Section 2: Research Paper

Understanding self-conscious emotions: how partners of individuals with dementia feel

about themselves

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Abstract

The current study explores the experience of self-conscious emotions in eight partners of people living with dementia in the community. Using an interpretative phenomenological analysis (IPA) approach, data from eight individual semi-structured interviews were collated and analysed. As a result, three themes were developed; 'guilt as a consequence of marriage beliefs and motivator of caring behaviour', 'discussing dementia elevates embarrassment but decreases guilt' and 'difficulty of feeling proud of caring within the traditional boundaries of marriage'. The findings highlighted the consequences of role expectations, particularly marital roles, on increasing negative self-conscious emotions such as guilt. Moreover, partners also identified how social interactions and relationships had consequences for both increasing and elevating negative self-conscious emotions. Consequently, recommendations are suggested for future research and clinical practice when working with partners of people living with dementia.

Currently, there are 47.5 million people living with dementia worldwide and this number is increasing by 7.7 million each year (World Health Organization, 2016). As a result, more family members are providing care to their loved ones in community settings (Prince, Prina, & Guerchet, 2013). Moreover, partners or family members can experience a deterioration in their own health and wellbeing due to providing care to someone living with dementia. Specifically, one meta-analysis found that people who provided care to adults with a variety of mental and physical needs, experienced higher levels of stress and depression compared to non-carers (Pinquart & Sorensen, 2003). Additionally, after taking on the caregiving role, carers experienced a decline in subjective wellbeing, self-efficacy and physical health. Furthermore, a review of quantitative studies suggested that factors such as the presence of behavioural difficulties, reduced family support and the severity of dementia increased negative experiences of individuals who provide care to people living with dementia (Schoenmakers, Buntinx, & Delepeleire, 2010). However, there are differences in the experiences of partners compared to other family members who provide care. For example in the review by Pinquart and Sorensen (2003) differences in reported stress and depression between care providers and non-care providers were significantly larger in samples consisting of partners than in samples of adult children. Therefore, initial studies suggest that providing care to a partner can have a greater impact on emotional and physical wellbeing compared to other care providers.

While an increasing number of studies have explored general emotional experiences there remains a limited understanding about how this impacts upon care providers' emotional response to themselves. In particular, limited research exists on the experience of self-conscious emotions in individuals who provide care to their partner living with dementia. There are a number of theories which explore the development of self-conscious emotions, including the dominant self-discrepancy theory (Higgins, 1987). Specifically, this theory

suggests that self-conscious emotions, such as pride, guilt and shame, are the result of an individual's cognitive evaluations of their own perception of themselves comparative to how they and their behaviours are viewed by other people (Kim, Jorgensen & Thibodeau, 2011). Moreover, self-conscious emotions can also be a consequence of individuals comparing their 'ideal self' to their 'actual self' and behaviour (Higgins, 1987). As a result, individuals can become motivated to change their behaviour in order to make it consistent with their own and the expectations of others.

Furthermore, from an evolutionary perspective self-conscious emotions have an adaptive function in regulating behaviour and maintaining social relationships (Tomkins, 1963). For example, some negative self-conscious emotions aim to preserve an individual's social status and relationships through promoting prosocial and moral behaviours (Kim, Jorgensen & Thibodeau, 2011). For example, when an individual experiences feelings of guilt they are more likely to engage in reparative or prosocial behaviours, such as apologising or engaging in caring behaviours (Tracy, Cheng, Robins & Trzesniewski, 2009). Specifically, feelings of guilt may encourage individuals to put additional effort into the caregiving role by continuing to provide care for a longer period. Alternatively, experiences of shame are associated with feelings of inadequacy and inferiority which cannot be remonstrated by a change in behaviour (Gilbert & Andrews, 1998). As a result, individuals can withdraw from social situations to prevent further criticism of their personal abilities (Tangney, 1999). However, individuals who care for people with dementia may experience an increase in feelings of inadequacy due to criticisms that are sometimes made by other people (e.g., not providing good enough care or doing things for themselves rather than their partner). Therefore, individuals who provide care may be more likely to engage in prosocial behaviours to avoid feelings of shame and guilt, regardless of consequences for their own wellbeing.

In particular, negative self-conscious emotions can have implications for an individual's psychological wellbeing. Specifically, of the limited studies available, a meta-analysis suggested that an increase in experiences of shame were related to low mood (Kim, Jorgensen & Thibodeau, 2011). Moreover, feelings of inadequacy and subsequently low mood can be reinforced when caring for someone with a progressive illness, as the level of care required continues to increase (Martin, Gilbert, McEwan & Irons, 2006). However, there are mixed quantitative findings with regards to the consequences of other self-conscious emotions, such as guilt, on psychological wellbeing (Gonyea, Paris & de Saxe Zerden, 2008; Martin et al., 2006). For example, short term guilt can be a motivator for people to change their behaviour i.e. provide additional care to a relative. However, striving to provide more care initiated by prolonged feelings of guilt may ultimately result in psychological distress, exhaustion and depersonalisation (i.e. burnout as defined by Maslach & Jackson, 1981) for the carer. Moreover, an increase in caregiver burnout can result in people living with dementia being admitted to care homes at an earlier stage (Gaugler, Yu, Krichbaum & Wyman, 2009). Therefore, both the avoidance and experience of negative self-conscious emotions can result in a deterioration in psychological wellbeing.

Furthermore, positive self-conscious emotions (self-compassion and pride) can also have a positive impact on social relationships and psychological wellbeing. For example, in a study with nursing teachers, it was suggested through the development of self-compassion, individuals also developed empathy (Wiklund-Gustin & Wagner, 2012). Furthermore, a recent review of the literature suggested that self-compassion is important in the development of empathetic concern, altruism and the prevention of burnout in all healthcare professionals (Raab, 2014). Similarly to other self-conscious emotions a strong social function is associated with the experience of pride. Specifically, research has distinguished between the 'promotion of pride', which enhances an individual's social status and 'prevention pride', which protects

the individual from negative social appraisals (Grant & Higgins, 2003). Consequently, by maintaining social status and relationships individuals can reduce the psychological distress experienced as a result of social exclusion and isolation.

Consequently, the present study aims to explore the experiences of self-conscious emotions in people who provide care to a partner with dementia. Specifically, the experiences of participants within the current study will be captured and analysed using a qualitative methodology. Moreover, the study will take an interpretative phenomenological (IPA) approach, as described by Smith, Flowers and Larkin (2009). IPA aims to explore participants' lived experience of a particular phenomenon and how they make sense of their personal experiences (Smith, 2004). Moreover, IPA requires researchers to reflect on the understanding they bring to a subject area while allowing this understanding to be shaped and developed by 'stepping into the world' of participants (Fade, 2004). Consequently, this approach acknowledges the interaction between participant's construction of their lived experiences and also how these experiences are understood by researchers.

Method

Design and Epistemological Position

Phenomenology is concerned with exploring the lived experiences of individuals and the consequences this has for their understanding of the world (Fade, 2004). Specifically, individuals experience the world in different ways which is reflected in variations in language and behaviours displayed. As a result, IPA aims to study these differences and commonalities in understanding the lived experiences of participants. Indeed, IPA has been associated with a critical realism perspective which accepts that there are layers to how reality is constructed. Specifically, it is argued that there are 'truths' about reality but individuals develop their own perception and meaning of reality. Moreover, when

researchers explore the meaning that individual's create, they themselves are influencing the

interpretation of reality (Smith, 2009). Therefore, the current study aims to explore how

individuals develop the meaning they have of the world and the influence that the research

may have on understanding this.

Prior to the recruitment of participants, inclusion and exclusion criteria were

developed. Specifically, the inclusion criteria stipulated that (i) participants would be

partners of people with a diagnosis of dementia; (ii) to gain access to a large number of

partners of whose partner had received a diagnosis participants would be under the care of a

memory service; (iii) and in order to be able to compare what it was like to live with their

partner before the diagnosis, partners should have been cohabiting for at least five years prior

to the dementia diagnosis. Additionally, the term 'partner' refers to an individual in an

intimate relationship with a person with a dementia diagnosis. Furthermore, the following

individuals were not recruited for the study: (i) individuals who did not live with their partner

and (ii) individuals who themselves had a diagnosis of dementia.

Once participants were recruited to the study, their experiences were explored using a

qualitative methodology, using IPA as the specific method (protocol in section four, appendix

one). Data were collected through semi-structured interviews which lasted an average of 45

minutes. Each of the interviews were then transcribed by the lead researcher and

individually analysed using the six stage IPA approach described by Smith et al. (2009).

Data Collection

Eight participants were recruited from a memory assessment service within the north west of

England (table 1). Specifically, nurses within the service distributed study information packs,

which included information sheets (section four, appendix 9). Additionally, information

posters (section four, appendix 13) were displayed around the memory clinic, where

individuals would attend appointments. Potential participants then had the opportunity to

opt-in to the study and contact the researcher directly (section four, appendix 10). Following

recruitment, data were collected by audio recording eight semi-structured interviews with

eight individual participants. Specifically, prior to the start of the study a semi-structured

interview guide was developed with input from two members of a local service user group

(section four, appendix 12). The interview guide included questions regarding participants'

experiences of self-conscious emotions both prior to and following their partner's diagnosis

of dementia. Moreover, this ensured that the language used was appropriate and specific

enough for the target population. The audio recordings from each interview were

anonymised and transcribed individually by the lead researcher.

Analysis

The data from each transcript were analysed using the six stage IPA approach described by

Smith et al., (2009). Specifically, the first stage involved becoming familiar with the first

transcript by reading and re-reading the data. The next stage involved making three types of

initial notes exploring the semantic language and content used with each transcript (table 2).

In particular, descriptive comments regarding content, linguistic comments highlighting

language used and conceptual notes which are more interpretative are made. The third stage

involved developing emergent themes by combining similar emergent ideas highlighted

within the previous stage.   Stage four involved the identification of connections between the

emergent themes. Once the first four stages had been completed for the first transcript the

process was repeated for the remaining transcripts, noticing any repeated or new emerging

themes. Finally, patterns were observed across each of the transcripts in order to develop the

final themes.

Furthermore, throughout the analysis process the researcher utilised supervision sessions to reflect on how their own biases and experiences may have impacted upon the results. In particular, the researcher considered how being a newly married individual may have influenced their interpretation of marital vows and how this may have consequences for caring for a partner. Moreover, a reflective journal was completed following each interview to highlight any reflections or issues that may have arose during the interview. Therefore, supervision sessions provided an opportunity to objectively discuss the researcher's interpretations of the participant's experiences.

Quality

A number of frameworks exist to appraise the quality of qualitative research. Specifically, one frequently used method was suggested by Yardley (2000) and uses four broad principles. Specifically, the first principle is described as 'sensitivity in context' which relates to the study's acknowledgement of factors such as the socio-cultural context of the participants and existing literature within the research area. The second principle is 'commitment and rigour' which broadly refers to the thoroughness of the study procedure and how this is implemented. Similar to the previous principle, this involves the researcher being sensitive and responsive to the words of each participant. Additionally, the third principle, 'transparency and coherence' describes the clarity in which the research processes is written and ease at which the research could be replicated. Finally, the last principle is 'impact and importance' which aims to identify what the research contributes to the current understanding of the specific research field in addition to fulfilling the original aims of the study. Throughout the current study the lead researcher has reflected on these principles in order to maintain a consistent level of quality.

Ethical Process

Ethical approval was provided by a UK NHS Research and Ethics Committee panel and further approval was given by the Health Research Authority (section four, appendix three). All participants were informed that their participation in the study was voluntary and that they could withdraw at any point up to the analysis stage. Furthermore, all participants provided written consent and were informed about all known aspects of the study prior to agreeing to participate (section four, appendix eight). All audio recordings were anonymised at the point of transcription, including participants being referred to by pseudonyms. While it was anticipated that there would be no negative consequences to taking part in the study, participants were provided with information regarding local support services in addition to their GPs being informed of their participation (section four, appendix 11).

Results

Three themes were developed utilising the transcribed data from each of the interviews.

Guilt as a consequence of marriage beliefs and motivator of caring behaviour

The first theme describes the consequence of participants being aware of specific expectations associated with their role as a partner. In particular, many participants described how holding strong beliefs about marital roles and responsibilities had consequences for their perception of their care giving role. Moreover, partners reported feeling guilty if they did not fulfil their perceived marital responsibilities and as a result this motivated them to provide a more intensive level of care. Indeed, most participants, including the one participant who was not legally married, described their perception of marital roles, commitments and expectations of the relationship.

In relation to marital roles, James, for example, described how previously he and his wife had specific roles within their marriage but that this had changed as her dementia progressed:

> Well, she was…she did everything. I used to think that if ever she went before me I would have to get in the coffin with her because she just did everything, you know, the kids, all the insurances that was the type of person she was. She just, I was, I went out to work, came back and did the decorating whatever but she made all the decisions. She didn't need me to make a decision for her whereas now she couldn't even make a cup of tea. It's…it's degrading to see the way she is. (James).

 Moreover, all participants had experienced an unspoken expectation from friends, family and services that they would provide care to their partner living with dementia. Specifically, James described how he felt his wedding vows were an explicit expression of his responsibilities to his wife, '…it's just part of my duty, you know, you make those vows in sickness and in health. She's nursed me through my bad times so it's just the same.' (James). However, while most participants initially accepted and embraced the caregiving role, as their partner's dementia progressed, some began to feel restricted and burdened by these expectations. Specifically, some participants felt judged by other people if they did not meet the expectations of providing care, despite care demands increasing. One participant, Sandra, reflected on her experience of observing another partner being judged for placing his wife in long term care:

At first I judged him like everyone else and thought he was being selfish, he should

take care of his wife at home as long as possible. I feel sorry for him now because

everyone has said he shouldn't have put her in a home and he has a responsibility to

his wife. (Sandra).

Consequently, participants were concerned that they would be judged by other people and

this would result in feelings of guilt. As a result, a need to avoid feelings of guilt motivated

participants to engage in pro-social behaviours (e.g., providing care to their partner) as not

doing so may result in them being judged and rejected by other people.

However, for some participants, by providing high levels of care and not disclosing

any difficulties they were experiencing, this often gave the impression that they were coping

well. For example, John described how he would only disclose difficulties to some family

members but not others due to not wanting to appear that he could not cope,

I did tell me [my] sons and me [my] own but I wouldn't tell, like, her brothers or her

sisters. She's only got one sister left but I wouldn't tell them you know, cos they used

to say 'oh are you doing all right, are you?' and I'd say 'oh yeah, yeah, it's ok', you

know, but I wouldn't say 'oh it's hard and all that to them' and let them know. (John).

While it may have been possible to provide this level of care in the early stages of the

disease, as the disease progressed this may have become too much for partners to manage

alone. Consequently, in some cases this caused conflicts or difference in opinion about

caregiving between generations. In particular, some adult children did not understand the

impact of caregiving on their parent because caregivers would not admit they were

struggling. For example, Laura described how she and her children disagreed about her

husband being admitted to long term care but that this was partially due to her children not

being fully aware of the difficult situation, 'I honestly don't think it will be long before he has

to go away but our, my children don't want that but really they're not here all the while with

him are they?' (Laura). However, these opinions were often not conveyed to other family

members through fear of damaging relationships with people who provided some support.

Similarly, some participants reported negative experiences with healthcare professionals but

did not feel they expressed feelings of frustration or disappointment due to a perception that

they should be grateful of any support that was offered. For example, John described feeling

disappointed and abandoned due to inconsistent support from statutory services but had not

felt in a powerful enough position to express this:

> I remember when it started and ermm, Dr (psychiatrist) he, ermm, he sort of said a
> nurse would come out at the beginning. But no one ever came. And then I went to see
> the doctor, Dr (GP) and he ermm, he phoned them up and went mad and said 'oh I've
> got Mr (participant) here'. 'Oh there'll be someone there at 2 o'clock' and I was here
> and no one ever came so I never bothered, you know what I mean? I just ermm, either
> they're too busy or it was really. At the beginning there was no support you know?
> (John).

Consequently, participants often felt they would be judged as selfish or ungrateful by other

people if they were to express their own feelings or needs. Moreover, being judged as selfish

or ungrateful could suggest that they were putting their own needs before their partner's and

subsequently result in participants feeling guilty. Therefore, often participants did not

express their own needs and feelings to avoid being judged and subsequent experiences of

guilt.

Similarly, due to the lack of control associated with dementia, some participants

described feelings of guilt at not being able to make things better for their partner. One

participant, Sandra, described how she felt guilty that her husband's ability to engage in his

hobbies was deteriorating. As a result she felt a responsibility to support him to continue to

pursue his interests,

> I feel like he is imprisoned by it, he's trapped at home most of the time so I try to take
>
> him out every day. Usually I take him to the golf course, he can go hit a few balls, get
>
> some exercise and fresh air while I sit in the car and read. I don't like golf. I let him
>
> do his thing while I do mine. I do feel guilty, he's lost his freedom. (Sandra).

Moreover, all participants acknowledged that they could not be responsible for their partner's

dementia but nonetheless still felt guilty about the effect that dementia was having on their

life. Specifically, some participants acknowledged feeling guilty that dementia was reducing

their partner's independence and quality of life while in comparison they were still able to do

many of the things they used to do. For example, Sandra described feelings of guilt that her

husband could no longer access the community independently: 'I do feel guilty, he can't

drive. He's just not safe so I try to take him out as much as I can. It's not fair on him.'

(Sandra). Interestingly, participants rarely discussed the consequences their partner's

dementia diagnosis had on their independence and quality of life. For example some women

within this cohort relied upon their husband to drive but when this was no longer possible community access was limited for both individuals. As a result, many participants neglected their own needs as a way of coping with increased demands and also a way of managing feelings of guilt. For example, Sandra described how she put her husband's needs before her own physical health needs, '(husband) comes first (pause) but like now I need to arrange for a blood test so I have to make the appointment early again but I can wait. (husband) needs to be ok first and then I can think about myself.' (Sandra). Consequently, for some participants experiencing feelings of guilt in relation to their partner's diagnosis resulted in them attempting to reduce these feelings or alternatively avoid further experiences of guilt by putting their partner's needs before their own.

Furthermore, a couple of participants were unsure of how to describe their marriage since their partner's diagnosis. For example, when asked how long he had been married one participant (John) was unsure how to respond, 'It's been 49 years this month, ermm well it would have been, still is, I'm not sure how that works now (pause) we've been together longer than that though.' (John). Moreover, participants experienced feelings of guilt regarding changes in roles and power dynamics within their marriage. However, if participants did not take on a more involved role by providing care to their partner they also felt guilty that they were not adhering to their marital responsibilities. Therefore, due to a conflict between maintaining power balances within their marriage and their perceived marital responsibilities participants were unable to avoid all experiences of guilt.

Discussing dementia elevates embarrassment but decreases guilt

For many participants disclosing their partner's dementia diagnosis could both reduce and increase experiences of negative self-conscious emotions. Specifically, some participants felt that they wanted to disclose their partner's diagnosis when in public to explain their partner's

behaviour; however this could result in them feeling guilty or embarrassed for disclosing

their partner's personal information. For example, James recalled his embarrassment at his

response to disclose his wife's diagnosis,

> Sometimes, especially if you are just at the shops, (wife) loves kids, she loves the
>
> kids and sometimes she goes up and makes too much and come on…I feel
>
> embarrassed and I…I… without thinking I'm saying "she's got dementia" and I
>
> shouldn't be saying that just because she likes kids. (James).

While this quote suggests that James was embarrassed by his need to explain his wife's

behaviour, it also suggests that his wife's behaviour could be judged negatively by other

people. Specifically, James acknowledges that being over friendly with children at this time

in the UK is sometimes perceived as suspicious and potentially dangerous. However, for

older generations this behaviour would not have been perceived in a sinister manner. As a

result, this quote reflects the consequence of culturally acceptable values and behaviours on

an individual's experience of embarrassment.

Furthermore, participants whose partner was in the early stages of dementia and those

whose partners had been living with dementia for a long time appeared to be less concerned

with the responses of other people. One participant, Sandra, had started to see her husband's

dementia as something that was not always socially accepted, similar to other behaviours:

> I thought about being embarrassed but then I thought, sod it! (laughs). I always
>
> wondered why people would be offended by his behaviour. It's like breast feeding; I

never understand why someone would be so offended by a baby being fed? Anyway,

I've learnt not to feel guilty for other people being offended. (Sandra).

Therefore, it could be suggested that in the early stages of dementia fewer challenging

behaviours are exhibited and therefore there are fewer negative responses from others.

Additionally, for partners of those who have been living with dementia for a long time they

may have had multiple difficult experiences of which people making judgements about their

partner's behaviour in public was only one. Consequently, over time participants had made a

decision not to be concerned by the judgements made by others as they had more important

priorities to cope with when caring for their partner with dementia.

Furthermore, many participants managed their own understanding and the responses

of other people by describing their partner's dementia within an illness framework. For

example, Hannah, described how viewing her husband's dementia as similar to a physical

illness normalised the experience for her, 'No, I don't have any problems with other people,

no, cos the chap next door has got bad legs and (husband) is forgetful, (name) the other way

has a bad heart so no, no, it's just the same really.' (Hannah). Specifically, for some

participants describing their partner's dementia diagnosis as a neurological condition or

illness enabled other people to better understand their partner's behaviour and difficulties, as

this provided a familiar frame of reference. Therefore, when other people better understood

their partner's dementia, participants reported fewer experiences of shame and

embarrassment related to this.

Consequently, some participants found that attending dementia support groups was

helpful in reducing negative self-conscious emotions. For example, participants experienced

fewer feelings of guilt or embarrassment while in the presence of support groups and other

carers of people living with dementia. In particular, groups which promoted the importance

of self-care in carers and encouraged partners to discuss their experiences of providing care

were found to be the most helpful. Moreover, groups which were co-facilitated by carers of

people with dementia were found to be more beneficial than those which were primarily

facilitated by staff who they felt could not empathise with their situation. One participant,

Sandra, described how attending a local dementia support group helped her feel included and

that she was not alone: 'You get to learn that you aren't alone too, only people who live with

someone with dementia knows what you are going through, you don't know until you live

with it.' (Sandra). However, several participants recalled occasions when staff had disclosed

their own experiences of having family members with dementia and as a result participants

felt more connected to these staff members. In particular, Sylvia described the importance of

feeling the group facilitator could understand and empathise with her situation:

…it was just nice (support group) but the girl who was leading was just excellent,

very bubbly and very chatty. She told us a bit, oh somebody asked her, her own father

is in a home with Alzheimer's but she had only done the course within the past five

years when he took ill so but I mean she shared that with us, which was quite

something. (Sylvia).

Therefore, having validating and supportive interactions not only protected participants from

further experiences of guilt or embarrassment but also enabled them to experience

compassion and a sense of belonging.

Difficulty of feeling proud of caring within the traditional boundaries of marriage

Within this theme participants described their difficulty in accepting feelings of pride for behaviours they considered to be part of traditional marital roles. In particular, most participants were uncomfortable at the thought that they may be proud of how they were managing their partner's care. Moreover, participants felt that it was part of their role as a partner to provide care and therefore they should not feel proud. For example, John described feelings of embarrassment as a result of people suggesting he should be proud:

> Yeah, people tell me all the time that I should be proud but I hate that, like "oh you've done that well or you've done this or that, you've done marvellous"…I don't think about it, anyone would do it…I think well if you're man and wife you should do it really, shouldn't you? (John).

Moreover, some participants felt that they had let their partner down when they were admitted to respite care or had been prescribed medication. As a result, some participants felt there was no reason to feel proud and in some cases felt guilty and embarrassed that they were unable to manage their partner without the use of external interventions. In particular, John described feeling guilty that his wife was admitted to an in-patient hospital for a short period, despite acknowledging he had little control regarding the situation:

> I felt guilty that she got (admitted to hospital), it was out of my hands then that she got worse because they took her in but I just wanted to help to get her out of there. I

just wanted to, you know, get her out but the doctors used to say "oh you've got to

wait for meetings". (John).

It is therefore suggested that the expectation to provide care to a partner with dementia not

only increased the experience of some negative self-conscious emotions but also

compromised the experience of positive emotions such as pride. Moreover, the expression of

pride in their own achievements may not be socially acceptable if providing care to a partner

with dementia is perceived as an expectation of marriage. For example one participant,

Philip, appeared confused as to why someone would be proud when caring for their partner:

'I wouldn't say I was proud, proud? No, how can you be proud of looking after the person

you love? It's what you do isn't it?' (Philip). Moreover, unlike negative self-conscious

emotions, participants were less likely to share experiences of pride with other people - even

people who were caring for a partner with dementia. This would suggest that it is more

socially acceptable to experience and discuss negative self-conscious emotions than pride,

even with the shared understanding and empathy from people in similar situations.

Consequently, the inhibiting of pride may protect partners from social judgments and

potential rejection from individuals who perceive caregiving as a partner's duty.

Furthermore, some participants, particularly older participants, described how

emotions such as pride were not encouraged in the past. Specifically, some older participants

suggested that the expression of pride was often perceived as boasting and socially

unacceptable. For example, Hannah described how compliments and praise were often not

part of past interactions,

I don't think anybody ever did (praise) (chuckles)… you just got on with things. See,

it was different in those days to how it is now. You know when people say 'oh gosh

that's nice' they just didn't you know…you just have to do things. (Hannah).

As a result, the use of emotional language, in particular the expression of pride in their own

achievements, was limited in the interviews of older participants. Moreover, most

participants acknowledged that their comfort in reflecting on emotions and the use of

emotional language had not changed since their partner had developed dementia. Therefore,

it is suggested that within the interviews of older adults the lack of explicit references to pride

in their own achievements were due to long established social beliefs.

Despite participants explicitly rejecting experiences of self-pride in relation to

providing care to their partner, some participants did describe self-pride in relation to other

situations. Specifically, participants were able to reflect on feeling proud of themselves when

they had helped someone else. For example, one participant, Sandra, described feeling proud

that she had provided emotional support to another caregiver within a support group:

You get to learn that you aren't alone too, only people who live with someone with

dementia know what you are going through. You don't know until you live with it. It

also makes you feel good in a way just listening other people, you feel as if you are

helping them so yeah it makes you feel like you are doing some good. (Sandra).

This quote also suggests that Sandra may have few experiences of feeling that she was

benefitting others, despite providing a high level of care to her husband. Moreover, as this

role was not related to their perceived marital responsibilities, participants felt that they were

going above what was expected of them. As a result, they felt that they were supporting

others by choice rather than doing it through a sense of duty. Consequently, for many

participants, interactions in which there was a shared empathy were one of the few

experiences of compassion either from themselves or others.

Furthermore, participants were able to experience feelings of pride in relation to other

activities, such as volunteer work or other job roles. Additionally, most participants were

comfortable in expressing pride towards other people, such as their children or grandchildren.

One participant, James, described feeling proud of his children: 'Oh, I'm proud of the kids

and the wife but the kids yeah. Well, that's my eldest lad (points to photograph). Ermm

yeah… proud as punch, I'm proud of them all. We did something right (laughs).' (James).

This quote also implies that some participants had experienced repeated failures and as a

result had the perception that they are often wrong. It is anticipated that partners caring for

someone with dementia can experience repeated feelings failure or not providing good

enough care due to the progressive nature of the disease.   It is anticipated that not only was it

more socially appropriate to express feelings of pride in relation to behaviours which were

not seen as responsibilities but participants found it easier to express pride in relation to non-

challenging situations. Moreover, participants did report feeling proud when there were

positive outcomes for other people such as someone thanking them for their help or seeing

another person visibly happy. Additionally, it was noted that several participants questioned

their contribution towards the study but appeared pleased when they were reassured and

thanked for their help. For example, during Hannah's interview she commented,

Hannah: I'm not much help am I?

Researcher: Yes, you've given me some really useful answers, it's been helpful

talking to you.

Hannah: Oh good, I'm glad (chuckles). (Hannah).

Consequently, participants relied upon positive feedback and praise from others to

experience feelings of pride rather than being initiated by their own internal evaluations.

Therefore, as an individual providing care to their partner, it is anticipated that given the

difficult nature of dementia there is a reduced number of tangible positive outcomes.

In addition to experiencing increased feelings of self-pride, participants reported

fewer experiences of negative self-conscious emotions in relation to non-caregiving roles.

Specifically, participants reported fewer experiences of guilt and embarrassment as a result of

experiencing pride. For example, Simon described experiencing pride in the absence of

embarrassment, 'Yes, I suppose I am proud, I've got a few awards for the work I do… I

enjoy doing it, it's putting back into the community which I like and I'm proud of saying

that.' (Simon). It is suggested that compared to the role of care provider there are fewer

expectations and scrutiny of other roles which could result in individuals feeling guilty or

embarrassed about not meeting expectations. Therefore, the pressure of role expectations on

partners can hinder their ability to experience self-pride by increasing their experiences of

negative emotions such as guilt and embarrassment.

Discussion

The current study explored the experience of self-conscious emotions in partners of people

living with dementia in the community. While the experience of participants varied due to a

variety of factors (e.g., length of time since diagnosis, presentation of dementia and perceived

support) three common themes were identified. Specifically, marital beliefs were found to have consequences for how participants perceived their responsibility to provide care to their partner. Moreover, if participants felt they were not fulfilling their responsibilities this resulted in experiences of guilt. These experiences resonate with identity theories in which an individual's identity is derived from socially constructed roles and expectations (Hogg, Terry & White, 1995). Specifically, it is suggested that individuals frequently monitor the implications of their behaviour on maintaining the equilibrium between their own and others' perceptions of their identity. Moreover within the context of identity theories, Heise (1979) proposed an affect control theory in which individuals are motivated to engage in behaviours which seek to reaffirm the meaning both they and others attach to their identity. For example, within the present study participants felt that it was an expectation of their marital role to provide care to their partner and as a result engaged in behaviours which confirmed this role i.e. providing care. However, when these behaviours did not reaffirm their marital identity (i.e. participants felt they were not providing good enough care) participants may choose to withdraw from social interactions which would highlight this discrepancy. Consequently, engaging in role-congruent behaviours preserved individual's self-identity and prevented the experience of painful self-conscious emotions such as guilt.

Furthermore, within the current study participants reported increased feelings of embarrassment that they were disclosing their partner's personal information. However, as a result of sharing and normalising their experiences with other people in similar situations their experience of guilt reduced. Within identity theories it is argued that it is interactions with other people that create meaning for individual's roles and identities. Specifically, interacting with other people who occupy similar roles (e.g. partners of people living with dementia) enables the meaning of each role to adapt and develop based upon the experiences and expectations of both individuals (Hogg et al., 1995). Moreover, having reflexive roles

based on changing circumstances increases the opportunity for partners to feel that they are

fulfilling the expectations of each role. As a result, partners experience an increase in

feelings of self-worth and psychological wellbeing (Thoits, 1991). Therefore, within specific

interactions individuals are active agents in shaping and developing roles which meet their

current needs and subsequently reduce experiences of guilt.

Additionally, participants generally reported fewer experiences of positive self-

conscious emotions such as pride or self-compassion. In particular, participants felt

uncomfortable at the thought of experiencing pride in their caregiving role as they perceived

it as the duty or obligation. Consequently, participants had implicitly developed a hierarchy

of self-conscious emotions in which it was preferable to experience some emotions (e.g.

embarrassment) rather than other emotions which were more painful (e.g. guilt or pride).

Similarly, a recent review of the current guilt research has suggested that the experience of

sustained guilt can be more detrimental to an individual's psychological wellbeing than other

self-conscious emotions. Specifically, individuals often experience guilt in response to the

violation of moral and social norms, which can then result in depressive moods and social

isolation (Carnı, Petrocchi, Del Miglio, Mancini & Couyoumdjian, 2013). Despite

individuals attempting to avoid feelings of guilt by engaging in reparative or over-

compensating behaviours, feelings of guilt can be difficult to avoid. Comparatively,

experiences of other negative emotions, such as embarrassment, are perceived as 'light

hearted emotions' comparative to the impact of experiencing guilt which is seen as more

emotionally painful (Keltner, 1995). Specifically, embarrassment only occurs if an

individual's mistakes are exposed to others and usually occurs following unexpected events

over which individuals feel less responsible (Miller, 2007). Despite participants not

explicitly stating their experiences of shame within the current study, some of the emotional

experiences described did suggest feelings of shame. For example, several participants

recalled experiences of not telling their partner the truth about a situation in order to protect them; however this had left them feeling uncomfortable and as a result they concealed their actions from others. Importantly, the terms shame or ashamed were not used to describe their experience. It is anticipated that acknowledging feelings of shame would imply an acceptance that they had acted in an unfavourable way. As a result, by not explicitly describing their feelings of shame, they were attempting to avoid personal and social condemnation of their behaviour.

However, the preference of experiencing different self-conscious emotions over others is not consistent. Specifically, cultural values and expectations can have consequences for how individuals experience different self-conscious emotions. For example, for some eastern cultures experiencing shame is perceived as a way of demonstrating social awareness and connectedness (Mesquita & Karasawa, 2004). Therefore, in individualistic cultures, i.e. western cultures, individuals are more likely to internalise feelings of guilt which subsequently have a negative impact on their mood.

Furthermore, families of people who sustain a traumatic brain injury have reported experiences of guilt similar to the participants within the current study. During the early stages of their family member's injury, participants reported experiences of depression, guilt, despair and feeling imprisoned (Verhaeghe et al., 2005). Similarly, participants within the current study experienced feelings of guilt in relation to their partner's diagnosis despite knowing that this was out of their control. However, unlike traumatic brain injuries there is no recovery process with dementia and therefore the experience of guilt may differ between these two groups over time. Consequently, experiences of guilt may be related to the initial stages following diagnosis or an acute event rather than the specific illness.

Clinical Implications

As a result of the current study, a number of considerations for professionals and organisations working with partners of people living with dementia can be made. Specifically, participants within this study felt more comfortable with professionals who demonstrated empathy and compassion by disclosing appropriate personal information. However, this is often a debated issue within healthcare professions, particularly clinical psychology. A meta-analysis conducted by Henretty and Levitt (2010) suggested that personal disclosures by therapists enhanced clients' ratings of therapist warmth but did not have any reliable impact on other qualities traditionally deemed important to therapy outcomes, such as trustworthiness and empathy. Moreover, the review notes that there are currently a limited number of studies within this research area and of those studies there is a focus on formal therapeutic interventions. Therefore, there is currently a lack of understanding about how professionals' self-disclosure in less formal therapeutic settings (e.g. peer support groups) impacts upon the relationship and experience of the other person.

Furthermore, there are implications for how and when support is offered to partners of people living with dementia. Specifically, participants within the current study would avoid situations which may elicit feelings of guilt, particularly in the early stages of the illness. However, it was reported that with well-meaning intentions services, friends and family would often provide increased support at these stages which could inadvertently result in feelings of guilt. Conversely, participants were better able to accept support in the later stages when they had adjusted to the diagnosis and were less concerned about the opinions of others. Therefore, the provision of informal and formal support should reflect the fluctuating and unique experience of living with a partner with dementia.

Furthermore, encouraging partners to interact with other partners who provide care is important in facilitating role adaptations. Specifically, services could provide opportunities to normalise some of their experiences and adapt the meanings they hold about being a partner of someone living with dementia. Moreover, it is important that individuals are able to meet with a consistent group of other partners in order for relationships to develop (National Institute for Clinical Excellence, NICE, 2016). Although, guidelines do not specify the type of psycho-education and support groups that should be available to partners (NICE, 2016), it is suggested that information about the impact of emotions should be shared. Additionally, providing social groups or activities for people living with dementia at the same time as groups for partners is vital in ensuring partners can attend without further feelings of guilt.

Limitations

Additionally, the current study focuses upon the experiences of partners rather than other family members due to the specific role and relationship dynamics. However, it is acknowledged that higher levels of distress in partners compared to children and children-in-law can largely attributed to partners typically providing a higher intensity and frequency of care. Therefore, as the experiences of partners' self-conscious emotions are specifically related to their role and relationships dynamics, further research is required to explore how services meet the needs of various care providers.

Furthermore, the findings from the current study suggest that partners experience feelings of guilt when they feel that they are not fulfilling the role expectations of others. However, the role expectations can vary depending on cultural and cohort beliefs. and the current study included participants from one geographical area where there was a similar level of service provision and support. It is also acknowledged that including individuals

whose partners have a range of dementia diagnoses may influence the symptoms their

partners are experiencing and the treatment options available. Furthermore, the study

included participants across more than one generation with ages ranging from 60's to 80's;

which may have impacted upon their experiences and beliefs. Therefore, while the current

study did not focus one a specific dementia presentation or include participants from different

cohorts and cultural backgrounds the findings there are considerations for when working with

all partners of people living with dementia.

Furthermore, this study highlights the need for further research into the experiences of

partners of individuals living with dementia. Specifically, further research with individuals

of different cultural backgrounds is required in order to understand how factors such as

marital vows may influence care giving experiences. Moreover, it is necessary to understand

how cultural beliefs may have consequences for gender roles and expectations for providing

care within a marital relationship. Consequently, future studies should carefully consider

how older people from ethnic minorities can be better represented within research studies.

Conclusion

The current study identified three themes from the experience of self-conscious emotions in

individuals who provide care to their partner living with dementia. However, there was an

overall theme of the importance of social interactions of partner's identity and how they felt

about themselves. Specifically, partners used self-conscious emotions as a way of regulating

their behaviour in line with social expectations. This is particularly important when caring

for a partner with dementia as having good social support can improve partner's experience

of caring giving and their ability to provide care at home for longer. However, due to the

progressive nature of dementia partners often need to adapt the meaning they attached to

specific roles by embracing the experiences of people in similar situations. Moreover,

suggestions are made for future research with other cultures whereby social expectations and

experiences of self-conscious emotions may differ. Consequently, this study highlights the

need for further understanding of the emotional experiences that underpin behaviours which

aim to promote social support and inclusion.

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Appendices

Table 1

Demographic information of eight participants included in current study

Participant pseudo name	Gender	Age	Partner's age, type of dementia and length of time since diagnosis	Length of Relationship	Children?
Hannah	F	83	Husband (82), Alzheimer's disease diagnosed two years ago	60 years married	Five
John	M	69	Wife (69), mixed dementia diagnosed four years ago	49 years married	Four
James	M	73	Wife (73), Alzheimer's disease diagnosed 10 years ago	52 years married, engaged 7 months before	Three
Laura	F	82	Husband (81), Alzheimer's disease diagnosed four years ago	58 years married	Two
Simon	M	76	Wife (76), Alzheimer's disease diagnosed six months ago	50 years married	Three (one died as a baby)
Sylvia	F	81	Husband (84), Alzheimer's disease, diagnosed four years ago	57 years married, knew each other three years before	Two
Philip	M	71	Long term partner (71), Alzheimer's disease diagnosed one year ago	In relationship for approximately 10 years	Children with previous partners

Sandra	F	?	Husband (78), dementia with Lewy Bodies diagnosed four years ago	Married 36 years, known for 38 years	Husband has children from previous marriage

Table 2

Example coding of partial participant transcript

Thesis Interview 1: 'Hannah'- 32 minutes

Interviewer: Can I ask you how long you have been married to your husband?	Demographics Comparison of time- change
Respondent: We've been married for about 60 years and we have lived together for about that too. You see, people didn't live together before they got married in those days… not like now.	Couplehood- 'we'- consistent view of relationship Their time is in the past- different rules- better/fonder time? Looked on favourably compared to relationships now
Interviewer: Do you have any children together?	
Respondent: Yes, we have five grown up children. They're all adults now.	
Interviewer: How long has it been since your husband was diagnosed with dementia?	Pauses to clarify short answers Talking in detail is difficult- avoidance?
Respondent: About two years… yes a couple of years now.	
Interviewer: Can I ask what you did before you started caring for your partner?	Not important- 'just'- view of own role- social gender norms? Low self-esteem- importance of relationship roles vs 'job' roles
Respondent: Ermm I was just a housewife.	
Interviewer: And how long did you do that for?	Thinking about answers- short, factual- only wanting to convey certain information?
Respondent: Ermm since the eldest was born. Ermm he's… he's fifty-seven now.	

Interviewer: And how would you have described yourself as a person back then?

Saying/metaphor

Respondent: Errmm, just like, just like happy go lucky, you know we went out, walked miles, we were just a family really… you know (pause) and as the other children came along they went with us, (pause) you know, we were always keen on music, well you know (husband) still likes his proms and ermm (pause) just just the way people were then, you know.

Interviewer: And how would you say you felt about yourself?

Respondent: Oh I've never bothered (pause) never worried (pause)

Interviewer: Would you say you were quite a positive person?

Thinks about disclosure   No choice

Respondent: Yeah… mind you with (husband) now you've got to be positive… and you have to make all of the decisions now so you know, you know.   Reassurance

Interviewer: And were you happy with being a positive, laid back person?

Reassurance

Respondent: Yes, oh yes, I was… I've never been unhappy (pause) thank god (chuckles). Thinking about disclosure? Nervous?

Interviewer: That's good. Ermm and how would you have felt if you did something really well and other people gave you praise?

Respondent: I don't think anybody ever did (chuckles)… you just got on with things, see it was different in those days to it is now… you know when people say 'oh gosh that's nice' they just didn't you know… you just have to do things… oh you had to scrub your step… (chuckles) oh you have to remember… No choice

Not important- hierarchy? Not important/unusual- 'just'

Importance of family and enjoying life

'we'- couplehood, stable view of relationship

Family as a whole unit, enjoy life, values, importance

Holding back admitting difficulties- what would this mean to self and view of marriage? Accept it as part of marriage responsibilities?

Weakness in admitting struggles- no choice, brave face, 'coper' 'fixer'? View of negative emotions

Doesn't say happy- avoidance of positive emotions

Grateful for what she has- generational? Gender?

Acceptance of past struggles- 'all in it together'

General examples- not personal, distance, 'you don't understand?'

Don't question things/emotions- 'good enough' how is it viewed if you question it? Embarrassed?

<u>Key to coding notes:</u>

Descriptive notes = black

Language notes = blue

Conceptual notes = red