What Happens to the ‘Self’ in Dementia: Implications for the Health Care System?

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Abstract
The prevalence of dementia in the community will increase over the next twenty to thirty years by as much as three-fold, making it the most common cause of disability in the community. It can cause great distress to the sufferer but also to the family, who has to manage the functional decline as well as any psychological and behavioural issues. One aspect of the illness, which is rarely mentioned in the textbooks, but is responsible for considerable psychological distress and family stress is the loss of sense of self that accompanies many cases of dementia. Some of this loss of ‘self’ is inherent in any degenerative disease involving the brain but, in addition, our systems for the assessment and management of dementia in the community can aggravate this loss.

It is vitally important that all services for dementia, whether in the community or in residential facilities, should be based on principles that promote a sense of self and avoid any interactions that are likely to undermine the ‘self’. A model operates in the community in Newcastle, Australia, that meets these principles, but it is vital to develop similar services in all areas of Australia. The concept of ‘self’ as outlined by Hofstadter provides a framework to develop appropriate services for all stages of dementia, from initial assessment to end-of-life care.

INTRODUCTION
The purpose of this review article is to highlight an aspect of dementia that, I believe, is both poorly understood and inadequately emphasised. I refer to the real, or perceived, loss of ‘self’ which, if properly understood, would alter our approach to the assessment and management of dementia in the community. The importance of this change can only be understood when we realise that there has been no major advance in treatment options for dementia for the last 20 years and no realistic hope of any significant development in the near future [1].

Textbooks on dementia and Alzheimer disease list, among the non-cognitive symptoms, such issues as apathy, anosognosia, delusions, hallucinations, mood disorders, agitation and sun downing [2], but rarely perceived loss of ‘self’. Although rarely mentioned, the loss of ‘self’, perceived by both sufferers of dementia and their families, may be the most feared aspect of the disease. Part of the perceived loss of ‘self’ in dementia is inherent in most degenerative diseases of the brain. There is a danger, however, that aspects of our assessment and management of dementia also contribute to the erosion of ‘self’. With the increase in prevalence of dementia over the next 20-30 years [3] and the lack of any significant advance in treatment [1], it is essential that we organise systems of care to minimise our own contribution to the disintegration of ‘self’.

Manifestations of perceived loss of ‘self’ in dementia
From my experience of 30 years in community geriatric medicine, it is not uncommon for people with mild cognitive impairment to fear the possible development of dementia to the extent that they declare a wish to terminate their life in the event that their memory progressively fails. Once dementia develops, sufferers often express the belief that they are treated like non-persons and ignored in public, “as though I no longer existed”. They frequently complain that health professionals talk only to their spouse or children.

Families also perceive this loss of ‘self’. It is common to hear statements such as “he is no longer the man I married” or “it’s like living with a stranger”. Unfortunately, as dementia progresses,
the demands on the carer can increase, while the person with dementia becomes less communicative and less appreciative. Caregivers often experience an anticipatory grief, which is poorly understood by others, including health professionals. Jonathon Franzen expresses this eloquently in the description above of his father’s journey through Alzheimer’s disease.

I also wonder if the erosion of the ‘self’ is so threatening that even health administrators and health professionals try to ignore dementia. Despite the increasing prevalence of the disease, which will make it the most common cause of disability in our community, community-based services for assessment and management of dementia, are poorly funded by most governments, including Australia [4].

Health professionals also seem to be uncomfortable with dementia, in a manner similar to that in which cancer was handled 30 years ago. Many doctors are reluctant to make the diagnosis or to inform the patient. It is only recently that specialist palliative care has taken an interest in the terminal phase of dementia.

**The nature of the ‘self’**

One of the reasons for these taboos regarding dementia may be our confusion regarding the nature of the ‘self’. Up until the sixteenth century, the ‘self’ was a transcendent or immaterial entity, identified with the soul, which outlived the death of the body. In the seventeenth century, Descartes, while trying to determine whether there was any sound basis for knowledge, believed that he had defined the mind [5]. Following the prevailing ideology of scepticism, he started by doubting every perception, sensation and conception, finally accepting that he could not doubt his capacity to think. He believed, however, that the entity responsible for thinking was not part of the material body, a philosophical position known thereafter as ‘Cartesian dualism’.

Cartesian dualism remained the prevailing view of the self until the middle of the twentieth century, when philosophers like Parfit began to reject dualism and accept a Reductionist view of the ‘self’ as being solely material and based on psychological connectedness and continuity [6]. Cognitive neuroscientists, have since defined the characteristics of the ‘self’ and shown how these can be undermined by diseases of various parts of the brain, particularly the frontal lobes and its connections [7].

**Perceived loss of ‘self’ in dementia**

Dementia is a degenerative disease that develops initially in one or more areas of the brain but eventually spreads to involve the brain globally. The frontal lobes can be involved early or later in the disease depending on the type of dementia. This leads to an objective view of the inevitable erosion of ‘self’ in dementia. This does not seem helpful, however, in our approach to the management of people with dementia and their families. It leads to stereotyping of people with dementia, a sense of futility in advanced dementia, and alienates families who remember the person as they were before the onset of dementia.

One attempt to overcome this stereotyping is Kitwood’s ‘personhood’ and person-centred approach. Kitwood defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” [8]. He believed that the perceived loss of ‘self’ by people with dementia was due to the inappropriate manner used by others to address people with dementia, which he called ‘malignant social psychology’ [9]. While representing an admirable gold standard, the person-centred approach of Kitwood can be challenging for carers and staff, perhaps adding to the guilt of families and health professionals, who may find it difficult to maintain this attitude in the face of emotional coldness, aggressive behaviour and personality change.

In my practice as a geriatrician dealing daily with dementia, a more useful understanding of ‘self’, has been developed by Hofstadter [10]. Hofstadter believes that the ‘self’ is an epiphenomenon that results from a series of loops that link various parts of the person’s brain; the brain with the body; one person’s brain with those of their significant others; and the brain and body with the environment which includes all aspects of culture, belief and religion. Hofstadter does not directly address the ‘self’ in dementia but it is easy to extrapolate his analysis to the situation of people with dementia and their families. Hofstadter’s loops present a similar view of the ‘self’ as the ‘situated embodied agent’, described by Hughes [11].

**The ‘self’ in dementia and implications for the care system**

If we accept Hofstadter’s concept of the ‘self’ as a series of loops, we can then consider what happens to these loops in dementia. The strength of the loop deteriorates in the person with dementia, but may deteriorate little or much less rapidly in families and significant others. For the person with dementia, the rate of deterioration of the loop depends not only on the severity of dementia, but also on the nature of care. As Sabat explains, “It is in the social dynamics of everyday life, beyond the neuropathological processes in their brains, that people with dementia can be supported in, or experience assaults on, their personhood” [12]. For the family, the preservation of their loops depends on the duration and quality of the relationship in the past, the personality and belief system of the family, and the level of communication with, and behaviour of, the person with dementia.

Our systems of assessment and care in dementia can also contribute significantly to the erosion of ‘self’ and to the strength of loops in both the person with dementia and their families. It is imperative that all aspects of care of dementia, in the community and in residential aged care, including end-of-life care, need to be designed to optimize the preservation of ‘self’ in dementia. In addition, understanding the ‘self’ as loops that link the person with dementia to their family and friends, have implications for our approach to advance care planning and end-of-life care.

**Assessment and management of dementia in the community**

Assessment of cognitive impairment should include a history from both the person concerned and a corroborative history from the family, friends or carers. Failure to obtain a corroborative history will deprive the practitioner of valuable information, essential for a complete assessment and for a comprehensive
management plan. Obtaining this history in the presence of the patient, however, may undermine their ‘self’, may impair the relationship between patient and family, or result in a failure of open disclosure. Families do not wish to discuss changes in personality, behavioural difficulties, functional impairment, delusions, hallucinations, or capacities such as driving, in the presence of the person with dementia.

In my experience, the best way for this essential history to be obtained, without embarrassment to either party, is for the doctor and another health professional to work as a team. The Newcastle model for the assessment and management of dementia in the community has been developed over the last 10-15 years in the three Local Government Areas of Newcastle, Lake Macquarie and Port Stephens, in the Hunter Region of New South Wales, which has a combined population of 400,000. It includes six teams, each involving a geriatrician and a Community Dementia Nurse (CDN). Each team covers a population of 40,000 to 80,000, and provides weekly clinics and visits to homes and aged care facilities.

In the clinic, the geriatrician starts by seeing the patient and family together, but ensures that questions are directed initially to the patient as the central person in the encounter, to minimize any erosion of sense of self. After that, questions directed to the family, in the presence of the patient, are confined to non-threatening details about the duration and progress of symptoms, co-morbidities, family relationships and the health of carers.

When the geriatrician is ready to examine the patient, the family is asked to leave the room, for the alleged provision of privacy. This allows the family to be taken to an adjacent room to be interviewed by the CDN, to allow for full disclosure of all features of the illness without embarrassment. The CDN can ask all the potentially embarrassing questions about behaviour, personality change, delusions, hallucinations and capacity. After completion of the physical and cognitive assessment, the geriatrician joins the nurse to hear details of the interview, to ask any supplementary questions and to inform the family of the likely diagnosis.

When the patient and family are reunited and the diagnosis of dementia is broached, it is rarely received without some emotion. It is important at this stage to allow all parties time to vent their feelings but, in my experience, there is little value at this stage in long discussions about the disease or management strategies. It is only necessary to provide immediately required support services, written information, and details as to where further education and support can be obtained.

Our experience is that detailed discussion is best left for a couple of weeks, to be carried out by the CDN, visiting the patient and family at home. This allows the nurse to answer all questions but also to witness the family relationships and living environment. The contact details for the CDN are then left with the family to allow them to call at any time about any aspect of the illness or change in behaviour, thus providing on-going case management. On-going case management is particularly important to support people with behavioural or psychological problems or stressed families, and has been shown to delay residential placement [13].

Community management of dementia

It is easy to fall into the trap of focusing on the deficit aspects of dementia, such as memory loss, challenging behaviours, impaired judgement, apraxia and dysphasia. This focus on the deficit aspects of dementia can undermine the sense of self and it is important to organise our care around the autonomy and capacities of people with dementia. This starts by involving the person with dementia in all aspects of management, assuming that the person with dementia has the capacity to make decisions, until there is clear evidence to the contrary.

As well as identifying the cognitive and functional deficits, it is important to uncover the strengths and capabilities of people with dementia and to encourage the continuation of these. Many people can still play music, sing in choirs, attend senior’s classes, do quality art and craft, cook, garden, and repair things around the house. Tasks may take a little longer and may require occasional assistance, but should be encouraged. Appropriate exercise, such as walking, swimming, cycling, dancing and tennis, is vital for ‘self’, for physical and cognitive well-being, but also because these activities can be shared and contribute to social involvement.

One aspect of the management of dementia, with great capacity to undermine ‘self’, is the removal of a person’s driver’s licence. This needs to be handled with utmost delicacy. In my experience that questions about driving capacity should never be directed to the family in the presence of the person with dementia. If the licence is revoked, it is critical to family cohesion, that the person with dementia believes this is solely the decision of the doctor. It is important, however, to discuss the issue with the patient and the family in a general way at all consultations, so that licence removal doesn’t come as an unexpected shock, which may people then see as a major attack upon their sense of self.

Unnecessary repeated cognitive testing is another aspect of on-going care that has the capacity to undermine ‘self’, particularly for people with little formal education or anxiety facing such tests. After the first couple of assessments, once the diagnosis is clearly established, further cognitive testing is often unnecessary. Adequate information about the progress of the illness can be obtained by a report of functional capacity from the family.

Residential aged care

The decision to relinquish one’s own home and move into residential care can be a similar assault on ‘self’ as losing a driver’s licence. The move into residential care can easily be associated with a feeling of abandonment. It is almost never appropriate for a carer to be told to keep away from the residential facility “to allow for settling in”, whether the admission is for respite or permanent care. If the admission is for permanent care, strategies for the preservation of ‘self’, include decorating the room with photographs, pictures, and other memorabilia, that foster a sense of belonging; regular visits by family; and involvement in activities that promote a sense of pride.

The staff of the aged care facility should document a life-history of the new resident so that they can understand the pre-dementia ‘self’, as it is perceived by the family, rather than seeing...
only the person with dementia. This will minimise any tension between staff and family who, otherwise, will have quite different perceptions of the person, with whom they are both involved. Once the life history is known to the facility staff, there will be opportunities to use a range of strategies to engage the person with dementia and to promote their ‘self’ [14].

If any important aspect of life is stifled or obstructed, then the ‘self’ is inevitably diminished. Facets of life that are likely to be restricted in an aged care facility, include physical activity, involvement with nature, grooming, touching and sexuality. Areas for wandering, gardens, facilities for make-up and hairdressing, and privacy for sexual expression, are important elements of any aged care facility that aims to minimise the erosion of ‘self’.

**Advance care planning and end-of-life care**

Once dementia is reasonably advanced, end-of-life care becomes of vital importance, supported by advance care planning. If we accept the ‘self’ in dementia as a series of loops including family, carers and close friends, this has significant implications for this stage of care. The ‘person’, to whom person-centred, end-of-life care, including advance care planning, is directed, is no longer just the person with dementia, but now includes other significant loops. This particularly involves the spouse and children, but also may include siblings and close friends. Failure to involve significant loops in discussions about care planning can lead to unnecessary, and avoidable, family disharmony.

**SUMMARY**

The prevalence of dementia in our community will double in the next twenty to thirty years, possibly tripling in prevalence by 2050 [3], making it not only the most common cause of disability, but the major focus of aged care services, including residential care. The assessment of impaired cognition and the diagnosis of dementia will be a large part of the work of general practice, and the bulk of the activities of geriatric medicine clinics and community aged care services.

Assessing dementia in the same manner as we use for non-cognitive issues of older people, is inappropriate. It can add to the erosion of ‘self’, alienate patients and families, and lead to inaccurate diagnoses from lack of a complete history. It is essential that services and programs be designed to avoid these errors and adverse consequences. It is my view that the basic components of an adequate dementia assessment and management service in the community is another health professional, preferably a Registered Nurse, working with a geriatrician or other cognitive specialist, in close collaboration with general practitioners. One Dementia Nurse for a population of 40,50,000 (500-600 people with dementia) would, at the least, allow for case management of those families with difficult behaviours or carer stress.

It will be a tragedy if our funding bodies and health administrators do not soon accept the challenge of dementia in the community. In the absence of any major treatment advance, sensitive assessment and case management, ensuring the minimal erosion of ‘self’ and supporting the family to provide care, will be the most effective strategy in preventing expensive institutional care. Dementia is a difficult disease for both the person involved and the family, even if care is sensitive and supportive. Assessment services and care systems, that are not adequately funded to allow for sensitivity and support, can turn difficulty into damage.

**REFERENCES**