



CHANGING THE CARE PROVIDED PERSONS WITH DEMENTIA

The Role of Experiential Knowledge and Philosophy of Science

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This discussion is both cautionary and hopeful, for it addresses the remaining ability of those persons with dementia as well as the effect of such lack of recognition, upon the care delivered to all vulnerable older adults. A series of vignettes are presented that reach across time, each describes the nature of such remaining ability in dementia. The vignettes present a nurses' "remembered" experience; each vignette is also reflective of a given philosophy of science position affecting such nursing care. The discussion also describes how our current research has taken note of these changes in earlier philosophy of science positions, in order to improve the quality of care for older adults today and hopefully in the future.

The "Back Ward"

Undergraduate nursing students are now as in the past, provided psychiatric-mental health nursing experiences required for state licensure of registered nurses; these experiences were/are several months in length. This first vignette dates back to post mid-twentieth century when such experiences were provided primarily within psychiatric hospitals. Psy-

chiatric patients were not greatly medicated in the sixth decade, for neuroleptic medications developed at mid century were still a minor force in psychiatric care in the United States.

On a small Back Ward in a private psychiatric hospital, the women who were all beyond the age of fifty shared a “dual-diagnosis” of major psychosis complicated by dementia. All were physically well cared for but because of their physical violence with both patients and staff, this small group was “cuffed” with fleece lined leather “muffs” for most of the day. They rarely left their unit because of their persistent violence toward others. Many if not all of these women had been well educated, one as a pianist, another as a singer. But for the most part the others had led more private lives until their conditions made functioning outside of custodial care impossible.

The “nursing care plan” for these patients included “uncuffing during bathing.” Such uncuffing was for both hygienic and physiologic purposes, but was necessarily brief because their violence followed uncuffing. The nursing care plan was based upon the theory that the “delusional banter and behavior” of these patients, was to be ignored, rather than commented upon or discussed with them. Such attention was posited to reinforce negative behavior.

Nursing students assigned to shower bathe the pianist knew, however, that if you “un-cuffed” her near a piano as the bath was prepared, she would begin to play. The playing consisted mostly of disparate piano pieces. Students welcomed this playing though, because occupation with the piano seemed to distract this woman from violence.

A fellow patient (who consistently stated she was the “French King”), would sometimes monitor this piano playing, as if discerning some remembered melody. Students also knew that the former singer could hum along with various wisps of tunes. No matter that such interaction lasted for only a few brief minutes, these women during these times appeared to co-exist in some sort of common space/time, perhaps remembering some past concert.

Such interactive episodes worried students, for when

these women interacted in this manner, it meant the students were not complying with the mandated care approach. The care was to be focused only upon the “reality” of the patients’ lives, i.e., that they were severely mentally ill, and their care was not to be focused upon reinforcing “delusional actions” or fantasy situations. Students, however, discussed these interactions as taping some sort of “alternative reality,” or some remaining but non-reinforced ability. At various reunions across time, these former students would revisit this and similar scenarios, but without resolution as to what it represented or as to how they should have responded.

From a philosophy of science viewpoint, however, the care that was then mandated for these women was focused only upon a strict interpretation of reality, i.e. that these women were psychotic and permanently demented. That this diagnosis was confirmed, via verifiable sense data, was of prime importance. In essence, a philosophy of science position known as logical positivism was firmly in place at this time and its application mandated a reinforcement of the grim realities of these women’s lives. In this positivistic view, there was “nothing left” of these women’s ability, and any “so-called” remembered talents and experiences, were non-substantiated via testing and thus were counter-productive to mandated “curative” actions.

“Nothing is Left”

Ten years later, one of these students entered a Master of Science Program in Psychiatric Mental Health Nursing. The above “quandary” was almost forgotten, until the day students selected patients (now termed clients) to work-with on a supervised “one to one.” A community based Mental Health Out-Patient Clinic provided a roster of clients who might possibly profit from additional help. One of the clients had a dual diagnosis of major psychosis and “probable” dementia of the Alzheimer type. The family caregiver requested assistance in

providing their relative with a more satisfying (versus agitation provoking) environment.

Although the student requested this client, the request was denied by a mental health worker who explained that “there is really nothing left” to provide a “satisfying experience” for either the student or client. Although the student complied, the thought of the pianist, the singer, and the “French King” were recalled along with the possibility that “there really was something left.” The student believed the underlying assumptions of the then “current mental health theories”, were probably in error. Search of electronic databases, however, did little to dispel this mental health workers’ assertion or to support the students’ tentative insights.

Postmodernism and dementia care

In the late 1980’s, reports in the scientific literature began to appear suggesting the existence and persistence in dementia of something termed “Implicit Memory” (IM)⁽¹⁾. Also called “unconscious memory,” IM was described as the opposite of Explicit Memory, which is focused upon the “correct” identification of time, place, and person, etc. IM was further described as a type of memory everyone uses each day, for example, drivers may arrive at their usual destination, without conscious recognition of each step of the route taken. IM had initially been tested and documented as existing in young, healthy college students, but several years later research began to emerge that described IM as remaining in dementia.

Were the patients on that Back Ward tapping IM? Did this finding suggest the need for a therapeutic shift from doggedly insisting persons with dementia recognize and “live within” the grim reality of the “here and now”? As nursing science progressed, these questions began to be explored by several like-minded researchers working with persons with dementia, for it presented alternatives to care for these persons. It also meant that rather than prescribing care focused upon these persons

“accepting the non-controvertible sense data” of their mental illness (e.g. their permanent residence in a nursing home), that newer approaches should be crafted and tested.

A Neomodernist approach

Now in the 21st century, both the context of illness as well as physiologic data from quantitative and qualitative studies are united in a philosophy of science position known as Neomodernism²⁻³ This approach is focused upon a synthesis of data that contributes to the effective care of persons with dementia. Our research also focuses upon the person with dementia, their remaining ability and desires, not upon the illness alone and the inabilities of the condition.⁽⁴⁻¹⁶⁾ As posited within the “Need-driven, Dementia-compromised Behavior” (NDB) model, the NDB model posits in effect, that “persons with dementia are trying to tell us their needs and desires, but their condition compromises such ability.”⁴

The last vignette concerns a small pilot study with thirty plus participants in nursing homes; we addressed the relationship between preferred environments and agitated and aggressive behavior in persons with dementia. In effect, the NDB model guided examination of the relationship between care environments and agitation and aggression in persons with dementia. (A more complete discussion of this study can be found in reference 5).

One of the persons referred to us was a woman in her eighties who (it was thought) could no longer speak, but would scream (often for hours) un-discernable words; this behavior had continued for several months. We asked the staff what seemed to draw the woman’s attention. The nurse aide assigned to her care suggested that she would watch birds outside her window, and when doing so seemed to decrease screaming.

As completing the shower bath had been the major care problem (since her screaming in a small enclosed and tiled

room was almost impossible for caregivers' to bear), the nurse aide was eager to try almost anything that might help with a more acceptable completion of this woman' shower bath. We changed the shower room to include plants, pictures of birds, and had a small pudding snack for a picnic-like atmosphere. To entice the woman into the shower, we played a tape of birds singing, frogs croaking, i.e., sounds from a setting with a stream or a pond. The woman had had the ability to hold onto the doorframe of the shower room, prohibiting her wheelchair from proceeding into the shower room. We played the bird sounds in the hallway outside the shower room and the woman began looking into the shower with interest and allowed her wheel chair to enter the room.

The aide had been told to engage her in conversation, so the aide asked "do you hear a bird?" To the aide's amazement the woman spoke her first word in many months, she said "duck". The aide asked "have you ever cooked a duck?" and the woman replied "fat". Both the woman and the aide laughed for evidently both had experienced how fat seems to become air-born during this cooking process. The conversation, although stilted and confined by the woman to single words, had a positive outcome; no aggressive behavior/screaming occurred during the bath.

Based in a newer philosophy of science position, i.e. Neomodernism, the NDB model unifies both empirical knowledge with personal, ethical, and aesthetic knowledge⁽¹⁷⁾. Care is, therefore, focused less upon the completion of the care procedure itself, but upon uniting the care task with aspects of the remaining abilities and preferences of the person with dementia. Studies undertaken by the group of nurse researchers in Gerontological nursing at Oakland University School of Nursing are reflective of this Neomodernist approach. Not each program of research deals with care of persons with dementia, however, but each program of research does deal with promoting the remaining physical and mental health of older adults who by age alone, tend to be vulnerable. Such an ap-

proach has great promise for a new age of care for vulnerable older adults.

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