordingly, in addition to providing an academic and intellectual critique of how society views dementia, I have also tried to offer up ways that we might enact theory in practice. I did this by drawing from my own personal experiences working alongside people with dementia. In doing so, I was able to connect theory and practice, as well as center the voices of those with dementia, thereby resisting normative understandings that they have nothing of value to share with “the rest of us.”

The importance of recognizing the humanity of people with dementia is a lesson I was fortunate to learn early. It is my hope that all the stories I have shared, as well as the theories these stories have informed, will now enhance future theory and practice.

In conclusion, it is important to keep in mind that societal conceptualizations of dementia do not need to be fixed or static. Dementia was not always subject to biomedical interpretations and understandings, as it was considered a “normal” part of aging. Perhaps it is time for a new evolution in the history of dementia; one in which dementia is not considered a tragic disease without a cure, but rather a disability, subject to societal meanings and cultural contexts. Doing so would certainly benefit the field of gerontology, which is currently limited in its analysis of disability by typologies of aging, such as “normal aging,” “successful aging,” and “pathological aging.” Furthermore, viewing dementia as a disability also opens up new possibilities for disability studies and the disability rights movement. The timing is ideal, as people with dementia are increasingly advocating for their rights. Additionally, involving people with dementia challenges disability studies to consider how we include or exclude people with “severe” mental and neurological impairments on a broader scale.

As a society, we must constantly be examining, questioning, and challenging our view of dementia and how they affect the lives of people with dementia. Theoretical integration would benefit the fields of gerontology/aging studies and disability studies. More importantly, it would hopefully ultimately enhance the lives of people who experience dementia and other impairments, whether recently acquired or lifelong, in later life.

**[SLIDE 27]**

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It is important to thank the many people with dementia I have known who have shaped my thinking about dementia and challenged me to think outside the box of normalcy: Annette, Rebecca, Maureen, Bettie, Steve, Richard, and many others.

**[SLIDE 28]**

Questions?

Stay Connected! Continue the conversation: #rethinkdementia