Exploring the impact of younger onset dementia: Finding meaning in the face of loss

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This presentation will reflect on the stories of two younger people with Alzheimer’s disease, who were interviewed as part of my PhD research.

Major themes include:
- impact of illness on the person’s sense of self
- finding meaning in their illness experience
- coping day to day
- impact of relationships
Nature of Study

Qualitative study using narrative inquiry exploring the subjective experiences of younger people with Alzheimer’s disease.

Aim:
To improve counselling support for younger people with dementia by enhancing the counselling profession’s understanding of the experience of younger onset Alzheimer’s disease.

Scope:
• 7 people with younger onset.
  - 3 semi-structured interviews each
• Their carers - one interview
• Focus groups with Alzheimer’s Australia ACT staff
Methodology

Rationale

Literature acknowledges younger onset dementia a neglected area of research posing unique and complex challenges
People with dementia have been marginalised and silenced

Recruiting and screening

Participants recruited through Alzheimer’s Australia ACT staff, key ethical issues.
Criteria: Onset of dementia symptoms before 65 yrs

Notable Changes in the Field

Robert Neimeyer (2000) – social constructionist-meaning making and narrative

Grief is individual, unique and constructed within a social and cultural context.
People search for a personal narrative that makes sense of loss and provides ‘narrative coherence’.

Tom Kitwood - ‘Personhood’ (1997)

Need to take a holistic, person centred, strengths based, relational approach
Snapshots from Interviews: ‘John’

John was 60 years old, a retired Math’s teacher, living with his partner and carer. Diagnosed 4 years earlier.

Diagnosis- the Inner Journey: shock, grief and fear

E: What was that like for you to receive that diagnosis?
J: Ah-Oh well, I know one thing, I was feeling very angry- 

I thought, right, you know, um I’m going to um, you know-I’m going to end up, you know- ‘kaput’

Yes, I was scared, I thought I was going to have a lot of pain and an awful time,
A critical turning point and new perspectives

J: …but after that, I er-changed
E: Oh?
J: and I thought you know, I can’t act like this, because what’s the use of it …the anger dissipated and I thought well, I’ve got to make the most of this. You know, you can’t just sit in a room and …feel sorry for yourself.
… I thought, you know, you’ve got to do the best.
E: So that was a conscious decision on your part…
J: Exactly, exactly. Because, I thought, well. You know, everyone has to die and I thought, well, the best thing is to go with it…
The Inner Journey

A strong narrative - the heroic father whose stoic toughness in the face of adversity became an inspiration

J: I thought of my father too, because he was a merchant seaman and a really tough sort of bloke. I wanted to be like him … and I think when I had the diagnosis I thought of him a lot and what he would think, that he’d say ‘Come on, get on with it.’

E: So that was important to you?

J: Yes, very important actually… that was a very pivotal thing in my-um coming to grips with things.
Support

Linked to the story about John’s father - a deep friendship with a support group member, who has also become a role model.

J: There was an older bloke called ‘A.’ in the group. He’s a bit older than me…He was very good for me, getting me into the right frame of life. He was like my dad actually, you know, a tough bloke…When I discovered him, I don’t know whether he was plain hardy, as they say, or not, but he was very good for me, he really was.
Life today

Further movement reflected in John’s narrative reflecting on life today, four years after diagnosis.

J: I think a lot of, everyone who gets this problem, what really happens is that we just go into a, you know, one phase which is ‘Oh my God no, it’s the end of life’. Well now I have felt that, um, there’s life outside and aah, and the aaah, with the people that look after us, they are wonderful… and ah I have no, no fear of anything, absolutely none…
Reflecting on John’s Story

- A story of resilience and transformation? Has John’s changing sense of self and his meaningful quest to ‘be like his father’ helped him to integrate losses?
- Or are there deeper issues yet to be acknowledged?
- Impact of role models.
- The transformative impact of the illness - didn’t want to be ‘a shrinking violet.’
- Impact of support received and the new life he has created.
‘Kathleen’

Kathleen (67) lived alone and was assisted by a very supportive neighbour and her brother. She had received a diagnosis of dementia in her early sixties, after a long period of consultation with several specialists, including a neurologist. She had been experiencing significant difficulties at work and had become uncharacteristically forgetful around the house.
Pathway to Diagnosis

Key factor - reflections on family history.

K: And then I started to think about mum’s family and how many of them had had Alzheimer’s, had dementia. I started to remember things mum had spoken to me about years ago, that she hadn’t spoken to the young ones about it because, I think she was embarrassed, but she wanted me to know, because in her days, things like that in the family were an embarrassment and you would just cut off.

…she admitted to me about her grandfather having had it and she didn’t know him at all, because he had been locked up, in those old buildings they used to build in those days, that were more like big jails …
Impact of relationships

Kathleen’s siblings do not accept her diagnosis.

K:… I knew when I tried to talk to my brother and sister …about it, it was a case of, ‘Oh, where do you get these ideas from? I’m not that much younger than you and I get the same problem. It’s only a thing that you get with age.

And yet

K … I thought that if it would come to me, then my brothers and sisters might be free of it. (Kathleen smiles) But that’s me.
Belonging

A place of belonging and acceptance, particularly in times of crisis.

K: …the staff there are absolutely marvellous, and the people themselves get the caring and loving from one another, because they’ve got the problem too, we understand it when they get sick from time to time, and when they get back we make a big fuss over them and what have you, and they love it.

…now the whole group know everything about one another … it has been something that has been much easier to take.
Staying connected

Families and community need to stay connected with people with dementia, to reduce stigma and fear.

K: I think just people becoming more aware of it and giving more time to those who do have it, because there are so many of them, when they get put into private homes, they have areas for dementia people and its almost like at * … I could never go into there in a 100 years… sitting in chairs, sound asleep, every day of the week. Now that’s not healthy …but if people are made more aware …people coming to see them… children into see them, they may not remember at first, but it will come to them.

E: So more life

K: More life put into their lives!
Reflections on Kathleen’s Story

- Meaning of family history significantly shaped the way Kathleen made sense of her diagnosis.
- Meaning making dramatically demonstrated by Kathleen’s belief ‘if it (dementia) would come to me, then my brothers and sisters might be free of it’.
- Family narratives influenced hopes and fears for the future - taking charge through respite.
- Very positive view of community support
- People with dementia know what’s important
Final Reflections

- Rocky pathway to diagnosis

- Meaning making included impact of role models; the legacy of family history; ‘saving siblings’ from a similar fate.

- Benefit finding- what’s been learnt; appreciation of the support.
Final Reflections

- Participant’s experience of sense of self included reflection on previous working lives; important roles; and aspects of competence before and after diagnosis.

- Some focus on loss and new understandings of life.

- Relationships with family a mixed dynamic, some constrained by social context and invalidated by responses from significant others. In contrast, support provided also created a new positive reference group.
Background References


References


