

Noticing fears of loss of control – the importance of recognising existential concerns about dementia

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My background

- Worked in NHS for 25 years as a Clinical Psychologist
- Moved to UWE in 2012
- Research and clinical interests
 - understanding dementia as an existential threat
 - using psychotherapy to meet this threat

Two methods of looking at knowing/ not knowing

- In the laboratory
 - Terror management theory
 - Mnemic Neglect
- In the clinic
 - Changes in how dementia is described
 - LivDem groups
 - Assimilation of Problematic Experiences

Threat in the laboratory - mnemic effect

How do people manage the threat of dementia?

- Established body of research in Social Psychology looking at how identity-threatening information is processed
- Mnemic neglect - the tendency for information that is threatening to identity to be less well processed and less well recalled than neutral information
- Studies typically ask participants to remember sentences that vary in their level of threat to identity – either about “*Self*” or “*Chris*”

Mnemic neglect and dementia

- 60+ statements about dementia from self-help literature – rated for level of threat
- The 12 **most** threatening statements:
 - “*The illness may make you/Chris feel confused*”
 - “*Your/Chris' illness is a progressive disease*”
- The 12 **least** threatening statements:
 - “*Your/Chris' illness doesn't change who he is/you are*”
 - “*In the illness, proteins can build up inside your/Chris' brain*”
- Participants randomised to Chris or Self conditions

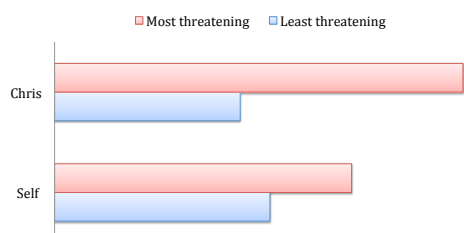
Participants

- Recruited 66 different participants from memory clinics
- Mean age 80.23 (SD=7.44)
- 34 men, 36 women
- 52 living with partner, 13 alone, 5 with family
- 43 had Alzheimer's, 13 vascular and 12 mixed dementia
- Mood – mean GAI of 3.23 and GDS of 2.75
- Cognition – MOCA of 19.45, ACE III of 76.11 and M-ACE of 25.69
- No significant differences between conditions

We hypothesised that:

- For the most threatening information, recall will be better when it is about Chris than about self
- For the least threatening information, there will be no difference in recall between Chris and self

Recall of dementia statements by level of threat



Results

- A significant interaction ($p = .01$) between conditions (Self/Chris) and level of threat.
- No difference between recall of least threatening items
- Significantly more threatening descriptions of dementia being recalled in the Chris than the self condition ($p = .015$)
- The interactions disappeared for both recognition and delayed recall
- Strong recency effect

Intrusive Errors

- Three possible types of error: valence reversal, repetition, novel intrusions.
- We defined errors as either:
 - **Protective** (Valence reversal of high threat statements and repetition of low threat statements)
 - **Threatening** (Valence reversal of low threat statements and repetition of high threat statements)
- We hypothesised that there would be more errors protective of identity, and fewer threatening errors in the self than in the Chris condition

Memory intrusions: protective and threatening errors



The level of threat affects recall

- Memory failures may act to protect the identity of people affected by dementia:
 - The recall of the most threatening information was significantly better when it was about Chris than about the self
 - The memory errors that participants made were also protective of self identity

Processing and recall

- Mnemic neglect effect disappears for recognition, and for people with high levels of affect
- Suggests it is due to inadequate processing
- As if the threatening material is rejected because it does not fit existing self-concept

Threat in clinical work – fear of loss of control

Robert – week four

... you keep saying you have Alzheimer's, has that been formally diagnosed, because it's not the same thing as memory loss, you know?

Now there's a premise here that I just don't agree with. The way you're talking, you sound as though you've accepted the fact that you've got Alzheimer's. Now I don't think anyone in this room has got Alzheimer's

Robert - week nine

I find I've, I've got a great deal of moral uplift by coming here, meeting you, listening to the way you do it. And I don't see the problem now, it frightened me, the problem of declining memory, until I came here, and now I'm not frightened
It frightened me because I thought, well, I'm going mad, I'm going crazy.

*What am I going to be like in another five years?
 But now I realize that everybody is getting this problem*

From Watkins et al, (2006)

Len

I think that if people know, they understand, but if you hide it as I did, first going, they get frustrated with you. ... I think you've got to be open with people and they may understand instead of thinking 'oh that silly old fool is losing his marbles'

I mean I tried to cover up, which I suppose is a natural thing to do. Yeah, you try to cover up and swear blind that you haven't been told, you know, what you have been told, and eventually you accept the reality that you're not right.

From Lishman, Cheston and Smithson (2016)

Retrospective accounts of mnemonic neglect?

- Both Len and Robert describe
 - Previously pushing away knowledge of their dementia
 - Fears about the implications of the diagnosis
 - Concerns about threat to their identity (being mad)

The fear of loss of control dilemma

- Expressions of a choice or a dilemma – between
 - whether to continue to think about a problematic experience (and risk loss of internal control over emotions)
 - or to retreat away from thinking about the dementia (and risk loss of control over external world)

Ways of resolving the dilemma

- Warding off or pushing away dementia
- Referring only indirectly to dementia
- The Voldemort phenomena
 - It, that thing
- Using metaphors, telling stories
 - Often relate to conflict
- Naming the demon directly

Mr E – pushing dementia away

I find what we're doing now, it brings all memories to me, so and being around listening to you all talking. I find I just want to be I'm trying to make a point that I'd rather be at home doing what I need to do and want to do. And this is why I really don't want to talk about that you know, I mean I'm sure it's being selfish but, it's just the way I feel about it. I don't really want to be here.

Well I just don't want to be here. I just want to be. I've got lots of things I'd like to do, and er. Well, I can't think about coming here, it just brings it all back.

Henry – indirect exploration

*It [memory loss] has been in my mind yes, erm , because in a way it's almost writing you off and I don't think that is right at all but you are suddenly becoming somebody totally different to what you used to be and mentally you don't want that, mentally you don't want to accept that and I think that's a good thing because once you start **waving the white flag**, you pack up and I don't want that ...*

*Well I think, you have got to have a positive attitude in life if you don't you **just wave the white flag** and you pack it all in ...*

*I mean once you have reached the age of 80 it's ever so easy to **wave the white flag** and say oh I can't do this I can't do that*

From Lishman, Cheston and Smithson (2016)

Terry Pratchett, (The Observer, 15.03.15)

It occurred to me that at one point it was like I had two diseases – one was Alzheimer's and the other was knowing that I had Alzheimer's.

There were times when I thought I'd have been much happier not knowing, just accepting that I'd lost brain cells and one day they'd probably grow back or whatever. It is better to know, though, and better for it to be known

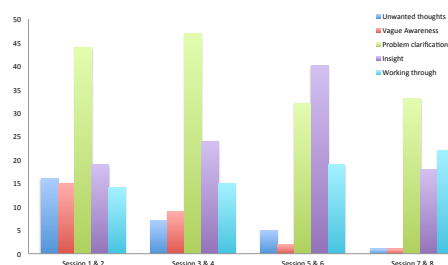
The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon, then first we have to speak its name.

Once we have recognised the demon, without secrecy or shame, we can find its weaknesses.

Providing post-diagnostic support

- Living Well with Dementia Groups (LivDem)
- 10 week support groups
 - Preliminary session (with family)
 - 8 week structured course led by memory clinic nurses
 - Post-group session (with family)
- Pilot study showed strong trend towards improved self-esteem and QoL
- Also looked at changes in how people talked about their dementia

Coding of levels of assimilation across sessions



So ...

- Dementia represents an existential threat – i.e. one that challenges identity
- Threatening information may be less well processed – leading to worse recall
- More generally, people may need to balance knowing (risk of loss of internal, emotional control) and not knowing (risk of loss of external control)
- Post-diagnostic support both necessary and involving containing emotional distress

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