

**ENGAGING WITH LIFE IN
DEMENTIA:
THE SELF AND OTHER MATTERS OF
IMPORTANCE IN THE JOURNEY
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Finding meaning: spirituality, society, (culture) and dementia

How we see dementia makes a difference

Do we see:

- dementia as a purely biological disease?
- the overlay of cultural and therefore social understandings of dementia?
- the spiritual possibilities of the lived experience of dementia?

What is dementia: the bio-medical picture

- When we think of dementia we think of memory loss. (memory dysfunction). Memory loss is but one part (though for many a significant part) of the changes that may occur.
- Also different behavioural changes that can have a great impact on quality of life for the person with dementia and for their family and friends.
- But, behavioural changes are not the same in everyone: the experience for each person who has dementia varies and is a combination of ***personality, biological, psychosocial, emotional and spiritual factors.***

It's not just a physical disease

Dementia: the social disease

- Fear the most important issue.
- Myths and the power of language:
- Victim, sufferer, burden. AD personified as ‘mind robber’, ‘attacks or strikes the brains’
- Yet, despite the best of person-centred care and attempts at culture change, ‘this totalizing language continues to guide popular understandings of dementia as a blanching of selfhood’ (George 2010, p.586).
- Those who have a diagnosis of dementia have to fight to be counted as real people.

The journey into dementia

Two important questions about having dementia were raised by Christine Bryden diagnosed with early onset dementia when 46 years of age.

- ▣ Will I lose God as I travel into dementia!
- ▣ Where do people with dementia find meaning?

20 years later we are still on that journey. It has informed the research I have done, my reflective practice and my whole life work

Questions

- Who am I as I travel into this disease?
- As Christine asked: “Who will I be when I die”
- How long do I have before I lose control?
- Will I know that I am losing it?
- What does my life mean now that I have dementia?

A new way of seeing dementia

1995 Christine diagnosed with younger onset Alzheimer's disease (later fronto-temporal dementia)

2017 *Challenging the discourses of loss:*

A continuing sense of self within the lived experience of dementia. Doctoral thesis completed.

A case study of one? *Needed further knowledge as evidence to base new practice.*

But major funded study (2002-2004) ARC Linkage grant plus other funded study from 2001-2014 gave support to new ways of seeing the person who has dementia. (MacKinlay & Trevitt, MacKinlay et al)

Understanding the whole person



‘Biological and psychological dimensions of the human being can be understood in unity once the spiritual dimension is brought into play. Without this dimension, we see only determinant and reductionist views of the person’ (Frankl 1988, p26).

A spiritual focus

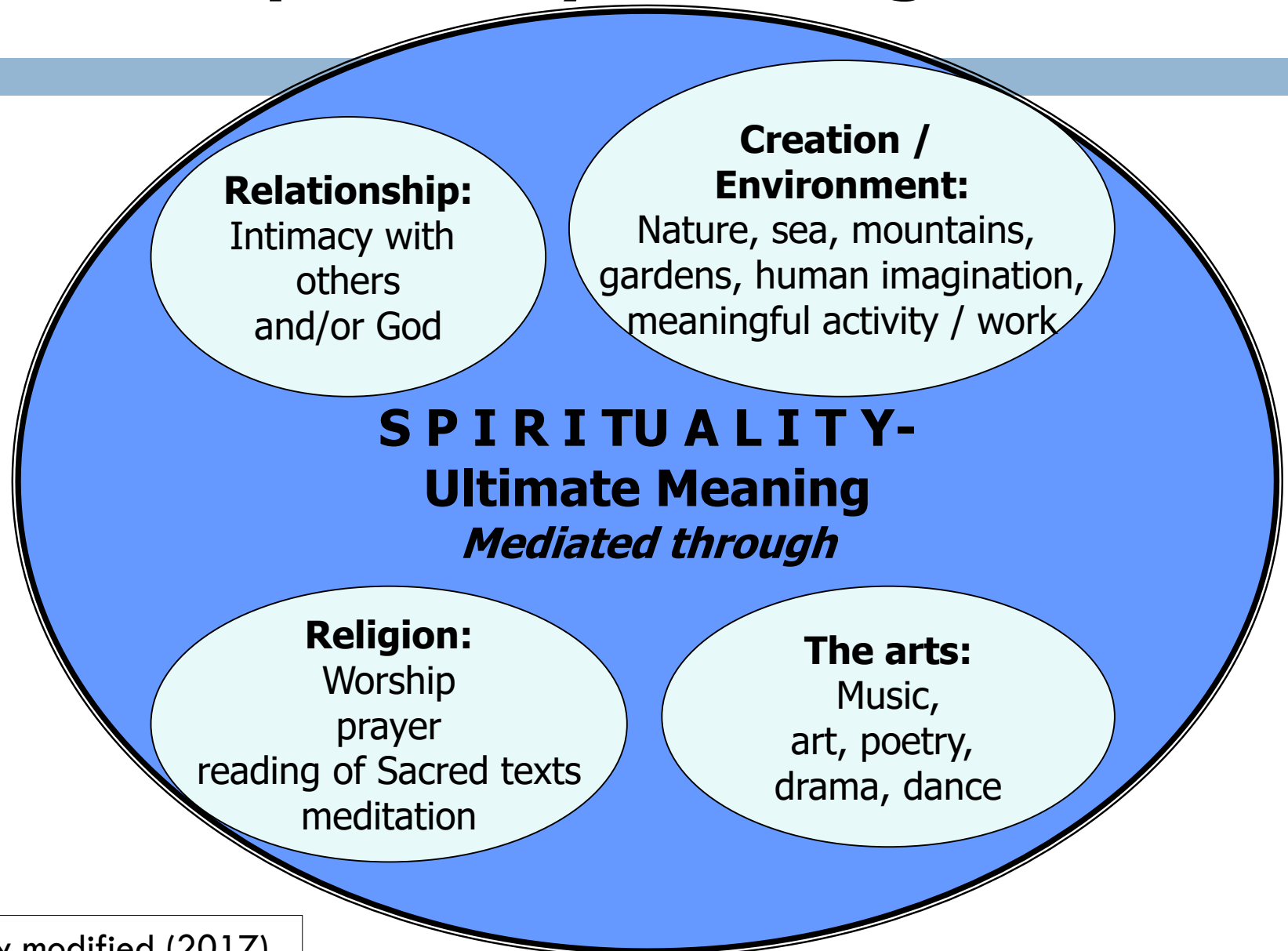
Life as a spiritual journey

- ▣ Facing bodily decline
- ▣ Facing challenges of later life
- ▣ Living with uncertainty
- ▣ Growing spiritually

AND –

- ▣ Finding meaning and hope in the journey

Spirituality and Religion



Relationship and dementia



‘people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all our lives’. Hughes et al. (2006,p.35)

A new way of seeing

Relationship is pivotal to connecting with people who have dementia,

relationship is not just dependent on cognition, and spirituality is not a separate matter, but intricately linked with all that we are and all that we do.

Culture and our stories

Story forms an important context from which to be and to function in any cultural setting. MacIntyre (in Hauerwas & Jones 1997) sees functions of narrative as:

- Intelligible human action is worked out in story
- Human life is fundamentally story shaped
- Humans are story-tellers by nature
- People place their lives and arguments in contexts of storied histories
- Communities and traditions receive their continuities through story
- Understanding who we are as a community comes from the construction and reconstruction of more adequate story (narrative) and forms of narrative.

The person who has dementia in context of story and language

The culture often carries the story of separation and alienation of the person – as ‘not normal’

- *No longer a person, living death, an empty shell*
- But these notions are challenged by other stories that show different outcomes – the person remains, even if communication becomes more difficult
- Cognitive loss, but emotional and spiritual ways of connecting remain, including wisdom, humour & insight
- The challenge: not to be trapped in negative stereotypes, not to be trapped by fear

Nothing about us without us!

The self in dementia

- Does the self disintegrate?
- The term: she /he's not the same person anymore
 - (I don't want to visit, I want to remember her/him as they used to be)
- What do we understand by 'the self'? Is it just the cognitive part of being human? Is it the whole person?

The self in dementia

“As I travel towards the dissolution of my self, my personality, my very ‘essence,’ my relationship with God needs increasing support from you, my other in the body of Christ. Don’t abandon me at any stage, for the Holy Spirit connects us. It links our souls, our spirits-not our minds or brains. I need you to minister to me, to sing with me, pray with me, to be my memory for me.”

Bryden & MacKinlay(2002), p.74 *Dementia-A spiritual journey towards the divine: A personal view of dementia.*

Bryden (2017) *Challenging the discourses of loss: A continuing sense of self within the lived experience of dementia.* (Title of Ph.D)

'A continuing sense of self within the lived experience of dementia' Bryden

□ Embodied self

'I' - feeling of self in first person, my sense of still being me as an embodied person, able to distinguish self-from non-self

□ Relational self

▣ Embodied self in relation with others and associated with meaning

□ Narrative self

▣ Able to have a sense of narrative identity in the present moment also associated with meaning

Christine's model of self: Will I still be me? 2018

Dementia as a topic of conversation

For the first time in my professional career as a nurse, I was challenged to meet with Christine as **a person first** and as someone **with dementia, second**.

With Christine,

- I was able to talk freely about dementia, we named it,
we focused on the meaning of it for her.
Christine was the centre of our conversations.
- Important to be a person journeying with her, as a partner, not an expert.

Acknowledge my own vulnerability

The role that fitted best was pastoral care. An intentional friendship with Christine. If person-centred care is properly practised, then it too will serve well as a model for care.

Issues for people with dementia, and their partners, following diagnosis

- Fear of the future
- “I remember my aunt had dementia and I don’t want to end up like her”
- Loss of sense of self worth
- Should I tell others?
- How will people treat me, now I have Alzheimer’s (or any type of dementia)?
- Can I still drive?
- Will I need to move into assisted care?

Things that people with dementia experience

- Recall dysfunction (*loss of memory*)
- Inability to find the right words
- Needing time to respond to others
- Feeling that loved ones take over their lives (in protection, but perceived as loss of control)
- Will I still know God? (but what if I am a vegetable?)

More than a disease of the brain

Dementia is more than a disease of the brain, it encompasses the whole human being and their physical, mental, social, emotional and spiritual being.

Hope now lies in enabling people who have dementia to live as normal human beings

Hope now lies in the abilities each person with dementia has, and the degree to which they can use these.

Recognising these people as always being worthy of love and respect.

Christine Bryden: “Do not stop visiting me because you think I might not be able to remember your visit”

Conclusion: Ageing and Spirituality, finding hope and meaning within social and cultural diversity

- Culture underlies much of what we believe and our attitudes to life
- We are born and socialised into a culture – there are implications for us when we move from one culture to another
- How we respond to people who have dementia will be influenced by social and cultural factors
- The spiritual dimension goes to the core of human being and meaning –underlying hope, and especially important in dementia

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