

**Experiences of Living with a Partner with Depression:
A Thematic Analysis**

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Abstract

According to the Office of National Statistics (2011), approximately six million people provide unpaid care to a family member. The growth of interest in the carer role has helped establish the idea that the provision of informal care warrants attention because of the relationship between caring and burden. It has been suggested that living with someone with depression is comparable to that of other serious mental health problems, such as schizophrenia or dementia. Furthermore, there is evidence that partners are most at risk of burden within the informal caregiving context. The meta-ethnography of existing research indicates that qualitative studies which specifically explore the experiences of living with a family member with depression are somewhat heterogeneous regarding types of relationship with the depressed individual. Combining different relationships (e.g. partners, siblings and parents) within the same study makes it difficult to disentangle data and therefore gaining an in-depth understanding of specific experiences is almost impossible. This study therefore aimed to explore the experiences of living with a partner with depression.

In-depth interviews were conducted with nine female and four male participants who live with a partner with depression. A critical realist perspective was held and data was analysed using Braun and Clarke's six phases of thematic analysis (2006), with the assistance of MAXQDA.

Results identified five key themes: 'making sense of the depression'; 'the depression cannot be compartmentalised'; 'a light at the end of the tunnel'; 'learning to navigate the 'depression' maze'; and 'gaining a new perspective'.

The findings illustrate that living with a partner with depression is not a static process and that the needs of the depressed partner are constantly changing. Furthermore, although the findings outline a sequential process that appears cyclical in nature, recognition is given that the phases are dynamic and may overlap. Clinical implications and recommendations are discussed within the context of the Care Act (2014).

Chapter 1 Introduction

This chapter will begin by discussing the concept of caregiving, its effects on the wellbeing of caregivers and the subsequent growth of interest in both policy and practice. It will then provide a brief summary of the diagnostic criteria for depression and outline any changes in the criteria following the recent introduction of the DSM-5 (5th ed., American Psychiatric Association, 2013). Relationship theories and the idea of concordant mental health in couples will then be discussed. Following this, identity control theory (Burke, 2006) will be used to explore the expectations that individuals have within their role as a romantic partner and what happens when these expectations cannot be met. The concept of self-stigma will then be explored and the impact it can have on partners of individuals with mental health difficulties. Finally, this chapter will provide a meta-ethnographic synthesis of existing qualitative literature in the area of living with a relative with depression.

Caregiving

The concept of 'care' has received more attention in recent years in legislation, policy and practice (DoH, 1995; DoH, 1999a; DoH, 1999b; DoH, 2004; DoH, 2010; DoH, 2012, DoH, 2014). Approximately six million people provide unpaid care to a family member (Office of National Statistics, 2011) therefore care has been placed at centre stage and policy has sought to outline who carers are and what support they might need. All UK carers are now entitled to be informed about and receive an assessment of their needs (DoH, 2014). The growth of interest in the carer role has helped establish the idea that the provision of informal care warrants attention because of the relationship between caring and burden (Heaton, 1999; Henderson & Forbat, 2002; Lloyd, 2000).

Researchers generally agree that chronic mental health problems represent a burden to the patient and their family (Loukissa, 1995). Burden refers to the significant amount of strain experienced by relatives, including a range of emotional, psychological, social and financial problems (Loukissa, 1995). Factors associated with higher levels of burden are living with the patient and being closely related to them (Ostman & Hansson, 2004). In light of this information, it has been posited that partners experience the most burden compared to other relatives (Ostman, Wallsten, & Kjellin, 2005). There are mixed findings regarding the relationship between type of diagnosis and burden strength. Some studies suggest that the burden of depression is comparable to schizophrenia (van Wijngaarden et al., 2009) or dementia (Yeatman, Bennetts, Allen, & Ames, 1993). However, others

argue that caring for a relative with depression produces less burden than caring for a relative with bipolar affective disorder or dementia (Chakrabarti, Kulhara, & Verma, 1992; Rosenvinge, Jones, Judge, & Martin, 1998). Women are between 1.5 and 2.5 times more likely to experience depression than men (NICE, 2010) which may imply they are at greater risk of burden. Supporting this idea, Dudek et al. (2001) found that female partners of depressed husbands reported greater levels of depression than vice versa. Conversely, other studies have found little evidence of gender differences (Idstad, Ask, & Tambs, 2010; Pinquart & Sorensen, 2006). Within family caregiving literature, studies tend to focus predominantly on the negative experiences, such as burden and stigma. However, researchers have found that relatives also acknowledge several rewards, including: satisfaction about providing care; character and life experience; and increased cohesion within the family (Bauer, Sterzinger, Koepke, & Spiessl, 2012).

The increased interest in the carer role has also led to a more formal identity of ‘carers’ and they are often viewed as part of the ‘care team’. Some welcome this identity (e.g. Szmukler & Holloway, 2001), arguing that informal carers can support progress through the supervision of medication and encouragement to attend treatment interventions. However, services that construct family carers as being an extension of the professional care team have been criticised for polarising the roles of the carer and cared for (Henderson & Forbat, 2002). By professionalising caregivers, it perpetuates the myth of the carer/cared for taking diametrically opposed positions and ignores the intimate and complex relational aspects of informal care. Furthermore, the shifting balance of care relationships are not recognised and little view is given to the reciprocal and multidimensional aspects of interpersonal relationships (Henderson & Forbat, 2002; Lloyd, 2000).

Heaton (1999) argues that where social policy fails to identify particular groups, they remain invisible and out of reach of services. Therefore, when policies focus on dichotomous carer/cared for identities, the notion of the ‘relationship’ is left invisible when actually the relationship is seen as central to the experience of care and is much more complex than policies make space for (Henderson & Forbat, 2002; Lloyd, 2000).

The labels applied to people involved in informal care relationships, such as ‘carer’ and ‘cared for’, have been described as unsatisfactory, implying a passivity and lack of agency in the relationship

(Henderson & Forbat, 2002). Furthermore, many studies have found that informal carers do not define themselves as such (Heaton, 1999; Henderson & Forbat, 2002).

Depression

DSM-IV criteria. According to the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text revision, American Psychiatric Association, 2000), a Major Depressive Episode (MDE) is diagnosed when five of nine listed symptoms are present during the same two-week period. These symptoms must represent a departure from previous functioning and must cause significant subjective distress. One of the five symptoms must be either depressed mood or anhedonia (loss of interest/pleasure). Other symptoms used as diagnostic criteria include: appetite and sleep disturbance; psychomotor agitation or retardation; fatigue and loss of energy; feelings of worthlessness or inappropriate guilt; decreased ability to concentrate; and passive or active suicidal ideation (APA, 2000). Major Depressive Disorder (MDD) is defined by one or more MDE. Furthermore, MDD is only diagnosed if an MDE is not better explained by a psychotic disorder and if there is no history of mania or hypomania (APA, 2000).

The DSM-IV-TR distinguishes Major Depressive from Dysthymic Disorder in terms of duration and severity of symptoms. Episodes of Major Depression are not diagnosable disorders in and of themselves, rather they comprise the building blocks for a diagnosis of MDD-Single Episode or MDD-Recurrent (> 1 episode) (APA, 2000). In contrast to MDD, a diagnosis of Dysthymic Disorder requires that an individual experience a chronically depressed mood for most of the day for a period of two years. In these terms, Dysthymia represents a more pervasive depressed mood, and consequently, may be viewed as more typical of the individual's behaviour (APA, 2000). In addition to a chronically depressed mood, an individual must experience at least two of a possible six symptoms: poor appetite or overeating; insomnia or hypersomnia; low energy or fatigue; low self-esteem, poor concentration or difficulty making decisions; and feelings of hopelessness. Like MDD, these symptoms must cause clinically significant distress or impairments in social, occupational or other important areas of functioning (APA, 2000).

Numerous specifiers for both MDD and Dysthymic Disorder are also presented in the DSM-IV-TR (APA, 2000). These allow clinicians to specify the current clinical status of the disorder as mild, moderate, severe, in partial remission, in full remission, or chronic. After meeting the diagnostic

threshold, depression severity is determined by the total number of criteria met, where the greater the number of symptoms present, the more severe the depression.

DSM-5. The DSM-5 was published on May 18, 2013, superseding the DSM-IV-TR. The changes in diagnostic criteria for Major Depressive Disorder (MDD) from the fourth to the fifth edition of the DSM are minimal. The most visible change is that the ‘Mood Disorders’ chapter of previous editions has been split into two separate chapters, ‘Bipolar and Related Disorders’ and ‘Depressive Disorders’. MDD is located in the ‘Depressive Disorders’ chapter and the number of categories across these two chapters have increased.

Three main changes have been made in the MDD criteria (APA, 2013). Firstly, the statement that mood congruent delusions and hallucinations should not count towards the diagnosis of MDD or MDE has been removed. Secondly, the word ‘hopeless’ has been added to the subjective description of depressed mood. Therefore, an individual who reports feeling hopeless but not sad still fulfills the mood criterion in the DSM-5 but not DSM-IV-TR. Thirdly, the bereavement exclusion has been removed and replaced by a footnote calling for clinical judgment when diagnosing MDD or MDE in the context of a significant loss.

In DSM-5, the new category of Persistent Depressive Disorder (PDD) aims to combine Dysthymia and Chronic Depression. It is stated that “Individuals whose symptoms meet Major Depressive Disorder criteria for 2 years should be given a diagnosis of Persistent Depressive Disorder as well as Major Depressive Disorder” (APA, 2013, p. 170-171). The symptomatic criteria for PDD and MDD differ; criteria for PDD are the same as the DSM-IV-TR Dysthymia criteria (APA, 2013).

A symptom based approach combines an emphasis on quantification and replication with a focus on aetiology, be it biological, psychological or social. The new DSM-5 (APA, 2013) framework has been criticised by the British Psychological Society (BPS, 2011) as potentially medicalising patterns of behaviour and mood. Furthermore, the validity of these disorders has been questioned as there is little evidence that the disorders are distinct from one another (Hirschfield, 1994). The BPS argue that trying to fit individuals into a diagnostic category is not useful and instead classification systems should work from the bottom up, starting with idiosyncratic experiences, problems or complaints (BPS, 2011). Although the subjective nature of the DSM-5 criteria and its reliance on

clinical judgement raises concerns over its reliability and validity, much research has nevertheless relied on it as a classification system.

Relationship Theories

Relationship theories suggest that couples experience a 'honeymoon period' at the beginning of their relationship, which has been labelled as limerence (Tennov, 1979), infatuation (Sternberg, 1986) and passionate love (Hatfield & Rapson, 1993). This is characterised by feelings of joy, euphoria and ecstasy. Indirect evidence of the biological processes involved in falling in love is provided by cross-cultural studies which suggest that it is present in virtually all societies and is, perhaps, genetically determined (Jankowiak and Fischer, 1992). Neuroscientific investigations suggest that this altered mental state lasts between 18 months and three years (Marazziti, Akiskal, Rossi, & Cassano, 1999) after which couples enter 'companionate love' characterised by mutual respect, attachment, affection and trust (Hatfield & Rapson, 1993). Once a couple is formed and into the 'companionate love' stage, a conscious effort needs to be made on both parts to maintain emotional closeness and show love (Hatfield & Rapson, 1993).

Having a single distinction between passionate and companionate love could be viewed as over simplified. Some theoretical perspectives support the idea that love, satisfaction and joy should increase early in a relationship but then level off or even decrease over time. For example, according to the principles of learning theory, the partner's behaviour or mere presence becomes less rewarding over time due to habituation effects (Huesmann, 1980). Furthermore, according to the self-expansion model (Aron & Aron, 1986), love and satisfaction are likely to decrease over time as partners offer each other fewer opportunities for self-expansion.

On the contrary, early theories of relationship development proposed that couples move through a sequential series of stages that are characterised by increasing amounts of commitment and involvement (e.g. Kerckhoff & Davis, 1962; Murstein, 1970). However, the majority of theorists now agree that romantic relationships develop gradually over time rather than by passing through a series of discrete stages. These process models (e.g. Altman & Taylor, 1973) allow for growth, decline and stability in relationship properties over time and suggest that relationship development is

fueled by sometimes imperceptible changes in intimacy, self-disclosure, and other interpersonal processes.

Concordant Mental Health in Couples

There is overwhelming evidence for concordant mental health in couples, especially regarding depressive symptoms (Coyne et al., 1987; Cutrona, 1996; Hinchcliffe, Hooper, Roberts, & Vaughan, 1975; Meyler, Stimpson, & Peek, 2007; Teichman, Bar-El, Shor, & Elizur, 2003). Similarities in couples' mental health have been shown to increase in accordance with the length of time they have been living together (Butterworth & Rodgers, 2006).

The theory most frequently used to explain the concordance of depressive symptoms among partners is affective contagion (Meyler et al., 2007). This refers to the tendency for emotions between people sharing an interdependent relationship to converge. In accordance with the notion that the marital relationship is considered to be one of interdependence and reciprocity, each spouses' reactions, responses, attitudes and emotional states influences the other (Cutrona, 1996). Empirical evidence for affective contagion among spouses has been demonstrated in a number of studies (Bookwala & Schulz, 1996; Goodman & Shippy, 2002; Joiner & Katz, 1999; Tower & Kasl, 1995).

An alternative theory is assortative mating, which suggests that individuals are more likely to select life partners who share similar characteristics such as demographics, attitudes and behaviours (Lillard & Panis, 1996). Assortative mating occurs for a variety of phenotypic traits, including both genetically determined traits (e.g. height) and environmentally determined traits (e.g. religion) (Merikangas, 1982). Research into assortative mating has almost always taken a variable-centred approach; that is, researchers compute a correlation between couples' scores on the same characteristics across all couples in a particular sample, and a sizable positive correlation is interpreted as evidence for similarity.

Although results from studies examining assortative mating are complex and correlations often differ widely across studies (Nicholson, 1992), the accumulating data supports the existence of assortative mating (e.g., Bouchard & Loehlin, 2001; Buss, 1984; Mathews & Reus, 2001; Vandenburg, 1972). However, the degree of similarity observed depends on the particular domain

studied, with romantic partners showing strong similarity in age, political and religious attitudes, moderate similarity in education, general intelligence and values, and little or no similarities in personality characteristics (Watson et al., 2004). Assortative mating has been identified among individuals with affective disorders (Mathews & Reus, 2001).

Luo and Klohen (2005) raised a number of limitations with the methods used to test the assortative mating theory, including the inability to provide information on how similar partners are in terms of more global, overarching domains, such as attitudes and values systems. Additionally, the correlation is computed between partners' scores on a specific characteristic across all participants in a sample and thus characterises the sample rather than each couple.

Another hypothesis is the shared resource hypothesis (Smith & Zick, 1994), which posits that partners share the same environment and experiences (e.g. life events) and therefore may be similarly affected by these external factors. A shared environment translates into shared health risks that can be beneficial or detrimental depending on the environment and health behaviours of the spouses. Living with a partner can provide a stable, coherent and regulated environment. Spouses can provide one another with social, instrumental and emotional support (Ross, Mirowsky, & Goldsteen, 1990). If a spouse cannot be counted on for this support and the partnership becomes characterised by an unequal division of decision making then increased levels of depression can ensue (Ross et al., 1990).

Finally, depression in couples is also strongly associated with marital distress, however establishing a causal direction within this relationship is complex (Beach, 2001). Individuals are embedded in their spousal relationship and the depression inevitably affects and is affected by the couple's day-to-day interactions. Research has focused on the importance of interpersonal aspects of depression, such as marital quality (Beach, 2001; Benazon, 2000; Coyne et al., 1987). Studies investigating the impact on individuals living with a depressed partner report significant psychological burdens (Benazon & Coyne, 2000; Fadden, Bebbington, & Kuipers, 1987). Coyne et al. (1987) compared the amount of burden and psychological distress reported by individuals living with a currently depressed partner with individuals living with a formally depressed partner. Results showed that those living with a currently depressed partner experienced greater burdens and psychological

distress, thus highlighting the interpersonal linkages between depression and marital discord. Feeling emotionally supported is a fundamental expectation of a romantic relationship and is linked to relationship satisfaction (Pasch & Bradbury, 1998). However, increased burden can lead to negative attitudes towards the depressed partner, which has been shown to trigger or exacerbate depression and relapses (Hooley, Orley, & Teasdale, 1986; Keitner, Ryan, Miller, Kohn, & Epstein, 1995). Conversely, some evidence suggests that just being married increases the effectiveness of depression treatments (Thase & Simons, 1992) and that the supportiveness of a spouse decreases the incidence of depression (Brown & Harris, 1978). Therefore, the relationship can be a source of strength and an asset to recovery or a hindrance to the health of both partners.

Interpersonal perspectives of depression are important because they provide a framework to understand the impact of depression on the lives of people who live with someone with depression (Rehman, Gollan, & Mortimer, 2008). Three prominent interpersonal theories of depression are Coyne's (1976) interactional model, the stress generation model (Hammen, 1991) and the marital discord model (Beach, Sandeen, & O'Leary, 1990).

Coyne's (1976) interactional model posits that depression leads to marital distress, which subsequently leads to a cycle that exacerbates the depression. The model suggests that interpersonal behaviours of depressed individuals elicit rejection from others. When an individual is depressed they seek reassurance from those close to them (e.g. their partner). Initially, their partner yields to these demands but as time progresses and demands continue, it produces increasing hostility and resentment within the partner, which subsequently leads to feelings of guilt. In an attempt to reduce the hostility and resentment, the partner responds with superficial reassurance which is only partially successful in providing support to the depressed individual, who can sense the discrepancy. This causes them to feel rejected and subsequently they display increased negative symptoms in an attempt to regain support. However, this leads to further alienation and the cycle often continues until the partner is forced to withdraw. Empirical findings for this model are inconsistent (Rosenblatt & Greenberg, 1991; Strack & Coyne, 1983). Furthermore, research suggests that this model is most likely to manifest itself in the context of long-term relationships rather than in interactions with strangers (Marcus & Nardone, 1992).

The stress generation model of depression (Hammen, 1991) purports that individuals with depression inadvertently make behavioural choices that increase the amount of interpersonal stress in their lives. This model is often presented as accounting for depression in women because most empirical tests have been conducted on females (e.g. Davila, Hammen, Burge, Paley, & Daley; Hammen, 1991). Similarly to Coyne's (1976) model, it proposes that depression leads to marital distress. Models by both Coyne (1976) and Hammen (1991) describe how interpersonal factors maintain and exacerbate depression but do not outline mechanisms by which depression first occurs. Therefore, they may be more accurately conceptualised as relapse theories of depression.

The marital discord model (Beach et al., 1990) suggests that marital distress leads to depression by reducing available support while increasing levels of stress and hostility. Marital support is decreased by a reduction in couple cohesion, self-esteem support, dependability and intimacy. Stressors within the relationship that can contribute to depressive symptoms include verbal and physical aggression, threats of separation, criticism and blame, and disruption to routines. Studies involving observations of marital interactions (e.g. McCabe & Gotlib, 1993) support this model. However, given the correlational nature of these studies, it is impossible to tell whether the increased negativity or decreased positivity evidenced in these interactions contributed to the development of depression or are a result of previously existing depression.

Learning how interpersonal factors may influence the onset and course of depression is crucial in promoting treatment strategies and is an important public health concern. However, determining the temporal primacy of depression or marital distress may not be the most relevant focus, but more the reciprocal influences occurring within the relationship. Until recently treatments for depression have focussed primarily on the individual with depression, such as Cognitive Behavioural Therapy (CBT) and Interpersonal Therapy (IPT) (NICE, 2004). However, such inextricable associations between depression and marital distress are now reflected in the application of Couples Therapy in the treatment of depression (NICE, 2009). Couples Therapy is a time-limited psychological intervention derived from a model of the interactional processes in relationships where the intervention occurs to help the couple understand the effects of their interactions on each other as factors in the development and/or maintenance of the symptoms (NICE, 2009). The aim of Couples Therapy is to change the nature of the interaction so the couple may develop more supportive and less conflictual

relationships (NICE, 2009). Leff et al. (2000) conducted a randomised controlled trial comparing anti-depressant medication and Couples Therapy for the treatment of people meeting the criteria for depression living with a critical partner. They found that Couples Therapy is at least as efficacious as anti-depressant medication both in the treatment and maintenance phases of depression. Furthermore, randomised controlled trials have also shown that Couples Therapy yields greater increases in marital satisfaction than individual therapy (e.g. CBT) or medication therapy (Beach & O’Leary, 1992; Emanuels-Zuurven & Emmelkamp, 1996).

Identity Theory and Role Shifts

Individuals enter a relationship with beliefs and expectations about what it means to be part of a couple. Subsequently, if one partner becomes chronically depressed then the other may experience multiple limitations and losses concerning the partnership (Wittmund, Wilms, Mory, & Angermeyer, 2002). Living with a depressed partner often requires a role shift in which the non-depressed partner takes on more of a caregiving role (Badger, 1996a, 1996b; Muscroft & Bowl, 2000; Stjernsward & Ostman, 2008). According to Burke’s (1991) conceptualisation of identity theory, the central aspect of one’s identity is the categorisation of the self as an occupant of a role, and the expectations associated with performing that role. These expectations and meanings are known as one’s ‘identity standard’ for that particular role. According to the identity control theory (ICT) (Burke, 2006), when an individual is faced with a situation that produces a discrepancy in their perceived identity within a particular role (for example, having to care for a chronically depressed partner), their ‘identity standard’ will gradually shift to fit into the new situation. This is an adaptive response that allows individuals to fit into new situations where the new perceptions are persistently different from the standard (Burke, 2006).

The discrepancy between the perceptions and the identity standards not only governs behaviour but also produces an emotional response. The larger the discrepancy, the more distress an individual experiences (Burke & Harrod, 2005). This emotional response provides some motivation for reducing the discrepancies between perceptions and identity standards. Studies exploring the experiences of individuals living with a depressed relative illustrated that many family members gradually adapted to their caregiving role and incorporated the depression into their lives (Harris, Pistrang, & Barker, 2006; Muscroft & Bowl, 2000).

However, Simon (1997) posited that the meaning a role has for an individual is pivotal for understanding its psychological impact. Individuals derive a sense of purpose and meaning in life from the roles they enact (Thoits, 1986), both of which are essential for mental wellbeing (Frankl, 1959; Thoits, 1986).

The meaning that individuals assign to events and strains in their role domains can be understood from a range of different perspectives. A contextual approach uses information about an individual's social circumstances to specify the meaning of an event or strain in terms of its emotional significance. For example, Wheaton (1990) found that an important context that alters the meaning and impact of an event is the level of pre-existing stress in the role or the individual's role history. While contexts are crucial for understanding the circumstances surrounding stressors, this approach avoids individuals' interpretations of the meaning of stressors.

Interpretative approaches (e.g. Lazarus & Folkman, 1984) advocate that the significance of stress is based on cognitive processes in which individuals actively try to make sense and cope with difficulties. While interpretative approaches are important for understanding why stressors become stressful and how people come to terms with adversity, they fail to highlight individual's own understandings of the meaning of their experiences.

The self and identity approach suggests that the impact of stressors depend on whether the role identity involved is important for self-conception. Thoits (1995) proposed that undesirable events or strains in salient role identities are more likely to be appraised as major losses, highly threatening and psychologically harmful because they disrupt a valued aspect of the self. In order to protect self-esteem, individuals may compensate for a loss or threat to a salient role identity by acquiring a new role or attaching greater importance to an existing identity. Hence, according to the multiple role occupancy hypothesis (Thoits, 1986), the possession of multiple role identities is viewed as a protective factor because they provide individuals with several possible sources of self-esteem. Simon (1997) found that the mental wellbeing advantages of multiple role occupancy were greater for men than women.

The values and beliefs approach asserts that an individual's general values and beliefs determine the meaning of stressors. An individual's values are closely associated with a variety of factors, including their gender, age, religion and social class. Events and strains that threaten people's most

strongly held beliefs are perceived as highly distressing because they question their fundamental assumptions about the world.

Simon (1997) argued that the above theoretical approaches ignore individual's own understandings of the meaning of their role identities. Simon (1997) suggested that individuals assign meaning to their role identity in terms of perceived costs and benefits and therefore the impact of stressors on the relationship will be determined by these perceived costs and benefits. For example, separation would be less distressing if the benefits of the relationship are less than the perceived costs (Simon, 1997). Furthermore, the relationship would be perceived as dissatisfying and stressful only if the positive meanings assigned to the spouse identity are not actualised or if the stressor challenges or threatens a perceived benefit of the spouse identity role (e.g. individuals for whom the spouse identity means fulfilling social expectations would be less distressed by an emotionally distant marriage than those for whom the same role identity means intimacy and companionship).

Stigma by Association (Self-Stigma)

According to Link and Phelan (2001), stigma exists when elements of labelling, separating, stereotyping, status loss and discrimination co-occur in a power situation that allows these processes to unfold. Evidence suggests that relatives of people with mental health problems can experience psychological factors of stigma by association (Ostman & Kjellin, 2002). Known as self-stigma, this refers to people holding negative beliefs and attitudes about themselves as a result of internalising stigmatising ideas held by others (Corrigan & Watson, 2002). The degree to which two or more people are bonded together into a meaningful social unit influences how they are perceived by others (Pryor, Reeder, & Monroe, 2012). Not surprisingly, spousal relationships are perceived as among the highest in social groups in terms of closeness. Therefore, when people are perceived as bound to a stigmatised person, particularly a spouse, consciously held attitudes about the stigma are likely to come into play in how others perceive them too (Pryer et al., 2012).

Psychological factors related to stigma by association include the reduction of social networks in anticipation of rejection due to stigma, subsequently leading to isolation and reduced self-esteem (Ostman & Kjellin, 2002). Identification with a group who share a stigmatised identity will help individuals develop more positive self-perceptions through sharing a common ground (Corrigan &

Watson, 2002). This implies that relatives of people with mental health problems may benefit a great deal from support groups. However, the fear of stigma is often the key factor preventing people from seeking support in the first place (Wrigley, Jackson, Judd, & Komiti, 2005). Ostman & Kjellin (2002) suggested that other psychological factors of stigma by association include mental health problems in the relatives themselves. Furthermore, they found that relatives often perceived exchanges with professionals as stigmatising experiences in which they felt inferior, thus reducing the amount of support obtained from professional services. A qualitative study by Dinos, Stevens, Serfaty, Weich, and King (2004) suggested that individuals with mood and anxiety disorders may experience stigma differently when compared to individuals with psychotic disorders, subsequently influencing the experiences of the relatives too. However, other studies argue that the diagnosis of the family member does not impact the experience of stigma by association (Lazowski, Koller, Stuart, & Milev, 2012; Ostman & Kjellin, 2002).

Existing Literature

A wide range of qualitative literature has explored the experiences of living with a partner with different mental health problems, for example schizophrenia (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004) and bipolar affective disorder (Tranvag & Kristoffersen, 2008). However, few have explored individuals' experiences of living with a partner with chronic depression. Therefore, the following section within this chapter will provide an overview of the literature exploring the experiences of family members providing care for a relative with depression.

Experiences of Providing Care to a Relative with Depression: A Meta-Ethnographic Synthesis

Introduction

Qualitative research focusing specifically on caregivers for people with depression is limited and has not previously been subjected to a synthesis. Therefore, the aim of this paper is to provide an overview of the literature exploring the experiences of family members caring for a relative with depression.

Method

Design. The diversity of approaches to synthesising qualitative research has grown steadily over recent years and has itself become a topic for review (Barbour & Barbour, 2003; Campbell et al., 2011). It has been posited that a key dimension of difference between the plethora of qualitative syntheses available is their varying epistemological positions (Gough, Thomas, & Oliver, 2012), ranging from a highly constructivist view of knowledge (e.g. meta-narrative methods) to a scientific realism viewpoint (e.g. ecological triangulation). Meta-ethnography is informed by objective idealism, which sits between these two epistemological poles. Its interpretative nature implies a degree of constructivism; however it does not uphold the constructivist recognition of multiple realities. Instead, the emphasis is predominantly on examining commonalities across accounts, ultimately seeking to provide a ‘whole’ which has greater explanatory power.

Another position that sits between these two poles is that of critical realism, which is the epistemological position informing the data analysis within this current thesis. Despite an assumption of reality which is less interpretative than that of objective idealism, the two positions do share some similarities. Indeed, synthesis methods informed by a critical realist approach (e.g. thematic synthesis) combine and adapt approaches from meta-ethnography and other similar synthesis methods informed by objective realism (e.g. grounded theory). Similarly to meta-ethnography, thematic synthesis involves interpretation of data, seeks commonalities across accounts, and explains and explores discrepancies between accounts through context rather than multiple realities.

Despite thematic synthesis (Thomas & Harden, 2008) being the main method underpinned by the epistemological position informing this thesis (i.e. critical realism), it was not chosen to conduct the

present literature synthesis because of the differences in its relevance to particular research domains and questions. Thematic analysis (TA) was developed out of a need to conduct reviews that addressed questions relating to intervention need, appropriateness and effectiveness (Thomas & Harden, 2008), whereas meta-ethnography is particularly popular in research areas seeking to understand individuals' experiences of illness and care, such as lay experiences of illness (e.g. Campbell et al., 2003). Therefore it was decided that meta-ethnography would be more appropriate in synthesising the experiences of providing care to a relative with depression.

Meta-ethnography is an interpretative approach originally developed by Noblit and Hare (1988) for combining ethnographic research in the field of education. However, the approach has since been successfully applied using a larger numbers of studies (Pound et al., 2005) and non-ethnographical studies (Atkins et al., 2008; Britton et al., 2002; Campbell et al., 2003), thus demonstrating that meta-ethnography has evolved since its introduction.

A meta-ethnographic synthesis refers to a process that takes individual components of a study and organises them innovatively to form a holistic representation (Noblit & Hare, 1988). Interpretations and explanations in primary studies are treated as data and key themes and metaphors are translated across several studies to produce a synthesis (Noblit & Hare, 1988). Within a meta-ethnographic synthesis studies can relate to each other in one of three ways (Noblit & Hare, 1988): they may be directly comparable as reciprocal translations; they may conflict in which case a refutational synthesis can be produced; or taken together they may represent a line of argument. In terms of process, Noblit and Hare (1988) outlined seven iterative phases of meta-ethnography (see Table 1.1). The worked example of a meta-ethnographic synthesis by Britton et al. (2002) has been praised for its transparency in describing the activities undertaken in order to arrive at a final synthesis (Lee, Hart, Watson, & Rapley, 2014) and therefore will be used to guide the present synthesis. Britton et al. (2002) included only four studies in their synthesis, therefore due to the larger number of studies included in the current synthesis, methods were also taken from the work of Atkins et al. (2008) who conducted a much larger meta-ethnography.

Phase 1: Getting started. According to Noblit and Hare (1988), 'getting started' involves determining a research question that could be informed by qualitative research. Qualitative research

focusing specifically on the experiences of providing care to a relative with depression is limited and has not previously been subjected to synthesis. Therefore, it was felt that exploring this area in more detail would not only contribute to the wider literature regarding living with a relative with a mental health problem but also begin to open up further interest in this under-represented research field.

Table 1.1

Seven steps of Noblit and Hare's (1988) meta-ethnography

| Phase | Description |
|--------------|---|
| 1 | Getting started |
| 2 | Deciding what is relevant to the initial interest |
| 3 | Reading the studies |
| 4 | Determining how the studies are related |
| 5 | Translating the studies into one another |
| 6 | Synthesising translations |
| 7 | Expressing the synthesis |

Phase 2: Deciding what is relevant to the initial interest.

Selection Criteria. This synthesis aimed to include all published, peer reviewed articles that used qualitative methods to explore the experiences of providing care to a relative with depression. Qualitative methods were defined as face-to-face interviews or focus groups followed by a form of in-depth analysis. To ensure the greatest clarity of caregivers' experiences, articles were excluded if data from caregivers of depressed relatives were combined with data from caregivers of relatives with other mental health problems (e.g. schizophrenia or bipolar affective disorder). Articles were also excluded if they compared experiences between caring for someone with depression and other mental health problems.

Articles were excluded if the primary caregiver was under 18 years of age, due to the specific ethical and practical issues raised with this population (Roberts, Bernard, Misca, & Head, 2008). Therefore articles focusing specifically on children or adolescents providing care to a depressed relative were not eligible. However, articles were eligible if the wider sample included children or if a whole family was interviewed together and the family included younger children. Articles were included if caregivers were interviewed independently or jointly with their depressed relative. Where the

individual with depression was part of the interview or focus group, the synthesis solely focussed on caregivers' perspectives.

Search Strategy. An initial electronic search was conducted using the databases CINAHL, Medline and PsychARTICLES in August 2014. The strategy involved searching for published journal articles using the option 'Abstract' and the terms and limiters shown below (see Table 1.2).

Table 1.2

Database search

| Search No. | Search Terms | Limiters | CINAHL, Medline, PsycARTICLES | PubMed |
|------------|--|------------------------------------|-------------------------------|-----------|
| 1 | depress* | Adult (18+ years) Peer Reviewed | 53, 893 | 297,029 |
| 2 | experienc* OR perspective* OR manag* OR explor* | Adult (18+ years) Peer Reviewed | 259,627 | 1,804,411 |
| 3 | family member* OR relative* OR spouse* | Adult (18+ years) Peer Reviewed | 85,029 | 1,135,131 |
| 4 | care* OR caring | Adult (18+ years) Peer Reviewed | 209,420 | 897,358 |
| 5 | interview* OR focus group* | Adult (18+ years) Peer Reviewed | 95,822 | 221,148 |
| 6 | Search #1 AND #2 AND #3 AND #4 AND #5 | Adult (18+ years) Peer Reviewed | 137 | 426 |

Following a detailed scan of article titles and abstracts, three articles were identified for inclusion (Harris et al., 2006; Muscroft & Bowl, 2000; Radfer, Ahmadi, & Khoshknab, 2014). The same search was conducted on PubMed (see Table 1.2) which elicited eight new articles for inclusion (Ahlstrom, Skarsater, & Danielson, 2009; Badger, 1996a; Bottorff, Oliffe, Kelly, Johnson, & Carey,

2014; Hansen & Buus, 2012; Highet, McNair, Davenport, & Hickie, 2004; Highet, Thompson, & McNair, 2005; Nosek, 2008; Skundberg-Kletthagen, Wangensteen, Hall-Lord, & Hedelin, 2014).

The reference lists of these 11 articles were examined and an author search conducted and four additional studies were identified (Badger, 1996b; Gonzalez, Romero, Lopez, Ramirez, & Stefanelli, 2010; Oliffe, Kelly, Bottorff, Johnson, & Wong, 2011; Stjernsward & Ostman, 2008). Finally, all reference lists were re-examined and authors names were searched iteratively until no further articles could be identified that met the inclusion criteria. Therefore, a total of 15 studies were selected for analysis (see Figure 1.1).

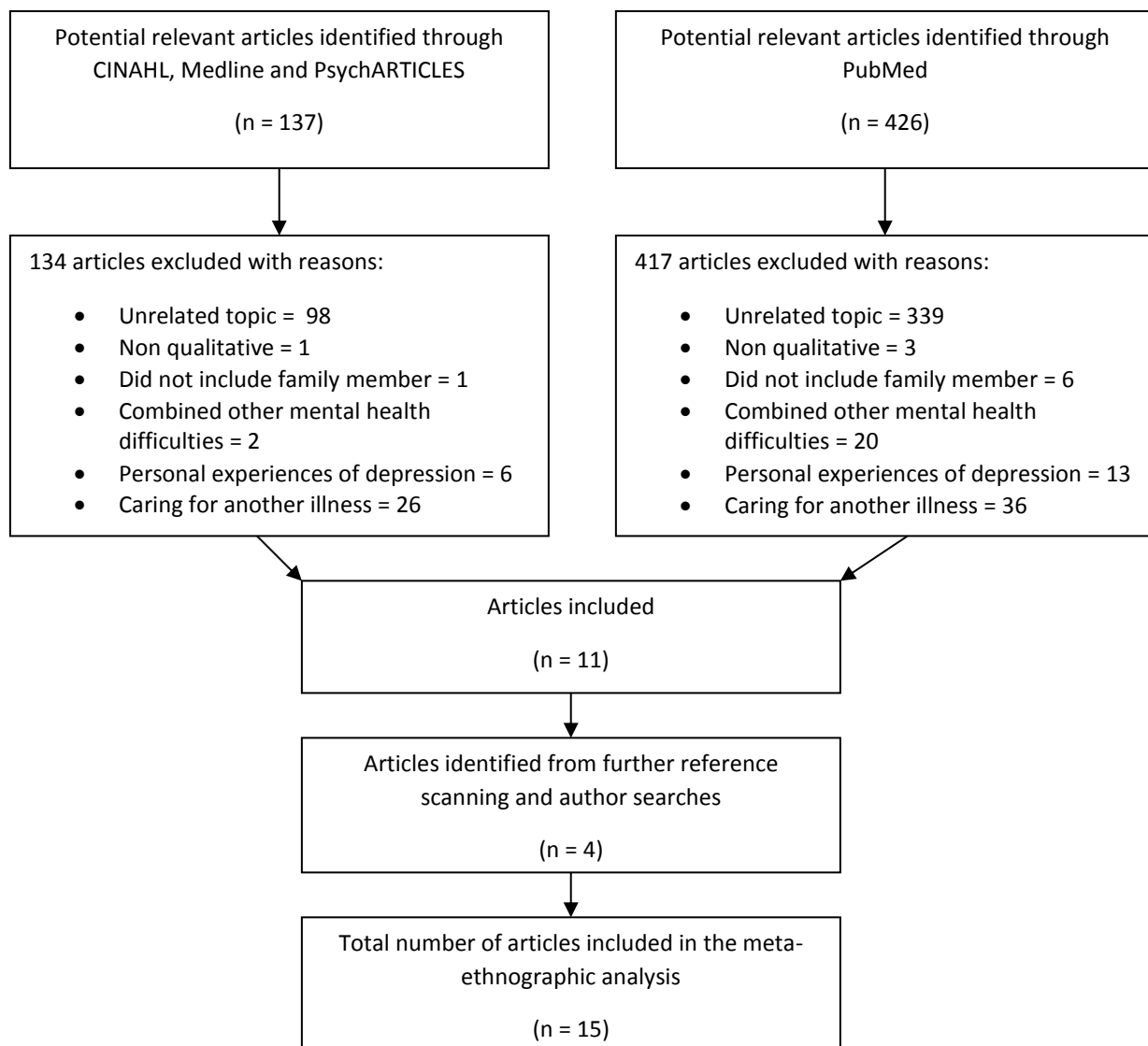


Figure 1.1. Consort diagram for retrieved articles

Quality Assessment. The application of quality criteria to qualitative research is widely debated, with no current consensus on whether criteria should be applied, which criteria to use and how to apply them (e.g. Seale, 1999; Spencer, Ritchie, Lewis, & Dillon, 2003). Noblit and Hare (1988) originally discussed quality in terms of quality of metaphor, while more recent use of meta-ethnography has involved some form of quality assessment, often using an amended version of the Critical Appraisal Skills Programme tool (CASP; Public Health Resource Unit, 2006).

Authors of published meta-ethnographies hold contrasting views about the application of quality assessment, with some choosing to eliminate poor quality studies (e.g. Fosse, Schaifel, Ruths, & Malterud, 2014) and others choosing not to eliminate any studies but instead to use the quality assessment information to explore the contribution of each study to the synthesis (e.g. Atkins et al., 2008). Given that there are no globally accepted, or empirically tested, methods for excluding qualitative studies from syntheses on the basis of their quality (Daly et al., 2006; Dixon-Woods et al., 2006) the current meta-ethnography used an adapted version of the CASP quality assessment tool (Atkins et al., 2008) and included all articles regardless of their quality (see Table 1.3).

Phase 3: Reading the studies. This stage involved thoroughly reading the chosen studies in order to become as familiar as possible with their content and beginning the process of identifying the main concepts. In addition to the key concepts, important study details were also noted in order to provide context for the interpretations and explanations of each study (e.g. Atkins et al., 2008; Britton et al., 2002).

Table 1.3

Quality assessment and results

| Question | Ahlstrom et al. (2009) | Badger (1996a) | Badger (1996b) | Bottofff et al. (2013) | Gonzalez et al. (2010) | Hansen et al. (2012) | Harris et al. (2006) | Highet et al. (2004) | Highet et al. (2005) | Muscroft et al. (2000) | Nosek (2008) | Oliffe et al. (2011) | Radfar et al. (2014) | Skundberg et al.(2014) | Stjemsward et al. (2008) |
|---|------------------------|----------------|----------------|------------------------|------------------------|----------------------|----------------------|----------------------|----------------------|------------------------|--------------|----------------------|----------------------|------------------------|--------------------------|
| 1. Is this study qualitative research? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 2. Are the research questions clearly stated? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 3. Is the qualitative approach clearly justified? | Y | Y | Y | Y | N | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| 4. Is the approach appropriate for the research question? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 5. Is the study context clearly described? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 6. Is the role of the researcher clearly described? | N | N | N | N | N | Y | Y | N | N | N | N | N | N | N | N |
| 7. Is the sampling method clearly described? | Y | Y | Y | N | N | Y | Y | N | N | Y | Y | Y | N | Y | N |
| 8. Is the sampling strategy appropriate for the research question? | Y | Y | Y | U | U | Y | Y | U | U | Y | Y | Y | U | Y | Y |
| 9. Is the method of data collection clearly described? | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 10. Is the data collection method appropriate to the research question? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 11. Is the method of analysis clearly described? | Y | Y | Y | Y | N | Y | Y | N | N | N | Y | N | Y | Y | Y |
| 12. Is the analysis appropriate for the research question? | Y | Y | Y | Y | Y | Y | Y | Y | Y | U | Y | Y | Y | Y | Y |
| 13. Are the claims made supported by sufficient evidence? | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | N |

Note. Y = Yes; N = No; U = Unclear

Phase 4: Determining how the studies are related. The fourth stage involved reviewing the 15 studies for common and recurring concepts and developing a table in which to enter this information (Britton et al., 2002). The emerging concepts were: recognition; impact; role reformation; coping strategies; healthcare professionals; community support; changing sense of self; adapting to depression; and looking to the future.

Table 1.4 provides an example of one study to illustrate how the data was organised, with each study listed in columns and the key concepts placed in rows. The first four rows contain relevant details of the study setting and design; these methodological details are essential contextual information for the synthesis.

Each remaining row represents a key concept. The last row represents the central theory or explanation arising from each study, also described as second-order interpretations by Schutz (as cited in Britton et al., 2002). For full details of all the included studies, please see Appendix A.

Table 1.4

Sample of tabulated study details and key concepts

| Methods and Concepts | Badger (1996a) |
|---|---|
| Key Study Details | |
| Purpose | To describe family members' experiences in living with a member with depression |
| Setting | U.S.A |
| Sample | 11 family caregivers (9 spouses, 2 parents) |
| Data Collection | Interviews |
| Key Concepts | |
| Recognition | Observing the metamorphosis |
| Impact | Lack of emotional and material support |
| Role reformation | Assuming the role tasks of relative with depression |
| Coping strategies | Protective vs. coercive strategies |
| Healthcare professionals | Searching for reasons and solutions Frustrations at exclusion in treatment Being an advocate |
| Community support | Living two lives to defend against embarrassment or stigma |
| Changing sense of self | Preserving oneself – to care for others I must care for myself |
| Adapting to depression | Accepting realities and limits of involvement Redesigning the relationship |
| Looking to the future | Hope mixed with caution |
| Explanation/Theory (Second-Order Interpretation) | Families experience a social psychological transformation process involving three stages: acknowledging the stranger within, fighting the battle, and gaining new perspective |

Phase 5: Translating the studies into one another. Translation was done by completing the tables for each study (Britton et al., 2002) preserving terminology from the original papers (Appendix A). Empty cells represent no data for that particular study. After identifying the actual concepts described in the paper concerned, checks were made to ensure that the concept was encompassed by the key concept (Britton et al., 2002). Thus, by completing the tables, it confirmed

that that each concept in the paper was encompassed by one of the key concepts. Table 1.5 shows a cross comparison of studies by concepts. At this point, the key explanation or theory (also known as second-order interpretations) arising from each paper was included (as shown in Table 1.4). Interpretations in quotation marks use the original author(s)' own words; those not in quotation marks are based on the researcher's paraphrasing of the original papers (Britton et al., 2002).

Phase 6: Synthesising the translations. It seems to be generally accepted that the synthesis process, like analysis in primary qualitative research, "cannot be reduced to mechanistic tasks" (Britton et al., 2002, p. 211) and therefore may be difficult to replicate in practice. Due to the amount of studies included in the current synthesis, and the variety of focus of studies, it made conducting synthesis in accordance with Britton et al. (2002) difficult. Therefore, guidance was instead taken from Atkins et al. (2008), who used a much larger study sample (n=44).

The tables were printed and laid alongside one another, in order to aid comparison. By reading the concepts and interpretations of each of the 15 studies, it was possible to see the commonalities between the studies. It became apparent that the relationships between the studies were not refutational of one another but rather that the relationship seemed to be reciprocal. The key concepts were synthesised into four broader concepts: making sense of depression, changes in family dynamics, overcoming challenges, and moving forward (Figure 1.2). Subsequently, an overarching model linking the key concepts, broader concepts and interpretations was developed in order to produce a line of argument synthesis (see Figure 1.3).

Phase 7: Expressing the synthesis. There are different approaches to expressing a meta-ethnographic synthesis, which are based on the audience and what form of synthesis would be appropriate (Noblit & Hare, 1988). The present synthesis is presented below with each of the four broad concepts described in detail. Thereafter, the way in which these were linked together to form a line of argument synthesis is depicted.

LIVING WITH A PARTNER WITH DEPRESSION

Table 1.5

Cross comparison of studies by concept

| Concepts | Ahlstrom et al (2009) | Badger (1996a) | Badger (1996b) | Bottorff et al. (2013) | Gonzalez et al. (2010) | Hansen & Buus (2012) | Harris et al. (2006) | Highet et al. (2004) | Highet et al. (2005) | Muscroft & Bowl (2000) | Nosek (2008) | Oliffe et al. (2011) | Radfar et al. (2014) | Skundberg et al. (2014) | Stjernsward & Ostman (2008) |
|-----------------------------|-----------------------------|-------------------|-------------------|------------------------------|------------------------------|-------------------------------|----------------------------|----------------------------|----------------------------|------------------------------|-----------------|----------------------------|----------------------------|-------------------------------|-----------------------------------|
| Recognition | | * | * | * | * | * | * | | * | * | * | | | | * |
| Impact | * | * | * | * | * | * | * | * | * | * | * | * | * | * | * |
| Role reformation | * | * | * | * | * | * | * | | | * | | * | * | * | * |
| Coping strategies | * | * | * | * | | * | * | | | | * | * | | * | * |
| Healthcare professionals | | * | * | * | * | * | * | * | | * | * | * | | * | * |
| Community support | * | * | * | | * | * | * | * | * | | * | | * | * | * |
| Changing sense of self | | * | * | * | | * | | | * | * | | * | | | * |
| Adapting to depression | * | * | * | | | * | | | * | * | | | * | | |
| Looking to the future | * | * | * | | * | | * | | * | * | * | | * | * | * |

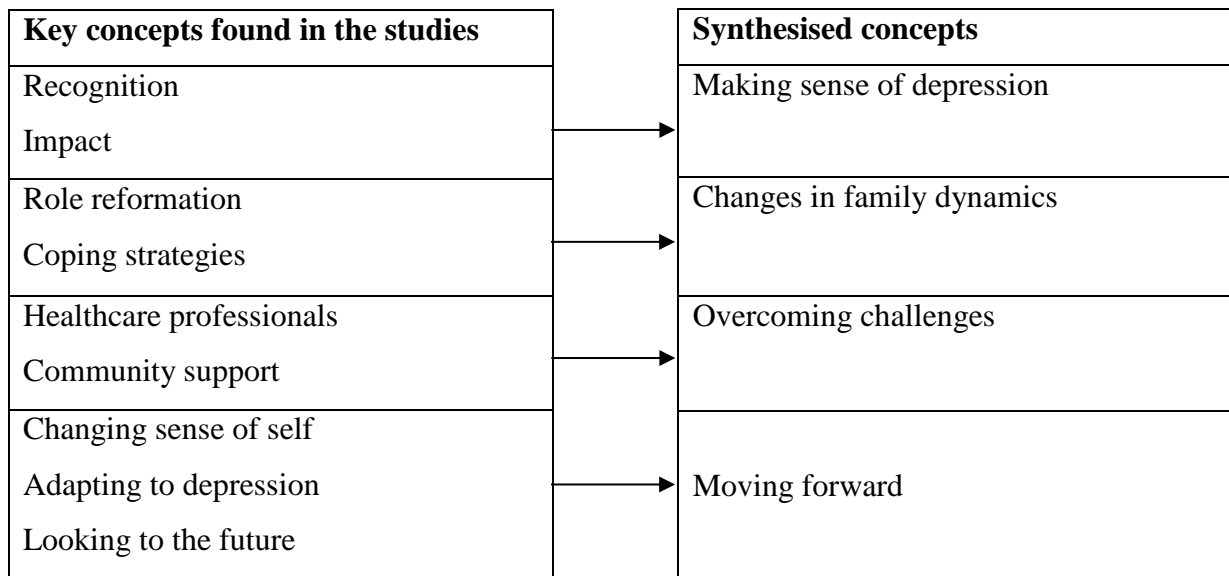


Figure 1.2. Overview of key concepts and synthesised broader concepts

Results

Making sense of the depression.

Recognition. Whilst the majority of studies described the process of recognising depression as gradual, ranging from months to years, Harris et al. (2006) stated that for some couples the onset had been “sudden and dramatic” (p.7). A common feature across studies was the misattribution of depressive symptoms to other factors, such as work-related stress or physical illness. This need to find socially acceptable explanations formed the first stage of Badger’s (1996a; 1996b) family transformation process and the second stage of Muscroft and Bowl’s (2000) four-stage model, labelled ‘the adaptation phase’. Badger (1996a; 1996b) reported that following diagnosis, caregivers maintained these explanations “to protect against potential stigma” (p. 156).

Commonly the changes noticed were only attributed to indicators of depression in hindsight. Families often questioned their own role in these changes, as highlighted by Muscroft and Bowl (2000) who stated that “those closest to the evolving patient notice but do not understand changes in manner and behaviour and strive to find causes in themselves” (p.124). In a study exploring women partners’ perspectives of men’s depression, Bottorff et al. (2013) found that the women also internalised changes as their fault. Interestingly, in the only study focussing on older

people with depression, Gonzalez et al. (2010) found that family caregivers associated depression with the natural phase of the life cycle as opposed to internal causes.

Impact. The considerable impact on family members providing care to a relative with depression was highlighted across all studies. In their interviews with 26 family caregivers, Radfar et al. (2014) reported that psychological, physical and financial factors imposed on families result in a ‘turbulent life’, which seemed to encapsulate the intense burden experienced by caregivers across all of the studies. A wide range of emotions were described, including guilt, despair, anger, frustration, confusion, sadness and shock. Caregivers carried these emotions at all times to some level, which was described by Highet et al. (2004) like “never being able to be off duty” (p. 8).

Gonzalez et al. (2010) described depression as a ‘family disease’, a term which highlighted the profound impact depression had on those living with a depressed individual. Many of the studies reported how caregivers’ needs were marginalised in the face of depression, which often had adverse effects on their own wellbeing that required professional support (Badger, 1996a, 1996b; Highet et al., 2004, 2005; Muscroft & Bowl, 2000; Nosek, 2008; Skundberg-Kletthagen et al., 2014).

Family life became tense, uncertain and conflicted, sometimes leading to temporary or permanent separation in couples (Ahlstrom et al., 2009; Badger, 1996a, 1996b; Highet et al., 2004, 2005). Badger (1996a) reported that threatening the relationship was common in all caregivers. Although parents and children felt they could not separate in the same way that couples could, some parents threatened to ask their child to live elsewhere (Badger, 1996a, 1996b) and children would sometimes spend more time away from home (Ahlstrom et al., 2009).

Changes in family dynamics.

Role reformation. Studies described the significant reorganisation of roles required to adapt to living with a relative with depression. Most caregivers felt the burden of taking on extra responsibility, including the role tasks of the depressed relative (Badger, 1996a, 1996b; Bottorff et al., 2013; Hansen & Buus, 2012; Radfer et al., 2014; Skundberg-Kletthagen et al., 2014). Stjernsward and Ostman (2008) highlighted the role reversal between parent and child “with the ill parent becoming like a child in need of care” (p. 362). Children took on more responsibility by protecting younger siblings and helping with chores (Ahlstrom et al., 2009). Describing the

impact of role reversal on children, Badger (1996a) reported that “children within the family expressed the loss of parental love and attention” (p. 156), instead sometimes perceiving themselves as their parent’s therapist (Skundberg-Kletthagen et al., 2014).

There were contrasting views on how parents coped with role reformation. Stjernsward & Ostman (2008) described how parents were often concerned about hampering their child’s development by upholding the parent-child relationship. However, Muscroft and Bowl (2000) reported that “mothers did not mind as it was merely an extension – albeit unplanned – of their habitual role” (p. 128).

Partners were also impacted by unwanted role reformations. Some experienced feelings of loss, despair and sadness at the lack of emotional and practical support received from their depressed partner. This switch in couple dynamics from being equal adult partners to taking on the care of a sometimes child-like spouse invariably led to disconnection and reduced relationship satisfaction (Bottorff et al., 2013; Harris et al., 2006; Stjernsward & Ostman, 2008). In a study examining how heterosexual couples may be challenged to make adjustments that impact their gender relations within the context of the male partner’s depression, Oliffe et al. (2011) found three key couple patterns. The most common pattern was ‘trading places’, describing how couples often took on atypical gender roles to compensate for the depression. The ‘business as usual’ pattern was underpinned by complicit masculinity and emphasised femininity to conceal the depression, while the ‘edgy tensions’ pattern revealed a mismatch of gender expectations that fuelled resentment and relationship dysfunction.

Coping strategies. Caregivers developed a wide range of coping strategies but this was often fraught with uncertainty. They generally started out with little or no idea about how they should support their loved one, often resulting in a process of trial and error with strategies depending on the context of the relationship and the needs of their relative. Some caregivers masked their own feelings in order to provide support (Bottorff et al., 2013; Skundberg-Kletthagen et al., 2014) and worried that their strategies might have an adverse effect on their depressed relative (Harris et al., 2006). Sometimes caregivers and the depressed relative had diverging perceptions on the best way to cope with the depression, which could lead to ambiguous feelings such as sympathy and spitefulness (Hansen & Buus, 2012).

The studies highlighted that the needs of the depressed relative were constantly changing and this subsequently effected caregiver coping ability. Coping strategies that worked one day could

have a detrimental effect the next, so caregivers eventually grew frustrated and employed more forceful strategies such as excluding the relative from routine activities (Badger 1996a, 1996b) and threatening the relationship (Ahlstrom et al., 2009; Badger, 1996a, 1996b; Highet et al., 2004, 2005). In line with this idea, Badger (1996a; 1996b) outlined five protective and five coercive strategies applied by caregivers and Oliffe et al. (2011) described tough love strategies. Often these harsher strategies were utilised for caregiver self-preservation. Interestingly, all but two of the studies (Gonzalez et al., 2010; Stjernsward & Ostman, 2008) focussed on coping strategies employed by the caregiver to support the relative with depression rather than to support the caregiver themselves.

In a study exploring the experiences of families caring for a depressed and suicidal loved one at home, Nosek (2008) outlined an ongoing, cyclical process that begins at the point of 'not knowing'. Through 'identifying', 'gaining awareness', 'knowing' and 'understanding', relatives are able to 'take action', 'watch and wait' or take the position of 'not wanting to know'. Deciding which of these three strategies to apply depended on the level of depression, risk of suicide and the wellbeing of the caregiver themselves (Nosek, 2008).

Overcoming challenges.

Healthcare professionals. Twelve out of the fifteen studies included in this synthesis included the concept of healthcare professionals yet only one consisted of positive experiences (Stjernsward & Ostman, 2008). Relatives were not only keen to seek support for their depressed loved one but were hopeful that it would provide them with reasons and solutions regarding the depression (Badger 1996a, 1996b; Skundberg et al., 2014). Gaining access to care was a key frustration; caregivers felt that they were not taken seriously despite numerous attempts to seek help and that GPs often lacked understanding about mental health services. Often the depressed relatives were reluctant to seek professional help so caregivers were forced to be strategic with their encouragement and frequently took on an advocate role.

There was a general sense of frustration at the lack of resources available but even when professional support was put in place, most caregivers complained about feeling excluded from their relative's care (Badger 1996a, 1996b; Hansen & Buus, 2012; Highet et al., 2004, 2005; Nosek, 2008), often leading them to feel unimportant and insignificant. The only exception was Stjernsward and Ostman (2012) who reported that parents of depressed children were often

“welcomed by healthcare staff to participate” (p. 363). However, they later stated that “parents felt that they were excluded from care as soon as the child attained the age of majority” (p. 363). Relatives were provided with little practical assistance on how to cope with living with a depressed relative and were therefore left to work it out for themselves (Harris et al., 2006). Hansen and Buus (2012) reported that professionals often asked caregivers to convince the depressed relative to commence or adhere to treatment, putting them under increased pressure and often in a conflicting position with how they perceived their role with the relative.

Community support. Stigma was a key factor linked with difficulties experienced among friends, wider family and colleagues, who often associated mental illness with moral weakness or failure (Badger 1996a, 1996b). Caregivers attributed this to a general lack of awareness around depression within the community (Highet et al., 2004, 2005; Radfer et al., 2014). Some caregivers described sharing stigma with their depressed relative and noticed that friends began to treat them differently. Negative and unsupportive comments were not a rare occurrence and often led to increased social isolation, thus exacerbating feelings of loneliness and despondency (Stjernsward & Ostman, 2008).

For some caregivers, becoming more isolated was a personal choice and used as an active protective mechanism against stigma (Badger 1996a, 1996b; Hansen & Buus, 2012). Other caregivers actively sought out social support; however they were usually selective in their choice of company (Ahlstrom et al., 2009; Stjernsward & Ostman, 2008). For these caregivers, gaining acknowledgement from friends and family was highly valued because it provided them with extra strength to endure their situation through difficult times (Harris et al., 2006; Skundberg-Kletthagen et al., 2014).

Overall, the studies were in agreement that social circles were reduced to some level as a result of perceived stigma and increased isolation. However, these connections were usually regained during the later stages of their relative’s depression, as a result of caregiver’s changing sense of self.

Moving forward.

Changing sense of self. The idea of a changing sense of self was conceptualised in different ways among the studies. For example, Nosek (2008) depicted a cyclical process of

living with a suicidal and depressed relative, highlighting that the cycle is ongoing and that caregivers may find themselves switching to different positions depending on the current situation. Other studies described a transformational process, during which caregivers pass through different phases whilst coming to terms with their relative's depression (Badger, 1996a, 1996b; Hansen & Buus, 2012; Muscroft & Bowl, 2000). Despite different conceptualisations, all caregivers felt that their own lives were put on hold when their relative was diagnosed with depression. They often had little choice but to focus all their energy and attention on their relative to the detriment of aspects of their own lives, such as employment, hobbies and socialising.

Some studies described a sense of grief experienced by caregivers (Highet et al., 2004, 2005; Hansen & Buus, 2012; Muscroft & Bowl, 2000) which often led to ambiguous feelings towards the depressed relative. Studies that highlighted this sense of loss emphasised the importance of mourning in order to eventually come to a realisation that life cannot return to how it was prior to the depression. This realisation forced caregivers to rework their sense of self, enabling them to step back and distance themselves from their relative. From this new perspective, priorities and values could be re-evaluated (Stjernsward & Ostman, 2008) and often a sense of self-preservation prevailed (Badger, 1996a, 1996b; Bottorff et al., 2013; Nosek, 2008). Caregivers were usually able to engage in a more balanced relationship with their relative and regain an identity separate from that of a caregiver by doing so.

Hansen and Buss (2012) outlined a similar journey in their study exploring how caregivers negotiate their social identity whilst living with a depressed relative. They depicted a psychosocial transformation process during which a caregiver's sense of self moves from initially being 'absorbed' by the depression to gradually developing a new 'integrated' identity.

Adapting to depression. Caregivers reported practical changes made within the relationship or family home that occurred in parallel to developing a new sense of self, allowing them to accommodate the depression to some extent and begin to move forward with their lives. The concept of adapting to depression was conceptualised in different ways across the studies. Labels such as the adaptation phase (Muscroft & Bowl, 2000), the recovery phase (Harris et al., 2006) and gaining a new perspective (Badger, 1996a, 1996b) all encompassed a sense of integrating the depression into the relationship and family life. Caregivers realised that both they and their relatives had changed; they learnt to find a balance between showing love and concern

whilst maintaining emotional distance and limiting their responsibility, many opening up to friends and family for the first time for support.

Similarly to the concept ‘changing sense of self’, Radfer et al. (2014) emphasised that mourning is necessary before acceptance can be reached and many studies highlighted that caregivers also had to accept the realities and limits of their adapted life (Ahlstrom et al., 2009; Badger, 1996a, 1996b; Highet et al., 2005). When this was not possible, for some caregivers the acceptance of depression left them with no choice but to terminate the relationship; this separation occurred mainly in spouses (Ahlstrom et al., 2009; Badger, 1996a, 1996b; Highet et al., 2004, 2005)

Looking to the future. For caregivers who were able to adapt to the depression and find a way of integrating it into their lives, they looked to the future with a mixture of apprehension and hope. The majority of studies included the concept of looking to the future, highlighting the persistent impact that depression can have on caregivers even when the depression appears to be under control. The main fear among caregivers was that of relapse (Harris et al., 2006; Highet et al., 2005; Radfer et al., 2014), which resulted in them feeling helpless (Radfar et al., 2014), anxious (Skundberg-Kletthagen et al., 2014) and uncertain about the future (Stjernsward & Ostman, 2008). This level of unpredictability was encapsulated by Muscroft & Bowl’s (2000) powerful description of depression as a ‘sleeping presence’ and summarised in Nosek’s (2008) grounded theory model as ‘maintaining vigilance’.

Line of Argument synthesis. A line of argument synthesis involves the construction of an interpretation and serves to reveal what is hidden in individual studies and to discover a whole among a set of parts (Noblit & Hare, 1988). Figure 1.3 embraces all of the studies included in the synthesis, thus representing a further level of conceptual development.

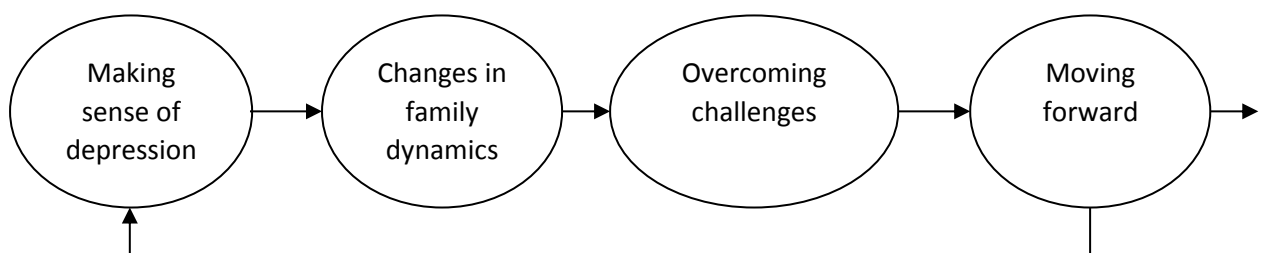


Figure 1.3. Line of argument synthesis: Experiences of providing care to a relative with depression

What emerged from the synthesis was a cyclical psychosocial process consisting of four phases that caregivers pass through during their experiences of providing care to a depressed relative. Caregivers initially experience a period during which they try and make sense of the changes in their loved one, often seeking socially acceptable explanations or searching for causes within themselves. Once the realisation is reached that their loved one has depression, the significant impact on the family requires a reformation of roles and the development of coping strategies in order to adapt to living with a relative with depression. Caregivers take on extra responsibility and often experience a sense of loss and despair as a result of the considerable changes in their family dynamics. Families are also faced with external challenges, such as accessing professional and community support. Lack of awareness about depression, the stigma associated with having a mental illness, and feeling excluded from their relatives care are some of the key frustrations. In order for caregivers to move to the final phase, moving forward, they need to accept that life cannot return to how it was prior to the depression. Regaining an identity separate from that of a caregiver is achieved by allowing themselves to re-evaluate their own priorities and gaining more of a balance between their relationship and other areas of their life, such as employment or hobbies. Caregivers can remain in this stage indefinitely with the depression now integrated into their family life. When this is not possible, moving forward may entail the breakdown of the relationship between the caregiver and their depressed relative.

The process is cyclical because people with depression often experience relapses, thus taking the caregiver back to phase one of the process. However, caregivers in this situation often pass through the phases more quickly, now being more experienced at identifying the changes in their relative and familiar with the subsequent phases.

The model proposes that caregivers need to pass through these distinct phases and overcome certain obstacles in order to reach a point of acceptance whereby the depression is integrated into their lives. The model purports that all caregivers can be located somewhere on this trajectory but acknowledges, as highlighted by the studies, that the length of time spent at each phase may vary greatly among caregivers. Furthermore, although the model outlines a sequential process that is cyclical in nature, it recognises that the phases are dynamic and may overlap.

Discussion

This meta-ethnographic synthesis of 15 qualitative studies revealed a cyclical, psychosocial process that family caregivers undergo whilst providing care to a relative with depression. The process consists of four phases: making sense of depression; changes in family dynamics; overcoming challenges; and moving forward. The findings illustrate that care giving is not a static process and that the needs of the depressed relative are constantly changing. In line with previous research, this synthesis indicated the need for many caregivers to seek professional support for their own mental health needs (Benazon, 2000; Coyne et al., 1987; Fadden, 1987).

Strengths and limitations. The synthesis provided two novel insights. Firstly, through translation, it showed that there is a pattern of key concepts that are common across a plethora of factors, including: country; caregiver age, gender and relationship to the depressed relative; settings (e.g. inpatient, community); and stage of depression (e.g. suicidal, remission). This heterogeneity could be regarded as problematic; however, for the purposes of this synthesis it was considered integral in order to explore the similarities and diversities among individuals caring for a relative with depression. Secondly, by employing a line of argument approach, the synthesis indicated that for caregivers to reach a stage of acceptance and feel able to move forward with their lives, a number of phases need to be passed through as part of a cyclical process. These new insights suggest that the meta-ethnographic method provides a greater degree of understanding and conceptual development than other methods, such as a narrative literature review.

Due to time limitations, only one researcher conducted the synthesis. As with any form of qualitative research, a pertinent issue is the subjective understanding and interpretation of the data. Therefore it is particularly important that the process is well documented and that the reader can follow the interpretative process and analysis steps. Rigour and credibility were enhanced by using a systematic and transparent approach, employing Noblit and Hare's (1988) seven-step procedure.

Although the quality assessment found that many of the studies failed to provide sufficient contextual information, including details about sample selection, data collection, and analysis, the studies were considered sufficiently rich in information for the purposes of this synthesis. The majority of studies failed to provide basic demographic information about the caregivers or depressed relative, and in all but three studies (Bottorff et al., 2013; Harris et al., 2006; Oliffe et

al., 2011) caregivers were a mix of relationships to the depressed relative. Although informant triangulation demonstrates credibility, studies were often unclear in their findings about which type of relationship was being referred to thus inhibiting the ability of the researcher to extract and compare concepts across different caregiver relationships in this synthesis.

Research Question

The meta-ethnography highlighted that qualitative studies which specifically explore the experiences of living with a family member with depression are somewhat heterogeneous regarding types of relationship with the depressed individual. Combining different relationships (e.g. partners, siblings and parents) within the same study makes it difficult to disentangle data and therefore gaining an in-depth understanding of specific experiences is almost impossible.

Three papers within the meta-ethnography focussed on the spousal relationship (Bottorff et al., 2013; Harris et al., 2006; Oliffe et al., 2011). Specifically, Harris et al. (2006) focussed on how partners attempt to support a depressed spouse and how each of the couple experience the support process. Couples were interviewed together and data was subjected to interpretative phenomenological analysis (IPA). The individual with depression was required to have had one episode of depression in the past four years. Both the remaining studies focussing on the spousal relationship (Bottorff et al., 2013; Oliffe et al., 2011) concentrated on the female partners of depressed men and explored how the men's depression impacted on gender regimes. Bottorff et al. (2013) interviewed 29 female partners of depressed males and analysed the data using grounded theory. Oliffe et al. (2011) interviewed 26 couples individually but were not clear about the method of analysis used. Additionally, neither Bottorff et al. (2013) nor Oliffe et al. (2011) were explicit about an eligibility criteria and therefore no information regarding the depression history of the male partners could be drawn from these studies.

Therefore, exploring the experiences of individuals living with a chronically depressed partner would help to disentangle existing research and develop a more comprehensive understanding of these experiences.

In light of suggestions that living with someone with depression is comparable to that of other serious mental health problems (e.g. schizophrenia or dementia), this is an under-represented area that urgently requires further exploration. Furthermore, with evidence that partners are most

at risk of burden it is pertinent that this population are investigated independently in order to develop an in-depth understanding of their experiences. This could 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 marital relationships.

Therefore, this study has the following aim:

- To explore the experiences of individuals living with a partner with depression.

Chapter 2 Method

This chapter will detail how the study was conducted. It will begin by outlining the theoretical underpinnings of the study. It will then discuss the choice of qualitative data analysis and how this method was conducted. This will be followed by the sample, recruitment procedure and data collection. Ethical considerations will then be discussed, followed finally by quality assurance.

Theoretical Underpinnings

Qualitative vs. quantitative research. Researchers have long been engaged in a debate about the use of qualitative and quantitative methodologies. The distinction has seen the two approaches positioned in opposition as if they were mutually exclusive to one another. However, the heart of the debate lies in the fundamentally different philosophies and epistemologies of the two approaches, rather than the methodological techniques alone (Yanchar & Westerman, 2006). Generally, the main tenet of positivist or quantitative philosophy is objectivity; positivist epistemology assumes that knowledge is gained through the adoption of experimental methods to look for constant relationships between variables and to measure and establish cause and effect (Robson, 2002). Quantitative research primarily investigates ‘what’, ‘where’, and ‘when’ questions, often with the aim being to classify features and construct statistical models in an attempt to explain what is observed (Jones, 2002). Within mainstream social sciences, quantitative methodologies have traditionally been given more precedence than qualitative methodologies (Denzin & Lincoln, 2000). This supports the longstanding implicit assumption that quantitative approaches possess more rigour, robustness and legitimacy than qualitative approaches, and that statistics denote a level of precision that allows findings to be more accurately replicated and generalised to the wider population (Boutilier, Rajkumar, Poland, Tobin, & Badgley, 2001).

Nevertheless, qualitative research can provide a unique and robust theoretical and methodological framework within which subjective, in-depth and personal experiences can be studied in ways that quantitative research methodologies cannot (Denzin & Lincoln, 2000). In contrast to quantitative methodologies, advocates of the constructivist or qualitative philosophy disagree with the notion of an objective reality which can be known, instead arguing that the task of the researcher is to understand the multiple social constructions of meaning and knowledge

and that the best way to understand a phenomenon is to study it in context (Robson, 2002). Furthermore, qualitative research has more flexibility for interpretative creativity which can increase the clinical utility of research findings (Denzin & Lincoln, 2000).

Rationale for a qualitative design. Research exploring the experiences of living with a partner with depression has largely been quantitative. The meta-ethnography conducted in preparation for the present study highlighted that when qualitative studies have been conducted, these findings are integrated within larger studies that are somewhat heterogeneous regarding types of mental health problem or types of relationship with the depressed individual. Combining a range of mental health problems (e.g. depression, schizophrenia and bipolar affective disorder) and/or different relationships (e.g. partners, siblings and parents) within the same study makes it difficult to disentangle data and gain an understanding of this under-represented area.

While this demonstrates that qualitative research clearly has a role within the area of living with someone with a mental health difficulty, its role appears to be under appreciated in the specific area of living with a partner with depression. Therefore, qualitative methodology was chosen for this study in an attempt to gain an in-depth insight of specific experiences regarding living with a partner with depression.

Epistemology.

Positivism, relativism and critical realism. The central tenets of positivism stipulate that knowledge must be fact based and value free (Sayer, 2000). There is a strong emphasis on measurement of phenomena, control and prediction. This scientific view has been heavily contested, particularly when the context shifts from the natural to the social world (Robson, 2002). The pursuit of knowledge in the 'real world' of people and social environments is complex and dynamic, unlike the strictly controlled environment of the laboratory (Pawson & Tilley, 2003).

An alternative philosophy, which sits at the opposite end of the continuum to positivism, is offered by relativism or interpretivism. This approach stipulates that there is no external (objective) reality independent of the mind (Robson, 2002). The relativist lens sees knowledge and knowledge-production as relative to context (cultural, material and societal) and does not embrace the search for one truth; instead accepting the existence of multiple realities and truths.

Social reality is constructed by language, discourse, perceptions and the different meanings that individuals attach to the world (Robson, 2002). Relativism emphasises the view that people are not 'passive puppets' to be manipulated and moulded by the world, but that they are conscious and purposive actors that create their own social realities (Robson, 2002).

Between the epistemological positions of positivism and relativism lies the middle ground philosophy of critical realism. Critical realism postulates 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) postulates that knowledge and reality are inherently linked to one another, and therefore reality without the context of knowledge has little meaning. This supports the rationale for a critical realist approach to understanding the experiences of living with a partner with depression. Whilst relativism has an important role in understanding these experiences, they should not be solely defined at the 'micro' subjective level at the expense of ignoring the 'macro' level influence of the wider social context (Sayer, 2000). A critical realist approach, however, takes the position that acknowledges the desire to incorporate the individual experiences and the meanings attached to them whilst also considering the impact of the wider social context on these meanings.

Research Methodology

A qualitative methodology was chosen to explore the experiences of living with a partner with depression, as this was found to be lacking within the current literature. The qualitative research tradition includes a number of epistemological and theoretical assumptions that focus on the development of an understanding of human experience (Silverman, 2000).

Methods of qualitative data analysis. There are many analytic methods that seek to illustrate patterns and themes across qualitative data, including grounded theory (GT) or interpretative phenomenological analysis (IPA); however both GT and IPA are theoretically bounded.

IPA is aligned to a phenomenological epistemology, which is about understanding individuals' everyday subjective experiences of reality in order to gain an understanding of the phenomenon in question (Smith, 2008). This methodology was not deemed the most appropriate approach for this study due to its strongly interpretative nature and dual focus on individual characteristics of participants (i.e. idiographic focus) and on patterns of meanings across participants (Smith, 2008). Due to the lack of existing literature in the area of living with a partner with depression, it seemed more appropriate at this stage to gain a larger sample and focus mainly on the patterns across participants.

Despite GT coming in many varieties (Charmaz, 2002), the overall goal of the analysis is to allow the systematic exploration of the research data in order to generate a plausible and useful theory of the phenomenon (Lyons & Coyle, 2007). GT would attempt to identify and provide a detailed account of contextualised social processes, with the aim developing a theory about living with a depressed partner. Although GT can answer questions regarding the experiences of living with a partner with depression, its goal of theory generation is incongruent with the study's aims; GT would not allow a broad understanding of these experiences to be achieved which is considered essential at this early stage of partner-focussed research.

Thematic analysis. TA is a widely used concept, tool, process, method or approach for analysing qualitative data, however it is often poorly delineated, acknowledged and defined (Braun & Clarke, 2006). TA is increasingly seen as a method in its own right and not merely a process within 'major' analytic traditions such as IPA and GT (Braun & Clarke, 2006). TA differs from GT and IPA because it is not attached to a specific theoretical framework or epistemological position; therefore it can be applied to a range of theoretical approaches including critical realism, acting as a 'contextualist method' that sits between the philosophical positions of positivism and relativism (Braun & Clarke, 2006).

TA is designed to provide structure and order on a large amount of qualitative or narrative data so that it can be synthesised, interpreted and communicated in a logical manner to the research community (Polit and Beck, 2008). TA also allows greater transparency of the approach due to the level of clarity encouraged by Braun and Clarke (2006) in the form of a series of decisions that researchers must make in order to understand and make clear their theoretical position

towards their own TA. Furthermore, this focus on transparency allows greater clarity for other researchers wishing to carry out similar studies in the future (Braun & Clarke, 2006).

TA reflects the philosophical tenets of this study in maintaining coherence between its epistemology, methodology, methods and data analysis (Crotty, 1998). The study focussed on meaning, depth, rich description and the reality of the complexities of living with a partner with depression (Quinn-Patton, 2002). Therefore TA provided a sound analytic tool to explore the experiences of living with a partner with depression. In accordance with Braun and Clarke (2006), an inductive, semantic and critical realist approach to TA was carried out. The analysis was data-driven, as it was concerned with each individual's personal perception/account of living with a partner with depression as opposed to an attempt to produce an objective account of the event itself. Moreover, the analysis took a semantic approach, that is, the themes were identified from the "explicit or surface meanings of the data" (Braun & Clarke, 2006, p 84). This is in contrast to analyses at the latent level, where the researcher goes beyond the semantic content in order to identify underlying ideologies or ideas that govern what people say. The study aimed to provide a rich thematic description of the entire dataset rather than provide a more detailed account of one particular theme within the data. This type of analysis has been highlighted as particularly useful when investigating an under-researched area (Braun & Clarke, 2006).

Participants. Initially a purposeful criterion sampling strategy was used in order to select 'information-rich' participants who could yield in-depth insight into the research issue (Patton, 2002). In contrast to random sampling methodology which is generally utilised in experimental clinical research (Ritchie, Lewis, & Elam, 2003), purposeful sampling is the deliberate selection of participants due to specific characteristics or experience (Patton, 1990).

Within qualitative research there is an emphasis on the use of small sample sizes (Lyons & Coyle, 2007). For example, it has been suggested that a minimum of five participants are required for a reasonable student project (Smith & Osborn, 2003) but that a sample of eight to twenty is desirable (Turpin et al., 1997). The sample size for the current research was therefore determined in accordance with the above; the aim was to recruit a total of twelve to twenty participants.

The sampling strategy ensured that participants were able to give informed consent. They did not have to be legally married but needed to be in a long-term relationship with a person with

chronic depression. Depression varies across the lifespan in ways that are connected to development and will be expressed uniquely in childhood, adolescence and adulthood (Berry, 2004). Recently, Arnett (2000) argued that 18-25 years is a new and distinct developmental period known as 'emerging adulthood', due to its transitional nature. It has been described as a time of experimentation and exploration which frequently involves feelings of instability and uncertainty (Arnett, 2000). Since its advance into the developmental literature, the period of emerging adulthood has gained increasing amounts of support as a distinct developmental period (Berry, 2004; Nelson & Barry, 2005). It has also been argued that depression will be expressed uniquely in emerging adulthood, just as it is in other developmental periods (Berry, 2004). Nelson and Barry (2005) posited that separation, loneliness, exploration and failure are common themes of emerging adulthood which increase the likelihood of developing depression during this time. In light of this literature, participants and their partners needed to be 28 years or above to take part in the research. This inclusion criterion ensured that the relationship would have started when both the participant and their partner were 25 years or above and therefore considered within the developmental period of adulthood. In accordance with the relationship literature discussed in chapter one, participants needed to have been in a relationship with their partner for at least three years. It could therefore be assumed that participants were in a companionate stage of their relationship. Depression was confirmed by the participant during the screening stage. Participants whose partners had bipolar affective disorder or post-natal depression were not eligible for the research, due to the nature of presentation of these disorders. Similarly, participants whose partners had a diagnosis of a psychotic disorder (including schizophrenia) were not included.

Recruitment procedure. Initially, in order to aid a purposeful sampling strategy, posters were used to recruit participants from community locations around the North Essex region, such as libraries and community centres (Appendix B). The same advertisement was placed in an online national carer's forum in order to increase the likelihood of recruitment. Those interested in finding out more about the research were invited to contact the primary researcher via telephone or email. During this initial contact, the researcher went through the screening questions (Appendix C) to ensure that the respondent was eligible for the study. If the respondent met the inclusion criteria they were provided with an information pack, which included a detailed description of the research (Appendix D). Individuals still wishing to participate were invited to contact the researcher to arrange an interview.

This initial sampling strategy received a poor response rate, possibly due to the nature of the community sample, many of whom may be quite isolated and therefore unlikely to see the advertisement posters. Furthermore, the advertisement placed on a national online carer's forum may have received limited responses due people not deeming themselves as a carer and thus not accessing this resource. Therefore, an amendment was submitted to the University of Essex ethical committee (Appendix E), which suggested that recruitment chances may be increased by the implementation of snowball sampling. Snowball sampling involves asking people who have already been interviewed to identify other people they know who fit the selection criteria (Ritchie & Spencer, 1994). It is recommended to supplement other methods when the key selection criteria are characteristics which might not be widely disclosed by individuals. The amendment also requested that the advertising recruitment area was extended to include the East of England and London, and include any community venues run by local authorities or charities who agree to put up the advertisement poster. Lastly, it requested the inclusion of online community forums, with the permission of site moderators. The amendment was granted approval and the changes took immediate effect (Appendix E).

A total of 19 respondents contacted the author by telephone or email to request further information about the study. Following the receipt of the information pack 13 respondents contacted the author to arrange an interview. The remaining six respondents who had not responded within two weeks of requesting further information were contacted by the author via the media initially used by the respondent. However, none took up the study invitation and no further contact was attempted.

The participants could choose whether they wanted the interview to be conducted face-to-face or over the telephone, depending on their location and personal preference. Due to geographical distances two participants were interviewed by telephone and the remainder were interviewed face-to-face, either in a community venue or the University.

Data collection. The data was generated and gathered during 13 in-depth interviews. A topic guide was designed to facilitate the interviews whilst simultaneously encouraging a participant-led narrative. The term 'topic guide', as opposed to 'interview schedule' or 'interview guide', is preferred because it emphasises the focus on outlining topics rather than specific questions (Arthur & Nazroo, 2003). In contrast to semi-structured interviews where the interviewer asks

key questions in the same way each time and does some limited probing for further information, in-depth interviews involve a broad agenda which maps the issues to be explored across the sample, but the order, wording and way in which they are followed up may vary significantly between interviews (Arthur & Nazroo, 2003).

A topic guide was developed which tapped into the findings highlighted by the meta-ethnographic synthesis; this included five broad topics. Each topic consisted of suggestions for prompts and directions for probing. Open-ended, neutral prompts (E.g. “Can you tell me more about that?”) were also asked to facilitate the interviews and minimise any potential influence of the researcher (Kvale, 1996).

1) Depression - Please start by telling me about your partner’s depression.

Prompts:

- *When did you notice it?*
- *What did you notice?*
- *Who noticed it?*
- *Sudden or gradual?*
- *Journey of seeking help.*
- *Length of depression.*
- *Relapses?*

2) Relationship - Has your relationship changed at all because of your partner’s depression?

Prompts:

- *Role changes?*
- *Caregiving?*
- *Positive changes?*
- *Negative changes?*

3) Stress/Burden - Have you experienced any pressures or stress as a result of your partner’s depression?

Prompts:

- *Work / Hobbies / Social?*
- *Depression/anxiety?*

- *Illness?*

How do you manage these stresses?

Prompts:

- *Positives – e.g. hobbies, time with friends?*
- *Negatives – e.g. drinking more, becoming more withdrawn?*

4) Support - What support, if any, has been available to you?

Prompts:

- *Useful/not so useful?*
- *Positive experiences?*
- *Negative experiences?*
- *Professional support?*
- *Friends and family?*
- *Colleagues?*
- *Perceived stigma?*
- *Feelings about seeking support*

5) Reflection - Do you feel that you have learnt anything about yourself through this experience?

- *Is there anything else you would like to add about your experiences?*

Method of data analysis. In this study, the in-depth thematic analysis followed six phases in a recursive manner in order to reach an understanding of the experiences of living with a partner with depression (Braun & Clarke, 2006).

Phase one: Familiarising yourself with the data. Immersion of the data started during the process of transcription (Bird, 2005). The transcripts were then read repeatedly in order to become familiar with the depth and breadth of the content, and any initial ideas for coding were noted as they arose. During this phase the interviews were also listened to again, following transcription, to allow the researcher to relive the social encounter.

Phase two: Generating initial codes. This phase involved the generation of initial codes from the data and organising them into meaningful groups. Due to the analysis being data-

driven, the codes were derived from the data itself rather than any pre-existing theories or questions. Coding was conducted systematically though the entire dataset. As a vast amount of information was generated through the in-depth interviews, the computer programme MAXQDA was used to manage the data coding.

Phase three: Searching for themes. Codes were sorted into potential themes using MAXQDA and all relevant coded extracts were collated within the identified themes. The researcher was continually mindful of the potential relationships between codes, themes and between different levels of themes. During this phase, a log of the researcher's decision-making processes and reflections were maintained using the memos and audit trail functions within MAXQDA.

Phase four: Reviewing themes. This phase involved the refinement of themes and consisted of two levels. Level one involved re-reading all the collated extracts for each theme and ensuring that they formed a coherent pattern. Level two involved the consideration of the validity of each theme in relation to the whole dataset and to add any additional data within themes that had been missed during phases two and three. Patton (1990) emphasised that themes should cohere together meaningfully whilst maintaining clear distinctions between one another, a dual judging criteria known as internal homogeneity and external heterogeneity.

Phase five: Defining and naming themes. Themes were further defined by determining what aspect of the data each theme captured. Theme names were generated and sub-themes for each main theme were identified.

Phase six: Producing the report. The write-up consisted of a narrative account and themes were supported by data extracts to demonstrate their prevalence within the dataset. Commonalities, variations and contradictions within the dataset were highlighted and possible explanations for this considered.

Ethical considerations. Full ethical approval was gained from the University prior to the commencement of data collection (Appendix F).

Informed consent. Informed consent ensures that participants are aware and knowledgeable about the research and that any questions or concerns they may have are

addressed (Strydom, 2002). 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 (Appendix G) had been completed by the participant. Where the interviews were conducted via the telephone, written informed consent was received via a scanned email or via post. Verbal and written informed consent to participate in the study were gained from all participants.

Confidentiality and anonymity. Confidentiality ensures that no data is reported which may identify participants, and this is particularly pertinent when investigating topics that are personal to the participants. To maintain confidentiality, interview transcripts were anonymised so that all identifiable information was removed. Transcripts and audio-recordings were stored in separate password-protected files on an encrypted laptop and all audio-recordings were deleted from the digital recorder once they had been uploaded securely onto the laptop. Transcription of the audio-recordings was conducted solely by the researcher and each participant was assigned a reference code during the data collection and analysis processes, and pseudonyms within the final write-up. Participant reference codes were stored in a separate password-protected file on an encrypted laptop.

Participants were informed that only the researcher and their supervisors would have access to the whole transcripts during the data analysis. They were also advised that extracts from the transcripts may be used in the write-up of the research but that these would be anonymised to prevent identification.

Interviewing. Due to the geographical distances of some participants, face-to-face and telephone interviews were offered in order to increase the recruitment levels within the study. Conducting interviews, both face-to-face and via the telephone, can be a complex process fraught with uncertainties (Banister, Burman, Parkerm Taylor, & Tindall, 1994). The key to any successful interview is the ability to develop a warm, safe and empathic relationship in order to enhance the enquiry process (Sturges & Hanrahan, 2004), which can be more difficult to establish during telephone interviews due to the lack of availability of non-verbal cues (Garbett & McCormack, 2001; Rungapadiachy, 2001). However, respondents have been described as relaxed on the telephone and willing to talk freely and disclose intimate information (Kavanaugh & Ayres, 1998). Qualitative telephone data have been judged to be rich, vivid, detailed, and of high quality (Sturges & Hanrahan, 2004). Within the study two interviews were conducted via

telephone. The researcher utilised their interpersonal and clinical psychological skills to facilitate these interviews. Paralinguistic skills such as the utilisation of verbal cues and paraphrasing participant responses helped to reduce miscommunication and enhance the interview experience.

Risk of Harm.

Participant Safety Issues. Qualitative research interviews involving sensitive topics may provoke emotional or distressing responses in participants. Therefore participants were informed that their taking part was voluntary and that they could withdraw from the study at any time without giving a reason and without any negative repercussions. Participants were informed that they could refrain from answering any questions during the interview if they wished and could take a break or stop completely at any time. Upon completion of the interview, participants were given the opportunity to discuss their experiences of the interview and debrief with the researcher. A handout of support resources was also available (Appendix H).

Participants were informed that if they disclosed information that suggested they may be a risk to themselves or others, or expressed significant distress, then steps would be taken to ensure safety and alert relevant professionals (e.g. GP). No ethical difficulties were encountered whilst collecting the data and none of the participants requested debriefing following the interview.

Participants were offered a £10 high street store gift voucher for their participation. The amount of £10 seemed substantial enough to incline individuals towards participation without being large enough to be considered coercive. The payment was also used to acknowledge the participant's contribution towards the research. Participants were asked to sign a form to acknowledge receipt of payment (Appendix I). Participants will also be offered a short report detailing the findings of the research once the thesis is completed, as all participants expressed an interest in the study's results.

Partner safety issues. Participants were informed that the researcher has a duty of care to report any information disclosed that suggests the participant's partner is a risk to themselves or others. Participants were advised that if they disclosed information suggestive of current risk then steps would be taken to alert relevant professionals (e.g. GP, care-coordinator or duty team). No ethical difficulties of this nature were encountered when collecting the data.

Researcher safety issues. Interviews were conducted either via telephone or face-to-face in community locations or at the University of Essex. In these cases another member of staff was present on the premises and available if required. An online support system for lone working was available (i.e. Guardian 24) but was not required. Within this system, the lone worker logs their visit online with an agreed check-in time after the event. If the lone worker fails to check in on time, the service calls the user to verify their safety. If the lone worker fails to respond then emergency services are called.

Quality assurance. In order to strengthen reader's confidence in the data interpretations and findings generated, credibility checks were incorporated into the study's design, data analysis and interpretation. Yardley's (2000) assessment criteria for evaluating qualitative research were employed for guidance.

Sensitivity to context. Yardley (2000) argues that by looking for data that contradicts emerging themes and ensuring that these themes are accounted for within the theoretical framework of the study, sensitivity can be achieved. Throughout analysis, unexpected findings and observations were actively sought and consideration was given to how they differed from the other themes. The use of summarising and clarification during data collection, also referred to as respondent validity (Henwood & Pidgeon, 1992), was used to ascertain if the researcher's understanding matched that of the participant.

Commitment and Rigour. Evaluation of commitment to the research topic and rigour in data collection and analysis are essential components in assessing qualitative research (Yardley, 2000). Commitment was demonstrated through the prolonged engagement of the researcher in the data analysis process; the researcher made the decision to transcribe all of the interview recordings in an attempt to become fully immersed in the data.

According to Lincoln and Guba (1985), one of the most crucial techniques for preventing data misinterpretation is via 'member checks'. Member checking is a process in which the data, themes and findings are tested with participants or members from the same research population for perceived accuracy and perceptions. However, this technique relies on the assumption that there is one fixed reality that can be accounted for by the researcher and confirmed by the participants. In light of the study's epistemological positioning of critical realism, which postulates that individuals experience different aspects of reality and thus provide only a partial

account of a phenomenon, this may create a dispute as to whose interpretation should prevail if the participants were to disagree with the researcher's data interpretation (Sandelowski, 1993). Furthermore, participants may provide narratives during an interview that they later deny or change their opinions on in light of new information. Considering the difficulties experienced in recruiting participants for this study, finding individuals that did not participate but fitted the inclusion criteria to check the accuracy and feasibility of the research would have proven difficult (Angen, 2000). For these reasons, it was decided not to incorporate this technique.

Triangulation is a method used by qualitative researchers to check and establish validity in their studies by analysing a research question from multiple perspectives (Patton, 2002). Methodological triangulation, which refers to the use of more than one method for gathering data, is frequently used to enhance research validity and rigour (Denzin & Lincoln, 2000). Whilst this technique can be helpful, it was felt that the application of additional methods may dissonate with the study's theoretical framework (Risjord, Moloney, & Dunbar, 2001) and therefore this method was not utilised. Investigator triangulation with the research supervisor was utilised in order to ensure corroboration of the study's data interpretations and finding credibility.

Transparency and Coherence. Transparency is imperative within qualitative research because it highlights decision-making processes throughout the research, thus rendering them accessible and auditable by the audience (Baxter & Eyles, 1997). Using TA principles and procedures, which are grounded within an epistemological position in line with the aims of the research, helped minimise instances of data misinterpretations. TA as a research method allows a systematic and transparent process within which to analyse large quantities of data, and generate findings that are grounded within the text (Braun & Clarke, 2006). To enhance transparency, evidence of analytic decision-making throughout the research process has been kept, offering an audit trail of how the research was conducted. Please refer to Appendix J for a sample of coded transcript.

Topics covered during the interviews were developed from previous literature in the area of living with someone with a mental health difficulty, and the sparse amount of existing qualitative research exploring experiences of living with a family member with depression. This ensured that the researcher's agenda did not dominate the data collection process and that pertinent issues determined the direction of enquiry during the interviews.

Yardley (2000) also proposes that the researcher reflects on how their assumptions and motivations shape the research process. For this study, the researcher also held the role of a clinician with previous experience of working with carers of people with mental health difficulties. It was the researcher's previous experience in this area that led to the conceptualisation of the current study. In particular, reflections upon the lack of recognition of individuals who live with somebody with a mental health difficulty, ideas around their identity as a carer and their development of coping strategies often in the absence of professional interventions. It is therefore imperative to acknowledge that the researcher had their own preconceived beliefs regarding the experiences of living with an individual with a mental health difficulty. However, the researcher's previous clinical experience did not solely focus on the experience of partners but on a range of caring relationships; the specific interest on the impact on partners came to light during the researcher's exploration of existing literature coupled with their interest in working therapeutically with couples.

The researcher was mindful of their relative power as a Trainee Clinical Psychologist during the interviews. The researcher's experience as a clinician influenced their response to many of the participant's distress but they maintained awareness of remaining neutral yet empathic to see the research through rather than respond in a more familiar therapeutic manner.

Impact and Importance. It is essential to evaluate the usefulness of research, and arguably the most significant measure to ascertain this is its quality (Yardley, 2000). 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 marital relationships.

Chapter 3 Results

The results of this study will now be presented. Table 3.1 can be used to situate the sample.

Table 3.1

Situating the sample

| Participant Pseudonym | Age | Age of Partner | Length of Relationship (Years) | Length of Depression (Years) | Interview Type |
|------------------------------|------------|-----------------------|---------------------------------------|-------------------------------------|-----------------------|
| Kerry | 44 | 45 | 14 | 10 | Telephone |
| Loren | 32 | 46 | 15 | 10 | Face-to-face |
| Clare | 54 | 55 | 8 | 3 | Face-to-face |
| Alicia | 35 | 38 | 5 | 4 | Telephone |
| Amy | 57 | 75 | 37 | 37 | Face-to-face |
| Katie | 62 | 72 | 40 | 40 | Face-to-face |
| Rick | 35 | 35 | 5 | 20 | Face-to-face |
| Jenna | 62 | 68 | 33 | 50 | Face-to-face |
| Matt | 28 | 29 | 5 | 2 | Face-to-face |
| Nicky | 73 | 72 | 50 | 50 | Face-to-face |
| Tom | 55 | 55 | 21 | 40 | Face-to-face |
| Gemma | 43 | 45 | 4 | 20 | Face-to-face |
| Barry | 45 | 43 | 4 | 20 | Face-to-face |

Study Sample

Research participants' ages ranged from 28-73 years with a mean age of 48 years. There were nine females and four males. All participants were from a White British background; nine of the participants were married. Participants reported the length of their partner's depression to the best of their knowledge; this ranged from 2-50 years with a mean length of 23.5 years. Three of the participants reported experiencing depression themselves.

Analysis

Themes were developed using thematic analysis (Braun & Clark, 2006). Table 3.2 illustrates the themes and subthemes.

Table 3.2

Results themes and subthemes

| Theme | Sub-Theme |
|--|---|
| Making sense of the depression | Hindsight is a wonderful thing If there's a reason, we can fix it |
| The depression cannot be compartmentalised | An invisible coat of lead In sickness and in health, you just do it, don't you? |
| A light at the end of the tunnel | Seeking professional support I get by with a little help from my friends (and family) |
| Learning to navigate the 'depression' maze | Looking after myself Building a toolkit to manage the depression No maps provided – living with uncertainty |
| Gaining a new perspective | Something in me shifted Looking to the future |

Making sense of the depression. Recognising and acknowledging their partner's depression was an important process described by all participants. Frequent references to the wish that participants had recognised the signs and understood them within the context of depression are discussed in the first subtheme *hindsight is a wonderful thing*. This subtheme also explores the subsequent guilt experienced by some participants for not having picked up on the signs earlier on. During the process of beginning to understand their partner's depression, participants often found it helpful to think about a perceived cause, which not only provided them with hope but also a direction for negative emotions such as anger and frustration. These ideas are illustrated within the second subtheme *if there's a reason, we can fix it*, which also explores how participants coped once their initial perceived reason could no longer explain their partner's depression.

Hindsight is a wonderful thing. The process of recognising that their partner was experiencing depression varied among participants. For some, it was a sudden realisation brought to light by an abrupt and obvious change in their partner:

He got out of bed one morning and he just said “I can’t go to work, I just cannot go”. And he literally then could not get out of bed. It just hit him like a steam train; it was just immediate. (Clare)

However, for the majority of participants the process was more gradual and any changes noticed in their partner were initially attributed to everyday life stressors, such as work related stress or financial difficulties. Having an explanation for the depression provided a form of comfort, which links in and is explored further in the next sub theme, *if there’s a reason, we can fix it*. Almost without exception, participants expressed that in hindsight they recognised their partner was actually exhibiting signs of depression for a length of time before it became openly acknowledged. This idea was encapsulated by Alicia:

So he’d have, like, 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)

Some participants described that their partner had, in hindsight, been depressed from the outset of their relationship. Initially this was interpreted as just being part of their personality:

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 Vicky 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)

The experience of guilt was common among participants, who often felt that they should have recognised the signs and noticed that something was not quite right. This was highlighted by participants not only in relation to recognising the first episode of depression but also subsequent episodes too. One participant expressed his frustration at himself for not picking up on his wife’s deteriorating mood, “I kicked myself this year, I really did kick myself because I absolutely should have seen this coming” (Tom), thus increasing his sense of self-blame.

Three participants also experienced depression themselves and explained that both they and their partners had been open about their depression from the beginning of the relationship. Subsequently, they did not face the same obstacles as other participants in relation to recognising the existence of the depression; however, the difficulties they faced in trying to make sense of the depression seemed akin to the other participants' experiences:

I think it's a learning curve. Not only do you get to know the person, because we all have our own way of doing things and mannerisms. In between all that there's the problem of the background issue of the depression and so it's learning to try and pick out what is and what isn't a depression issue. (Barry)

If there's a reason, we can fix it. Identifying an explanation for the depression enabled participants to begin to make sense of their experiences:

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)

For some, the explanations appeared obvious and were linked to current stresses such as work, financial problems and unresolved previous marriage difficulties. For others, explanations were more deep-rooted and were attributed to childhood trauma. There was a shared sense that having an explanation was necessary to be able to tackle the depression. This idea was encapsulated by a participant who described the strong desire for there to be a reason for their partner's depression "so we can fix it and make it go away" (Gemma). A solution focussed approach was common among participants because it enabled them to have a sense of control over the situation:

Sometimes she thinks that I think there is a magic solution, you know like 'if you just try this you'll get better', which I don't, but I suppose my way of dealing with it is to think of all the things we can do, you know, that we can control, and work through them. (Rick)

Having an explanation for their partner's depression also gave participants a direction for their anger; if they could project their anger onto the perceived cause of the depression it meant they did not have to acknowledge the anger and frustration they sometimes felt towards their partner.

Comparing her husband's first episode of depression to the current episode, one participant described this idea:

It was not as bad as it has been this time because there was something to be cross with. But at the moment there's only him to be cross with and I don't do that because...because I'm not cross with him, really, but it just makes it more difficult for me to deal with I think. (Kerry)

For many participants the initial perceived causes for their partner's depression gradually diminished. This was often a difficult experience as it reduced participant's sense of having any control over the situation, thus increasing the levels of uncertainty. The idea of learning to live with uncertainty is explored further within the theme *learning to navigate the 'depression' maze*. Up until this point having an explanation provided participants with hope, with one participant acknowledging "it didn't make any difference whatsoever to my husband's mental health, but it made a difference to mine" (Kerry). The same participant expanded on this idea, highlighting the difficulties experienced by partners when they are forced to acknowledge the possibility that perhaps there is no obvious reason for their partner's depression:

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)

The majority of participants had at some point questioned their own role in their partner's depression and many had experienced a sense of self-blame. Often the self-blame occurred after initial explanations could no longer be accepted; at this point participants turned towards themselves seeking answers:

You sort of question yourself almost, you say 'is it me?', you know, 'why can't I cheer him up?' so to speak? That's putting it quite mildly I suppose. I think there was a part of me for a long time wondering if I could have done something different and I was frustrated at myself. (Alicia)

The depression cannot be compartmentalised. The impact of the depression on the lives of participants was extensive. The subtheme *an invisible coat of lead* encapsulates the impact on the participants themselves at points during their experience of living with their

depressed partner. It discusses the idea of participants suppressing their own, often conflicting, emotions in order to support and/or protect their partner, and the impact this can have on the participant's wellbeing. An equally affected area of the participant's life, not surprisingly, is their relationship with their partner. These ideas are captured in the subtheme *in sickness and in health, you just do it, don't you?*, which explores the attitudes and roles within the relationship and how they are affected by the depression. Across both of these subthemes is the idea that the experience of living with a depressed partner can also, at times and over time, provide positive growth for the participant and their relationship.

An invisible coat of lead. Living with a partner with depression had a huge effect on all participants in one form or another. Many described the depression as all-encompassing and emphasised that the extent of the impact on partners is often overlooked or underestimated:

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)

Participants experienced the depression as 'insular' and 'inward facing'; often partners were unable to notice the affect it had on others until they themselves were feeling better. Many participants articulated a wish for a 'non depression-focussed' life, however for some the depression remained a big part of their lives even during periods of wellness: "either we're celebrating because he's well, or he's unwell. Either way it's there, all the time" (Kerry). Feelings of uncertainty were common and often elicited an underlying sense of pressure, although how strong or apparent this was varied among participants. For some, living with a constant sense of pressure had become the norm:

When Rich was in hospital, oh the relief, it was apparent how heavy the weight was then. I knew he was safe, he couldn't go anywhere, he couldn't get out, and the weight that lifted that I didn't even know I was carrying at the time, was immense. (Kerry)

Participants described that living with a partner with depression could be 'draining' at times, feeling like they were being 'pulled down' with their partner. Many had noticed negative changes in their own personalities, such as reduced confidence, increased stress and worrying

more than usual. Some felt unable to partake in their usual hobbies due to a sense of responsibility towards their partner, whereas others lost motivation for these activities and became more withdrawn:

It makes me feel very down as well; it's not how I envisaged living my life, you know? It restricts a lot of the things I do. It makes even just being at home not very nice sometimes, just not a nice place to be. (Rick)

Some partners were described as almost unrecognisable during periods of depression, with one participant stating that it was like "living with a complete stranger at times" (Alicia). However, a common yet frustrating experience shared by many participants is described below by Kerry:

A really annoying thing is that when other people are here, he's ok or can be ok. And it's like 'if you can do it for them why can't you do it for me?'. He tends to be able to turn on the positivity for friends, visiting family and children. But as soon as those people leave the house it's like the black cloud descends back in the house. (Kerry)

The way these experiences were interpreted varied among participants. Some believed it was their own fault and that they should be doing more to help their partner, whilst others directed the blame at their partner and felt immense anger and frustration. Tom described how his interpretation changed over time: "you realise that actually it's about putting on a brave face for other people and that she feels safe and secure enough to feel depressed in front of me. But that took a long time to realise". Some participants who shared this realisation relished this temporary normality as it provided them with hope for the future:

It didn't bother me that he was pretending because it was such a relief to see him how he was. So I almost didn't care that it was a bit fake, it was just a relief. And I suppose that made me carry on because I could see glimpses of how he used to be so I knew he was still there underneath. (Alicia)

Participants listed a vast array of emotions that they experienced towards their partner, including: anger; rage; frustration; sorrow; pity and sympathy. Often these emotions were experienced simultaneously, leading to confusing internal conflicts that one participant likened to having a "good fairy on one shoulder and a bad fairy on the other" (Clare). Almost without exception, participants described the need to suppress their own emotions for the sake of their partner at times, often meaning they were saying and doing something different to how they actually felt. A key example of this was in situations where they felt they needed to be extra positive to

compensate for their partner's negativity, which they all agreed was a tiring and draining job. For most this was about protecting their partner; however, a small minority were upfront with their partner about their frustrations from the outset. Some participants described a gradual decrease in how much they suppressed their own emotions, often due to the negative effect it had on their own mental wellbeing over time. This idea is explored more in the theme *gaining a new perspective*.

A consequence of suppressing one's own emotions was that participants' feelings were often overlooked. Many felt that the inward facing nature of the depression resulted in them feeling unable to have a bad day themselves because they were required to look after their partner. One participant summarised this point by stating, "it can't be both of us, so we survive" (Loren). For those who experienced depression themselves, this could sometimes have a detrimental effect: "trying to keep him stable means I'm not focussing on keeping me stable" (Gemma).

Depression is frequently labelled as an invisible illness and participants emphasised how the invisible nature of depression can lead them to feel helpless at times:

Because it's nothing physical you just don't know what's going on in that person's head. There's a feeling of helplessness; you're seeing the person in front of you disintegrate and you don't know what to do to help. You can't stick a plaster on it or go and get them a lemsip. There's nothing you can do. (Jenna)

Furthermore, participants described how this invisibility also envelopes them:

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)

The sense of wearing an invisible coat of lead resulted in many participants feeling overwhelmed and lonely. The loneliness was experienced by some as feeling alone with the responsibility of their children and other external pressures, and by others as a sense that nobody really understands what they are experiencing. One participant described feeling most alone during so-called positive experiences, such as a wedding anniversary, when their partner was unable to share the joy due to his depression. A sense of feeling unappreciated by their partner was also highlighted by some participants, with one woman voicing her frustrations: "I sometimes want to say, 'when will I get this back?' you know, 'what do I get in return?', because nobody notices or says thank-you" (Kerry).

Many participants emphasised that given the chance they would like their partner's depression to not exist at all; however, some highlighted that it had created positive changes within themselves, such as increased patience, a stronger and more courageous character, the ability to identify depression in others and also the provision of different and more fulfilling life opportunities (i.e. having a higher paid job to be able to provide for the family).

In sickness and in health, you just do it, don't you? All participants agreed that living with a partner with depression has some form of negative impact on the relationship, although the extent and frequency varied greatly. Some participants expressed great loyalty towards their partner and supported them almost without question; this tended to be participants who had been married the longest. For these participants, there was a sense that making adjustments was paramount in maintaining their marriage: "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 almost forced. The extract below encapsulates this idea from a lady married for over 30 years to someone with depression:

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 or marriage panning out: "I did not sign up for this" (Clare). Despite participants having varied attitudes about the role of depression within the relationship, it seemed that those who experienced greater resentment did not necessarily provide less support to their partners; nor did they come from relationships of shorter duration. This may be due to the ability of many participants to suppress their own emotions, an idea discussed in the previous subtheme *an invisible coat of lead*. Many participants viewed the depression as something they tackled alongside their partner and recognised the impact they can have on its progress. For participants who experienced depression themselves, some expressed gratitude towards their partner for being able to learn from one another.

The depression had such a profound impact that for a few participants it led to the relationship breaking down; for some this was only a temporary separation but for others it was permanent. Many 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)

Almost without exception, participants noted that the relationship felt unequal when their partner was experiencing depression. Many had to take on extra responsibilities around the house or felt like they undertook the role of a 'counsellor' at times. This shift in balance within the relationship caused difficulties for the some couples, often leading to bitterness in both parties:

He finds it very difficult to deal with me being the breadwinner. I think that affects his self-esteem a lot. And that affects our relationship because sometimes he's resentful of me and then I resent him and I do the 'well I wouldn't be doing this if you were not ill'. So there is resentment both ways about how we've ended up. (Kerry)

However, other couples seemed to accept that this was part and parcel of a marriage, with one lady summarising her view: "you just work together on things and sometimes one takes the lead and sometimes the other one takes the lead, and that's how it is" (Amy).

Another significant role change expressed by a number of participants was that of feeling like a mother and/or carer. Some participants attributed this label to themselves, whereas other participants had it highlighted to them by others, such as family and friends. One lady, married for over 30 years to her husband who had experienced depression for the length of the marriage, described how staff at the hospital where her husband was an inpatient had informed her that she was a carer and therefore entitled to extra support. She described: "I didn't even realise I was a carer. You just think well you're married and it's what you do, you know" (Amy). For those that experienced this particular role change, it seemed to elicit strong emotions as participants tried to comprehend this shift in the relationship whilst simultaneously maintaining their role as a partner. One lady 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" (Clare).

Communication between the couples was significantly affected during times when partners were experiencing depression. Participants who described their usual communication style with their partner as open and supportive found this particularly frustrating: "He just would not talk. That is how we, as a couple, resolve matters. And when that's taken away you become quite angry" (Alicia). During the depths of depression some participants described their partners as being

unable to hold even a basic conversation or make simple decisions. They also found that their own feelings about the situation were overlooked as the communication often centred around the depression. One lady described a conversation with her husband during which she tried to highlight this to him:

He said, 'we talk about my depression all the time'. And we do. But he meant talking about his medication, his counselling, about him being ill. I meant how it makes me feel. And he immediately, even though he was saying he's not self-focussed, his immediate reaction was totally self-focussed. (Kerry)

For participants who were able to talk to their partners about the depression it seemed to have a positive impact on the relationship by enabling an openness that facilitated understanding and support. However, many of the participants expressed a fear that talking may trigger or exacerbate the depression, which played constantly on their minds: "am I going to send him back into depression by saying that or behaving in that way?" (Clare). This sense of responsibility was even greater for participants whose partners were suicidal:

I was in a position whereby I felt as if I was totally responsible for his life because when he got into the 'I'm going to kill myself' mode, if I tried to challenge him, if I put one foot wrong, it would just make the situation worse. (Jenna)

Learning to be more open with one another was acknowledged by all participants as an ongoing, joint process fraught with ups and downs. What appeared to be successful one day may not be on the next; this idea is explored further in the theme *learning to navigate the 'depression' maze*. Participants agreed that it was lengthy process, sometimes taking years to develop.

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, with one participant stating: "now anything that anyone throws at us, we're like 'bring it on'" (Barry).

A light at the end of the tunnel. Participant's and their partners faced many challenges in accessing support. The first subtheme *seeking professional support* explores participants' experiences of accessing professional help for their partner and some of the hurdles involved. It also captures some of the frustrations shared by participants at the lack of opportunities to be

involved in their partner's care and the lack of support provided for them as caregivers. The second subtheme *I get by with a little help from my friends (and family)* describes the important role played by family and friends in supporting participants. In addition to often being a valued outlet for participants, this was regularly conflicted by the fear of stigma and a lack of understanding about depression by many.

Seeking professional support. For some participants their partners were already involved with services when they met and started the relationship; for others accessing professional support was not a smooth journey and many 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)

Many partners had accessed different services during times of increased need, such as Community Mental Health Teams (CMHT) and Crisis Teams. Three partners had spent time in hospital in relation to their depression. However for most participants, their partner's first step towards professional support began with the GP. Many attended GP appointments alongside their partner due to concerns that their partner would not be fully honest about the extent of their difficulties. Experiences of GPs were mixed; most participants agreed that they did an acceptable job at monitoring their partner's medication, however the majority expressed frustration at the lack of knowledge about local services to refer participants for further specialist support. This frustration led a number of couples to seek out and pay for their own private support. Many participants said it would have been helpful to be referred to services earlier and one participant even reported changing the GP due to unsatisfactory service.

For participants whose partners received a diagnosis of depression from a GP or psychiatrist, some initially found it a useful explanation for what they had been experiencing and it also led to a treatment plan: "having a psychiatrist say 'yes there is a problem, we can diagnose it, we can treat this' was actually a real relief. At that particular point for somebody to hand over a prescription, that was very useful" (Tom). Participants were in agreement that a diagnosis could be both a help and a hindrance and that living with someone with depression highlighted

complexities that could not be conveyed with a single label. Tom went on to describe how his view changed as time went on:

Although the labelling was very useful early on to get some treatment, I'm not sure the labelling actually fits very well because then you try and assume that they're a bunch of symptoms that fit in with that one diagnosis which actually don't fit. (Tom)

Medication and talking therapies were raised a lot during the interviews. The majority of partners were taking antidepressant medication, which had often felt like a trial and error process during which participants described contending with a variety of side effects, such as weight gain and lethargy. Many referred to a 'flattening' of their partner's mood, with one participant describing: "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 by their GP, participants complained of long waiting lists for brief, time limited support. This included participants who were offered talking therapies post-2008, following the introduction of the Improving Access to Psychological Therapies (IAPT) service (Layard et al., 2006). A recent report (NHS England, 2015) stated that by March 2016, 75% of people referred to the IAPT service will begin treatment within six weeks. The aim of IAPT is to provide evidence based interventions to individuals with mild to moderate anxiety and/or depression; however, participants who visited their GP after the introduction of IAPT described being asked to wait up to 16 weeks for the service for their partner.

Views about attending therapy alongside their partner varied among participants; some felt it was something their partner should do on their own whilst others wanted to attend all sessions. Nonetheless, most agreed that attending at least one 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. However, no participants were offered to attend therapy sessions which led some to feel excluded and unimportant. A sense of disheartenment was expressed by some participants whose partners had tried various medications and talking therapies over the years, which had only led to temporary improvements.

Joint therapy was mentioned by a few participants but mainly in the context of frustration at the fact it was not offered by the GP. Lack of GP knowledge about local and national resources 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)

Participants were keen to suggest ways in which services could be improved for individuals experiencing depression. A key frustration expressed by the majority of participants was the lack of involvement of the partners of individuals with depression at all stages of the support process, ranging from the GP to inpatient wards. Participants felt that as someone who spends the most time with their partner and knows them better than anyone else, they had a lot to offer services. Concerns were also raised about the lack of acknowledgement by professionals about the impact on wellbeing for those living with a partner with depression. It was suggested that GPs should check in with partners and provide information for support if required. Some participants were accessing individual therapy in relation to their partner's depression; however, this was sought independently rather than offered via the GP. Many suggested that a group for people living with a partner with depression could also be helpful in order to share experiences and ideas. The final suggestion raised was that of clearer pathways and more transparency within services. Couples felt that they were not fully informed of what was on offer or how to access services, often leaving them feeling confused, frustrated and dispirited.

I get by with a little help from my friends (and family). Participants were divided as to whether they spoke to friends and family about their situation and how helpful they found this support. For some, friends and family provided practical help 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, a lot of participants reported that they did not like to talk to anybody about their partner's depression. Many acknowledged that there continued to be a stigma attached to this label:

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)

The fear that others may not understand led some participants to only discuss other, more socially acceptable, problems with their friends and family rather than the depression itself. 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). Many couples were selective about who they spoke to about the depression, often 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, a small number of participants reported that they purposefully spoke about their partner's depression to other people in order to try and reduce the stigma surrounding it. Furthermore, many participants found that they had been more open during subsequent episodes of depression, often because they experienced more and more pressure that they did not want to deal with on their own: "this time round I have been honest with most people and said that our relationship is bad because of the depression and everybody has said 'I'm not surprised', and it's really good you know (starts crying), it doesn't make me feel that bad" (Clare).

During the process of trying to make sense of their attitudes and views about their partner's depression, many participants referred back to their own (and their partners') family values around mental health:

I come from a very proactive family for whom someone suffering from long term depression would have been incredibly supported and well received and it would have been priority to get that person help, but he comes from a very different sort of family where no-one does anything, talks about anything, says anything to rock the boat about anything. (Loren)

Similarly to Loren, above, some couples struggled with conflicting attitudes towards mental health and how it should be understood and approached. Many participants shared insights from their own upbringing and made links to how it affected their experience of living with a partner with depression. Some described how the reality of being in this situation had forced their initial attitudes to shift over time. This concept is explored further in the theme *gaining a new perspective*.

Not all participants felt bound to silence by the fear of stigma from others. For some, the decision not to talk about their partner's depression was about embracing time spent with friends and family: "I suppose it affects life so much that when I'm with my friends and family I don't want it to be there as well. Otherwise all we ever do, or say, or think about, is depression" (Kerry). For others, not wanting to discuss their problems with others came down to a more

general coping strategy of keeping things to themselves; those that shared this view were all male.

Many participants expressed a sense of disloyalty towards their partner when discussing the depression with others. Some experienced this during the interview process despite discussing and seeking permission from their partner before agreeing to take part. This was often another reason that participants decided to keep it to themselves. Below, Tom encapsulates this idea:

I do feel disloyal talking about Carly like this. It feels critical. I don't feel comfortable describing her as having anything that's wrong with her. And yet I know that she has got something wrong with her, I absolutely know that. But I love her to the point that it feels uncomfortable even saying that. (Tom)

Learning to navigate the 'depression' maze. Participants experienced their partner's depression as an ongoing, and at times very difficult, journey. During this journey, frequent references to the development of personal coping strategies are discussed in the subtheme *looking after myself*. This subtheme also explores the idea of participants recognising the need for self-preservation and the different forms this may take. Equally as important as developing personal coping strategies was the idea of participants developing ways of managing their partner's depression, which is captured in the subtheme *building a toolkit to manage the depression*. This subtheme highlights processes involved in building the toolkit, which was often perceived by the participants as a trial and error process beset with unpredictability. The third subtheme *no map provided – living with uncertainty* describes the idea that there are no definitive answers or correct ways of managing the situation. Feelings of having things under control are often only temporary and no matter what participants (and their partners) try, the nature of depression means that there will always remain some uncertainty and unpredictability even on a day-to-day basis.

Looking after myself. Every participant referred to ways in which they cared for themselves during times of stress. Looking after oneself was easier for some than others, partly due to the varying abilities of participants to recognise when they themselves are stressed but also due to practical constraints such as work, childcare and spending time with their partner.

Most strategies were those of a practical nature with the most popular being exercise; participants found exercise helpful not just because they enjoyed it but many also acknowledged the well-publicised benefits of exercise on mental wellbeing. Generally keeping busy and active was important for most participants with some recognising that they need to push themselves to do so but will always feel better for it in the end. Gaining more information about depression was another popular strategy; many participants reported the need to acquire a further understanding, often due to a lack of information provided by professionals. This gave participants some sense of control regarding their situation and allowed them to seek advice on how to cope with their partner's depression; this idea is explored further in the following subtheme *building a toolkit to manage the depression*. Other practical strategies included writing feelings down, turning to faith and religion, and spending some time away from their partner.

In contrast to external and practical approaches were internal strategies used by the participants, which involved how they interpreted their situation. Many participants described a gradual change over time that occurred solely through experience. For example, Tom spoke about how a key strategy for him is “knowing that an episode will end, knowing that it will stop at some point and it is not a continuous thing”. Having the ability to provide oneself with this level of perspective appeared equally as powerful as the practical and external strategies in reducing levels of stress and improving the wellbeing of participants. These participants also noticed a subsequent change in how they reacted and dealt with situations linked with their partner's depression. An example of this is described below:

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)

For participants like Katie, looking after herself meant learning to put herself first at times, something that she admitted took a long time to do and still led to feelings of guilt and doubt. Participants like Katie described these changes as a form of necessary self-preservation; focussing solely on their partner and the depression could be wearing at times and this provided an outlet which allowed them to conserve some of their strength and energy. This idea links in with and is explored further in the following theme *gaining a new perspective*.

Building a toolkit to manage the depression. Participants described a vast amount of strategies they had used to try and help their partner during times of depression. Almost without exception this was highlighted as being 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 day. This led many 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 need to get him out of that?” (Gemma). However, the experience of constant uncertainty was tiring for participants; this idea is encapsulated and explored further in the following subtheme *no map provided – living with uncertainty*.

Two of the most popular strategies discussed by participants were trying to distract their partner and giving their partner more space. Again, it was often difficult to know what to do for the best and participants experienced this as very much a trial and error process. For those that experienced depression themselves, drawing on personal experiences helped participants understand what their partner might be going through and provided ideas about how to support them.

A sense of hope was held by most participants and described as a powerful tool in helping them deal with their partner’s depression. It was experienced by some as a long term hope for the future and others as a more temporary, day-to-day hope. For example, many participants hoped for a ‘good’ day when their partner was feeling less low; they learnt to make the most of the good days in order to make the not-so-good days more bearable:

You do tend to almost hysterically grab onto the good days. You throw off the lead coat and kick your heels in the air, you know. You really grab it and have a good day whilst the good days are here. (Kerry)

During times of depression, some participants held onto hope by breaking their life down into short-term markers and using these as a focus:

Things would push me through, like his job. He had to go through a tribunal and I thought ‘maybe when the tribunal is finished?’ and that would be like a goal, something to head towards. Then that would be done and it would be something else. If I did not have those markers I don’t know how I would have managed really. (Alicia)

Almost without exception, participants reported that their strategies had developed over time, an idea summarised by Tom: “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 towards 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)

Another form of assertiveness that some participants developed over time was that of taking more control and responsibility for their partner. Participants would often find themselves advising their partners about whether or not they should return to work or attend certain social events. At times, some were supervising their partner’s medication or hiding objects in the house that may be used by their partner to harm themselves. These types of strategies were usually unwelcome by both members of the couple but often deemed necessary by participants. These ideas link with the role changes discussed in the previous theme *the depression cannot be compartmentalised*. In relation to strategies being developed and refined over time, participants attributed this to experience and learning to recognise the signs of their partner’s depression. However, participants were in agreement that the uncertainty and unpredictability associated with depression was a cause of great despair and frustration; strategies or approaches that appeared successful one day could be completely unsuccessful the next and this was something all participants struggled with at times.

No map provided – living with uncertainty. Without exception participants described high levels of uncertainty at times and many experienced a continuous feeling of uncertainty in relation to their partner’s depression. The idea that their partner’s presentation could change from one day to the next, or even one minute to the next, was highlighted by Tom:

One day she might be absolutely fine and literally the centre of a party. You know, she tells fantastic anecdotes she really does, they’re very funny and people love to hear them. But then the next day she may be incapable of actually going to the party. (Tom)

This unpredictability 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 on guard 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).

During times when their partners began to show signs of depression, participants were faced with the added uncertainty as to how bad things would get: “sometimes it’s just an afternoon but sometimes that turns into weeks in bed. It’s very difficult for me to gauge sometimes, what level is this?” (Rick). Living with this level of uncertainty was difficult for participants and in order to tolerate it, many experienced a shift in how they viewed the depression and their own position within the situation. This was often described as a form of self-preservation, an idea that is explored in the next theme *gaining a new perspective*.

Gaining a New Perspective. A longer term process occurred during which most participants reached some form of acceptance about their partner’s depression. The subtheme *something in me shifted* explores the idea that over time participants experience a change, albeit big or small, in how they view the situation and their position within it. Sometimes this shift in thinking may result in the participant questioning the relationship itself. This subtheme highlights that some form of shift is essential in order for the relationship to continue and to allow the relationship to adapt to the depression. The final subtheme *looking to the future* describes how participants look to the future both with a sense of hope and trepidation.

Something in me shifted. Participants described how their attitudes towards their partner, the depression and other peoples’ perceptions had changed and developed; this was likened to an ‘inner shift’ or reaching a level of ‘acceptance’ by some participants. For some a specific trigger could be pinpointed as the point of change. An example of this was a suicide attempt by one partner which led the participant to move from a position of frustration to one of empathy and protectiveness. For others the shift occurred gradually and could only be recognised upon

reflection on time spent with their partner. A shift highlighted by several participants was that of reducing the sense of self-responsibility:

Tom: That realisation that actually in the end I'm not going to resolve this. I am not going to be able to cure her.

Interviewer: How did it feel to have that realisation?

Tom: 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.

As illustrated above, this reduction in self-responsibility led to a mixture of conflicting emotions. Some participants described feeling helpless at times but overall 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; many admitted that in order to cope with their own conflicting emotions they had developed ways of coping. This was described as a form of self-preservation by many participants. For some 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'. For others it was about learning to be more assertive with their partner rather than constantly worrying if they might say something to hurt their feelings or possibly trigger off their low mood.

Although at times it seemed that the depression consumed their lives, some participants spoke about how they had developed more of a sense of perspective and were able to view the depression as just one part of their partner:

There are so many fantastic positive things about her that the depression is just a part of. So it's realising that actually 90% of my life is great and 10% of my life and my relationship is not great. But actually the 90% makes the 10% of it ok. So that sort of takes the burden away I think. (Tom)

Maintaining this different perspective was not always easy and almost all participants talked about times where they struggled to do so. Tom, who has been married for over 20 years, went on to admit that he still finds it difficult to say that his wife suffers with depression. However, it seemed that without some form of shift or level of acceptance from the participant the relationship became in danger of breaking down, as was the case for a small number of couples.

Personal perceptions about depression itself had been challenged for a few participants. They described how they had grown to see it as a more complex and dynamic set of difficulties than what is portrayed by the media. Furthermore, some participants spoke about how their views towards other people had also shifted during their relationship with their partner; this seemed to occur as a result of reaching a level of personal acceptance regarding the depression:

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 many continued to struggle with the fear of stigma and lack of understanding from their social circles and the wider community.

Looking to the future. Partners of the participants were all at different stages of their journey with depression at the time the interviews took place. Nevertheless, all participants described a sense of trepidation when looking towards the future. Some expressed desperation as to whether any intervention was going to help or provide long-term improvements. One lady whose husband was currently in hospital due to his depression encapsulated these concerns:

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)

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. One participant described how every major event was a cause for heightened concern: "there's always the worry now, anything that goes wrong or any major event you just think 'is it going to trigger it off again?'" (Alicia). It also made it difficult for

couples to make future plans as participants were unable to predict how their partner would be feeling.

A further anxiety was the inability of some partners to recognise or acknowledge when the depression is returning, despite concerns raised by participants, thus making it harder to encourage intervention and support at an earlier stage: “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?’” (Gemma).

Imagining a life without the depression was very difficult as it had become a part of everyday life and integrated itself within the relationship for most couples:

I do wonder what would happen if it just stopped and he was ok because he’s only been medication free for about six months in 11 years. Our relationship, the way we are and the way our lives have developed, depression is a huge part of all of that. What would happen if it just went away? (Kerry)

Chapter 4 Discussion

This chapter will summarise and discuss the research findings in relation to the main study aim. Clinical implications and recommendations will be highlighted throughout the chapter and then drawn together in relation to the Care Act (2014). It will conclude by considering limitations of the study and ideas for future research.

Study Aim

To explore the experiences of individuals living with a partner with depression.

A thematic analysis identified five main themes incorporating 11 subthemes. Participants described a period during which they 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 participant's 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.

This discussion includes identification of what this study adds to existing literature. It demonstrates internal validity and consistency with existing data, as all of the papers in the meta-ethnographic synthesis considered similar findings to those found in this study. This includes papers that depicted similar overall stages/themes to those of the present study and papers that focussed on particular concepts that have also been identified within the current study. Similarly to the meta-ethnography, the results of this study could be viewed as a cyclical process or model as many 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'. However, the methodology used in this study (i.e. thematic analysis) is not designed with the creation of a model in mind.

By comparing the results of the current study with that of the meta-ethnography, it suggests that experiences of living with a partner with depression share many similarities to living with other relatives with depression. However, this study highlighted that there are also some key differences when focussing solely on the romantic relationship.

In keeping with the meta-ethnographic synthesis, this study found that participants experience a period during which they try and make sense of their partner's depression; however, participants in the current study laid more emphasis on the idea that having a concrete explanation for the depression gives them the sense that they have something to 'fix'. This study was also able to add in-depth insight into the impact the depression can have on a couple's relationship, something which has not been attempted in previous research in the same way. This study found that couples experience similar but more intense role changes within the relationship, which can often lead to feelings of resentment between both parties.

Barriers to seeking professional help appear to be similar to those found in the meta-ethnographic synthesis; participants in the current study expressed frustration around their lack of involvement in their partner's care and a lack of support for them as an informal caregiver. Interestingly, 13 out of 15 papers in the meta-ethnography focussed on strategies that individuals had developed to support their relative with depression but not to support themselves. In contrast, this study highlighted how participants developed ways to look after themselves during times of stress and views this as a pertinent point when thinking about advising services and professionals who may come across individuals in similar situations. The current study also added further data on the idea and process of gaining a new perspective about the depression and participants laid more emphasis on how difficult this process can be.

This leads to discussion of the themes identified in the study, which appear to follow a recursive, non-linear process.

Making Sense of the Depression

Within this theme, more is learnt about how individuals attempt to make sense of their partner's depression. Attributing the initial changes in behaviour to everyday stressors has been highlighted in previous studies (Badger, 1996a, 1996b; Muscroft & Bowl, 2000). According to these studies, the stressors provided socially acceptable explanations that protected individuals from perceived stigma around mental health. The current study adds to this idea by suggesting that individuals also gain a sense of control within an otherwise uncertain and bewildering experience. Having a perceived explanation for their partner's depression provided some 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 second 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. The frequency of this view amongst participants may highlight the power of medical discourse surrounding conceptualisations of depression. However, for most participants who held this viewpoint, it gradually became apparent to them through time and experience that depression was not so clear cut but was actually much more complex and dynamic. This process experienced by participants highlights the debate regarding the medicalisation of patterns of behaviour and mood (BPS, 2011; Pilgrim & Bentall, 1999). In line with views of the BPS (2011), participants expressed their realisations that their partners' experiences were idiosyncratic and not always directly linked with a particular event or cause. Some participants reflected on the reassurance and sense of certainty that a diagnosis provided in the early stages of their partner's journey with depression; however, this was only a temporary position held by participants.

Professionals coming into contact with or working with partners of individuals with depression need to be mindful of these commonly held views and be prepared to help people consider alternative views in order to begin the process of acceptance.

The Depression Cannot be Compartmentalised

The validity of the significant impact on individuals living with a partner with depression is confirmed by the meta-ethnography subtheme *impact*. Participants in the current study reported

feeling 'pulled down' by their partners at times and many noticed negative changes in their own personalities. This adds to the vast amount of research on concordant mental health in couples, which has a large literature base focussing specifically on depressive symptoms (Coyne et al., 1987; Cutrona, 1996; Hinchcliffe, Hooper, Roberts, & Vaughan, 1975; Meyler, Stimpson & Peek, 2007; Teichman, Bar-El, Shor, & Elizur, 2003). In line with this research, Butterworth and Rogers (2006) suggested that similarities in couples' mental health increase in accordance with the length of time they have been living together; however, this was not found to be the case in the present study. Due to the nature and methodology of the current study, it would be impossible to attribute a particular theory of concordant mental health to the changes noticed in participants.

Participants also noted several positive aspects of living with a partner who experiences depression, thus supporting a previous study by Bauer, Sterzinger, Keopke, and Spiessl (2012) highlighting the acknowledgment of the rewards as well as the challenges of living with a depressed relative.

Participants reported experiencing a range of conflicting emotions towards their partner, something which most of them felt unable to speak to their partner about due to the fear of exacerbating the depression. The idea of depression being an invisible illness that envelopes the partner but often goes unnoticed by professionals and social circles provides further evidence that these individuals require support themselves. Professionals need to be aware of the extent of the impact depression can have on partners and offer support and assistance where necessary. 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. Furthermore, an appointment with the GP on their own should be offered if they appear to need extra support.

The current study offers a clearer insight into the impact on couples' relationships when one (or in some of the cases in this study, both) of the couple experiences depression. Findings in this study highlight the importance of considering the interpersonal aspects of depression rather than solely an individual approach. 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 many 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. For some this led to feelings of resentment towards their

partner and created a negative cycle between the couple, thus supporting previous studies focussing on interpersonal patterns (Hooley, Orley, & Teasdale, 1986; Keitner, Ryan, Miller, Kohn, & Epstein, 1995).

Almost without exception, participants reported a role shift within their relationship, namely from being equal adult partners to becoming more of a carer or mother figure towards their partner. This experience is validated by consistency with existing literature (Badger, 1996a; Harris et al., 2006; Stjernsward & Ostman, 2008). Most participants who reported at times taking on a mother role noted that this was an unwelcome change in the relationships' dynamics and resulted in a change in attitude and behaviour by the participant towards their partner during times of depression. This supports previous findings that suggest that taking on a mother role can lead to disconnection and reduced relationship satisfaction (Bottorff et al., 2013; Harris et al., 2006; Stjernsward & Ostman, 2008). However, this was not the case for all participants and this can perhaps be explained by the findings of Simon (1997). Simon (1997) suggested that a relationship is only viewed as dissatisfying and stressful if positive meanings assigned to the spouse identity are not actualised or if the stressor challenges a perceived benefit of the spouse identity role. It may be the case that participants who held the attitude of "this is just what you do when you are married" as opposed to "I did not sign up for this" may have held different spouse identity roles.

Oliffe et al. (2011) suggested that there are three adjustments that couples make within the context of a male partner's depression. The most common pattern was 'trading places', which described how couples often took on atypical gender roles to compensate for the depression. The 'business as usual' pattern was underpinned by complicit masculinity and emphasised femininity to conceal the depression, while the 'edgy tensions' pattern revealed a mismatch of gender expectations that fuelled resentment and relationship dysfunction. Within this study, it appeared that participants mainly utilised the 'trading places' and 'edgy tensions' patterns. Business as usual was not reported by participants, as all of them described role changes during times of depression.

Although many participants described taking on the carer role, some did not use this term at all during the interview. For those that did refer to themselves as a carer there was a mixture of both welcome and unwelcome responses; caring was seen by some as a way to gain extra support and resources but by others as a burden that highlighted an unwanted inequality within their relationship. The fact that some participants did not use the term carer at all supports previous

literature suggesting that not all informal caregivers define themselves as such (Heaton, 1999; Henderson & Forbat, 2002). Subsequently, this also impacts on professionals and services working with individuals who live with a partner with depression; these professionals must be aware that many people do not refer to themselves as carers and some may even be offended by the term in relation to their partner. Therefore, the ability to use alternative terminology when necessary is important in order to attract more of these individuals into services for support if required.

There have been contrasting views about the term 'carer' within this study yet social policies focus on the formal identity of 'carers' and the 'cared for' (Henderson & Forbat, 2002). Heaton (1999) argues that where social policy fails to identify particular groups, they remain invisible and out of reach of services; therefore, the notion of the 'relationship' is left invisible and out of focus due to the emphasis on carer/cared for identities. This study draws attention to the importance of the relationship when one or both of the couple are experiencing depression and highlights that the relationship is dynamic and continuously shifting (Henderson & Forbat, 2002; Lloyd, 2000). Therefore, this study implies that social policies need to consider the relationship as central to the experience of care. In line with these suggestions, this study also supports the application for Couples Therapy in the treatment of depression (NICE, 2009).

A Light at the End of the Tunnel

Findings in the present study regarding participants' struggles with professional support for their partner are validated by the meta-ethnographic synthesis. Participants felt excluded by professionals in their partner's care (Badger, 1996a, 1996b; Hansen & Buus, 2012; Highet et al., 2004, 2005; Nosek, 2008). When working with individuals with depression, professionals need to be mindful that interventions occur within a wider context, often involving partners. By taking advantage of partner's willingness to be involved then strategies could be more complimentary. This form of partnership working could not only help to reduce the frustration and sense of exclusion experienced by partners but also benefit the depressed individual. It is expected that not all partners will want to be involved in their partner's care (as seen in the present study) and this decision should be respected; however, partners should have the choice given to them by professionals.

Participants also agreed that professionals did not acknowledge the significant impact that living with a partner with depression can have on an individual (Badger, 1996a, 1996b; Highet et al.,

2004, 2005; Muscroft and Bowl, 2000; Nosek, 2008; Skundberg & Kletthagen et al., 2014). This provides further emphasis on the importance of the relationship when working with someone with depression. It also implies that professionals need to remain mindful of these findings when working with such individuals and have the skills available to identify partners who may require further support.

Once an individual with depression has been identified as requiring further support, participants expressed concern at the lack of knowledge of many GPs about what support is available, both for the individual with depression and their partner. Although the NICE guidelines (2009) suggest Couples Therapy, not one participant in the current study had been offered this intervention. Furthermore, despite literature suggesting that self-help or facilitated groups may reduce stigma by developing more positive self-perceptions through sharing common ground (Corrigan & Watson, 2002), none of the participants were aware of any such local groups nor had they been signposted by their GP. Many of the participants had searched for a group for partners of individuals with depression but could not find one, and nearly all of the participants thought they would find a group helpful. With this in mind, local services may find that providing a group for partners may be cost-effective compared to partners accessing individual therapy due to the stresses that can occur from living with a partner with depression.

Improving Access to Psychological Therapies (IAPT) was introduced in 2008 (Layard et al., 2006) with the aim of providing evidence based interventions to individuals experiencing mild to moderate anxiety and/or depression. This primary care service aims to provide treatment within six weeks of an individual being referred to their local IAPT team (NHS England, 2015). Many participants' partners did not receive a referral to their local IAPT service at any point during their journey with depression. Similarly, participants experiencing stress as a result of living with their depressed partner and providing informal care did not receive a referral. It is hard to be fully clear why this was the case; however, this study suggests that GPs may need more training regarding the benefits of the IAPT service and its possible preventative role in reducing the number of individuals requiring more intense support through secondary and specialist services.

This study highlighted the continued presence of stigma around mental health, a concept that was expressed by the majority of participants. 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 regarding the idea

of 'self-stigma' (Ostman & Kjellin, 2002) which suggests that individuals reduce their social networks in anticipation of rejection due to stigma. Stjernsward and Ostman (2008) reported that people can subsequently feel lonely and isolated; however, this study did not fully support this idea as some participants actually described a feeling of liberation as a result of choosing to focus on 'stronger' and more 'loyal' friendships and relationships. In a sense, it seemed to highlight to them who their true friends were.

Learning to Navigate the 'Depression' Maze

The methods that some participants used in order to look after themselves during times of stress concurred with the theory of multiple role identities (Thoits, 1986). Participants sought to focus more on other roles such as friendships or work to provide them with space from their partner; many described these as an outlet during times of increased pressure and stress. Thoits (1986) reported that people may compensate for the threat to a salient role by attaching a greater importance to other existing roles. This is a protective factor as it maintains mental wellbeing by providing the individual with more than one source of self-esteem. In light of this information, professionals working with individuals with depression and their partners may wish to encourage them to consider other important roles they hold and facilitate a discussion about the importance and benefits of holding these different identities.

Findings in the present study regarding the experience of gaining strategies in order to help understand and manage their partner's depression are validated by the meta-ethnographic synthesis. All participants described this as a trial and error process fraught with uncertainty. Using more coercive tactics has also been reported in previous literature (Badger, 1996a, 1996b; Oliffe et al., 2011). These findings could be used by professionals to normalise feelings of frustration and despair for individuals having similar experiences. By highlighting the difficulties experienced by others it may provide a form of reassurance to partners of individuals with depression; subsequently, this may help to reduce the amount of distress that can be caused by feeling like they are the only one going through such circumstances.

Uncertainty was a concept that participants expressed across all stages of their journey of living with a partner with depression. Mason's (1993) framework *towards a position of safe uncertainty* (Figure 4.1) provides an understanding of the benefits of working with uncertainty, both as a partner of someone with depression and as an individual experiencing depression. Mason (1993) suggests that when an individual seeks help in distress, they do so in one of two

states: unsafe uncertainty or unsafe certainty. When an individual holds a position of unsafe uncertainty they may feel a great sense of insecurity; options for change are perceived as absent and they want somebody to make it better but may not be entirely sure how this can be achieved. In contrast, when an individual holds a position of unsafe certainty they are much clearer about what change is required and who is responsible for actioning the changes.

Both of these positions were reflected during participants' journeys of living with an individual with depression. Whilst trying to make sense of the depression many participants described a sense of bewilderment and confusion, which could be likened to a position of unsafe uncertainty. At this point they were unsure about what was happening and did not know who to turn to for advice. During this stage participants often searched for a 'concrete' causal explanation for their partner's depression, reflecting a wish for a position of safe certainty. This position was also sought further along the journey by attempting to access professional support; many participants at this stage wanted answers and solutions and felt that this could be provided by professional services. Furthermore, in an attempt to manage the often unpredictable nature of the depression, participants developed a range of coping strategies in an effort to gain a position of safe certainty.

Mason (1993) describes working towards a position of safe uncertainty as "not a technique but an always evolving state of being" (p. 197). This position enables space in which to develop ideas and options, and allows alternative solutions to be tried and tested. Individuals holding this position accept the fact that there is not always a clear cut solution and remain open to new possibilities.

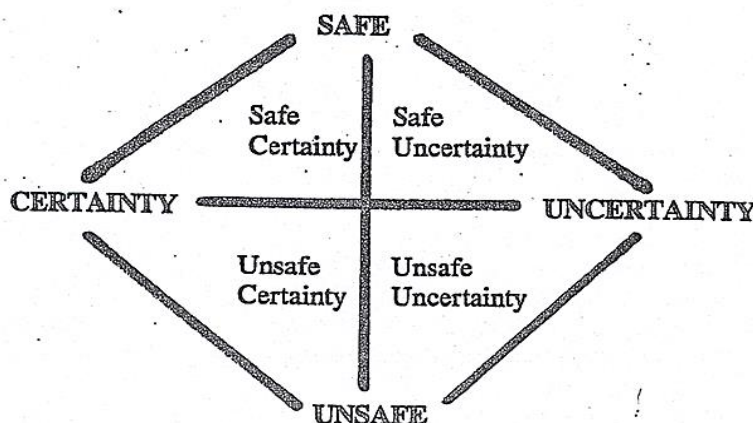


Fig 1

Figure 4.1. Mason's towards a position of safe uncertainty framework

This study suggests that working towards an ‘inner shift’ or ‘acceptance’ is working towards a position of safe uncertainty. Applying this framework within the context of the current study, it seemed that participants held different positions at different times, thus in keeping with the idea of the framework being in a constant state of flow. Some participants clearly described a shift in perspective towards a position of safe uncertainty, for example when Tom expressed strong relief at the realisation that he was not expected to resolve/cure his partner’s depression. However, he also admitted that there were still moments when he felt confused and desired a solution, thus reflecting a position of unsafe uncertainty but a wish for safe certainty.

In line with this framework, Mason (1993) also encourages the stance of *authoritative doubt*, which encompasses both expertise and uncertainty. This could be considered in the context of the individuals living with a partner with depression but also professionals. Mason (1993) suggests that by becoming less certain one is more receptive to other possibilities, ideas and perspectives.

It could be helpful, both for individuals living with a partner with depression and professionals, to understand the experiences described in this study within the framework *towards a position of safe uncertainty* and to aim to hold a belief of *authoritative doubt*. It would be beneficial for professionals to have an awareness of this framework and avoid assuming a certain position which is unhelpful and unrealistic given the complex and dynamic nature of depression.

Gaining a New Perspective

The concept of individuals experiencing an ‘inner shift’ or ‘acceptance’ has been highlighted in previous literature exploring the experiences of living with a relative with depression (Badger, 1996a, 1996b; Hansen & Buus, 2012; Nosek, 2008; Stjernsward & Ostman, 2008). This idea can be linked to Burke’s (2006) identity control theory, which posits that one’s identity standard (i.e. the expectations associated with a particular role) will gradually shift to fit a new situation if the new perceptions are persistently different from the initial identity standard. This is seen as an adaptive response and therefore some form of shift needs to occur in order for the role to continue. Participants in the current study spoke in great detail about role changes within their relationships, the majority of them unwelcome, but most went on to describe how they had come to terms with these changes in one way or another. For example, some participants reminded themselves that it was only a temporary change and during this time it was necessary for them to acquire different roles for the sake of their partner’s wellbeing. According to Burke (2006), when

a shift is not possible then the relationship is more likely to breakdown, something that was also found within the present study.

Experiencing a sense of trepidation and uncertainty when contemplating the future was common among participants and this idea was also highlighted in the meta-ethnography. Managing this persistent uncertainty was difficult for participants; some described a sense of it being something they ‘just had to live with and get on with’, albeit most unwelcome, whilst others described the continued wish to ‘find a cause and fix it’. Moss, Waugh, and Barnes (2008) propose the practice of mindfulness as a way of managing uncertainty. In line with Mason’s (1993) framework *towards a position of safe uncertainty* (outlined above), Moss et al. (2008) suggest that mindfulness may be described as a practice of safe uncertainty by “cutting through safe certainties onto which we may cling” (p. 141).

Mindfulness has roots in Buddhism traditions although has more recently been developed with a contemporary, secular outlook to offer tools for developing a non-judgemental awareness of what is arising in the present moment. Mindfulness is characterised by “dispassionate, non-evaluative and sustained moment to moment awareness of mental states and processes, including physical sensations, perceptions, affective states, thoughts, and imagery” (Grossman, Niemann, Schmidt, & Walach, 2004, p. 36). According to a meta-analysis of mindfulness across a range of different samples (clinical and non-clinical), health related benefits include: enhanced emotional processing and coping regarding the effects of stress; improved self-efficacy and control; and a sense of wellbeing in which stress plays a natural role but still allows enjoyment of life (Grossman et al., 2004).

Mindfulness has predominantly been studied as a complimentary therapy for stress in a wide range of chronic medical conditions, including pain (McCracken, Gauntlett-Gilbert, & Vowles, 2007), fibromyalgia (Grossman, Tiefenthaler-Gilmer, Raysz, & Kesper, 2007), diabetes (Whitebird, Kreitzer, & O’Connor, 2009) and cancer (Ledesma & Kumano, 2008). 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. Epstein-Lubow, McBee, Darling, Arney, & Miller, 2011; Hou, et al., 2013; Minor, Carlson, MacKenzie, Zernicke, & Jones, 2006; Whitebird et al., 2012).

This study suggests that mindfulness may be helpful for individuals living with a partner with depression, in order to help them move towards a position of safe uncertainty and thus a level of acceptance. It may also provide several health benefits, as previously listed above. In line with

this information, professionals should consider encouraging individuals to attend a local mindfulness class or to research it independently via the internet or self-help books. Furthermore, the need for local support groups aimed at the partners of individuals with depression has been highlighted and emphasised in this study and the inclusion of a mindfulness based element within these groups should also certainly be considered.

Reflections

The use of the term ‘depression’ in the study could be viewed by some readers as being aligned with a medical model of mental health. Implicit in the use of the word depression is the assumption that the thoughts, feelings and behaviour incorporated under this label are manifestations of an underlying illness or disorder. However, the study does not seek to align itself with any particular model of depression. The term ‘depression’ is used in the study, not necessarily to refer to individuals who meet the criteria for a diagnosis of depression as per the DSM-5 (APA, 2013), but to refer to individuals who understand and construct their experiences as depression.

Although the study did not set out to specifically look at the differences in the sample in terms of the duration and severity of the depression and the couple’s relationship duration, some differences were indeed noted. For example, the study found that participants who had been together longer tended to have a greater sense of loyalty towards their partners; although this sense of loyalty was sometimes experienced as a pressure by the participants. In clinical practice, professionals may benefit from being aware of this and how it might impact these individuals’ help-seeking behaviours (e.g. they may be less inclined to seek or accept support for themselves as they see caring as part of their role as a partner). Another difference noted in the study was gender based; men generally tended to take a more solution-focussed approach towards their depressed partner; although both genders experimented with different approaches over time. With such a small sample size, it is hard to make generalisations to the wider population; however, it may be noteworthy for professionals when working with these individuals to offer alternative suggestions and normalise the experience of ‘trial and error’ as seen in the current study.

The poor response rate for the study was unexpected considering the statistics for the prevalence of depression among adults ranging from 4 to 10% worldwide (NICE, 2009). Depression is considered one of the most common mental health difficulties and therefore, perhaps naively, I

did not foresee any recruitment difficulties. On the contrary, it was expected that there may be a need to turn down respondents once the maximum number of participants had been met. In reality, 19 respondents contacted me for further information regarding the study but only 13 went on to arrange an interview, despite being sent a reminder after two weeks. It is impossible to know for certain why almost one third of initial respondents dropped out; I was unable to request this information from respondents for ethical reasons and therefore relied on respondents providing a reason unprompted. This happened with only one of the initial respondents, who reported a sense of disloyalty towards their depressed partner and felt that discussing the depression during an interview would be like a breach of their partner's trust. Obviously this response cannot be generalised to the other five respondents that dropped out of the study; however, it should be noted that this sense of disloyalty was also highlighted by many of the participants who took part in the study. It is therefore a possibility that fears of disloyalty, betrayal and untrustworthiness may have held people back from taking part in the study.

This sense of disloyalty could be understood within an identity theory framework. Depression, and mental health issues in general, still remain a stigmatised subject despite improvements over recent years through campaigns such as Time to Change (Henderson & Thornicroft, 2009). Almost without exception, participants in the current study described a fear of stigma towards themselves and/or their depressed partner, and thus could be described as 'stigmatised individuals'. It was often this fear of stigma and discrimination that prevented participants from telling other people about their partner's depression. Lee and Craft (2002) suggest that individuals keeping a perceived negative secret about themselves or a loved one face a dilemma: opening up about the secret invites rejection, labeling and punishment yet remaining secretive can jeopardise relationships with others. This results in complicated social relationship patterns in which some people are informed and others are not. Link, Mirotznik and Cullen (1991) postulated that the responses of stigmatised individuals to social perceptions fall into three categories: secrecy, withdrawal and preventive telling. Secrecy involves concealing the information from others in a bid to avoid rejection. Withdrawal involves avoiding contact with those who are not aware of the perceived stigma and preferring interactions with those who accept, or even share, the stigma. Finally, preventive telling involves informing others before the secret is exposed because it is affecting the social relationship in some way (e.g. the individual cancels several meetings due to caring responsibilities). In line with this information, it seems that the responses of stigmatised individuals are motivated and constrained by self and social processes. In relation to the present study, secrecy and withdrawal were undoubtedly the most

common responses described by participants and it certainly seemed that the fear of stigma and discrimination informed these decisions.

Within identity theory, Lee and Craft (2002) posit that there is a psychological need for individuals to 'self-verify'. Self-verification means to seek confirmation of a previously held image of the self (i.e. image of the self before their partner experienced depression). The authors suggest that in day-to-day events, individuals' behaviours will reflect (verify) their active identities. If interactive feedback from others implies that the individual is not acting as intended, the individual will experience distress and alter their behavior to shift other peoples' perceptions back to their own self-meaning. However, stigma provides a form of symbolic negative social feedback that acts as a barrier to the process of self-verification. Therefore, social relationships are necessary in order for individuals to self-verify but there is always a risk of rejection if the secret is disclosed, hence the dilemma outlined by Lee and Craft (2002).

Individuals become anxious because demands to preserve their social relationships and demands to preserve their previous self-meanings compete. One of the key reasons individuals decide to tell their secret is because they believe that the person they are telling is open-minded (Lee & Craft, 2002). Participants in the present study spoke about the views of particular family members and friends towards mental health (including family scripts) and how that helped them decide who to approach or avoid. Another reason individuals decide to tell their secret is if it is getting in the way of normal social relationship patterns. An example of this was provided by Clare in the present study; Clare felt that one of her friends could sense the increasing levels of stress she was experiencing and saw no option but to admit that her husband was depressed. Her friend responded with empathy, sympathy and reassurance. By experiencing this acceptance from others, it strengthens the social relationship and also fulfils the need for self-verification.

This highlights the importance of social relationships on the management of perceived stigma. It seems that individuals who cope best are those who can tell others about their secret without experiencing disapproval; in other words, individuals without opportunities for acceptance appear to be most at risk. Therefore, it is imperative that individuals try and find support within their existing networks or create support within new networks in order to help prevent or overcome the negative effects of stigma. Professionals should help partners of individuals with depression locate people within their social network that they can open up to, as well as attempting to help them access support groups in order to cope with and manage the stigma.

It is also important to consider the implications of possible feelings of disloyalty within the context of seeking help and support from professionals and services. If it is known that many people are unlikely to seek help despite being under significant stress, considerations should be given to alternate and more discrete ways of accessing support. One suggestion is for more online options such as support forums or counseling services, or to increase advertising for existing resources that deliver similar services. Some examples of online resources include Big White Wall (www.bigwhitewall.com) and Depression Alliance (www.depressionalliance.org). Another option, highlighted within the current study, is joint therapy for both the individual with depression and their partner. Despite recommendations by NICE (2009) for Couples Therapy for depression, all participants in the present study reported that they were not offered such a therapy but would have found it very helpful. Accessing a service together not only supports existing literature around the importance of the relationship within depression but may also reduce the feelings of disloyalty towards the depressed partner due to an increased sense of tackling the difficulties together. Couples Therapy provides an opportunity for couples to explore the difficulties they are faced with in a safe and supportive environment. It also allows the therapist (and in time the couple themselves) to gain an understanding of their relational dynamics and contextual processes that influence the quality of the relationship. As highlighted both in the current study and existing literature, high levels of stress often means that communication within the relationship is significantly affected and therefore Couples Therapy aims to help the couple clearly and appropriately communicate their thoughts and emotional states to one another. Working interpersonally with couples as opposed to individually with people facing these difficulties means that pertinent issues can be addressed that would not otherwise be possible. In light of these benefits, I agree with recommendations outlined by Leff et al. (2000) that more primary care professionals should be trained in the skills of Couples Therapy to enhance the access to such interventions.

Although I certainly think it is necessary to take the steps outlined above to help improve access to support and to tailor the support to the needs of individuals living with a partner experiencing depression, I believe this actually reflects a much wider need for more work around stigma in society so that it is not necessary to be discrete about accessing help. The issue of stigma has undoubtedly started to be challenged more over recent years, for example through campaigns such as Time to Change. Time to Change is an anti-stigma and discrimination campaign run by leading mental health charities, Mind and Rethink. It was initiated in 2007 and is funded by the Department of Health, Comic Relief and the Big Lottery Fund. Time to Change describe

themselves as “a social movement made up of hundreds of thousands of individuals and organisations across England, who are all doing their bit to change the way the nation thinks and acts when it comes to mental health” (Time to Change, 2015). As part of the campaign, an annual survey asking a representative sample of the English population questions about their knowledge, attitudes and intended behaviour towards people with mental health difficulties is commissioned. Time to Change report that since the campaign began in 2007 there has been an overall 6.4% improvement (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014). Whilst this is positive news and suggests that the views of society are starting to shift in relation to mental health, the results of the current study illustrate that many individuals living with a partner experiencing one of the most common mental health problems continue to fear stigmatisation and discrimination.

It is also important to reflect on my joint role of interviewer and Trainee Clinical Psychologist and whether my experience as a Trainee Clinical Psychologist may have influenced my response to participant’s distress. An example which made me reflect on this idea occurred when I asked participants to reflect on their experience of the interview and a few commented that it had felt like a therapy session. When I asked them to elaborate the participants said it was because they had not previously told anybody all of this information and therefore the process had helped them make sense of their experiences. Words used to describe the interviews were “interesting”, “helpful”, “cathartic”, “emotional” and “eye opening”. This made me think about my nature of questioning and implicit focus on building a therapeutic alliance in order to make both clients and participants feel comfortable enough to open up to me. I wondered if participants would have responded in the same way during interviews had I not been a Trainee Clinical Psychologist or whether they just welcomed the opportunity to talk to someone about their experiences. Another illustration of the line between being a researcher and Trainee Clinical Psychologist becoming slightly blurred was when, on a couple of occasions, participants made reference to my profession during the interviews. Examples of this are when Tom stated “it’s not my job to cure depression, that’s your job” and when Katie and Barry asked me about what local services are available and how Cognitive Behavioural Therapy works. In response to these examples I provided answers but signposted the participants to appropriate websites in order to gain more in-depth information.

Like all other researchers, I began this study with my own preconceived ideas and assumptions about my chosen topic. Having previously worked with carers of people with mental health difficulties in a group context, I was aware of the great levels of burden that can be experienced

at times and was expecting that to be the key point to come out of the interviews during the current study. Although this was indeed one of the key themes, I found it refreshing to hear participants also speak about positive experiences. Furthermore, the nature of these in-depth interviews gave me and participants the opportunity to explore the processes involved with living with a partner with depression. For example, the process of making sense of the depression and the process of developing a different perspective over time. This is something that I had not previously encountered during my group work, possibly because the groups that I facilitated were for individuals living with any form of mental health difficulty and were psycho-educational rather than therapeutic in nature, thus not necessarily providing the space for these issues to arise.

The interviews also made me reflect on my own marriage and think about how difficult it would be if my husband was to experience chronic depression. During the interviews I often found myself imagining myself in the participants' shoes, which increased my empathy (and admiration) towards them. I became more mindful of the complexity of their situations and the difficulties in having to tolerate uncertainty and long periods of stress. It was shortly into the interviews that I began to reflect on these feelings, and in response to them I made a conscious effort to also think about the partners of the participants and remind myself how difficult the situation is for them too. It made me think that there are two sides to every story and how easy it is to find oneself siding with the story one is presented with.

Limitations

It has been argued that the use of telephone interviews can make it more difficult to establish a safe and empathic relationship due to the lack of availability of non-verbal cues (Garbett & McCormack, 2001; Rungapadiachy, 2001). However, respondents have been described as relaxed on the telephone and willing to disclose intimate information (Kavanaugh & Ayres, 1998). Qualitative telephone data have been judged to be rich, vivid, detailed, and of high quality (Sturges & Hanrahan, 2004). The researcher utilised their interpersonal and clinical psychological skills to facilitate these interviews. There is no evidence that the two telephone interviews conducted in the study were less valid than the 11 face-to-face interviews.

Furthermore, Silverman (2000) suggested that breaks in normal turn-taking conventions during interviews can affect the validity of the data produced. However, it is hard to objectively respond to this suggestion without conducting some form of conversational analysis, something that was

not carried out during this study. Notably, every participant commented on the usefulness of the interview in sharing their experiences and some even admitted that this was the first time they had ever shared the information with anybody. However, it is acknowledged that potential bias, such as response bias and self-reports, may be present.

In order to provide further rigour within the study, Lincoln and Guba (1985) and Yardley (2000) emphasise the importance of 'member checking'. This is a process during which the data, themes and findings are checked with a proportion of the sample with the aim of providing a deeper understanding of the identified themes. This technique was not employed due to the contradiction it poses to the epistemological position of the current study, namely critical realism. Critical realism postulates that individuals experience different aspects of reality whereas the use of member checking relies on the assumption that there is one fixed reality that can be accounted for by the researcher and confirmed by the participants. To add to rigour, the use of MAXQDA increased explicitness as it enabled the researcher and supervisor to view data, codes and themes throughout the research process.

Some may consider it a limitation that the study used a community sample whereby depression was not necessarily officially diagnosed and was instead confirmed by participants. The majority of previous literature in this area has used outpatient clinic and/or hospital samples with participants who have received an official diagnosis of depression. The researcher felt that gaining a community sample was pertinent for the study as it reflected the reality of living with a partner with depression, namely that not all individuals with depression seek professional support and neither do the partners of these individuals. Therefore, by recruiting participants through NHS services there is a high chance of missing out a large number of this population. The findings of this study validated this view as some of the participants reported that their partner had experienced depression for a number of years but neither of them had accessed professional support. It could therefore be argued that recruiting participants in this way allowed access to participants who would not have been recruited through NHS channels and thus added a different dimension of experiences to the study. An official diagnosis of depression by a trained professional was not considered mandatory in order to be included in the study although many had received a diagnosis at some point along their journey. This was considered to be an important factor as it moved away from the conceptualisation of depression as an 'illness' and allowed for an under-represented subset of this population to have the opportunity to share their experiences. Depression literature highlights that many individuals do not seek help for a very long time, if at all, and thus do not always receive a diagnosis. By excluding the partners of these

individuals from participating in the study it could prevent a potentially novel set of experiences from being shared.

Methodological Limitations

Due to recruitment difficulties the sample size was at the lower end of the suggested range (i.e. 12-20). However, this still fell within the same range as the studies used in the meta-ethnography, which ranged from nine to 37 participants with a mean average of 18.

Cultural differences in the experiences of living with a partner with depression could not be considered due to the sample being White British. Similarly, all participants were in a heterosexual relationship and therefore any possible differences between same-sex and heterosexual relationships could not be considered.

Specific differences of experience relating to gender, age, marital status, and duration of depression were not included. This study suggests that individuals share similar experiences despite these issues; however, it could be argued that the study has created more entanglement of data thus preventing specific differences amongst these issues from being identified.

Due to the sample being self-selective, it may mean that there was a degree of self-selection bias in the study (i.e. the decision to participate in the study may reflect some inherent bias in the characteristics of these participants). It would be interesting to consider whether the six initial respondents that dropped out of the study, or those who decided not to contact the researcher at all, would have shared different experiences to those participants that took part.

Further Research

Over two thirds of the sample were females living with a male partner. Therefore it would be helpful to focus on recruiting more males living with a female partner in future studies, in order to gain a more gender-balanced perspective of living with a partner with depression. As previously stated, recruitment for this study proved to be more difficult than initially expected and therefore in order to appeal to more males it may be worth considering specific recruitment locations (e.g. internet forums for dads). However, in relation to the meta-ethnography that took place in preparation for this study, the only paper that aimed to recruit couples where either the

male or female was depressed (Harris et al., 2006) found that in all but one of the nine couples the person with a history of depression was female and the partner was male.

No previous studies have included same-sex couples so this is something that should be purposefully encouraged in future research, in order to establish whether similar issues arise.

The themes identified and outlined in this study (Table 3.2) could be used to see if they apply to partners of individuals experiencing other mental health difficulties or medical conditions. If so, then some of the clinical implications outlined in this study may prove relevant in other areas, such as the application of Mason's framework *towards a position of safe uncertainty* or the use of mindfulness.

As with any interview exploring an individual's experience of living with someone with a particular set of difficulties, the researcher is only hearing one side of the story. A strength of this approach is that the researcher was able to gain an independent and clear narrative from each of the participants. However, in light of literature highlighting the importance of the relationship, future research may consider interviewing couples conjointly and analysing the joint account of the couple as a single unit (as per Harris et al., 2006). Alternatively, couples could be interviewed separately and their perspectives subsequently compared and contrasted with one another.

Differences of experience relating to age, stage of depression, history of depression (i.e. number of episodes), and length of relationship could be analysed further in order to see if this affected the issues raised in the current study. However, the generalisability of these findings may be problematic and recruitment may prove difficult.

Despite not necessarily all having a formal diagnosis of depression, participants reported that they believed their partners had experienced depression for between 2-50 years. Therefore in accordance with the DSM-5 (APA, 2013), partners would likely be eligible for a diagnosis of either Major Depressive Disorder – Recurrent or Persistent Depressive Disorder. Either of these diagnoses would imply a longstanding and chronic experience of depression. Samples used in the meta-ethnography did not all distinguish the length of depression; therefore, it would be helpful for future research to specifically compare the experiences of individuals living with a chronically depressed partner with individuals living with a partner experiencing their first episode of depression, to see if there are significant differences in these experiences.

Clinical and Policy Implications

Clinical implications and recommendations have been highlighted throughout this chapter but will now be drawn together and discussed directly within the context of the Care Act (2014). The Care Act (2014) came into effect in April 2015 and replaces most current laws regarding carers and people being cared for. The act has within it some mandate to provide the recommendations outlined in the present study; therefore, this section will discuss this in more detail as well as provide suggestions as to how these recommendations could be implemented.

The Care Act (2014) states that local authorities are now responsible for providing a carer's assessment to all carers over 18 if they have support needs. Previously, in order to be entitled to a carer's assessment an individual had to show that they provided 'regular and substantial care'. A key difference in the Care Act (2014) is that anyone who appears to require care and support, regardless of their likely eligibility for state funded care, is eligible for the assessment. Therefore, this increases the likelihood for individuals such as the participants in the present study to get support. Furthermore, whereas previously only social workers could carry out a carer's assessment, under the Care Act (2014) more professionals, including organisations and charities, can perform the assessment. This should mean that assessments can be carried out more quickly, thus making support more readily accessible. Carers' assessments can be carried out individually or jointly, if it is in the interest of both parties. Having this choice is important if individuals experience feelings of disloyalty towards their depressed partner, as highlighted in the present study. After an assessment, a support plan must be provided outlining the support needs of the individual. These needs must be met directly by the local authority (or the local authority must arrange for another organisation to provide the support). According to the Care Act (2014), the plan must consider the carer's wellbeing and how they can lead a fulfilling life rather than focusing solely on the immediate needs that arise from their role as a carer. This is particularly relevant in relation to depression, which is often chronic and dynamic in nature. This study has also highlighted that even during periods of remission from depression, many partners still experience stress due to the persistent worries of the depression returning.

The Care Act (2014) introduces a general duty on local authorities to promote wellbeing. If a carer's wellbeing is significantly impacted then the eligibility criteria are likely to be met. The local authority then have a duty to look at what can be done locally in order to prevent the need for the carer to access support services. In light of the results of the present study highlighting the often substantial impact on people living with a partner with depression and the fact that

several participants were seeking their own individual support through counseling or therapy, one could predict that many of these individuals would likely be eligible for extra support.

Once the carer's assessment has been carried out, the local authority decides if the carer is eligible for support. This depends on whether they meet the Care and Support (Eligibility Criteria) Regulations 2014 (Appendix K). The Carers Act (2014) has introduced a national eligibility criteria whereas previously local authorities had the power to decide if support should be provided or not. A national eligibility criteria makes the assessment more uniform and systematic and therefore increases the likelihood of individuals receiving the support they need.

The carer's assessment will identify the amount of money that the local authority feel is required to pay for the support of a carer. The Care Act (2014) suggests support such as relaxation classes. In light of the results of the present study, local authorities should consider providing access to mindfulness courses and support individuals to access local depression groups and Couples Therapy, covering travel costs where necessary.

IAPT was set up for individuals experiencing mild to moderate anxiety and/or depression (Layard et al., 2006). The present study highlights that there may be a lack of knowledge by some GPs about this service and what it offers, as few participants or their partners were offered a referral to their local IAPT team. This study suggests that local authorities and professionals carrying out carers' assessments should be aware of these services and prepared to signpost individuals as part of their support plan if necessary. On a wider scale, this study suggests that IAPT should specifically consider improving access for carers into their services, given the vast amount of literature and policies that highlight the significant impact informal caring can have on people's wellbeing. At present IAPT has special interest groups for the following areas: black and minority ethnic communities; older people; perinatal care; offenders; long term conditions; medically unexplained symptoms; veterans; and learning disability (Department of Health, 2008). Although IAPT states that these groups are not exhaustive (Department of Health, 2008), other groups are identified based on the perceived needs of different localities, therefore making it seem like a postcode lottery for carers as to whether their local IAPT service provides any specific interventions for this population.

The Care Act (2014) states that local authorities should work with the NHS to identify carers who are in need of support. This process should involve the development of a plan of how to identify carers, including details of local organisations such as GPs, nurses, pharmacies, benefit advisors, housing officials and employment workers. Local authorities need to increase the

awareness of organisations about the potential risk to wellbeing of people living with a partner with depression. Anybody coming into contact with individuals with depression should make explicit enquiries about the partner, ensuring this is done in a sensitive and supportive manner.

According to the Care Act (2014), local authorities should establish an information and advice service for carers to keep them informed about local resources applicable to their needs. The present study highlighted the lack of knowledge of many professionals about local services available for individuals living with a partner with depression whilst simultaneously providing suggestions about particular types of support that could prove extremely beneficial for these individuals, such as mindfulness, couples therapy and support groups. Therefore, local authorities should consider gathering information about these types of support in their local areas so that the information is freely available for people who need it. Having this information available would reduce the levels of frustration and despair experienced by many individuals living with a partner with depression, thus improving their help-seeking journey and experience of professionals and health services.

Despite all of these important and relevant points from the current study being discussed within the context of the Care Act (2014), there still remains a pertinent issue, also raised within the current study, which may hinder their implementation in clinical practice: some people living with a partner with depression do not consider themselves to be a carer. These individuals are therefore unlikely to agree to a carer's assessment as they may not see themselves as requiring support. Professionals coming into contact with individuals with depression and their partners and also professionals involved in conducting carers' assessments need to be aware of this potential barrier. Gentle encouragement may be necessary to make people aware of the support they may be entitled to. Professionals should also be prepared to have a discussion with these individuals about the terminology used and what the modern day use of the term 'carer' means, including the concept of informal caring. Ultimately, professionals need to respect the decision of the individual but should consider at least signposting individuals to the information and advice service and perhaps the online resources if it feels appropriate.

In summary, the Care Act (2014) includes mandate to provide the recommendations outlined in this study and this section has made suggestions as to how this could be implemented by local authorities. It appears that the introduction of the Care Act (2014) will allow for more individuals to access the support they need as a result of providing informal care. This is a

positive step for those living with a partner with depression, a form of informal caregiving that has long been ignored or not given the true recognition it deserves.

This study argues that the implementation of the above suggestions would be in the best interests of local authorities due to the long-term cost effectiveness. By providing the support outlined above, local authorities may find that money is saved through the likely reduction of access to personal NHS therapy, GP appointments, other NHS appointments and days off sick from employment.

Dissemination

The researcher will offer to provide a copy of the study to all participants who took part. It will also be considered for a peer-reviewed scientific journal.

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Appendices

Appendix A: Meta-Ethnography Study Details

Appendix B: Recruitment Poster

Appendix C: Screening Questionnaire

Appendix D: Participant Information Pack

Appendix E: University Ethics Amendment Application and Approval Letter

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Appendix J: Sample of Coded Transcript

Appendix K: Care and Support (Eligibility Criteria) Regulations 2014

LIVING WITH A PARTNER WITH DEPRESSION

| Methods and Concepts | Ahlstrom, Skarsater & Danielson (2009) | Badger (1996a) | Badger (1996b) |
|--|--|---|---|
| Key Study Details | | | |
| Purpose | To describe the experiences of living with major depression in families | To describe family members' experiences in living with a member with depression | To understand the role of the family in the treatment process and to determine the needs of these families during treatment |
| Setting | Sweden | U.S.A | U.S.A |
| Sample | 14 family caregivers (7 families) | 11 family caregivers (9 spouses, 2 parents) | 11 family caregivers (9 spouses, 2 parents) |
| Data Collection | Family interviews including the depressed person | Interviews | Interviews |
| Key Concepts | | | |
| Recognition | - | Observing the metamorphosis | Observing the metamorphosis |
| Impact | Family life becomes uncertain and unstable Everyday life becomes hard | Lack of emotional and material support | Lack of emotional and material support |
| Seeking causes | - | Finding socially acceptable explanations | Finding socially acceptable explanations |
| Role reformation | Taking on responsibility | Assuming the role tasks of relative with depression | Assuming the role tasks of relative with depression |
| Coping strategies | An uncommunicative way in everyday life | Protective vs. coercive strategies | Protective vs. coercive strategies |
| Healthcare professionals | - | Searching for reasons and solutions Frustrations at exclusion in treatment Being an advocate | Support was not offered A need for support groups, family sessions, information about medication, dealing with stigma |
| Community support | Careful selection of informants | Living two lives to defend against embarrassment or stigma | Living two lives to defend against embarrassment or stigma |
| Changing sense of self | - | Preserving oneself – to care for others I must care for myself | Preserving oneself – to care for others I must care for myself |
| Adapting to depression | Finding some kind of satisfaction within the bounds of possibility | Accepting realities and limits of involvement | Accepting realities and limits of involvement |
| Looking to the future | Worry about how depressed person will manage | Redesigning the relationship Hope mixed with caution | Redesigning the relationship Hope mixed with caution |
| Explanation/ Theory (Second-Order Interpretation) | “Families get into demanding conditions in the presence of depression which they try to manage together” | Families experience a social psychological transformation process involving three stages: acknowledging the stranger within, fighting the battle, and gaining new perspective | Families experience a social psychological transformation process that can be aided by education, support and partnering from professionals |

LIVING WITH A PARTNER WITH DEPRESSION

| Methods and Concepts | Bottorff, Oliffe, Kelly, Johnson & Carey (2013) | Gonzalez, Romero, Lopez, Ramirez & Stefanelli (2010) | Hansen & Buus (2012) |
|--|--|--|---|
| Key Study Details | | | |
| Purpose | To describe how depression impacts women spouses in terms of their experiences living with depressed men. | To understand the meanings family caregivers of depressive patients attribute to the disease in its cultural context | To explore how cohabitant relatives make personal sense of living with their depressed family members and negotiate their social identity |
| Setting | Canada | Chile | Denmark |
| Sample | 29 female spouses | 9 family caregivers (1 husband, 2 wives, 3 nieces, 1 sister, 1 daughter, 1 daughter-in-law) | 13 family caregivers (7 husbands, 5 wives, 1 parent) |
| Data Collection | Interviews | Interviews | Interviews and focus groups |
| Key Concepts | | | |
| Recognition | - | - | - |
| Impact | Forced into taking life day by day Emotional and pragmatic burden | Physically and psychologically affected Depression is a family disease | Conflict and reciprocal negative attitudes |
| Seeking causes | Uncertainty about the roots of depression | Difficult to understand Causes linked to later stage of life | Legitimise depression with reference to socially acceptable explanations |
| Role reformation | Wanting to exhibit care but feeling ineffective Taking care of a child-like spouse Shouldering family responsibilities | Rupture family organisation | Control and undertake all tasks and duties |
| Coping strategies | Masking own feelings to be supportive | - | Diverging perceptions of coping between relative and person with depression |
| Healthcare professionals | Being strategic in accessing support for partner | A need for psycho-educational programmes or other forms of healthcare | Marginalisation in treatment Held partially responsible |
| Community support | - | Turning to faith and religion Fear of being a nuisance to rest of family | Protection from stigma results in social isolation and loss of personal freedom |
| Changing sense of self | Self-preservation | - | Crushed dreams of life with depressed person lead to ambiguous feelings and eventually realise life cannot return to how it was |
| Adapting to depression | - | - | A balanced relationship is essential – need to live out own personal dreams |
| Looking to the future | - | Prefer not to think about a future with depression | - |
| Explanation/ Theory (Second-Order Interpretation) | “Depression can eclipse many of the gender practices that are core features of hegemonic gender relations” | The depressed patients’ feelings extend to caregivers, increasing their risk of depression. | A psychosocial transformation is driven by the twin challenges of attitudes towards the depressed family member and of stigma |

LIVING WITH A PARTNER WITH DEPRESSION

| Methods and Concepts | Harris, Pistrang & Barker (2006) | Highet, McNair, Davenport & Hickie (2004) | Highet, Thompson & McNair (2005) |
|--|---|---|--|
| Key Study Details | | | |
| Purpose | Examine how partners support a depressed spouse and how each member experienced the process | To explore the experiences of carers and families of people with depression | Exploring carers' experiences of the onset and progression of a depressive illness in a family member |
| Setting | U.K | Australia | Australia |
| Sample | 9 couples | 37 family caregivers (19 parents, 15 spouses, 3 siblings) | 37 family caregivers (19 parents, 15 spouses, 3 siblings) |
| Data Collection | Interviews including the depressed spouse | Focus groups | Focus groups |
| Key Concepts | | | |
| Recognition | Sudden and dramatic vs. gradual onset | - | Protracted process of detection Indicators only recognised in hindsight |
| Impact | Disconnection during long grey periods | Living on the edge of my seat Adverse impact on interpersonal functioning and wellbeing | Strong emotional responses – including shock, denial and disbelief |
| Seeking causes | - | - | Symptoms attributed to other factors during early stages Guilt and helplessness after diagnosis |
| Role reformation | Shifting roles and responsibilities within the relationship | - | - |
| Coping strategies | Lacked confidence in home-grown strategies Worry relative might be adversely affected | - | - |
| Healthcare professionals | Little practical assistance resulted in relatives working it out for themselves | Lack of access to care Lack of inclusion Need for support groups | - |
| Community support | Support from family, friends and work colleagues was valued | Lack of awareness of depression Lack support from friends and family | Lack of awareness about depression |
| Changing sense of self | - | - | Anticipatory grief at the realisation of the consequences of depression |
| Adapting to depression | - | - | Acceptance of diagnosis comes with increased understanding of depression |
| Looking to the future | Threat of relapse hovering in the background | - | Fear of relapse |
| Explanation/ Theory (Second-Order Interpretation) | Support occurs against a backdrop of shifting roles and expectations within a relationship | Everyday difficulties are exacerbated by the nature of the illness, feelings of social isolation and a lack of understanding from the wider community | A lack of community understanding provides a barrier to detecting and contextualising signs and symptoms of depression |

LIVING WITH A PARTNER WITH DEPRESSION

| Methods and Concepts | Muscroft & Bowl (2000) | Nosek (2008) | Oliffe, Kelly, Bottorff, Johnson & Wong (2011) |
|--|---|---|---|
| Key Study Details | | | |
| Purpose | To explore family experiences of living with a relative with depression | To understand the inner world of families as they care for their suicidal family member at home | To explore how masculinities and femininities intersect to forge particular heterosexual gender relations in the context of men's depression. |
| Setting | U.K | U.S.A | Canada |
| Sample | 10 family caregivers (including spouses, older children and siblings). | 17 family caregivers (7 spouses, 8 parents, 1 sibling, 1 daughter) | 26 couples |
| Data Collection | Interviews | Interviews | Interviews |
| Key Concepts | | | |
| Recognition | Changes are noticed prior to diagnosis | Seeking information and learning as part of the recognition process | - |
| Impact | Own needs are marginalised; health may become jeopardised | Constantly vigilant | Exhaustion |
| Seeking causes | Look for causes in themselves prior to diagnosis Following diagnosis seek causes from own actions or life circumstances | Need professional support themselves Information sought from professionals, internet and books | Changes in sexual intimacy - |
| Role reformation | Redefinition of family relationships | - | Gender roles can be strengthened, swapped or ambivalent |
| Coping strategies | - | Move from knowing to understanding Switch between active involvement to not wanting to know | Tough love strategies Emotional caretaking |
| Healthcare professionals | Lack of understanding about how services function | Lack of access to information due to confidentiality | Partners may need encouragement to seek support |
| Community support | - | Wider family in a position to be able to stand back | - |
| Changing sense of self | Need to mourn losses and re-work sense of self | - | Learning not to blame self for the depression |
| Adapting to depression | Attempt to integrate depression into life and getting on with daily business | - | - |
| Looking to the future | Depression is a sleeping presence | Maintaining vigilance | - |
| Explanation/ Theory (Second-Order Interpretation) | Depression integrates into the family system falls in four distinct phases: "acquisition, accommodation, adaptation, appropriation" | Families experience an ongoing, cyclical social process of maintaining vigilance through managing | Three couple patterns emerged: trading places, business as usual and edgy tensions |

LIVING WITH A PARTNER WITH DEPRESSION

| Methods and Concepts | Radfar, Ahmadi & Khoshknab (2014) | Skundberg-Kletthagen, Wangensteen, Hall-Lord & Hedelin (2014) | Stjernsward & Ostman (2008) |
|--|--|--|---|
| Key Study Details | | | |
| Purpose | To explore and describe the experiences of the family members of patients suffering from depression on the impact of provision of care to the patients | To explore how relatives conceive their daily life in relation to the person diagnosed with depression. | To explore significant others' experiences of living closed to a depressed individual, with the overarching aim of developing a website addressing the needs and wishes of relatives with a depressed kin |
| Setting | Iran | Norway | Sweden |
| Sample | 26 family caregivers of 22 people with depression (including spouses, parents, siblings, children and grandchildren) | 24 family members (6 spouses, 2 parents, 2 siblings, 12 children, 2 other) of inpatients | 18 family caregivers (9 spouses, 6 parents, 3 daughters) |
| Data Collection | Interviews with 1-2 members of family | Interviews | Interviews and focus groups |
| Key Concepts | | | |
| Recognition | - | - | Gradual onset Lack of understanding affected relationship |
| Impact | Disturbance in rhythms of family life Uncertainty in daily life Risk of developing depression | Negative feelings followed by bad conscience Physical and mental afflictions | Own needs become secondary Constant feeling of worry |
| Seeking causes | - | - | - |
| Role reformation | Extra work to pay for treatment costs Extra responsibility | Roles shift among the family Role reversal with parent/child Taking responsibility | Taking on caregiver role |
| Coping strategies | - | Avoid revealing own feelings to reduce conflict and give support Self preservation | Physical and meditative exercises Utilising social network Seeking professional help |
| Healthcare professionals | - | Knowledge about depression is helpful | Unsupportive and non-understanding Scarce healthcare resources |
| Community support | Stigma of mental illness | Acknowledgement from others helps ability to endure situation | Friends sometimes became avoidant Socially restricted Negative attitudes led to isolation |
| Changing sense of self | - | - | Re-evaluate priorities and values |
| Adapting to depression | Mourning process is necessary before acceptance is reached. | - | - |
| Looking to the future | Helplessness to control the future Concerns about relapse | Underlying anxieties about the future | The future is uncertain and unpredictable |
| Explanation/ Theory (Second-Order Interpretation) | “psychological, physical and financial factors imposed on families result in turbulent life” | Relatives live on the depressed persons' terms which can affect everyday life to the extent that they need help and support themselves | “Relatives express a feeling of not living their own life, struggling to balance relationships, adapting to and re-evaluating their life circumstances, and struggling to voice their ill relatives' and their own needs” |

Appendix B: Recruitment Poster

**Do you live with a husband/wife/partner with
longstanding depression?**

Are you and your partner both over 28?

**Have you been in your relationship for at least 3
years?**

As part of a Doctoral qualification in Clinical Psychology at the
University of Essex,

I would like to hear about your experiences.

If you agree to take part in this study, you will be asked to
attend an interview at a venue which is convenient for
you. The interview will last approximately 1 – 1 ½ hours.

You will be offered a £10 Amazon voucher for your
participation.

All information will be confidential and your participation
in this study is entirely voluntary.

For more information, please call Jemma Priestley
(Trainee Clinical Psychologist) on [REDACTED] or email
[REDACTED]

Appendix C: Screening Questionnaire

1. Are you and your partner both over the age of 28?
2. Have you been in a relationship with your partner for over 3 years?
3. How many years have you been in a relationship with your partner?
4. How long have you been living with your partner?
5. Do you and your partner have any children? If so how many and how old are they?
6. Does your partner have a diagnosis of depression?
7. Does your partner have any other psychiatric diagnoses?
8. When was your partner first diagnosed with depression?
9. If so, who made the diagnosis?
10. Has your partner experienced more than one episode of depression?
11. Approximately how many episodes have they experienced?
12. Can you remember when your partner was last well?
13. Have you ever sought professional help yourself for mental health issues?
14. If so, please provide brief details.

Appendix D: Participant Information Pack

Study title: Experiences of Living with a Partner with Depression

Introduction

My name is Jemma Priestley and I am a Trainee Clinical Psychologist. I am carrying out this study as part of a Doctoral qualification in Clinical Psychology. The research is being supervised by [REDACTED].

This study aims to gain an in-depth understanding of the experiences of living with a partner with depression. Learning about your experiences will help us to understand how services can support other individuals also living with a partner with depression.

Who will be taking part in the study?

We are looking for people who:

- Currently live with a partner with depression.
- Have been in a relationship with their partner for at least three years.
- Both of the couple are aged 28 years or over.

We hope that between twelve and twenty people will agree to take part and share their experiences.

Do I have to take part?

No. It is up to you to decide to join the study. If you agree to take part, we will ask you to sign a consent form. However, you are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you would like to take part, please contact me using the details below. I will need to ask you some questions which will allow me to ensure that this study is right for you.

The interview will last between 1 to 2 hours and take place either on the phone, at a local community venue, the University of Essex ([REDACTED]) or in your own home. It will be voice recorded to ensure all important aspects of your experience are captured. You are free to stop the recording at any time.

Will my taking part in this study be kept confidential?

All information will be kept strictly confidential and known only to the research team (please see details below). Any details which could potentially identify you, such as names and locations, will be removed or changed.

As with any health professional, there are limits to confidentiality. If you disclose any information which suggests that you pose a risk to yourself or others then I am obliged to breach confidentiality and inform your GP. Similarly, if you disclose information which suggests that you're partner's safety is at risk then I will also need to breach confidentiality and inform the relevant professional. In either case, I will always notify you beforehand if I am going to do this, and explain why.

What will happen to the results of the study?

I will write up a report of the research which will form part of my qualification as a Clinical Psychologist. Within this report I may include anonymous extracts of the interview. These extracts will not include any information that could identify participants. I will also ask if you would like me to send you a summary of the research findings when the study is complete.

What if there is a problem?

If you have a concern about any aspect of this study, you can contact me and I will do my best to answer your questions. Alternatively you can contact my research supervisor, [REDACTED], through the University of Essex (see contact details below).


Further information and contact details

Jemma Priestley (Trainee Clinical Psychologist) [REDACTED]

[REDACTED] (Academic Supervisor, University of Essex) [REDACTED]

Thank-you for reading this information

Appendix E: University Ethics Amendment Application and Approval Letter



28th January 2014

Dear 

Re: Ethical Approval Application (Ref 12037)

To increase chances of recruitment for my study I would like to extend my recruitment area to include the East of England and London. This would include any community venues run by local authorities or charities who agree to put up my advertisement poster. I would also like to include online community forums, with the permission of site moderators.

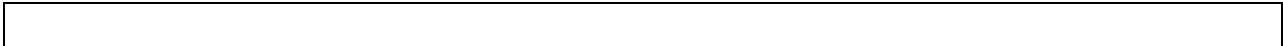
Due to the nature of my community sample, many of whom may be quite isolated and therefore unlikely to see the advertisement posters, I would like to increase chances of recruitment with the use of snowball sampling.

Please let me know if I need to take any other actions concerning these changes in order to retain a favourable ethical opinion concerning my study.

Yours sincerely

Jemma Priestley

Trainee Clinical Psychologist



School of Health and
Human Sciences



20 February 2014

MISS J.F. PRIESTLEY



Dear Jemma,

Re: Ethical Approval Application (Ref 12037)

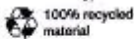
Further to your letter requesting an amendment to your application for ethical approval, I am pleased to confirm that [REDACTED] has approved this amendment (request to extend your recruitment area to include the East of England and London).

Yours sincerely



Ethics Administrator
School of Health and Human Sciences

cc. [REDACTED] Supervisor
REO



Application for Ethical Approval of Research Involving Human Participants

This application form should be completed for any research involving human participants conducted in or by the University. 'Human participants' are defined as including living human beings, human beings who have recently died (cadavers, human remains and body parts), embryos and fetuses, human tissue and bodily fluids, and human data and records (such as, but not restricted to medical, genetic, financial, personnel, criminal or administrative records and test results including scholastic achievements). Research should not commence until written approval has been received (from Departmental Research Director, Faculty Ethics Committee (FEC) or the University's Ethics Committee). This should be borne in mind when setting a start date for the project.

Applications should be made on this form, and submitted electronically, to your Departmental Research Director. A signed copy of the form should also be submitted. Applications will be assessed by the Research Director in the first instance, and may then be passed to the FEC, and then to the University's Ethics Committee. A copy of your research proposal and any necessary supporting documentation (e.g. consent form, recruiting materials, etc) should also be attached to this form.

A full copy of the signed application will be retained by the department/school for 6 years following completion of the project. The signed application form cover sheet (two pages) will be sent to the Research Governance and Planning Manager in the REO as Secretary of the University's Ethics Committee.

1. Title of project:
Experiences of Living with a Partner with Depression

2. The title of your project will be published in the minutes of the University Ethics Committee. If you object, then a reference number will be used in place of the title.
Do you object to the title of your project being published? Yes / No

3. This Project is: Staff Research Project Student Project

4. Principal Investigator(s) (students should also include the name of their supervisor):

| Name: | Department: |
|-------------|---------------------------|
| Jemma Darcy | Health and Human Sciences |
| ██████████ | ██████████ |
| ██████████ | ██████████ |

5. **Proposed start date:** 01/07/2013

6. **Probable duration:** 01/07/2013 – 01/04/2015

7. Will this project be externally funded? Yes / No
If Yes,

8. What is the source of the funding?

9. If external approval for this research has been given, then only this cover sheet needs to be submitted

External ethics approval obtained (attach evidence of approval) Yes / No

Declaration of Principal Investigator:

The information contained in this application, including any accompanying information, is, to the best of my knowledge, complete and correct. I/we have read the University's *Guidelines for Ethical Approval of Research Involving Human Participants* and accept responsibility for the conduct of the procedures set out in this application in accordance with the guidelines, the University's *Statement on Safeguarding Good Scientific Practice* and any other conditions laid down by the University's Ethics Committee. I/we have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my/our obligations and the rights of the participants.

Signature(s):.....

.....

Name(s) in block capitals:

Date:

Supervisor's recommendation (Student Projects only):

I have read and approved both the research proposal and this application.

Supervisor's signature:.....

Outcome:

The Departmental Director of Research (DoR) has reviewed this project and considers the methodological/technical aspects of the proposal to be appropriate to the tasks proposed. The DoR considers that the investigator(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in this application, and to deal with any emergencies and contingencies that may arise.

This application falls under Annex B and is approved on behalf of the FEC

This application is referred to the FEC because it does not fall under Annex B

This application is referred to the FEC because it requires independent scrutiny

Signature(s):

Name(s) in block capitals:

Department.....

Date:

The application has been approved by the FEC

The application has not been approved by the FEC

The application is referred to the University Ethics Committee

Signature(s):

Name(s) in block capitals:

Details of the Project

1. **Brief outline of project** (This should include the purpose or objectives of the research, brief justification, and a summary of methods. It should be approx. 150 words in everyday language that is free from jargon).

Living with someone with chronic depression can lead to high levels of burden, including a range of emotional, psychological, social and financial problems. It has been suggested that partners are at greater risk of burden compared to other relatives. However, to date there has been limited qualitative research exploring this area. Therefore, this study aims to develop an understanding of individuals' experiences of living with a partner with chronic depression.

Twelve to twenty partners will be purposively recruited from community locations in the region of North Essex. An advertisement will also be placed in an online national carer's forum. Each participant will complete an in-depth interview either via telephone or face-to-face, informed by a topic guide, and data from the interviews will be subjected to thematic analysis.

This exploratory study will inform clinicians and wider services about the specific needs of partners and may help to develop more tailored support to this population. The study will contribute to the developing body of research into the importance of the interpersonal aspects of depression and its treatment within the context of marital relationships.

Participant Details

2. Will the research involve human participants? (indicate as appropriate)

Yes

No

3. Who are they and how will they be recruited? (If any recruiting materials are to be used, e.g. advertisement or letter of invitation, please provide copies).

Participants will be individuals living with a husband, wife or partner with chronic depression. They will be recruited through advertisement posters (please see attachment) which will be placed at community venues around the North Essex region (e.g. libraries, cafes and community centres). The poster will also be placed on an online national carer's forum.

Will participants be paid or reimbursed?

Individuals will be offered a payment of £15 for their participation. The amount of £15 seems substantial enough to incline individuals towards participation without being large enough to be considered coercive. The payment will also be used to acknowledge the participant's contribution towards the research. Participants will be asked to sign a form to acknowledge receipt of payment.

4. Could participants be considered:

(a) to be vulnerable (e.g. children, mentally-ill)? Yes / No

(b) to feel obliged to take part in the research? Yes / No

If the answer to either of these is yes, please explain how the participants could be considered vulnerable and why vulnerable participants are necessary for the research.

Due to the extensive amount of literature regarding burden associated with living with someone with a chronic mental health problem, the participants in this study may be considered vulnerable. In light of suggestions that living with someone with depression is comparable to that of other serious mental health problems (e.g. schizophrenia or dementia) and also that partners are more at risk of burden compared to other relatives, these participants are necessary for the research because they are an under-represented population that requires further exploration. The research could 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 marital relationships.

Active steps will be taken to support the participants during the study. Participants will be offered a debrief at the end of the interview, which will enable them to discuss their experience of the interview and any issues that may have been raised for them during the interview. They will also be provided with a list of local resources. As a Trainee Clinical Psychologist, the researcher has the ability to provide support and interventions to people in distress and would therefore be able to debrief the participants following the interview if necessary. If the participant reports significant distress, the researcher may ask them if they feel able to contact their GP for further support or even offer to contact the GP on their behalf, with the participant's permission.

When conducting research within a clinical service, Trainee Clinical Psychologists usually have access to supervision with a qualified Clinical Psychologist based within the service. As this research will be conducted with a community sample, it has been agreed that a qualified Clinical Psychologist from the supervisory team within the Doctorate of Clinical Psychology course will act as a clinical supervisor to the researcher. This will enable the researcher to seek advice and support themselves if necessary.

Informed Consent

5. Will the participant's consent be obtained for involvement in the research orally or in writing? (If in writing, please attach an example of written consent for approval):

Yes No

How will consent be obtained and recorded? If consent is not possible, explain why.

People who are interested in finding out more about the study will be invited to contact the researcher by phone or email, which will be available on the advertisement poster (please see attachment). At this point, the researcher will run through the screening questions (see attachment) in order to establish eligibility for the study. Potential participants will then be sent an information pack about the study in the post (please see attachment). People willing to participate will be invited to contact the researcher by phone or email, during which the researcher will answer any questions they may have and plan a suitable date and time to conduct the interview. Depending on the location of the participant, interviews may be conducted via telephone or face-to-face. At the start of the meeting, the researcher will go through the consent form with the participant, answer any further questions and if they are still happy to continue, the researcher will ask the participant to sign the consent form (please see attachment).

Please attach a participant information sheet where appropriate.

Confidentiality / Anonymity

6. If the research generates personal data, describe the arrangements for maintaining anonymity and confidentiality or the reasons for not doing so.

The principal investigator will use a digital voice recorder to record interviews and will transcribe each interview themselves. Pseudonyms will be assigned to each participant to ensure anonymity. Any other details which could potentially identify the participant, such as names and locations, will also be removed or changed. During the time when interviews are being transcribed, the digital voice recorder will be kept in a locked storage facility at the University of Essex, accessible only by the principal investigator and the research supervisor. A sample of voice recordings and anonymised interview transcripts will be reviewed by [REDACTED] to ensure accuracy. All voice recordings will subsequently be destroyed when the interviews have been transcribed and reviewed. Anonymised interview transcripts will then be stored electronically in password protected folders on an encrypted computer accessible only by the principal investigator. Participants will be informed in the participant information sheet that anonymised extracts from their interview may be used in reports of the research. They will be asked to sign to consent to this within the consent form.

Data Access, Storage and Security

7. Describe the arrangements for storing and maintaining the security of any personal data collected as part of the project. Please provide details of those who will have access to the data.

During the time when interviews are being transcribed, the digital voice recorder will be kept in a locked storage facility at the University of Essex, accessible only by the principal investigator and the research supervisor. A sample of voice recordings and anonymised interview transcripts will be reviewed by [REDACTED] to ensure accuracy. All voice recordings will subsequently be destroyed when the interviews have been transcribed and reviewed. Anonymised interview transcripts will then be stored electronically in password protected folders on an encrypted computer accessible only by the principal investigator.

It is a requirement of the Data Protection Act 1998 to ensure individuals are aware of how information about them will be managed. Please tick the box to confirm that participants will be informed of the data access, storage and security arrangements described above. If relevant, it is appropriate for this to be done via the participant information sheet

Further guidance about the collection of personal data for research purposes and compliance with the Data Protection Act can be accessed at the following weblink. Please tick the box to confirm that you have read this guidance (http://www.essex.ac.uk/records_management/policies/data_protection_and_research.aspx)

Risk and Risk Management

8. Are there any potential risks (e.g. physical, psychological, social, legal or economic) to participants or subjects associated with the proposed research?

Yes No

If Yes,

Please provide full details and explain what risk management procedures will be put in place to minimise the risks:

Participants may become distressed as a result of talking about their experiences of living with a partner with depression. The following procedures will be implemented in order to minimise these risks. At the beginning of the interview, participants will be informed that they can pause for a break, or stop completely at any time if they wish. They will also be advised on the limits of confidentiality and under what circumstances the researcher will be required to breach confidentiality. Specifically they will be informed that if they disclose information that suggests they may be a risk to themselves or others then steps will be taken to ensure safety and alert relevant professionals (i.e. their GP or local crisis team) but that the researcher will inform them before doing so.

Participants will also be informed that the researcher also has a duty of care to report any information disclosed that suggests the participant's partner is a risk to themselves or others. This will be made clear on the participant information sheet (see appendix 3) and consent form (see Appendix 5). If the participant discloses information which is suggestive of current risk then steps will be taken to alert relevant professionals (e.g. GP, care-coordinator or duty team). This information has been discussed and approved by

_____).

If the participant becomes distressed during the interview the researcher will suspend the interview and stay with the participant until the distress has diminished and only continue if the participant wishes to do so.

Participants will be offered a debrief at the end of the interview, which will enable them to discuss their experience of the interview and any issues that may have been raised for them during the interview. They will also be provided with a list of local resources. As a Trainee Clinical Psychologist, the researcher has the ability to provide support and interventions to people in distress and would therefore be able to debrief the participants following the interview if necessary. If the participant reports significant distress, the researcher may ask them if they feel able to contact their GP for further support or even offer to contact the GP on their behalf, with the participant's permission.

When conducting research within a clinical service, Trainee Clinical Psychologists usually have access to supervision with a qualified Clinical Psychologist based within the service. As this research will be conducted with a community sample, it has been agreed that a qualified Clinical Psychologist from the supervisory team within the Doctorate of Clinical Psychology course will act as a clinical supervisor to the researcher. This will enable the researcher to seek advice and support themselves if necessary.

9. Are there any potential risks to researchers as a consequence of undertaking this proposal that are greater than those encountered in normal day-to-day life?

Yes No

If Yes,

Please provide full details and explain what risk management procedures will be put in place to minimise the risks:

Depending upon the participant's preference, interviews will be conducted either via telephone, at a local community venue in the North Essex region, a venue belonging to a local carer's group, the University of Essex or in their own home. Where possible, another member of staff will be present on the premises at all times and available if required. If this is not possible (i.e. participant's home) then further steps will be taken to ensure safety. An online support system for lone working will be used, such as Guardian 24 or a similar service. Within this system, the lone worker logs their visit online with an agreed check-in time after the event. If the lone worker fails to check in on time, the service calls the user to verify their safety. If the lone worker fails to respond then emergency services are called.

10. Will the research involve individuals below the age of 18 or individuals of 18 years and over with a limited capacity to give informed consent?

Yes No

If Yes, a criminal records disclosure (CRB check) within the last three years is required.

Please provide details of the "clear disclosure":

LIVING WITH A PARTNER WITH DEPRESSION

| |
|---|
| Date of disclosure: |
| Type of disclosure: |
| Organisation that requested disclosure: |

11. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Ethics Committees

| |
|-----|
| N/A |
|-----|



University of Essex

School of Health and
Human Sciences



05 July 2013

Miss Jemma D'Arcy

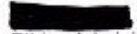


Dear Jemma,

Re: Ethical Approval Application (Ref 12037)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by [redacted] on behalf of the Faculty Ethics Committee.

Yours sincerely



Ethics Administrator
School of Health and Human Sciences

cc. [redacted]



Appendix G: Participant Consent Form

Consent Form

Title of Project: Experiences of Living with a Partner with Depression

Name of Researcher: Jemma Priestley (formally Darcy), Trainee Clinical Psychologist

**Please
initial
box**

I confirm that I have read and understood the participant information sheet.

I have been given the opportunity to ask questions about the study.

I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part.

I understand that my interview will be voice-recorded, solely for the purposes of the research study described in the participant information sheet.

I understand that if I disclose information that leads to concerns about the safety of myself, my partner or others, the researcher may be required to inform a third party (e.g. GP).

I understand that all names, references to places and anything that could identify me will be anonymised or removed from my interview transcript.

I give consent for the researcher to use direct quotes from my interview transcript in reports about the research (which I understand will be anonymised).

I understand that this research may be published in a scientific journal and I give consent for the researcher to use direct quotes from my interview transcripts for this purpose (which I understand will be anonymised).

I agree to take part in the above study.

Name of participant [printed] _____ _____
Signature Date

Researcher [printed] _____ _____
Signature Date

Appendix H: Participant Support Resources

Useful Numbers for Further Support

- Samaritans 08457 90 90 90 (24 hours a day)
- Saneline 0845 767 8000 (6pm – 11pm)
- Essex Carers Support 01255 474410
- Action for Family Carers 01621 851640

Appendix I: Voucher Receipt Confirmation Form

Title of Project: Experiences of Living with a Partner with Depression

Name of Researcher: Jemma Priestley (formally Darcy), Trainee Clinical Psychologist

Thank-you for your participation in my doctoral thesis study. Please accept a £10 gift voucher as a gesture of my appreciation for your participation.

**Please
initial
box**

I, _____ confirm that I have received a £10 voucher for my participation in the above study.

Please return this form in either of the following ways:

1. Via email: _____

2. Via post to: Jemma Priestley



Name of participant [printed] Signature Date

Researcher [printed] Signature Date

Appendix J: Sample of Coded Transcript

with depression, he hasn't returned to alcohol, for nearly four years now, which is brilliant.

22 I Mmm absolutely, that's fantastic.

23 C Yep, um, so he had been pretty much well, um, and he even had a period off medication about 18 months ago, I think. 18 months ago, something like that. And, but, has just, has *just*, quite recently over the last six months has gone down hill again and is currently on the top whack of his current medication, has been referred for counselling again, all that kind of stuff. So it seems to have come back again.

24 I Ok.

25 C So what's that, a decade? Just over a decade, now, he's lived with it. We've lived with it.

26 I Mmm. So a longstanding and difficult story there.

27 C Yes, and, kind of, it is an up and down illness, definitely, and at the beginning, I found it, kind of easier to say "oh it's because of this" and "it's because of that". Because we'd just lost a business and then there was the alcohol and all that kind of stuff. But kind of, as life settles down and the alcohol's gone, the depression's still there. I think he finds it very difficult now, when it comes back, because, well, you know, he says himself "what's the reason for it?". There is no reason for it. So I think he finds that difficult to accept. There's no rhyme or reason to it, there's no... You know, we've got a nice house and a nice life. He had a good job, he's not worked now for a couple of months, 2-3 months. He's off sick. Um, so it's an odd illness.

28 I Mmm. So at times it made sense

..Depression is a cycle

..Depression is something we live with together

..Depression is a cycle

..ATTRIBUTING THE CAUSE OF DEPRESSION TO SOMETHING

..Initial reason no longer fits

because its reactive to something and you can pinpoint it to something and say "well when this happened he felt very depressed" but at the moment or when there are times when there isn't anything to pin it onto...

29 C Yes.

30 I And there doesn't seem to be a valid reason for it.

31 C Yes.

32 I That must be difficult.

33 C It's really difficult. Um, it's difficult for him I think because it makes it, not, there's nothing to hang it on if you know what I mean? Which means that you can't see an end to it. So, when this changes it will be ok. Um, and it's difficult for me because, I don't understand it anyway and I've got nothing to be angry at, I suppose, when there isn't a reason.

34 I Ok, yeh, and I can, that makes sense. So if there's a loss of the business or the alcohol it gives you something to direct the anger at.

35 C And also to *do* something about.

36 I Mmm.

37 C So I can help and go to groups and if not help him then help somebody else, and there's something to, kind of, *do*. But when there isn't anything, its, it's very difficult. I've just come home this evening and he'd had a few really good days and I've just come in today and he said he's had a bad day today. And even now, ten years down the line, I say "and why is that, do you think?". I know there's no reason for it but I suppose it's just this never ending want to have a reason, so that you can help fix it, I guess.

38 I Yeh. And on days like today where

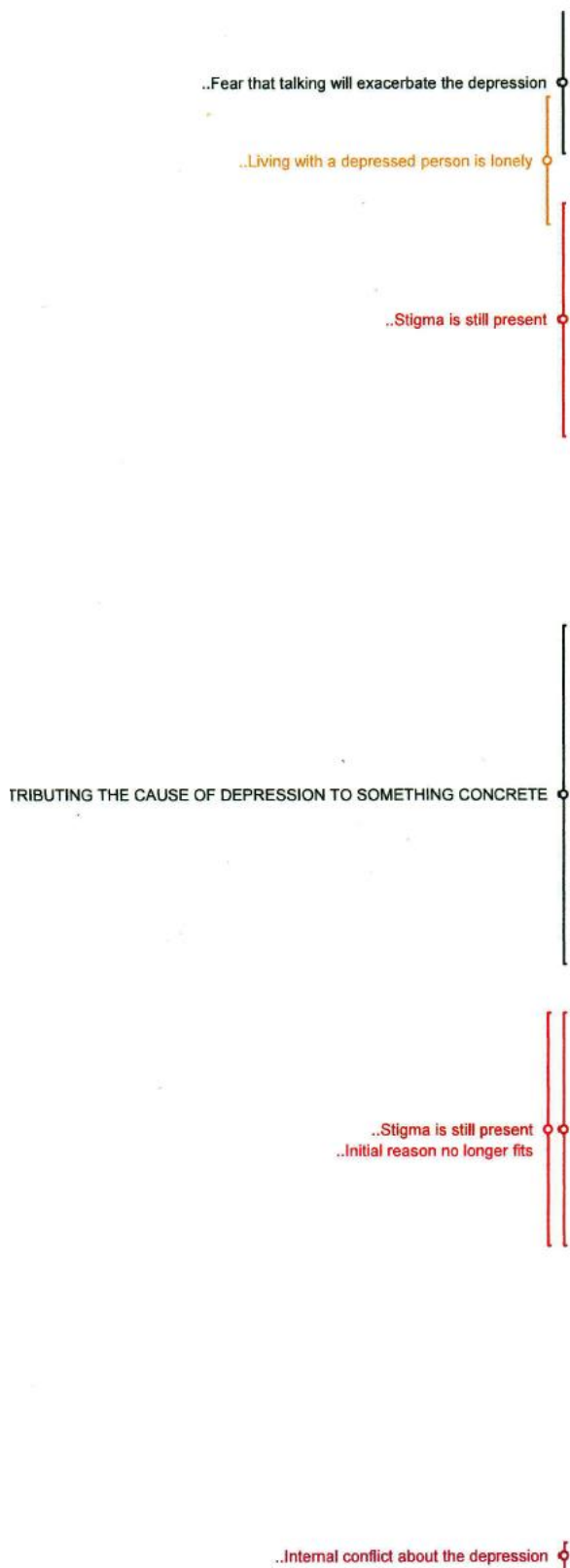
..Initial reason no longer fits

..A perceived reason provides a direction for anger

..The urge to "fix" things and make them better

| | | | |
|--|---|------|---|
| ..Range of emotions felt towards PWD simultaneously | } | 39 C | maybe there isn't any obvious reason, and he can't give you that answer, how does that make you feel? |
| ..Suppressing own emotions | } | 39 C | Um, sometimes sad. Sometimes really frustrated. Sometimes cross with him, still. "What do you mean you don't know? Of course you must know. Everybody knows why they're feeling fed up". Um, a lot of time helpless, and, quite often, frustration. Um, especially if I'm having a bad day. Or if I'm having a good day, like, you know, the extremes. If I'm having a bad day you know, selfishly I think, "well when's it my turn to have a bad day?", "when can I be pissed off and grumpy?". |
| ..Unable to share happy moments with PWD because of depression | } | 40 I | That's understandable. |
| | | 41 C | Yep. And also if we've got a positive thing going on. For example, a couple of weeks ago was our wedding anniversary, and it was a bad day. And that was hard to deal with. And the day we picked up the keys to our new house, that was a bad day for [REDACTED] as well and that was very difficult for me to deal with because it was something we had been working, you know since we lost the business we hadn't had a house, so that was a real, major, turning point and really positive and [REDACTED] could barely get out of the house. So that was really hard, to be able to share that kind of joy. So that's when you kind of get angry and frustrated and a bit woe is me, it's not fair, and all of that stuff. |
| ..Fear that talking will exacerbate the depression | } | 42 I | Yeh... |
| | | 43 C | But its difficult to, because I cant talk to him about it, about that, because that makes him worse. Because then he feels guilty and that causes |

LIVING WITH A PARTNER WITH DEPRESSION



depression and all that kind of stuff. So it just, it's a big circle of feeling quite, its very lonely being the wife of somebody who's depressed. Because you can't, nobody understands, *really* understands. I still find, that even though lots and lots of people say they know somebody, or they've had depression themselves over time, people still don't properly talk about it, I find.

44 I Ok, so even when you meet people who are maybe in a similar position?

45 C Yeh, I think because it's not often that you find somebody, well I don't know anybody, who has had depression as long as [REDACTED] has. So, people's depression tends to be linked to something that's happened. So a divorce, or a loss of a business, or you know, we live in quite a naval area so, and sometimes when people leave the navy they, it's that identity loss thing again. So that kind of comes up, but its for a reason and for a period of time, and it stops. And I don't know anybody else who has the same story as us. Sp people say "well why is he down at the moment?", and it's very difficult, well it's difficult for me to understand and accept so, of course it's difficult for everybody else outside it to accept and understand.

46 I And what goes through your mind when people do ask, now that, you know, like you say, it's not as easy to hang it on anything at the moment, so how does that affect you?

47 C Um, I think, I think I try and um, make it ok for him, so I try and protect *him*, so I'm better. I say all the, you know I've got the good fairy

| | | | | |
|--|---|--|--|--|
| ..Internal conflict about the depression | ○ | | | <p>sat on one shoulder that understands that this is an illness and there's no reason for it and it's very probably a chemical thing and then that's the good fairy sat on one shoulder. And so she comes out and tells these people all of these things – well there doesn't have to be a reason for it. You know so I tend to protect him with other people instead of going with the other side of it, which is my frustration and fed-upness. I don't talk about that. I go into protecting [REDACTED] and trying to make them understand that he's poorly. He's not weak or wrong or any of those things, he's just poorly.</p> |
| ..The need to protect PWD from outsiders | ○ | | | <p>48 I So there's almost two sides of it like you describe it – there's the two fairies?</p> |
| ..Experiencing despair at times | ○ | | | <p>49 C Yeh and sometimes, most of the time, I get it and I can deal with it. But sometimes, I can't. And I don't care that it's an illness; I just don't want it in our lives anymore.</p> |
| ..The urge to "fix" things and make them better | ○ | | | <p>50 I Mmm</p> <p>51 C And I want there to be a reason for it so we can fix it and make it go away.</p> <p>52 I Yeh, so there's almost, there's a proactive part of you that wants to find something tangible that you can do something about..</p> |
| ..Doing something about it makes me feel better ..A perceived reason provides a direction for anger | ○ | | | <p>53 C Exactly</p> <p>54 I And when there's nothing there to see or do something about, it makes it more difficult to deal with?</p> <p>55 C Yeh it does. Because actually all of the things that I did when there was a reason for it didn't make any difference at all, to him. But it made a big difference to me because I had something to point it at, if you like.</p> |
| ..Doing something about it makes me feel better | ○ | | | <p>56 I Mmm.</p> <p>57 C And again, it didn't make any</p> |

Appendix K: Care and Support (Eligibility Criteria) Regulations 2014

Needs which meet the eligibility criteria: carers

3.—(1) A carer's needs meet the eligibility criteria if—

- (a) the needs arise as a consequence of providing necessary care for an adult;
 - (b) the effect of the carer's needs is that any of the circumstances specified in paragraph (2) apply to the carer; and
 - (c) as a consequence of that fact there is, or is likely to be, a significant impact on the carer's well-being.
- (2) The circumstances specified in this paragraph are as follows—
- (a) the carer's physical or mental health is, or is at risk of, deteriorating;
 - (b) the carer is unable to achieve any of the following outcomes—
 - (i) carrying out any caring responsibilities the carer has for a child;
 - (ii) providing care to other persons for whom the carer provides care;
 - (iii) maintaining a habitable home environment in the carer's home (whether or not this is also the home of the adult needing care);
 - (iv) managing and maintaining nutrition;
 - (v) developing and maintaining family or other personal relationships;
 - (vi) engaging in work, training, education or volunteering;
 - (vii) making use of necessary facilities or services in the local community, including recreational facilities or services; and
 - (viii) engaging in recreational activities.
 - (3) For the purposes of paragraph (2) a carer is to be regarded as being unable to achieve an outcome if the carer—
 - (a) is unable to achieve it without assistance;
 - (b) is able to achieve it without assistance but doing so causes the carer significant pain, distress or anxiety; or
 - (c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the carer, or of others.
 - (4) Where the level of a carer's needs fluctuates, in determining whether the carer's needs meet the eligibility criteria, the local authority must take into account the carer's circumstances over such period as it considers necessary to establish accurately the carer's level of need.