

## ORIGINAL ARTICLE

# Sustaining relational subjectivity: The experience of women with dementia

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## Abstract

The experience of dementia can only be understood adequately if the influence of gender is fully recognised. Research accounts have, however, tended to portray dementia in gender-neutral terms. This qualitative research study aims to redress this imbalance by investigating the gendered experience of women with dementia. The research addressed women's negotiation of relationships with spousal partners, other family members, professionals, support groups and services. The study included 10 mixed-sex spousal couples in which the woman had been diagnosed with dementia. Women took part in semi-structured joint interviews alongside their partners. This research focuses on the responses provided by the women with dementia within these interviews. Four principal themes were identified within the data: upholding gendered subjectivities; the broader relational context; closer networks; and gendered care relationships. These themes elucidate the challenges women face in sustaining relational subjectivity via the spousal relationship and wider social associations while also dealing with the cognitive impacts of dementia. The article concludes by highlighting that a more nuanced social scientific perspective on dementia is required that acknowledges the complexity of gendered experience. This can assist policymakers and

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practitioners to tailor support to meet the requirements of women with dementia.

#### KEYWORDS

couplehood, dementia, gender, relational sociology, relationships

## INTRODUCTION

Dementia presents one of the most pressing issues in contemporary health and social care. In the United Kingdom, it is estimated that 900,000 people have dementia, and this figure is projected to increase substantially over the forthcoming decades (Wittenberg et al., 2019). While dementia presents a significant societal and economic challenge in terms of the provision of services and support, it also presents significant challenges to those experiencing the condition first-hand. People living with dementia and their family members encounter multiple practical and emotional difficulties associated with a neurodegenerative condition that affects memory, communication and behaviour (Hughes, 2014). Social scientific research and theorising have helped demonstrate that the person with dementia should not be defined by the neurodegenerative basis of the condition. Rather, both the experience of the person in question and the consequences for their surroundings are inherently and essentially relational. Concepts such as personhood (Kitwood, 1997) and couplehood (Hellström et al., 2005) highlight how people with dementia can be supported by recognising the relational and social dimensions of experience. Moreover, concepts such as couplehood acknowledge the significance of close relations for an understanding of the experience itself. Dementia as a condition can threaten a person's sense of their own relational competence, that is, the ability to maintain positive, close relationships (see L'Abate et al., 2010), and disrupt the foundations of the couple.

However, this relational and social understanding of the experience of dementia must be attuned to the circumstances of the relational composition. This relates to the concept of social location (Fletcher, 2021; Hulko, 2009), which highlights how personal characteristics (and associated sociocultural definitions of these characteristics) shape the experience of dementia and care. An example of such a characteristic is gender: personhood cannot be adequately understood without addressing the person's gender. 'Gender, the complex of social relations and practices attached to biological sex, is one of the most important sociocultural factors influencing health and health-related behaviour' (Evans et al., 2011, p. 7). However, it is an underexplored factor within dementia research (Bamford & Walker, 2012; Erol et al., 2015; Sandberg, 2019).

Within academic research, public discourse and national strategies, people with dementia are usually presented in gender-neutral terms (Bartlett et al., 2018). Due to this gender-neutral approach, there is a tendency in qualitative dementia research to recruit a mixed-sex group of participants. Findings are then presented in a manner that elides any differences in perspective between men and women. This therefore compounds a gender-neutral portrayal of people with dementia and limits the scope to evaluate the relational and social basis of experience. The ungendering of people with dementia is part of a process 'by which established identities are often rendered invisible and a dementia identity is imposed' (Boyle, 2017, p. 1792). It is also argued that this gender-neutral orientation has implications for the representation of women, even though women experience more direct impacts of dementia as both people with the condition and also as carers. Dementia 'disproportionately affects women but the experiences and voices of women are missing from the research and literature' (Savitch et al., 2015, p. 1).

A very limited number of studies directly address the impact of gendered experience in relation to women with dementia. Some accounts address the experience of women with reference to specific interventions or topics. For example, in a qualitative interview study, Borley and Hardy (2016) address the experiences of eight women in relation to assistance with activities of daily living, such as shopping and cooking. They found that the women's experience of being cared for affected their own perspective on their gendered selves. A decreasing ability to undertake domestic tasks could negatively impact self-identity, as women might feel these are responsibilities aligned with social standards of female competence. Buse and Twigg (2014) focus in particular upon the significance of handbags upon the identity of women with dementia. They found that material objects can adopt biographical or memory-supporting functions: handbags helped women 'tell their lives' and helped them remain connected to personal memories and histories.

Van Dijkhuizen et al. (2006) undertook a qualitative study in which nine women with early-stage dementia were interviewed. Social connectedness was a key element of experience for women with dementia. The challenges of the condition, including an impact on memory, presented a threat to their sense of connectedness with family and friends, as well as their engagement with wider social roles and their surroundings. A positive sense of self is intrinsically linked to the readiness of others to facilitate and support this sense of connectedness. In a further qualitative study, Scott (2021) found that women would modify their behaviour in the endeavour to address a loss of self-esteem and self-confidence. In their secondary analysis of qualitative and quantitative studies, Bamford and Walker (2012) address the impact of gender upon women with dementia. They found that women with dementia face 'triple jeopardy' because of their association with stigma related to gender, age and declining cognitive function. It is argued that further research must disaggregate the variable effects of gender more effectively.

As this brief overview indicates, the experience of dementia is shaped by both concrete close relations and gendered subjectivities. In an ethnographic study on the topic, Boyle (2017) found that women (and men) define themselves according to their gendered social identities. Relationships were central to women's identity and sometimes marital harmony was prioritised over their own wellbeing. Gender and relationality thereby interrelate in at least two distinct ways: on the one hand, understandings of the relational experience of dementia can only be partial and inchoate if the influence of gender is overlooked, and, on the other hand, gendered subjectivities need to be understood within relational practices and structures.

It is a challenge to identify particular experiences that apply to women, as there will of course be experiential overlap between women and men. Recognition of gendered experience does not imply an essentialism whereby an illegitimate unity is ascribed to a group of people (Sibeon, 2004). There is a substantial diversity of experience for women with dementia, and this includes how other features of social location, such as age, sexuality and ethnicity, influence personal circumstances. However, if we recognise that practices and subjectivities within (heterosexual) couples are strongly influenced by gendered assumptions and enactment (Hank & Jürges, 2007), a focus on the gendered experience of couplehood seems crucial for an understanding of the experience of dementia. To support people with dementia effectively, it requires acknowledgement of the fact that personal experience and care relationships are gendered phenomena (Weicht, 2015).

Accordingly, this research aimed to evaluate the relational experience of dementia for women with the condition, addressing the negotiation of their relationships with spousal partners, other family members, professionals, support groups and services. The analytical process sought to elucidate the challenges women face in sustaining relational subjectivity via spousal relationships and wider social associations, while also dealing with the cognitive impacts of dementia.

The resources of relational sociology (Crossley, 2011; Donati & Archer, 2015) are drawn upon to guide this evaluation. This theoretical approach focuses on the reflexive orientation of subjects towards the relational products that they themselves generate. It therefore captures the intrinsically relational basis of subjectivity whilst also recognising the role the person plays in shaping their relationships and social contexts.

## METHODS

### Recruitment and sample

This qualitative research study included 10 mixed-sex spousal couples where the woman had been diagnosed with dementia. Nine couples were recruited from two different dementia support groups in the Midlands of the UK, and one was recruited via a church organisation. Invitation letters and information sheets were shared by managers within these organisations with couples who met the recruitment criteria. The couples were then able to contact the researcher to set up an informal meeting to discuss the research. If both members of the couple were happy to proceed, an interview was arranged.

Table 1 shows the characteristics of the women with dementia who participated. All women had mild or moderate levels of dementia at the point of the (first) interview. There was no exclusion criterion with regard to the type of dementia: eight participants had Alzheimer's; one participant had vascular dementia; and one had frontotemporal dementia. The age range of the participants spanned from 61 to 78. All participants were white-British. All participants had retired from employment, their principal occupation is noted in Table 1. The timescale following diagnosis varied considerably across the participants. It must be recognised that the temporal proximity to diagnosis is a factor that is likely to shape experience. The interviewer noted the apparent level of understanding demonstrated by each participant, and their scope to engage with the interview process. This subjective judgement informs the classification of the severity of the condition stated in the table. Age is a further factor that is likely to influence the experience of dementia, and it should be noted that the age range of participants is broad. The influence of factors such as age and proximity to diagnosis will be highly complex and will not have a simple or linear effect; for example, the challenges of the condition do not simply increase or decrease

TABLE 1 Participant characteristics (at date of first interview)

	Name	Age	Type of dementia	Severity	Time since diagnosis	Occupation
1.	Natasha	76	Alzheimer's	Mild	2 years	Care work
2.	Kay	78	Vascular	Moderate	1 year	Clerical
3.	Fiona	69	Frontotemporal	Mild	2 years	Care work
4.	Della	62	Alzheimer's	Mild	4 years	Retail
5.	Emma	69	Alzheimer's	Mild	9 years	Catering
6.	Louise	78	Alzheimer's	Mild	7 months	Retail
7.	Liz	72	Alzheimer's	Mild	1 month	Clerical
8.	Jackie	61	Alzheimer's	Mild	3 years	Care work
9.	Kath	73	Alzheimer's	Moderate	3 months	Teacher
10.	Colette	67	Alzheimer's	Moderate	4 years	Retail

with age (Tolhurst, 2016). The key point to note is that experience is composed of many interrelated elements, and that this complexity must be acknowledged when evaluating the influence of gender.

## Data collection

Women took part in semi-structured joint interviews alongside their partners. Couples were interviewed on two occasions (by a male interviewer), with a 6-month gap between interviews. This two-stage process was adopted to obtain extensive and in-depth accounts from participants of their experience with the condition. Interviews took place in participants' homes, apart from one interview for the second phase of data collection that took place in a care home. One couple did not participate in the second interview for health reasons. A total of 19 interviews were therefore undertaken. Interviews had a mean duration of 67 min.

The interviews followed a flexible schedule, in line with the research aim, which allowed respondents to raise matters important to them. Topics addressed included negotiating the spousal relationship; sustaining relationships with other family members and friends; and engaging with professional services and support groups. The interviewer actively sought the engagement of both participants within the conversational process. Written informed consent was obtained from participants by the interviewer just prior to the commencement of every interview. In terms of the ethical conduct of the research, the interviewer was mindful that all interviewees should feel comfortable with the interview process. It was highlighted to interviewees that they could take a break from interviews if required. If any interviewee had exhibited distress, then the interview would have been terminated. Ethical clearance for the research was obtained from Staffordshire University Research Ethics Committee.

Interviews were undertaken with couples rather than the women alone, as the emphasis of this research was on the relational experience of dementia for women with the condition, addressing, in part, the negotiation of the relationships with their spouse. Moreover, the condition's impact on the women's relational competence also shapes the narrations during the interviews. As highlighted by Pesonen et al. (2011), interviewing people with dementia alongside their partners can cultivate a sense of security within a mutually supportive setting in which the two interviewees are able to support each other. This provides a relational context that can assist in the elucidation of expansive shared experiential accounts. Whilst there is scope for conflict between two participants during joint interviews (Voltelen et al., 2018), there are also ethical challenges with undertaking individual interviews in family homes. Disclosing sensitive matters to an interviewer while the other person is elsewhere in the house could be difficult for respondents and could even generate unrest within the relationship (Morris, 2001).

The joint interview approach allows access to the perspectives of two participants and how these are co-constructed. They can also be valuably employed to focus on one set of perspectives (see Tolhurst & Weicht, 2017). Disaggregating the views of women with dementia from the joint interview enables an in-depth evaluation of the factors shaping their relational subjectivity. This does not understate the value of the perspectives of the man or the importance of directly scrutinising dyadic conversational dynamics; it is a limitation of the article that these are not addressed. What is being asserted is the value of an undiluted focus on the perspectives of the women with dementia expressed within the interviews while acknowledging the context in which these views were expressed.

It must be recognised that the relational setting (comprising the spousal partner and male interviewer) will inevitably shape the nature of these personal accounts. While this recognition

is crucial, obtaining views within a joint interview setting is particularly valuable and can add to the authenticity of expressed perspectives (Molyneux et al., 2012). There is no such thing as an account that is free from relational and contextual influences and pressures; the contextual influences within a joint interview reflect the social and relational circumstances of women with dementia (in a spousal relationship), as many situations they negotiate will be undertaken alongside their partner. For example, many interactions with professionals will be undertaken on a triadic basis (Quinn et al., 2013), with both partners and the professional being present.

## Data analysis

Thematic analysis enabled the key themes from interviews to be established, recognising patterns of narrative content and the salience of experiential topics for participants (Braun & Clarke, 2006). The first stage of the analytic process required listening to recordings of the interviews and reading and re-reading the transcripts. While this article focuses on the experiences of women with dementia, due to the conversational exchanges and co-construction during the interviews, women's experiences were entangled with those of their spouses. The next phase of the analytical process was therefore to demarcate the personal accounts of the women with dementia within the transcripts. A process of initial coding was then undertaken, whereby notes and labels were applied to the text. Labels with an underlying commonality were next organised to generate key categories. These principal categories were then evaluated and arranged into themes that provide an account of the key experiential dimensions expressed by the women with dementia. To ensure a credible process of analysis was undertaken, transcripts were reviewed by two researchers independently. The key themes were then discussed and agreed upon.

## FINDINGS

The findings below present the four key themes and their dimensions. The presentation follows different aspects of the construction of intersubjectivities and their gendered notions: upholding gendered subjectivities; the broader relational context; closer networks; and gendered care relationships. As shown in the data, the significance of gendered subjectivities relates to the importance of caring histories within relationships.

### Upholding gendered subjectivities

Women with dementia conveyed different personal strategies for dealing with the impact of the condition. One strategy that was drawn upon was a stoical acceptance of circumstances:

“But I aren't moaning,” I said, “I've got my yearly [driving] licence,” I said, “I'm quite happy,” I said, “I'm doing what I want to do and making the most of it.” And I just think, “Well, the house can fall down, I'm just all right.”

(Fiona)

While stoicism is stereotypically aligned with a masculine response to challenges (Moore et al., 2013), Fiona demonstrates that women also utilise this strategy. For example, Fiona highlights that she is making the most of her situation, and this could represent the intention to resist cultural constructions that could position her in a passive victim role (MacRae, 2008). The reference to the retention of her driving licence shows how she is able to sustain her previous activities.



In the excerpt below, Emma asserts the importance of meaningful activity (see also Bielsten et al., 2018) and feels pleased that she is able to continue undertaking strenuous tasks. Her perspective also underscores the requirement to recognise how selfhood relates to physical attributes, activity and embodiment (Kontos et al., 2017):

And I can always find things to do, you know, I mean this last year I've done quite a lot in the garden and I've, I've done a man's job really, doing quite heavy things, so I was quite pleased really that I could do them.

(Emma)

References to doing 'a man's job' indicate that she feels she is exceeding what might have been expected for a woman with dementia regarding physical tasks. To some extent, Emma's narrative strategy might be resisting the 'triple jeopardy' of age, gender and decline discussed by Bamford and Walker (2012).

Clare and Shakespeare (2004) highlight that different modes of resistance might be drawn upon. For example, *psychological* resistance refers to an endeavour to defy the cognitive impacts and manifestations of the condition by appealing to continuity and enduring abilities. A *political* resistance, on the other hand, is predicated on the person seeking to talk openly and candidly about the challenges they are experiencing. In the previous excerpts, the perspectives being offered align with a psychological resistance to the condition. However, in the excerpt below, whilst Natasha also refers to the importance of activity as a means of dealing with her situation, she offers a less positive assertion than those provided by Fiona and Emma. Natasha describes the effort that she puts into the task of knitting, but also refers to the challenges she experiences doing this. There is the sense that this immersion in this endeavour is employed to distract her from the emotional challenges of her situation. It therefore seems as though she is navigating both psychological and political strategies of resistance to the condition in this instance:

I try to keep myself occupied. I get up, I'm knitting like fury and doing this, that and everything else, to sort of take it off my - I'm knitting like fury, [laughs], but as well, I can't concentrate long enough to do it, and I think I've done it wrong as well, pull it all undone again. But I'm going to keep, I keep - I don't stop. I can't.

(Natasha)

Undoubtedly, individual resistance strategies have important consequences for women's experiences of the condition. However, gendered experiences cannot be reduced to individual, psychological strategies and behaviours. Rather, they are inherently based within structures and networks of close and wider relations.

Building on the platform of this first theme, the subsequent themes explore the structures and networks of close and wider relations, starting from the broader relational contexts and moving towards the closest relationship, the couple. The emphasis is on different levels of relationality, which demonstrate the significance of gendered practices and assumptions.

## The broader relational context

The interview data shows the significance of broader relational situations beyond the spousal dyad. This includes links to support groups and health-care professionals, as well as more informal friendship-based associations. As most participants were recruited via support groups for

individuals with dementia and their family members, responses to these settings were likely features of the interview discussions. Colette discusses the value of social contact afforded by the support group setting. Although her partner is available, she appreciates meeting other people and sharing experiences:

It's just meeting people and talking to people. Not that I'm in here all the time on my own, I know Roger is here but it's nice to get out and I like the company, it'd be nice to meet some more people and share with them what I do, I don't want anything they can have, it's just companionship, more than anything.

(Colette)

The perspective of Liz reinforces this view. The interview excerpt below shows how social contact helps to provide support that can mitigate personal fears and worries about the potential impacts of the dementia. Sustaining supportive relational networks can act as a protective factor against the effects of dementia, both socially and functionally (Sabat & Lee, 2012):

Because it was very frightening, I mean I knew what it was all about because of my mother erm and the thought of ending up like my mum was just absolutely terrifying. But, you know, with going to [support group] it really has been a big help really and obviously it's given me all this support.

(Liz)

The format of support group delivery is important to Fiona. She highlights how she appreciates the upbeat nature of the support group events that she attends. This shows that it is not simply about being provided a social space, but how a positive relational experience can be facilitated by a support group. Also important to Fiona is that she has the scope to attend groups of her own volition, without depending on others. This relates to her point stated in the first theme, where she discusses the importance of still having her driving licence. This again demonstrates that women with dementia might seek activities and social engagements separately from their spouse and immediate family members. As will be shown below, closer relationships are strongly based on long-term, continuously developing (gendered) structures and practices. Social engagements specifically for women with dementia can provide valuable spaces away from (care) structures and practices within family settings and foster a sense of independence within a supported environment:

What I like about it is it's all very upbeat, and it's all very nice when you walk in. And, like, it's not like being in a church hall and being, you know, I don't know, it's all just nice. And they do, like, everything with the food, the entertainment and just going round all the time and making sure you're all right, and all stuff like that. And I think that's really lovely. So it is, it is nice. And you're getting entertainment all the time. As long as I'm able to get out and about and go to wherever I want to go, and have independence, I'm fine. I dread being stuck at home, and asking for lifts here, there and everywhere is going to be a nightmare.

(Fiona)

In contrast to Fiona's positive account, Jackie adopts a more negative tone when discussing attendance at support groups. She finds the experience dehumanising and infantilizing as a



consequence of the nature of the social interactions in these settings and asserts that the groups are configured to support family members rather than the person with dementia, with the latter's identity often just being defined by the condition:

What I'm trying to get over is it's the person with the Alzheimer's or dementia, or whatever it is, that is the patient or the client or whatever else, and more should be done to listen to them instead of their partners. It's like that [support group], which again are fantastic in the cafes that help Liam, I can't go there because I feel like strangling everybody because they either treat the people with Alzheimer's as if they're not there or as if you know [*adopts patronising tone*] "would you like a cup of tea?" and you know I feel like strangling them. You're still a human being, you're still a person inside and whatever.

(Jackie)

Women might feel the impacts of infantilisation acutely due to prior experience and exposure to language and attitudes that position women as subordinate. For example, it has been highlighted that women are more prone to 'benevolent sexism' and being treated in a paternalistic manner in medical settings (Chrisler et al., 2016).

Moreover, being labelled by the condition cannot be reduced to an individual phenomenon. Rather, as the following example demonstrates, people are considered part of a group with shared struggles and losses. Natasha highlights the challenges of engaging with support groups, to which she is not sure if she wishes to return. Attending the group is negatively affecting her sense of self, and she wishes to avoid being labelled. It seems that concerns over her own personal performance are impacting her willingness to engage with this particular mode of social connectivity (Van Dijkhuizen et al., 2006). Natasha also finds being presented with manifestations of dementia in other people very difficult. Whilst support groups intend to generate a shared experience, Natasha's account shows that they can instead diminish a positive sense of relational subjectivity by reinforcing negative associations and experiences. A simple model cannot be conceived whereby an increase in social connections is positively associated with robust relational subjectivity:

I don't want to be sort of labelled like that, I don't want to be, I don't want to keep - I don't want to go to somewhere that's got something like I've got and I don't want, you know, sort of it's going to happen, sort of in the future. And when it started to go, I know myself, I stutter with my words a lot now, and that worries me, so when I try to say something, then I can't get it out. And I don't like that. But it's going to happen, and that's that, but I don't want to be, I couldn't be like they are, I don't want to do, I don't. That's probably why I don't want to go, yeah. I'm sure they'd help you, but I'm not altogether certain.

(Natasha)

The importance of social contact was also raised in relation to health-care professionals. Women with dementia noted that a valued aspect of engagement with health-care professionals was the social contact that this has the potential to provide. However, Fiona describes the lack of direct interaction she has had with health services, which results in her feeling detached from the service and generates challenges when she contacts them. Fiona also refers to health professionals being

uninterested in knowing her, which underscores the importance of contact having a meaningful social dimension:

I'd like to be telling you that somebody has been out talking, and knowing more about what is going to happen, if there is going to be any changes or if I just carry on plodding as I am, which I think is how it's going to be, anyway, but you know, sometimes you just think, well it's like when that form comes, and I think, "oh, I'm phoning up for a Consultant", they've given me a name, who the hell is it? I think I don't know them, and I'm sure they're not interested in knowing me, or they would have phoned me, wouldn't they?

(Fiona)

Social connections could also be sought through professional services if informal networks have diminished. In the excerpt below, Kay talks about how she would be happy to attend a respite care setting as long as people were awake and engaging with her socially (she referred to attending a facility previously where other attendees spent most of the time asleep). This could be of value as she feels her informal social contacts have diminished:

I'll be quite happy to go and see somebody, as long as they were awake and talking to me. It's talking to me that I want. Because none of my friends ever comes to talk to me anymore.

(Kay)

Evaluation of how broader social settings are negotiated by women with dementia highlights the complex factors that shape relational subjectivity. Meaningful social contacts are very valuable, but challenges inhere within each milieu where these can be obtained and sustained. Support groups, for example, offer an excellent opportunity to engage with other people sharing similar experiences. Nevertheless, it has been shown how this format contains an intrinsic challenge to some women with dementia, as they are exposed to manifestations of the future impacts of the condition. Intersections between the condition, interpersonal relationships and broader social settings also raise difficulties. This underscores that it is the nature and quality of social contacts that are valuable, rather than simply the number of connections. The following sections (on closer networks and care relations) will further underscore this point.

## **Closer networks: Friendships and couplehood**

Sustaining friendships can raise particular challenges following the onset of dementia. Natasha discusses a friend who doesn't grasp the impact of the dementia. It seems that this friend does not take into account the fact that she might now need to adjust her communication approach.

I've got a friend who is, she's been my friend for donkey's years, but she sometimes winds me up because she doesn't understand at all. She keeps on and on and on. And when she's talking she's saying, she's talking, "so and so and so as you know". I said "No, I don't know, I don't know, I don't know," you know, I'm sort of like. She doesn't, she doesn't get it.

(Natasha)

It has been highlighted that the impacts of dementia upon communication and behaviour can take their toll on friendships (Harris, 2012). Natasha alludes to being bombarded with information by her friend, who assumes Natasha can recall particular events. Her friend seemingly struggles to grasp that Natasha finds it difficult to retain the same shared memories. Again, this shows that it is not just about social connections, but the quality of interpersonal relations. Being presented with challenging interactional encounters has the potential to frustrate Natasha and diminish her positive sense of relational subjectivity. The value of positive friendships is highlighted by Emma:

What do they say, what are friends for? You always seem to know them when you're in trouble and they can come to the rescue and that's how you know really what true friends are, because we have got quite a few good friends.

(Emma)

Looking closer at women's relational structures, we can observe similar tensions within couplehood. Not only can the partners provide help or support, they can also cause annoyance and frustration. Natasha, referring to her knitting work, talks about her partner's reactions:

And you keep saying to me "put it away, don't, don't", but I can't. But I've got to, I've got to. I mean it's like this. I'm sitting on it now, it's all, but I think, uh, and then I thought, oh, flippin eck I've done it wrong but I just, I'm quite patient with it. I think that, sometimes irritates you because sometimes you tell me off.

(Natasha)

The quote shows how her partner, in a well-meaning endeavour to help, seeks to prevent her from engaging in this activity, but she feels compelled to continue. She also refers to her partner becoming irritated and admonishing her; however, the impact on the woman's experience should not be reduced to the behaviour of the partner. Rather, experiences within the couple interrelate:

I mean I think things are all right, I mean we have days where I'm a bit you know sort of, blank and you know if he's feeling calm then there's no problem at all but of course, as you do, you know if things are a bit stressed or whatever you know then obviously you know [laughter] but on the whole yes. I mean he'll tell you better what he thinks about, well he can say how I am because he's the one I drive mad [laughter] but you know, on the whole I think, I feel okay.

(Liz)

When Liz has days when she is not functioning well, it appears this is manageable when her partner is also in an emotionally robust position. Although she does not provide details, Liz also suggests that the interpersonal situation can also become challenging. It is important to note that engagement with the spousal dyad also provides a foundation for engaging with other people. Below, Jackie discusses the challenge of sharing experiences with other people when her recollections diverge from those of partner. It appears that there is a tendency for others to favour the perspective offered by her partner, as it is assumed the dementia means her memory is less reliable. Recollections and reminiscences being necessary for sustaining a sense of self is undergirded by a historical reconstruction of events in which the person has been involved (Crossley, 2011). This also shows that narrative is a key element of relational subjectivity and that sustaining a

preferred narrative can be challenging when one's preferred account diverges from that of a partner (Tolhurst et al., 2017). It could therefore present significant challenges if one's own version of events is automatically subordinated to another person's. Jackie is also keen, however, not to dismiss her partner's own perception of events:

No disrespect to Liam but you know sometimes when he's talking about different things that've happened it's like everybody experiences it differently and what he says isn't how I remember it sort of thing. But then they say "you've got Alzheimer's, so". So it's a vicious circle sort of thing and I'm not saying Liam wasn't right, that is how he felt he experienced it and everything, but...

(Jackie)

While certain situations might lead the woman with dementia to seek to manage separately from her partner, there are also acknowledgements of how support is valuable. Emma queries whether she would be able to manage in an unfamiliar place without the presence of her partner:

Sometimes I can't understand, I can't understand myself. If I'm in a different place, I can't get used to it. I mean Nick's with me so that's fine, but if I was on my own, whether I would cope I don't know.

(Emma)

Emma, alluding to them functioning well as a couple, emphasises the importance of the different strata of subjectivities. While on her own she feels uneasy, as a couple, coping and functioning are more secure. Kath also discusses the support offered by the spousal relationship:

I mean like Giles and I, we're, we're healthy aren't we, we get about? But you don't know what would happen to you if, you know. It's all right thinking "oh well I've got, we've got all these children", they're not really children are they? But they've got their own life to lead. Like Giles says, they don't live near us.

(Kath)

Interestingly, Kath referring to 'like Giles says' indicates the co-constructed narrative of the couple. The couple's situation is framed by its association with other family relationships, and in this instance the spousal relationship is key, as their adult-age children are not readily available to offer support (see also Vreugdenhil, 2014). There could also be pressure placed on women with dementia if they feel they are negatively affecting their children. This could intersect with cultural discourses on nurturing and maternal values, which shape feminine subjectivity as well as perceived standards of moral worthiness (Paoletti, 2002). The reference to good health by Kath also indicates a concern for mutual support being contingent upon enduring wellbeing. The differentiation between the couple and the wider family structures can also be seen in Della's account:

Yeah [laughter] he's the only one I do laugh about it with, I wouldn't like anybody else laugh at me, like my daughter or something.

(Della)

Della highlights how she feels able to laugh about the impact of the condition with her partner. Sharing a humorous vantage point offers a good source of support and shows a joint

relational approach to dealing with the situation. The fact that this joint strategy is exclusive to the spousal relationship shows the importance and distinctiveness of the spousal relationship.

Exploration of the navigation of spousal interdependence demonstrates the complex relational underpinnings of the experience of dementia for women with the condition. The spousal relationship offers an excellent source of support but can also present challenges. It must be recognised, of course, that the challenges of navigating spousal relationships are not exclusive to couples where a person has dementia. Nevertheless, the impacts of dementia do intersect with the negotiation of relationships. For example, women have concerns that the impacts of dementia could create challenges with their reduced cognitive functioning or changes to behaviours that present difficulties to their partners. In addition, women might also seek to address some aspects of their dementia-related experiences separately from their partners. This approach can be a personal preference but is also undertaken to shield their spouse and other family members from difficulties. Taking on roles of protecting and/or guarding others, or practices of caring for others within family settings, must furthermore be understood as highly gendered activities (Fletcher, 2021). And this leads to the final relational context in which gendered patterns of care shape couplehood structures and practices.

## Gendered care relationships

Couples and intimate relationships are marked by histories of care patterns and roles. Caring roles usually result from ‘continuous interpersonal negotiations, saturated by social values, through which rationales are retrospectively aggregated to justify unequal trajectories’ (Fletcher, 2021, p. 78). Both social values and interpersonal negotiations continuously shape practices and role distribution within the spousal setting. This role distribution is not immediately overruled by the diagnosis of dementia, rather the experience of the condition is shaped by the established care patterns:

It’s getting not critical but it’s getting to be a bit of an upset to us because like Liam’s got his own health problems and this has always been my concern about somebody caring for me you know, it’s such a big thing but it isn’t you know, well it’s hard to explain. It isn’t about me it’s about people looking after me and I don’t want that to happen and this is why, you know, I’m so strict about wanting some control of my life, as I progress sort of thing.

(Jackie)

Jackie’s partner’s health problems compound her concerns. She is therefore resisting the condition to mitigate the burden placed on others. This shows how resistance to the condition is framed by both relational considerations and her status as an active subject seeking to maintain control. Established gendered patterns of care and control shape Jackie’s response and it could be the case that she feels cultural expectations, which position women as ‘natural’ carers (see Ungerson, 2000), are being subverted. These elements are taken further when she states her support for euthanasia. Here, she continues to assert her requirement for personal control over her circumstances, while also minimising the difficulties the progression of the condition could impose upon others:

I think the right to be able to, what’s it called, to die sort of thing, what’s it called? [...] euthanasia, I think it should be brought in because like as I progress, I don’t want to be a burden to people.

(Jackie)

Not wanting to be a burden on others, that is, not wanting to be the one receiving care within the relationship, is a common feature of the interviews. On occasions, candid concerns for the impact of the condition were stated by interviewees. Natasha discusses her intense fears for what the future holds. This relates to uncertainty and a lack of control. Reference to *letting herself down* also seems to relate to concerns over a possible failure to maintain expected standards of conduct. At the end of this excerpt, Natasha apologises for becoming overly emotional:

If I'm honest, I'm absolutely petrified of what the future holds, if I let myself down. Just knowing what's going to happen. And that it's going to happen, and there's nothing I can do about it, it still upsets me, really, sorry.

(Natasha)

At another point in the interview, Natasha reflects on the emotional impacts of dementia but then asserts that this reaction is not acceptable:

I do feel, I mean I do feel sorry for myself at times; I do. But then that's selfish isn't it, you know.

(Natasha)

Not wanting to be a burden, not wanting to seem upset, and not wanting to appear selfish all reflect the gendered trope of unequal distribution of caring roles within (heterosexual) relationships (Swinkels et al., 2019). A feature of navigating spousal interdependence also relates to undertaking some key activities apart from the partner. In the excerpt below, Fiona discusses how she obtained the diagnosis of dementia on her own and had not discussed the appointment in advance with her partner:

So, he went off and I went off. And that's how I did it. But, I thought that if it came back fine then you don't have to know anything. But I knew it wouldn't, but I just thought that I can deal better with it myself. I know I can deal better with it myself, you see, because Geoff isn't very good at, er, dealing with things.

(Fiona)

Fiona felt able to deal with this process better on her own and also asserts that her partner would not be well equipped to negotiate this situation. Acting separately therefore requires justification which here falls back onto classic gendered associations, indicating a response to the sociocultural expectation that a woman in a spousal relationship carries the emotional labour (Weicht, 2015). A similar approach to withholding information on the early stages of clinical intervention is demonstrated by Emma:

I hadn't told anyone about what was happening, I didn't want to worry anybody, especially Nick, because obviously it was a strain to him because he might have thought that I was either, you know, not being fair on him or whatever, 'cause we used to argue such a lot on different things, so really it was for my own benefit and for the family.

(Emma)

She highlights that this personal strategy was employed to limit challenges being imposed on her partner and other family members. This shows that operating independently does not imply



relational autonomy. Emma preferred to address this situation on her own, but her key concern was shielding other people from the burden and impact of the diagnostic process.

However, the influence of dementia can also lead to a renegotiation of longstanding roles within the relationship (Fletcher, 2020). Below, Liz's perspective shows how a change of roles subverts the (gendered) expectation that she is the one who should fulfil the 'looking after' role in the relationship:

I've spent all this time looking after him now he's looking after me, I feel a bit of a fraud [laughter].

(Liz)

While caring roles are seen to be subverted, Liz's remark of feeling a fraud again reinforces the culturally shaped and relationally embedded gendered role expectations. The experience of dementia and subsequent requirements of dealing with the burden of the knowledge and the caring labour are embedded within gendered relationship structures and practices.

## CONCLUSION

The findings above detail the challenges women with dementia encounter when seeking to sustain their own relational subjectivity. This demonstrates the complexity of experience and how personal strategies, the negotiation of spousal relationships and engagement with wider social settings are intertwined. Importantly, the experience of dementia and associated personal responses must not be reduced to individual psychological processes. Rather, they are experienced within, and shaped by, the relational context and its cultural composition. Further to previous research literature (e.g. Van Dijkhuizen et al., 2006), the value of positive relationships and friendships is highlighted by women with dementia. Cultural norms on gender also affect women, as they feel the pressure to maintain relational competence. This is apparent in their endeavours to protect their partners from the impacts of the dementia and also in the perception that expressing negative perspectives on the condition is selfish (see Gilligan, 1982). In the women's narrations on the impact of the condition on the people in one's closest networks, the significance of gendered norms, attitudes and structures becomes most apparent. In particular, the historical development of caring relationships and their deeply ingrained cultural norms, provide a gendered framework within which people make sense of their own relationships. The gendered shaping of subjectivities can therefore not be identified in individualised perspectives; rather, the development of (caring) relations shapes the particular impact for the interviewed women.

The centrality of relational competence to a positive self-identity means that relationships can be a source of challenges. For example, a decline in the quality of friendships or diminishing social networks could be felt acutely. However, a simplistic portrayal of gendered experience must be eschewed; women also drew upon strategies that are culturally more associated with male approaches to sustaining positive self-identity when presented with health-related challenges. This included a stoical response to circumstances and references to strenuous physical activity (Moore et al., 2013). It is noteworthy, however, that Emma aligned her performance at a strenuous task with masculine values, that is, doing 'a man's job'. This implies a hierarchy of value, with men's (physical) efforts being culturally defined as more substantial.

Crucially, the focus on women with dementia contributes to a more nuanced gendered perspective of the experience of dementia, in particular when considering the impact on care

relationships. This helps to provide more effective social scientific accounts of dementia that can positively inform policy and practice. Enhanced awareness of the relational and social pressures associated with gender can help to facilitate constructive interactions with services and professionals, enabling women (and men) with dementia to negotiate the impacts of the condition more effectively, and articulate their perspectives and preferences.

Conceptualisations of the gendered basis of dementia must also be updated so that the complexity of relational experience is appropriately represented. Recent developments in social-scientific dementia research sometimes cloud this complexity. For example, 'couplehood' has adopted a central position within social scientific dementia research: the 'meaning of couplehood suggests that couples should be viewed as a unit rather than two separate individuals' (Swall et al., 2020, p. 2). Although there is recognition of the challenges of dementia within the corpus of couplehood literature (e.g. Førsumd, 2015), there is also a tendency to promote an affirmative view of experience aligned with 'living well' discourses that seek to provide counterbalance for negative societal representations of dementia (see McParland et al., 2017). For example, the rhetoric is oriented to the couple being a team (Hernandez et al., 2019) and defined by an 'us identity' (Davies, 2011). This therefore promotes a sense that relational experience is defined by togetherness and 'doing things together' (e.g. Bielsten et al., 2018; Hellström et al., 2005).

Drawing on relational subjectivity as a concept for exploring the experience of dementia might tackle those challenges. The concept retains the centrality of relationships to experience but does not elide individuals' dispositions and preferences under a hermetic conceptual unity. The human subject is intrinsically relational, but this does not mean that people become subsumed under relational configurations. While the person is embedded in relationships, personal intentions should not be held to be derived from collective intentionality (Donati & Archer, 2015). Relational subjectivity can therefore account for the emergent basis of complex spousal relationships, rather than conflating two individuals under a unified 'couplehood' (Tolhurst & Weicht, 2018). Additionally, the concept of couplehood might cloud the inequalities and cultural constitution that influence relational practices (such as care). As the final theme has demonstrated, caring roles have gendered histories and connotations that cannot be reduced to the couple as the unit of investigation.

It was apparent within this research that there are situations where the positive maintenance of relational subjectivity leads women to seek activities without their partner. Sometimes, this strategy had relational foundations as the women sought to protect their partners and other family members (e.g., from involvement with the diagnostic process) and, in that sense, to continue their own caring role. It was also apparent, however, that relationships can present direct challenges to the maintenance of a positive relational subjectivity. While relationships are central to the experience of women, this does not mean that the significance of independence should be understated (see also Boyle, 2017).

The impact of dementia can, of course, limit the scope for people to pursue activities independently of their partners. This is recognised by Emma when she considers how the future impact of the condition could increase her need to depend on her partner. The impacts of dementia upon the care relationship therefore mean that couples should be supported to deal with the condition together. What should be avoided is the sense that there is a neat hierarchy of relational formations, from 'working alone' at the bottom to 'working together' at the top (see Keady & Nolan, 2003). While positive relational dynamics and shared perspectives can provide a good foundation for dealing with the impacts of dementia, it is vital that this does not provide a restrictive standard by which relationships are judged. This has the potential to compound the challenges of those living with dementia. These challenges could be felt particularly by women where cultural standards on gender generate an expectation that spousal 'togetherness' will define their personal goals.

## AUTHOR CONTRIBUTIONS

**Edward Tolhurst:** Conceptualization (lead); data curation (lead); formal analysis (lead); funding acquisition (lead); investigation (lead); methodology (lead); project administration (lead); writing – original draft (lead); writing – review & editing (supporting). **Bernhard Weicht:** Formal analysis (supporting); writing – original draft (supporting); writing – review & editing (lead). **Jessica Runacres:** Writing – original draft (supporting); writing – review & editing (lead).

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## DATA AVAILABILITY STATEMENT

For ethical reasons, the full dataset is not being made publicly available.

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