

# **A QUALITATIVE STUDY OF THE SHARED EXPERIENCE OF HUMOUR BETWEEN PEOPLE LIVING WITH DEMENTIA AND THEIR PARTNERS**

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## **ABSTRACT**

Humour is a complex social and emotional experience which could constitute a positive resource for people endeavouring to live well with dementia. However, little is currently known about the shared use and value of humour in dyads where one person has dementia. The purpose of this study was therefore to explore how people with dementia and their care partners experience, use and draw meaning from humour in relation to their shared experiences of dementia and their ongoing relationships. Ten participant dyads (the person with dementia and their spousal partner) took part in joint semi-structured interviews. Interpretative Phenomenological Analysis revealed eight subthemes that were subsumed under three superordinate themes: 'Humour has always been there and always will be'; 'Withstanding Dementia' and 'Renewing the Value of Humour in Dementia'. Overall, the findings suggest that humour, in different forms, can represent a salient and enduring relationship strength that helps dyads maintain well-being and couplehood by providing a buffer against stressors associated with dementia. The findings highlight the potential value of integrating a dyadic perspective with strengths-based approaches in future research into how people live well with dementia.

Key words: dementia; humour; couplehood; relationships; Interpretative Phenomenological Analysis

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## INTRODUCTION

Supporting people with dementia to live well is a public policy objective and research priority across nations (e.g. Department of Health, 2015), but relatively little is known about what living well comprises, what factors support it and how it is best facilitated (see Clare *et al*, 2014). If living well with dementia means the continued presence of well-being and related positive experiences then it is important that these are fully understood so that they can be sustained to the greatest extent possible.

The use and expression of humour is highly pertinent to understanding what it means to live well with dementia. From a positive psychology perspective humour represents a trait-like character strength regarded as part of the virtue of 'transcendence' – an ability to 'forge connections to the larger universe and provide meaning' (Peterson & Seligman, 2004, pg.412). However, styles of humour use also vary in their valence and social functions. In contrast to the aggressive or self-defeating use of humour, positive humour styles involve maintaining a humorous approach to life to sustain well-being in the face of adversity and/or using humour to enhance relationships (see Overholser, 1992; Martin, 2007). As such, humour is an inherently social experience (Provine, 2004) and existing research highlights how positive humour enhances intimacy, harmony and empathy in close relationships (e.g. see Butzer & Kuiper, 2008; Hampes, 2010).

Humour has long been considered an important indicator of well-being in dementia (see Kitwood & Bredin, 1992) but researching this connection is not straightforward. The use or study of humour in dementia may be objected to on moral grounds (e.g. Hunt, 1993) because of the potential threat posed to dignity and self-hood should people with dementia themselves become the targets of negative humour. Used aggressively, humour could trivialise important personal experiences and marginalise people perceived as 'others' (see Guenter *et al*, 2013), processes antithetical to person-centred approaches to dementia (see Kitwood, 1997). Research into humour in dementia is further complicated by the view that cognitive impairment precludes, rather than augments, its full appreciation and expression (see Mak & Carpenter, 2007). Narrow, bio-medical perspectives on dementia that emphasise losses and deficits (Mitchell, Dupois & Kontos, 2013) do not easily accommodate

the possibility that humour remains valued and actively embraced by people living with the condition.

Despite this there are good reasons to take seriously the role of humour in dementia. A systematic review of positive lived experiences in dementia confirmed that humour is a salient and meaningful aspect of people's attempts to cope positively (Wolverson, Clarke & Moniz-Cook, 2016). Several studies have directly explored humour use in dementia. The ability of some people with moderate to advanced dementia to use and benefit from aspects of humour was documented using case study approaches by Moos (2011). A qualitative study by Liptak and colleagues (2013) found that in focus groups of people with mild cognitive impairment and Alzheimer's disease humour was present and formed themes including silliness, sarcasm, and commenting about the difficulties in dementia. Such findings suggest that people with dementia can engage in humour and actively use it as a coping mechanism despite cognitive impairments. Intervention studies conducted to date support this view by demonstrating that it is possible to engage people with dementia in humour interventions that have a demonstrable effect on well-being (see Stevens, *et al.* 2011; Low *et al.* 2013).

Whilst research also indicates the likely value of humour for carers (e.g. Tan & Schneider, 2009), people with dementia and their care-partners tend to have been researched separately and how humour functions in the context of relationships where one partner has dementia therefore remains unclear. This is a pertinent area of enquiry given that humour can facilitate empathy and bonding but also because sustaining self-hood and well-being in dementia inevitably must occur in a positive social context (Kitwood, 1997; Sabat & Harré, 1992; Langdon, Eagle & Warner, 2007). As such, there is a growing interest in taking a dyadic perspective on living well with dementia (Braun *et al.* 2009) and, specifically, investigating experiences of couplehood, i.e. how people preserve a sense of shared identity and well-being in their close relationships (Hellström, Nolan, & Lundh, 2007). A dyadic perspective focusing on couplehood seeks a relational and transactional understanding of well-being, identity and person-hood, recognising that people with dementia can remain active partners in their close relationships, rather than passive recipients of care.

Whilst the importance of humour within the context of couplehood in dementia has been suggested by previous reviews of lived experiences (see Snyder, 2001) and isolated personal accounts (see Smith & Smith, 2002) no research to date has directly examined how both members of a couple dyad experience and draw meaning from humour and what functions it has in their relationship. This has important implications for further developing interventions and approaches to dementia care that can foster positive emotional experiences within the context of ongoing relationships. The subsequent aim of this study was to explore shared experiences of humour in the lives of people living with dementia and their partners. Reflecting the nascent state of literature in this area, an exploratory approach was taken, utilising qualitative methodology. The study aimed to answer two research questions:

1. How do couples experience and use humour together in relation to living with dementia?
2. What meanings does humour hold in the relationship between the person with dementia and their partner?

## **METHODOLOGY**

### ***Sampling and Setting***

Participants were recruited on a volunteer basis from both NHS and voluntary sector settings in the North of England. Ethical and research governance approval was obtained via an NHS Research Ethics Committee and two NHS sites.

Sampling was opportunistic yet purposive in that participants were only invited to take part if they were willing and able to talk about humour in the context of living together with dementia as a couple. People were invited to take part in the study if:

- They were aged 65 or over as it is likely that younger adults define and experience humour differently (Herth, 1993).

- They had received a dementia of diagnosis more than 12 weeks previously in order to reduce the potential influence of adjusting to the diagnosis itself (see Vernooij-Dassen, *et al.* 2006).

In addition, participant dyads were invited to take part if only one member of the couple had a formal diagnosis of dementia.

The included sample consisted of 10 participant dyads. All dyads were in spousal relationships and co-habiting in the community at the time of the research. Table 1 outlines participants' demographic details (pseudonyms are used to preserve anonymity). Age range was 66-90 years (average age 75.9, SD = 6.74). Average duration of relationships was 44.5 years (SD = 9.42). In each dyad, one member had a (self-reported) clinical diagnosis of dementia, the types including Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Mixed Dementia. The approximate average length of time since receiving a diagnosis of the dementia (self-reported) was 43.6 months (SD = 42.6).

**Table 1. Self-reported Demographic Data**

<b>Dyad Number</b>	<b>Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Time Since Diagnosis of Dementia</b>	<b>Length of Relationship</b>
<b>1</b>	<b>Jim</b> - living with Vascular Dementia	79	Male	8 months	57 years
	<b>Marjorie</b>	78	Female		
<b>2</b>	<b>Angela</b> - living with Alzheimer's Disease	71	Female	4 years, 3 months	36 years
	<b>Dave</b>	68	Male		
<b>3</b>	<b>Val</b> - living with Vascular Dementia	72	Female	4 years	53 years
	<b>Roy</b>	74	Male		
<b>4</b>	<b>Agnes</b> - living with Mixed Dementia	90	Female	5 years	27 years
	<b>Howard</b>	88	Male		
<b>5</b>	<b>Iris</b> - living with Alzheimer's Disease	82	Female	5 years	42 years
	<b>Betty</b>	73	Female		

6	<b>Raymond-</b> living with	72	Male	7 months	42 years
	Alzheimer's Disease				
	<b>Sheila</b>	72	Female		
7	<b>George-</b> living with Mixed	86	Male	6 months	57 years
	Dementia				
	<b>Pat</b>	80	Female		
8	<b>Dereck-</b> living with Lewy	79	Male	4 months	45 years
	Body Dementia				
	<b>Sue</b>	69	Female		
9	<b>Joan-</b> living with Alzheimer's	75	Female	4 years	40 years
	Disease				
	<b>Peter</b>	75	Male		
10	<b>Judy-</b> living with Alzheimer's	66	Female	12 years	46 years
	Disease				
	<b>Steven</b>	69	Male		

### **Data Collection**

As part of the recruitment phase of the study, prospective participants were provided with an information pack prior to obtaining their written consent to participate. In keeping with recognised good practice in dementia research (Hubbard, Downs & Tester, 2003), interview questions were included in information packs at the recruitment stage to aid informed decision making regarding participation and also to subsequently help participants prepare for the interviews and fully consider their experiences. Data was collected through one-off semi-structured interviews conducted jointly with each couple in their own homes. Brief demographic data was gathered from dyads using a written form prior to commencing each interview so that closed questions were not used within the interviews themselves. An interview schedule was designed based on a phenomenological perspective and which incorporated 'funnelling' (Guba & Lincoln, 1981) whereby open questions were combined with probes in order to elicit information about particular experiences of humour in participants' relationships currently and prior to diagnosis and also the meaning (perceived role and functions) of humour (e.g. *How does humour affect your relationship with each other? Does humour play a part in your lives together now since the diagnosis of dementia?*). Interviews lasted between 24 and 81 minutes. Each interview was video-recorded and the recordings were transcribed verbatim.

### **Analysis**

Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin., 2009) was used as a framework for designing the semi-structured interviews and for subsequently analysing transcribed data in relation to the research questions. IPA aims to understand how people make sense of their lived experiences and is applicable to exploring couples' experiences of living with dementia (e.g. Robinson, Clare & Evans, 2010). Interview data were analysed using the process described by Smith and colleagues (2009). Initially, interview transcripts were carefully read and re-read by the lead researcher (HH). Initial descriptive, linguistic and conceptual comments relating to couples' lived experiences were then noted for the first transcript and converted into emergent themes. Patterns in these themes were then identified and grouped. This process was then repeated for each transcript. Finally, themes from each of the transcripts were integrated and connections and patterns between themes were explored iteratively by the research team. Overarching themes were then identified,



defined and subsequently reviewed and audited to ensure they were grounded in the transcripts. Non-verbal data arising from the video-recordings was not formally analysed but was used where appropriate to help contextualise and enrich verbal data at the transcription stage.

IPA recognises the significant role played by the experiences and assumptions of researchers in the process of interpretation as they attempt to make sense of the participants trying to make sense of their experiences (the ‘double hermeneutic’ process). We therefore acknowledged our own assumption that people can live well with dementia and that it is possible for people with dementia to have meaningful experiences of humour. These assumptions reflect our experiences and values as clinicians and researchers and our critical awareness of the impact of negative social discourses surrounding dementia (e.g. Mitchell, Dupois & Kontos, 2013). The undue influence of these assumptions was recognised and mitigated through the use of peer supervision, continual critical reflection and iterative checking that themes were grounded in the data (see Chan, Fung & Chein, 2013; Morrow, 2007).

## FINDINGS

Three superordinate themes comprising 6 sub-themes emerged from the data. These are summarised in Table 2 and described in full below.

**Table 2. Themes in Couples’ Shared Experiences of Humour**

<b>Superordinate theme</b>	<b>Subtheme</b>
<b>Humour has Always Been There (and always will be)</b>	<i>Our Humour</i>
	<i>Still Laughing Together</i>
<b>Withstanding Dementia</b>	<i>Changes and Challenges</i>
	<i>Holding onto Humour</i>
<b>Renewing the Value of Humour</b>	<i>Making Light of It</i>
	<i>Increasing Positive Emotions</i>

### **Superordinate Theme 1: *Humour Has Always Been There (and always will be)***

This overarching theme encapsulates the enduring presence of humour within participants' relationships and their implicit expectation that this would continue into the future. Humour was experienced as a natural and spontaneous aspect of their couplehood, almost to the extent they did not need to question its presence or role.

*It's natural humour, people don't think about it, you don't analyse it, it's just there'*

(George)

Within this, the first subtheme reflects the intimate nature of couples' shared humour, how they felt shared ownership of it and how it therefore helped to define their couplehood. The second subtheme reflects the enduring nature of their humour over time and through adversity.

#### ***Our Humour***

Humour was experienced as an intrinsic part of each couple's relationship that occurred without thought or intention. Some couples explained that humour occurred so naturally in their relationship they were not consciously aware of actively being humorous with each other. In addition, all of the couples felt that humour had always been a feature of how they related to each other and therefore constituted something of a cornerstone of their relationship. Some acknowledged they had originally made a conscious decision to find a partner with a good sense of humour. For others it was the process of the interview that enabled an exploration of how humour may have brought the couple together:

*'....this [humour] might have been some of the attraction between us...we were poles apart on our backgrounds erm but that is possibly thinking about it something that erm we'd got in common'* (Howard)

Shared humour was an intimate experience for several couples. It had evolved within their relationship into a unique, private experience:

*'I mean we don't need to say a lot to make each other laugh because we know what we're talking about before we start (Sheila laughs)' (Raymond)*

*'We can say things and do things....we find humorous, but other people wouldn't appreciate' (Dave)*

Although couples described humour as something that was 'just there' (spontaneous and natural) it was evident by their descriptions that humour played an active role in the success and longevity of their relationships. Raymond described this in terms of a 'bonding process'. Some couples, in particular Judy and Steven, were very aware of this process:

*'Yeah we were saying humour's kept us together' (Judy)... 'Together' (Steven)...  
'Throughout, like you know' (Judy)... 'Yeah' (Steven)*

*'.....people who don't seem to have humour, don't seem to last long' (Judy)*

Another couple implied that humour was an important mechanism in maintaining a happy relationship but without seeming to be consciously aware of this:

*'We've always had banter' (Howard) 'Yeah we've never had a good fall out have we?'  
(Agnes)*

### ***Still Laughing Together***

This sub-theme represents the ways that participants' experienced continuity in the ways they expressed humour with each other. Couples described how humour continued to manifest itself in shared amusement and laughter in their everyday lives. Couples often cited holidays or special occasions that were experienced as ongoing sources of mutual humour:

*'We've got lots to laugh about and be you know [sic] about. We're old and yet we're still having a good life, we can still go on holiday and buy nice things....' (Betty)*

The enduring presence of expressions of humour was evident throughout interviews as couples shared humorous stories and jokes and laughed together. This appeared to mirror the presence of humour in participants' everyday lives:

*'Oh we don't stop laughing (both laugh)'* (Val)

Whilst shared expressions of humour remained present in couples' lives, for some there appeared a tension between maintaining this whilst acknowledging changes brought about by ageing.

*'I mean we are old ladies, our sense of humour is different to what it was when we were young'* (Betty)

However, whether or not couples experienced changes in their shared sense humour, continuity in the expression of humour together remained salient and valued.

### **Super-Ordinate Theme 2: *Withstanding Dementia***

This overarching theme relates to couples' experiences of actively holding onto humour within their relationship whilst facing threats to their humour that emanated directly or indirectly from dementia.

Dementia was perceived to bring a number of changes and challenges which posed a threat to the continuity of humour and because of this it appeared that couples were faced with having to reappraise and renegotiate aspects of their lives together. Protecting their shared humour and holding on to it appeared a key aspects of this process. However, there was a continuum in the extent to which dementia was experienced as a potential threat to humour. For some couples, dementia undermined the quality of humour and the frequency of its expression:

*'It's [humour] not what it was'* (Jim).....*'I don't think you laugh as much, just things get you down more than anything'* (Marjorie)

For others, dementia was not perceived as a direct threat to humour, again highlighting how its experience was enduring:

*'it has always been there and personally I don't think it's changed....it's all just the same in our relationship now and with Agnes' dementia'* (Howard)

Overall, couples exhibited a commitment to hold on to humour but, to varying degrees, oscillated between trying to maintain the same shared experience of humour i.e. maintain the same sense of identity as a couple, and adjusting their humour i.e. renegotiating their shared identity, in order to adapt to the changes brought about by dementia.

### ***Changes and Challenges***

Couples varied in the extent to which they felt prepared to recognise changes in humour that might be caused by dementia. Some couples had not actively reflected on the potential for dementia to change humour within their relationship prior to the interview and only came to this realisation as they spoke about their experiences. Others recognised that their shared experiences of humour could be lost in the future as a result of the progressive nature of the condition.

*'I suppose people start having a sense of humour and say we've got to laugh about it then some people in about three or four years can't laugh very much can they?'*  
(Betty)

Challenges experienced by couples seemed to reflect key points of transition and adjustment in dementia. The process of coming to terms with the diagnosis of dementia signified a particularly challenging time, where humour was displaced by negative emotions such as shock, worry and fear:

*'There's not been so much [humour] there because it was a big shock you know and we are still coming to terms with it'* (Sheila)

Couples also reflected on how humour re-emerged further on in the adjustment process, possibly linked with a process of acceptance and coming to terms:

*'I couldn't accept the fact that she couldn't do what she did before...but now I have accepted it more and we just laugh about it, we have to'* (Peter)

Cognitive changes linked with dementia represented a threat to couples maintaining shared humour within their relationships. Couples described how they noticed that the person with dementia was finding it more difficult to understand and appreciate the humour they had always shared as a couple:

*'... but many times she's thought we'd been arguing and we haven't'* (Steven).... *'and I think that's maybe more since I've got Alzheimer's int it?'* (Judy)... *'mm yeah'* (Steven) *'...the more his dry sense of humour...I've taken it the wrong way'* (Judy)

Dave spoke about how the changing abilities of his wife meant that it became more difficult for him as a caregiver, and this stress and tiredness as a caregiver had a significant impact on his humour:

*'We get depressed, demoralised, demotivated, all this comes in and it's difficult to keep pulling yourself and keep going... it all impinges on our everyday humour'* (Dave)

Some couples felt that as a result of dementia their lifestyles had changed and this, combined with physical and cognitive decline, meant that some activities that they had previously enjoyed were more difficult to do now, in turn resulting in less opportunities for humorous experiences:

*'Well we have such a limited lifestyle erm that there aren't, there don't seem to be the opportunities, funny opportunities that come up sort of thing'* (Pat)

### ***Holding on to Humour***

Despite the challenges to humour dementia posed, or even because of them, it was evident that couples were also actively striving to maintain the place of humour in their

relationships. There was an evident active need to hold on to humour even when this was difficult. For some this was experienced almost as a necessary part of adjustment:

*'We are still coming to terms with it but I mean we still do try and laugh at things you know because you have to you know otherwise you would go barmy wouldn't you'*  
(Sheila)

Active attempts to maintain humour represented a change in how several couples had previously experienced humour within their relationship:

*'I think years ago it was more natural, just come naturally, whereas now.....yes that's changed, I'm working at it now'* (Dave)

Similarly, there was often a need to re-evaluate and adapt humour in order to ensure it remained a shared experience within their relationship, a role described usually by care-partners:

*'Things are changing all the time and it's just thinking of different things to make her laugh'* (Dave)

*'That's the problem actually, it's the fact that he does forget but you've got to sort of do it in the moment otherwise it's not good'* (Sue)

In addition, there was a sense that being able to hold on to humour was enabled through couples' loving and supportive relationships:

*'I think if you love somebody and you're with somebody you do laugh about it. Alright I'm not saying you're gonna laugh all the time, sometimes I'm gonna go argh, but not very often'* (Betty)

### **Super-Ordinate Theme 3: *Renewing the Value of Humour***

This super-ordinate theme encompasses two subthemes that relate to couples' shared sense of the increased significance of humour for them in living with dementia. Humour was considered an increasingly important resource in relation to living with dementia by all of

the couples and was often framed as a shared coping strategy. The meanings and perceived functions of humour as a shared coping strategy were encapsulated in the sub-themes, *Making Light* and *Increasing Positive Emotions*.

Whilst for some couples humour was *'just as important now as it used to be'* (Howard), there was also a clear sense that the value of humour was undergoing renewal and gaining salience in living with dementia. Some couples appeared to have been consciously aware of the increasing importance of humour prior to being interviewed. For them, living with dementia had already increased the salience and meaning of humour:

*'I couldn't imagine dementia without humour.... I think if there wasn't humour in a dementia situation, the situation must be a lot more sad'* (Peter)

Progressing through the interviews, participants revealed how crucial humour had become in their relationship since the diagnosis of dementia and how humour was helping them cope with dementia going forward. This reflected a growing appreciation that humour was becoming increasingly valued:

*'I always felt that a little bit of humour here and there helps everyday but er I think it's now become a little more so'* (Howard)

For others, however, the interview process itself seemed to be a new realisation about the meaning and significance of humour for the couple:

*'I never realised how important it was, but now I do. I've had a reason to try and analyse it and see what benefit it is'* (Raymond)

As couples sustained and renewed the value they placed on humour, they described shared experiences relating to its role in coping with dementia and sustaining their well-being.

### ***Making Light of It***

Humour was used by couples to maintain a shared positive attitude in response to living with dementia. This was often linked with choosing to accept and stay in the present



moment rather than worrying about the future, particularly with regard to the personal prognosis of dementia. Raymond expressed this as a positive feature of his relationship that allowed him and his wife to find a new perspective on living with dementia:

*'It makes you come to terms with the presence [sic] because it's so much in the presence [sic].....I certainly see it as a positive aspect, one of the few positive aspects that I can come up with at the moment (laughs).....But if it changes me perspective, our perspective I think on that then that will be good for us'* (Raymond)

Similarly, humour was used by other couples to re-appraise and find a new perspective on situations connected with the challenges of living with dementia. Often, couples described using humour in a general way to avoid feeling overwhelmed by dementia:

*'I sometimes think if we didn't laugh we'd cry (laughs)'* (Pat)

During the interviews couples told numerous stories of times they have laughed together when the person with dementia would do things that would make them both laugh:

*'Was it flour I put in the fridge and milk in the cupboard? (both laugh)'* (Judy)

Couples told detailed stories of experiences that made them both laugh at the time. Jim and Marjorie told a story of when Jim had lost the white bucket that he was using to do the gardening. The couple explained how they had both searched long and hard for this bucket, coming to the shared conclusion that someone else had taken it. Eventually, Jim realised that he had not even been using a white bucket. The couple laughed together whilst they retold these stories.

As such, couples appeared to unite against and effectively externalise dementia by regarding it as a new source of humour in their relationship:

*'Mainly you get some more material out of it [dementia], to you know have some fun and a bit of a laugh'* (Sue)

This shared approach made it safe to laugh at dementia or its effects (rather than laughing at the person themselves) as a way of coping. This characterised several evident humour-based coping strategies including:

- Turning a negative into a positive: *'I can put the same carry on movie on every day (laughs)'* (Dave)
- Joking about dementia itself: *'...and we didn't ask to join [dementia] it just came! (both laugh)'* (Jim)
- Masking or minimising impairments: *'...age dunt know, month, date, year, dunt know' (Roy) 'I never take any notice of those things you see (laughs)'* (Val)
- Person with dementia making fun of themselves: *'Go get the gun! (both laugh)'* (Val)

The apparent use of negative styles of humour between some couples is striking but can be interpreted in relation to relationship context and intended function. For example, whilst Val's exclamation of "Go get the gun!" could appear self-defeating (and also potentially aggressive on Roy's part), it was not conveyed in this tone during the interview (i.e. their non-verbal behaviour toward each other at this moment indicated warmth and closeness) and was not uncomfortable to observe. In the context of their relationship this appeared to be a consensual form of humour that Val and Roy had previously enjoyed together and which they were now both using to diffuse tension by actively making fun of the felt gravity of their situation.

### ***Increasing Positive Emotions***

*'It's the best medicine is laughter'* (Roy). *'It is'* (Val)

Couples experiences of humour included a recognition that the act of laughing itself increased their experience of positive emotions and improved their mood:

*'Whatever worries you may have they disappear with humour don't they?'*  
(Raymond)

To this end, some couples described actively trying to make themselves and their partner laugh:

*'....just have a good laugh and you seem to relax and er immediately feel better....it lifts your spirits'* (George)

Participants described how humour helps to foster more positive feelings in social situations that may otherwise be difficult to negotiate:

*'helps you feel more comfortable and that helps you to relax in company'* (Raymond)

The use of humour as a way of increasing positive emotions was particularly important for partners without dementia. Some partners described that, in the caregiving role, humour and laughter provided them with relief from the negative emotions that emerged from the various emotional challenges they face:

*'It's a release, it's breaking the frustration, the tension, the aggravation, the anger...'*  
(Dave)

## **DISCUSSION**

This is the first study to seek insight into shared experiences of humour in the lives of people living with dementia and their partners. Research in this area has isolated the experiences of people with dementia from their partners / families and has mainly focused on experiences of humour from the perspectives of caregivers. This is not consistent either with a dyadic perspective on living well with dementia or an interpersonal account of the positive functions of humour. Conjoint interviews in this study therefore enabled dyads to co-construct and communicate the meanings of shared lived experiences of humour, thus revealing its role in the preservation of their sense of couplehood.

Overall, the findings highlight not just the presence and salience of humour for the couples but also their active attempts to maintain its continuity and utilise it as a way to positively adapt to and cope with dementia. In turn, this represented couples' ongoing efforts to

maintain a shared sense of identity as a couple whilst negotiating a tension between maintaining humour as it once was and changing and adapting humour in response to the challenges of dementia. Renewing the value of humour appeared a key process in resolving this tension.

The findings of this study require further examination with larger samples in order to explore their generalisability but they have important conceptual and clinical implications in their own right. The finding that humour is experienced as an enduring and salient feature of close relationships that is actively drawn on in living with dementia highlights its importance as an enduring character strength linked with the ability to transcend adversity (Peterson & Seligman, 2004). This echoes previous research findings that indicate the importance of experiencing and expressing humour as an aspect of living positively with dementia (Wolverson, Clarke & Moniz-Cook, 2016; Liptak *et al.* 2013).

At the same time, a dyadic perspective allows us to frame humour as a potential *relationship strength* in dementia that couples utilise together within the context of their pre-existing and ongoing partnership. One way it has been suggested couples sustain their sense of couplehood this is through 'making the best of things' through 'experiencing life's little pleasures', 'searching for the positives' and 'living for today' (see Hellström *et al.*, 2007). Our findings resonate with these themes as humour appeared to serve different functions for the couples at different times. These functions included fostering the experience positive emotions, maintaining a positive perspective, and being in the present rather than worrying about the future. As such, the findings indicate that humour functions as a resource that couples use together to sustain their resilience and remain sensitively attuned with each other despite dementia (see Wadham *et al.* 2016).

It is possible that partners with and without dementia play differing roles in their relationships with respect to the positive functions of humour. For example, partners without dementia may initiate humour more and experience it as a coping resource whilst partners with dementia use humour to maintain positive relationships and stay focused on the present. Because the current study focused on shared experiences and meanings, such issues were not explored directly but further research in this area could be valuable in

clarifying the degree to which specific positive functions of humour in dementia are shared and which are specific to partners with / without dementia.

The findings highlight how further work is needed to develop humour-enhancing interventions for couples living with dementia. To date four studies have evaluated the impact of humour interventions in dementia (Hafford-Letchfield, 2013; Low *et al.*, 2013; Stevens, 2011; Walter *et al.*, 2007) but they did not consider dyadic experiences of humour and how these might be facilitated and sustained over time. As such, clinical initiatives could usefully adopt a relationship-centred approach to humour in dementia in order to help dyads find ways to renew the mutual value of humour and maintain ways to laugh together, thereby maximising the potential for humour to continue to act as a shared coping strategy that facilitates well-being and couplehood. Further longitudinal research is needed to test such an approach and to further explore potential links between dyadic humour styles (including their complementarity) and levels of well-being experienced by both members of the dyad over time. The potential ability of people with dementia (and their care-partners) to treat dementia itself as target for humour is particularly relevant here. Superficially, partners with and without dementia appeared at times to engage in negative styles of humour (self-defeating / aggressive) when discussing the challenges of dementia. However, using these styles of humour in a shared and complimentary way, in the context of a close and supportive relationship, actually appeared to represent a meaning-based coping strategy that allowed couples to protect their relationship and well-being by taking ownership of and subverting dementia stereotypes. As such, further research into the complementarity of humour styles and also the use of 'dark' forms of humour by and with people with dementia is warranted.

Methodological considerations also highlight the need for further research to examine the generalisability of our findings. As this was a cross-sectional study experiences of humour in relation to dementia over time remain highly pertinent given the temporal nature of dyadic adjustment to dementia (e.g. Clare *et al.* 2012). In keeping with a qualitative and phenomenological approach, our sample size was small and fairly homogenous but included one same sex couple, leaving open the possibility that diversity influences the way humour is used and experienced in dementia. The purposive element of our sampling method could

have created volunteer bias; participants may have had a pre-existing positive bias towards humour and / or strong pre-existing relationship quality. Negative experiences of humour may therefore have been under-represented.

Providing participants with interview questions prior to semi-structured interviews taking place is consistent with good-practice in dementia research (Hubbard, Downs & Tester, 2003). It is possible that in this study this strategy inadvertently constrained spontaneous meaning making within the interviews if participants pre-planned their answers but this was arguably mitigated by the fact that interviews were semi-structured; as such, participants were invited to further elaborate and explore experiences and themes elicited by pre-prepared questions. Levels of cognitive impairment were not formally assessed but it was likely that participants were experiencing mild to moderate dementia and the findings clearly indicate that the participants living with dementia had the capacity to appreciate and engage in humour. However, the experience and function of humour with respect to progressive cognitive impairment remains an important area to explore; couples in this study expressed a fear that humour would be lost as dementia progressed. Observational methods could be used to further investigate humour experiences in advanced stages of dementia and in relation to couplehood and caregiving (see Moos, 2011).

There is a realistic concern that connecting dementia and humour may inadvertently victimise people and trivialise their experiences (Hunt, 1993). This perhaps mirrors how applied positive psychology can be criticised for minimising the struggles of people experiencing real adversity (Schneider, 2011). However, in keeping with a dialectical positive psychology perspective (see Lomas & Ivtsan, 2015), we fully acknowledge the interplay between the adversities experienced by our participants' and their active use of humour in their relationships. The findings of this study therefore support a balanced and asset-based approach to understanding how people draw on strengths and resources to cope, maintain quality of life, and live well with the challenges of dementia (see Clarke & Wolverson, 2016). This study highlights how people with dementia and their partners can (re)claim and renew their shared styles of humour and how this could have positive effects on their couplehood and well-being. This is a powerful way of reversing social stereotypes whilst contributing to

a conceptually-informed account of how people and their care-partners can live well with dementia.

**Declaration of Conflicting Interests:**

The authors declare no conflict of interest.

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