

Dementia in medical ward: a case report on preservation of 'personhood'

Norhayani, M.A and Agong, L

Institute of Health Sciences, Universiti Brunei Darussalam, Brunei Darussalam.

Abstract

Epidemic of dementia is globally acknowledged and cure for dementia is yet to be discovered. Patients with dementia often 'landed' in medical wards where 'generalist' professionals appear to struggle to care for them. The psychosocial model of care has been recommended to guide the provision of nursing care for this group of population. We report a case of 73 years old man who presented with physical symptoms, however his symptoms of dementia in particular 'losing self' had made him to be quite 'popular' among staff and was labelled as a 'difficult patient'.

Key words: Dementia, Psycho-social model, medical wards, personhood, case study

Introduction

There is a growing problem of dementia as a global public health challenge. It is estimated that there are about 47.5 million people have dementia and there are 7.7 million new cases every year (WHO,2015) (30 million people with dementia in the world (Alzheimer's Disease International (ADI) with 4.6 million new cases annually (one new case every 7 seconds) (Ferri, 2005). It is projected that and driven by the ageing population, the number of people affected will be tripled to 100 million by 2050 (WHO 2011). The estimated proportion of the general population aged 60 and over with dementia at a given time is between 5 to 8 per 100 people (WHO, 2011).

Dementia is also the leading chronic disease contributor to disability and dependence among older population worldwide (WHO, 2011). Dementia has physical, psychological, social and economical impact on caregivers, families and

society (WHO, 2015). Research has been conducted to search for its treatment and yet to produce outcome that can cure the disease.

Patients with dementia often 'landed' in medical wards where 'generalist' professionals appear to struggle to care for them. Not only that, evidence support the burden of caregiver in providing care to the individual with dementia and this burden is a response of stress they faced every day. In some cases, the care of dementia patient was criticised due to the use of chemical and physical restraint. Hence, the psychosocial model of care provides alternative as it aims to provide a therapeutic care which validates the person with the illness, builds on strengths, and meets the person's needs (Patel, Bhamini, et al. 2014). It also provides the patient with a therapeutic social environment and emphasized the central role of relationships.

The aim of this case study is to understand the challenged behaviour in dementia patient and explore therapeutic approach towards dementia care. The specific objectives include a) to examine underpinned nursing approach towards dementia patient b) to analyse challenged behaviour in dementia in relation to psychosocial approach and c) to discuss the importance of personhood in dementia care.

Corresponding Author:

Norhayani Mohd Amin

norhayani.amin@ubd.edu.bn

CASE REPORT

Ahmad (Pseudonym), 73 years old was admitted to the medical ward primarily due to his uncontrollable blood sugar level. He has a known case of Type II diabetes mellitus. He was on metformin 1gm BD and Glicazide 80mg BD. During his admission, he appeared confused, lethargic and had tachycardic. His random blood sugar was 22mmol while his electrolytes were within normal range. Other investigations that included chest X-ray and urine test were negative for infection. He was put on insulin infusion and his blood glucose level had settled during his hospitalisation. However, Ahmad still appeared confused, elated in his mood, speak incoherently, wandering around ward at night, disoriented in time and place.

During one night shift, Ahmad pulled out his intravenous (IV) line and stated that "I am taking all these fruits, they are already ripe and ready for sales". When his behaviour was thought to be difficult to control, 2mg of Haloperidol was administered intramuscularly with the intention to calm him and to allow other patients to sleep peacefully. "He is old and demented and it is a pity that he does not know what is going on. He is going back to 'being a child' sighed the nurse". Although, Ahmad was not formally diagnosed with Alzheimer's disease, his behaviours showed similar manifestations of those with dementia. Nurses find it particularly challenging to care for him due to his combative behaviours. This has made Ahmad to be quite 'popular' among staff and was labelled as a 'difficult patient'.

Analysis of nursing approach towards dementia patient

Fear to care, restraints and biomedical approach

Care interventions including physical and chemical (sedatives) restraints often used in past and at times present in managing dementia patients. Schofield and Heath (1996) reported that 'inappropriate' or 'difficult' behaviours are often perceived as the inevitable result of dementia which leads to the thought that nothing positive can be done aside from containing or controlling the behaviour. Levine et al. (1995) cited in Watson (2001) argued that one of the main misconceptions of applying restraint is that it

can contribute to safety. Such perception may be the underlying reason for restraining Ahmad. It could be argued that nurses might believe that their actions are to safeguard Ahmad from any harm and protecting themselves against the accusations of negligence. However, few studies reported that such interventions only add risk to patients leaving ill effect on them (Hanger et al 1999, Roper et al. 1999, Watson 2001). As studied by Watson (2001) physical restraint not only can cause injury to the patients' body, it also exacerbates confusion for the confused patients. Roper et al. (1991) also pointed out that the administration of tranquilisers can complicate patient's condition causing their health to further deteriorate, delay recovery and result in them becoming more dependent.

Indeed, several researchers revealed that many people with dementia leave hospital in a worse state than when they were admitted (Ekman et al. 1991, Tolson et al. 1999, Royal College of Nursing and Help the Aged 2000). It is proposed that people with dementia deteriorate naturally as a result of the condition but Kitwood (1990, 1997), Sabat and Harre (1992), Sabat (1994) argued that negative social psychology also contribute to such deterioration. Following his research, Kitwood (1997) identified various elements of malignant social psychology at care settings including infantilisation, labelling, stigmatisation, invalidation, objectification, disruption and mockery which can have damaging effects on self-esteem and personhood of people with dementia.

Kitwood (1997) posits that fear of growing older as one of the factors that is likely to increase malignancy. Most of us fear growing older particularly if it means becoming frail and highly dependent on others (Pritchard and Dewing 2001), and working closely with the elderly can provoke such fear and anxiety that is held at an unconscious level (Kitwood 1997). One of the ways to cope with the fear of ageing is by pretending that it is not going to happen to us but to others and to exclude those with dementia as much as possible from the mind and from society (Dewing 1999). Consequently, older people have been treated negatively by nurses and other healthcare team members (Normann et al. 1999, Stokes 2000) and those with dementia are doubly stigmatised (Dewing 1999). Post (1995) noted that our culture has become

'hypercognitive' and those people with declining cognitive abilities or intellect such as dementia have been negatively stereotyped. It is easy to wrongly presume that due to impaired cognitive ability, the person with dementia is unable to reflect their experience (Biernacki 2000) and they do not have any feelings (Pritchard and Dewing 2001). Such views are embedded within the biomedical model which tended to focus on signs and symptoms rather than the individual (Kitwood and Benson 1995). The staff who nursed Ahmad may have based their 'nursing care' upon the biomedical approach that would allow them to retreat from emotional involvement when they do not have adequate personal resources to deal with people with dementia (Kitwood 1993a).

Epistemology of 'Personhood' in relation to dementia
To examine the care situation of Ahmad from the epistemological perspective, attention should be paid around the nurse stated that "He does not know what is going on". Analysis on this statement suggests that the nurse believed that the patient has lost his rationality and self-awareness. This perhaps explains why degrading or humiliating comments that might otherwise be made 'behind the person's back' are now made in front of the person such as in Ahmad's case (Sabat 2002a). Hence, where does the assumption or thinking about one losing one's 'self' or 'personhood' derives from?

According to Quinton (1973) there are five criteria for describing personhood which includes consciousness, rationality, agency, morality and the capacity to form social relationships. Warren (1973) cited in Jenkins and Price (1996) claimed that there are six criteria for personhood which involves consciousness, reasoning, self-motivating activity, the capacity to communicate, the presence of self-concept and self-awareness. If all these criteria are necessary conditions for personhood, people with dementia will certainly be excluded (Dewing 1999). For instance, the nurse assumed that Ahmad had lost his rationality and self-awareness which are both 'necessary' criteria for personhood. Hence, failing to fulfill such criteria might lead to the assumption that Ahmad has lost his identity and personhood. Post (1995) commented that the normative philosophical theories place a high value on rationality and he is critical on the ethics of personhood because of this. This rationalist view rooted from Decartes who reinforced ideas about the

existence of self-originating from the certainty of the thinking mind (Davis 2004).

In a similar vein, Locke (1996) contends that to be a person entails the capacity to undertake certain kinds of mental activity and to have psychological continuity. This also includes having intact memory function which enables one to reflect their own existence and identify themselves as who they are. In short, the root of our personhood is self-consciousness (Locke 1996). This consciousness depends on the memories that link who we are now with the who we were in the past (Locke 1996). Parfit (1984) also offered similar views stating that personal identity depends on psychological continuity. Both agreed that the essence of personhood and personal identity lies in the ability to continuously think of oneself as oneself and continuing to remember one's past life, and that it has nothing to do with biological and physical continuity (Matthews 2006). This suggests that someone with dementia although still living and breathing is no longer a person and certainly no longer the person they once were if they failed to relate with any past actions or activities or when all the personal memories are destroyed (Matthews 2006). For example, even though Ahmad still looks the same, he is no longer considered to be the same person because he cannot recall very much about his past life.

Butler (1736) cited in Matthews (2006) rejected the Lockean view and argued that a person cannot be defined solely in terms of self-consciousness, because consciousness cannot exist on its own unless there is already existence of self to be conscious of. This argument is supported by Merleau-Ponty who described the human person as a 'body-subject' (Matthews 2006). 'Body' is referred to the fact that a person is indeed a kind of biological creature and 'subject', indicates that they are capable of thought, reflection and communication. Thus, to exist as a person, these two elements must exist and they cannot be separated from each other as opposed to Decartes's dualistic view of mind and body as separate and distinct things (Matthews 2006). Obviously, the 'body' (biological organism) must exist first before one can even begin to think, this implies that personal life emerges from pre-personal bodily existence. We have an identity of our own from birth which become more distinctive and more complex as we accumulate

memories of our experiences and reflect upon them, this gradually becomes embedded in our unconscious habits as described by Merleau-Ponty (1962, 1965) cited in Matthews (2006). In a way, Locke and Parfit are right in saying that thought and reflection are essential in order to form our identity but they ignore other features and concepts of a person that are indeed important prior to this self-conscious life (Matthews 2006).

Matthews (2006) also pointed that the notion of body-subject is not only about our existence as a person from our embodiment, our bodily existence is equally important as an expression of our individuality such as our body language, gestures, habits of behaviours and so forth. Thus, those who accept Merleau-Ponty's view about a person, are likely to reject the idea that the person dies or ceases to exist when they cannot recall their personal memories, in fact it is believed that something about their individuality will survive even in the most severe cases of dementia (Matthews 2006). Now, it can be challenged that the perception of the person with dementia as a child is not acceptable. The 'difficult' behaviours that Ahmad presented to the nurse cannot be compared with child's behaviour, it should be seen as part of Ahmad expression of his individuality which has become sedimented in his way of living.

Hence, we argue that personhood has a number of different philosophical concepts and each of them can influence the way we nurse our dementia patients. For instance, early dualist philosophies on personhood seem to underpin the biomedical model where it is assumed that mind and body can be treated separately (Bond 2001). Thus, nurses who believe in them are likely to approach their patient using such a model. Bond (2001) criticised that the biomedical model does not acknowledge the ways in which the caregiving relationship and conditions of the caregiving context can have an impact on the individual with dementia.

Sabat and Harre (1992) and Sabat (2002a) have argued that the loss of 'self' in the person with dementia is related to the ways in which others view and treat them.

Application of Personhood approach in dementia care

Locke (1996) proposed that our personhood and personal identity lies in the conscious thinking of oneself as 'me'. Matthews (2006) criticised that if we rely on conscious thinking alone without any other criteria to support it, it would then be difficult to justify if that individual person is indeed the same person by simply saying 'I am the same person', and the reality is he or she might not be the same individual person. Sabat and Harre (1992) and Sabat (2002a, 2002b) argue that it is not an intact memory and self-consciousness that constitutes one's personal identity in the sense of self but it is the use of first person indexicals ('I', 'me', 'myself', 'my', 'mine') according to the social constructionist view that confirms the existence of the self of personal identity. Tappen et al. (1999) in their qualitative study exploring whether there is an awareness of self in people with moderate to severe Alzheimer's disease found that their participants frequently used first person indexical when they talked about themselves which suggests the persistence of self.

Sabat and Harre (1992) acknowledged that there is a possibility that a mere verbal habit of the use of first person may persist, which could result in the illusion of a survival selfhood. However, Sabat (2002a) suggests that the moment a person uses 'I', 'me', 'my' or even uses gestures to express it, it indicates that the person is experiencing or expressing his or her personal identity and it also indicates to others his or her singular, unique point of view. This is what they call the self of personal identity (Self1) and it is claimed that it will remain intact even into the moderate to severe stages of dementia (Sabat 2002a). This Self1 according to Sabat (2002a) does not rely upon one's personal history or memories. For example even if Ahmad could not recall his place of birth or address, he could still have an intact Self1 and if we look back at the nursing situation Ahmad even employed first-person pronouns where he stated that "I am taking all these fruits, they are already ripe and ready for sales". Of course, such a statement may sound irrational to us particularly when it is said in the middle of the night and in hospital but this does not mean that it is not real to Ahmad. Bush (2003) found

that people with dementia generally communicate within the context of a reality and frame of reference that are alien to others. Sabat (2002c) warns that when doing assessments or interviews with someone with dementia, we must acknowledge that they might be vulnerable to being embarrassed and humiliated particularly when discussing their problems with strangers. They might become less open or avoid discussing about major issues in their lives in order to avoid any embarrassment and humiliation. Clare (2000) cited in Sabat (2002c) claimed that such avoidance may reflect a heightened awareness and insight into their problems. Unfortunately, it is often assumed that when a person fails to reflect or discuss their deficits openly, it is associated with the symptoms of the dementia alone (Dewing 1999), and we tend to overlook the possibility that such reactions can be quite normal (Sabat 2002c). This indeed reflects the lack of insight and ignorance from others into important aspects of the subjective experience of another human being. In some cases, Dewing (1999) reported that people with dementia have been regarded as 'non-people' which led them to be treated as inactive objects that only need to be kept clean, dry, fed and watered. This leads Kitwood and Bredin (1992) to conclude that dementia is partly the result of the way society treats these particular people. Indeed, if Kitwood (1997) is right about his view on personhood which is something that emerges within a social context, then we all are responsible for not helping others to maintain their personhood.

As emphasised by Sabat and Harre (1992) and Sabat (2002a) there is another aspect of personhood which is the socially presented selves, or *personae* (Selves₂) which can be lost, not directly as a result of dementia, but rather related to the way others treat the person with dementia. The important difference between Self₁ and the Selves₂ is that in order for us to sustain Selves₂, it requires the cooperation or support from others (Kitwood and Bredin 1992, Sabat and Harre 1992, Sabat 2002a). Thus, those who have dementia might be in a vulnerable position to lose Selves₂, particularly if others only emphasise their deficits or predominantly view them as 'demented' (Sabat 2002a). For instance, in Ahmad's situation, he presented himself to us as a gardener and a greengrocer. However, the nurse strictly viewed his presentation as part of the dementing process. As a result, it would be impossible for Ahmad to sustain his

Selves₂ without any cooperation from those who were around him. Sabat and Harre (1992) argued that such loss of Selves₂ can, in many cases be prevented, provided that the caregivers and others are willing to try to refrain themselves from interpreting all acts or behaviours from the person with dementia as part of the disease alone. Preservation of personhood according to Kitwood and Bredin (1992) is the central issue in care of people with dementia.

Discussion

Reviewing early dualist philosophy and traditional concepts on personhood has helped to understand the underlying reasons why the person with dementia is sometimes treated as if they were no longer a person anymore. In short, as Sterin (2002) put it 'without a mind it is not a human at all'. Consequently, it makes sense why 'caring' has become nothing more than attending to a patient's physical body that only needs to be kept clean (Wylie 2003). While acknowledging the contributions of biomedicine, Dewing (1999) commented that it can also bring problems. This is true particularly in dementia care. Bond (2001) stated that the biomedicine is a product of the Enlightenment where it creates a belief that all human life can be improved through science and technology. Biomedicine is reductionist in a way that it only explains disease in biological terms and ignoring other important aspects of psychological and social factors (Bond 2001). Kitwood (1993b, 1997) has argued that dementia is not simply the result of cognitive impairment but it is also a result of a complex interaction between social, physical health, life history and environmental factors. This indeed has been demonstrated using Kitwood's theory (1997) of malignant social psychology and the social constructionist approach (Sabat and Harre 1992, Sabat 2002a, Sabat 2002b). This leads to the conclusion that dementia is socially constructed not only in the sense that it is a diagnostic category arising out of social interaction and discourse by the medical profession but also, in that it is the result of society acting upon individual people (Kitwood 1990, 1997).

Kitwood and Benson (1995) refuted the assumption that those with dementia are 'non-people' and promoted the culture of dementia care which emphasises the view that people with dementia are people first and foremost. They might have lost some

part of what made them the distinctive complex individual, the things that really make us ourselves where others can sense who we are as adults (Matthews 2006). However, this does not put them in the same position as a child as assumed by the nurse because they still can retain some elements of their conscious identity in a way that a child necessarily cannot (Matthews 2006). Hence, regardless of the level of knowing and abilities that the person with dementia retain, they are still people and not 'the demented', and entitled to have the same rights as anyone else (Dewing 1999). This includes the absolute right not to be subjected to treatment which is inhuman or degrading as stated in article 3 in the UK Human Rights Act 1998. Restraining the patient without any proper justification for example could be viewed as violating their human rights.

If we studied the nursing situation and literature that has been presented carefully, we can trace that the problem with dementia care depends on how one views a person with dementia. As demonstrated by Goldsmith (1996) we either view that due to the nature of the disease, the person with dementia gradually becomes 'loss' and there is little that we can do to stop this from happening. Or we take the view that it is part of the medical condition but believe that there is still a way of helping the person to rediscover and maintain his or her personal identity. Bush (2003) however criticised that it seems counterproductive in a humanistic sense to focus on the patient in terms of signs and symptoms only and the fact that there is a person with feelings, beliefs and values beyond the perceived surface dysfunction. Hence, although dementia results in a variety of cognitive problems which includes the disruptions in recall memory, this does not result in the loss of Self1 and only contributes indirectly to possible losses in Selves2 (Sabat and Harre 1992).

Touhy and Lynn (2004) posit that due to the communication and memory impairments, people with dementia might have difficulty expressing their personhood or might express it differently from those of us who do not have dementia. They suggest that it is essential that nurses practice from a belief that the person with dementia is still a whole person who can think, feel, grow and be in relationships. This is what

Kitwood (1997) called a person-centred approach. It encourages us to look beyond the patient's presenting problems and disabilities and acknowledge their unique life history, personality, personal preferences, strengths and abilities (O'Donovan 1996). This approach helps to maintain one's personhood (Kitwood 1997) and this is also supported by Parse's human becoming theory (1992, 1996, 1998). Yet, some argue that the whole concept of 'person-centred care' is too idealistic and is far from reality in practice (Health Advisory Service 1998, Help the Aged 1999), therefore it should simply be dismissed (Packer 2000). It should be remembered that the important concept of person-centred approach is to treat the person as a whole rather than just concentrating on one of the factors (neurological impairment) (Kitwood 1993b, Kitwood and Benson 1995) which is rather too idealistic. If people with dementia are viewed as less than a whole, it would then be impossible for nurses to come to fully know them (Boykin and Schoenhofer 2001). Consequently, it would be difficult for people with dementia to sustain their personhood.

Boykin and Schoenhofer (2001) suggest that nursing as caring is relevant in supporting relationships that nurture personhood. Nursing as caring theory posits that a person should be viewed as whole and complete in the moment, and there is no insufficiency, no brokenness or absence of something (Boykin and Schoenhofer 2001). In the context of dementia care, this means believing that the person with dementia remains caring, human, whole and complete (Touhy and Lynn 2004). Hence, the focus of nursing care should be directed towards coming to know a person and understanding how they are living rather than trying to discover what is missing or looking for problems that are assumed can be fixed through nursing (Boykin and Schoenhofer 2001, Touhy and Lynn 2004). As stated by Parse (1994) only the person living the life can describe its quality, and this applies to all people – even those who are having cognitive impairment (Parse 1996).

Conclusion

This paper has reflected on a nursing situation which was used to study and understand the concepts of personhood and the issues arising within dementia care. This study reveals that the 'self' can survive even

into the severe stage of dementia provided that caregivers and others help to preserve their personhood. A person-centred care has been proposed as an approach that can help to maintain one's personhood. It emphasises seeing a person as a whole and beyond the disease in order to encounter

the person. This has been supported by the human becoming theory and nursing as caring theory. Hence we conclude that the preservation of personhood is indeed an essential part of dementia care.

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