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Reframing Person-Centered Nursing Care for Persons With Dementia

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Abstract

Alzheimer's dementia manifests in a complex clinical presentation that has been addressed from both biomedical and phenomenological perspectives. Although each of these paradigmatic perspectives has contributed to advancement of the science, neither is adequate for theoretically framing a person-centered approach to nursing care. The need-driven dementia-compromised behavior (NDB) model is discussed as an exemplar of midrange nursing theory that promotes the integration of these paradigmatic views to promote a new level of excellence in person-centered dementia care. Clinical application of the NDB promotes a new level of praxis, or thoughtful action, in the care of persons with dementia.

Keywords

dementia; biomedicalization; personhood; person-centered care; need-driven dementia-compromised behavior model

All forms of man's understanding, including our scientific ones, are really no more than justifiable forms of interpretation, developed on the basis of certain assumptions.

(Kockelmans, 1985, p. 10)

Alzheimer's disease (AD), the most common form of dementia, afflicts 4.5 million Americans currently, and this number will increase to 14 million by 2050 (National Institute on Aging, 2003a). The trajectory of AD is long; on average, persons with dementia live about 8 years after diagnosis, with some living up to 20 years postdiagnosis (National Institute on Aging, 2003b). Across this prolonged trajectory, AD poses significant threats to health; in fact, it is a major cause of increased mortality and morbidity in older adults. It is the eighth leading cause

of death in the United States, accounting for 21.4 deaths per 100,000 people in 2003 (National Institute on Aging, 2003b).

Although these statistics are alarming, framing AD epidemiologically minimizes understanding of the significant impact that ripples throughout the social networks of persons suffering this devastating disease. Communities, families, and individuals are affected as dementia contributes to increased health care utilization trends (Guterman, Markowitz, Lewis, & Fillit, 1999; Leon, Cheng, & Neumann, 1998). As the degree of cognitive impairment advances, persons with dementia require ongoing supportive care to manage everyday life. Although the deleterious effects on informal caregivers' physical, psychological, and financial health have been well documented (Moore, Zhu, & Clipp, 2001; Schulz, O'Brien, Bookwala, & Fleissner, 1995), experiences surrounding living through the course of debilitating dementia permeates the whole person of the caregiver, including spiritual, social, and relational ramifications. These effects extend beyond the sphere of the personal; for example, dementia care costs businesses in the United States alone more than \$61 billion when lost productivity and absenteeism for workers are coupled with the cost of covered care (Koppel, 2002). Thus, the significance of dementia care is apparent: AD presents profound ramifications that, though highly personal and individualized, hold profound implications for multiple layers of society.

The purpose of this article is to demonstrate how diverse forms of interpretation may be integrated into a practice-based theory of dementia care that promotes a higher level of praxis, or thoughtful action, in the nursing care of persons with dementia. First, we explore two distinct paradigmatic perspectives that have directed the progress of dementia research and practice. The biomedical perspective is discussed here to establish a platform for understanding how a positivistic approach has enabled, yet constrained, the nursing care of those with dementia. We then turn to examine the phenomenological perspective of living with AD to illustrate the broad impact of the changing self on public identity and personhood across the trajectory of this progressively debilitating condition. Finally, the need-driven dementia-compromised behavior model (NDB; Algase et al., 1996) is presented as an exemplar of the union of these divergent paradigmatic influences in a midrange theory that promotes an evidence-based, person-centered approach to nursing care for persons with dementia.

It is imperative that nursing science advances toward developing and testing effective and efficient dementia care models to meet the complex care needs of people with dementia in order to constrain the rippling effects that can be devastating to families and, ultimately, to society. An essential feature of such care models is a focused integration of expert disease management with comprehensive understanding of the patient's/family's experiences of illness. Nursing models of dementia care cannot be so focused on the diseased body that critical changes to the biopsychosocial-spiritual realms of health are ignored. Rather, nursing science must address the whole-person systems of the patient, families, and care providers involved in dementia care.

PARADIGMATIC PERSPECTIVES INFLUENCING DEMENTIA RESEARCH AND PRACTICE

Paradigms are belief systems centered on metaphysical issues, such as the nature of truth (i.e., ontology), the relationship between researcher and researched (i.e., epistemology), and appropriate strategies for seeking enhanced understanding (i.e., methodology). Paradigmatic perspectives are high-level abstractions that influence the state of a given science by promoting a collective view regarding how to theoretically frame issues and legitimately conduct scientific endeavors. Both biomedical and phenomenological paradigms have been utilized in Alzheimer's research, generating distinct bodies of knowledge about living with dementia and

related care. In the following discussions, autobiographical accounts of living with dementia as described by McGowin (1993) are used to illustrate key points.

Biomedical Perspectives

Traditional approaches to scientific inquiry in a positivistic paradigm have relied on maintaining a distance between the researcher and the phenomenon of interest in a quest to reveal “truth” or a high degree of certainty. The researcher carefully designs a study to maximize this distance by maintaining a degree of objectivity and a neutral context-free approach. In essence, the researcher attempts to hold himself over and against a phenomenon, assuming a bird’s-eye view from a predetermined vantage point. Methodologically, control and manipulation of determinants of study variables are emphasized. Using such experimental approaches, a handful of neuroscientists launched the AD movement in the 1960s, resulting in rapid growth in four major areas of dementia research and practice (Fox, 1989).

Research Initiatives

First, dementia became a leading research topic following the establishment of the National Institute on Aging within the National Institutes of Health (NIH). During this time, funding rapidly increased for the problem of dementia and AD, further fueling biomedical research on dementia (Fox, 1989). Such a success was achieved through the increased NIH funding for the establishment of centers focusing on the medical problems of AD and aging, which redefined a social problem into a medical one behind technical-sounding diagnostic labels (Elliott, 2004; Estes & Binney, 1989). The most widely used diagnostic criteria for AD are the National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer’s Disease and Related Disorders Association (NINCDS–ADRDA) criteria (McKhann et al., 1984) and the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (*DSM–IV*) criteria (American Psychiatric Association, 1994). Though all of these criteria address functions, the major emphasis is on medically ruling out other disease conditions and labeling the problem as a medical diagnosis. Medical diagnoses are about pathology.

Recent research has focused on identifying AD even earlier in the preclinical phase, which results in the development of a diagnostic entity: mild cognitive impairment. Diagnostic criteria for mild cognitive impairment were originally developed by Petersen et al. (1999). These criteria have not been without controversy, yet they have created a new focus for drugs, imaging, and research funding, leading to an even earlier biomedicalization of this condition. Present therapies for mild cognitive impairment and dementia are almost exclusively targeted at the use and development of medications and toward preserving brain function.

Pharmacological Therapy

A second area of rapid growth is the development of new drugs for AD prevention and treatment, such as neurotherapeutics and vaccines (Petersen & Morris, 2005; Roses & Pangalos, 2003). In 2002, the Food and Drug Administration reported a total of 11,544 active investigational new drug applications, the fastest growing of which were central nervous system–active medications (413 applications), many of which are used for dementia (Moore, 2003).

Acetylcholinesterase inhibitors were the first class of drugs found to improve cognitive symptoms in persons with dementia and to delay nursing home placement. Recently, memantadine has been targeted for those with moderate to severe dementia. Despite the promise of anticholinesterase inhibitors, their long-term side effects and effect on quality of life have yet to be fully investigated. A current meta-analysis has called into question their clinical significance and raised the issue of equal benefits for all persons with dementia (Birks, 2006).

Recent studies also have demonstrated the dangers of antipsychotics and other psychotherapeutic agents in persons with dementia (Sink, Holden, & Yaffe, 2005), yet individuals with dementia continue to be targeted for new drug therapies to treat behavioral and social symptoms, delirium, depression, and anxiety. Often these medications suppress the offending behavior while dampening the individual's ability to interact with others. The benefits of controlling behavior symptoms in persons with dementia and the potential to delay nursing home placement needs to be balanced against the loss of ability to interact with the environment and the potential for serious adverse drug events.

Diagnosis

A third example of the biomedicalization of AD, which is gaining increased research attention, is the use of neuroimaging and biological markers to diagnose and predict the condition (Pressley & Kettl, 2000). Considerable progress has been made in the use of positron emission tomography (PET), single photon emission computerized tomography (SPECT), and functional magnetic resonance imaging (fMRI) in both research and clinical practice in the past decade. The genetics of AD and neuroimaging in dementia promise to be the new frontier in research and clinical practice, but their feasibility, cost utility, and usefulness are in need of ongoing assessment.

Care Delivery

Last, the rise of specialized care units (SCUs) and services for persons with dementia, including personal care managers, and locked institutions is geared toward the safety of the residents. Alzheimer's SCUs are based on the premise that a diagnosis directs living preference and care. SCUs have experienced rapid growth and funding, despite evidence that older adults prefer to age in place and that SCUs may not improve the quality of care of individuals. The primary purpose of these spatially defined environments is to prevent injury to the physical body, decrease problem behaviors, and prevent escape from an institution. Some studies have suggested outcomes in traditional units may be better than care in SCUs (Phillips, Hamel, Covinsky, & Lynn, 2000) and that persons with dementia prefer privacy and personalization as important environmental features (Zeisel et al., 2003). Further studies are needed on the influence of environment and, ultimately, the quality of life of those living in Alzheimer's SCUs.

The biomedical perspective has aided persons with dementia and their families by increasing awareness of the distinct pathophysiology of dementia, thus reducing the stigma of the disease and the silent suffering of the past. In addition, the prior two decades of increased funding and establishment of AD centers have been characterized by enhanced service availability for caregivers of persons with dementia and a recent focus on nonpharmacological interventions for dementia (e.g., exercise and cognitive fitness). Together, these activities have afforded those with dementia and their caregivers more options beyond treating symptoms of the disease (Woodhead, Zarit, Braungart, Rovine, & Femia, 2005).

These insights from the biomedical perspective are illustrated by McGowin (1993), who described her initial symptoms of memory loss and visuospatial disorientation in her office building as she "wandered silently through the work-space searching for the restroom" (p. 19), carefully following corridors, retracing her steps at each dead end, and then entering another hallway. She subsequently saw a neurologist who suggested extensive neuropsychological testing. McGowin went to each of the diagnostic examinations unaccompanied, and, oftentimes, she would get lost in the maze of departments in the medical facilities. She adapted by allowing herself several hours to find the testing facility and, then, to find where she should report for the next exam. Although the neurologist and other staff saw her coming by herself, no one questioned her ability to do so; despite her difficulties, she accommodated well. Some

time after the completion of the multiple diagnostic studies, she received a letter from the neurologist notifying her that she had a form of dementia that was, most likely, a familial form of AD. The journey had just begun.

Once the diagnosis of dementia is made, there are several medical and related social issues to face, none of which were reported by McGowin (1993). The resultant effects of neuropathology warrant an assessment of home safety, driving risks, caregiver availability/education, nutritional needs, and weighing the benefits and risks of a variety of pharmaceutical approaches. The biomedical perspective also may enable ethical decision-making regarding preventive screening and use of certain medications, assessment and early detection of medication side effects, as well as common acute problems in persons with dementia, such as dehydration, pneumonia, constipation, delirium, and urinary tract infection. Attending to these concerns is paramount, as dementia is associated with an increased risk of death from pneumonia (Attems, König, Huber, Lintner, & Jellinger, 2005; Chamandy & Wolfson, 2005; Keene, Hope, Fairburn, & Jacoby, 2001), as well as urinary tract infection and dehydration (Fick, Kolanowski, Waller, & Inouye, 2005).

Phenomenological Perspectives

Rather than attempting to achieve a distance from the phenomenon (as in more traditional positivistic research approaches), researchers under the phenomenological paradigm attempt to get into the lifeworld of others in order to better understand that world of being. Objectivity and a quest for certainty are replaced by plausibility to allow a faithful representation of the phenomenon within that context, at that time, and at that point in history. Such an interpretive understanding is possible only through an open exchange of the human condition, a reliance on subjectivity. Interpretive or naturalistic methods are used to gain understanding of the lived world without an emphasis on control or manipulation of identified variables. Research conducted under this paradigmatic perspective is, therefore, primarily aimed toward theory generation. For example, Orono (1990) explored the loss of identity from the caregivers' perspective; Sabat (1994) documented a case study illustrating excess disability affected to social relationships; Harris and Sterin (1999) proposed a typology of reactions and approaches used by persons with dementia to preserve a sense of self; and Nygard and Borell (1995, 1998) described daily life in the world of altered meaning imposed by dementia.

Over the past two decades, researchers have increasingly recognized the importance of understanding the experiences of people living with dementia to help better the care for this population (Burgener, Shimer, & Murrell, 1993). Although several obstacles, like recruitment difficulty, the credibility of certain subjective information, and language deficits, might have limited our understanding of living in the world of dementia, the imperative for including those data in planning person-centered nursing care is already clear (Cotrell & Schulz, 1993). Insights regarding persons with dementia's life experiences are synthesized in two themes in the following sections: the changing self and public identity and the importance of personhood.

The Changing Self and Public Identity

Living with dementia has been described as a heteronomous existence; that is, persons with dementia become strangers in their own world (Svanstrom & Dahlberg, 2004). Self-identity is changed—not totally lost—and typically is preserved into the end stage of advanced dementia (Harris & Sterin, 1999; Sabat & Harré, 1992). The consequence of this changing self-identity is a new form of life, a new way of living in the world that is fraught with incoherence and unknown meaning. As a result, imbalances in responsibility, futility, hopelessness, and even homelessness can occur (Svanstrom & Dahlberg, 2004), posing a continuous threat to perceptions of order and control (Nygard & Borell, 1998). As neurological impairment progresses in dementia, new opportunities for uncertainty surge, eroding one's confidence in

interpreting daily life experiences (Phinney, 1998). The shifting sense of self-identity prompts emotions, such as frustration, embarrassment/humiliation, anger, despondency, fear, disempowerment, and uselessness (Harris & Sterin, 1999). McGowin (1993) poignantly summarized this experience:

I feared the possibility of someday losing control over my own home, my own meals, my own family, and my own automobile. In short, I feared losing my last shred of dignity and control over myself. My diagnosis exposed me to the elements. My rights had become tenuous and delicate. They existed only so long as nothing untoward occurred. This rendered me helpless, stranded with my tender underbelly exposed to the vagaries of family and strangers alike. (pp. 82–83)

On the other hand, elements of the person's public self are lost. Families work to maintain the person's identity based on who the person once was (Orono, 1990) and defining a person with dementia based upon their capacities for such things as physical expression, achievements, and individual characteristics (Jenkins & Price, 1996). As described by McGowin (1993):

The fact finally dawned on me that we were viewing my condition from opposite positions. It was as though I was standing at one end of a telescope and my family at the other, each peering intently into the instrument, each with a quite opposite perspective. (p. 97)

For many people living with dementia, efforts to maintain some semblance of normal life or a comfortable way of being in the new world of AD emerge, including self-monitoring, keeping an active mind, staying engaged in the world, and downplaying errors in this disturbed new world (Harris & Sterin, 1999; Phinney, 1998). McGowin (1993) described posing as a tourist to minimize the distress of seeking directions in her well-traveled routes. She carefully relearned basic directions (i.e., left-right or up-down) and composed maps annotated with landmarks for directional assistance to aid her navigation through the neighborhood in which she had resided for decades. For others, unawareness deficits mark a lack of insight regarding the impact of their new way of being in social contexts (Bahro, Silber, & Sunderland, 1995; Cotrell, 1997; Sevush & Leve, 1993; Vasterling, Seltzer, Carpenter, & Thompson, 1997).

Thus, from this body of work, the key insights for nursing are that self-identity is partially a social construction (i.e., how one perceives the self is a reflection of an understanding or interpretation of meaning that is derived through interactions with others), and how others respond to the person influences how well the public self is maintained (Downs, 1997). From the eyes of the person with dementia:

I was and am inordinately appreciative of each and every kindness afforded me by friends and acquaintances, alike. I realize that everything we do, does indeed matter. There is no substitute for graciousness, no excuse for rudeness nor churlish behavior. (McGowin, 1993, p. 111)

The Importance of Personhood

Perhaps the most refined alternative theory for understanding the life experiences of persons with dementia was proposed by Tom Kitwood and his colleagues affiliated with the Bradford Dementia Group (Kitwood, 1990). This theory of dementia care challenged the deterministic and causal relationship between neuropathology and etiology espoused in the biomedicalization of dementia. Their theory was based on subjective reports of persons living with dementia and their family members, in-depth observation, and interactions using the ethnogenic approach (Harré, 1993). The theory emphasizes the personhood of those living with dementia, which “opens up the way for a more personal and optimistic view of care giving” (Kitwood, 1990, p. 177). The primary assertions of this theory are refocused on the dementing process rather than the demented state, emphasizing the social-psychological milieu

in which that process unfolds. Thus, the primary goal of dementia care must be centered on maintaining personhood.

The concept of personhood is rooted in an existential ontology that disputes mind/body dualism, instead promoting the view that “who one is and who one can be are defined in the context of authentic relationships” (Malloy & Hadjistavropoulos, 2004, p. 152). Kitwood and Bredin (1992) define personhood as a socially based understanding of “the human being in relation with others” (p. 275). In order to understand the nature of personhood, one must first disentangle the notion of individualism from personhood (Kitwood & Bredin, 1992). Individualism is focused on self as a unique being in relative isolation from others that is predicated on a self-reliance that minimizes the value of being with others in an interdependent mode. On the other hand, personhood is rooted in relationships with others and, therefore, requires the presence of another human being. Personhood is a dynamic concept that is influenced by social intercourse (Jenkins & Price, 1996).

As human beings interact, their personal universes, or subjective views of reality, intersect. Simply put, this is the notion of intersubjectivity: the intersection of one person’s subjectivity with the subjectivity of another (Munhall, 1993). In a frozen state of personhood, intersubjectivity is constrained; the person focuses on the self over the world shared with others. This state is manifested in our everyday being when we do not open ourselves to others in a genuine way; we acknowledge others but do not appreciate their worlds. A more dynamic state of personhood (called fluid) emerges when the person focuses on the shared world, as intersubjectivity opens new opportunities for growth through synthesizing alternative ways of being. This state involves engaging self with others in a more authentic way that is dependent on social interactions, and, in the process, individuals are changed by new appreciation or understanding brought forth by interaction with another.

In sharp contrast to these forms of personhood, people with dementia are predisposed to become progressively more detached from others and to evolve eventually into a state of solitude, lacking intersubjectivity even when in the midst of others. In this state, personhood is not lost; it is shattered as cognitive skills that support intersubjectivity are diminished (Mor et al., 1995). McGowin (1993) cried out against such detachment:

If I am no longer a woman, why do I still feel I’m one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? If no longer sensitive, why do moving song lyrics strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone! (p. 114)

As dementia progresses, cognitive skills that enable the person to meaningfully interact with others within in a complex world are lost. This deterioration prevents the person from achieving the degree of intersubjectivity formerly possible. In fact, even subjectivity is threatened in advanced dementia.

Because well-being among persons with dementia is fragile and short-lived, the need for responsive person-centered care is pressing. Such care can help build an interdependence that fosters opportunities to experience well-being, which is not based on the person’s capacity for everyday function but on a new perspective of personhood. The person-centered care environment highlights supportive care and basic needs for attachment, comfort, identity, occupation, and inclusion, which builds toward a central care need of being loved. Although the individual pattern of needs varies according to personality and cognitive impairment, these needs are recognized and responsively addressed by caregivers in a person-centered care environment (Kitwood, 1997). In other words, intersubjectivity is reestablished, and through these person-to-person interactions, caregivers appropriately foster the personhood of those

with dementia to build an environment in which they sense being loved; this, in turn, frees them to experience more positive emotional states.

In stark contrast, caring environments that focus on biophysiological concerns in a more mechanistic manner are skewed from recognizing the importance of personhood. These care milieus may actually become malignant and have deleterious effects on persons with dementia (Kitwood, 1990). Common care issues such as infantilism, disempowerment, and labeling patients are insidious behaviors implicitly rooted in the taken-for-granted world of caregivers who lack intersubjectivity and who operate within a world stressed by being busy with tasks rather than being reflective. They consider those with dementia as personless—an empty body—a shell of the person who used to be. This malignant social pathology impacts the nature of being, which breeds disability and depersonalization. Caregivers' negative expectations and attitudes, therefore, become a self-fulfilling prophecy that fuels disablement. Caregivers who pessimistically expect decline and loss in competence treat the declining person with an increasing emphasis on biophysiological concerns and lose sight of the person who dwells within the new lifeworld of dementia.

Thus, though personhood is severely challenged in dementia, even in advanced stages, the nurse or family member's appreciation of the individual as a person "with whom he or she is in a genuine living dialogue" (Malloy & Hadjistavropoulos, 2004, p. 155) is critical to the provision of high-quality individualized care. This so-called person-work builds a care milieu that "offsets degeneration and fragmentation" (Kitwood & Bredin, 1992, p. 285). Yet this is not a one-way exchange. Through intersubjectivity, based in social interaction, the caregiver's personhood may also evolve to new levels of fluidity.

DISCUSSION

In isolation, neither of the two paradigms directing dementia research and practice is adequate for addressing the complex needs of persons with dementia and their families. Focusing on the disease process from a positivistic perspective has significantly advanced the understanding of dementia pathophysiology, diagnosis, and treatment. For example, now some evidence exists that exercise and brain fitness can delay or retard the development of dementia (Kramer, Bherer, Colcombe, Dong, & Greenough, 2004; Yu, Kolanowski, Strumpf, & Eslinger, in press); however, funding for these interventions has been far less than that for pharmacological interventions. Present therapies for mild cognitive impairment and dementia psychosis are almost exclusively targeted at the use and development of medications and toward preserving the intact physical body. Similarly, as dementia progresses, the focus of nursing care shifts toward the physical body and related medical problems, such as feeding, hydration, injury, incontinence, weight loss, dysphagia, falls, fractures, pneumonia, sepsis, and skin breakdown (Amella, 2004; Fick et al., 2005; Guerin et al., 2005; Kayser-Jones & Pengilly, 1999; Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999; Magaziner et al., 2005).

Yet the emphasis on physical/bodily needs often comes at the expense of the personhood needs of those with dementia. Although medication use may stop disturbing behaviors, one must balance this benefit with the risk of oversedation and loss of ability to interact with others and the environment. Though the use of medications has undoubtedly saved lives, avoided some invasive procedures and surgeries, and extended life for many older adults, polypharmacy remains a significant issue. As the person with dementia is treated for multiple comorbidities and symptoms of dementia, it is imperative that nurses realize that the single most important predictor of adverse drug events is the number of drugs an individual is taking. Pharmacotherapy, though useful, is particularly hazardous to the well-being of vulnerable older adults suffering with dementia, as research shows that older adults are more vulnerable to adverse reactions, such as falls, hip fractures, delirium, and a diminished quality of life from

inappropriate medication use than persons without cognitive impairment (Gurwitz et al., 2005).

Approaching dementia solely from a positivistic perspective focused on mind-body dualism poses serious challenges to holistic nursing care. We risk forever erasing any definition and acceptance of normal aging and normal cognitive decline and have suddenly made forgetfulness unacceptable (Kaufman, Shim, & Russ, 2004). Meanwhile, the exponential growth of medical interventions and invasive procedures undertaken into the ninth decade of life has made refusing or withdrawing medical intervention and dying naturally somewhat unacceptable. Despite the need to care for the “body as machine” in order to sustain life, findings from the past two decades of phenomenological research on persons with dementia support the notion that nursing care based purely on a positivistic perspective will not produce excellent or even adequate nursing care.

Nursing care is inherently based on intersubjectivity (i.e., the nurse-patient relationship), requiring human interaction in the process of care delivery. Of all the complexities faced in nursing, dementia is one of the most challenging because it requires the nurse to understand compromised physical states within an altered way of being in the world. The person who occupies this world is not easily understood. Care is doomed to fail if this changed lifeworld is ignored or if this changed world is perceived as an inconvenience and its outcome as a disturbing behavior. Therefore, we must blend paradigmatic perspectives to integrate these silos of knowledge into a nursing theory that addresses both the world of the failing body and of altered personhood, for this whole-person approach is the heart of excellence in nursing care of persons with dementia. Nursing is exceptionally positioned for this endeavor; we have emergent theoretical models that aptly merge the biomedical and phenomenological worlds of the person with dementia.

Several years ago, a group of nurse researchers reconceptualized dementia behaviors from the perspective of the person with dementia and developed a midrange theory called the need-driven dementia-compromised behavior (NDB) model (Algase et al., 1996). This midrange theory is an exemplar of nursing theory that promotes a new level of praxis in dementia care. The NDB model promotes intersubjectivity in the care process by explaining the unique source of needs in each person with dementia. In the NDB model, dementia behaviors such as wandering, screaming, or physical aggression are viewed not as disturbing but as the person's expression of an unmet need. Rather than extinguishing these behaviors with physical or chemical restraints, caregivers are guided to engage in social interactions with the person and attempt to identify factors that may be the root cause of their behavior and, by extension, of their needs. The theory gives direction for addressing both the biomedical and phenomenological needs of those with dementia in a more holistic manner than either paradigmatic perspective used in isolation.

In the NDB model, background factors are characterized as the more enduring characteristics of persons with dementia that place them at risk for dementia behaviors. They include biophysical factors: neurological changes of the disease process, current cognitive abilities, general health status, and psychosocial history (premorbid personality, gender, and socioeconomic status). In contrast, proximal factors are the more changeable, contextual factors that precipitate dementia behaviors in at-risk individuals. Integrating the biological and phenomenological worlds of living with dementia, proximal factors include physiological and psychological need states as well as the qualities of the physical and social environments. Background and proximal factors dynamically interact with one another. Some background factors have a direct influence on behavioral symptoms, independent of proximal factors. Other background factors mediate the response to proximal factors to produce behavioral symptoms, which are conceptualized to be the most integrated response a person with dementia can make

given the limitations imposed by the dementia, strengths preserved from abilities and premorbid functioning, and the constraints or supports offered by the environment.

From this point of view, the model combines both the biomedical and phenomenological perspectives. In a very basic manner, the model facilitates understanding of who this person is at this point in time; background factors provide clues to personal identity by focusing on the lifetime patterns of environmental interaction (premorbid personality), which are preserved through late stages of dementia, and by considering the impact of the disease process on the ability of the person to engage in intersubjective interactions (including neurological changes, cognitive abilities, and physical health status). The quality of the physical and social environments and physiological and psychological need states is a contextual factor that is used to direct the caregiver's response to dementia behaviors. When, through intervention, these proximal factors are adjusted in a manner that is consistent with the person's background factors, they promote the flow of intersubjective communication in the here-and-now world of the person with dementia. For example, Colling (2004) found that family caregivers' approaches to encouraging engagement in persons with dementia demonstrated synchrony with selected background and proximal factors in the NDB model. Use of humor, faith, and patience were identified as positive interventions for apathy and passivity in community-dwelling adults with dementia.

Kolanowski, Litaker, and Buettner (2005) derived recreational activity interventions from the NDB model that resonated with each individual's unique need for a level of sensory input (proximal factor in the NDB model) that was within their range of tolerance. This range of tolerance is influenced by an individual's cognitive abilities, health and functional status, and premorbid personality (background factors in the NDB model). The researchers found that nursing home residents who received activities that were matched to their background factors exhibited greater engagement, more positive affect, and fewer behavioral symptoms than nursing home residents who received unmatched activities or usual care. The theoretical approach used in both these studies shifts the focus from the perspective of the caregiver to the perspective of the person with dementia, enabling a holistic approach to a new level of excellence in dementia care. Recently, the model has been extended to illustrate the negative consequences of not meeting the needs expressed by persons with dementia through behavioral symptoms (Kovach, Noonan, Schlidt, Wells, & Ellis, 2005).

Consider the implications of combining both the biomedical and phenomenological perspectives through the NDB model, a midrange theory that provides clear guidance for intervening with persons with dementia. Understanding background and proximal factors, both pharmacological and nonpharmacological treatments are employed to delay cognitive decline. Family members and supportive friends are educated to support the person with dementia emotionally by accepting her as she is now, as a complete human being rather than as a shell of the woman she used to be. In close cooperation with the nurse who understands the NDB model, key members of the supportive network build strategies to maintain the independence of the person with dementia by carefully adapting the social and physical environments to capitalize on preserved strengths. The network of care is fortified as the person with dementia and the informal caregivers are counseled through advance care planning that establishes the path for future care, should the trajectory include severe disablement during which the person with dementia is unable to express desires. Through the lens of the NDB model of care, the nurse and the family understand that behavioral changes are manifestations of unmet needs that require exploration and resolution by integrating biomedical and phenomenological strategies. Together, they implement a dynamic set of strategies that bolster preserved strengths, even in the face of escalating debility.

The NDB model facilitates an understanding that obliterates the telescopic distance between who the person with dementia was and what abilities that person has lost (as described by McGowin, 1993) by focusing intensely, in a highly individualized approach to person-centered care, on who this person with dementia is today. Such person-centered, theory-driven intervention may have eased the troubled journey to a more enlightened world of care for McGowin and countless others who endure fragmented, narrowly focused care for a complex condition whose effects ripple throughout their worlds of being.

CONCLUSION

The two perspectives guiding the development and progress of dementia research and practice each fosters an interpretation of the presented signs and symptoms related to dementia that subsequently inform the focus of strategies for intervention and research, yet they need not be mutually exclusive. The biomedical and phenomenological perspectives have yielded significant advances in the care of persons with dementia, but in order to be useful to nursing, there must be a greater effort to integrate these contrasting perspectives into a more holistic theoretical scheme for clinicians. Without such integration, knowledge remains fragmented, creating silos of knowledge, and limits the potential impact of advanced science on the nursing care of persons with dementia. We must see beyond the body as a machine gone awry and beyond personhood as the total essence of being in order to holistically comprehend the dynamically changing states of living with dementia. Although the best dementia care model is not yet clearly understood (Kaufman et al., 2004), the NDB model is an exemplar of the successful integration of the two major paradigmatic perspectives for dementia care and, we believe, sets a path toward a new level of praxis through person-centered nursing care of persons with dementia.

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