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Dementia in the Context of Disability

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Abstract

Patients and caregivers often associate dementia with devastation and a loss of productive contribution to society. People with dementia are often depicted as confused individuals struggling through embarrassing episodes, followed by a loss of independence. The burden and devastation of the diagnosis on the families of people with dementia is exacerbated by their assumption of the role of caregiver with inadequate preparation or training. Disability scholars, in contrast, offer physical and occupational therapists a non-tragic view of disability that recognizes the importance of countering the stigma and discrimination that too often accompany dementia. This case example of a woman diagnosed with dementia provides insight into the negative impact of these tragic, dependent views of dementia throughout and following the diagnosis process. Viewing her experiences through the lens of disability scholarship can increase awareness and improve the quality of care on the part of both therapists and family caregivers.

Keywords: caregivers, caregiving, dementia, disability studies

Dementia in the Context of Disability

Imagine yourself in a time in your life when, like Sarah B., you begin to suspect that you are slowly losing your memory. The unintended glances, sighs, and comments from your loved ones seem to confirm your suspicions and lead to embarrassment and fear as you grow to realize that there is a problem. Soon arrives the dreaded moment when your child suggests that you get tested for dementia. You finally muster up the courage to go through the process of testing only to have your fears blatantly confirmed as you complete tests that make you feel stupid, inadequate, and unimportant. After hours of this grueling ordeal, the physician reviews the results, calls you in for another appointment, and pronounces the verdict: dementia. You return home feeling helpless, alone, scared, and still stupid. You also start to overhear family conversations planning your future. Gradually your family members convince you that your memory loss and the consequent safety concerns require that you be placed in a supervised home setting. Once you get to this “better place,” the professionals and caregivers assume they know what is best for you, and you notice that they slowly stop asking your opinion on things and seem to value your family members’ opinions over yours. They make decisions about what they think you would like to do and events you should attend and talk you into attending even when you don’t want to. They do not seem to understand or care that you would prefer to be left alone to watch your favorite TV shows with your best friend, your dog, and munch on your favorite if unhealthy treats every once in a while. You just want to be, and they just want to help.

This push and pull between the lived experience of Sarah B. (pseudonym) and the best intentions of her caregivers illustrates the tension between the predominant medical view of dementia and the social view of dementia advocated by many scholars within the field of disability scholarship (Swain, French, & Cameron, 2003). Medically, dementia of the

progressive type is defined as a chronic, progressive disease with an irreversible deterioration of cognition that typically advances over 8-10 years (Alzheimer's Society, 2013; Merck Manual for Health Care Professionals, 2013). As numerous scholars have observed, most of the medical literature portrays the disability associated with dementia as a personal tragedy (Swain et al., 2003; Volicer, 2005) for both persons with dementia and their families (Dooley & Hinojosa, 2004; Gitlin, et al., 2003; Miyamoto, Tachimori, & Ito, 2010). Further, the depictions that appear in the media typically cast this disease as destructive, mysterious, frightening, unforgiving, crippling, and ultimately fatal (Goldberg, 1996; Hyman, 2008; Media Smarts, n.d., National Institute on Aging, 2012). The stereotypical portrayal of a person with dementia is that of an older, well-dressed Caucasian with a blank stare walking aimlessly down a hall or sometimes being hugged by a small child (Gray-Vickrey, 2009). Indeed, the word *dementia* itself is synonymous with terms such as *mania*, *madness*, *insanity*, and *lunacy*. Such depictions and associations lead to the common belief that all stages of dementia present a devastating loss of cognition and dependence on others.

However, the actual course of dementia is gradual and varied among individuals, with wide-ranging implications for people with dementia and their familial and social environment. For example, in the early stages of dementia, people typically experience only a mild cognitive decline, leading to forgetfulness, misplacing or having trouble finding commonly used objects, and difficulty with word-finding that affects their communication skills and therefore their social functioning (Alzheimer's Association, 2013; Alzheimer's Society, 2013). Only in the middle stages of the illness do these memory impairments become more obvious and serious, manifesting as difficulty with recalling recent and some historical events, completing complex mathematical computations, planning complex tasks, and performing basic and instrumental

activities of daily living (ADLs). People with dementia are often aware of their decline in memory, which has a direct impact on their desire and ability to engage socially. In the later stages of dementia they may also experience difficulties with spatial and temporal orientation, basic arithmetic, basic ADLs, awareness of recent and past events, and distinguishing between familiar and unfamiliar people. These changes can lead to behavior challenges, safety concerns, significant personality changes, disrupted roles and routines, and a decline in overall well-being (Alzheimer's Association, 2014). As the disease progresses, dementia care becomes a necessity. In fact, the Alzheimer's Association (2012) estimates that unpaid family members provide 80% of care for people with dementia, which if paid would amount to over \$210 billion annually.

Although a diagnosis of progressive dementia is indeed fatal and its effects increasingly disabling, much of the medical literature fails to view the disease as anything other than a tragic prognosis—one that has negative effects not only on the person diagnosed but also on the immediate family. Disability scholars, in contrast, adopt a non-tragic view of disability, describing dementia less strictly in terms of its physical manifestations than as a long-term limitation of the physical, mental, or social functioning and focusing instead on the physical and social barriers that limit the person with dementia's engagement with the community (Bartlett & O'Connor, 2007). The medical model of care often results in people with disabilities undergoing various tests, treatments, and procedures in a manner that tends to continually remind them of their limitations and their role as "patient." Thus an understanding of some concepts from a social model of disability can positively influence physical and occupational therapists' interactions with people with disabilities and their family members. This knowledge has the potential to improve the quality of client care by decreasing the unintended consequences of well-intending clinicians who view disability as undesirable and try to "fix" or reduce symptoms,

which then feeds the negative “patient” identity and underscores the power of the clinician (Kielhofner, 2005). The field of disability scholarship is broad and contains some controversial points of view. For example, there is an uncertainty that lends to disagreement when distinguishing impairment as it relates to occupational engagement and implications related to policy and activism (Asch, 2001). Even so, seeing people with disabilities through a non-tragic lens of disability and exploring their unique experiences through this lens can improve the awareness of physical and occupational therapists in this area of practice. Emerging evidence also suggests that seeing dementia through a social model of disability can improve the communication skills of therapists in caring for both people with dementia and their family caregivers (Bartlett & O’Connor, 2007; Gilliard, Means, Beattie, & Daker-White, 2005).

Although the dynamics of caregiving following the onset of dementia have a longitudinal impact on the family and social context of the person with dementia, little has been written about the positive experiences of those with dementia and their caregivers (Allen, Kwak, Lokken, & Haley, 2003; Boerner, Schulz, & Horowitz, 2004; Cohen, Colantonio, & Vernich, 2002). This paper aims to explore the personal, social, cultural, and environmental experiences of one such person with dementia through the lens of disability scholarship in hopes of providing insight into the everyday dealings of people with dementia that can be useful to both therapists and family caregivers and improve the quality of care and of life for such patients.

Case Example

The particular mother-daughter dyad interviewed for this illustrative case example, Sarah B., and her daughter, Mary S. (also not her real name), were selected because of an established rapport between them and the authors that had developed during a prior study of people with dementia and their caregivers. The interview, which took about an hour, was conducted

informally at a mutually agreed-upon restaurant over a cup of coffee and some bakery treats, and followed principles in the Declaration of Helsinki – a set of ethical principles that guide medical personnel interactions in regards to human research participants. The purpose of this interview was to explore the client and caregiver experiences of diagnosis; services that were used or were desired; an understanding of each of their unique backgrounds, interests, and roles; how they each managed their roles given their new context and their reflections on the past; and their views of present and future. The interview was audio recorded and transcribed verbatim. Coding through qualitative content analysis for comments focused on four main areas discussed in disability scholarship including power, identity, temporality, and injustice. In addition, emerging areas highlighted the process of the medical diagnosis, the physical context, and caregiver burden. These themes demonstrate how specific concepts from disability scholarship can improve the awareness of physical and occupational therapists, and caregivers that can potentially improve the quality of life and treatment of clients with dementia and their families.

At the time of the interview, Sarah was a 70-year-old middle-class Caucasian woman born and raised in a small town in the Midwest. She had attained a high school diploma and worked as an administrative assistant for 25 years. She rated her health as good, with no major health issues except minor cardiac concerns and her recent diagnosis of dementia in May 2010. When Sarah was first diagnosed, she moved from her home in another state into her daughter's home so that Mary could provide care for her. Mary is a single, working mom of older children and the main caregiver for her mother. She receives limited support from others in her family, and therefore recently placed her mother in a supervised care/assisted nursing facility where she is expected to stay until her insurance coverage for this type of care is exhausted.

Medical Diagnosis

After her first symptoms started to emerge, Sarah underwent multiple diagnostic tests to determine the cause and was referred to a neurologist who diagnosed her with early-stage dementia. Sarah could not remember receiving the actual diagnosis, nor could she share much from recent memory; however, during the interview Mary filled in some of the gaps. At the time of the interview, Sarah met all of the criteria for early-stage dementia and variable criteria for middle-stage dementia as classified by the Alzheimer's Association (2013). A recurring theme during our interview was how distressing and difficult receiving the official medical diagnosis had been for both women, illustrating how the medical model focuses on the damage and injury of the disability (Swain, et al., 2003). Sarah became aware of her memory deficits within her daily living, however when she had to undergo hours of neuropsychiatric testing, she reported feeling that her occasional memory deficits were grossly magnified. Sarah described how frightening and disconcerting the course of the disease had been:

I was working, I had a lot of things that I had to remember—write up and everything—so it was quite a blow to come down to here. It's kind of like you've lost your mind because you can't remember anything. I don't hardly remember anything in the back—in the past. I knew something was wrong.

According to Mary, "It was very hard because she was very good with everything and how this happened to her; I couldn't figure out *why* it happened to her. It was pretty sad. Overwhelming." This emphasis on the negative outcomes of the disease process can often trigger feelings of guilt or blame for hastening the onset or course of the disease (Swain et al., 2003). Mary, for instance, stated, "There's things that I think she probably could have done to prevent it" and acknowledged that she sometimes believed that Sarah was selective in her memory.

Sarah's case also demonstrates Swain et al.'s observation that professionals have the

power and ability to establish their patients' needs, to define their goals, interventions and outcomes, and to provide them with resources needed to access services and cope with their current situation (Swain et al., 2003). The manner in which Sarah received the diagnosis demonstrates not only the power that medical professionals have to define patients but how the limited resources provided to patients and families with dementia under the current medical model of care, which often forces families to seek information on their own. As Mary put it, "All the things that I have done, my resources, that's stuff that I've done on my own." Medical professionals' communications with their patients may be impacted by patients' challenges with communication and may further impact their access to resources. In Sarah's case, when I asked how she deals with her memory loss, she stated, "You can't do anything about it. I just do what I can. But it's harder to talk. I mean I used to be able to talk like crazy." Sarah's autonomy has been affected by both her diminished ability to communicate and the macro system that provided her with a diagnosis and sent her and Mary home without educational information, resources, or a clear course of action. Accessing supports and services, and health care provider communications and attitudes were noted as major themes of a meta-ethnographic analysis of people with dementia and their caregivers (Prorok, Horgan, & Seitz, 2013). Moreover, given the progressive nature of dementia, people with dementia and their caregivers tend to be more reliant on professionals than many with other, non-cognitive disabilities.

Power

Sarah's experiences also support disability scholars' claims about the negative impact of the delineation of power between the client and medical professionals and the resulting feelings it can produce (Kielhofner, 2005; Swain et al., 2003). This was true even during our interview, when, as interviewer, I directed the course of the interview, took notes, and referred back to

those notes as a memory aide. During our conversation, however, Sarah reported feeling as though she was being held to a different standard since I could ask for clarification and take notes to aid my recall while she could rely only on her declining memory and her daughter's input. This was certainly an unintended consequence of the interview, but one that deserves thoughtful consideration by therapists gathering information.

This power differential also represented a significant loss of personal identity for Sarah, as when she recalled that she *used* to be "bossy," an aspect of her personality that she had clearly lost over the past two years since her symptoms began to emerge. For example, during our conversation, Mary would clarify and correct answers that Sarah provided and inadvertently suppress Sarah's prior "bossy" nature. More importantly, this observation exemplified Sarah's loss of power from the hierarchical nature of rehabilitation professional relationships and how these services may "unwittingly collude with social oppression" (Kielhofner, 2005, p. 492).

Identity

Accepting the medical establishment's definition of her as disabled and in need of care also contributed to the loss of what Sarah saw as valuable aspects of her identity. For instance, she reported losing her identity as a mother, saying, "I'm a mother--well, not anymore," as she looked over at her daughter. Other important roles in her life included being a grandmother and proud great-grandmother. Since the onset of her dementia, however, the caregiving role assumed by her daughter has directly undermined Sarah's sense of her role as a mother. As disability scholars note, maintaining a positive identity is critical to patients' sense of well-being, raising the question, "at what point are clients ready to acknowledge disability as a component of their identity?" (Kielhofner, 2005, p. 493). The answer to this question is different for each individual. Further, it is important for medical professionals to ensure that the personhood and values of

each individual is taken seriously (Bamford, Holley-Moore, & Watson, 2014; Teitelman, Raber, & Watts, 2010). At that point in her illness, Sarah did not view herself as disabled. In fact, she reported separating herself from the other residents at her senior living complex, citing her physical abilities compared to others' limitations as her reason for not attending activities. Sarah described other individuals in the complex as engaging in inappropriate behaviors and did not identify with them.

Very real consequences of oppression become evident as a result of the relationship between the patient and therapists within the social context of the disability. Disability scholars discuss the assumption made by many, that people with disabilities want to be different than they are (Swain et al., 2003). Engaging in occupations can help older adults view life experiences in a more positive light (Bass-Haugen & Larson, 2005), and for this reason, Mary and the activity aides at the nursing facility usually try to convince Sarah to attend various programs. Under a client-centered approach, choosing not to attend activities should ultimately be Sarah's choice. When she attended group activities like bingo, she felt she was obligated to help her many peers who had mobility challenges. Sarah was often asked to bring them their money and supplies, which she did not view as fun or relaxing. The aides running bingo thought perhaps that Sarah would enjoy having an important job, when in fact it had the opposite effect. She stated that she would rather watch television in her room alone with her dog. Isolation is a common behavior associated with dementia (Bamford et al., 2014; Smith & Buckwalter, 2005), which Mary tries to counteract by going out with Sarah weekly, but stated that Mary would be fine staying home. Oppression and stigma can potentially occur through well-intending professionals and caregivers in assuming they know what is best for the person with disability (Kielhofner, 2005; Swain et al., 2003). Mary reported that Sarah makes breakfast and lunch on her own and eats only dinner in

the dining room, although Mary tried to talk her into going more often, noting that Sarah “holds court” in the dining room: “She talks to everybody, she’s friendly to everybody.” Yet seeing others with feeding difficulties and other disabilities is depressing to Sarah; therefore, she finds one meal a day in the dining room a good balance, even though her daughter thinks that socializing is important. These examples show how even Mary’s best intentions in her role as daughter and caregiver can collide with her mother’s experiences and wishes.

Caregiver Burden

The later stages of dementia are characterized by the absolute need and magnitude of caregiver involvement. Most caregivers are unpaid, informal caregivers who tend to be family members. Although caring can be a positive experience, the majority of information on the culture of dementia caregivers pertain to burden and stress (Dooley & Hinojosa, 2004; Gitlin et al., 2003; Miyamoto, Tachimori, & Ito, 2010; Volicer, 2005). As Sarah’s dementia continues to progress, Mary reported that Sarah will likely move back in with her. However, moving in with an adult child presents with additional opportunity for a loss of power and identity. When Sarah was initially diagnosed, she had moved from her home in Florida into Mary’s home in the Midwest, and during our interview Mary said she felt bad that Sarah stayed in her room and felt as though she was a bother to the family. Sarah interjected, “I did that because I didn’t feel like I should be running around in *your* house.” When Mary reported she had also dropped the idea of attending law school when Sarah moved in with her, Sarah objected, “Don’t blame me . . . all you had to do was bring me my pills, that’s all You’re going to make me cry.” When the roof is no longer your own, you become a guest rather than the host. No matter how well intending, the very nature of Mary’s role as family caregiver can contribute to the over-arching loss of power and personal identity.

Temporality

As dementia progresses, patients and family members struggle to make meaning of the temporality of the disease as their roles and situation continue to shift (Kielhofner, 2005; Rowles, 1991; Seymour, 2002). This was evident in Sarah's current living situation compared to her independent living situation just two years earlier, and two years later, there will likely be yet another change as new challenges and issues surface. "The meaning of care and who is deemed to require it varies over time and across cultures" (Swain et al., 2003, p. 143). While Mary's role will be continually changing, so too will her mother's. When discussing her vision of the future, Sarah was optimistic, stating, "I'm not going to get worse," while Mary replied, "Well, I know reality is that things *will* get worse." Due to the progressive nature and her current stage of dementia, Sarah, like many people with dementia, does not have the sense of being in an illness trajectory (Seymour, 2002), although Mary does. Mary, like most caregivers, also tries to make sense of dementia by predicting the progression and impact of this disability on her own life (Seymour, 2002). It is important to note the differing perspectives of temporality among care recipient and caregiver so that appropriate training and resources can be allocated to both parties.

Physical Context

Letts, Rigby, and Stewart (2003) point to the impact and importance of the environment on daily life, as well as the rights to live outside of an institution. Sarah's environment is set up for successful and independent living. Mary recalls an incident with the onsite social worker that provided another example of how professionals and even caregivers can exert their power and influence by defining the problems of the disabled (Swain et al., 2003). Since Sarah has a dog, the social worker approached Sarah to ask if she would like a ground-level apartment with direct access to a courtyard for her dog. Although her intention was to be helpful, her question led

Sarah to start packing boxes and call Mary in a panic because she did not want to move. The social worker's suggestion was not only confusing to Sarah, but it would eliminate her main source of socialization--that is, walking through the halls to take her dog outside and encountering individuals along the way. Another example of environmental influence on daily living is that some of the residents throughout the floor are loud, causing additional frustration and confusion. In addition to this, Sarah is beginning to experience sundowning (i.e., late day confusion), leading her to rearrange her living space at odd times, resulting in some minor scrapes and bruises. Sarah also perseverated on the fact that she no longer has access to a bathtub. Sarah cannot relax into baths as she would like, nor are her neighbors conducive to her sleep-wake cycle. Although the living environment is set up to encourage independence, some aspects may unintentionally diminish the residents' sense of independence and well-being.

Injustice

The theme of oppression noted by disability scholars arises in many forms throughout the progression of dementia, including the limited reimbursement available for in-home dementia care. As Mary stated, "I think the injustice of it all is probably in your health care," leading disability scholars to call upon the state and federal government to adopt a more inclusive financial approach to address the needs of the disabled (Barnes, 2001). It also shows the direct influence that macro systems have on dementia and the culture of caregiving. As Kielhofner notes, in our system, "Reimbursement for rehabilitation services . . . is consistently tied to the aims of increasing an individual's likelihood of being an accountable, productive societal member or of reducing costs associated with necessary care" (2005, p. 489), which raises the question of whether people with dementia are viewed by health care systems as incapable of being productive members of society. That persons with dementia are not afforded many of the

same benefits and services offered patients with other physical disabilities cannot help but affect their and their families' sense of how they are valued by the larger society.

Media Influence

Finally, the view of dementia throughout society is strongly influenced by media representations (Kirkman, 2006). Although these largely reflect the tragic view of dementia, Sarah reported she thought that the present day media depiction is actually better than it had been in the past, when people with dementia were depicted in asylum-type settings in comparison to today's typical portrayal at home or in a pleasant senior living facility. Mary's description of her experience as a caregiver was similar to the depiction of how Dr. Meredith Grey's life in the television series *Grey's Anatomy* was impacted by her mother's dementia (Rhimes, 2005). Just as Meredith's mother tried to hide her symptoms, Sarah initially tried to minimize the impact of her symptoms in order to continue living independently. The same series also depicted the changing relationship between Dr. Richard Webber and his wife, Adele, who was also diagnosed with dementia. As her illness progressed, Adele was shown as happy and lost in her delusions, while Dr. Webber was portrayed as the tragic hero left to deal with the reality of the situation alone. In both cases, the caregiver's life of burden and sacrifice is portrayed as a result of disability, revealing once again the predominant theory of dementia as personal tragedy and strife (Swain et al., 2003).

Discussion

Sarah now lives her life in a facility where the effects of aging on mind and body are glaring – with reminders of her declining cognition present within her current living environment and throughout her daily activities. As Seymour (2002) observes, this experience is complex and without any sort of predictable timeline. Even so, Mary tries to predict this progression in order

to prepare for the future because of the limited funding available for care after this phase of the disability. In the meantime, Sarah's identity as a person with dementia is compromised as she now lives under the advice of her daughter and staff who think they know best. Sarah's feelings of isolation coupled with her loss of identity are due in large part to a health system that makes decisions for clients, further facilitating their sense of oppression (Swain, et al., 2003). Sarah does not feel as though she fits or belongs in this setting. This temporal dimension of dementia will continue to affect contextual barriers as well as her interactions with medical professionals throughout the progression of her disease. Like many unpaid family caregivers, Mary also unintentionally contributes to further stigma and a sense of guilt for being a burden on the part of people with dementia, such as when she encourages her mother to attend social events that lead Sarah to feel further isolated.

Although client-centered care is a staple term used throughout various health care agencies and facilities, the manner in which client-centered care is delivered and defined— especially in dementia care – points to rhetoric versus reality. Tom Kitwood first wrote about client-centered care in the context of dementia as a way to both emphasize and merge communication and relationships together (Brooker, 2003; Brooker, 2007). While client-centered care is often times synonymous with better care, and means different things to different people given their context and situation, Brooker (2003) discusses the VIPS framework. Essentially, the VIPS framework emphasizes the importance of valuing people with dementia and those who care for them (V); treating people as their own, unique, individual self (I); altering their view of the world through the perspective of the person with dementia (P); and highlighting the importance of a positive social environment where the person with dementia can experience their own relative well being (S) (Brooker, 2003). The literature within dementia care points specifically to the need for

applicable strategies to improve service delivery with enhanced client-centered care (Prorok et al., 2013; Teitelman et al., 2010). These four elements encompass client-centered care in a manner consistent with Kitwood's (1988) seminal work, as well as in a manner that truly places the care of the individual at the center of the medical experience.

This case also demonstrates that the macro systems of reimbursement and resources also play a critical role in accessing services, support, and funding needed to provide client-centered services. As disability scholars such as Kielhofner (2005) argue, the notion of client-centeredness is key toward empowering the disabled. With continued education, options, and resources, we can empower the people with disabilities and their caregivers. In fact, the literature points specifically to the need to educate dementia caregivers on the scope of available services to prevent barriers to access and enhance the caregiving experience (DiZazzo-Miller, Pociask, & Samuel, 2013; Ducharme, Le'vesque, Lachance, Kergoat, & Coulombe, 2011; Prorok et al., 2013).

Palliative care is another important area of education and training within a client-centered approach to dementia care given that there are currently no effective treatments to reverse the effects of dementia (Raymond et al., 2012). Palliative care provides an emerging alternative approach to care (Raymond et al., 2013), which focuses on improving the quality of life and decreasing suffering rather than curing and prolonging life (Morrison & Meier, 2004). Bryant, Alonzo, & Long (2010) discuss the focus on the person's comfort, the incorporation of the person's life story to his or her plan of care, anticipating rather than responding to behaviors, and empowering caregivers. Palliative care may offer an alternative to common challenges such as sundowning, unexplained weight-loss, behavior challenges, and use of antipsychotics and restraints (Bryant et al., 2010). Additional research in this area of care can lead to core

guidelines, innovative approaches, and interventions that will address the palliative needs of people with dementia and their families, further contributing to client-centered care (Lloyd-Williams, Abba, & Crowther, 2014; Torke, 2014).

Further, this case supports the call for additional longitudinal research to take into account the temporal aspect of well being among individuals (Doble & Santha, 2008; Watson, 2012). Finally, research and discussion on reducing daily barriers, decreasing stigma, and providing support (Batsch & Mittelman, 2012) must continue to enable greater client-centeredness and macro environmental support.

Implications for Practice

The question for caregiving professionals remains – how we can affect change given the established norms for dealing with dementia from diagnosis to long-term care? If physical and occupational therapists can take time to switch roles with the person with dementia with whom they are interacting with – even for a moment – we might begin to find ways to alter our assessments, communication, and recommendations to be more empowering than invoking feelings of oppression and inadequacy. Certainly difficult decisions need to be made regarding medical plans, including power of attorney, early on. As difficult as they may be, these actions can empower the person with dementia and ensure family caregivers that their actions later on are in line with the person with dementia's wishes. Viewing dementia through the lens of disability scholarship has the potential to shed light on our inadequacies as physical and occupational therapists so that we can enhance and enlighten our future work in dementia care.

Although usage of the term client-centered can be over used and misaligned with current policy, implementation of the VIPS framework can guide client-centered care in a manner that accurately views the client in the context of dementia given his or her own individual, personal,

and social self (Brooker, 2003; Brooker, 2007). If our assessments can be altered to prevent potential embarrassment to patients who provide incorrect responses, if our communication and diagnostic processes can be truly client-centered and holistic per the context of each individual with dementia, and if our publications and media can communicate positive images and experiences of dementia, perhaps we can spare those yet to be diagnosed with dementia from embarrassment and oppression, however unintentional.

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