

A CRITICAL ASSESSMENT OF THE RESEARCH LITERATURE THAT EXPLORES THE DISCLOSURE OF A DIAGNOSIS OF DEMENTIA TO THE PERSON WITH DEMENTIA AND THEIR CARERS.

Abstract

Being diagnosed with dementia can impact on an individual's emotional, vocational, spiritual, physical, social, intellectual and personal dimensions of wellness (Montague, 2013). The stigmatisation that comes with the diagnosis can be as devastating as the disease itself. For this reason alone, seeking a diagnosis when suspecting that there could be something wrong with one's cognitive functioning, is not a simple or easy decision.

Christine Bryden, in her book "Dancing with Dementia" (2005), makes the statement *"It took me three years before I could speak openly about my diagnosis, overcoming the hopelessness and depression that exacerbated my dementia and took me on a downward spiral of dysfunction"* (Bryden, 2005, p39).

The psychological impact of a diagnosis (Lee et al., 2014) is severe, taking some individuals up to six months to adjust and cope with the feelings of loss before they can start to create new coping strategies and mechanisms of living with dementia.

Dementia diagnosis in lesser developed countries like those on the African continent, where research is scarce and stigmatisation can put lives in danger (Kalula and Petros, 2011), is in itself problematic. Bunn et al. (2010) allude to the transferability of research findings that are mostly geographically limited, implying that the disclosure of a diagnosis might be even more complex in non-western cultures.

Not disclosing a diagnosis raises ethical concerns (Rai, 2009) that seem to be missing in much of the research.

Disclosure

Downes and Bowers (2008) refer to the studies by Bamford et al. (2004) and Carpenter and Dave (2004) as the “most comprehensive dementia disclosure research to date” (p274). The research results were combined for physicians, carers and persons living with dementia, finding a wide range of facts in how physicians dealt with telling their patients that they have dementia, how carers communicated the diagnosis to family members and what people living with dementia wanted to know about their condition.

Their argument for disclosure as found in the research corresponds with that of Brooker et al. (2014) and Maki and Yamaguchi (2014). A proper diagnosis that is obtained at the right time can help the individual and his/her support network to plan for the future and create an advanced directive that will guide families, friends and carers to assist in creating the life that the person living with dementia would prefer to live. The person receiving the diagnosis is given the opportunity to seek help in dealing with the emotional impact and repercussions of the diagnosis whilst they can still have the autonomy to make decisions. From an ethical standpoint, an early and timely diagnosis disclosure is the right of the individual (Rai and Eccles, 2009), and gives them the opportunity to set in place legal processes to help protect their dignity and autonomy. It gives the opportunity to choose what care, medical treatment and end of life processes would be preferred and will protect the family from making these difficult decisions in emotional times.

The arguments against disclosing the diagnosis would include a fear that the person living with dementia would be exposed to emotional or psychological stress, that he/she would be unable to understand what is happening to them and will forget what they have been told, that the costs incurred with diagnosis are not worth it when considering the fact that the outcomes will be the same regardless, that there is no cure and that further decline cannot be prevented, and that disclosure will bring with it the stigma and labeling of society.

In his latest book, "Dementia beyond disease" (2014) Dr. Allen Power makes a very strong case for listening to the opinion of the "true experts" (p.14), being the people who are living with dementia. Whereas the research presents solid arguments for and against disclosure, the only people "qualified" to express an opinion on this matter are often the least heard. Quoting amongst others Dr. Richard Taylor and Christine Bryden who both live with dementia, it becomes clear that the diagnosis itself is often not as devastating as the struggle to actually get a proper diagnosis, the manner in which the results are conveyed, the lack of support from the healthcare system and the stigmatisation of society. Tanner (2013) refers to "hearing seldom heard voices" in which she highlights the need to listen to the voices of the people living with dementia and the fact that there is not enough research that includes people living with dementia.

Psychological impact

Considering the work of Mate et al. (2012) and Robinson et al. (2011), the way in which a diagnosis is presented, as well as the setting (hospital or at home) can have an impact on the wellbeing of the individual who is being diagnosed. Considering the lack of knowledge of General Practitioners and their subsequent hesitance to disclose the diagnosis, it is clear that the real problem does not necessarily lie with the inability of the person living with dementia to deal with the diagnosis, but rather with the GP's lack of knowledge and inadequate counseling skills. In fact, the ability of the person living with dementia to understand and comprehend is often underestimated thanks to stigma and preconceived ideas of the biomedical model. Tanner (2013) holds that the manner in which a diagnosis is presented could contribute to a loss of identity, autonomy and self-esteem of the individual, giving the new label of being demented as the replaced identity. The social nature of being in the world, through and with others, can become intensely distorted when this label "dementia" is all that is seen in social interactions (Beard and Fox, 2008).

Whilst the arguments for and against disclosure make sense within the context of what the world thinks is good for people living with dementia, it could be seen

as a one-dimensional argument. The saying “if you have met one person living with dementia, you have met one person living with dementia” sums up the complexity of this argument. Understanding the complexity of identity and personhood sheds some light on the process of disclosure for the individual (Tanner, 2013). Quoting Wolverson et al. (2010) and Pearce et al. (2002), Tanner explains that people living with dementia are well aware of their own reality and of the way that they are treated by society. As much as they are trying to come to terms with this reality, they are also trying to adjust to their new reality and form a new sense of self. The same issues are highlighted by Johannessen and Möller (2013), where people with early onset dementia are negotiating between “intrapsychic challenges and social challenges” (p413). Again, the challenge lies with society to create a supportive environment free of stigma, which will make disclosure less frightening for both practitioners and people living with dementia.

Robinson et al. (2010) emphasise the important point that people living with dementia want to know their diagnosis, even though more often than not they will forget when asked in the moment if they have been diagnosed. The manner in which the diagnosis is communicated and the particular words that are used have an impact on the way in which people being diagnosed experience their new reality. It is however interesting to note that there is not evidence of long-term effects of depression after a diagnosis, which again attests to the ability of individuals living with dementia to cope with and adjust to their new reality.

The South African context

Kalula and Petros (2011) shed some light on the reality of people living with dementia in their article “Responses to dementia in less developed countries with a focus on South Africa”. In a country with eleven official languages, a diverse population consisting of vastly different cultures, ethnic groupings, values and belief systems, a wide spectrum of religious beliefs, a complex socio-political history and a huge gap in income groupings, individuals living with dementia are often the most marginalized in society. Linked to witch craft, the

stigmatisation of a disease for which there is no word in nine of the eleven official languages, presents a major challenge to society. To educate people on a disease for which they have not words seems almost impossible. Access to basic health care is the privilege of few South Africans, and even those who can afford to have access have little if any chance of obtaining a proper diagnosis.

Medical students in one of the major universities in South Africa spend a total of four hours on geriatric medicine in their total studies, according to Dr. Sebastiana Kalula, Affiliation Senior Specialist: Internal Medicine and Head of Geriatric Medicine, The Albertina & Walter Sisulu Institute of Ageing in Africa. In my practice in South Africa older people are seldom screened properly to exclude other reasons for confusion, which seem no different to GP's in other parts of the world (Downs et al., 2002). The result is a social label, with no proper diagnosis, which greatly affects many of the people that I work with on a daily basis. Doctors take their cues from families, who thanks to popular media have a skewed picture of dementia. In rural areas the problem is often ignored and the person living with possible dementia ostracized by the community in fear of "evil spirits" attacking them when they connect with the person with cognitive or memory problems. Quite often older people also see their own memory loss as simply a normal part of ageing, with no desire to create pathology. Again the challenge lies with the attitude of society.

Moore and Cahill (2013) found that Swedish and Irish doctors are no different. Taking their cues from families, they find making an early diagnosis difficult, and she away from what they considered to be the repercussions of a diagnosis. Even when they do feel the need to disclose a diagnosis, they would steer away from using the words "dementia" or "Alzheimer's". The lack of undergraduate training is consistent with what is found in South Africa. The need for ongoing support after diagnosis and diminishing stigma is as relevant in Sweden and Ireland as it seems to be anywhere else. (South Africa has a total of eight geriatricians for a population of 55 million people).

Ethical issues

Harding and Palfrey (1997), quoting Gubrium (1988) hold that “Carers *need* a disease label to be applied” for them to make sense of what is happening to the person living with dementia. The stigma afforded the disease through the media and marketing campaigns for research funding creates linguistic labels like “suffering” and “the slow death”. The lack of knowledge and skills of physicians are often also a result of the (popular) media, bringing with it a belief that there is no sense in disclosing a diagnosis for a disease that will only bring suffering and for which there is no cure. Diagnosing itself becomes a skillful mix of science and art. The physician has to deal with second-hand facts from carers when language is no longer intact for the person living with dementia, mixed with knowledge based on limited exposure to scientific education and research, polluted by popularization, to then engage in the highly skillful art of diagnosis (Harding and Palfrey, 1997).

Milne (2010) takes this argument to the next level when questioning the need to create a medical label for what could be considered a normal part of the ageing process, as well as the risks associated with misdiagnosis. Quoting Elson (2006) “This evidence highlights the need to deal with each case on an individual basis and not to *either* routinely disclose or *not* disclose (p.69). The conflict between the perceptions of the medical fraternity, which are based mostly on medical conditions and symptoms, and those of people living with dementia and their families, based on the fear of a loss of social status, identity and capacity, make for a complex navigation into disclosure of diagnosis. These two issues should be balanced alongside on another, with a greater emphasis on the lived experience and support of the individual than on the creating of pathology in need of medication.

The benefits and risks of a disclosure should not override the rights of the individual - every person has the moral and ethical right (Rai, 2009) to know what they want to know. This right is eroded by cultural issues, lack of education of medical doctors, fears of carers, stigmatisation in society and a popular belief

that it is better for the person living with dementia to not know, as they will soon forget the diagnosis in any case. This erodes not only the personhood, but also the very essence of citizenship of the individual living with dementia (Bartlett and O'Connor, 2010). Milne (2010) concludes that a new approach should be taken in this debate, one that is not dominated by "existing medically confined discourse" (p.73) but by a discourse of living well with dementia, creating opportunities of care by the broader community in which each individual is afforded the support to have a life worth living.

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