

A CRITICAL COMPARISON OF THE STRENGTHS AND LIMITATIONS OF THE PSYCHOLOGICAL AND GERONTOLOGICAL APPROACHES TO UNDERSTANDING DEMENTIA

ABSTRACT:

The phrase “Understanding Dementia” is perhaps the ultimate oxymoron. For how can we even begin to “understand” something of which we know neither the cause nor the cure? In his introduction to Al Power’s book “Dementia beyond drugs” (Power, 2011), Bill Thomas, founder of The Eden Alternative says: “Conventional wisdom, if you can call it that, holds that dementia represents a peculiar, deadly, and completely irredeemable kind of decline.” (p.ix). A phenomenon that has been around as long as human beings themselves have been around, dementia presents an existential crisis to humanity in that it threatens everything that most people aim for – superficial or not – in living what Socrates described as a long, good life. In Jewish tradition it is customary to wish someone a long life when a relative passes away. Is this a good, happy wish or is it a curse when someone is diagnosed with Dementia every four seconds in the world? (World Health Organization, 2012)

The Psychological and the Gerontological approaches constitute an expansion on the purely biomedical perspective of the disease, exploring the impact that dementia has on the individual living with it, as well as the impact that it has on the broader community. It is argued in this assignment that while Psychology and Gerontology have expanded on the narrow viewpoints of the biomedical approach, the heterogeneous nature of the manifestations of dementia, especially in the Developing World where research is not on the political agenda, leaves the world none the wiser in how to deal with this epidemic.

INTRODUCTION:

The Psychological perspective expands upon and challenges the Biomedical assumption that the behaviour of people living with dementia is the direct result

of a loss of neurons in the brain. Al Power (2012, p12) alerts us to the difference between “*brain and mind*” and, by the same token, to the distinct difference between “*brain disease and the experience of dementia*”. Psychology sheds light on the latter by looking at the experience of the person living with dementia, caregivers and family. However, Hardy and Palfry (1997), as quoted in the Course Handbook (2013, p55) point out that early psychological theory also focused mainly on “diagnosis, assessment and behaviour modification”. The emphasis of the early Psychological approach was still within the paradigm of the “patient” in need of “therapy”. Each of the three Psychological schools of thought that subsequently developed, namely Cognitive, Behavioural and Social Psychology, addressed dementia from a different perspective.

When looking closely at the terminology used in these schools of thought, one notices a common thread that tells one something about the approach: “behaviour modification”, “appropriate behaviour” or “responding appropriately”, to name but a few, indicating that the person living with Dementia needs to be helped to fit in, conform, act properly and behave in a manner that is socially acceptable (whatever that might mean). A strong emphasis on deficits created wonderful opportunities for therapies – a dimension of Psychology that flourishes to this day. Validation therapy, Reminiscence therapy, Cognitive Behavioural therapy, Reality therapy, Orientation therapy and Cognitive Stimulation therapy are but a few of the more mainstream therapeutic offerings. This list is expanded in “Creative Approaches to Dementia Care”, edited by Lee and Adams (2011):

- Reigniting the human spirit (Spark of Life)
- The Laughter Boss™
- Drama therapy
- Dance movement psychotherapy
- Music therapy
- Art therapy
- Life Story matters in dementia
- Reminiscence

- Using photography, video and visual material
- Creative processes etc.

One can add to the list – Pet therapy, Horticultural therapy, Multi-sensory stimulation therapy etc., all leaving the impression of a “sick” person who needs all the help that they can get in order to conform to some societal rule of how “normal” people should or should not behave.

Whilst a lot of time could be spend on the development in the field of psychology up to this point, it is my opinion that it is with the arrival of Tom Kitwood on the dementia scene that the landscape started to change. This is the juncture on which I choose to focus my attention in terms of a critical comparison with gerontology. The relevance of gerontology for the Dementia debate cannot be over-emphasized. As mentioned at the beginning of this assignment, the prevalence of Dementia demands it be addressed in more than just the medical and psychological arenas. “Dementia is a truly global phenomenon within the context of cultural, economic and social globalisation” (Bond, Corner *et al.*, p220). The rights of people living with Dementia, their wellbeing, participation in society and their role as citizens must be protected – across the globe – along with every other vulnerable group. In a changing landscape of politics and economy, the positioning of older people and people living with Dementia needs to be secured through advocacy and lobbying to ensure their standing in society.

PERSON-CENTRED CARE:

A shift in focus occurred with the seminal works of Tom Kitwood, which were based on the principles of humanist psychology and considered the whole person and not just the disease. The concept of Person-Centred Care brought about a new awareness of the dynamics and interactions between the person living with dementia and the care environment, as well as of the significant people present in that environment. As per Kitwood’s well-known definition of this, “...thus we arrive at a definition of personhood. It is a standing or status that

is bestowed upon one human being, by others, in the context of a relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p8).

A significant new spectrum of questions was sparked by the concept of *personhood*, resulting in a shift of focus away from deficits to a more holistic view of the person functioning within a social context, and not just being an object without a subjective sense of self. A whole new discourse is developed based on the equation $D = NI + PH + B + MSP$ described as a “dialectical process”. For the first time, the experience of the person living with Dementia (D) is seen within a broader framework, an interplay between the neurological impairment (N), his/her physical health (H), biography (B) and the impact of a non-supportive, hostile environment (termed “malignant psychology” (MSP)) (Kitwood, 1997).

TRANSCENDENCE:

The discourse incorporates not only the physical reality of neurological disorder, but also the moral and ethical considerations in care. The idea of *transcendence* explores the sacredness and uniqueness of the individual living with dementia, and the ethical imperative to value their status absolutely. (Kitwood, 1997). Guidelines for practice cover avoiding “malignant psychology” through “positive person work” (Kitwood, 1997). These were expanded upon by Prof. Dawn Brooker in her book “Person-Centred Dementia Care”. Brooker proposes the VIPS model, which creates a framework of care in which the person living with dementia and their Caregivers are valued (V) for who they are as individuals (I), the world is seen from their perspective (P) in a positive social environment (S) creating a sense of wellbeing (Brooker, 2007). Once again, this is a holistic approach that takes the person living with Dementia into account, within a context that has the potential to enhance their quality of life.

When considering the Psychological Model from this viewpoint, it is evident that it has greatly advanced the understanding of Dementia by moving away from perceiving it as a disease and embracing a more holistic approach and deeper understanding of the experience of individuals living with the condition. The

question that remains is: has this movement progressed far enough to change the world for people living with Dementia? Sadly the answer is not a conclusive yes, as the implementation of this theory and line of research in everyday practice is far from simple and the measurement of its success still elusive.

CRITICISM OF PERSON-CENTRED CARE:

Dewy (2008) claims that there is a lack of clarity in terms of how person-centred care actually translates into practice, and questions the understanding of *personhood* on a philosophical level. In his opinion, Kitwood's work does not move beyond focusing solely on the person living with dementia. In my interpretation the focus of Kitwood's work is the first shift away from such restricted focusing on the person living with dementia. His description of "malignant psychology" and "positive person work" creates awareness of how important other people are in the quest for optimal care of the person living with Dementia. The notions of "malignant psychology" and "positive personhood" provide family, caregivers and long-term care operators with guidance, in cognizance of their importance in the care relationship. Dewy, however, sees this as a "philosophically messy definition" (p10).

A LACK OF EVIDENCE:

Though Dewy does acknowledge that Kitwood brought a "radical approach" (p10) to the understanding and care of Dementia, he questions his research methods and arguments. One interesting point in Dewy's critique is that Kitwood characterizes personhood as a "status" rather than a "process", in other words a static entity. It is unclear whether this was Kitwood's intention, (perhaps because Kitwood died before his work could be scrutinized and consequently developed further). When considering the philosophical nature of Kitwood's argument for personhood as being "a moral concern for others" (p10), the debate takes on a transdisciplinary angle and leads us to perhaps the place where dementia research should be heading – a firm basis in the intersection of

the disciplines of philosophy, psychology, gerontology, geriatrics, theology, medicine, psychiatry, neurology, sociology, nursing and anthropology.

Person-Centred Care is considered a construct that is impossible to measure and hence lacks empirical evidence of its efficacy, as seen in amongst others an article in the Journal of Clinical Nursing (2009) by Edvardsson, Fetherstonhaugh and Nay. Here person-centred care is described as “abstract and vague”, again reiterating Dewy’s concerns around the evidence base, methodology of research and highly theoretical nature of Kitwood’s work.

Given the lack of empirical evidence, one might well ask what such evidence would entail? Without entering into a discussion of the differences between quantitative and qualitative research, it does seem that the validity of person-centred care in improving the quality of life of people living with Dementia is questionable in the absence of a clear vision of what exactly the outcomes should be. Edvardsson maintains that “most publications seem to agree that person-centred care is a multi-dimensional concept describing care that is based on and includes people’s subjective experience of illness” with reference to studies by Brooker (2004, 2007) McCormack (2004), Edvardsson *et al* (2008) and McCane *et al* (2009). If this is the case, does this argument not fall squarely back into the biomedical model where the focus is purely on the *illness*? Are people living with Dementia usurped by the *illness* to the extent that it becomes their only marker of identity? I think not. If this argument were valid, it would mean that the psychological approach is indeed still only a model of illness, for which therapy is the answer. Fortunately Edvardsson *et al* found that this is not the case and that person-centred care is indeed a tool capable of promoting “a continuation of self and normality” (p2614). By creating an environment in which care providers are aware of the individual living with Dementia’s life story, their likes and dislikes, and committed to providing what The Eden Alternative would call their “simple pleasures” referring to the small things that used to bring them joy, a life worth living can be facilitated. The important role that family plays in supplying such insights can also enhance the well being of both the person living with Dementia

and the family, who often are severely traumatised by the manifestations of the disease.

Taking this further, “therapy” is no longer something that happens to be “inflicted” on the person living with dementia; it flows into everyday life in the form of meaningful activities and, even more importantly, meaningful occupation. In my experience, creating a “home” for individuals living with dementia, knowing who they are, what gives them joy, what upsets them, what their “simple pleasures” are, what occupation or hobbies they enjoy, their life story and the nature of their relationships with friends and family, all contribute to creating a person-centred care environment where the individuals not only live, but where they can flourish.

Questioning the static nature of personhood leads to more questions pertaining to self and identity, as explored in an article by Caddell and Clare (2009). In spite of the efforts of groups all over the world, many people still regard Dementia as a “slow death”, a process that leaves a physical body “with no person left inside”. A recent surge of research has called into question the inner experience of the person living with Dementia and the common belief that the person actually disappears, leaving behind just the body. A new body of work on concepts like self and identity, levels of awareness of people living with dementia, stereotyping of both self and society, have broadened the preceding one-dimensional discourse (Caddell and Clare, 2009; Downs, 2010; Kelly, 2010; Sabat and Harré, 1992).

A SENSE OF SELF AND AWARENESS:

From this perspective, the *person* living with dementia is at the centre, rather than the *disease*. As a real interest has developed in the subjective experience of *self* and the *awareness* of such a self, fewer assumptions have been made about what the “experts” think appropriate and there has been a decreased tendency to throw a host of “therapies” at people living with Dementia. Sabat and Harré (1992) demonstrate that the *self*, that which defines who we actually are as a

unique individual, is never lost, nor are the “personae”, i.e. the different selves that we obtain through our social being and interactions. In their opinion, the only loss that occurs is as a result of the impact of what Kitwood describes as “malignant psychology” (Kitwood 1997). “In normal circumstances each human being is the seat of just one person, but of many personae” (Sabat and Harré, 1992, p446). The latter relies upon social interactions in which we are validated.

Downs (2005) considers “awareness”, and concludes that people living with dementia are indeed aware of who they are, their role and place in society as well as how they are viewed (and treated) by others. Downs also alludes to the lack of “evidence” in the literature, but very aptly points out that, in this instance, there should be no need for more evidence to encourage person-centred care. If we are serious about care being “a moral concern for others” (Dewing, 2008, p11) there should be no need for more empirical evidence. Kontos (2004) gives moving examples of what she describes as “embodied selfhood” (p836) – that people living with Dementia are aware of their being in time and place, that they are aware of who they are in that time in place, and that this is not necessarily affected by their neuropathology, but that it is a part of their being.

Kelly (2010) identifies three aspects of *self*, following on from the work of Sabat and Harré (1992), calling this “*self-1, 2 and 3*” (p106). Self 1 is the identifying of self and individual standing in the world, self 2 is our life experiences and capabilities built around emotions and aspects of character formed by these, while self 3 is the way in which we present ourselves to the outside world. This study highlights the importance of the way people living with Dementia are treated by others, and how if the aspects of self are acknowledged and encouraged, a greater sense of wellbeing will be facilitated. “This has made evident the transactional nature of interactions in influencing wellbeing and self-expression” (p120).

In recent years, Psychological research has gone a long way towards creating a new awareness and discourse in Dementia Care. It has shifted the emphasis to placing the individual at the core of the debate as a living, growing, participating

agent with an intact sense of self and an awareness that was previously unrecognized. It gives a new status, which is not static as previously assumed, with possibilities of participating in creating a meaningful existence in spite of neurological decline. However, as most of the work done in relation to the study of Dementia in psychology is focused on the developed world, there are vast populations living with Dementia in developing countries, for whom this research has little relevance. It is thus imperative that the plight of all people living with Dementia, regardless of race, creed or continent, be put on the agenda of researchers and world authorities.

Moreover, an area in which psychology does not succeed is considering the impact on the person living with dementia who is mostly not regarded as a participating citizen within the broader socioeconomic and political arena. Gerontology takes up this discourse in addressing the need to include people living with dementia in the mainstream political agenda.

GERONTOLOGY:

According to the Course Handbook, Gerontology is considered an “interdisciplinary-disciplinary” (p112) field of study. As such, it engages various disciplines in presenting a more integrated debate on the ageing phenomenon.

In comparison with the psychological approach, gerontology takes a much broader and more multi-faceted view of the role that the person living with Dementia plays in society, questioning the stigmatization and marginalization that all too often prevail. Within gerontology there are a number of schools of thought, among them the Structural Functionalist-, Political Economic-, Environmental- and Cultural gerontologies, each contributing to the larger debate. It is however within Critical Gerontology that an active debate has emerged, as the more traditional discourse on ageing is questioned, and the previously accepted view that people living with Dementia are “passive recipients of care” and “simply a burden to the state” is challenged (Bartlett, O’Conner, 2010, p4).

The success of the critical gerontology debate would be in “acknowledging the personhood of all people living with dementia – regardless of, for example, their ethnicity, religious beliefs, sexuality or other sources of multiple oppressions” (Innes, Archibald *et al.*, 2004).

HETEROGENEITY:

Gerontology aims to give people living with Dementia their own platform and voice. Very few of the so-called specialists who speak on behalf of those living with Dementia as “experts” have any subjective experience of Dementia. The Gerontological approach encourages people living with Dementia to express their own, subjective reality of what living with Dementia is actually all about. The lived experience is influenced by, among other things, culture, language, sexual orientation, race, gender, and politics and socio-economic environment. The challenge in this multi-dimensional approach is to encompass the “heterogeneity of people with dementia” (Bartlett, O’Connor, 2010. p6). Priestly (quoted in Bartlett, O’Connor, 2010, p7) points out a further challenge, namely that it is impossible to look at the plight of people living with Dementia as something that is the same for every individual. Again this emphasizes the shortcomings of the psychological debate – as Dawn Brooker so aptly put it in a lecture: “If you have met *one* person living with dementia, you have met *one* person living with dementia” (Lecture in Cape Town, 2009).

The role of critical gerontology is perhaps best described by Estes *et al* (quoted in Bartlett, O’Connor, 2010, p8): “From a gerontological stance, a critical perspective is one that ‘goes beyond everyday appearances and the unreflective acceptance of established positions”. Dementia is not a singular event; it is part of the life-course of millions of people who deserve more serious consideration in terms of the social status afforded them. Gerontological discourse questions the role of people living with Dementia as mere “welfare recipients” (p10) in order to engage them as participants in creating a non-biased society in which they can advocate for their own rights and influence policy.

Two spheres of thought that should be seriously considered in the debate on Dementia are Intersectionality and Transdisciplinary research. The more traditional approach – that all behaviour is a result of neurological pathology – is simply no longer accepted. Behaviour is influenced not only by the disease, but also by discriminating practices like ageism, sexism, racism, homophobia, ableism and classism, amongst others. Research therefore needs to take a more integrated approach to understanding the impact of transdisciplinary influences in the lived experience of Dementia. Hulko (2009) says that dementia is a “bio-psycho-social phenomenon” (p141). Her study provides insight into the lived experience of dementia, asserting that it is not always the monster that it is made out to be. People have different experiences, and could perhaps even live well with dementia if they are within a caring environment. Hulko reiterates the importance of taking other contexts into consideration before writing dementia off as the Grim Reaper.

CARE IN THE COMMUNITY:

The concept of *care* needs to be discussed in a broader sense than simply the domain of institutionalization and nursing. In countries like South Africa, where the availability of institutional care is limited to a very small percentage of white people, and the quality of such care is questionable, (Shabangu, Roos, 2012) the integration of people living with dementia in society is a given. The challenge must be addressed in political spheres: to re-engineer environments to enable people living with dementia to continue to have active, engaging lives, free from the limitations of discrimination, stigma, marginalization, institutionalization and other forms of abuse. John Myles (1983) is quoted by Minkler very aptly in this regard as saying that “politics, not demography” will determine the way that Older People are positioned in society. Within the South African and African context, the real killer then would be politics, and not dementia. Minkler (1996) quoted Carrol Estes: “it starts with the proposition that the status and resources of the elderly and even the trajectory of the aging process itself, are conditioned

by one's location in the social structure and the economic and social factors that affect it" (p469).

GERONTOLOGY AND THE DEVELOPING WORLD:

Gerontological research often refers to minority groups that are marginalized and not part of the main body of research. Again, in South Africa the situation is the reverse. There is very little research done that could enlighten the world to the plight of African people (the majority) living with Dementia. While in the Western world Gerontological discourse is engaged in concepts like "successful ageing" (Baltes, Carstensen, 1996) or "active ageing" (Bowling, 2008), the nuance for Gerontological research in Africa should perhaps be "survival" – where it will most probably have to reflect on the old adage "survival of the fittest". On a Continent where life revolves around a fight for food and water, where Dementia is demonized, primary healthcare is almost non-existent and the fantasy of the nuclear family that cares for their Elders is exactly that, a fantasy, critical Gerontological research has a long way to go. Cultural, political, ethnic, language, spiritual and geographical realities of people living outside the Western world pose a startling challenge to Western academics. The WHO (2002) policy framework on active ageing is quoted by Bowling (2008) as stating that active ageing is "the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age" (p12). This statement underlines the critical role that gerontology plays in the debate on ageing and people living with dementia, as all three aspects of the definition are steeped in politics and would mean vastly different things to a person living with dementia in America and someone living in Ruanda, Kenya or Ethiopia.

- Opportunities for health – very limited access to basic, primary healthcare
- Participation – elders seldom have a voice
- Security – issues of security on all levels of society are extremely problematic in Africa.

“The South African Study” referred to by Clarke, Wilkinson *et al* (2011) gives some indication of the issues that gerontology research does not address adequately in the Developing World context. (The question whether South Africa should be considered a Developing Country is open to debate). As a result of Apartheid and a very slow process of transformation, so-called Black and Coloured South Africans face a very stark reality when living with Dementia. South Africa is a multi-cultured, multi-lingual society where vast numbers of people live in “informal settlements”. Clarke, Wilkinson *et al* point out that: “An epidemiology of dementia is not yet available in South Africa for many reasons, among them:

- the low priority afforded the mental health care of older persons in the public health sector
- the lack of culturally appropriate cognitive function screening instruments for older black South Africans
- the relatively low proportion of cognitively impaired older black people who seek support from the health care system (Ferreira and Makoni 1999)”.

The study showed that crime, abuse of people living with Dementia in informal settlements, lack of awareness of Dementia, neglect in recognizing the need for help, stigmatization and a general lack of human rights are but some of the issues that are not addressed adequately. The authors express their hope that the South African Older Person’s Act of 2006 would address at least some of these issues. To my knowledge, sadly, this has not been the case.

SUMMARY:

Neither field, Psychology nor Gerontology, has extended its discourse widely enough to even begin addressing the plight of people living with dementia in the developing world.

Research capacity must be created in Africa, for and by African people, in order not to perpetuate the Colonialist debate. However, the political landscape of

most African countries, including South Africa as the most resource rich country in Africa, is simply not ready to face the elephant in the room. Minkler's (1996) statement that "ageing is in large part socially constructed" (p479), emphasizes the need for research in order to better understand the landscape in which ageing and Dementia takes place and hence the experience of people living with Dementia.

RAYNE STROEBEL

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