We're in this together?..... The reciprocal influence between family relationships and dementia

Jenny La Fontaine
Young Onset Dementia Development Officer, Worcestershire Health and Care NHS Trust and PhD Student, University of Bradford; jenny.lafontaine@hacw.nhs.uk
Professor Jan Oyebode, University of Bradford

Aims

- Background to the synthesis
- A Shared History
- Negotiating the impact of dementia upon the relationship
- Openness and Awareness
- Shifting Sands
- Implications for research and practice

Why Focus on Relationships?

- The meaning and value of relationships in our lives cannot be understated;
  - Opportunities to be in relationship with others and contribute to their well-being
  - Feeling a sense of belonging in valued relationships and experiences (Papadopoulos *et al.* 2011)
- 41,700 people living with dementia in Ireland, with the majority living at home either with or close by family
- Evidence that family caregiving is the ‘lynchpin’ of dementia care

The experience of living with dementia

A life experience that will be influenced by;

- The people you are with
- The environment
- The course of the illness
- The opportunities to enjoy life over time
- The availability of support to help you through difficult points

Family Life with Dementia

- Our lives with dementia involve considerable changes and challenges; each family's experience is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia require that all family members engage in an on-going process of assimilation, adaptation and adjustment

The experience of dementia

- A relatively recent shift in research to a relationship focus
- However, the majority of this research;
  - Focuses on couples
  - Has rarely extended to include other family members;
  - Or the potential impact upon the wider family
  - Often excludes the perspective of the person with dementia
- Families absorb dementia into their collective identity, it becomes the whole families challenge to manage (Garwick, *et al.* 1994)

Qualitative Synthesis

- In-depth qualitative studies
- Often the results have not been included in systematic reviews
- Not generalisable but can provide a deeper insight
- What is currently known about the reciprocal influences between family relationships and dementia from the perspective of the family, including the person with dementia
- What implications might this have for research and practice

Qualitative Synthesis

- 11 articles
- Central theme of the relationship between the person living with dementia and their family
- In-depth interviews
- Eight interviewed families at a single point in time, three were longitudinal
- Eight of the articles interviewed co-habiting couples
- Three focused on adult daughter/ mother relationships or a three generational family
- Alzheimer’s disease, vascular or mixed dementia

Limitations

- Lack of representation of different relationships such as
  - parent /child (of both genders)
  - Intergenerational families
  - Young people and children
- Lack of representation of different forms of dementia
- Families from migrant and minority communities
- Largely cross-sectional design

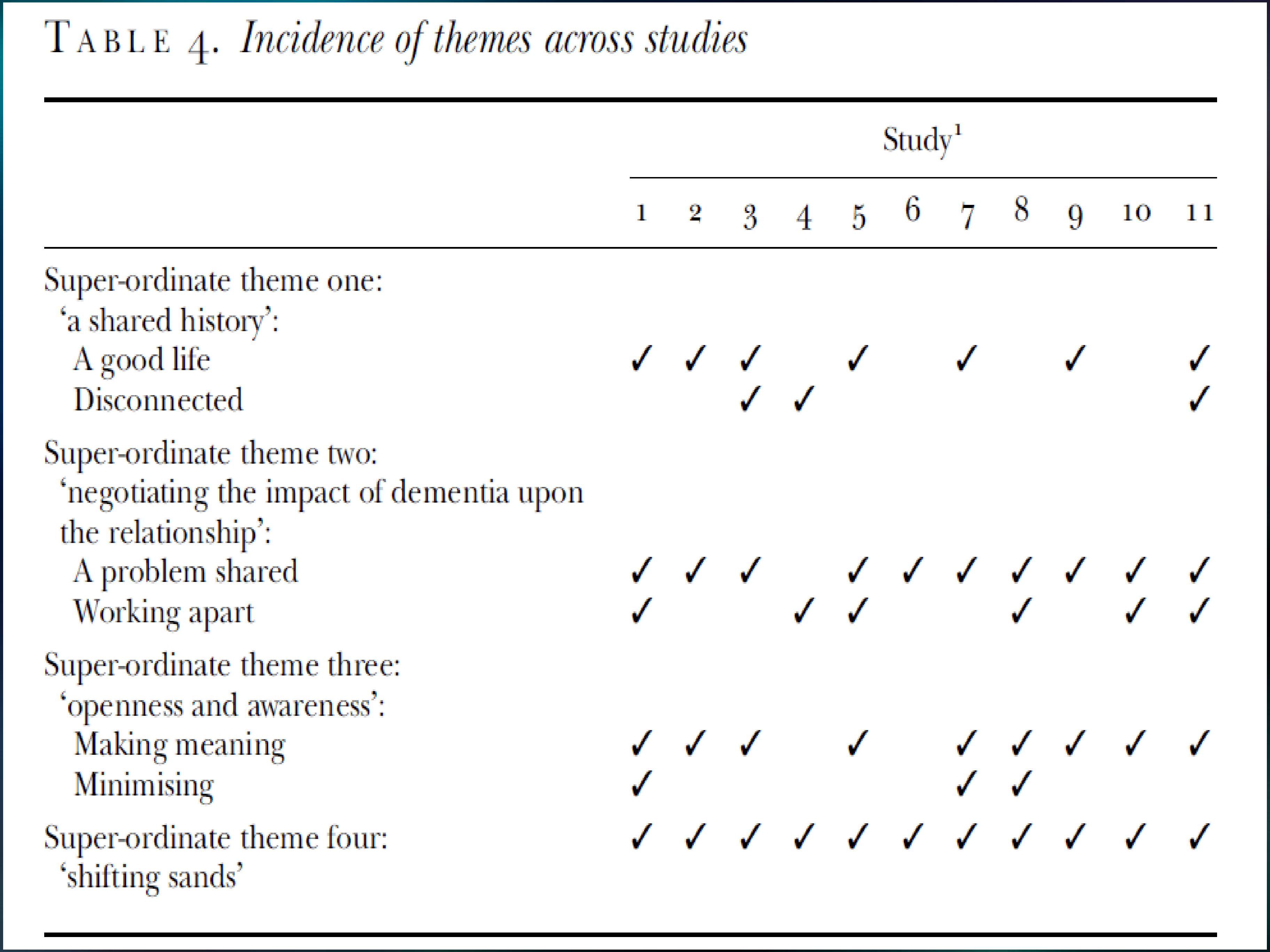

TABLE 4. *Incidence of themes across studies*

	Study[1]										
	1	2	3	4	5	6	7	8	9	10	11
Super-ordinate theme one: 'a shared history':											
A good life	✓	✓	✓		✓		✓		✓		✓
Disconnected			✓	✓							✓
Super-ordinate theme two: 'negotiating the impact of dementia upon the relationship':											
A problem shared	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
Working apart	✓			✓	✓			✓		✓	✓
Super-ordinate theme three: 'openness and awareness':											
Making meaning	✓	✓	✓		✓		✓	✓	✓	✓	✓
Minimising	✓						✓	✓			
Super-ordinate theme four: 'shifting sands'	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

A Shared history; **A good life together**

- Positive feelings about their shared history
- *"although Jane's statements were brief, such as 'he's just the best thing I've ever had' they were often paired with grins and glances towards Tom as she reached for his hand or arm to hold"*
- *"Tom made statements such as 'She's been a wonderful wonderful wife', and 'I don't think I could have found a better match for me, because uh, we've just everything's been agreeable and we've always got along"* (Daniels et al, 2007, 168)

A Shared History: **a good life together**

- Commitment to each other including the need to compromise to maintain togetherness;
- "Mr Martin, 'for better and for worse and on and on. It was the natural, natural thing that we would do and that's what we believed in'
- Mrs Martin, Well yeah, I mean we've been together long enough to sort of, at that plateau, we haven't seen things the same. But together we also come around. We don't segregate, we don't separate. We're together" (Davies 2011, 222)

A Shared History: **A good life together**

- Recognising the contribution that each had made to the relationship and each other
- Resolving or accommodating disagreements
- *"It's a balance and we've, at least I look at it, well if I want to be okay between us, then I just have to make sure that nothing goes between us an he does the same thing, you know. We don't go to bed with a bad attitude, you know"* *(Davies, 2011, 229)*

A Shared History; **Disconnectedness**

- reflecting negative perceptions of the shared relational history
- *“Barbara tells me: [about Mavis, her mother] ‘Oh yeah! She could be quite violent!... She’d throw knives, forks, saucepans, you name it, she threw it” (Forbat, 2003: 74)*
- Links between past and current relationship quality were clearly made

Negotiating the impact of dementia upon the relationship; **A problem shared**

- Managing the impact of dementia together, continuing commitment to each other
- *"Peter; you've got to, I was just going to say yeah, you've got to be, you've got to stick together. Denise; Yeah, there's lots of love in this house. Peter; That's the main thing to me anyway"* *(Molyneaux, et al. 2012, 490)*
- *"I think my relationship with Diane is good. I depend on her quite a bit and she is always there…* *(Ward-Griffin,* et al.2007, 25)

Negotiating the impact of dementia upon the relationship: **a problem shared**

- Open communication and managing things together
- Mutual respect, appreciation and reciprocity
- Supporting continuation of valued activities, maintaining the identity and functioning of the person with dementia
- *"When I was in the hospital, she was able to talk to the doctors and nurses in a way that I couldn't… She also goes to the doctors with me. She listens. She keeps it all straight in my mind"*

(Ward-Griffin, et al. 2007, 26)

Negotiating the impact of dementia upon the relationship; **a problem shared**

- ‘scaffolding’ strategies to support the family member with dementia
- *“He will say, shall I make you a cup of tea?, now I know if I go out there, there’ll probably be tea spilt… it doesn’t matter because it’s just tea… I get up early in the morning and I’ll just clean it”* *(Merrick et al. 2013, 11)*
- Continuing to compromise to sustain the relationship and live for today
- *“It is nothing to be happy for, but you have to accept these conditions and do as good as possible… The disease is on another plane, it doesn’t have to affect others”* *(Hellstrom, et al. 2007, 396)*

Negotiating the impact of dementia upon the relationship

- **Working Apart** **(Keady & Nolan, 2003)**
- A loss of connectedness
- *"You live in two small worlds. You have a common world and then you have your own world besides too".* *(Hellstrom, et al. 2007, 402)*
- In some this created feelings of powerlessness or breakdown in relationships;
- *"There are no rewards in this relationship at all and over the couple of years that she's been here, I find myself so stressed and so upset… I would just say to my husband I wish she were dead"* *(Ward-Griffin* et al. *2007, 24)*

Negotiating the impact of dementia upon the relationship; **working apart**

- Positioning the person with dementia as the problem;
- *"No he doesn't react. He doesn't care. Surely that's why it's getting worse so quickly… He quits, he has quit everything. He doesn't care and that's why it goes so quickly" (Svanstrom and Dahlberg, 2004, 679)*

Negotiating the impact of dementia upon the relationship: **working apart**

- Blaming the person for the difficulties and using deception and confrontation
- *"Alex: And you have to raise your voice to him to stop him doing it, and then he's fine. And then give him half an hour and he'll be really nice to Sarah, but that time when it's happening, he can be awful to her. He doesn't do it to me"*
- In response people with dementia used resistance or denial as a way of maintaining identity and self-esteem

Openness and Awareness

- **Making Meaning**
- Open Communication as a central strategy, even though this means difficult conversations
- *"Alistair; [our] relationship with each other is about... it's more... it's not so much husband and wife these days, is it?*
- *Kate; No.*
- *Alistair; No. Brother/sister/friend.*
- *Kate; Yes. It's changed. That's, I think, the hardest thing. For me it's changed our relationship, hasn't it?*
- *Alistair; Mm.*
- *Kate; And I find that hard. I miss... I don't know how... I don't know... it doesn't feel right any other way."*

Openness and Awareness; **making meaning**

- Positioning dementia as the problem;
- *Kate Because you don't... I mean you lost it again the other day. But since the diagnosis, and we all of us know what's going on... we kind of work round it, don't we?*
- *Alistair Yes.*
- *Kate So we're more patient. When something happens we can go, well that wasn't him."*
- A gradual adjustment, taking things one day at a time

Openness and Awareness

- **Minimising**
- Denial appeared central to this process, used by either the person with dementia or their family
- *“Person with dementia; There’s no way I want to be gaga with somebody looking after me all the time, not by anybody*
- *FM: Well don’t worry about it (Clare and Shakespeare, 2004, 222)*

Openness and Awareness; **Minimising**

- Resistance:
- *Sue; I said "This shower needs cleaning.", because it's just, doing the tiles, I can't stretch up. So I said "Would you do it for me?"... and I left him. I said "I'm not going to interfere, you don't like me interfering." And I had all of the things for what it's needed, and other things. And he was squirting the bathroom cleaner on the tiles with this grouting brush, but no water.*
- *Roy: I'm not a domestic.*
- *Sue: No, but since we've been here you have done it numerous times. But he just completely forgot how he'd got to do it.*

Shifting Sands

- **Shifting responsibilities**
- Changes in abilities brought a complex process of negotiation involving noticing and managing risk, identifying the help needed and maintaining the person’s identity
- *“Colin; so you’re going to come swimming with us*
- *Rose; oh is that right?*
- *Colin; yeah… Cause Dad’s not going to be home… Alison are you excited? Grandma’s coming to swimming lessons [again]* (Purves, 2011, 49-50)

Shifting Sands

- **Time together and time apart**
- Continued opportunities for time together and apart important,
- However shifting roles and responsibilities impacted upon this
- **Loss**
- ***"And then, and it also happened… it also happens today, that he doesn't know who, who I am" [someone said] yes her name is X… no.. Her name is X. Yes that's my wife's name too he said then, in some odd way" (Svanstrom and Dahlberg, 2004, 681)***

Implications: A psychosocial typology

- This synthesis highlights the particular psycho-social challenges that dementia brings
- Rolland 1994, psycho-social typology of chronic and life threatening illness
- Duration
- Course
- Degree of incapacity and outcome
- The life stage
- The impact they have on the relationship

Implications; relationships

- The quality of previous and current relationship
- Dementia impacts differently on couple and wider family relationships
- Coping strategies such as ‘scaffolding’ or positioning the person
- People living with dementia are active participants in;
  - Working actively to maintain relationships
  - Make sense of the impact of dementia
  - Manage the changes it brings
  - Continued emotional awareness

Implications; relationships

- Positions of denial and resistance appear to be the consequence of;
  - A previously poor relationship
  - Poor communication
  - Being positioned as the problem
  - A lack of synchronicity in awareness and understanding

Implications; relationships

- Effective adaptation to dementia involves
  - Emotional connectedness and open communication
  - ‘working together’ (Keady and Nolan, 2003)
  - Positioning dementia as the problem
  - Holding the dementia apart from the relationship while managing it’s impact on day to day life
  - The active participation of the person with dementia in this process

Implications for research

- Research commonly focuses on strengths and adaptive characteristics of couple relationships
- Minimal material about negative impact
- Or how past conflicts influence current experiences
- Polarisation is a risk
- Recruitment to research
- Need to extend to broader, intergenerational relationships

Implications for research

- Largely focused on Alzheimer’s disease
- How are other forms of dementia experienced and is it different?
- Potential for differences in psychosocial adjustment
- Cross sectional design; how does this change over time
- Many of the studies didn’t give enough detail to contextualise the experience
- Focus on traditional family relationships

Implications for practice

- Using the label ‘carer’
- Respect for relational context in which dementia occurs
- How can we support the person with dementia to engage in relational work
- How we define families and who is in relationship with the person with dementia
- Assessment of previous and current relationship quality

Implications for practice

- Psychosocial consequences of dementia for the family
- How relationships are negotiated
- How roles are defined
- How challenges have previously and are currently managed
- Must inform timely and early interventions

Thank you for listening!
Questions

Jenny La Fontaine;
jenny.lafontaine@hacw.nhs.uk