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Tolhurst, E., Carey, M., Weicht, B., and Kingston, P. (2018) 'Is living well with dementia a credible aspiration for spousal carers?' *Health Sociology Review Online* access: 21st May

Is living well with dementia a credible aspiration for spousal carers?

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ABSTRACT

In England there has been substantial policy development and an academic drive to promote the goal of 'living well' for people with dementia and their family members. This article critically evaluates the feasibility of this intention, with reference to the experience of those caring for people with the condition. Qualitative data are utilised from a study which explored how couples negotiate relationships and care. The focus of this paper is the perspectives of spousal carers and the challenges they encounter within their caring role. Views were obtained via semi-structured joint interviews where the carer participated alongside the person with dementia. The extent to which living well with dementia is a credible aspiration for carers is examined via three themes: identity subsumed under care responsibilities; the couple as an isolated family unit; and barriers to professional support. The findings highlight that experience of caring is highly complex and fraught with multiple practical, emotional and moral pressures. It is asserted that research into dementia and care relationships must avoid a zero sum situation, prompted by living well discourses, where attempts to bolster the position of people with dementia compound the marginalisation and stigmatisation of informal carers.

KEYWORDS

Care; couplehood; dementia; intergenerational relationships; spousal relationships

Introduction

The prevalence of dementia and its consequences is frequently characterised with reference to the challenge of ageing societies (Higgs & Gilleard, 2017). The nature of ageing societies has led to a distinction being drawn between a 'third age', underpinned by a healthy and active later life and a 'fourth age' of dependency and decline. Investigating the 'fourth age' concept, Higgs and Gilleard (2014) identify a social imaginary in which this age-related status is needed for society to uphold a particular ideal of individual identity and personhood. People with dementia are judged according to an emerging 'neuroculture' that prioritises the value of cognitive competence and health: dementia 'is the antithesis of the agentic mentally competent individual' (Williams, Higgs, & Katz, 2012, p. 70) and is intrinsically aligned with the fourth age (Grenier, Lloyd, & Phillipson, 2017).

The condition therefore functions as demarcation, social signifier or socially negotiated biomarker that allows a process of 'othering' carried out by society. This reflects the societal establishment of divisions between successful and unsuccessful ageing (Pickard, 2014). These cultural constructions have become subtly aligned with particular societal narratives, including 'exaggerated claims of dependent populations or financial collapse' (Carey, 2016, p. 357). Such moral panics reinforce assumptions about older people personifying decay and generating resultant risks that threaten the normative foundations of society. This includes the potential for older people to cause economic havoc and damage the life chances of younger people (Phillipson, 2013).

These discourses contribute to dehumanising representations of dementia. It has been argued, for example, that disgust and terror lead to people with Alzheimer's disease being socially apprehended as 'the living dead' (Behuniak, 2011). Dementia has also been represented as 'a social death' (Sweeting & Gilhooly, 1997). Such a cultural inheritance can have direct causal impacts upon a person with dementia, furthering their decline and potentially leading to mistreatment and a lack of appropriate care (Kitwood, 1997).

When confronted by such discourses, it is understandable that a more positive and humanistic version of the experience of dementia is sought. This is represented by the policy context in England that promotes a 'living well with dementia' aspiration; a central feature of England's Dementia Strategy (Department of Health, 2009), which continues to shape the tone and orientation of current policy (Department of Health, 2015). This is reinforced by academic discourses that seek to promote a more affirmative lexicon that resists a focus on neurodegeneration, loss and carer burden (e.g. Sabat, Johnson, Swarbrick, & Keady, 2011).

The rejection of a focus on decline and loss of capacities mirrors the influential debate in the sociology of health and illness based on the disability movement's critique of theorisations of care. While the traditional feminist evaluation of care has emphasised genderbased duties and burdens due to care needs, a disability

perspective has focused attention on the social construction of needs itself (Fine, 2014). In the recently emerging sociology of dementia, these lines of argumentation continue to shape the conceptualisation and evaluation of care and policy interventions in which, for example, a social disability model seeks to shift the focus away from passivity and vulnerability towards active citizenship (Birt, Poland, Csipke, & Charlesworth, 2017). However, as an exclusively positive discourse on so-called active ageing (Lloyd, 2015) seems unattainable in relation to dementia, the concept of personhood is linked to notions of embodied, relational selfhood (Kontos, Miller, & Kontos, 2017). This emphasises that the experience of dementia must not be thought of as an isolated, abstract phenomenon. Rather, it needs to be understood as closely linked to a body's particularities and embedded in relational contexts and meanings through which personhood is actualised.

Relationships are a crucial factor in shaping a person's experience and in the case of significant health conditions the support offered within close relationships takes on additional salience. With regard to dementia, it is vital to recognise the condition has experiential implications that extend beyond its biological basis. This relates to the concept of personhood, which highlights that the experience of dementia is shaped by key relationships and is not merely defined by neurodegenerative decline (Kitwood, 1997). In turn, caring relations do not take place in a societal void but are part of the social and moral order (Paoletti, 2002), 'produced by an interplay of political structures and ethical attitudes and practices' (Winch, 2006, pp. 6–7) that define the 'proper thing to do' (Williams, 2004, p. 7). Within this context, a diversity of experiences, roles and identities, ambiguities and uncertainties (Olson, 2015) impact on the lives of carers, those in need of care and their relationships.

Within relationships, people with dementia can receive the support and encouragement required to sustain a meaningful life and identity (MacRae, 2011). Caring relationships can thus build the foundation of a positive experience and the possibility of citizenship for both people with dementia and those caring for them (Kershaw, 2005). In contrast to an individualising focus on active ageing, this understanding seeks to concentrate on the concept of interdependence (Bowlby, McKie, Gregory, & MacPherson, 2010; Tronto, 1993), i.e. a process of 'reciprocity between partners, exchanges between dependent actors over time, and the networking of these relations of dependence' (Fine & Glendinning, 2005, p. 612). Recognition of the centrality of social relations between concrete others (Hanlon, Halseth, Clasby, & Pow, 2007) demands an approach in which relationality is understood as decisive for the flourishing of the human subject (Donati & Archer, 2015).

This article draws upon empirical insights obtained from joint interviews which included people with dementia and their spousal carers, with the analytic emphasis on the perspectives of the carers.¹ Other studies that adopt a dyadic approach (e.g. Hellström, Nolan, & Lundh, 2007; Svanström & Dahlberg, 2004) reflect the dilemmas of academic discourses on ageing, dementia and care discussed above. This is concerned with navigating a course that captures the experience of the condition faithfully but also avoids compounding damaging societal representations. For

example, from their dyadic study that addressed care relationships, Svanström and Dahlberg (2004) found that a very negative perspective of experience was conveyed, underpinned by feelings of perplexity and futility. This perspective is challenged by Hellström et al. (2007), who propose the concept of couplehood as a supplement to personhood. This concept recognises the centrality of the spousal relationship in shaping experience, and from their dyadic data they found that couples strived to maintain a positive relational context. This more positive view of dementia and the co-construction of relationships is endorsed by several joint interview studies, where the authors also identify with the 'couplehood' concept (Davies, 2011; Merrick, Camic, & O'Shaughnessy, 2016; Molyneaux, Butchard, Simpson, & Murray, 2012). While this demonstrates that recent dyadic studies have tended towards a positive portrayal of the experience of dementia, Wawrziczny, Antoine, Ducharme, Kergoat, and Pasquier (2016) diverge from this trend somewhat, addressing the deterioration of marital interactions and eventual dissolution of the relationship.

A polarisation of discourses thus underpins dyadic approaches to dementia and care relationships, with negative accounts (such as that offered by Svanström and Dahlberg) facing stern resistance. McParland, Kelly, and Innes (2017) argue that such binary understandings of dementia promulgate a dichotomy of 'tragedy' or 'living well' discourses, which fail to capture the experiential complexity of dementia. The review of dyadic studies above further suggests that there is a recent social scientific tendency to endorse a 'living well' account. While it is certainly laudable to provide counterbalance to negative representations of dementia, it is possible that such norms could lead to a relentlessly positive perspective (Bartlett, Windemuth-Wolfson, Oliver, & Dening, 2017). The intrinsic complexity of interdependent relationships suggests that a binary model (with care relationships being defined as either positive or negative) is likely to be inadequate.

Rather, the challenges inherent in seeking a balanced relational perspective should be taken seriously in examining the consequences of political interventions, such as the 'living well' agenda, for the person with dementia, the carer and their relationship. Personhood, understood as being relational, consequently means that dementia also affects carers' identities and experiences. This article accordingly sets out to explore the credibility of the 'living well' principle and whether it is a feasible aspiration in relation to spousal care. Moreover, does the positive orientation towards living well with dementia generate unintended consequences that could actually compound the challenges that inhere within care relationships?

Methods

This article utilises data collected from a UK-based qualitative research study which obtained the perspectives of spousal carers. The research set out to obtain in-depth insights into how people experience dementia, addressing the negotiation of the spousal relationship, family relationships more widely, and professional support. Fourteen semistructured joint interviews with men with dementia and their spousal carers were undertaken. Interviews were also undertaken on a one-to-one basis with an additional two female carers (Susan and Kate), as their partners did not have the

mental capacity to participate. This evaluation was made by the researcher with reference to the Mental Capacity Act (2005) when meeting with each couple. Under this Act the person must be able to understand, retain and weigh up information and then communicate their decision. In both of the aforementioned cases, with reference to the principles of the Mental Health Act, it was clear that the man with dementia would neither be able to provide informed consent nor participate in an interview.

A total of 16 carers therefore participated in the study, 15 of which were female. The names of all participants have been changed. Interviews were undertaken by a male interviewer:

it has to be acknowledged that the gender of the interviewer, inter alia, will shape the dynamic of conversational exchanges and accordingly the construction of data.

Table 1. Participant characteristics (at date of first interview).

Carer	Age	Principal occupation	Partner's condition	Length of time since diagnosis
Florence	52	Health/clinical	Alzheimer's	Six months
Elizabeth	55	Teacher	Alzheimer's	Six months
Susan	56	Retail	Alzheimer's	Three years
Jennifer	56	Teacher	Alzheimer's	Six years
Martin	56	Retail	Lewy body	Six months
Julia	63	Retail	Alzheimer's	One year
Sally	64	Administration	Alzheimer's	One year
Irene	66	Business owner	Alzheimer's	Two years
Caroline	67	Childcare	Alzheimer's	One year
Kate	68	Social Care	Mixed	One year
Claire	71	Social Care	Alzheimer's	Five years
Rachel	73	Retail	Alzheimer's	One month
Hayley	74	Administration	Alzheimer's	One year
Anne	74	Housewife	Vascular	Three years
Eleanor	77	Pub landlady	Alzheimer's	Three years
Michelle	84	Housewife	Alzheimer's	Five years

All of these 16 carers were White-British. The carers' principal occupation is noted in Table 1, but only Florence, Jennifer and Martin were still in employment over the course of the research. Fourteen of the 16 couples had adult-age children. The age-range of the carers is broad, from 52 to 84. It has been widely noted that younger people with dementia (defined as under age 65) and their carers might encounter additional emotional and practical challenges associated with the condition (e.g. Lockeridge & Simpson, 2013). A relative lack of research on younger carers reflects a wider tendency within health services, and society more widely, to overlook (and even misconstrue) the experience of young onset dementia (Clemerson, Walsh, & Isaac, 2014).

Interviews took place in participants' family homes and had a mean duration of 70 minutes. An interview schedule provided a broad framework for discussion, which allowed participants to raise matters that were important to them. Respondents were recruited via National Health Service (NHS) Trusts in England, and dementia support

groups. Ethical clearance for the study was granted by an NHS Research Ethics Committee. Written consent was obtained from both interviewees, by the interviewer/principal researcher, before the interview was convened. It was highlighted to all interviewees that they could take a break from the interview at any time, or bring it to a close if they encountered any difficulty with the process. Interviews would also have been brought to a close by the researcher if respondents were to exhibit any distress.

Each set of interviewees was interviewed twice in the endeavour to obtain extensive experiential insights, with a six-month interval between these interviews. One carer, Anne, did not participate in the second interview as a consequence of her partner's health. In addition, two other carers, Irene and Eleanor, took part in one-to-one interviews for the second interview, as their partners were unable to take part for health-based reasons. Thematic analysis was undertaken of transcripts, which enabled identification of key patterns within the data (Braun&Clarke, 2006). The first analytical stage enabled immersion in the data through listening to recording of the interviews and reading/re-reading transcripts (Green et al., 2007). Transcripts were parsed on multiple occasions to ascertain the perspectives of men with dementia, their carers and how these were constructed within interactional exchanges. This article focuses on the key topics derived from the spousal carers. A process of initial coding was then undertaken whereby labels and notes were manually applied to the transcripts. This provided a structured means for establishing key elements of interview content. Codes with an underlying commonality were then reviewed across the sample to establish key categories. These principal categories were then organised into themes that offer a coherent account of key experiential dimensions of caring for a man with dementia. Three key themes were identified and these were also related to the academic and policy context of 'living well with dementia'. These three themes are: identity subsumed under care responsibilities; the couple as an isolated family unit; and barriers to professional support. Relating these themes to the 'living well' agenda provides an explanatory framework that draws together patterns identifiable across the interviews and links these to the sociocultural context of personal experience and relationships.

Limitations

The orientation of this article enables focused exploration of the perspectives of spousal carers.

It is important to underscore, however, the basis from which these views were obtained.

Qualitative interviews are inevitably shaped by relational influences within the interview setting. The joint interview format (which applied to the majority of interviews) will influence the expression of personal viewpoints due to the pressures imposed by the co-presence of

interviewees (Taylor & de Vocht, 2011). Moreover, it has been highlighted that joint interviews can prevent the researcher from giving an equal voice to both partners (Zarhin, 2018).

These challenges can have particular salience where a carer/cared-for dynamic shapes the relationship of the interviewees. This could affect the nature of the interviews with carers, for example, dominating the conversational exchanges. This could be compounded by communication difficulties engendered by dementia upon the person with the condition.

Within this research process, the interviewer actively sought the views of both participants.

For example, information sheets sent to prospective participants stated that the research was aiming to gather the distinctive perspectives of both the man with dementia

and the spousal carer. Within the interview process itself the interviewer used prompts to

draw an interviewee into the conversation if they were less forthcoming with their views.

While it is vital to acknowledge the challenges inherent in joint interviews, it can be argued that their interactional basis adds to the authenticity of captured perspectives when interviewing couples (Molyneaux et al., 2012). People experience dementia not as

autonomous individuals but in the context of relationships: while a number of different

relationships will be crucial, the spousal relationship is likely to be of particular significance

with each member of the couple spending substantial time in each other's presence.

The way

that people think about the condition, and feel able to express their views about the condition,

will inevitably be shaped by this context. The joint interview is aligned with these relational conditions. Moreover, it is not only the pressures of the interactional situation

that shape perspectives: care relationships will also be influenced by more diffuse social

and cultural factors, with these pressures influencing the basis of expressed accounts.²

Findings

Identity subsumed under care responsibilities

While views expressed across the sample were not uniformly negative, all carers in the

sample experienced practical or emotional difficulties as a consequence of their partner

having dementia. This was sometimes presented in extreme terms. The interviews with Kate, for example, demonstrated the seemingly ceaseless nature of responsibilities that can arise when negotiating a spousal relationship with a person with dementia. Kate felt that she was caring '24/7' and even struggled to go to the toilet or take a shower as a result of the intensity of her caring role. When a break is afforded, Kate does not even use this time to recover, as she needs to undertake basic personal tasks that she is unable to do when her partner is at home: When he goes to the day centre I am always here, I never go out. I ought to go and get something done with my hair, but the first time he went I was going to go to bed and get some sleep, but I never did. I take that opportunity to have a shower, because I can't go to the loo, shower, I can't do anything without him being at my back all the time. (Kate – first interview)

It should be recognised that Kate's partner was in an advanced stage of the condition and this situation is likely to present particular difficulties to the carer. Nevertheless, as noted above, intense challenges associated with caring were recounted by carers across this sample. The extensive nature of caring requirements can even impinge upon the carer's scope to articulate their agency and sustain a self-identity. For example, Anne highlighted the limitations engendered by the extent of her care responsibilities within the relationship. Anne suggested that the inability to operate independently from her caring role prevents her from expressing her personal identity. There is even a suggestion that the role of carer is incompatible with core aspects of self-expression:

It's just a matter of sometimes you just want to get out on your own and be you. You know, and you can't be you because you're a carer. (Anne – first interview)

It has been highlighted that identifying as a carer can have positive benefits, including a greater sense of connection to a wider community (O'Connor, 2007). Alternatively, it has been asserted that energies devoted to care can compromise social networks (Lloyd & Stirling, 2011). Anne's perspective aligns with the latter view and shows that carers might desire (and struggle) to sustain a personal identity that is not subsumed under responsibilities associated with the care relationship. The nature of selfhood has received

significant attention with reference to people with dementia, and it is argued that there is a tendency to elevate the condition to the defining element of a person's being. Other aspects of the social self (such as neighbour, parent, loving partner) are thus relegated (Sabat, 2001). A similar situation might apply to spouses (or other family members) if they feel their existence is solely defined by caring. This demonstrates one of the intense challenges inherent in contexts of informal care: carers are under pressure to support their partner's relational and social being, but at the same time their own relational and social conditions might be highly diminished.

Hayley also stated that everything she does or thinks about seems to relate to her caring role. She states that her partner no longer takes responsibility for anything around the house, so this places all of the responsibility on her:

You've got no free time or time to be yourself, if that's the right word. There are all the jobs to do, every single thing that's done; it's up to the person caring rather than anybody else. Nobody else takes any responsibility; he doesn't take any responsibility for anything. So everything is left to me. (Hayley – second interview)

Further to Anne's views above, Hayley's views indicate the challenge of maintaining a positive sense of self when faced with substantial caring responsibilities. A decline in reciprocity, alongside sustained obligations, places pressure upon Hayley in the domestic sphere and reduces her potential to obtain personal meaning away from the care relationship.

While Hayley feels frustration that her partner does not take responsibility, it was likely that his scope to contribute had been limited by the impacts of his dementia. It has been noted that carers might feel that the person with dementia is deliberately trying to annoy them, when in fact their behaviour is due to cognitive impairment (Sabat, 2001).

It should also be noted, however, that changes to the basis of the spousal relationship were not always recounted negatively. Claire highlighted that her partner Philip's inability to undertake household tasks means that she has been exposed to new experiences:

But you do learn to do a lot; I mean [he] used to do such a lot years ago. I never picked a screwdriver up. But then you learn to pick a screwdriver up, because there's nobody else to do it for you. So you do learn all these different things that you've never done before.

(Claire – second interview)

There is, therefore, a sense that this situation is personally liberating for Claire: her former reliance on her partner to perform such traditionally masculine-oriented tasks meant that she did not fulfil such roles. To some extent then the influence of the dementia on her partner's capabilities has broadened Claire's breadth of experience and even enhanced her self-identity.

The couple as an isolated family unit

While there was a diverse range of experience with regard to the input of younger family members, carers often reported that the degree of help they received from their (adult-age) children was insubstantial in practical terms. Factors such as geographical mobility have increased, meaning that children often move further away from the family home on reaching adulthood than previous generations. The primacy placed on this mobility is intimately linked to the project of modernity where the lifespan becomes increasingly freed from pre-established ties to other people and groups (Giddens, 1991).

The geographical distance of a younger family member is discussed by Caroline below with reference to her daughter, but she also highlights the moral imperative to preserve the independence and opportunities of younger people: They've all moved out of the area. Especially if they go to university, they don't tend to come round the same area and I think that is right, young people today if they've got the opportunity they've got to take it. And you can't stop them. And I think if you try, it doesn't work.

We have never wished her to live by us or anything. (Caroline – second interview)

Even when younger family members lived in close proximity support was often limited.

Nevertheless, respondents were generally uncritical of their children and felt that this situation was understandable as a result of the lives that younger family members are living. Further to Caroline's perspective above it is considered that younger family members will have their own lives and commitments; therefore, it would be inappropriate to impinge upon their independence. For example Claire stated:

You keep in touch by phone, but you can't keep thinking that your son or daughter is going to keep coming up all the time. They've got their own lives to lead and why spoil their lives saying 'Oh, you haven't been this weekend'. They've got their own lives to lead. (Claire – first interview)

Furthermore, even when help could be offered by family members it seemed that it was not easy to accept, as a consequence of the carer's perception of their own obligations: they must cope with the challenges of caring for their partner, and also prevent these challenges from being dispersed across the family. Irene's perspective underscores this point: she had highlighted during the interview that she felt she should care for her partner as long as she could before contemplating residential care. The same principle, however, does not apply to her children: she asserts her desire to shield them from caring responsibilities. Irene conveys her commitment to protecting others by expressing the extreme view that a programme of senicide would prevent older people being a burden upon the younger generation. Irene therefore shows that the desire to avoid being a burden relates to impacts not only upon the immediate family, but also society and the economy more widely:

Because I've told the girls they must put him into care and me. They must put us into care, you know, do what you like but don't burden yourselves. I'd rather take an overdose and that's the God's honest truth. I'd do myself in if I thought I was a burden. My philosophy of life is that when you get to 70 you should have a needle. You've had your three score years and ten, let the young uns carry on. I think it's your 70th birthday you can have a little party and here's your tablets. I do honestly think that. (Irene – first interview)

The pressure to cope self-sufficiently also means that carers might feel unease if a particular role is handed over to a younger family member. Below, Jennifer discusses the challenge of dealing with her partner's incontinence, and feelings of guilt that her daughter-in-law is better at dealing with this aspect of the caring role:

[He] enjoys being with my daughter-in-law, who he's been with today. He really enjoys her company. And we've got over the tricky one that I was a bit concerned about, about things with the incontinence. But she's OK with that, so that's 'pew'. In fact she's a lot better with it than I am. I'm not too good at all and I feel incredibly guilty that somebody else can cope with it and I can't. It's all guilt – it's vile, horrid. (Jennifer – second interview)

It should also be recognised that not all accounts from carers stated that support from younger family members was circumscribed or problematic. In the excerpt below, Elizabeth highlights the positive support she receives from her children:

They're brilliant. They were all here yesterday, they said 'Mum have a rest day because you're not feeling too good'. I said 'OK'. So they all came to visit with the grandchildren. To make sure that we were all right, they are a big support. (Elizabeth – second interview)

While the findings above show that support from within the extended family was limited, it is crucial to avoid criticising younger family members. For example, adult-age children who do care for an older relative with dementia will also often have to balance this responsibility with paid work and supporting children or grandchildren (Vreugdenhil, 2014). The intention in this article is to highlight the social and cultural conditions that mean spousal care can be an isolating and atomised experience. 'Living well', regardless of a person's circumstances, is likely to be diminished if social contacts and networks of wider support are circumscribed.

These limitations are a consequence of families being increasingly geographically dispersed and, as noted above, younger family members facing other challenges. In addition, discourses on informal care mean that those in need might feel reluctant to seek support from the extended family, even when it could be available. This, again, shows the multifaceted challenges of caring. The carer is charged with helping the person with dementia to live well and also creating a care context where

the person's status as an independent agent is sustained. Alongside this, the carer must cope resiliently and self-sufficiently with their duties to prevent the independence and autonomy of other family members being threatened. Individualised contemporary Western societies require a working-age population comprised of self-oriented and flexible individuals (Fine, 2005). Spousal carers thereby take on a crucial (and unacknowledged) function in supporting this socio-economic context: carers relinquish their own independence to sustain the independence of others.

Barriers to professional support

While seeking support from within the family proved problematic for spousal carers, pursuing professional support also presented moral dilemmas: carers were often concerned that seeking external support would indicate that they were 'relinquishing' their care responsibilities. For example, Julia stated that her experience had shown that the carer needed a break on occasions from the person with dementia. She then proceeds, however, to state that her partner would have to be 'really bad' before she pursued an option such as day care:

Because when you start out on this path you don't realise how bad they are going to get. Memory goes a little bit and you think 'oh well, you'll manage' but you don't realise how they change. I do think, yes, you do need a little bit of a break from them. But [he] would have to get really bad before I thought of day care or anything such as that. (Julia – second interview)

A distinct difficulty is presented when spousal carers try to reconcile their own needs with their partner's best interests (or at least what might be perceived by others to be their partner's best interests). Even when the point has been reached where the carer feels unable to cope, it seemed that it was useful to cite external endorsement when accessing additional support. This was presented by Susan below to demonstrate that she was not exercising a personal choice, but was obliged to seek support in line with a professional recommendation. This thereby helps to counter any potential social judgement that the carer is placing their own needs first:

We had a rough patch with him one weekend and no sleep again for four nights and I cracked, I really cracked, so I phoned the CPN [Community Psychiatric Nurse] and she made an emergency visit and I've always turned respite down. And she said I've got no choice, I've got to have it. (Susan – second interview)

Restrictions on professional support, whatever their basis, are likely to impact upon the scope of carers to 'live well'. Negotiating moral dilemmas in relation to seeking support is likely to contribute further to such difficulties. The impact of such dilemmas should not be underestimated (Gilligan, 1982). As noted above, age is a factor that could compound such emotional impacts. Susan was one of the youngest carers in the sample and was dealing with her partner being diagnosed at an atypically young age. It is also important to recognise, however, that it is not just moral impediments that create barriers to accessing care. The availability and format of services, as well as the need to navigate professional services can also present practical obstacles. The professionalised structures and logic of formal support organisations will present the carer with different interactional challenges from those that inhere within informal relationships. With regard to such challenges, Jennifer highlighted the complexities of negotiating multiple professional agencies. Jennifer was also one of the youngest carers in the sample and needed to address these practical challenges alongside her paid employment role: I popped into the day centre, and I said 'Do you take people with Alzheimer's?' They said

'Yes, we do.' 'Oh right, okay.' But you have to be referred by your doctor. So I got in touch with the doctor about being referred and he said 'Okay, fine I'll get in touch with Social Services.' Now Social Services were aware that [he] needed it, so why wasn't something done? Very frustrating. I find it, the whole situation, is dreadful. People are not helping. You have to ask, but you have to know what you need to ask in order to find out. (Jennifer – second interview)

One of the most consistent themes presented throughout the interviews was the difficulty respondents had negotiating (or even contemplating) the arrangement of future professional support. Dementia policy (Department of Health, 2009, 2015) places an emphasis on the importance of early diagnosis, as this enables people to make plans for the future.

The findings from this research, nevertheless, demonstrate that making plans for the future under professional guidance was not occurring to a discernible degree. In several interviews, carers stated that planning for the future was not undertaken as they preferred to operate on a 'day-to-day' basis:

I don't go beyond tomorrow at this stage because for me looking to the future is not good because I have no family around me, I have absolutely no one. And the isolation.
(Rachel
– first interview)

Discussions on planning for the future in the interview were often considered with reference to residential care. The anticipation of residential care impinges substantially upon carers' perspectives of the future. This is highlighted in the excerpt below. A question presented to Sally on plans for future care and professional support appears to be interpreted with exclusive reference to residential care. She stated that the need to make plans for residential care is not required, as this will only be accessed when support via the spousal relationship is rendered impossible. Sally thus situates her partner's needs at the forefront of her endeavours as a carer, and shows that she intends to meet her pledge to support him:

Interviewer: Are you making plans for future professional support or care?

Sally: No, because I said I'd look after him as long as I could. I'm quite willing to look after him as long as I possibly can. (Sally – first interview)

As discussed above, carers feel under pressure to live up to the notion of the ideal carer.

This pressure limits the extent to which carers feel they can draw upon additional support; either from within the family, or from professional services. In addition, such anxieties render planning for the future deeply problematic. There is consequently a tension between offering selfless, unconditional support and making concrete plans for the point at which the provision of care is, at least in part, handed over to others. Being a good carer (see also Pickard, 2010) is perceived as caring for as long as reasonably possible; openly anticipating the point at which care will be 'relinquished' is accordingly incompatible with this moral imperative. This relates to the earlier discussion with regard to carers feeling

their sense of self is defined by the extent of their caring role. Moral pressures that inhibit contemplation of the future will further circumscribe the experiential parameters of carers. Constraints on personal circumstances are likely to be felt more acutely if consideration and discussion of the future is deemed morally 'off limits'. The personal horizons of spousal carers are therefore further constrained by social and cultural standards of 'good care'.

Conclusion

A monolithically negative portrayal of the experience of dementia and associated care was certainly not conveyed by spousal carers in this research. Nevertheless, carers did express in a candid fashion the substantial practical and emotional difficulties prompted by their partner's condition. Spousal carers are thereby presented with multiple moral challenges that compound the practical challenges of caring, and limit the extent to which carers can seek personal support (which could benefit them and also the person with dementia). It appears that more socially inclusive methods of support are required to counter the tendency for spousal caring to become a hermetic phenomenon, which is detached from wider (familial and professional) support mechanisms. This potentially calls into question the credibility of a living well agenda with reference to care relationships and dementia. The need to reconcile one's own personal needs with the needs of the partner (in an isolated care context) while contending with wider social and cultural influences and pressures, presents substantial challenges for spousal carers to negotiate.

Academic and policy discourses need to adopt a genuinely relational approach that recognises the complex interdependencies of relationships: spousal relationships are not a simple aggregation of two individual viewpoints. It has been highlighted, for example, that people might adopt particular strategies to counter the experiential impacts of dementia. A psychological resistance might be employed by which the significance of dementia is underplayed and the capacity to carry on as normal is asserted. Alternatively, a political resistance could be adopted which relates to people seeking to convey the difficulties

that they are experiencing openly and candidly (Clare & Shakespeare, 2004). It can be argued that discourses associated with 'living well with dementia' and couplehood are more readily aligned with psychological resistance to the condition. While it is laudable to pursue a more positive portrayal of dementia, there is the risk that this commitment could suppress more negative accounts (oriented to political resistance).

Within a complex relationship it might be difficult to reconcile these different coping strategies, which are not necessarily compatible (i.e. the assertion that everything is carrying on as normal versus the need to candidly convey difficulties). Endorsing one of these particular vantage points from a policy and academic perspective could therefore mean that the other perspective needs to be suppressed. Supporting people with dementia and their carers in a balanced manner should mean that different strategies are acknowledged, so that people can be appropriately supported within complex care relationships. Endeavours to illuminate the experience of interdependent relational subjects should avoid the elision of divergent perspectives in the (well-meaning) pursuit of a unified couplehood.

It is important that, in the eagerness to promote a more affirmative view of the condition, academic approaches do not promote a partial representation of dementia, thereby stigmatising carers who wish to convey the palpable challenges that they are encountering. Attempts to avoid the 'othering' of people with dementia must also avoid the 'othering' of informal carers. A relational approach, which acknowledges the complex linkages between human subjects, the interactional domain and wider social contexts, can help to overcome this zero-sum individualism. An excessive focus on couplehood and the co-construction of a shared identity could also distract attention from the needs of carers to derive purpose and meaning away from the locus of the care relationship.

McParland et al. (2017) argue that the current academic and policy agenda could create divisions among people with dementia themselves, by marginalising the particularly vulnerable who are unable to measure up to societal definitions of 'living well'. From the insights into carers offered in this article, it can be asserted that the 'living well' agenda is also at risk of creating divisions between people with the condition and their informal carers. A credible and balanced account of dementia must resist excessively negative portrayals of dementia without offering a sanitised version of reality that denies its palpable

practical and emotional impacts. The goal of empirical studies should be to convey the concrete actuality of experience, rather than aprioristically counter particular sociocultural representations. The intense practical, emotional and moral pressures experienced by carers, allied to these pressures being encountered within increasingly atomised societal conditions, demonstrate that sustained research into spousal dementia care is still required.

Notes

1. The perspectives of the men with dementia have been addressed elsewhere (Tolhurst & Weicht, 2017).
2. The interactional and sociocultural influences upon individual and shared perspectives within the joint interview setting have been addressed elsewhere (Tolhurst, Weicht, & Kingston, 2017).

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

- Bartlett, R., Windemuth-Wolfson, L., Oliver, K., & Dening, T. (2017). Suffering with dementia: the other side of 'living well'. *International Psychogeriatrics*, 29(2), 177–179.
- Behuniak, S. M. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31(1), 70–92.
- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199–211.
- Bowlby, S., McKie, L., Gregory, S., & MacPherson, I. (2010). *Interdependency and care over the lifecourse*. London: Routledge.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Carey, M. (2016). Journey's end? From residual service to newer forms of pathology, risk aversion and abandonment in social work with older people. *Journal of Social Work*, 16(3), 344–361.
- Clare, L., & Shakespeare, P. (2004). Negotiating the impact of forgetting: Dimensions of resistance

in task-oriented conversations between people with early-stage dementia and their partners.
Dementia, 3(2), 211–232.

Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia*, 13(4), 451–466.

Davies, J. C. (2011). Preserving the ‘us identity’ through marriage commitment while living with early-stage dementia. *Dementia*, 10(2), 217–234.

Department of Health. (2009). *Living well with dementia: A national dementia strategy*. London: DH Publications.

Department of Health. (2015). *Prime minister’s challenge on dementia 2020*. London: DH Publications.

Donati, P., & Archer, M. (2015). *The relational subject*. Cambridge: Cambridge University Press.

Fine, M. (2005). Individualization, risk and the body. *Sociology and Care*, 41(3), 247–266.

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Fine, M. (2014). Nurturing longevity: Sociological constructions of ageing, care and the body. *Health Sociology Review*, 23(1), 33–42.

Fine, M., & Glendinning, C. (2005). Dependence, independence or inter-dependence? Revisiting the concepts of ‘care’ and ‘dependency’. *Ageing and Society*, 25, 601–621.

Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Cambridge: Polity Press.

Gilligan, C. (1982). *In a different voice: Psychological theory and women’s development*. Cambridge, MA: Harvard University Press.

Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L., & Daly, J. (2007). Generating best evidence from qualitative research: The role of data analysis. *Australian and New Zealand Journal of Public Health*, 31(6), 545–550.

Grenier, A., Lloyd, L., & Phillipson, C. (2017). Precarity in late life: Rethinking dementia as ‘frailled’ old age. *Sociology of Health & Illness*, 39(2), 318–330.

Hanlon, N., Halseth, G., Clasby, R., & Pow, V. (2007). The place embeddedness of social care: Restructuring work and welfare in Mackenzie, BC. *Health & Place*, 13, 466–481.

Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining ‘couplehood’: Spouses’ strategies for living positively with dementia. *Dementia*, 6(3), 383–409.

Higgs, P., & Gilleard, C. (2014). Frailty, abjection and the ‘othering’ of the fourth age. *Health Sociology Review*, 23(1), 10–19.

Higgs, P., & Gilleard, C. (2017). Ageing, dementia and the social mind: Past, present and future perspectives. *Sociology of Health & Illness*, 39(2), 175–181.

Kershaw, P. (2005). *Carefair: Rethinking the responsibilities and rights of citizenship*. Vancouver: UBC Press.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

Kontos, P., Miller, K., & Kontos, A. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182–198.

Lloyd, B., & Stirling, C. (2011). Ambiguous gain: Uncertain benefits of service use for dementia carers. *Sociology of Health & Illness*, 33(6), 899–913.

Lloyd, L. (2015). The fourth age. In J. Twigg & W. Martin (Eds.), *The handbook of cultural gerontology* (pp. 261–268). London: Routledge.

Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, 12(5), 635–651.

MacRae, H. (2011). Self and other: The importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies*, 25, 445–456.

McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, 39(2), 258–269.

Mental Capacity Act. (2005). Chapter nine. England and Wales. Retrieved from http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. *Dementia*, 15(1), 34–50.

Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia*, 11(4), 483–502.

O'Connor, D. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21(2), 165–174.

Olson, R. (2015). *Towards a sociology of cancer caregiving: Time to feel*. Farnham: Ashgate.

Paoletti, I. (2002). Caring for older people: A gendered practice. *Discourse & Society*, 13(6), 805–817.

Phillipson, C. (2013). *Ageing*. Cambridge: Polity Press.

Pickard, S. (2010). The 'good carer': Moral practices in late modernity. *Sociology*, 44(3), 471–487.

Pickard, S. (2014). Frail bodies: Geriatric medicine and the constitution of the fourth age. *Sociology of Health & Illness*, 36(4), 549–563.

Sabat, S., Johnson, A., Swarbrick, C., & Keady, J. (2011). The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, 12(4), 282–292.

14 E. TOLHURST ET AL.

Sabat, S. R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell.

Svanström, R., & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. *Western Journal of Nursing Research*, 26(6), 671–687.

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19(1), 93–117.

Taylor, B., & de Vocht, H. (2011). Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research*, 21(11), 1576–1587.

Tolhurst, E., & Weicht, B. (2017). Preserving personhood: The strategies of men negotiating the experience of dementia. *Journal of Aging Studies*, 40, 29–35.

Tolhurst, E., Weicht, B., & Kingston, P. (2017). Narrative collisions, sociocultural pressures and dementia: The relational basis of personhood reconsidered. *Sociology of Health and Illness*, 39(2), 212–226.

Tronto, J. (1993). *Moral boundaries: A political argument for an ethic of care*. London: Routledge.

Vreugdenhil, A. (2014). Ageing in place: Frontline experiences of intergenerational family carers of people with dementia. *Health Sociology Review*, 23(1), 43–52.

Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M. J., & Pasquier, F. (2016). Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia*, 15(5), 1082–1099.

Williams, F. (2004). *Rethinking families*. ESRC CAVA Research Group. London: Calouste Gulbenkian Foundation.

Williams, S. J., Higgs, P., & Katz, S. (2012). Neuroculture, active ageing and the 'older brain': Problems, promises and prospects. *Sociology of Health & Illness*, 34(1), 64–78.

Winch, S. (2006). Constructing a morality of caring: Codes and values in Australian carer discourse. *Nursing Ethics*, 13(1), 5–16.

Zarhin, D. (2018). Conducting joint interviews with couples: Ethical and methodological challenges. *Qualitative Health Research*, Advance online publication. doi:10.1177/1049732317749196