



THE UNIVERSITY
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The Journey from Dementia Diagnosis to Final Bereavement:



**An exploration of anticipatory grief, loss and bereavement
experienced by family carers of people living with dementia**

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There are many forms of dementia

46 million people throughout the world are living with Alzheimer's disease or a related dementia. By **2050** this number will have risen to **131.5 million**. In just **3 years' time**, the global economic cost of dementia will reach **US \$ 1 trillion**.
(ADI 2015)

<http://www.worldalzreport2015.org/>

Henning Mankell's character
the famous Swedish Police
Inspector Kurt Wallander
[val'lan:dər] diagnosed in the
final season of the television
series with Alzheimer's related
dementia.



Importance of Topic

To date few research studies have examined anticipatory grief and loss in relation to dementia care. (Pauline Boss 1996; 1999) even fewer have explored the caregiver's entire '***journey.***'

But ... reflexive questions (my '*inner compass*')

- **Why** should I do this?
- How should I **proceed: methodology**
- What perhaps would be the **outcome / benefit / application of findings?**
- If I do undertaken this study how may this **affect participants?**
- And minor issues: such as using the word '***journey***' ? (*cliché*)



But we ALL take '*journeys*' - *don't we?*
- physically (geographically) and mentally (reflectively)



Vasil Jacovitch Oleksuik

1947: geographically displaced

2009: cognitively displaced

Background – ‘my’ research journey

Academic:

- **Commenced 2008** (full time **PhD scholarship**) at Northumbria University / Alzheimer’s Society North Tyneside (**staff**). Branch / Trustee and Chair of Cruse Bereavement Care – Newcastle / Gateshead / North and South Tyneside (**trustee and bereavement volunteer**).
- Follow on from a similar **MSc research** – six older male carers in North Tyneside completed in 2003.
- 2010 - **part time study to manage** the day-to-day activities of the Healthbridge Project. An evaluation of the **National Dementia Strategy** for England.
- 2011- move to **University of Edinburgh** to take up lecturing post.

Personal – routes and detours:

- Interruptions of study – illness, road accident and **5 family bereavements**
- Submission April 2016.

We ALL take 'journeys' – *the planning*

*The traveller must first find in himself [sic] a good and **sufficient reason** for going ...*
*Next he must plan his trip in time and space choose a **direction and a destination**. And last he must **implement the journey**. How **to go, what to take, how long to stay**. This part of the **process** is invariable and immortal. I set it down only so that newcomers ... will not think they invented it.*



(Steinbeck, *Travels with Charley: In search of America* 1986:3-4)

Research aims

To explore the complex experiences of family carers relating to:

- **Psychological**
- **Interpersonal**
- **Socio-cultural experiences**

To identify ways of:

- meeting the physical and psychological needs integral to the overall **well-being** of (family) carers of people with dementia
- considering the **format and development** of future service interventions



The cartography of the landscape - outline

Exploring the **experiential** and **personal detours** of carers of people with dementia, mapping the **cartography of care**, the '**landmarks and landslides**' of their '**journey**' which is so often full of **ambiguity**

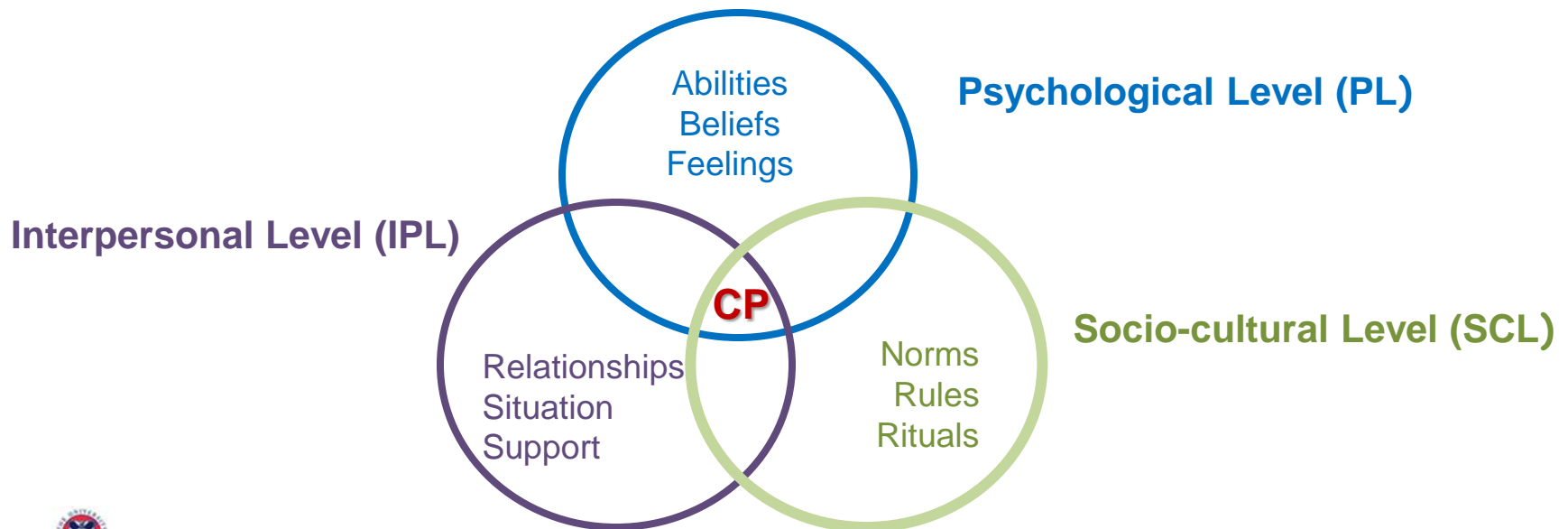
The challenges of:

- mourning the loss of their **past** (what they had and who they were - relationships)
- perhaps not being able (understandably) to accept their **present** circumstances (**ambiguity** of caring/role change/life style. Dementia is so much **more than** merely memory loss – **impact!**)
- anticipating their **future** losses (their own and the person with dementia for whom they are caring)



Method: to elicit 'understanding'

- Using a **hermeneutic phenomenological** method of investigation inspired by the philosopher Hans-Georg Gadamer which is based on the **perceived** and **understood reality** of the person. In essence their '**lived experience**'
- **Thematic framework** of analysis using the **application of** and **building on** the three levels of analysis outlined in the seminal study of Fulton and Gottesman (1980) which explores **three levels of anticipatory grief** spanning the carer participants journeys relating to the:



Participants: the '*companions*' on the journey

- **Person-centred** qualitative research study undertaken within the parameters of involvement of **two** carer-participant group(s)
- **Gatekeepers (colleagues from Alzheimer's Society Branches in the North East of England)**
 - To avoid *insider* research bias. Colleagues knew people (avoid non-vulnerable participants) and could offer post-interview support if required.
- **30 care-participants (CPs): (Individual spousal carers and two carer dyads of husband/daughter each within CP group 1 and CP group 2 - white ethnic background = limitations – white British)**
 - **CP group 1:** 10 carers (who were currently caring) x **3** interviews over a period of one year (**1 carer – end of life**). 8 Spousal carers (male and female, **plus a father and daughter dyad and '*Lindi the dog*'**)
 - **CP group 2:** reflexive view of 20 carers x **1** interview (having previously cared for a family member and post the one year anniversary. **Spousal carers male and female, plus a father and daughter dyad**).



Results: themes, scenes and familiar landscapes

Psychological (PL): behaviour that carers found challenging - strategies

After he 'bashed' (hit) me the first time, I knew that if I was in the bedroom and wedged myself between the wardrobe and behind the door I would be fine.

You see he could never find me there. I'd just wait until he'd calmed down. After that I thought '**this can't go on**' ... but it did.

'Clare' (CP group 2)

Interpersonal (IPL): anger / guilt

Well, I had heard of MRSA (infection) but I didn't know what it was. But the X ward, (do you know it?) – Bloody filthy! That's where she got it I am sure and I told them [the nursing staff] that I wasn't happy! I got the local **MP involved**.

'Ernie' (CP group 2)

Socio-cultural Level (SCL): ritual

Spirituality. Every night I read Mary's prayers to her and then I prayed myself. Although recently I have gone back to writing **poetry** (mainly about Mary) – it helps put things into perspective for me.

My 'special moments'

'Bob' (CP group 1)



Discussion - retracing the steps of the journey

Fluctuating perceptions and representations of 'being': sense of self

Sense of Self in relation to:



Gadamaerian -
Horizons of the 'lived
experience'



1. **Core self - being-individual.**
(When will I return to being 'me'?)
(Being and Becoming, Sills 2009)
'Guilt – I wish he/she would die'
2. **Relationship self - being-to the person with dementia. Loss of partner / parent / lover / friend**
Ambiguity (Boss, 1999; Boss et al, 1996)
3. **Carer self - being-to the person with dementia and to others.**
Agnosia, disenfranchised grief, loss of 'couple-hood' (Doka, 2010; Kaplan, 2004)

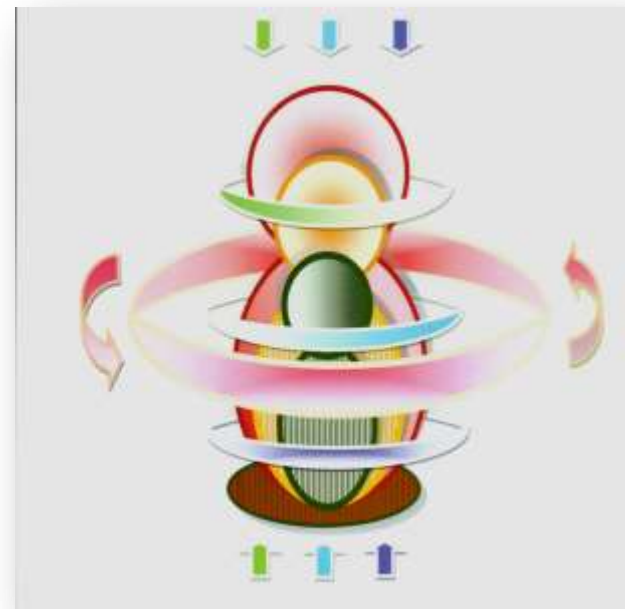


Discussion - retracing the steps of the journey

Fluctuating perceptions and representations of self - *Russian Doll theory*

... the wonder (is) that a world is worlding around us at all, that things are and we ourselves are in their midst, that we ourselves are and yet barely know why we are, and barely know that we do not know all this.

(Heidegger, 1962:83)



SCL



PL



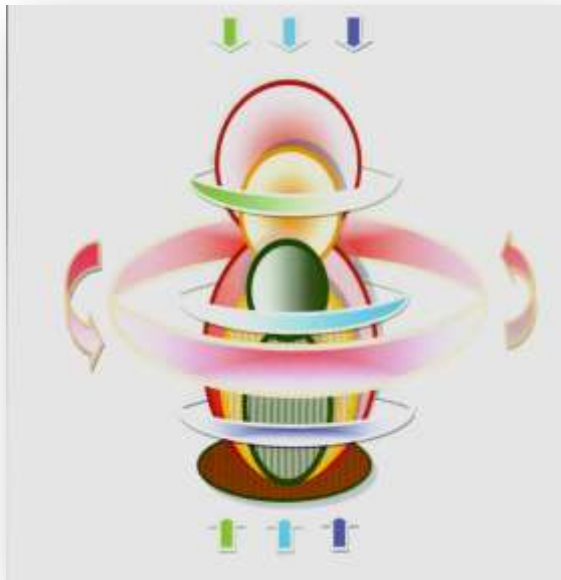
IPL



Well-being

Discussion - retracing the steps of the journey

Fluctuating perceptions and representations of self - *Russian Doll theory*



Maelstrom of emotions



Source:
http://www.allposters.co.uk/-sp/Metropolis-Posters_i8038800_.htm
accessed 05.08.2015



To summarise: looking back over the carer-participants' journeys - their landscape of care



Looking back ... reflexivity

A poem in memory of Vasil Jacovitch Oleksuik

Like a leaf

Like a leaf
Blow by the wind
You came
Displaced from your roots

The seeds of a new life
Sown
Far from the land you once knew

You laboured
Long days of toil and sweat
Black coal dust covered your body
Green fingers held prize winning chrysanthemums



Yet memories of the past
Tormented your present
The clarity of a life
Clouded by anger

Time passed and resentment
Dissolved into sadness
Mourning the loss of your child
And the man you once were

Your physical strength sapped
And your thoughts scattered
Like the leaves on the lawn
At Halloween

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