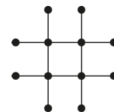

The Challenges of Dementia Care and the (Un)Making of Meaning: analysis of an online forum on carer spirituality

Hans Stifoss-Hanssen and Peter Kevern



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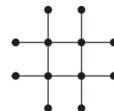
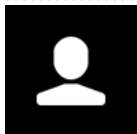
A starting-point:



Talking Point

For those of you who are spiritual, I'm just wondering if any of you have thoughts which lend a spiritual perspective to going through dementia. Are there any spiritual lessons to be gained through the journey of either the care giver or the victim?

Or do you have any spiritual perspectives related to any aspect of dementia which helps give you strength, or to make sense of the whole cruel dementia experience?



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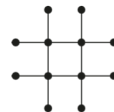
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WHAT WE DID

(1) Rhetorical analysis

62/64 posts by 23 people over a single week

- Forum posts as transient-permanent
- Posters choose when to post, and in what thread
- Are posters' names/titles significant?
- How to manage simultaneous threads?



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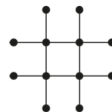
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WHAT WE FOUND

Narrative reasoning:

A distinct form of 'narrative reasoning' with a standardised structure comprising:

- A 'position statement' (12/23 participants).
- An affirmation of a previous poster or content. (29/62 posts).
- A testimony or narrative (29/62 posts)
- A reflection on the narrative which provides a conclusion



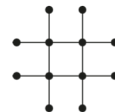
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Bruner (1986): different ways of knowing

- Paradigmatic mode of thought'
 - ...draws on reasoned analysis, logical proof, and empirical observation
 - -used to explain 'cause and effect', to predict and control reality, and to
 - create unambiguous objective 'truth' that can be proven or disproved.
-
- 'Narrative knowing'
 - Narrative knowledge - created and constructed through stories of lived
 - experiences, and the meanings created. Helps make sense of the
 - ambiguity and complexity of human lives.



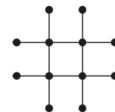
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Is the narrative format *already* giving shape, direction and so *meaning* to experience?

- Two levels of narrative:
 - - the group, the participation in the conversation. The embeddedness adds to the meaningmaking
 - - The individual contribution, the personal narrative



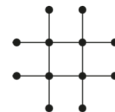
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The posts: Construction of meaning in reflection upon experience

- The act of narrating is an effort at making sense, combatting chaos, tolerating ambiguity
- Telling a story is in itself arranging selected moments from the mess in some order, and making it less painful



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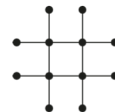


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WHAT WE DID

(2) Interpretative Phenomenological Analysis

- Thematic analysis across the whole archive to identify primary and superordinate themes
- Unpacking of hermeneutics by deep reading of individuals' contribution



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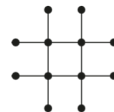


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WHAT WE FOUND

The primary question is posed as a dialectic between self-image as 'spiritual' and experience:

As a spiritual person, I try to look for the spiritual meaning, or the spiritual lessons or purpose behind everything in life, but I'm having a very hard time doing that in this situation (watching my wonderful, amazing mother whom I adore being destroyed by dementia . . . How could this happen to HER?! She does not DESERVE this!



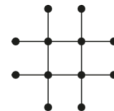
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Six responses:

1. Special revelation
2. Atheism
3. Soulmaking
4. Source of strength
5. Blessing for PWD
6. Caring as life's purpose



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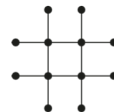
1. Special revelation

I was lying in bed . . . when a beautiful voice spoke to me. I had the knowledge but this was not spoken, that it was Gabriel. he/she told me . . . the nature of God was . . . that there was a plan and that evrything was going according to plan.

2. Atheism

"I'm not religious or spiritual, (I come from a science background) and I found that I viewed Mum's decline more as a machine getting old and worn out with more and more of the parts failing over time."

Those with faith often seem to feel sorry for those of us who haven't. Actually, from what I've read on TP and elsewhere, maybe it should be the other way round. ;) :)



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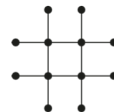
3. 'Soulmaking'

having my back to an Alzheimers Wall has forced me to develop areas of my brain that were dormant, one of those being the Spiritual Domain . . .

So is there a lesson/point/spiritual meaning in walking the Dementia Journey. Yes. Yes. Yes. And I am glad I am on it.

4. Source of strength

I am relieved God hasn't listened to me yet and will let him decide when it's the right time - it's in his plan. I also think it's okay that I can't pray anymore . . . There will come a stage when I will need God to help me some more and I know he will be there when I am ready to talk to him again.



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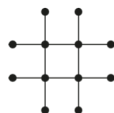
5. Blessing for PWD

. . . my mother had learned that which many advocate that we should do and that is to live in the present moment. . . For her, every day was new. Every day was as though she was experiencing things for the first time. . . .

6. Life's purpose

On reflection I can't begin to describe the tremendous benefits I've derived from such a background. . .

Best of all I thank God for providing the strength of mind and body to care for my wife on my own at home for her final five years. For me it was a privilege, an honour, humbling experience and the most rewarding time of my life

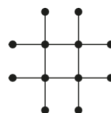
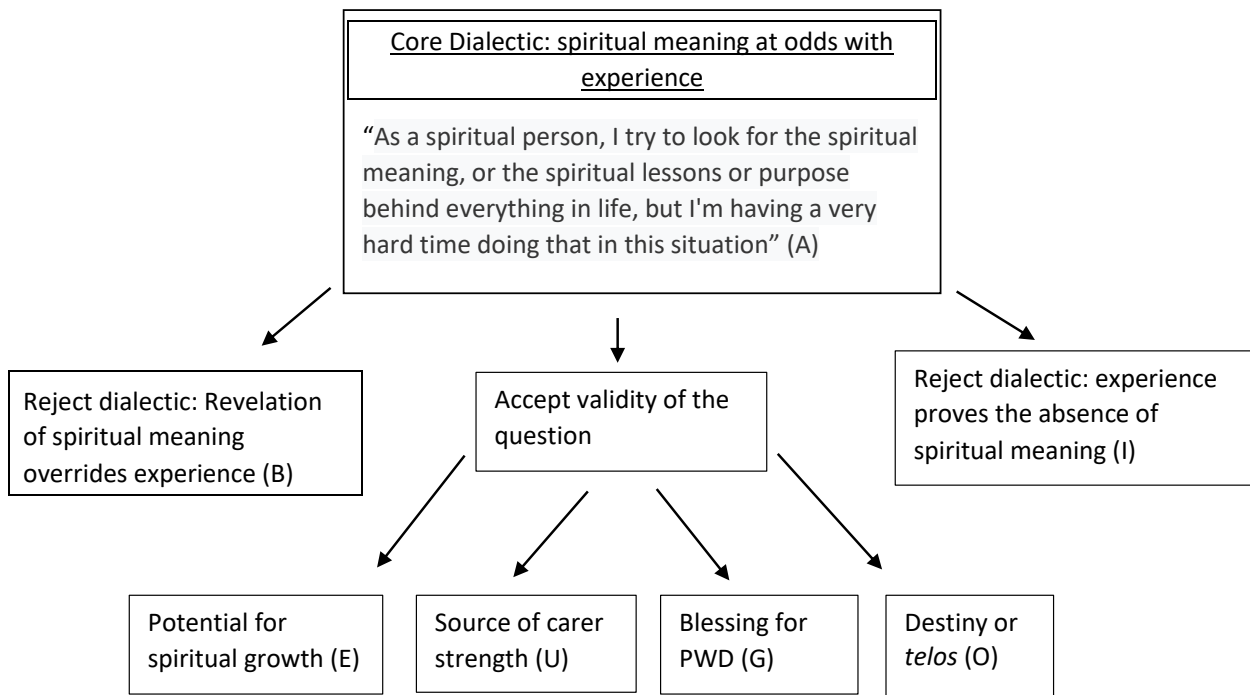


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Figure 1: diagram of the relationship between themes



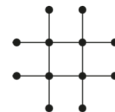
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Some interim conclusions

1. 'Non-religious' carers still may need and actively seek an account of the meaning of their experience
 2. Ambiguous character of S/R – can support or undermine resilience
 3. The active struggle for meaning may prove stressful and require support
 4. Strategies to resolve the dialectic take some standard forms familiar in theodicy
 5. Different accounts 'work' for different people
-



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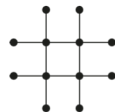
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Further work in progress

Arthur Frank (1997): The illness narratives of *The wounded storyteller* (a typology of narratives)

- 1. The restitution narrative
- 2. The chaos narrative
- 3. The quest narrative

The categories could be used for analysis; our material could include all three. They could even be seen as listening devices, for the carer to understand better what s/he is encountering



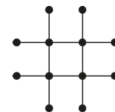
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For further studies: Different implicit theological models (cf Heelas & Woodhead, 2009)

- Are the narratives shaped according to the grand narratives 1. Spirituality of difference; harsh God, authoritarian practices (religion) or 2. Spirituality of the person/identity; individual sensemaking
- Posters of type 1 abandoned their beliefs, type 2 kept them in some form



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