

CARING FOR A FAMILY MEMBER WITH DEMENTIA IS FRAUGHT WITH BURDEN AND STRESS - A DISCUSSION OF THIS STATEMENT

“Adopting a sole identity as our care-giver highlights our illness and strips both of us of other identities, we have become care-giver and sufferer, in a relationship of co-dependence... In this role, you may feel soon overwhelmed by the multitude of tasks, of remembering for two, of planning and organizing for two, of covering up our deficits, and grieving over our losses, rather than looking for what remains. You can quickly become exhausted, sad, depressed and in despair...” (Bryden, 2005, p149).

Abstract:

The title “Caregiving for a family member with dementia is fraught with burden and stress” elicits more questions than answers. Who is this caregiver – husband or wife, son or daughter, second husband or wife, stepson or –daughter, daughter- or son-in-law, grandchild – a list with endless variations. Would the experience be different when caring for a mother to that of caring for a father, husband or wife, brother, uncle, aunt, cousin, and nephew? Can the term “caregiver” be considered a singular entity with a singular emotional experience? What is the role of - amongst others - culture, ethnicity, gender, sexual orientation, language, religion, age, personality, social environment and education? What role does the type of dementia of the care recipient play? Do all people deal with burden and stress in the same way, and if not, why not? What constitutes burden and stress, and how are these defined within the heterogeneous environment of caregiving?

It is often said, “If you have met one person with dementia, you have met one person with dementia”. The same might very well apply to the family caregiver. Nolan et al (2002) refer to Dilworth-Anderson and Montgomery & Williams (2001) when saying that “In essence the message is clear – caregiving can only be fully appreciated and adequately supported in its appropriate context” (p81).

Is it all about burden and stress?:

Hoyer and Rodin are quoted by Coetsee (2007) in a definition on what would constitute “burden of care”, referring to an *objective* and *subjective burden*. The former would relate to the physical circumstances that impact on the life of the caregiver, for example having to leave their work, not being able to socialise and having to transform their physical living space. The latter would describe the impact on the emotional wellbeing of the caregiver, their attitude to the role and emotional responses to the transition to caregiver. The burden of care would impact on the “physical, psychological and social” (Coetsee, 2007, p46) realities of becoming an informal caregiver.

It is interesting to note that a lot of research focus is on burden and stress, which in itself would question the stigmatisation of dementia care, putting a very negative focus on the caregiving relationship. Nolan et al (2002) sight a number of articles where the focus is purely on the negatives of the caregiver experience, and asks the question if this should in fact be the focus, and not a more positive approach that would enhance and support the efforts of caregivers. Ribiero and Paúl (2008) put forward a strong case for the positive outcomes of familial, informal caregiving. Interesting to note that the aim of this study was to find positive outcomes in the caregiving relationships, in contrast with many studies only focusing on the burden and stressors.

Of great relevance in this study, as well as noted in Nolan et al (2003), Carpenter and Mak (2007) is the impact that a healthy, loving premorbid relationship has on the new caregiving relationship. Where couples had affection and a healthy, loving relationship prior to the onset of the disease, this would continue into the caregiving relationship, with less chance of abuse and a longer stay at home or in the community.

Ribiero and Paúl (2008) conclude, “The rich and rewarding returns call for better understanding without the skewed presumption and perception that the caregiving experience is wholly negative” (p180).

Quoting Twigg and Atkin (1994), Nolan et al (2002) warn against the 'pathologising' of care. The article also points out the fact that the perception of burden and stress could possibly be more in the opinion of the researchers than in that of the people actually delivering the care, and suggest a different approach in research.

Why would someone decide to become a caregiver?

Camden et al (2011), Ribeiro and Paúl (2008), Nolan et al (2003) all point to the different reasons why people would take on the role of caregiver. In my practice experience I have seldom come across an individual who have make a conscious decision to become a family caregiver. Most people do not choose this role, very few are trained for it, and many take a long time before they realize that they are actually in a caregiver role (Carpenter and Mak, 2007). For spouses it is often the natural thing to do, a natural progression in the trajectory of a life together. Having lived with a Grandfather with Alzheimer's disease for many years, everyone in our family became a caregiver, without ever labeling ourselves as such, or even thinking of it as a role. We did what we had to do – take care of someone whom we deeply care for.

As noted in the articles cited, people might take on the role because of cultural expectations, as is certainly the case in many African cultures where daughters are expected to take care of their ageing parents. In my work practice (I employ 500 staff members), it is not uncommon for female staff members to resign from their work in order to go to the family home to care for an ageing parent. There is no formal support for informal caregivers in South Africa at all, which makes this decision a very brave one. It is also noted that religion might motivate people to care, as well as a feeling of reciprocity. Camden et al (2011) makes a strong case for the fact "that motivations for caring influence the well-being of the care recipient, and possibly also the carer" (p1448).

Camden et al (2011) point out that where caregivers take on the role as a result of external factors like peer pressure or a feeling of guilt or duty, the outcomes might not always be very positive. These relationships might be abusive and

institutionalisation happen a lot faster.

The complexities of the caregiver role:

The heterogeneous nature of relationships in general does not make the transition into a caregiving relationship easier. Carpenter and Mak (2007) point out that “Naturally, each type of couple has its own unique features, just as any individual couple has its own idiosyncrasies. Yet for all these variations, caregiving presents a common set of challenges and opportunities” ?? I would differ from this point of view, in that the reliance on the family-systems approach might work within heterosexual, Western cultures, but would be greatly challenged within other societies and social groups.

As a “gay” man, I see the complexities of care partnerships in my circle of friends and family. There is often the expectation that the child “who is not married” should (and could) take on the caregiving role for ageing parents. As this so-called “not married” individual often has no children, it is automatically assumed that he/she would have more time and fewer responsibilities and should take on the role of caregiver. In same sex couples who have not made their union public, the assumptions of family members in terms of their right to intervene can lead to major trauma and stress for a loving caregiving partner. (Whitman DATE?) Same sex couples are often not recognised as couples, with the result that families might not consider a life partner taking on the role of caregiver (Newman, 2005 and Price, 2012). In spite of the very progressive Constitution of South Africa that allows civil partnerships and adoption for same sex couples, stigmatisation and discrimination are still very real issues especially in rural parts of the country.

What about the person living with dementia who is on the receiving end of care?

Very few studies have taken into consideration the views of people living with dementia that are on the receiving end of caregiving relationship. The dyadic (and often triadic) nature of this complex interaction could easily leave the most important role player out of the equation. Aggarwal et al (2003) conducted a study that took the perspective of people living with dementia into account,

concluding that people living with dementia do retain a sense of self, including a sense of values, in spite of their disability. Whilst most of the focus this far has been on the burden and stress of the caregiver, it is my opinion that much more attention should be paid to the person living with dementia. In my practice I deal with many families. It is often noticeable how families put their needs, desires, fears and anxieties before that of the person for whom they propose to care, often with disastrous results. It seems to be very hard for families and informal caregivers to stand back, to practice non-judgmental self-observation and analyse their own motivation for caring. This often results in family strife, with the person living with dementia being on the receiving end of abuse from so-called well-meaning relatives. I have often dealt with family caregivers who care for very selfish reasons of wanting to be seen to be the “good” person in the family, resulting in huge resentment towards the person living with dementia. As pointed out before, the reasons for entering into a caregiving role will dictate the trajectory of care.

A South African perspective on informal caregiving:

Joubert, in her study **A Profile of Informal Carers in South Africa (2005)** says “...in 2000, 26.9% of the population were Caregivers according to the definition used. This implies that an estimated 7.4 million persons in the South African population 18 years and older had informal caregiving responsibilities in the year 2000” (p89).

The 2011 census figures released by Statistics South Africa reveal that:

1. In the 2001 population census, there were 3,28 million people in the country older than 60.
2. In the 2011 statistics, the number of people over the age of 60 increased to 4 151 760.

“Population ageing, or demographic ageing, refers, in simplistic terms, to the process by which the older population (60 years and older) become a proportionately larger component of the total population.” (Joubert and Bradshaw, 2006, p204) According to this report, more than one person in ten

will be over the age of 60 in 2025 in South Africa. Considering the burden of diseases of lifestyle, the insistence of the Government on de-institutionalisation and a total lack of community health services as described in the above report, care responsibilities fall squarely in the lap of families and neighbours of vulnerable people in South Africa.

Joubert further states that *“The impact of demographic and epidemiological change in South Africa, through the simultaneous effects of population ageing and an intensified, quadruple burden of disease, have brought about changes in the health profile of the population. In turn, these changes have affected an increased need for care in the country. In the presence of this increased demand for care, evidence exists that formal public health care services fall short of providing adequate and satisfactory care to those who need care, while, at the same time, spiraling private health care costs place private health services beyond the financial reach of the majority of the population”* (p102).

South Africa has eleven official languages, of which only English and Afrikaans have an actual word for the term dementia. The different ethnic groupings have strong traditional values and beliefs, especially in terms of their Elders. With migration, the HIV/AIDS pandemic, poverty, the Apartheid legacy of non-education, migrant mineworkers and the impact of diseases of lifestyle on the quality of life of the majority of people in the country, the reality of informal caregivers tells a different story to that of the rest of the world.

Vally (2011) points out that the HIV/AIDS pandemic will give rise to a high incidence of HIV/AIDS related dementia, as most HIV positive people in South Africa will not have access to anti-retrovirals. The result is that those individuals, who die of AIDS, will leave behind parents and children who are often cast into caregiving relationships for which they are hardly equipped. As per the study by Ivey et al (2012) it is interesting to note that Filipino caregivers will often emphasise the positive aspects of caregiving. I have found in my work with African caregivers that they consider their role to be very important in their community, and that they also have a certain status for taking care of their Elders.

Joubert (2005) quotes statistics of a report by Age-in-Action that was conducted in South Africa in 1999, where 600 informal caregivers were interviewed. “The study found, inter alia, that 86% of the participants were female; over one-fifth were 60 years and older; over 60% spent on average more than 10 hours per day in caregiving activities; 28% were caring for more than 10 years at the time of the study; and about one-quarter were not able to take any break or time off from his/her carer responsibilities” (p47-48).

The reality of the life of a caregiver in rural South Africa is harsh considering the following statistics: 21% of households has no running water, 49% has no flush toilet, 14% has no toilet at all, 27% live in informal housing structures, 43% has no school education, 50% has no electricity and 67% of the population are “African”, amongst others Sesotho, Tswana, Venda, Pedi, Xhosa, Zulu, Ndebele, Pondo and Kholisan. (Statistics South Africa 2011).

In an article **Care for Elderly People with Mental Illness: A Global Problem**, David Skuse (Behavioural and Brain Sciences Unit, Institute of Child Health, London UK) says:

“We often assume that cultural factors in lower-income areas lead to greater respect for, and better care of, the elderly than we experience in many parts of the Western hemisphere. This appears to be a misapprehension, and attitudes towards the elderly are changing as the impact of industrialization increases” (p29).

Filial piety was believed to be one of the positive attributes of the African culture, which has now been eroded by industrialisation and urbanisation, leaving many Elders destitute in rural parts of South Africa. The total lack of infrastructure in primary healthcare, combined with poverty and a lack of education, makes the plight of caregivers and people living with dementia extremely desperate. With no chance of ever entering formal long-term care, Elders are cared for in communities until they die. In my practice I have come across wonderful stories of care, as well as devastating practices of abuse.

Conclusion:

Dartingdon (2007) gives an empathetic description of his role as a caregiver. It is clear that his skills allow him to write about his experience, giving him distance, separating him from what the world would see as the burden and stress of the caregiving relationship. These coping skills come with education and emotional intelligence, something that a social model of intervention could not provide in the short term. The sense of purpose that is so eloquently described in the study by Ribeiro and Paúl (2008) points to the fact that burden and stress of caregiving are perhaps also in the eye of the beholder. It can be heaven or it can be hell, depending on an uncountable number of variables.

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BIBLIOGRAPHY:

Bryden, C. (2005), *Dancing with Dementia*, Jessica Kingsley Publishers.

Nolan, M., Lundh, U., Grant, G. & Keady, J. (2003), *Partnerships in Family Care: understanding the caregiving career*, Open University Press.

Joubert, J. D. (2005), "A Profile of Informal Carers in South Africa", (submitted in partial fulfillment of the requirements for the degree Magister Artium (Demography) in the Faculty of Humanities, University of Pretoria.

Blood, I. (2010), "Older people with high support needs: how can we empower them to enjoy a better life", Joseph Rowntree Foundation.

Camden, A., Livingston, G. & Cooper, C. (2011), "Reasons why family members become carers and the outcome for the person with dementia: results from the CARD study", *International Psychogeriatrics*, 23:9, 1442-1450.

Ribeiro, O. & Paúl, C. (2008), "Older male carers and the positive aspects of care", *Ageing & Society* 28, 165-183.

Carpenter, B. D. & Mak, W. (2007), "Caregiving Couples", *Couples in Later Life, Generations*, American Society on Aging.

Lin, M., Macmillan, M. & Brown, N. (2011), "A grounded theory longitudinal study of carers' experiences of caring for people with dementia", *Dementia* 2012 11: 181.

Ivey, S. L., Laditka, S. B., Price A. E., Tseng, W., Beard, R. L., Liu, R., Fetterman, D., Wu, B., & Logsdon, R. G. (2012), "Experiences and concerns of family caregivers providing support to people with dementia: A cross-cultural perspective", *Dementia* 2013 12: 806.

Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G. & van Exel, J., (2011), "Coping with caring: Profiles of caregiving by informal carers living with a loved one who has dementia", *Dementia* 2012 11: 113.

Russell, R., (2008), "Their Story, My Story: Health of Older Men as Caregivers", *Generations*, American Society of Aging.

Aggarwal, N., Vass, A. A., Minardi, H. A., Ward, R., Garfield, C. & Cybyk, B. (2003), "People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care", *Journal of Psychiatric and Mental Health Nursing* 10, 187-197.

Nielsen, T. R., Vogel, A., Riepe, M. W., de Mendonca, A., Rodrigues, G., Nobili, F., Gade, A., Waldemar, G. (2011), "Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's Disease Consortium survey", *International Psychogeriatrics* 23:1, 86-95.

Newman, R. (2005), "Partners in care: Being equally different: lesbian and gay carers", *Psychiatric Bulletin* 29: 266-267.

Price, E. (2012), "Gay and lesbian carers: ageing in the shadow of dementia", *Ageing & Society* 32, 516-532.

Cartington, T. (2007), "Two Days in December", *Dementia* 6: 327.

Joubert, J., Bradshaw, D. (2006), "Population Ageing and Health Challenges in South Africa" in *Chronic Diseases of Lifestyle in South Africa since 1995 – 2005*, pp 204 – 218.

Nolan, M., Ingram, P. & Watson, R. (2002), "Working with Family Carers of People with Dementia: 'Negotiated' coping as an essential outcome", *Dementia* 2002 1: 75.

Vally, Z. (2011), "HIV-associated neurocognitive disorders", *The South African Journal of Psychiatry* Vol 17, No 4.

Whitman, L. (ed) (2009), *Telling Tales About Dementia: experiences of caring*, Jessica Kingsley Publishers

Skuse, D. (2010), "Care for Elderly People with Mental Illness: A Global Problem" *International Psychiatry* Volume 7.