



Giving Voice To Men's Stories of Caring in Dementia Through Narrative Analysis



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Overview



Exploration of the *understanding and meaning* of the experiences of caring for men in the context of dementia using a narrative framework

1. Describe and provide justification for my own developing narrative approach

2. Outline potential challenges and benefits as I embark on narrative analysis

3. Demonstrate how patterns of meaning in understanding how men construct their caring stories are emerging

Context of my study

Informal caring traditionally linked to women

Growing number of male carers in Ireland
(39% Census 2011)

- **Why?**
- Changing demographics and family formations, women's labour force participation, Gov policy focus on community, preference of individuals

Vital we learn to understand changing nature of informal caring (Eriksson and Sandberg 2008)



My Study

The aim is to gain an insight into *how* male carers make sense of their experiences, and in so doing *allow them* to tell their stories

- Social constructionist perspective: knowledge created within social contexts
- Narratives do not reflect reality but instead as way that individuals construct stories of their experiences and in so doing construct a sense of 'self'
- Men's stories: ways in which male carers construct meaning through social interaction, specific to time and place
- Qualitative in-depth personal interviews with 16 male carers
- Flick's (2009) 3 elements adapted (minimal interviewing).
- My unique approach to narrative analysis

My Interpretation

- ▶ Narrative is organising a sequence of events into a whole so that the significance of each event can be understood through its relation to that whole, in a particular context and at a specific moment in time.



Narrative Research Perspectives

- ▶ Extreme diversity and complexity
- ▶ No single way to do narrative research

My study is aligned to both ‘contextual’ as well as ‘experience-centred’ narrative research

Narrative Analysis is messy



Narrative Data Analysis

- ▶ Purpose: how respondents impose order on flow of experience to make sense of events and actions in their lives (Riessman, 1993)
- ▶ Challenges – placing this approach in context of my study
- ▶ What is best for this study – developing a systematic analytical approach
- ▶ Multitude of typologies e.g. Mishler 1986; Lieblich et al 1998, Cortazzi 2001, Riessman 2008 , Frost 2009, Phoenix et al 2010

My Research Question

How do male carers perceive their own experiences of providing care to their loved one of close relative with dementia?



My process of analysis



Case study approach: Narratives in a whole story manner (Lieblich et al, 1998)

Multiple narrative analytical techniques:

1. The content of the stories told – the *what* of the story
2. The way the stories are structured/ formed – the *how* of the story
3. The function of the story is being told in a particular way – the *why* of the story
4. The context in which the stories are being told – the *when* of the story

Process Continued



4. Analysis of the context (where, when, why)



5. Analysis across narratives



6. Understanding patterns of meaning through narrative storylines/ types

Emerging Patterns of Meaning

Intimacy and closeness



- ▶ At one end, men expressed loss and sadness for physical intimacy and closeness once shared:
Yeah, I miss, I miss female company. Do you know we've had marital relations together for over 20 years like you know so.

It was terrible, to wake up and nobody in the bed with you. Of course sex went by the way.

- ▶ Tone also NB: mixture of happiness and longing when recalling past experiences
- ▶ Imagery through personal photographs and metaphors

Intimacy and closeness

- ▶ Sense of confusion over boundaries:

And a big challenge is to love the person in front of you.....So I try not to chase after shadows...I don't want to love a shadow

- ▶ Role change = greater levels of emotional intimacy

So then we lie down. And I say like that's us talking now, that's you know us talking...

- ▶ Balancing physical presence with protecting individual's dignity:

...the other basic thing that you have to watch all the time is that... if she's having shower, I've got to make sure that the door's left open and be there.

- ▶ Apprehension over future role in personal care

...it's getting closer to the stage where I'm going to have to control it. I've found that she's not, she's not looking after herself hygienically properly at all

Intimacy and closeness

- ▶ Almost contradiction, men feeling closer than ever before:
I have someone beside me all the time, that's that's it. I have got to care for that person all the time.
- ▶ Accepting & learning new skills as well as adjusting own identities:
...she can't dress herself, she can't have a bath on her own all that kind of stuff, I've to do all that for her.
- ▶ Confidence & pride in assisting with intimate levels of care:
Ah I surprised myself. If she gets soiled and I have to clean her up and that you know. I thought I could never face anything like that and I just take it all in my stride.
- ▶ Problem solving approach to personal care:
you just get on with it... you just have to be pragmatic about it, and realise that if you don't do it, nobody else will. The distress it will cause for me, it will cause greater distress for X so the easiest thing to do is just, get on with it, clear the mess, and everybody's happier then.

Intimacy and closeness

- ▶ ‘New’ intimacy a way of ensuring devotion and showing commitment to caring:
...So I mean something like that is kind of, I mean, for me bonding, it can, it gets you very close to somebody.

- ▶ Determination in capability to continue, influence of ‘experience’ crucial:
There’s no resentment or anything. But I mean, my wife is my wife. And it is my duty to look after her. Simple as that. And I will do so to the best of my ability.

- ▶ Acceptance this was a developing scenario:
I know in my heart and soul it’s not going to get better. It’s probably going to get worse so I try and make the best of it. That’s it.


Wider Voices at Play



- ▶ Men's almost constant balancing act of juggling emotions and feelings
- ▶ Constantly on shifting ground as dementia gradually progresses
- ▶ In rising above adversity and burden of caring, these men may also defying traditional society expectations of informal care.



Conclusions

- ▶ **My approach:** a form of within–method triangulation to narrative analysis, viewing data from several perspectives (Frost, 2009)
 - ▶ **How?** Case–centred approach, privileging men’s narratives to guide me from one perspective to the next = multiple layers/ constructions in understanding of men’s experiences of caregiving at a particular moment in time and within a specific context
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A LOT DONE, MORE TO DO
THANK YOU

Questions

Απορίες

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