#### **Abstract**

This study is concerned with the impact of chronic depression on partners. Thirteen male and female participants who lived with a partner with chronic depression were interviewed. Data were analysed using thematic analysis. Findings highlighted a need for caregivers to be more centrally involved in their partner's care, given that they face stigma, shifts in role identity and uncertainty which all potentially threaten the level of support they can give their partner. In this sense depression might be described as a "couples disease" suggesting that couples therapy and group support for partners should be more widely available to help reduce the burden on partners and potentially prevent relationship breakdown.

Keywords: depression; caregiver burden; couple relationships; couples therapy; stigma

Couples Disease: The Experience of Living with a Partner with Chronic Depression

Symptoms of "depression" overlap with a number of diagnostic categories and therefore currently fall within a more generic category of "common mental disorders" (CMD) for the purposes of the UK Adult Psychiatric Morbidity Survey (APMS; Stansfeld et al, 2014). The 2014 APMS found that one in six adults were currently experiencing a CMD. While the majority of these fell into a generic "not otherwise specified" CMD category, a large proportion of these will have been experiencing some symptoms of depression along with other symptoms from the CMD family of diagnoses (anxiety, panic disorder, phobias, obsessive compulsive disorder). The APMS found that 3.3% of adults met diagnostic criteria for depression. Over a third of those scoring for CMD had never had a professional psychiatric diagnosis; and yet two thirds believed they had had depression at some point. These data indicate that while "depression" and depressive symptoms are common and also commonly used as a label by adults experiencing a range of CMD symptoms, many people are living in the community with undiagnosed depression or depressive symptoms and without professional help.

Depression poses a significant burden on individuals, their families (Loukissa, 1995) and the state in terms of health and social care costs and thus the benefits of treating depression effectively are widely recognised. UK national guidelines for depression management (2009) produced by the National Institute for Health and Care Excellence (NICE) recommend cognitive behavioral therapies (CBT), behavioral activation, interpersonal therapy, problem-solving therapy, counselling, short-term psychodynamic psychotherapy and couples therapy as well as some pharmacological treatments for depression. The systematic review underpinning these guidelines presents the cost and clinical effectiveness evidence on which these recommendations are based, following the

prevailing paradigm of evidence based practice in which Randomised Controlled Trial (RCT) designs are ranked more highly than others. This process of evidence review and guideline development was used as the basis for a successful economic policy case (Layard, 2007) for increased provision of psychological therapies in the UK (now known as "Increasing Access to Psychological Therapies" or "IAPT") and the significant expansion from 2008 onwards of first line IAPT centres for treating depression and anxiety.

Although couples therapy was included on the list of evidence based treatments for depression, IAPT services to date have primarily provided CBT with short-term psychodynamic therapy provided in some regions. Some IAPT services are now also beginning to offer couples therapy but this is relatively uncommon currently.

Qualitative research can highlight issues that quantitative research, within the strict hierarchical evidence based practice paradigm, is less able to do. Stepping outside of the RCT framework also enables viewing the problem from a community perspective, taking into account the experiences of adults who have not yet accessed assessment or intervention for various reasons. A recent meta-ethnography (Priestley & McPherson, 2016) examined 15 qualitative studies exploring the experiences of living with a relative or partner with depression which point towards the importance of considering relationships in the management of depression. Studies were heterogeneous regarding types of relationship with the depressed individual including parents, children, siblings, spouses, usually in mixed samples. The synthesis revealed a cyclical, psychosocial process that family caregivers undergo while providing care to a person with depression. Four phases were identified: making sense of depression; changes in family dynamics; overcoming challenges; and moving forward.

Only three studies in the meta-ethnography exclusively explored individuals' experiences of living with a partner with depression. Harris et al. (2006) interviewed 9 UK couples together focusing on mutual experiences of support. Bottorff et al. (2014) and Oliffe et al. (2011) interviewed female partners of depressed men in Canada and explored how the men's depression impacted on gender roles. None of these focused specifically on chronic depression which is important to consider given the greater burden and relationship strain likely in cases where depression is an enduring issue within a relationship.

Greater understanding of the specific experiences of partner caregivers is important because of the greater potential for and impact of relationship termination on couples and their families. Depression in couples is strongly associated with marital distress, however there is both evidence that a distressed relationship leads to depression (Papp, 2000) as well as the reverse, such that establishing a causal direction is complex (Beach, 2001). Increased burden can lead to negative attitudes towards the depressed partner, which has been shown to trigger or exacerbate depression and relapses (Keitner, Ryan, Miller, Kohn, & Epstein, 1995). The present study aimed to explore partner experiences in more depth including male and female individuals living with a partner with chronic depression to enable a focus on these critical aspects of couple relationships with a view to contributing a richer perspective on support and intervention needs. The study asks what is the experience of adults in the community living with a partner with chronic depression.

### Method

## Inclusion and exclusion criteria

Participants did not have to be married but needed to be in a long-term relationship with a person with chronic depression. Chronic was defined as depression lasting two years or more, although participants' partners did not have to have had any formal diagnosis of

depression because the aim of the study was to include adults in the community experiencing depressive symptoms who may or may not have had a professional diagnosis. Depression was therefore self-defined in this sample, given the findings of the APMS showing that many adults live in the community with undiagnosed depression. Long-term was defined as at least three years as this might be considered to indicate a couple is in a "companionate" stage of their relationship (Hatfield & Rapson, 1993). Participants whose partners had a diagnosis of a psychotic disorder, bipolar affective disorder or post-natal depression were not included. Only one partner in each couple took part as the aim was to interview caregivers only, although it is possible some of the caregiving partners were also experiencing depressive symptoms.

## Recruitment

Posters were used to recruit participants from community locations across a wide area of the UK, such as libraries and community centres. The advertisement was also placed on a range of online community fora. Initially anyone meeting the inclusion criteria wishing to take part was interviewed; followed by snowball sampling which involved asking people who had already been interviewed to identify other people they knew who fitted the selection criteria (Ritchie & Spencer, 1994).

# **Interviews**

Participants were interviewed about their experiences of living with their partner. A topic guide was designed to facilitate the interviews whilst simultaneously encouraging a participant-led narrative. Topic guides allow flexibility within the interview to follow the participant's lead and to frame questions based on the individual circumstances. There was therefore no fixed set of questions but the topics covered in each interview were the partner's depression, relationship changes, pressures resulting from partner's depression, management

of pressures, available support and reflection. Open-ended, neutral prompts (e.g., "Can you tell me more about that?") were used to facilitate the interviews and minimise researcher influence (Kvale, 1996). Interviews were audio-recorded and transcribed verbatim. Interview length ranged from 55 to 79 minutes with an average of 66 minutes.

# **Analysis**

Thematic analysis (TA; Braun & Clarke, 2006) was used to analyze the data, informed by critical realist theory. Critical realism argues that the world and the knowledge individuals have of it are not the same, because different aspects of reality are experienced. It acknowledges the contributions different perspectives offer and recognises that this perspective provides a partial account of a phenomenon (Joseph, 2004). Unlike relativism, critical realism does not suggest that reality itself is socially constructed, but rather it is the individual's ideas of reality and the associated methodologies used to investigate realities which are socially constructed (Bhaskar, 1978). Bhaskar (1978) argued that knowledge and reality are inherently linked to one another, and therefore reality without the context of knowledge has little meaning, which is pertinent to the present aim of understanding the experiences of living with a partner with depression.

The six phases of TA were followed in a recursive manner: familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. Credibility checks were incorporated into the design, analysis and interpretation. Yardley's (2011) assessment criteria for evaluating qualitative research were employed for guidance and some examples follow of how these criteria were employed. To ensure sensitivity to context, throughout analysis, unexpected findings and observations were actively sought and consideration was given to how they differed from the other themes. Commitment and rigor were demonstrated through the prolonged engagement of the authors

in the data analysis process; the first author (a trainee clinical psychologist undertaking a doctorate) transcribed all of the interview recordings in an attempt to become fully immersed in the data. The first author also carried out initial analysis independently; the first and second authors (an experienced qualitative researcher and academic) reviewed the initial analysis together and developed the themes further, checking interpretations of the data; where there were inconsistencies in interpretation, the third author (an experienced clinical psychologist) reviewed these and agreement was reached through discussion among all three authors. To enhance transparency, evidence of analytic decision-making throughout the research process has been retained, offering an audit trail on request of how the research was conducted. In terms of impact and importance, this study hopes to inform clinicians and wider services about the specific needs of partners and may help to develop more tailored support systems. It will also contribute to the developing body of research into the importance of interpersonal aspects of depression and its treatment within the context of couple relationships. In terms of reflexivity and bias, the first author, who was also the lead researcher and a trainee clinical psychologist, kept a reflective log throughout and discussed observations in supervision, considering how any biases may be impacting on the research process and how to counter the impact of this.

# **Ethics**

Ethical approval was gained from a UK university ethics committee. To ensure informed consent participants were encouraged to contact the researcher if they had any study-related questions following the receipt of their information pack. They were also given the opportunity to ask questions prior to the interview. Interviews took place only once a written consent form had been completed by the participant. To maintain confidentiality, interview transcripts were anonymised removing all identifiable information.

### **Findings**

Participants' ages ranged from 28-73 years (mean=48). There were nine females and four males; all were White British; nine were married. Table 1 describes participants' ages, partners' ages, length of relationship, length of partners' depression and format of interview. Thematic analysis identified four main themes incorporating 11 subthemes (see Table 2). Subthemes are indicated in italics throughout this section.

## **Dawn and Dusk of Diagnosis**

This theme highlights the ongoing process in which caregivers tried out different explanations for their partners' behavior, within which diagnosis of depression could seem at first like a realisation, but then eventually failed to deliver the hoped for solutions.

Participants experienced a period during which they tried to make sense of their partner's newly labelled depression which took the form of a realisation or dawning, *only possible with hindsight*:

So he'd have... days where he was quite down, but I presumed it was because of what was happening. It wasn't until about 2 years ago that we realised that he actually had really bad depression. I presume that he's had it for a number of years really but because of the circumstances, it was difficult to tell. (Alicia)

Participants emphasised that now having a concrete explanation in "depression," they had *something to fix* as a couple. For example, Gemma described a strong desire for there to be a reason for her partner's depression "so we can fix it and make it go away."

Participants attempted to make sense of their partner's depression by separating it conceptually from the person, which they had not done before the label was applied:

I just took it as that was her character. I just thought that was just her, I didn't realise to the extent how much of it was down to the depression. As I was getting to know

her I thought that's just the way Lisa is but then obviously, like I said, I got to know and learn and find out that it's not necessarily her but it was her feeling depressed. So in the early days I just took it that that was what she was like. (Rick)

Identifying stressors provided socially acceptable explanations that protected individuals from perceived stigma around mental health. Further, it seemed that the cause and cure model itself had an intrinsic appeal enabling partners to have a sense of control within an otherwise uncertain and bewildering experience:

But of course at that point it's easy. Of course he's depressed because he's working nights. Everyone knows working nights makes you depressed. Now I could really see it as a proper thing that had a cause: he's depressed because he's working nights on a job he hates. (Loren)

These ideas fit with a model of depression that assumes that a person's difficulties are manifestations of an illness with a contemporary identifiable cause, an illness which is a distinct and separate temporary encroachment of the otherwise boundaried individual. If you can identify the boundary between the individual and the illness, then you can isolate the current causal factors and solve the problem. However, as time passed after diagnosis, it became apparent that depression was more complex and dynamic:

It is an up and down illness definitely, and at the beginning I found it easier to say 'oh it's because of this or because of that'. But life settled down and the depression was still there. There is no reason for it and that is difficult to accept. There is no rhyme or reason, you know, we've got a nice house and a nice life. (Kerry)

## **Couples Disease**

Gonzalez et al (2010) referred to depression as a "family disease," a term which highlighted the profound impact depression has on those living with a depressed individual.

Similarly, the present study suggests that once the idea of curing or eliminating the cause no longer held promise (the "dusk" of diagnosis), depression became very much the couple's problem in that depression came to dominate the caregiver's life and they grappled with issues of loyalty to the person and the all-encompassing depression they brought with them into the relationship.

Participants described depression as all-encompassing, emphasising that the extent of impact on partners is often overlooked or underestimated, like an *invisible coat of lead*:

The biggest difficulty living with someone with depression is that it takes over your life as well and it's not something that can be compartmentalised or kept separate. It's not something that your partner has and deals with but you don't. I think that's very very difficult because it has a profound impact on your life, which is very difficult to manage and deal with. (Rick)

Clare described feeling "repelled" by the thought of being intimate with her partner during his depression, stating "I couldn't do it. I couldn't be that person as well as being his carer and his mother." Pasch and Bradbury (1998) suggested that feeling emotionally supported is a fundamental expectation of a romantic relationship and is linked to relationship satisfaction. A key concern raised by participants in the study was that they did not feel emotionally supported by their partner during times of depression and often felt as if they were left to deal with things on their own, creating a negative dynamic in the couple.

Some participants noticed negative changes in their own personalities, such as reduced confidence, increased stress and worrying more than usual:

Like, life goes on and you cook the dinner and deal with the kids and go to work and do the shopping and all those kind of things. But sometimes it feels like you are wearing a coat of lead. But an invisible one; no-one else knows it's there. (Kerry)

Reflecting the seriousness of couples' commitment to each other as reflected in the traditional marital promise *in sickness and in health*, some participants expressed great loyalty towards their partner and supported them almost without question; this tended to be participants who had been together the longest. For these participants, there was a sense that making adjustments was paramount in maintaining their partnership: "we both do whatever it takes because we value our relationship" (Katie). However, the loyalty was not always a natural experience and for some it seemed forced:

My feeling at this point is that I took him on with great love. At my age there is a great sense of loyalty towards the children and towards him. I'll stick with it, you know. It's not wonderful and it's not good. (Jenna)

Some participants experienced resentment towards their partner because this is not how they had envisaged their relationship panning out: "I did not sign up for this" (Clare). Depression had such a profound impact that for some participants it led to the relationship breaking down either temporarily or permanently. Some expressed despair at the damage caused to the relationship but also a determination to try and make things work:

I think I've fallen out of love with him but we are working on that and he is aware of it. He does know that there have been a lot of times when I've been very upset by it. He knows that it has damaged us. But you know, we are working to get that back together. (Clare)

Participants were clear that living with a partner with depression could be extremely tough at times; however, some expressed that in many ways it had strengthened their relationship by developing a deeper understanding of one another and increasing their confidence as a couple, for example, Barry commented: "now anything that anyone throws at us, we're like 'bring it on'."

## Learning to navigate the "depression" maze

This theme portrays the sense that participants seemed to go through some kind of learning or development process which involved finding ways to cope with their partners' depression. This process tended to begin with reaching a breaking point, followed by seeking support, reforming their own social support, finding ways to cope; yet all the while finding such was the uncertainty of depression, that any turn could lead to a dead end (the "maze") where new coping strategies needed to be constantly in development.

Seeking professional support was generally not a smooth journey and participants described *reaching the end of their tether* and having to really push their partner to seek extra support:

I would just spend days in tears because I didn't know what to do. I was frustrated at him because he wasn't looking for a job at all; he had no motivation. He seemed quite happy just to be at home all day, not really doing anything just staring into space. It was me who made him go and get some help. I said 'something has got to give. It's not fair, me going to work and coming home and being confronted by this'. (Alicia)

Generally, partner's first step towards professional support began with the General Practitioner (GP). Some attended GP appointments alongside their partner due to concerns that their partner would not be fully honest about the extent of their difficulties. Some had been prescribed antidepressants, which could have unexpected impact on the relationships: "the upside was that it stopped her feeling low, but there was also a downside of it and it really did knock some of her personality traits out" (Tom). For partners who were offered talking therapies, participants complained of long waiting lists of up to 16 weeks for brief, time limited support, in spite of a 6 week target for IAPT services (NHS England, 2015).

Although participants felt that attending at least one therapy session would have been helpful

in order to provide more of an understanding about their partner's depression and to be able to generalise the professional support to the home environment, no participants were offered this opportunity, which led some to feel excluded and unimportant. Lack of GP knowledge about local and national resources for joint therapy led some couples to search independently, but often to no avail:

We tried to find places where we could go to talk to people about how to interact with each other, like when someone else has depression how do you deal with that and what do you do? But we could not find anywhere, which was so frustrating because that could be very useful. (Rick)

In face of much frustration around professional support, friends and family provided practical help for some in the form of allowing participants time to have a break from their partner. For others, emotional support provided empowerment to try new approaches in dealing with their circumstances. However, some participants did not like to talk to anybody about their partner's depression. It appeared that participants undertook *selective reform of their social support networks*, often driven by awareness of stigma:

I think as soon as you mention the word depression people think of laziness. They just think 'they can't be bothered to work or go out'. I think depression is sometimes linked with the working class, people who just decide to sit at home watching Jeremy Kyle all day, on benefits. I think there is that sort of stigma. (Alicia)

Some couples kept the depression completely hidden from their friends and family, which sometimes meant avoiding them altogether for the fear of their reactions: "It was difficult to explain to them that actually we're in shutdown at the moment. So the easiest thing was actually not to see them or else it would just spark off another problem" (Tom).

Some couples were selective about who they spoke to about the depression, meaning that their social circle shrunk over time or during times of depression:

There's a stigma attached to it so you don't want everyone to know and then be defined by the fact that they have depression. So with some friends you don't really talk about it as much or at all, but with others yes. (Rick)

In contrast to this, some participants reported that they purposefully spoke about their partner's depression to other people in order to try and reduce the stigma surrounding it.

Looking after oneself was easier for some than others, owing to the varying abilities of participants to recognise their own needs and practical constraints such as work and childcare. Most strategies were practical including exercise, keeping busy and active, gaining more information about depression, writing feelings down, turning to faith and religion, and spending some time away from their partner. Participants described gradual internal shifts in their approach to their own needs over time:

We went to a party last Saturday with people we know quite well. But after an hour and a half he wanted to go home because he couldn't, you know, he couldn't find anyone to talk to. He couldn't engage with it. And I usually give in and go and do what he wants. But instead I thought 'sod it, I like these people and I want to talk to them'. So he went home and just for a change I stayed for another couple of hours and really enjoyed myself. (Katie)

Looking after oneself sometimes meant learning to put oneself first, which took time and often led to feelings of guilt and doubt.

Participants described an array of different strategies they had developed over time, as though they had been *building a toolkit* to manage the depression. Almost without exception this was portrayed as a trial and error process fraught with unpredictability; participants had

tried numerous approaches over time but found that what might work one day does not necessarily work the next. Tom commented, for example, "There's no approach that I used at the beginning that I'm still using or that I haven't refined tremendously."

A common change in approach was that of becoming more assertive with their partner: "the first time around I was on eggshells a lot, a bit like 'hmmm I don't know if I can push you this far' but this time it's very school ma'am type thing" (Clare). Some participants admitted that at times they had used even harder tactics out of desperation to try and encourage a change within their partner:

I became very short with him. I became quite disrespectful towards him. I used to try and shame him in many ways. I was trying everything I possibly could to try and get him out of this situation or prompt him, nudge him, to go in some sort of direction.

(Loren)

This led some to take more of a methodical approach and assess each situation individually: "ok we've got a situation. He's not feeling at all well, he's not right. So how do I... get him out of that?" (Gemma).

Participants described continuous high levels of uncertainty in relation to their partner's depression, as though they were *navigating unchartered territory* daily. The unpredictability of their partner's mood created tension, confusion and frustration: "on the one hand I understand that he is ill. But on the other hand, how can we go from everything being ok to the end of the world is nigh in three minutes?" (Kerry). Participants found themselves constantly monitoring their partners and looking out for signs that something might not be quite right. This sense of always being hypervigilant was described as "tiring" and "emotionally draining". When partners expressed suicidal thoughts or thoughts of self-

harm, participants described a persistent fear about their partner's safety: "I used to worry that I'd come home and find he'd killed himself" (Katie).

There was a large amount of fear shared by participants that the depression may return, which was likened to being on "red alert" or "on guard" at all times; this relentless feeling of uncertainty could be exhausting. For example, Gemma commented, "There are times when he's hit a really low point and I'm silently seething because I think to myself 'why can't you see it? Why can't you see that you were heading towards this?'."

# **Gaining New Perspectives**

Over the long term, some participants reached a form of acceptance about their partner's depression, which is portrayed in this theme. This acceptance seemed to occur as an extension of the leaning process seen in "learning to navigate the depression maze," but also represented a new phase of this process.

The subtheme *something in me shifted* explores the idea that over time participants experience a change in how they viewed the situation and their position within it, likened to an "inner shift" or reaching a level of "acceptance." For some a specific trigger led to change, for example a suicide attempt led one participant to move from a position of frustration to one of empathy and protectiveness. For others the shift occurred gradually and was characterised by a reduction of the sense of responsibility to find a cure:

That realisation that actually in the end I'm not going to resolve this. I am not going to be able to cure her... A mix of frustration, because you do want to cure something, and a release of actually I don't need to constantly worry about what the answer is to this. (Tom)

Although this realisation left some feeling helpless, most participants found the adoption of this position more conducive to their own wellbeing: "it takes too much personal strength, it saps too much energy if I spend too much time trying to do things to make things better for him" (Katie).

Another key shift articulated by participants was a sense of becoming "hardened" to their situation over time. It was sometimes difficult to maintain the same level of empathy towards their partner during long periods of depression or during subsequent episodes; this entailed, either consciously or subconsciously, creating emotional distance from their partner: "I feel like I have to be strong, do it myself, be on my own and do it myself. Because he can't be there for me" (Nicky). Similarly, others described a sense of "having to hold oneself together" and becoming more "inward," "cold" or "independent".

Personal attitudes about depression had been challenged for some participants. They described how they had grown to see it as a more complex and dynamic set of difficulties than that portrayed by the media, making explanation to others tiresome:

I've kind of stopped justifying it now to family and friends. And I've got to the point of thinking 'you either like us for who we are and want to be around us for who we are or you don't'. You know, I'm not going to spend time trying to explain this to everybody. (Tom)

This was certainly not the case for all participants and some continued to struggle with the fear of stigma and lack of understanding from their social circles and the wider community.

In spite of some degree of acceptance expressed, participants retained a sense of trepidation and *fearing the future*. Some expressed desperation as to whether any intervention was going to help or provide long-term improvements:

I just hope that something will work this time because if ECT hasn't worked, the medication hasn't worked, therapy hasn't worked, what then? What happens then? Is

that it? Does he have to go through the rest of his life like this? If we've exhausted all avenues, that's a worry. (Amy)

### **A Cyclical Process**

The four themes described could be viewed as a cyclical process or model. The model begins with a period during which participants tried to make sense of the depression, often wishing they had spotted the signs earlier on. Attributing the cause of the depression to something concrete provided hope and a direction for frustration; however, these explanations were sometimes short-lived. The impact on all participants and their relationships was significant, shifting the dynamics of the relationship in a number of ways as well as affecting participants' own wellbeing. Couples were also faced with external challenges, including accessing professional and community support. Perceived stigma around depression, lack of opportunities to be involved in their partner's care and the lack of support provided for them as informal caregivers were among some of the key frustrations. Participants described their experience of their partner's depression as an ongoing, and at times very difficult journey, during which they developed strategies to look after both themselves and their partner. Uncertainty and unpredictability were unwelcome yet pertinent aspects of all participants' journeys. A longer term process running in parallel with the other themes is that of participants reaching some form of acceptance about their partner's depression. It became apparent that some form of shift was essential in order for the relationship to continue and to allow the relationship to adapt to the depression. Highlighting the cyclical nature of the process, participants spoke about feeling like they had gone back to square one during subsequent episodes of depression and some even described their experience in their own words as "phases" or a "cycle."

#### **Discussion**

The present study identified four themes which are formulated above as part of a cyclical process of adaptation to a partner's depression. Similarly, in a meta-ethnography of qualitative studies on experiences of people caring for someone with depression, Priestley and McPherson (2016) proposed a cyclical process consisting of making sense of depression, changes in family dynamics, overcoming challenges and moving forward. The stages in the present study appear quite similar to this, however, there are some distinct aspects of the findings from the present study which have implications for the partner as opposed to family caregivers and implications for practice. The discussion focuses on three distinct aspects and how they relate to previous research, followed by discussion of practice and policy implications.

# "Dusk" of Diagnosis

Having a perceived explanation for their partner's depression initially provided hope that the depression could be "fixed" once the explanation was "dealt with." This idea fits with a medical model of depression, which is encapsulated more fully in the subtheme *if there's a reason, we can fix it*. The medical model of depression assumes that a person's difficulties are manifestations of an underlying illness or disorder, the origins of which are generally located within the biochemistry of the brain. Within this model, depression is viewed as a distinct and separate add-on to the rest of the individual and therefore if you can identify its boundary then you can isolate and treat it. This perspective appeared powerful for participants in the early stages, and yet it gradually became apparent to participants through time and experience that depression was not so clear cut but was actually much more complex and dynamic. Their partners' experiences were idiosyncratic and not always directly linked with a particular event or cause. This process experienced by participants highlights the debate regarding the medicalisation of patterns of behavior and mood (British

Psychological Society, 2011; Pilgrim & Bentall, 1999). The emphasis on diagnosis offering hope and then being found lacking is somewhat different to the theme "making sense of depression" seen in McPherson and Priestley's metaethnography (2016) and may be related to the community sampling in the present study as opposed to clinic sampling seen in other studies. This highlights that while IAPT and improvements in primary care diagnostic processes may improve detection and referral for psychological treatments, a large proportion of IAPT service users do not complete a CBT package or benefit from it and psychological services are much more limited beyond IAPT, leaving many "diagnosed" adults living in the community without current professional support.

# **Couples or Family Disease**

The present study focused on partner caregivers rather than families in general and while the findings do not negate the suggestion originating from Gonazalez that depression is a "family disease," the findings highlight some specific ways in which couples are affected and can also be central to recovery. In the absence of support for the participants, there seemed several risks to the partner or the relationship, including relationship breakdown or the caregiver becoming depressed or experiencing depressive symptoms. This fits with research on concordant mental health in couples, particularly with depression (e.g., Coyne et al., 1987; Meyler, Stimpson & Peek, 2007; Teichman, Bar-El, Shor, & Elizur, 2003).

Pasch and Bradbury (1998) suggested that feeling emotionally supported is a fundamental expectation of a romantic relationship and is linked to relationship satisfaction.

Because partners were largely providing rather than receiving emotional support, there appeared to be feelings of resentment creating a negative cycle between the couple, supporting previous studies focussing on interpersonal patterns (Keitner, Ryan, Miller, Kohn, & Epstein, 1995). The feelings of loyalty highlighted in the sub-theme *in sickness and in*Pre-publication version of Priestley, McPherson & Davies (2017), Couples' Disease: The Experiences of Living with a Partner with Chronic Depression. Journal of Couple & Relationship Therapy https://doi.org/10.1080/15332691.2017.1372833

health illustrate the difference between partner and other caregivers in that while children, parents or siblings of an adult with depression might be able to spend more time away from or even leave the family home, a partner might not feel at liberty to create this space for themselves. Nevertheless, the overall finding that partners go through a cyclical process akin to acceptance suggests a certain degree of resilience within this sample (e.g., building a toolkit, looking after myself). Similar to Bauer, Sterzinger, Keopke, and Spiessl (2013), some findings also highlight the sense of rewards as well as the challenges from living with a depressed partner. Partner support should perhaps both acknowledge and build on this resilience and positive potential.

# **Stigma and Resilience**

Being selective about which friends and family members they were open with about their partner being depressed was common among participants, with some actively avoiding people who they perceived would respond in a negative manner to their partner's diagnosis. These findings support literature on self-stigma (Ostman & Kjellin, 2002) which suggests that individuals reduce their social networks in anticipation of rejection. Specifically, Stjernsward and Ostman (2008) reported that depression caregivers can feel lonely and isolated as a result of stigma. McPherson and Priestley (2016) also found that stigma was a key challenge for family caregivers. Although there has been an overall 6.4% improvement since 2007 in knowledge, attitudes and intended behavior towards people with mental health difficulties in the UK (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014), the results of the current study illustrate that many individuals living with a partner experiencing depression continue to fear stigmatization and discrimination. However, relating to resilience and positive potential noted above, this study also found that *selective reform of social* 

liberation as a result of choosing to focus on "stronger" and more "loyal" friendships and relationships, whereas Priestley & McPherson note that family caregivers often restored previous friendships at later stages of depression. Again, it may be possible that in recruiting from a community sample who appeared not to be receiving much current support, the aspects of resilience found in the present study findings may result counter-intuitively from the lack of services experienced alongside the "dusk" of diagnosis. The focus on chronic depression may also account for participants appearing to make more permanent reform of their social networks, in the realisation that life needs to change fundamentally rather than temporarily.

### **Clinical and Policy Recommendations**

Findings highlighted that participants felt excluded by professionals in their partner's care and felt that professionals did not acknowledge the significant impact that living with a partner with depression can have. This emphasises the importance of considering couple relationships when working with someone with depression. Although NICE guidelines (2009) include Couples Therapy as an option, not one participant in the current study had been offered this. Bodenmann (2005) has suggested that "common dyadic coping" is where both partners work jointly to solve a problem, and can have better outcomes than "negative," "supportive," or "delegated" dyadic coping. Advocacy for and accessing a service as a couple or for couples by accredited practitioners not only supports existing literature around the importance of couple relationships in depression but may also reduce the feelings of disloyalty towards the depressed partner due to an increased sense of tackling the difficulties together, as in "common dyadic coping." Individuals that attend GP consultations alongside their depressed partner should be asked directly by the GP whether they would like further support and signposting options should be provided. This would require GPs to have greater

awareness of such resources and options. Furthermore, an appointment with the GP on their own should be offered if the partner appears to need extra support. Community based interventions would also be useful to encourage early help-seeking and reducing stigma.

Findings also highlighted that managing persistent uncertainty was difficult for partners (in *Learning to navigate the depression maze*). Moss, Waugh, and Barnes (2008) propose the practice of mindfulness as a way of managing uncertainty. Mindfulness has predominantly been studied as a therapy for stress in a wide range of chronic medical conditions, including pain, fibromyalgia, diabetes and cancer. Less research has been conducted on the effectiveness of mindfulness for caregivers; however, studies that have looked into this area have found positive results (e.g., Whitebird et al., 2012). Local support groups aimed at the partners of individuals with depression could potentially include a mindfulness based element or there could be a case for exploring the potential benefits of mindfulness interventions for couples.

Social policies around caregiver support focus on the formal identity of "carers" and the "cared for" (Henderson & Forbat, 2002). Heaton (1999) argues that the notion of the "relationship" is left invisible by this policy focus due to the emphasis on caregiver/cared for identities. Although many participants described taking on the caregiver role, some did not use this term at all during the interview. This study draws attention to the importance of the couple relationship in considering caregiver burden, whether or not a partner identifies as a "caregiver." In the UK, the Care Act (2014) marked (on paper) a radical shift in the entitlement of caregivers to access support. It entitled caregivers to a Carers' Assessment which assesses their support needs and produces a support plan to enhance their wellbeing and their ability to lead a fulfilling life alongside their caring role. This is particularly relevant in relation to depression, which is often chronic and relational. This study highlights that even

during periods of remission from depression, many partners still experience stress due to the persistent worries of the depression returning. Local authorities and health services therefore need to work jointly to ensure partners are enabled to access caregiver support, for example in having access to local caregiver groups and ensuring caregiver support information helps to reduce the potential stigma of attending. More proactive support for caregivers which builds on their own resilience could save money in the long term through preventing escalation of caregiver burden and potential relationship breakdown which could in-turn escalate depression in the depressed individual.

### Limitations

Although participants were not recruited through clinic populations, many participants reported that their partner had experienced depression for a number of years but neither of them had accessed professional support. This was considered to be an important factor as it moved away from the conceptualization of depression as an "illness" and allowed for an under-represented subset of this population to have the opportunity to share their experiences.

Unfortunately the sample did lack diversity in other respects in that all participants were White British and heterosexual, limiting transferability to an extent, though there was some diversity in terms of gender, age, marriage status, and duration of depression.

Information was not collected about income or family composition. There is likely to be some self-selection bias and, given that many participants talked about feeling guilty talking about their partner, guilt may have played a part for those who chose not to take part.

## **Future Research**

It may be useful for further similar qualitative research to specifically recruit samesex partners and partners from a range of ethnicities; it would also be useful to collect information on income and family composition and to recruit a diverse sample in these

respects. While further qualitative research in which greater diversity was built into the sample, it may also be helpful to explore trajectories of couples and families affected by depression through large household panel datasets such as Understanding Society (see <a href="https://www.understandingsociety.ac.uk">www.understandingsociety.ac.uk</a>) which follows individuals within households over a number of years and enables analysis of a number of social and economic variables alongside couple relationship quality (using the Dyadic Adjustment Scale) and mental health variables (e.g., General Health Questionnaire). Longitudinal household analyses such as this based on community samples rather than clinical samples have the potential to examine trends and trajectories in terms of the impact of mental illness within couples and families.

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