

## Experiences of Adults Providing Care to a Partner or Relative with Depression: A Meta-Ethnographic Synthesis

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## **Abstract**

**Background:** International interest in the informal carer role has grown in part because of the relationship between caring and caregiver 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.

**Methods:** This meta-ethnography included 15 studies exploring experiences of living with a relative or partner with depression. Studies were heterogeneous regarding types of relationship with the depressed individual.

**Results:** The synthesis revealed a cyclical, psychosocial process that family caregivers undergo whilst providing care to a person 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 person are constantly changing.

**Limitations:** Some of the studies presented in the review represent caregivers recruited via support groups and so the person cared for may not have had professional diagnoses of depression.

**Conclusions:** This synthesis indicated the need for professional support to be available to caregivers for their own mental health needs. The model put forward suggests that different types of support may be useful for caregivers at different stages of the process including couples or systemic therapy at the initial stages of management, addressing stigma to help those overcoming challenges of caring for their partner or relative and self-compassionate approaches for

caregivers who may need support to look after themselves, avoid feelings of guilt and move forward towards acceptance.

Keywords: caregiver burden; meta-ethnography; couples therapy; stigma

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## Introduction

The concept of 'care' has received more attention in recent years across the UK, US, Australia and Europe in terms of legislation, policy and practice (e.g. the Care Act (DOH, 2014); Carer Recognition Act (Australian Government, 2010)). Approximately 6 million people in the UK, 2.5 million in Australia and 65 million in the USA provide unpaid care to a family member (Office for National Statistics, 2011; Australian Bureau of Statistics, 2003; Caregiver Action Network, n.d.). 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 (Henderson & Forbat, 2002; Lloyd, 2000).

Twelve month prevalence estimates for depression vary between 6.7% in the US (Kessler, Chiu, Demler & Walters, 2005) and 3.2% worldwide (Moussavi et al, 2007). Researchers generally agree that chronic mental health problems such as depression 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). It has been suggested 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). 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).

The increased interest in the carer role has led to a more formal identity of ‘carers’ or ‘caregivers’ 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 and overlooking the fact that many informal carers do not define themselves as such (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).

A small body of qualitative research has emerged focusing specifically on the subjective experiences of adult caregivers for people with depression. This research has not previously been subjected to a synthesis; therefore, the aim of this paper is to conduct a meta-ethnography of the literature exploring the experiences of family members caring for a partner or relative with depression and to consider the findings in light of the impact on family relationships and how policy and practice might seek to best support caregivers in their role.

## Method

**Design.** The diversity of approaches to synthesising qualitative research has grown steadily over recent years and has itself become a topic for review (e.g. Campbell et al., 2011). A key point of difference between methods is their varying epistemological positions (Gough, Thomas, & Oliver, 2012), ranging from a highly relativist view of knowledge (e.g. meta-narrative methods) to a scientific realist viewpoint (e.g. ecological triangulation). Meta-ethnography (Noblit & Hare, 1988) is informed by objective idealism, which sits between these two poles. Its interpretative nature implies a degree of relativism; however it does not uphold the relativist idea of multiple realities. Instead, the emphasis is predominantly on examining commonalities across accounts, ultimately seeking to provide a ‘whole’ which has greater explanatory power. Meta-ethnography is particularly useful for synthesising research which seeks to understand individuals’ experiences of illness and care (e.g. Campbell et al., 2003).

Meta-ethnography has been increasingly applied to larger sets of studies (Pound et al., 2005) and to non-ethnographic sets of studies (Atkins et al., 2008; Britten et al., 2002; Campbell et al., 2003). 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 may be directly comparable as reciprocal translations; they may conflict in which case a refutational synthesis can be produced; taken together they may also represent a line of argument. Noblit and Hare (1988) outlined seven

iterative phases of meta-ethnography which were followed in the present meta-ethnography: getting started; deciding what is relevant to the initial interest; reading the studies; determining how the studies are related; translating the studies into one another; synthesising translations; expressing the synthesis.

**Article Selection.** All published, peer reviewed articles that used qualitative methods to explore the experiences of adults providing care to a relative with depression were included. 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 people caring for someone with depression were combined with data from people caring for people with other mental health problems (e.g. schizophrenia or bipolar affective disorder).

Articles were excluded if the primary caregivers were exclusively under 18 years of age, since the experiences of young carers is potentially different to that of adult caregivers, justifying a separate study. However, articles were included 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 the depressed person. Where the individual with depression was part of the interview or focus group, the synthesis solely focussed on caregivers' perspectives.

An electronic search was conducted using the databases CINAHL, Medline, PubMed and

PsychARTICLES in August 2015. The strategy involved searching for published journal articles

using the option 'Abstract' and the limiters 'Adult (18+ years)' and 'Peer Reviewed'. The search terms employed were:

1. depress\*
2. experienc\* OR perspective\* OR manag\* OR explor\*
3. family member\* OR relative\* OR spouse\*
4. care\* OR caring
5. interview\* OR focus group\*
6. #1 AND #2 AND #3 AND #4 AND #5

Following a detailed scan of article titles and abstracts, 11 articles were identified for inclusion (Harris et al., 2006; Muscroft & Bowl, 2000; Radfar, Ahmadi, & Khoshknab, 2014; Ahlstrom, Skarsater, & Danielson, 2009; Badger, 1996a; Bottorff, Oliffe, Kelly, Johnson, & Carey, 2014; Hansen & Buus, 2013; Hight, McNair, Davenport, & Hickie, 2004; Hight, Thompson, & McNair, 2005; Nosek, 2008; Skundberg-Kletthagen, Wangenstein, 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).

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 Critical Appraisal Skills Programme tool (CASP; Public Health Resource Unit, 2006) but included all articles regardless of their quality.

The quality assessment found that many of the studies failed to provide sufficient contextual information, including details about sample selection, data collection and analysis. They were also 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. Nevertheless, the studies were considered sufficiently rich in information for the purposes of this synthesis. As a whole the studies represent a diverse participant population; the participant sample sizes in the 15 studies included ranged from 9 to 37 with a total of 263 caregiver participants across all the studies. The studies were carried out in Australia, Canada, Chile, Denmark, Iran, Norway, Sweden, UK, US, reflecting a wide range of cultures and health care systems.

**Determining how the studies are related.** The 15 studies were examined to identify common and recurring concepts. 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 I 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 Britten et al., 2002).

**Translating the studies into one another.** Translation was done by completing the tables for each study following Britten et al. (2002) preserving terminology from the original papers. After identifying themes and concepts described in the original studies, checks were made to ensure that these were encompassed by the relevant key concept identified in the translation (Britten et al., 2002). Thus, by completing the tables, it confirmed that that each concept from the original studies was encompassed by one of the key concepts within the meta-synthesis. Table II 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 illustrated in Table I).

Table I: *Sample of tabulated study details and key concepts*

<b>Methods and Concepts</b>	<b>Badger (1996a)</b>
<b>Key Study Details</b>	
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
<b>Key Concepts</b>	
Recognition	Observing the metamorphosis
Impact	Lack of emotional and material support
Role reformation	Assuming the role tasks of person 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
<b>Explanation/Theory (Second-Order Interpretation)</b>	Families experience a social psychological transformation process involving three stages: acknowledging the stranger within, fighting the battle, and gaining new perspective

**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” (Britten et al., 2002, p. 211) and therefore may be difficult to replicate in practice. Following Atkins et al. (2008), the study tables described above 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 categories: making sense of depression, changes in family dynamics, overcoming challenges, and moving forward (Figure 1). Subsequently, an overarching model linking the key concepts, categories and second-order interpretations was developed in order to produce a line of argument synthesis (see Figure 2).

## Results

### **Making sense of 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. (2014) 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 partner or 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 Hight 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; Hight 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; Hight 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 person with depression. Most caregivers felt the burden of taking on extra responsibility, including the role tasks of the depressed person (Badger, 1996a, 1996b; Bottorff et al., 2014; Hansen & Buus, 2013; Radfar 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., 2014; 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 the depressed person. 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 the depressed person (Harris et al., 2006). Sometimes caregivers and the person they cared for had diverging perceptions on the best way to cope with the depression, which could lead to an ambiguous mix of sympathy and spitefulness (Hansen & Buus, 2013).

The studies highlighted that the needs of the depressed person 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 person with depression 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 person 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', caregivers 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 themes relating to healthcare professionals yet only one consisted of positive experiences (Stjernsward & Ostman, 2008). Caregivers 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-Kletthagen 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 people with depression 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 partner's or relative's care (Badger 1996a, 1996b; Hansen & Buus, 2013; Highet et al., 2004, 2005; Nosek, 2008), often leading them to feel unimportant and insignificant. The only exception was Stjernsward and Ostman (2018) 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). Caregivers were provided with little practical assistance on how to cope with living with a depressed person and were therefore left to work it out for themselves (Harris et al., 2006). Hansen and Buus (2013) reported that professionals often asked caregivers to convince the depressed person 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 depressed person.

**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; Radfar et al., 2014). Some caregivers described sharing stigma with the depressed person 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, 2013). 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 loved one'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 loved one's depression (Badger, 1996a, 1996b; Hansen & Buus, 2013; Muscroft & Bowl, 2000). Despite different conceptualisations, all caregivers felt that their own lives were put on hold when their loved one was diagnosed with depression. They often had little choice but to focus all their energy and attention on this person 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, 2013; Muscroft & Bowl, 2000) which often led to ambiguous feelings towards the depressed person. 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 the depressed person. 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., 2014; Nosek, 2008). Caregivers were usually able to engage in a more balanced relationship with their loved one and regain an identity separate from that of a caregiver by doing so.

Hansen and Buss (2013) 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 the depressed person 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’, Radfar 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; Radfar 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 2 embraces all of the studies included in the synthesis, thus representing a further level of conceptual development.

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 relative or partner with depression. 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 person 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 partner or relative's 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 partner or 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 loved one 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. Caregivers may be located at different points on this trajectory but, as highlighted by the studies, 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**

Through translation, this meta-ethnographic synthesis of 15 studies shows 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 person; 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 someone with depression.

The line-of-argument synthesis revealed a cyclical, psychosocial process that family caregivers undergo whilst providing care to a person with depression. The findings illustrate that care giving is not a static process and that caregiver needs are constantly changing, reiterating the need for the availability of support for caregivers (Benazon, 2000; Coyne et al., 1987). Different types of support could be made available for caregivers at different points in their trajectory e.g. systemic approaches or couples therapy may be useful at early stages to help the individual with depression and their family caregivers to understand and make sense of interpersonal changes and to understand and anticipate new family dynamics as they emerge. Addressing stigma associated with mental illness also remains critical to address perceived and real structural barriers to caregiver support at times when they are seeking professional and community based support. Self-compassion or acceptance based approaches may be useful to help caregivers look after their own emotional needs as they move forward and begin to accept the new challenges of life caring for a depressed partner or relative.



Both couples therapy and systemic therapies have a reasonable evidence base, for example they are recommended in UK NICE guidelines for depression in adults (NICE, 2009) and children (NICE, 2005) which are based on systematic reviews of effectiveness. It is unclear how commonly these forms of therapy are likely to be offered to patients presenting with depression, however, and this will vary within and between different countries. Findings from this metasynthesis suggest that these options should be more routinely offered given that they could potentially provide support not just for the person with depression but for their caregivers too which could have longer term benefits for the individual and the caregivers and prevent some of the wider burden on the family and social system associated with depression. It would also be useful to ensure that ongoing evaluation of these therapies take into account the long term impact on patients and caregivers rather than study the short term outcomes for the individual in isolation.

Depression still remains a stigmatised condition despite improvements over recent years through campaigns such as Time to Change (Henderson & Thornicroft, 2009). Several studies reveal that stigma played a role in preventing the provision of or seeking of support in the community or from professionals and thus continuing to tackle this is critical for supporting caregivers at the stage of 'overcoming challenges'. 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. 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). Responses of stigmatised individuals are therefore motivated and constrained by self and social processes. In relation to the present synthesis, secrecy and withdrawal were common responses by caregivers and fear of stigma and discrimination appeared to inform these decisions.

According to Lee and Craft (2002), stigma provides a form of symbolic negative social feedback that acts as a barrier to the process of 'self-verification' (confirming ones previously held self-image). Social relationships are necessary in order for individuals to self-verify but there is always a risk of rejection if the secret (the person with depression) is disclosed, hence the dilemma outlined by Lee and Craft (2002). This highlights the importance of social relationships in 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 caregivers 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.

Consideration should also be given to alternate and more discrete ways of accessing support where social stigma may be difficult to overcome. One suggestion is for more online options such as support forums or counseling services like Big White Wall (with sites in the UK, USA and New Zealand), or to increase advertising for existing resources that deliver similar services. Whilst some studies have shown a reduction in stigma through public campaigns (e.g. Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014), the findings of the current metasynthesis illustrate that being a caregiver for someone with depression still carries with it the fear of stigmatisation and discrimination.

According to a meta-analysis of mindfulness approaches (which includes self-compassion training) 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 depressed person, in order to help them move towards a position of safe uncertainty, although

more research on the potential of this approach for people caring for someone with depression would be useful.

### *Limitations*

Some of the studies presented in the review represent caregivers recruited via support groups and so their partners or relatives may not have had formal professional diagnoses of depression.

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Figure 1 : Overview of key concepts and synthesised broader categories

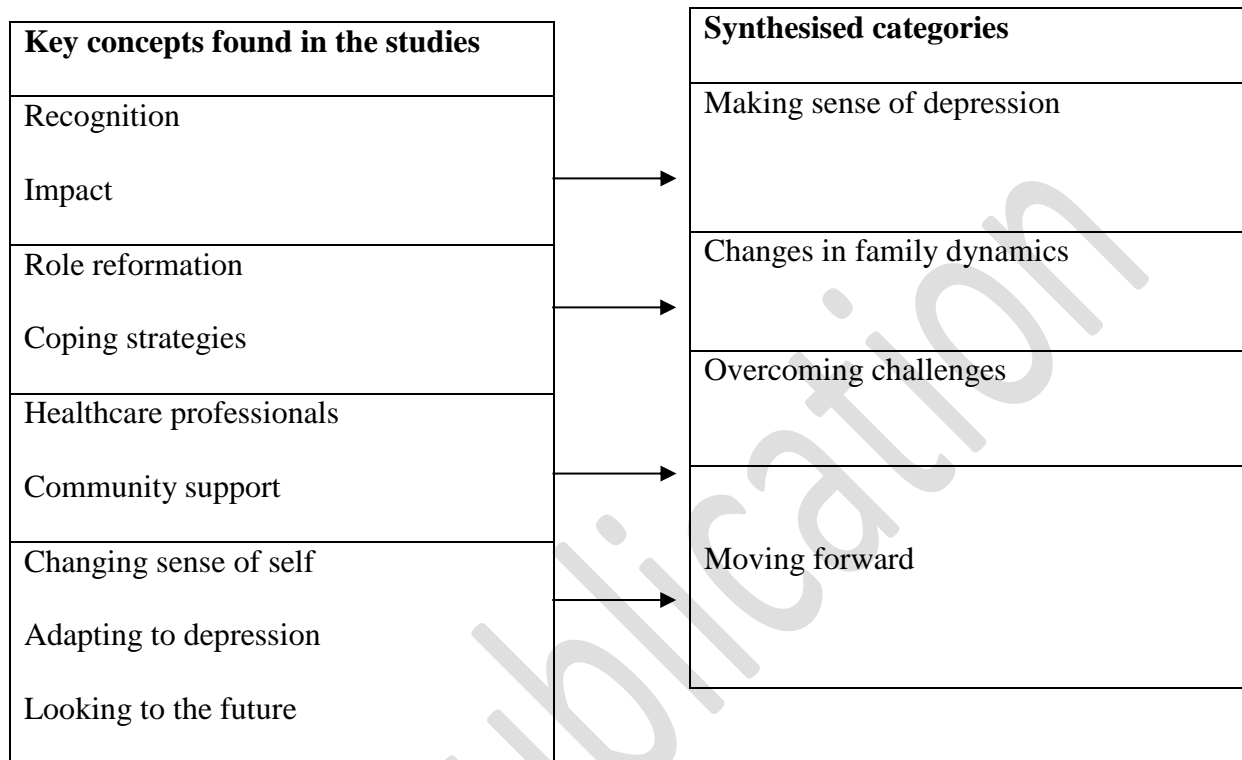


Figure 2. Line of argument synthesis: Experiences of providing care to a relative with depression

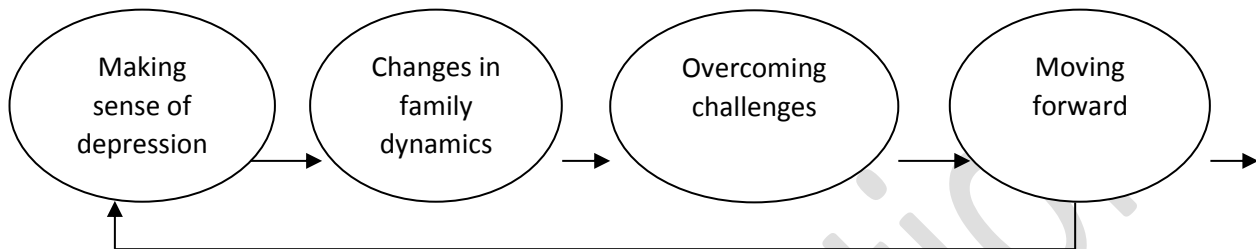




Table II: *Cross comparison of studies by concept*

Concepts	Ahlstrom et al (2009)	Badger (1996a)	Badger (1996b)	Bottorff et al. (2014)	Gonzalez et al. (2010)	Hansen & Buus (2012)	Harris et al. (2006)	Hight et al. (2004)	Hight 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	*	*	*		*		*		*	*	*		*	*	*

Pre-publication