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Health and Ageing Committee inquiry into dementia early diagnosis and intervention

Submission to inquiry

Centre for Ageing and Pastoral Studies

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The Centre for Ageing and Pastoral Studies (CAPS) is a multidisciplinary centre for research, education and ethics in ageing and spirituality across the health illness continuum. Its focus is on well-being and support of positive ageing through to living in the face of frailty and disability, including the experience of dementia and end of life issues. CAPS has conducted a number of longitudinal research projects into quality of life for people with dementia, aiming to find where these people find meaning in life, and optimizing wellness in the face of dementia. One major impact of dementia is depression; recent work has shown that statistically significant improvement in levels of depression among people with dementia in residential care, over 30 week programs.

It is from this perspective, of improving the level of mental health that this submission addresses.

There are two main paradigms that provide guidance for life with dementia – the biomedical paradigm and the psychosocial paradigm.

While the biomedical paradigm is used to find ways to treat and cure the different causes of dementia, the psychosocial paradigm seeks to gain best quality of life for people regardless of their stage of dementia. It is contended that both models are needed. The cost of adopting one without the other is too great.

This submission focuses on the psychosocial paradigm, and especially emotional and spiritual aspects in dementia.

This submission focuses on a particular and important aspect of the psychosocial paradigm, that of spiritual and emotional well being of people with dementia. It also takes account of families and care providers in affirming the personhood of those with dementia and seeking better ways to communicate and support them. Essentially this approach is a holistic approach to early intervention and continuing support and care of people with dementia and their families. In fact it goes even further, to empower those diagnosed with dementia and their families to engage in meaningful ways with this disease to live lives to the full.

One of the greatest challenges to people who are diagnosed with dementia is finding meaning in the experience of this disease. Meaning is essentially tied with hope and the diagnosis of dementia challenges both meaning and the hope that would otherwise be possible for these people.

Early diagnosis and intervention in context of the psychosocial paradigm and especially in the spiritual dimension seeks to provide recent knowledge and skills in this domain for those diagnosed with dementia and their families to find positive ways of living with dementia and lowering levels of fear and despair among these people. Moniz-Cook, Stokes & Agar (2003) noted “challenging behaviour is not inevitably the symptomatic consequence of neuro-degeneration, but the outcome of psychosocial factors that are responsive not simply to control, but to amelioration and resolution.” (p.204) They affirmed that how we see and interact with the person with dementia is important.

Facing the diagnosis

This is one of the most critical aspects of coming to terms with a diagnosis of dementia, for both families and the person with dementia. Christine Bryden (2012) when first diagnosed said it felt like ‘pointing the bone’ as her life completely changed, suddenly moving from a high functioning and competent person to one labeled as having Alzheimer’s disease. She quickly became painfully aware of her new status. The term Zombie (Bethuniak 2011) has recently been used to describe those with dementia, and although use of terms like this may bring more funds for ‘dementia sufferers’ it does little to lessen the burden of care, or the burden of being labeled with having dementia, which is frightening to many people. In a recent article in the Lancet, George wrote of need to overcome the social death of dementia that readily occurs through language (George 2010).

Fear is one of the greatest barriers faced by people with dementia and their families. Much needs to be done to reduce fear of the disease, before positive steps can be taken to really assist people with dementia. Stigma is clearly associated with dementia and affects people diagnosed with dementia and their families (Bethuniak 2011).

An important change occurs for many people and their loved ones once the diagnosis is made. There is often a sudden change of attitude towards the person with dementia and they are in a way ‘set apart’ from others, no longer deemed to be ‘normal’. Relatives feel this as well as the person newly diagnosed. These changes of attitude often lead to loss of confidence and the slow movement towards isolation of the person with dementia. Often it is felt that the person has to be protected and labeled as different. So much of what then happens is put down to ‘the disease’. It is vital that these attitudes can be overcome, so that people with dementia and their families and also care providers will be able to live as normal citizens in the community. It is imperative that people with dementia are able to obtain sufficient relevant information and access the latest research to support finding meaning in the experience of dementia.

Appropriate medical diagnosis and treatment is vital, but also, just as important are the acquisition of knowledge and skills to live effectively with the disease.

Means of finding meaning in the experience of dementia

Study of dementia (MacKinlay & Trevitt, in press) through the use of spiritual reminiscence and life stories and associations to reaffirm identity of these people through small group work has been found to be an excellent way to support those newly diagnosed; these are still people with identity and worthwhile futures. This

small group work taps into issues of meaning in the broadest sense of the spiritual domain.

Small group work needs to be long term, in the research we have completed (MacKinlay & Trevitt) small group participants were able to support each other, even when their dementia has advanced. Short groups that run typically over about six weeks and then stop are not nearly sufficient to make real changes, either in the initial stages or further into the disease.

The work done on spiritual reminiscence has been critical in enabling these people to gain confidence and improve communication, and even to make new friends within aged care facilities.

Many activity programs are conducted in residential aged care and community care that are a surface level. Not really engaging with those who attend, the outcomes are often of a distraction or entertainment level. These do not make a difference to levels of depression, which is widespread among people in aged care. Further, often current staffing arrangements mean that too many people with dementia are grouped together, and it has been shown that it is not possible to work effectively with large groups of these people.

Recent funded and completed research has been a longitudinal study and evaluation of activities over 30 weeks, titled: Minimising the impact of depression and dementia for elders in residential care. (Wicking Trust Grant). An ARC Linkage Grant: Finding meaning in the experience of dementia: The place of spiritual reminiscence work

Relevant publications:

MacKinlay, E. & Trevitt, C. (in press) *Finding meaning in the experience of dementia: The place of spiritual reminiscence work*. London: Jessica Kingsley Publishers.

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MacKinlay, E. & Hudson, R. (2008) Practice development – ageing, spirituality and nursing: A review of the literature in 2006. *International Journal of Older People Nursing*. 3, 139-144.

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Conclusion

The most critical factor in the well-being of people diagnosed with dementia is to be able to find meaning in their lives.

Meaning in life is crucial for the well being and flourishing of any person. This is no different for people who have dementia. Finding meaning is also vital for families and care providers, both formal and informal. It is contended that people living with dementia will function better if fear is lessened and hope can be found, grounded in finding meaning. Language commonly used to describe people with dementia in negative terms, such as dementia 'sufferer' or 'vegetable', non-person, or Zombie serve to continue the stigmatization of these people and their families. Much needs to be done to turn these attitudes and beliefs about the condition around.

Recommendations

- Further research to establish means of best practice in positive ageing from early diagnosis through to care of people with moderate to advanced dementia.
- Adequate funding to support translation of research findings to develop best practice resources.
- Urgent establishment of training and education programs to adequately prepare staff and volunteers to provide effective person-centered care using the translated findings of latest research.
- Adequate resourcing to bring knowledge of skills and training related to new and more effective practices in the field of psychosocial and spiritual wellness and care to all older people and aged care providers throughout the nation.
- Adequate remuneration of care providers in community and residential aged care to attract and retain quality staff.

References

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Moniz-Cook, E., Stokes, G., & Agar, S. (2003). Difficult Behaviour and Dementia in Nursing Homes: Five Cases of Psychosocial Intervention *Clinical Psychology & Psychotherapy*. 10, 197–208.

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