Dementia: A Developmental Approach (On Personhood and Spirituality)

D'Arcy Little, MD, CCFP, *Lecturer and Academic Fellow, Department of Family and Community Medicine, University of Toronto; Director of Medical Education, York Community Services; 2002 Royal Canadian Legion Fellow in Care of the Elderly at Baycrest Centre, Toronto, ON.*

Introduction

I was recently given the difficult task of creating a paper on the application of developmental theory to the human condition of dementia. Given the complexity of that endeavor, this article will address both content and process issues involved. I will start with a consideration of the relevant developmental stage as conceptualized by Erikson, and then demonstrate that the biomedical model of dementia is actually insufficient to allow a discussion of dementia in a developmental context. This will be followed by an introduction to a paradigm shift from the biomedical model to the social-environmental model whereby developmental issues in dementia can be more fully explored. The prominence of spirituality as a means to resolve Erikson's final crisis of integrity versus despair will be discussed with reference to both personal reflection as well as recent arguments by clinical ethicists and psychologists working in this field and a prominent patient with dementia. Finally, connections to a different developmental model will serve to confirm the views put forth here.

Erikson's Life Cycle: Application to Dementia

According to Erikson, the dominant antithesis in old age is "integrity versus despair".[1] As interpreted by Miller, integrity involves "the acceptance of one's limitations, a sense of being a part of a larger history that includes previous generations, a sense of owning the wisdom of the ages, and a final integration of all the previous stages".[2] Despair, conversely, refers to "a disgust of one's self, a regret for things done and not done, and a fear of death".[2] Erikson interpreted the basic strength at this stage as that of wisdom, or "an informed and detached concern with life itself in the face of death itself".[1] In essence then, "old age is a time of wisdom forged out of a search for meaning in the face of death".[3]

How can this developmental context be applied to dementia? One could argue that despair is the inevitable outcome here, because patients with advanced dementia often lack the faculties to forge such wisdom and meaning at this stage in their lives due to their illness. An equally simplistic view treats dementia as a representation of a reversal of the stages of Erikson's life cycle. This view might be supported by some caregivers who witness firsthand that, just like at the beginning of their lives, dementia patients need help with decisions, dressing, feeding and hygiene, and they tend to exhibit behaviour problems.[4]

The above approaches are not very satisfactory or hopeful and in reality are, I believe, rooted in the deterministic biomedical model that describes dementia as a disease with irreversible, progressive deterioration in specific regions and structures in the brain. According to this model, this neuropathological damage then causes inevitable declines in cognitive functioning, as well as behaviour problems.[4-6]

Limitations of the Biomedical Model of Dementia

Tom Kitwood argues that the biomedical model of dementia or, as he calls it, the "organic basis of dementia" is flawed by being too narrow. He points to the fact that there is a reasonable lack of strong and consistent correlation between the severity of Alzheimer's neuropathology (cerebral atrophy, neurofibrillary tangles and neuritic plaques) found at autopsy and the degree of symptomatology prior to death.[6,7] In addition, the biomedical model of dementia does not fully acknowledge that the brain is a "plastic" organ, a state embodied in Damasio's assertion that "…the design of brain circuits continues to change. The circuits are not only receptive to the results of first experiences, but also repeatedly pliable and modifiable by continued experience. Some circuits are remodeled over and over throughout the life span, according to the changes that the organism undergoes."[6,8]

Paradigm Shift: Social-environmental Model of Dementia

Kitwood has proposed a new model for looking at the brain affected by dementia that addresses this plasticity. In summary, this model suggests that any psychological event or state is also a brain event or state, "carried" by a brain whose structure has been determined by both developmental and pathological factors.[6] In essence, psychology and neurology are inseparably linked in both normal physiology and pathological conditions. Kitwood asserts that it is the developmental aspects of brain structure that have been largely neglected to date in the biomedical research on dementia. He further asserts that it is these developmental differences, the results of learning and experience, which allow different people to vary considerably in the degree to which they can cope with such neuropathological brain processes. He calls this the "neurology of personhood" hypothesis. He takes the theory one step further: the consequences of the way a patient with dementia is cared for are not simply psychological, but also have their effect at the neurological level.[6]

The term "malignant social psychology" was coined by Kitwood to describe ways in which the "personhood" of people with dementia is undermined in day

to day interactions with caregivers and others. A poignant vignette illustrates this concept:

> *The scene is the "Alzheimer Unit" of an American nursing home. A young male care assistant is pushing a woman of about 75 years across the room. She is protesting and resisting, but without words. Gradually he maneuvers her towards a beanbag chair, and manages to get her down into it. The chair is very low on the floor; it supports her back, but provides no way in which she can rest her head. She has not got the strength to get up out of it. She looks up at me, and suddenly expresses herself with perfect clarity: "It's cruel mental torture. They're doing it to me all the time."*[6,9]

The neurology of personhood hypothesis argues that all events in a person's experience have their counterpart in brain activity, and are slowly incorporated into brain structure. In other words, psychological factors such as poor dementia care initially have their counterpart in neurochemistry and then in neuronal structure. This can be conceptualized as a dialectical process and eventually as a downward spiral, where a patient's personhood is gradually undermined by an interaction of elements of malignant social psychology and neurological impairment (Figure 1).

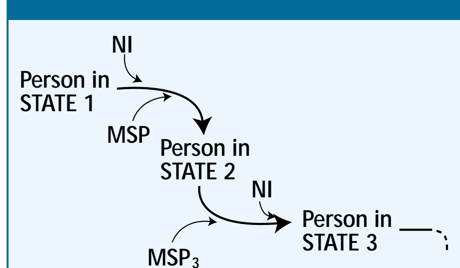
Social-environmental Model: Implications for Treatment

The social-environmental model of care focuses on changing the environment and a patient's interactions with others to minimize disability, whereas the biomedical model, simplistically speaking, places emphasis on the use of pharmacological interventions to slow cognitive impairment or to treat behaviour problems.[4] Although the dialectical process has, thus far, been described in a negative light, it can have implications for therapeutic interventions in dementia. In essence, if the social environmental influences are more positive (not the malignant social psychology previously described), they may serve to actually overcome some of the neuropathology of dementia. Anecdotal and case series evidence has suggested that person-centred care, also called "positive person work" by Kitwood, can have positive benefits in maintaining well-being, positively altering the course of deterioration and even recovering abilities that had previously apparently been lost.[6,10,11] However, the data is still fragmentary and more research with stricter methodology needs to be carried out.

If we reexamine the dialectical view of dementia in the context of person-centred care, then each advance in neurological impairment has the potential to be compensated for by a supportive psychological environment and positive person work.[6]

In developmental terms, this process is almost the opposite of what happens in infancy. In infancy, the infant responds to others, and interpersonal processes become internalized while the nervous system is maturing. In person-centred dementia care, many aspects of the psyche that had been internal are recreated in the interpersonal milieu. This will be made clearer in the discussion of the therapeutic techniques involved in person-centred dementia care.[6]

Figure 1



This figure illustrates the dialectical process between the neurological impairment (NI) of dementia and malignant social psychology (MSP) experiences in the patient's environment (as part of dementia care).[6]

Person-centred Dementia Care

Person-centred dementia care seeks to provide for the "needs" of dementia sufferers. The term "need" has been defined by Kitwood as "that without the meeting of which a human being cannot function, even minimally, as a person".[6] Needs in dementia are conceptualized by Kitwood as a cluster related to one primary need—love. This cluster includes comfort, attachment, inclusion, occupation and identity.[6,12]

The essential characteristic of person-centred dementia care, otherwise called positive person work, is the positive interactions with caregivers that preserve personhood by meeting these needs.[6] Kitwood likens positive person work in dementia to rehabilitation in stroke patients and coins the term "rementing".[6] Table 1 illustrates some of the techniques described by Kitwood that make up positive person work.

Personal Reflection: Erikson Revisited

Taking a step backwards, I have to admit that I did not come across the work of Tom Kitwood when I first began putting this article together. I tackled the consideration of a developmental approach to dementia in a slightly different way. Given that Erikson's antithesis at this life stage is "integrity versus despair", I undertook a personal reflection exercise to see how I could facilitate, instead, the transition from "despair to integrity" in the context of dementia. As stated previously, the essential task is to find meaning at the end of one's life. It is pretty clear that spirituality would be important for me to find ultimate meaning in life, if I were to be confronted with dementia. Spirituality, according to David McCurdy, is "our need and capacity for relationship to whatever or whoever gives meaning, purpose and direction to our lives. Spirituality… engages human capacities for self-transcendence and meaning-making".[13] Spirituality does not refer to any specific religious tradition.

As part of this exercise, I performed a Medline search on the Internet for the string "Dementia and Spirituality"; seven articles resulted. Perhaps I had been wrong, or at least academia didn't seem too supportive of my supposition. However, I then did the same search with the GOOGLE search engine. For the same search string, there were 9,120 hits! Perhaps I hadn't been so wrong after all, or perhaps academia hadn't kept pace with the everyday reality of meaning-making in dementia. Of note, in almost all of the

Table 1
Examples of Positive Person Work[6]

Positive Interaction	Description
Recognition	Acknowledging the dementia patient as a person, by name, with eye contact.
Relaxation	Allowing the dementia patient to relax, with others nearby, often involving actual body contact.
Negotiation	Consulting the patient about their preferences, desires and needs in the context of simple everyday issues, giving the patients some degree of control.
Validation	Acknowledging the reality of a person's emotions and feelings and giving a response on the emotional level.
Facilitation	Enabling the person to do what they otherwise would not be able to by providing those parts that are lacking.
Collaboration	"Working together" in care in a process that uses the patient's own initiative and abilities.

Medline articles I was able locate, Kitwood's work on personhood in dementia was cited as being pivotal.

Spirituality in Dementia

The relationship between religious commitment and health outcomes has been studied more thoroughly in conditions other than dementia. Most studies report a positive relationship between religious commitment and mental and physical health.[14-16] Spirituality is a multidimensional part of human life. Cognitively, it is a search for meaning. Emotionally, it involves feelings of hope, love, connection, peace, comfort and support. These factors occur within the person, as well as in relationships with others and with the community. Spirituality does not imply religion, and people can find spirituality through different routes: nature, music, art, values and meditation, among other things. A recent guide for caregivers published by the Alzheimer Society of Canada consciously recognizes that spirituality is "an often overlooked and neglected need for diagnosed people with a progressive dementia" and so devotes an entire section to "spirituality" and to "meaningful activities".[17]

Validation and Conclusion

First-hand Accounts and an Alternate Developmental Model: The Full Spectrum Model of Human Development

The above discussion regarding developmental issues started with Erikson and, through a somewhat convoluted consideration by way of Kitwood's person-centred dementia care, arrived at spirituality as a means for dementia sufferers and their caregivers to solve Erikson's final crisis and move from despair to integrity.

As a logistical confirmation, a developmental theory that ended directly at spirituality would help to tie these thoughts together. Such a theory does exist in the work of Ken Wilber. His "full-spectrum" model of human development is based on a cross-cultural examination of human development, philosophy and religion. This model views human development not as a series of antitheses, but as successive phases of growth that incorporate and integrate preceding ones—the analogy is made to the layers of an onion. The various stages can be roughly summarized as body identity, affective identity, rational/symbolic identity, existential identity and, finally, the spiritual or mystic identity.[18,19] This model brings us straight to spirituality without the meandering required in this paper.

Another validation for the above arguments would be authentication of the importance of spirituality by first-hand account. It happens that several of the 9,120 Internet hits on spirituality and dementia are essays by Morris Friedell, a former university sociology professor and dementia patient who writes and speaks eloquently about dementia. He likens a diagnosis of dementia to the Australian Aboriginal ritual of "bone-pointing", which apparently terrorizes a victim so much that they eventually sicken and die. However, as a patient, he believes this phenomenon can be overcome in a dementia diagnosis by "our psychic reserves, our social context and our spirituality".[20] Friedell goes on to assert that "our spiritual healing is the most valuable, as it provides a means to search for the final meaning and transcend a sense of loss".[2] ◆

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