Dementia, (gendered) relationships and care

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The relational basis of dementia and care

Key concepts: personhood and couplehood

Research insights into gendered experience

Relational basis to experience

- The socially-constituted personal experience of the person with dementia means that they are an agent whose personal beliefs and actions, as well as their social relations, transcend the biological basis of the condition

- The “experience of dementia is relational and not simply cognitive” (Bartlett & O’Connor, 2010:19).

Personhood

Personhood is “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997:8).

Malignant Social Psychology: A range of behaviours expressed in the interpersonal environment that impact negatively on the person with dementia, such as disempowerment and infantilisation.

Critique of personhood concept

- A narrow view of experiences is proffered, which understates the influence of wider social and cultural influences (Baldwin & Capstick, 2017)

- The focus on 'malignant social psychology' implies that carers are complicit in the process of generating social conditions that undermine the person with dementia's personhood (Davis, 2004)

Couplehood

Rather than the person with dementia being the principal focus, the couple might be seen as the primary unit of analysis, at least where spousal relationships are concerned.

- Couplehood studies tend to offer a positive view of relationships
  - It is more normative than ontological (Weicht & Tolhurst, 2023)

Key considerations

Balance is required: avoiding a zero-sum perspective where one person's perspective is prioritised over the other's

Complex relational experience is not captured by a '*Tragedy'* versus '*Living Well'* binary (McParland et al, 2017)

Sociocultural standards and moral discourses shape the experience of dementia and care

Research overview

To investigate how couples negotiate relationships and care, following a diagnosis of dementia

Two qualitative studies, with the sample configured regarding gender

Semi-structured joint interviews

Narrative thematic analysis

Method

- Joint interview provides direct insights into interaction
- Grants insights into individual perspectives and how these are interwoven in conversational exchanges
- Relational Ethics (aggregate calculations of beneficence/non-maleficence are not possible)

Context: Gender

"Gender, the complex of social relations and practices attached to biological sex, is one of the most important socio-cultural factors influencing health and health related behaviour" (Evans, 2011)

- People with dementia are usually presented in gender-neutral terms (Bartlett et al, 2018)

- Qualitative studies tend to elide differences of perspective from men and women (for people with the condition *and carers*)

Men with dementia

Themes relates to former activities and employment, “productive” adulthood; as well as ongoing social contributions

The communication strategy employed resists passivity and vulnerability (being positioned as dependent)

Appeals to continuity and positive future despite the impacts of the condition, and this included a positive views of services

I must admit we haven’t taken it up. Because I feel very happy with how things are going. I’m not saying that in the future we wouldn’t. If things get a bit - it could possibly be a good place to go to, and talk to other people in the same position. Or give advice to people in there who are perhaps newly diagnosed. I could be some help to them. To say that I’ve been there, and I’ve done it and there are ways of improving yourself.

Social pressures on female carers

- Frustration with challenges and constraints
  - Guilt is prompted by these frustrations
- Caring aligned with natural female role. Concern with own individual needs is branded as selfish.
- Desire not to burden others – family members, society more broadly

I just wanted to gag her. I wanted to say, “I don’t want this now. Come back and tell us that on another day, I don’t want David to hear this.” […] when she had gone it was the first thing David said. We then just sat and sobbed.

I think what I would tend to do is become the clinician in that. And I would be doing the “have you thought of doing this, and have you thought of doing that?” Now maybe that is very selfish of me, but I kind of don’t want to do that because I do it every day. No, maybe we’ll get to that stage where we’ll feel it will be helpful, but I almost feel - so maybe that’s very selfish, that is very selfish. But I don’t want to do it at the moment.

Narrative collisions

- Carer grappling with guilt and frustration – perceived social pressure to maintain image of 'good carer'
  - Requires a candid perspective of change and challenges

- Man with dementia grappling with diminishing cognitive abilities – pressure to maintain image of competent, skilful person
  - Requires a more positive perspective of continuity

(Tolhurst et al, 2017)

Florence: It’s the losing things.

David: I shouldn’t have a coat with so many pockets in.

Florence: No, we all lose things. But we’ve lost a couple of mobile phones haven’t we, and hearing aids somewhere. I think we just get on with it don’t we.

David: You’re going back a bit. We did used to lose quite a few things. We used to leave places and realise I’d not picked something up, whereas now I’m a little bit more -

Florence: Yes, because that’s mainly on holiday isn’t it. Because I actually go “have you got it, where is it?” You know, things like that. You’ll frequently go out in the evening without a wallet, which is a good ploy! But I can’t comment because you’d got your wallet last night, and I’d left my purse at work.

Strategic interaction and informal care settings

- The desire to always put the other person first creates ‘collisions’ of intent
- Selflessness also leads to complicated negotiations (Tolhurst & Weicht, 2018)
- Family care environments place emphasis on altruism (in contrast to the more utilitarian and rational-calculative economic arena)

Male Carers

- Traits associated with hegemonic masculinity do not leave much scope for nurturing qualities (Coston & Kimmel, 2013)

- Men who perceive care as a masculine task feel less frustrated in the carer role (Kluczyńska, 2015)

- Rather than making gendered assumptions, careful attention should be paid to individual needs (Hellström, 2017)

Making sense / solving problems

I explain to people what it is. I think of it as the lotto on the telly where the balls go round and then one drops out and all the numbers are mixed up and then all of a sudden they just flash and it's ‘one, two, three, four’, whatever. I think that's what’s happening in there and it's just trying to work out how…

We’ve got friends and their husbands can’t cope with them and they say “Yes sir, no sir, three bags full sir”. Now I won’t let that happen, I’m a bugger, I just won’t let it. I want her to get better you see. I keep pushing and pushing.

Final points

It is vital to avoid a gender-neutral perspective of dementia and care

However, it is also crucial to avoid presenting a binary (and stereotypical) representation of gendered experience

A gendered representation is compatible with acknowledging individual dispositions/ requirements

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