**“It isn’t the same”: relationships and dementia**

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**Abstract**

People living with dementia may live in relationship with partners, family members and significant others. Dementia has been shown to impact on such relationships but relationships also impact on the dementia condition. Thirteen people took part in the study: all were caring for a person living with dementia and two were themselves living with dementia. Semi-structured interviews were conducted with participants focusing on changes in close relationships, including changes in intimate (sexual) relationships where appropriate. Interviews were audiotaped, transcribed and analysed using thematic analysis. Four main themes were identified: changes in couple relationships; changes in non-partner relationships; talking about oneself in relationship; talking about people with dementia in relationship. In conclusion, participants’ lived experiences highlight the need for ongoing relational support and an education based counselling programme that could potentially address many of participants’ highlighted needs.

**Key words**

Carers, counselling, families, intimacy, sexual relationships

**Background**

Dementia is one of the most vital public health concerns in the UK and around the world. Approximately 7% of over 65s are affected in the United Kingdom (UK) and it is predicted that numbers will double every 20 years (Alzheimer's Society UK, 2014). It is estimated that there are currently 850,000 people living with dementia in the UK (Alzheimer's Research UK, 2018). Around 24 million people in the UK – 38% of the population – know a family member or close friend living with dementia (Alzheimer's Research UK, 2018) and there are approximately 700,000 informal carers of people living with dementia (Lewis, Shaffer, Sussex, O'Neill, & Cockcroft, 2014). Worldwide, around 50 million people are reported to live with dementia with an incidence of nearly 10 million new cases every year (World Health Organization, 2017).

Research literature has increasingly acknowledged the value of the relationship between people living with dementia and their carers and of understanding the experience of both parties (Colquhoun, Moses, & Offord, 2017; Henderson & Forbat, 2002; Keady, 1999; Keady & Nolan, 2003; Nolan, Grant, Keady, & Lundh, 2003; Nolan, Ingram, & Watson, 2003; Sheard, 2004), experiences of loss in the relationship (Colquhoun et al., 2017), and outcomes for the people living with dementia (Edwards et al., 2018). Living with dementia can have a significant physical, psychological, social, and economic impact, not only on the person with dementia, but also on their family system, carers and society in general. Dementia is one of the major causes of disability and dependency among older people worldwide (World Health Organization, 2017).

The person living with dementia may experience, alongside physical and psychiatric symptoms, destabilisation in their sense of identity (Caddell & Clare, 2011) and multiple losses (including loss of the planned/ anticipated future, participation in meaningful activity and relationships (Steeman, de Casterlé, Godderis, & Grypdonck, 2006)). The ability to engage in meaningful relationships, especially with family members, is vital to enable people to live well (Austin, O'Neill, & Skevington, 2016), even though they may have concerns about stigma and being perceived as a burden by others (Milne, 2010). For many people their partner/ spouse takes on a caregiving role (Prince, Albanese, Guerchet, & Prina, 2014), although spousal care partners may themselves experience psychological difficulties such as caregiver burden, anxiety and depression, associated with reduced relationship quality in respect of the cared for person (Sörensen, Duberstein, Gill, & Pinquart, 2006). Some positive aspects such as feeling useful and proud as well as a deepening in the relationship have been reported in Hong Kong Chinese family carers (Cheng, Lam, Kwok, Ng, & Fung, 2013). These findings suggest that changes in relationships are a key part of the experience for couples living with dementia, and may be associated with a range of psychological outcomes (Fauth et al., 2012; Rattinger et al., 2016). The importance of relationships in dementia care fits the argument advanced by Kitwood (1997) that a relational frame is essential for good dementia care.

People with dementia may live in relationship with many other people. For those who have partners, the development of dementia will have far-reaching effects on both partners. Other family members will also be affected by the illness. The dementia and its progression will impact on these relationships, and relationships will influence how the person lives with dementia. What do we know about relationships and dementia?

**The impact of dementia on relationships, and relationships on dementia**

Studying the impact of dementia on relationships is complicated by a number of factors. Gender is a major factor which may itself be complicated by power issues: does dementia impact differently on relationships where men are caring for women partners compared with women caring for men partners, and what about same sex partners (Hogg, 2010)? Family relationship is another complication: some studies involve partner relationships, others involve adult children caring for a parent with dementia, and in practice the role of carer may be taken on by a broad range of family members and sometimes by neighbours or friends.

Ablitt, Jones and Muers (2009) carried out a systematic review of the influence of relationship factors on living with dementia, including quantitative and qualitative papers, and found 14 papers relevant to the impact of dementia on relationships, mostly partner or adult child-parent relationships. They highlighted a number of changes in the quality of relationships following development of dementia, including decline in relationship quality; decline in intimacy; loss of reciprocity; changes in communication and decline in marital happiness. Alongside these negative changes they reported some positive changes too: increases in closeness, warmth and mutual affection. With respect to partner relationships, they noted that persons with dementia held more positive perceptions of overall marital quality than their partners did.

Most research that considers the impact of dementia on the marital/ partner relationship has primarily focused on the carers’ perspective, with a corresponding lack of research focusing on the perspectives of persons with dementia. La Fontaine & Oyebode (2017) conducted a review of 11 qualitative studies that addressed the perspectives of people living with dementia as active participants and of family members (partner and/or adult children). They identified four themes, a shared history, negotiating the impact of dementia upon the relationship, openness and awareness, and shifting sands, referring to the changing roles and responsibilities that dementia brought for the relationship. They reviewed was Hellström, Nolan & Lundh’s (2007) study, which looked at changes in couple relationships over time and identified iterative non-linear phases that they termed sustaining couplehood, maintaining involvement, and moving on. The literature finds that the accounts of individuals with dementia suggest an awareness of the impact of dementia on family members involved in their care (Ablitt, Jones, & Muers, 2009; Burgener & Twigg, 2002; Hellström et al., 2007; La Fontaine & Oyebode, 2014).

The impact of dementia on intimacy and sexuality has been a focus of research interest. Ballard et al (1997) found that almost a quarter of married people with dementia are involved in an ongoing sexual relationship. Davies et al (2010) studied spouses where one partner was living with dementia or mild memory impairment and found reduced sexual expression in both groups. They noted substitute activities, for example hand-holding and hugging: this may link with the new types of intimacy and closeness that Sanders & Power (2009) reported in husbands caring for wives with dementia. Baikie (2002) found that most wives reported a cessation of sexual activities “which has coincided with dementia” but commonly attribute it to physical illness or advancing age. She suggests that cognitive impairment is likely to affect the maintenance of sexual arousal.

Ablitt, Jones & Muers’ (2009) systematic review also found 16 papers relevant to the influence of relationships on living with dementia. They concluded that carers who report lower relationship quality prior to dementia report more negative experiences as carers, including higher levels of depression, distress, burden and strain, whereas those who report higher levels of relationship quality prior to the development of dementia report more positive aspects of caring, including greater rewards, satisfaction, higher quality of life and better communication (for example Lea Steadman, Tremont, & Duncan Davis, 2007).

**Relevance of relationships to health and social care**

A number of researchers have suggested that relationships are relevant to care planning in chronic diseases, in that the relational context affects disease management and specific relationships may operate as either protective or risk factors (Fisher, 2000). Perry & O'Connor (2002) regard partners as having a vital role in preserving the personhood of their spouse. Bassett and Graham (2007) argue that memory is not solely an individual phenomenon and highlight social and relational aspects of memory. Braun et al (2009) argue for a dyadic perspective in order to understand caregiving and design appropriate interventions. Similarly, Davies et al (2010) suggest that early therapeutic interventions aiming to modify spousal expectations and amplify substitute affectional activities might enable couples to maintain satisfaction with their relationship, potentially with decrease in carer burden, sustained quality of life, and delayed placement in care. Youell, Callaghan, & Buchanan (2016) make the point that sexual intimacies remain important and need to be accommodated in care provision.

Chesla, Martusan, & Muwases (1994) constructed relationships in dementia as continuous, continuous but transformed, and discontinuous, and suggested ways that health and social care professionals might respect and work with carers in these situations: for example, helping some carers to maintain closeness whilst recognising the changes in their loved one.

Baikie (2002) looked in depth at the impact of dementia on marital relationships including intimate/ sexual aspects. She calls for a shift in how health and social care professionals understand dementia and argues that they should see:

*the relationship primarily as an intimate relationship facing potentially major intrapersonal and interpersonal stresses rather than primarily as a medical disorder with behavioural consequences such as increasing dependency and self-care needs, which require practical support. (Baikie, 2002)*

and that there may be a role for relationship counselling either with the couple or with one partner.

Studying and trying to understand the person with dementia's relationships and the part they (and the dementia) play in the life of the person and those around them is complex. In terms of the practicalities of care planning, services often address the person with dementia in terms of what treatment is appropriate to try to keep them well (including treatment of concurrent physical health conditions, dementia specific treatments, and sometimes treatment of concurrent mental ill-health). In addition, the care plan may address carer issues, eg a carer assessment, what social support is needed. Do care plans address how to support the relationships important to the person with dementia? What difference would it make if they did?

In summary, a person with dementia does not live in isolation. They are embedded in a web of relationships with family and others. Where they have a partner, their partner relationship is likely to be their most important relationship, and their partner may become their carer as the dementia progresses. Carer/ family most often make the decision that a person should move into a care setting, and yet care plans rarely address how the person’s relationships are supported and sustained through the course of a dementia.

**Aim**

Existing literature about relationships and dementia is mainly concerned with the impact of dementia on relationships, and/or on how people cope with the condition, rather than how relationships change as the condition emerges and progresses. The purpose of the study was to explore and understand the changes in family relationships (including partner/ intimate relationships) associated with dementia.

**Method**

The study involved semi-structured interviews with people living with dementia and the family carers of people living with dementia.

**Ethical Considerations:** Approval for the study was obtained from Staffordshire University Research Ethics Committee. Prior to interview, potential participants were briefed that the interview may evoke strong emotions and advised that they could take a break or draw the interview to a close at any time. At the end of the interview, each participant was debriefed and given information about how they could access support, if they later become distressed by issues raised during the interview**.** People who agreed to take part gave written informed consent to meet the researcher and participate in an audiotape-recorded interview.

**Recruitment:** Carers and people living with dementia were recruited through third sector organisations, including dementia cafés: permission to recruit was given by the relevant organisations. The first author attended various dementia cafés and gave a short talk about relationships and dementia; she then distributed written information about the study to those present who expressed an interest, spoke individually with anyone who wished, and answered any questions. Potential participants could give the researcher their contact details at that time or contact her later by telephone. Written consent was taken prior to interview.

**Interviews:** Semi-structured interviews were conducted in the person’s home. The length of the interviews was generally about 1 hour: interviews ranged from 41 to 65 minutes in length. If the participant wished or there was an interruption (eg a phone call) there were breaks partway when recording was paused and pause time is not included in the interview duration.

The interviews covered the following areas:

* what changes have occurred in close relationships since the development of dementia symptoms;
* how has your condition/ your partner-relative’s condition affected your relationship;
* how has your condition/ your partner-relative’s condition affected your intimate (sexual) relationship (if appropriate and applicable);
* what do you think would help with relationship/ sexual issues and
* who should help with these issues?

The interview was free-flowing and flexible with breaks taken as necessary.

Interviews were audiotaped with consent and transcribed verbatim. Transcribed interviews were analysed using thematic analysis as the project aimed to explore commonalities and differences in the interviews in order to identify recurring themes and patterns (Braun & Clarke, 2006). Transcripts were analysed following the process below:

* familiarisation with the data;
* search for themes;
* review and clarification of themes;
* naming and definition of themes;
* synthesis of the overall analysis;
* discussion, refinement, clarification and naming was conducted by the research team in partnership.

A qualitative data analysis computer software package, NVivo11, was used to support the analysis (Bazeley & Jackson, 2013; QSR International, 2016).

**Results**

**Participants:** Thirteen people took part in interviews: nine women and four men. Their ages ranged between 65 and 82 years. One woman was the sister of a person with dementia and the rest were partners (four husbands and eight wives). One couple was included in the study: both had an early dementia and saw themselves as carers for one another. Hence, all the participants were carers and two also had dementia.

Ten people were caring for the person with dementia at home; in two cases the person with dementia was in a Care Home (one having been admitted to Care the week that the interview was conducted) and in one case the person with dementia had died prior to interview. In seven cases the person with dementia had a diagnosis of Alzheimer’s disease; two had a mixed dementia; and the remainder had one each of vascular dementia, fronto-temporal dementia, Parkinson’s disease dementia, and unspecified dementia.

**Thematic analysis**

Four main themes were identified: changes in the couple relationship; changes in specific relationships; talking about oneself in relationship; and talking about people with dementia in relationship. Participants are given pseudonyms in the quotations in order to safeguard confidentiality.

**1. Changes in the couple relationship** – see Figure 1 for illustrative quotations.Participants often talked about the closeness they had experienced as a couple in the past and described feeling lonely: several described a loss of reciprocity in the relationship. Some participants referred with sadness to not being number 1, not having a unique place, in their partner’s life any longer.The change in closeness links with changes in communication between the couple – see Figure 1.Some of the experiences described might be encompassed by “absent presence”, a term used by Youell et al (2016) to describe the person with dementia being present but having changed, not being the person that the carer had loved.

Some participants described powerful emotional reactions to changes in their relationship, and several participants talked about changes in intimacy, and the importance of touch, particularly cuddles and “snuggles”. Some described how they felt the person with dementia gained a feeling of safety from their couple relationship. Most described how their sexual relationship had ceased for physical health reasons e.g. diabetes, stroke, or (as they explained) because of advancing age. Two people described sexual activity between the couple ceasing in relation to changes connected with the dementia: in one the partner’s attention span affected their sexual relationship and in the other it ceased after the partner with dementia fell asleep during sexual activity. One man described how his wife had become less inhibited, more demanding and more adventurous following the onset of a dementia. One woman described her husband with dementia approaching her sexually and said:

*One minute you are dealing with incontinence pads and the next one he wants a cuddle.* (Kath)

She said that she sometimes “indulged” him but that she felt it was inappropriate and tried, if possible, to distract him and avoid sexual contact.

***Second marriages:*** Five spouses were in second marriages and described complications related to this fact. Eva described herself as having "second wife syndrome". When asked what she meant by that, she said:

*what shall I say? It was as if I didn’t exist.* (Eva)

And as her husband's dementia progressed:

*He couldn’t connect with me at all. He connected with his first marriage.*

His children from that first marriage understood this to mean that he really wanted to be with his ex-wife, not Eva, and persuaded their mother (his ex-wife) to start visiting him when he was dying in hospital. This was very distressing for Eva, who, when funeral arrangements were being made, found:

*The undertaker showed me and she had got her name right at the top as if she was his wife... I said ‘do you see that name there, I want that going down there’. I said ‘they have been divorced for twenty five years’. But how she got it to the top of the list I don’t know.*

The inference was that his daughter from his first marriage had put her mother (the ex-wife) at the top of the list.

Family conflicts (and how to deal with them) were an issue in relation to second marriages. There were also practical issues, as described here by Ann (another second wife):

*There are things prior to our marriage, like the other week, we were asked when we went to the [Support Group], we were asked if he had been in the Army, and I said yes. I knew he had been in the Army, but I hadn't really known. But then I found his Army books…* (Ann)

Ann went through her husband’s old papers to find out about his army service because it pre-dated their relationship and she knew very little about it.

**2. Changes in specific relationships** – see Figure 2 for illustrative quotations.Participants talked about not wanting to "burden" their children; not wanting to put responsibility onto them; and not wanting to interfere in their children's lives. Mike’s quotation (Figure 2) describes a change in the reciprocal balance of the relationship with his children.

Despite this some people described a great deal of support from adult children, and others valued being able to phone them up and talk. Where there were tensions in a relationship before the dementia, the problems were often magnified: for example, Diane had not been close to her daughter in the past but felt in need of support from her now that her husband has dementia and said:

*I have tried to get her to come out, to draw it out of her what is wrong with her. And I actually achieved it one time because she is quite hard, my daughter is. She has got a hard personality. My son has as well. I managed to get her to cry and I thought well, if I can get her to cry, that means there is some feelings there, there has got to be. But it has just gone back again to how it was. Like a habit.* (Diane)

*O*ne participant had a surviving parent (her father) and he had to cope with his adult child having a diagnosis of dementia. Gill (who herself has dementia) talked about how difficult her father found this (see Figure 2) and continued to say that her father ignores her when they meet and no longer includes her in conversations, talking to her partner instead.

Some participants described grandchildren as distant, whereas other grandchildren were sources of support, although sometimes the grandparent worried about them taking on responsibility for a grandparent with dementia.

Relationships with neighbours were not prominent and there was sometimes reluctance to involve them. Mike distinguished between neighbours whom he regarded as friends and could approach, and others who were “just neighbours”.However, some established friends can't "cope" with the changes that accompany dementia, and perhaps the friendship was also built on joint activities, which may become difficult (golf and bowls were two that were mentioned). New friends may become more important, often people who have been through similar experiences, see Jack’s comments in Figure 2, talking about meeting regularly with a man who was similarly coping with a wife with dementia. People met new people through attending Alzheimer cafes and found their new friends could be a source of friendship and support.

**3. Talking about oneself in relationship** – see Figure 3 for illustrative quotations. Participants talked about moving from we to I, sometimes with a hint of resentment. Partners with dementia became unable to make the decisions and do the practical things they would have done in the past, shifting the balance in the couple relationship so that their partner had to take over things they would not normally have done. People also came to realise that helping the person with dementia was also about helping the carer. Some difficult issues were raised in relation to new relationships. Barbara's husband (Bill) had gone into care and she still visited him frequently. But she had met up with a male friend from the past, and described feeling "disloyal" in spending time with this friend – see Figure 3. Similarly, Charles had developed a friendship with a female neighbour who was giving him support.

**4. Talking about people with dementia in relationship** – see Figure 4.

The way carers talked about the person with dementia showed a tension between continuity and loss. Some compared people with dementia to children. Distancing from the person with dementia describes how participants talked intermittently about people with dementia as ‘they’.Participants also used a number of different ways to describe confusion and the impact of changes on carers.

***Action suggestions***

Participants suggested actions that might be helpful.These included: phone support; carer groups; cafés (like Alzheimers cafés); books/ leaflets/ information; continued follow up - discharge from clinics doesn’t make sense; opportunities to talk about sensitive topics and experiences, for example:

*sometimes a subject has to be broached doesn’t it, to make it allowable to talk about it...* (Kath)

**Discussion**

In this study, carers were interviewed regardless of the relationship between them and the person with dementia. The focus was on participants’ perceptions of relationship changes broadly and not on specified relationships. This could be viewed as a strength of the study, but also as a limitation. It is important to recognise that it is not only partner relationships that are affected when someone is living with dementia. Partner relationships will almost inevitably be impacted when one partner has a dementia, but changes in other relationships will influence the person with dementia, their partner (if any) and any carers. Although this broad relational perspective is a strength it is also a limitation, because a specific focus on partner relationships could have perhaps led a greater understanding of these changes. Most participants were partners of people with dementia, although our intention had been to look at a range of relationships. Perhaps the focus on ‘relationships’ deterred adult child carers from taking part and future research might consider how best to frame the focus. All our participants were heterosexual: no lesbian or gay couples or couples where one or both partners identified as trans volunteered to take part. In addition all participants were white British. The All Party Parliamentary Group on Dementia reaffirmed in 2013 that dementia does not discriminate nor respect boundaries in relation to the experiences of black, Asian and minority ethnic communities (All-Party Parliamentary Group on Dementia, 2013): this is equally so for the dominant group sampled here. As a result, the findings of this study cannot be generalised to BAME communities; further research would need to explore BAME persons ‘experiences in terms of relationship changes in the context of living with dementia. Whilst our original intention was to include people with early dementia, it proved difficult in practice to recruit people with dementia to take part in the study. The aim of recruiting in community settings was to contact people living with early dementia who had capacity to decide whether to take part. The main obstacle was that carers were reluctant for the person with dementia to take part, expressing concern that it might distress them, and several carers expressed the view that the decision about whether a relative with dementia should take part was for them to make as carer.

Although the literature concentrates on partner/ spousal and adult child-parent relationships, participants described dementia as transforming people’s relationships and having both positive and negative impacts. Our construction of dementia as ‘illness’ leads to a focus on diagnosis and treatment. Where there is an ill person, there is likely to be a carer and when the carer is the person’s partner this change in identity, role and responsibility eclipses consideration of either partner as a sexual being. Dementia as illness offers a scientific lens and knowledge, but at the same time complicates the mutuality and reciprocity of emotional communication needed to maintain intimate and other relationships. It also narrows the focus of treatment and care to that of illness management. Perhaps the language of illness and suffering could be changed to that of transformation in identity, personality, communication, relationships, intimacy, resilience and quality of life in living with dementia. People’s lived experiences provides knowledge of a different kind and argues the need for a shift in perception, attitude and approach as a recognition and response to the transforming effect of dementia on interpersonal relationships and sexual health. This might open up the possibilities in terms of non-medical interventions.

Our participants spoke frankly about the relationship changes they were experiencing across a range of relationships, and described changes in their relationships with adult children, grand-children, parents, friends and neighbours. Parents who have an adult child living with dementia may find that fact difficult, as it reverses what might be the family’s expectation, and this is a potential area for future research. Participants talked about the impact of one family member’s dementia condition on a range of other family members. Offering dementia education or family meetings to family members and not just the main carer might be helpful and is an area for further research.

Partners shared changes in intimacy, closeness and sexual aspects of relationships. Several indicated that they had not had the opportunity to talk about these aspects before and felt alone in coping with the changes, despite the fact that participants were recruited from dementia cafés which offered a range of supports. This suggests that some carers (and probably people with dementia too) are reluctant to share some of the relational changes they are experiencing, leaving them feeling unsupported in coping with them. It may be that relational changes are harder to raise in big groups, that people feel ‘disloyal’ in raising them, or that they need to be given ‘permission’ to raise them, as Kath suggests in her quotation above: for example, café talks could be dedicated to a relevant topic as a way of opening relational aspects for discussion. Some aspects of relational change, for example changes in intimacy and sexual relationships, may be better addressed with the carer individually or with the couple rather than in a large group.

Second marriages raised a number of issues. Healthcare, social care and third sector staff supporting couples in a second marriage where one partner is living with a dementia need to be sensitive to the practical issues and potential for family conflict. It may be useful in these circumstances to consider offering family meetings or family counselling.

Figure 1 draws on the work of Ablitt et al (2009) and Hellstrom et al (2007) and represents possible sites for intervention in order to support partner relationships and maintain relationship quality. Relationship history, prior relationship quality and family context are influences on the current partner relationship. When dementia develops and is diagnosed the partners may endeavour to maintain their relationship quality, for example by continuing exchanges of affection, and this contributes to maintaining well-being of both partners. Other couples may experience negative changes, including increasing distance, reduced communication, and lack of closeness and affection. These contribute to a reduction in well-being in one or both partners. Two stages are highlighted in the figure for possible intervention. After a diagnosis of dementia is made early intervention could aim to maintain relationship quality and prevent negative relational changes. Alternatively when a couple starts to experience negative changes psycho-educational intervention at that stage could aim to improve and maintain relationship quality.

Further research is needed into ways to support relationships. Interventions might operate at a number of levels. Opening up discussion about relationship changes would help people to recognise that they are not alone in experiencing these changes. Services involved in supporting people with dementia and their carers would be in a position to do this. Linked with this could be relationship education and education about dementia looking at changes that might be expected and ways of dealing with them. For those people who are becoming distressed by relational changes, it might be possible to use a counselling approach to support and maintain the partner relationship by looking at ways of keeping connected, continuing to communicate, and continuing to show affection. In the early stages of dementia working with a couple might offer an opportunity to work with the couple’s expectations of one another whilst living with dementia and their hopes for the relationship as dementia progresses. In later stages strengthening family and/or friend relationships might offer a way to support the carer-partner as reciprocity in the partner relationship is challenged.

**Conclusion**

There is strong evidence from participants’ lived experiences that on-going support is essential because of the progressive loss of aspects of relationships as dementia progresses. Counselling has a vital role to play and should be considered in care planning. It would potentially benefit the person with dementia, their carer and other family members.

Education based counselling could provide an opportunity to:

* Talk and ask questions on sensitive issues related to intimate relationships
* Consider the dilemmas and boundaries of managing intimacy in living with dementia
* Explore beliefs around sexuality and illness
* Adapt to changing roles, identity and personality
* Adapt to changes in emotional communication, connectedness and intimacy
* Become aware of shifting power dynamics and responses to them (gender and culture are important here)
* Consider issues of loneliness, guilt and sadness
* Provide practical information and signposting

In a digital age carers could be offered the opportunity to access therapeutic support online, in particular someone to listen and to talk with.

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Both Prof Susan M Benbow and Victoria Sharman are independent systemic therapists.

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