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Living With a Depressed Partner

Bridget Logan

University of Massachusetts - Amherst

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LIVING WITH A DEPRESSED PARTNER

A Dissertation Presented

by

BRIDGET LINEHAN LOGAN

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

February, 2011

School of Nursing

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BRIDGET LINEHAN LOGAN

Approved as to style and content by:

Genevieve E. Chandler, Chair

Karen A. Kalmakis, Member

Naomi R. Gerstel, Member

Jean Swinney, Dean
School of Nursing

DEDICATION

To my husband and his encouragement to undertake this project, his support and sounding-board advice throughout the process, and his energy at the end that saw me through.

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ABSTRACT

LIVING WITH A DEPRESSED PARTNER

FEBRUARY, 2011

BRIDGET LINEHAN LOGAN, B.A., UNIVERSITY OF VERMONT

B.S., UNIVERSITY OF VERMONT

M.S., UNIVERSITY OF MASSACHUSETTS AMHERST

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Genevieve E. Chandler

Individuals who live with depressed partners have increased rates of anxiety, depression, and difficult coping. They experience greater burdens of parenting and financial responsibilities, and often feel isolated and restricted. Much of this is similar to what has been termed caregiver burden in the context of other illnesses.

This study used qualitative interviews to explore the day-to-day experience of what it is like to live with a depressed partner, as well as to test the fit of the term ‘caregiver burden’ in the context of depression. Participants were seven individuals who were in long-term relationships with depressed partners. Analysis of the interviews identified four stages of a helping process that individuals go through as they care for their depressed partners and transition from partners to caregivers. These individuals are experts on their partners and have important perspective and essential support to offer when their depressed partners are seeking care. Findings underline the importance of advanced nursing and medical care that recognizes the significant burden that nondepressed partners experience and the important ways that they can help their depressed partners seek and stay with treatment.

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CHAPTER 1

INTRODUCTION

According to the National Institute of Mental Health (NIMH) (2006), approximately 14.8 million people suffer from major depressive disorder, or about 6.7 percent of the U.S. population aged 18 or older in a given year. Dysthymic disorder, or mild depression, affects approximately 1.5 percent of the same portion of the population, or about 3.3 million adults in a given year (NIMH). The extensive body of literature studying individuals with depression reflects the widespread impact of this condition.

The impact of depression is not limited to the depressed individual; studies have documented the effects of living with a depressed person on families and children (Benazon, 2000; Coyne et al., 1987). Particular attention has been paid to the spouses of depressed individuals who often have a quasi-caregiving role and are widely seen by researchers to be in a uniquely difficult situation (Crowe, 2004). Anxiety, depression, stress, and difficulty coping are frequently felt by individuals in this situation (Halgin & Lovejoy, 1991; Coyne et al., 1987; Merikangas, Prusoff, Kupfer & Frank, 1985; Mitchell, Cronkite & Moos, 1983). During depressed episodes, nondepressed partners often have to bear heavier burdens as their roles expand to include more parenting duties or increased responsibility for financial concerns (Coyne et al., 1987). With depressed partners' decreased interest in activities that were once enjoyed by both partners, the nondepressed partners often feel restricted and isolated (Halgin & Lovejoy, 1991).

In many ways, these findings are similar to studies of individuals caring for partners ill with Alzheimer's disease, chronic pain, multiple sclerosis, cancer, or a host of

other physical conditions. The experience of giving non-professional care to a loved one has been termed ‘caregiver burden,’ and it has been studied extensively in the contexts of many different illnesses. When individuals care for their sick loved ones, they too have difficulty coping, experience stress, and perhaps most important to this discussion, they often experience depression themselves (Figved, Myhr, Larsen & Aarsland, 2007; Drentea, Clay, Roth & Mittelman, 2006; Jacobi et al., 2003; Nijboer, Triemstra, Tempelaar, Sanderman & van den Bos, 1999).

Despite the similarities between the experience of individuals who live with depressed partners and caregiving partners in the context of other illnesses, no studies could be located in which the focus of the study was ‘caregiver burden’ in relation to a depressed partner or spouse. Indeed, the very use of the term ‘caregiver burden’ in relation to a depressed partner may make some uncomfortable. After all, ‘caregiver’ may seem like an accurate way to describe a husband who feeds, medicates, and supervises his wife with Alzheimer’s, but it may not be the best term to describe a forty year-old husband who cares for his wife during her depression. Perhaps the lack of fit of ‘caregiver burden’ partially explains that lack of application of the concept to the context of individuals caring for depressed partners.

Whether the experience of living with a depressed partner is called ‘caregiver burden’ or not, the fact remains that, for many individuals, there is some degree of burden involved in their experiences (Coyne et al., 1987). This burden has been measured extensively in quantitative research focusing on nondepressed partners’ levels of stress, depression and anxiety, difficulty coping, and levels of marital distress (Spangenberg & Theron, 1999; Benazon & Coyne, 2000; Coyne et al., 1987; Benazon, 2000; Miller et al.,

2000; Merikangas et al., 1985; Siegel, Bradley, Gallo & Kasl, 2004; Coyne, Thompson & Palmer, 2002; Fincham, Beach, Harold & Osborne, 1997).

The Problem

The problem is that current research provides for clinicians an incomplete understanding of what individuals experience when they live with depressed partners. Despite the abundance of research available on partners and depression, there is still much that is unknown. This is partially because currently available research is very narrow in its focus. By measuring individual variables such as stress, burden, coping style, depression, marital distress, or anxiety, the larger picture of what it is like to live with a depressed partner becomes answered only partially. Current research largely focuses on the effects of depression on marriages (as opposed to the non-distressed partner) and how treating the marriage can be a means of helping the depressed partner (Dudek et al., 2004). As noted by Coyne et al. (2002), even the existing research on depression and marriage is more limited than generally assumed, and focuses almost exclusively on conflict and marital dissatisfaction.

Furthermore, the current body of literature offers discussion of only the variables that researchers have thought to explore, rather than the aspects of the experience as identified by those who live it. As a clinician, discussion of these isolated variables is not enough to understand individuals' daily lives. It leaves the reader asking 'yes, but what is it like? How do individuals perceive their situations?' Current research also offers findings that focus exclusively on the negative aspects of the situation.

The two exceptions to this narrow focus on quantifiable, negative experiences are qualitative studies by Harris, Pistrang, and Barker (2006) and Sandberg, Miller, and

Harper (2002). These two studies focus on the effects of depression on partners in different ways, and each with its own focus. The findings of both studies are discussed at length in the literature review in chapter two. As far as could be established, there has been no qualitative study that has asked open-ended questions about the experience of what it is like to live with a partner who has depression. By asking participants what it is like to live with a depressed partner, this study aimed to identify and describe aspects of the experience that have previously been unidentified or underemphasized.

Purpose

The purpose of this study is to provide the type of information about living with a depressed partner that is currently missing from existing research and in so doing broaden the understanding and improve the ability of clinicians to help individuals living with depressed partners. By asking open-ended questions as part of in-depth, phenomenologically-based interviews, individuals will be asked to describe the experience of living with a depressed partner. Their stories will provide context for the findings that are currently available in research, improving the ability of clinicians to understand and support individuals who live with depressed partners. By supporting individuals, their depressed partners and families are likely to be positively affected.

It is also hoped that new aspects of the experience of living with a depressed partner will emerge from these interviews— aspects of the experience that researchers have not thought to ask about yet and could only be identified by those who live the experience. For example, it is possible that there are positive results of living with a depressed partner that have been overlooked by previous focus on negative factors. Individuals may report pride in themselves, greater empathy for others, improved

communication patterns with their partners, or ability to handle some of life's other problems because they have had experience addressing the fallout of depression, or it may be that participants report no positive outcomes of their experience. The answer to this exploration cannot be known until the questions are asked.

It is also possible that previously underemphasized factors are among the most meaningful aspects of the experience for nondepressed partners. A particularly meaningful example of this is the lack of attention that most researchers have paid to the effects of depression on affection and sexuality. Complicated or impaired sexual relations are commonly part of couples' experience, caused either by the depression itself, by antidepressant side effects, or both. The impact of antidepressant-induced sexual dysfunction has been widely documented (Williams et al., 2006; Hirschfeld, 1999; Zajecka, 2001; Baldwin & Mayers, 2003; Ferguson, 2002; Rothschild, 2000), and these findings should be incorporated into the discussion of the partners' experience.

In one of the only studies located that addressed sexual function in relation to depression, Zieba, Dudek and Jawor (1987) reported that marital and sexual function was disturbed in couples where one partner was depressed, and that the disruption continued even after partial recovery from the depression. When one considers sexuality as an instrument of communication and healing, impaired sexual relations are an essential part of both partners' experiences, and failure to include this issue in discussion of the relationship is significant.

Other gaps in the literature are discussed in the literature review, including the effects of having and raising children on partners' depression, the need to recruit samples

that reflect more moderately depressed partners, and the need to characterize the depression in studies.

Given these specific, potential areas of exploration, there is much to be gained by asking individuals who have depressed partners to describe their experiences. This will be done through in-depth phenomenologically-based interviews that ask, “what is it like to live with a depressed partner?”

Significance

This study is important to nursing for several reasons. First, the high rate of incidence of depression in society means that nurses are very likely to encounter patients with depressed partners in nearly every setting. Second, because nurses are educated in the importance of attending to the psycho-social needs of patients, nurses—and particularly nurse practitioners—are ideally situated to help patients find support as individuals whose partners have depression. Third, the vast majority of research to date on partners has been done in the disciplines of psychology and psychiatry, and the participation of a nurse researcher in this area of study will, in contrast, offer an applied nursing perspective.

In addition to its significance to nursing, this study’s findings will be significant to clinicians and professionals in human services of many different disciplines. Social workers, therapists of any background, and clergy members are among many professionals who will be able to gain insight into the experience of individuals who live with depressed partners after the completion of this study.

Finally, this study has the potential to be important to the public at large. Many self-help and advice books are available for individuals who live with depressed partners,

but research offers findings that inform readers without advice or judgment. If the findings of this research are published in lay journals or in a book, readers will have the opportunity to gain understanding by reading the firsthand accounts in the words of those who live the experience.

Definitions

Depression

There are five forms of depression, the two most common being major depression and dysthymia, and the three less common being postpartum depression, psychotic depression, and seasonal affective disorder. Major depression affects an individual to the point that it impairs his or her ability to eat, sleep, work, enjoy once-enjoyable experiences, and function normally. Major depression may be recurrent throughout a person's life, or it may be one-time episodic. Dysthymia is the experience of these symptoms to a lesser extent so that individuals are not disabled by their depression, but are prevented from functioning normally and feeling well. As will be discussed in Chapter 3, inclusion criteria for this study will be major depression that has occurred at least once during the partners' time together.

Partner

The term 'partner' is used in this study to denote an individual in a committed relationship with another individual. The term 'partner' was chosen because it is not restricted to individuals who are married or are heterosexual, as the term 'spouse' generally is. The choice to use the word 'partner' is significant because it is divergent from the norm in research in this area. All the studies discussed in the literature review for this proposed research use the term 'spouse.' Instead of continuing with this standard,

it was determined that ‘partner’ would be a more inclusive and contemporary term given the following data:

According to the 2000 U.S. Census, there were 5.5 million couples that were living together, but who were not married, an increase from 3.2 million in 1990 (Simmons & O’Connell, 2003). These partners were self-identified couples who had close personal relationships and shared living quarters. The majority of these couples (4.9 million) were heterosexual, while approximately 1 in 9 (549,000) were same-sex partners (Simmons & O’Connell).

The use of the term ‘partner’ instead of ‘spouse’ is intended to de-emphasize the importance of the marriage itself and, instead, to broaden the scope of the study and include unmarried heterosexual couples as well as homosexual couples in the sample and, therefore, in the applicability of the findings.

Depressed Partner

For the purposes of this study, the term ‘depressed partner’ will be used to denote the member of the partnership whose chronic or recurrent depression has been diagnosed and recognized by both partners.

Nondepressed Partner

The term ‘nondepressed partner’ refers to the participants in this study. As will be discussed in the literature review, these individuals may develop symptoms of anxiety, depressed mood, distress and difficulty coping as they are affected by their depressed partner’s illness. However, their depressive symptoms are not the primary focus of the study. For the purpose of clarity in this study the individual is referred to as the nondepressed partner.

Caregiver Burden

The concept of caregiver burden refers to the strain that individuals feel when they provide informal care to a loved one. The term first appeared in research in 1984 and refers primarily to the burden of caring for an elderly family member, most often with dementia. However, caregiver burden has also been studied in the context of cancers, schizophrenia, lung disease, and other illnesses. Caregiver burden has not been used in reference to individuals caring for depressed partners, however there are similarities among the experience of individuals caring for a loved one with any illness. Further discussion of caregiver burden and its relevance to depression is presented in the literature review in chapter two.

CHAPTER 2

LITERATURE REVIEW

Introduction

The primary purpose of this literature review is to synthesize the current state of knowledge of how depression affects individuals living with depressed partners. Secondly, this review explores the similarities among what caregivers experience in the context of other illnesses. The first portion of this review focuses on partners and depression and will demonstrate that, while much study has been done on partners and depression, the focus of study to date has been narrow and there is much to still be explored. The second portion of this review focuses on caregiver burden and will demonstrate that much is known about caregiver burden generally and in the context of other illnesses, and that some of what is known about caregiving for other illnesses is relevant to individuals with depressed partners.

Each review will discuss: the background of the review; previous researchers' perspectives; samples; methods; study purposes; designs and instruments; findings; and lingering questions that the literature has not answered. A comparative matrix containing the details of each article can be found in the appendix.

Partners And Depression

Background

A search of the CINAHL, Pubmed, and Psyclit databases using the search words 'depression' and 'spouse' or 'partner' yielded thousands of articles that explored depression in couple relationships, usually in the context of another illness. Since so

many of these articles were not relevant to this search, only titles of articles that indicated a focus on depression within a partner/spousal/couple relationship were selected.

Snowball sampling was then used to locate other relevant articles. The vast majority of studies that were located used quantitative methods, so a separate search for qualitative studies was also done. Fifteen research articles were located, all of which were closely related to the following research question: How are individuals affected by their partners' depression?

Several of the articles focus on the experience of the individual who lives with a depressed partner. Most articles focus on the marriage and how it is affected by the depression. The following sections describe these articles in a literature review.

Researcher Perspective

Of the fifteen articles reviewed here, most were written by researchers in the United States (n=11), two written by researchers in the United States jointly with researchers from Wales (n=1) and Poland (n=1), and two written by researchers in South Africa (n=1) and Italy (n=1). This reflects a western orientation to the research perspective and conceptualization of mental health and marriage dominated by the United States and developed European nations. The articles date from 1985 through 2007, and this coincides with the vast body of literature that is available on affective disorders and married couples. There seems to have been a proliferation of research in this general area since the early 1980s.

All the studies reviewed here were done by researchers in the fields of psychology and psychiatry. This is significant because the discipline of origin may affect the scope of researchers' questions, the research methods used, and their general perspective based on

what is relevant in clinical practice for their discipline. For example, the homogeneity of researchers' training has likely contributed to the vast majority of studies being done using quantitative research methods. This will be discussed further in the Methods Section. Homogeneity of the researchers' training has also made the samples similar across studies, and this will be discussed in the Sample Section.

A final characteristic of researchers' perspective that is worthy of comment is the use or nonuse of theory as a basis for research. Three researchers in this sample of studies discussed theoretical frameworks that were essential to their point of view in studying partners and depression. Spangenberg and Theron (1999) studied the stress and coping strategies of individuals with depressed partners using Lazarus & Folkman's Transactional Model. This model was used to explain the transformation of stress felt when living with a depressed spouse into the emotional manifestation of their stress as anxiety and depression, which was measured in Spangenberg and Theron's (1999) study. The Transactional Model was also used in this study's examination of how spouses cope with stress through continuous cognitive and behavioral attempts to manage a stressful situation.

With focus on the marriage rather than the individual, Benazon (2000) tested the application of Coyne's Interactional Model. This model posits that for depressed individuals any negative responses to their behavior play a key role in the maintenance, or even the cause, of the depression. Thus, the marital relationship is integrally related to the depression and management of it, and the spouse potentially plays a key role in the path of the depression, potentially making the depression worse by reacting negatively to the depressed spouse's behavior.

Fincham et al. (1997) studied the relationship between marital discord and depression using the Marital Discord Model of Depression. Similar to Coyne's Interactional Model, this theory suggests links between the etiology of depression and marital discord, possibly in a bidirectional way. The remaining studies did not discuss specific theoretical frameworks on which their studies were based.

Samples

One of the inclusion criteria for this literature review was that the samples of studies contained partners or spouses of depressed patients. With this commonality as the unifying factor, there were many differences in the samples. Nearly all of the studies recruited their participants from either psychologist or psychiatrist referrals or psychiatry specialty clinics that provided services to either inpatients or outpatients or both (Spangenberg & Theron, 1999; Benazon & Coyne, 2000; Coyne et al., 1987; Miller et al., 2000; Merikangas et al., 1985; Coyne et al., 2002; Dudek et al., 2001; Basco, Prager, Pita, Tami & Stephens, 1992).

This exclusive sampling from specialty psychiatric facilities creates a bias in the sample toward severely depressed patients. The severity of depression for these patients is likely to be greater than samples that were recruited from community sites or from primary care providers who were effectively managing the depression without psychiatric referral. In the case of Coyne et al. (1987), many participants were more severe and were considered treatment failures at the psychiatric clinic or inpatient facility.

Comparisons of demographics across studies demonstrates that samples were fairly similar. Most studies had samples that were mostly white, evenly divided between male and female, and were in their middle adult years. Exceptions to this are Coyne et

al.'s (1987) study of exclusively women, and Siegel et al.'s (2004) study of retired couples. While the term 'partner' was often used in studies, the samples most often included married couples only (and therefore heterosexual). One exception to this was Whisman, Uebelacker and Weinstock's (2004) study that included unmarried, cohabiting, heterosexual couples, but even in this case 91% of couples were married. The uniformity of recruiting married couples may be in part due to the need for researchers using quantitative methods to use instruments that have had their validity and reliability documented, and many of these instruments are for married couples (e.g. Locke and Wallace's marital adjustment test).

Other important characteristics of the samples include the attempt to clarify that one partner has depression, and though the other partner may have depressive symptoms, researchers sought to clarify that one person was more symptomatic and was diagnosed with either dysthymia or major depressive disorder. Finally, it is important to note that, among the studies that provided the data, the average length of time that couples had been together ranged from 10 years (Merikangas et al., 1985) to 16 years (Benazon, 2000; Whisman et al., 2004). The exceptions to this were Fincham et al.'s (1997) study of newlyweds and Siegel et al.'s (2004) study of retired couples. Only one study commented on whether sample couples had children or not (Spangenberg & Theron, 1999).

Study Purposes

To generally characterize this group of studies, it could be said that researchers have explored the variety of ways that a partner's depression affects his or her marriage and his or her spouse/partner with the goal of determining if marital therapy might be a productive therapeutic intervention for depressed individuals. Several studies were

specifically focused on the reciprocal or interactional relationship of the effects of depression on marital satisfaction, discord, or maladjustment, and vice-versa (Spangenberg & Theron, 1999; Merikangas et al., 1985; Coyne et al., 2002; Whisman et al., 2004; Fincham et al., 1997).

Note that the viewpoint of the studies is reflected in the order of the phrasing: depressed individuals and how their depression affects their partners and their marriages. Alternately, it could be said that a major focus of this group of studies is on marital relationships and how depression affects them. In both cases this is different from a focus on the nondepressed partner as one who is affected by the depression. One exception to this focus among these studies is a study of the impact of depressive illness on spouses of depressed patients by Dudek et al. (2001). This is an important distinction because the research for this doctoral dissertation aims to add the latter perspective: a focus on the nondepressed partner.

Methods, Designs, and Instruments

The vast majority of studies in the fields of psychology and psychiatry employ quantitative methods, and this group of studies was in keeping with this pattern. Of the fifteen studies reviewed here, thirteen used quantitative methods. One study was a review (Barbato & D'Avanzo, 2006). Among the quantitative studies, all used non-experimental descriptive or correlational designs. The two qualitative studies used phenomenological methods (Harris et al., 2006) and grounded theory (Sandberg et al., 2002).

A variety of instruments were used in these studies to measure depression, anxiety, marital satisfaction, coping, expressed affection, marital distress, psychological distress, marital adjustment, childhood adversity, burden, and other variables. The

variables that were studied can essentially be sorted into two groups: those factors that characterize one of the spouse's experiences, and those that characterize the marital/partner relationship. As mentioned previously, most of these studies had a dual focus on individuals and the marital relationships. The variety of instruments used allowed researchers to demonstrate many important findings, and these will be discussed next.

Findings

Though the purposes and foci of the studies in this review are varied, the findings fit into five major groups. They are as follows:

- How individuals are *affected by* their partners' depression.
- How nondepressed individuals *affect* their partners' depression.
- How couples' relationships are affected.
- What nondepressed partners need.
- Differences in how men and women manage effects of partners' depression.

The remainder of this section will provide a synthesis of the findings of this collection of studies organized under these five headings above.

How Individuals Are Affected By Their Partners' Depression

The most common finding among this group of articles was that individuals are indeed affected by their partners' depression. It seems to be inherent in the situation that nondepressed partners have excessively high levels of stress, and many experience depressive symptoms themselves (Coyne et al., 1987; Mitchell et al., 1983; Siegel et al., 2004). Spangenberg and Theron (1999) found that 54% of individuals with depressed partners had some symptoms of depression. Coyne et al. (1987) found that 40% of adults living with depressed partners had levels of psychological distress that made them

suitable for therapeutic intervention. However, it should be noted that depressed mood among nondepressed partners did not reflect substantial risk for major depression (Benazon & Coyne, 2000).

Along with depressive symptoms, nondepressed partners often experience anxiety and psychological distress (Spangenberg & Theron, 1999; Benazon, 2000). The degree of difficulty or burden experienced by individuals is directly related to the psychological distress that they experience (Benazon & Coyne, 2000) and it was found that their degree of reported distress was significantly greater if they participated in research while their partner was currently in a depressive episode (Coyne et al., 1987).

In their study of the role of personality characteristics and severity of depression in relation to family functioning, Miller et al. (2000) found that no demographic variables were significantly related to the effects of depression on partners and families. Rather the effects cut across all ages, educational levels and social backgrounds. Additionally, and perhaps surprisingly, the severity of depression was not found to be significantly related to the level of family functioning, but the nature of the depression and personality characteristics of the depressed partner were predictive of family functioning. This is important because it indicates that the ‘flavor’ of the depression (angry, withdrawn, tearful, irritable) can play a key role in the way nondepressed partners are affected.

How Nondepressed Individuals Affect Their Partners’ Depression

Just as individuals are affected by their partners’ depression, their ability to manage their own distress affects their partners’ depression. Spangenberg and Theron (1999) found that poor coping and high stress in nondepressed partners can cause poor emotional support to their depressed spouses, and this can aggravate the depression.

Miller et al.'s (2000) study of families with one depressed member supported this idea of a cyclic exchange of high stress, demonstrated by family members causing increased depressive symptoms in partners.

How Couples' Relationships Are Affected

Apart from the effects that partners experience as two individuals, the relationship that they share incurs damage that is reflected in their communication and behavior.

There is a well-established association between depression and marital distress (Whisman et al., 2004). Yet, the causative nature was different for men and women: for men depression led to marital discord; but for women marital discord led to depression (Fincham et al., 1997). These researchers proposed that this might be because men tend to withdraw from and denigrate their relationship when depressed, leading to marital dissatisfaction, while women often feel greater responsibility for resolving relationship difficulties and are therefore more vulnerable to marital stressors than men. Benazon (2000) points out that seeking a causative pathway can be problematic since depression is a complex interpersonal process.

Regardless of the direction of any causal nature between marriage and depression, there are many studies that have documented the effects of depression within a marriage or partner relationship. Couples with a depressed partner are likely to have decreased marital adjustment, decreased expressed affection (Coyne et al., 2002), and increased conflict (Spangenberg & Theron 1999; Benazon & Coyne, 2000; Siegel et al., 2004; Sandberg et al., 2002). Whisman et al. (2004) found that marital satisfaction was predicted by each partner's own level of anxiety and depression, but was also influenced

by his or her spouse's level of depression (but not their anxiety). This points out that the effects of depression on a relationship are greater than the effects of anxiety.

Merikangas et al., (1985), found that marriages with one depressed member scored significantly worse in all areas of functioning and couples reported being generally unhappy in their marriages. These couples viewed their marriages as worse than most marriages they knew, and their sexual relationships were significantly less satisfying to them than for control couples. Couples with one depressed member have more destructive and less constructive conflict resolution tactics (Siegel et al., 2004). These couples were also found to show less affection and had more complaints about their marriages (Coyne et al., 2002). Very few were found to have well-adjusted marriages (Spangenberg & Theron, 1999).

In their study measuring communication and intimacy, Basco et al. (1992) found that depressed couples had greater marital dissatisfaction, poorer communication and problem-solving ability, and were more likely to have an impaired capacity for establishing and maintaining intimacy. Poor problem-solving skills and impaired capacity for intimacy may account in part for accumulation of marital problems in depressed couples' relationships that are characterized by emotional deprivation and unresolved tension (Basco et al.). The ways that partners respond to the marital problems and stressors have further effects on their relationship. Spangenberg & Theron (1999) found that avoidant coping strategies were correlated with anxiety and depression.

What Nondepressed Partners Need

The literature demonstrates that nondepressed partners need to be involved in the psychological interventions that address their partners' depression (Harris et al., 2006).

Because of the interactional nature of depression and marital distress, marital therapy has often been suggested as a treatment for depression. Yet in their review of studies concerning this question, Barbato and D'Avanzo (2006) found that there is no evidence that marital therapy is more or less effective than individual psychotherapy or drug therapy for the treatment of depression. However, couples can expect improvement in the couple relationship through marital therapy, and this may be one of the most important findings available regarding nondepressed partners.

More broadly than what nondepressed partners need from therapy, health care providers need to be aware of the effect on patients when partners suffer from poor mental health (Siegel et al., 2004). Because of the psychological distress and formidable burden that many of them experience nondepressed partners are suitable targets for therapeutic interventions (Coyne et al., 1987). Therapeutic interventions should include encouragement of social support for the nondepressed partner (Sandberg et al., 2002).

Differences In How Men and Women Manage Effects of Partners' Depression

Just as men and women have different roles in their partnerships, they also have different patterns of managing the effects of their partners' depression. Benazon and Coyne (2000) found that gender is an important factor in that couples in which the depressed partner was male, both members of the couple had significantly more depressed mood than couples in which the wife was depressed. While women bear more of the burden for addressing relationship problems and report less satisfaction earlier, men often respond to their own depression by withdrawing, and their levels of relationship dissatisfaction are delayed (Fincham et al., 1997). Wives of depressed partners showed more depressive symptoms in response to their partners' depression than

men did, and they perceived the quality of their marital relationships as poorer than husbands with depressed wives did (Dudek et al., 2001).

Qualitative Studies

Two qualitative studies concerning partners and depression both offer valuable information that complements what is known from the quantitative studies reviewed here. In their phenomenological study of the experience of the support process in depression, Harris et al. (2006) interviewed nine couples with a depressed spouse. The purpose of the study was to see how partners attempt to offer support when their spouse is depressed, to see what partners do or say that is perceived as helpful or unhelpful, and to see how each member of the couple experiences the support process.

This study reported that nondepressed partners felt anger, frustration, and impatience at their situation, but that they tended to avoid expressing it for fear of the impact on their depressed partner. This led to feelings of being heavily burdened by a load of unexpressed feelings. Partners worked very hard to find ways of helping, but did so carefully for fear of doing harm. The couples' accounts were characterized by bewilderment and struggle (Harris et al., 2006).

This study offers descriptive insight into what it is like for nondepressed partners that is extremely informative to clinicians. Limitations of this study are that the focus is on the coping process, a particular aspect of the experience of living with a depressed partner, and that both members of the couples were interviewed together. This would be likely to have affected the candid nature of responses about effects of depression on the nondepressed partner (Harris et al., 2006).

A second qualitative study by Sandberg et al. (2002) also offers descriptive data that complements what is known from the quantitative work discussed in this review. This grounded theory study was based on interviews with ten couples with a depressed partner, and sixteen nondepressed couples. Couples in this study were an average of 62 years old and had been married for an average of 34 years. The purpose of the study was to determine which interactions are most and least helpful during depression, to compare the daily interaction of depressed and nondepressed couples, and to see how older couples are coping with depression in their marriages.

This study demonstrated that living with a depressed partner, especially for decades as many of these participants had, is an experience in which the two partners are inextricably linked while one is depressed. As one participant commented, “It’s hard to live with a depressed person and not catch it yourself” (Sandberg et al., 2002). Conflict and confrontation characterized these couple relationships more than nondepressed couples, in the form of criticism and outbursts. A pattern of antagonistic communication, ongoing criticism, and outbursts were common. Empathy was often lacking. These frustrated interactions exacerbated the depressive symptoms in the depressed partner, leaving them feeling isolated and misunderstood, while the nondepressed partners felt confusion and frustration at their failed attempts to help (Sandberg et al.).

This study is valuable because it has a specific sample of older adults, yet that is also a limitation to its broader transferability. Older couples that have remained together may be more likely to have adapted effectively to the presence of depression in their relationships, and that would be a noteworthy characteristic of the study for clinician-readers. The overarching value of both of these qualitative studies is that they offer

description and identification of concepts that begin to fill in the gaps between what has been learned from the quantitative studies reviewed here. By reading the quantitative findings about the effects of depression on marriages and on nondepressed partners, and then reading the discussion sections of the two qualitative studies, one has a greater sense of understanding the meaning and context of the quantitative findings.

Caregiver Burden

In times of serious illness, patients seek support and care. Some individuals depend solely on the care provided by nurses, doctors, and other formal caregivers, while others receive the care of informal caregivers such as family members and friends. As informal caregivers, these family members and friends make significant contributions to the wellbeing of their ill loved ones, and in so doing the caregivers can bear a considerable physical and emotional burden. Caregiver burden has been defined as the extent to which caregivers experience adverse effects on their health, social life and financial status because of their caregiving duties (Zarit, Todd & Zarit, 1986). It is important to nursing because nurses play a pivotal role in helping patients recognize their unique role as caregivers and by counseling, educating and supporting them in their role (Edwards & Ruettiger, 2002).

The historical development of the term ‘caregiver burden’ is helpful in understanding the current body of literature. To provide this historical context, and extensive search was done of the Pubmed and CINAHL databases (see table 1). The term ‘caregiver burden’ first appears as a keyword for an article in English in the Pubmed database in 1984 (Panella, Lilliston, Brush & McDowell, 1984), and first appears as a

keyword in a nursing journal in 1989 (Klein, 1989). Since that time the bulk of the research done on caregiver burden has appeared in nursing journals (see table 1).

Table 1
Searches of Pubmed and CINAHL databases (12/1/07)

<u>Search Terms</u>	<u>PubMed</u>	<u>CINAHL</u>
<u>“Caregiver Burden”</u>	<u>727</u>	<u>3264</u>
<u>“Caregiver Burden”</u> <u>Limited to Nursing Journals</u>	<u>134</u>	<u>1528</u>
<u>“Caregiver Burden”</u> <u>Spouse</u>	<u>68</u>	<u>157</u>
<u>“Caregiver Burden”</u> <u>Spouse</u> <u>Limited to Nursing Journals</u>	<u>13</u>	<u>62</u>
<u>“Caregiver Burden”</u> <u>Spouse</u> <u>Limited To Nursing Journals</u> <u>Refined to “aged” Keyword</u>		<u>44</u>
<u>“Caregiver Burden”</u> <u>Partner</u>	<u>12</u>	<u>38</u>
<u>“Caregiver Burden”</u> <u>Partner</u> <u>Limited to Nursing Journals</u>	<u>2</u>	<u>18</u>

The growing use of the term ‘caregiver burden’ over the past twenty years can also be seen in this database search. For example, 1984 is the first time the term was used as a keyword, and there were only three other articles using the term as a keyword that year. The use of the term grew slowly over the following sixteen years until there was a relative explosion of the use of the word by researchers in multiple disciplines. 527 of the

total 727 articles in Pubmed using ‘caregiver burden’ as a keyword were published in 2000 or after.

This change reflects growing recognition of an important concept, but it also reflects increasing societal dependence on informal caregivers at a time of transition in U.S. healthcare. In the 1990’s, U.S. insurance companies transitioned en masse to an HMO-dominated system in which cost cutting occurred and lengths of hospital stays shortened, thus increasing the need for informal caregivers. By 2000 researchers were beginning to study the effect of this increased demand in much higher numbers than they had previously.

Today in the United States, informal caregivers play an essential role in our health care system. As of 2004, 34 million adults (or 16% of the population) were providing care to adults 50 years and older (National Alliance for Caregiving and AARP, 2004). The contribution made by caregivers to our national health care system is valued at \$306 billion annually (U.S. Department of Health and Human Services, 2007). These services significantly reduce the cost to Medicare, Medicaid and private payers (U.S. Department of Health and Human Services, 2007). Informal caregivers will likely continue in their role as the largest source of long term care and are estimated to reach 37 million caregivers by 2050 (an increase of 85% since 2000) (U.S. Department of Health and Human Services, 2003).

‘Caregiver burden’ was first used regarding family members caring for elders, usually with Alzheimer’s Disease (A.D.) or dementia. In her literature review of social support and caregiver burden from 1980 to 1995, Vrabec (1997) found two sources that defined caregiver burden as “the strain or load borne by people caring for an elderly

family member” (p. 384). In 2002 Edwards and Ruettiger reported that most research in caregiving has been directed toward caregivers of people with dementia. Even today the database search using ‘caregiver burden’ yielded more articles about A.D. and dementia than any other single illness (see table 2), and approximately two-thirds of nursing articles on caregiver burden are in the context of studying elders (see table 1).

Table 2

Review of 62 articles from CINAHL search for “Caregiver Burden” and “Spouse” (12/1/07)

<u>Diagnostic Context</u>	<u>Number Of Articles</u>
Alzheimer's Disease	10
Dementia	6
Cancers	6
Stroke	4
Lung disease/COPD	3
Terminally ill	3
CABG	2
Elder care	3
Parkinson's Disease	2
Heart failure	2
General c.g.b.	4
Dialysis Schizophrenia Apoplexy Chronic illness	1 each
Phenomenology and c.g.b.	2
Social support and c.g.b. Hospice and caregivers Support to caregivers QOL instruments Korean caregivers General experiences of older caregivers	1 each

In most studies, ‘caregiver’ was defined as a family member or friend who was providing informal care, and partners and spouses were not specifically studied as a separate population (i.e. out of 3,264 articles on caregiver burden in CINAHL only 157 were about spouses and only 38 were about partners). This reflects the fact that the most common relationship of caregivers to care recipients is an adult child assisting an elderly parent; this accounts for 38% of informal caregiving, whereas only 11% of informal caregiving is provided by spouses, most often to their elderly wives or husbands (U.S. Department of Health and Human Services, 1998).

Many studies had ‘spouse’/ ‘partner’ as a keyword but spouses and partners were only part of a study that also included friends and other family members (Chessick et al., 2007; Pirraglia et al., 2004; Grunfeld et al., 2004) and were therefore excluded from the review. There is merit in studying partners/spouses as a separate entity because their relationship with the care recipient is unique and because they usually live with the care recipient. Figved, Myhr, Larsen & Aarmland (2007) found that, of caregivers, spouses had higher levels of distress and lower levels of quality of life as compared to adult children, parents and friends.

Purpose

The purpose of this review of caregiver burden is to present a synthesis of literature pertaining to the experience of caregiver burden among individuals who provide informal care to their partners. A goal of this synthesis is to explore the experience of caregiver burden in a variety of different illnesses and to discuss the relevancy of the construct ‘caregiver burden’ to the study of individuals with depressed partners.

It should be noted that in this paper ‘patient’ refers to the individual suffering from a given chronic illness, while ‘partner’ refers to the non-ill caregiver.

Method

Sample and Procedure

The process of selecting the articles for this literature review consisted of two phases. The first phase began with searches of the Pubmed and CINAHL databases using the search words ‘caregiver burden,’ ‘partner,’ and ‘spouse.’ A purposive sampling method was then used to select studies in which the samples reflected a variety of illnesses. Ten quantitative articles were located, all of which were closely related to the following research questions:

- What is the experience of partners who are caregivers?
- Do partners’ caregiving experiences vary based on the illness?
- What are the primary determinants of the degree of caregiver burden?

The process of selecting articles began with a search of the Pubmed and CINAHL databases using the term ‘caregiver burden,’ which yielded over three thousand articles (see table 1). Many of these were about formal caregivers or family caregivers without any differentiation between caregivers who were family members, partners, and friends. To specify the relationship type, adding the terms ‘spouse,’ and ‘partner’ brought up a much narrower selection of articles. Using just ‘caregiver burden’ and ‘partner’ yielded 12 articles, while ‘caregiver burden’ and ‘spouse’ yielded 157 articles, many of which were relevant. Since Alzheimer’s and dementia are the most frequent topics of study of caregiver burden, one sample of each was selected. In order to insure a diverse

sample of illnesses as context for caregiver burden, purposive sampling was then used to select articles on a variety of other illnesses.

To narrow the focus of this review, it was determined that only articles published in the past ten years would be included. A further goal of the inclusion criteria would be to include as much variety among illnesses as possible. Therefore, when several articles on partners of patients with rheumatoid arthritis or spinal cord injury were found, the most recent or the most relevant article was selected to avoid redundancy and to maximize variety among the sample of articles. Two articles that studied Alzheimer's disease were included because one was authored by nurses (Edwards & Ruettiger, 2002) and one was authored by non-nurses (Drentea, Clay, Roth & Mittelman 2006). Seminal articles in nursing including Wright, Hickey, Buckwalter, Hendrix and Kelechi (1999), Lindgren (1993), Schott-Baer (1993), and DesRosier (1992) were all considered for inclusion because of their impact (i.e. each of them is cited 20-33 times in the CINAHL database), but among them only Wright et al. was focused on a specific disease and was therefore included.

The final sample for this literature review consisted of ten research articles that are focused on partners and caregiver burden. The illnesses that patients were affected by included: stroke, cancer, rheumatoid arthritis, fibromyalgia and osteoarthritis, coronary artery bypass, spinal cord injury, and Alzheimer's disease. The sample included nine descriptive research studies and one intervention study. With such a diverse range of illnesses, the author's hope was to sort out the broad use of the term caregiver burden and to then be able to make statements about its applicability to other illnesses to which it has not yet been applied, specifically depression.

Analysis

Theory

Nijboer, Triemstra, Tempelaar, Sanderman, and van den Bos (1999) used a conceptual model in their study of the caregiving experiences and mental health of partners of cancer patients. An illustration of the model was included in the study, which served to clarify the place of this particular study in the larger framework. Edwards and Ruettiger (2002) also described and illustrated a theoretical model for perceived burden of caregivers of Parkinson's disease patients. Apart from the Nijboer, et al. and the Edwards and Ruettiger articles, neither theory nor theoretical framework was explicitly discussed in any of the other articles in this review. However, in the absence of discussion of theoretical framework, the purpose for each article was made clear and each study's literature review created a framework for the study's design.

A further notable point regarding the absence of conceptual or theoretical model discussions is that one of the authors, G. van den Bos, is among the authors for the Nijboer et al. (1999) article, the Scholte op Reimer, de Haan, Rijnders, Limburg, and van den Bos (1998) article, as well as the Jacobi et al. (2003) article. These studies examine caregiving in the context of three different diseases: cancer, stroke, and rheumatoid arthritis, respectively. Yet, as mentioned, the Nijboer et al. article is the only one in this review to explicate a conceptual model. It is unfortunate that the conceptual model was not carried over to the other three articles in which van den Bos was involved, or that another conceptual framework was not discussed that could link the three works. Such linkage between caregiving in different illnesses is an excellent opportunity for a

meaningful conceptual or theoretical framework and could at the very least explain why one author has been studying these different applications of caregiving.

The absence of discussion of theory or theoretical framework may be related to the researcher's discipline. As best as could be determined from notes about the authors, the researchers' disciplines ranged from psychiatry, epidemiology, public health, and medicine (Figved et al., 2007; Post, Bloeman & de Witte, 2005; Jacobi et al., 2003; Nijboer et al., 1999) to psychology (Reich, Omsted & van Puymbroeck, 2006), sociology (Drentea et al., 2006), and nursing. Four articles were authored by nurses or groups involved with nursing (Halm, Treat-Jacobson, Lindquist & Savik, 2007; Edwards & Ruettiger, 2002; Wright, et al., 1999, Scholte op Reimer et al., 1998).

Methods

All ten of the studies in this review used quantitative methods to assess the role or importance of caregiving. Nine of the studies were descriptive and one was an intervention study (Drentea et al., 2006). The nine descriptive studies used face-to-face interviews combined with phone interviews (Wright et al., 1999), or questionnaires either in combination with an in-person interview (Figved, et al, 2007; Drentea et al., 2006; Nijboer, et al, 1999; Scholte op Reimer, et al, 1998) or by mail (Halm, et al, 2007; Reich, et al, 2006; Post, et al, 2005; Jacobi, et al, 2003; Edwards & Ruettiger, 2002).

One of the studies used a cross-sectional design (Halm et al., 2007), one used an intervention design (Drentea et al., 2006), and three used longitudinal designs (Reich et al., 2006; Nijboer et al., 1999; Wright et al., 1999). While cross-sectional design may be an appropriate fit for some studies, it is questionable whether it is effective to measure caregiving using cross-sectional design and to make meaningful comparisons between

groups. For example, Halm et al.'s study measured and compared caregiver outcome and burden among three groups of spouses: those at three months post surgery, six months post surgery, and twelve months post surgery. Yet the three groups may have had significantly different trajectories over the course of their twelve years post surgery. Halm et al. recognized the cross sectional design with three groups as a limitation.

When attempting to make comparisons of caregiver burden over time, the longitudinal design used by Nijboer et al. (1999) appears to be much more meaningful. Nijboer et al. examined the determinants of caregiver outcomes by questioning caregiver dyad participants at three months and again at six months post hospital discharge. By making comparisons among the same groups over time the results of this study would be more likely to reflect true changes in caregiver experiences rather than the possible differences among groups that Halm et al. (2007) found.

Instruments

A variety of instruments were used to measure caregiver burden, including the Zarit Perceived Burden Inventory (Edwards & Ruettiger, 2002), the Caregiver Burden Scale (Halm et al, 2007; Reich et al., 2006), the Caregiver Distress Scale (Figved, et al., 2007), the Bakas Caregiver Outcomes Scale (Halm et al.), and the Caregiver Reaction Assessment (Jacobi et al., 2003; Nijboer et al., 1999). However, an even broader array of instruments was used to measure caregiver burden indirectly, such as using a Loneliness Competency Questionnaire (Scholte op Reimer, 1998), the Locke Wallace marital adjustment scale and the Mishel Uncertainty in Illness Scale (Reich et al.), among others.

Reliability, validity and internal consistency were discussed for all the tools to measure caregiver burden except that Post et al. (2005) provided information on one of

the self-developed questionnaires used, but not the other, and Reich et al. (2006) discussed reliability and validity of many of the tools used, but not the Deimling Caregiver Burden Scale.

Each group of authors chose their instruments based on the specific aspects of caregiver burden on which they were focused, as well as certain variables that related to a given illness. For example, Reich et al. (2006) saw functional disability as an important aspect of fibromyalgia and rheumatoid arthritis, so the WOMAC instrument was used to assess functional disability. Disease-specific variables were measured in the most appropriate way for that study, such as in Edwards and Ruettinger's (2002) study of the influence of caregiver burden on patients' management of Parkinson's disease, in which the authors used the Management of Parkinson's Disease Instrument.

However, there are other variables measured in these studies that illustrate the grey line between caregiver burden and quality of life, marital satisfaction, uncertainty, and social support. These concepts are distinct from caregiver burden but they are closely related. Therefore, during the first decade of concentrated study of a concept it is logical that multiple variables would be measured so that the grey area around the term 'caregiver burden' can be more clearly defined. Interestingly, the seminal article by Wright et al., (1999), which has been cited 27 times in other nursing journal articles on caregiving, does not measure caregiver burden directly. Instead, the three factors of emotional and physical health of spouse caregivers of patients with Alzheimer's and stroke were measured using the Zung depression scale, an Older American Resources questionnaire, and three other instruments which together create a picture of the spouses' caregiver burden.

A final critique of the methods used in the various studies in this review is the variety of questionnaires and the ways that they were administered. It was helpful when authors included sample questions from their questionnaires in their articles, as was done by Figved et al. (2007) and Scholte op Reimer et al. (1998). Providing these sample questions gives readers a greater understanding of what it felt like to be a participant in the study and how the researchers arrived at their findings. It is also important to consider the length of the questionnaires and how they were delivered to participants. For example, Halm et al. (2007) recognized that giving participants a 24-page booklet of questions to answer by mail might have biased the findings as only relatively unburdened caregivers could take the time to sit and fill out such an extensive survey.

Participants

For the purpose of summarizing current knowledge related to caregiver burden among partners, the most important difference among the studies in this review was whether they studied partners separately from other caregivers or together with other caregivers. Several studies' samples included both the partners and the ill loved ones for whom they were caring (Reich et al., 2006; Post et al., 2005; Jacobi et al., 2003; Nijboer et al., 1999). This allowed the authors to make comparisons among the patients' and partners' experiences and perceptions.

A notable detail regarding the inclusion criteria is the various researchers' choice of the word 'partner' versus 'spouse.' Several studies' samples contained only spouses (Halm et al., 2007; Drentea et al., 2006; Wright et al., 1999), while Scholte op Reimer et al. (1998) included only partners (Reich et al., 2006; Post et al. 2005; Jacobi et al., 2003; Edwards & Ruettiger, 2002; Nijboer et al., 1999), yet none of the studies defined the

terms. Figved et al. (2007) mixed use of the words, ‘married,’ ‘partner,’ and ‘spouse,’ making it a bit unclear whether participants had to be married to be included in the study. A possible explanation for why Halm et al. used ‘spouse’ was that the Marital Satisfaction Survey was used in the study. This may be a case of the instrument dictating the sample, which may indicate a need for instruments to be updated to suit current societal trends.

In the end, the reason that ‘partner’ versus ‘spouse’ matters is that limiting inclusion criteria to only spouses effectively excludes homosexual couples and other committed and cohabiting couples whose experiences may be equally informative and relevant. After a concept analysis of the term ‘partner,’ this author has concluded that, unless there is a specific reason to focus on ‘spouses,’ continued use of ‘spouse’ for research inclusion criteria only serves to limit the findings in today’s social climate. The appropriateness of using ‘partner’ for health care research is best illustrated by Blue Cross and Blue Shield of Massachusetts’s (2007) modification of their rules for whom subscribers can designate as their domestic partners: “A ‘domestic partner’ is a person of either sex with whom the *subscriber* [sic] has entered into an exclusive relationship.”

The use of ‘spouse’ versus ‘partner’ may also reflect age differences. For example, in their study of caregivers of spouses with Alzheimer’s disease, Drentea et al. (2007) may have believed that ‘spouse’ and ‘partner’ were virtually synonymous because of assumptions about more traditional marriage patterns among elders. The use of ‘spouse’ versus ‘partner’ may also reflect cultural differences. In this review’s sample of ten studies, five were done in the United States and five were done in Europe. All the studies

done in Europe used the term ‘partner.’ This may reflect a more liberal interpretation of ‘domestic partner’ in those cultures.

The culture of origin for these studies may also be relevant when assessing the various studies’ discussions of their samples’ race and ethnicity. Four out of five of the studies conducted in the United States (Halm et al., 2007; Reich et al., 2006; Edwards & Ruettiger, 2002; Wright, et al., 1999) provided detailed information about their samples, including a racial and ethnic breakdown of the participants. Among the four studies in which racial and ethnic data was provided, the majority of participants were white, with percentages of whites ranging from 86% (Wright et al.) to 96-100% white (Reich et al.). Of the five European studies, four were conducted in the Netherlands (Post et al., 2005; Jacobi et al., 2003; Nijboer et al., 1999; Scholte op Reimer et al., 1998). The four Dutch studies did not provide a racial or ethnic breakdown of their samples.

All studies included a breakdown of their sample by gender, and in half of the cases the sample was approximately half men and half women. In cases in which the ratio was not approximately half and half the ratio of female caregivers was larger (Figved et al., 2007; Halm et al., 2007; Post et al., 2005; Jacobi et al., 2003; Nijboer et al., 1999; Scholte op Reimer et al., 1998). The gender differences are notable because, as Post et al. (2005) found, women suffered higher degrees of caregiver burden, and as half of the sample demonstrates, women are either more likely to be providing care or are more likely to become involved in research. This raises an interesting question for further research.

Results

Given the variety and complexity of the variables involved in caregiver burden, as well as the varied approaches from which researchers approached the topic, the findings of these articles were numerous and varied. However, the bulk of the findings fit into the following four themes:

- What elements make up caregiver burden
- Determining caregiver factors that influence caregiver burden
- Determining patient factors that influence caregiver burden
- What caregivers need, suggestions

The remainder of this section will be a synthesis of the findings of this collection of articles organized under these headings.

What Elements Make Up Caregiver Burden?

Nearly all the studies made contributions to an understanding of what the caregiver experience is like for partners. As we know from previous work, caregiver burden has been viewed as the negative effects of caregiving on caregivers' health, social life and financial status (Zarit et al., 1986). However, the major themes that emerge from this review include psychological, social, occupational, and, to a lesser degree, financial effects.

The most significant effects of caregiving, and therefore the largest topic of discussion in these articles, were psychological effects. Expectation of what caregiving would entail may have had some effect of psychological burden. For example, in their 2007 study of spouses of patients who recently underwent coronary artery bypass surgery, Halm et al.'s hypothesis (and therefore possibly also the spouses' expectations) was that

over the course of the year post-surgery the caregiver burden would gradually decrease. However, the researchers found that there is, in fact, a steady caregiving demand over the first year post surgery.

In a study of partners of stroke survivors (Scholte op Reimer et al., 1998), burden was expressed as feelings of heavy responsibility, constant worries and uncertainty about patients' care needs. On the positive side, partners in two studies gained a high level of self-esteem from giving care (Jacobi et al., 2003). In their study of partners and patients with cancer, Nijboer et al. (1999) found that partners who had low levels of education experienced the greatest increases in levels of self-esteem. Halm et al. (2007) found that men had more positive caregiving outcomes than women.

Social isolation played an important role for spouses of Alzheimer's patients (Drentea et al., 2006) and partners of stroke survivors (Scholte op Reimer et al., 1998). When an intervention in the form of a social support network was mobilized to support these partners, in the form of more visits, more emotional support, and more social network members it was found that positive longitudinal changes in social support satisfaction occurred.

The negative effect of caregiving on caregivers' occupations was seen as an increased inability to work regular hours and increased lost work hours, particularly in the terminal period. Therefore, it is remarkable that in a study of partners of stroke survivors (Scholte op Reimer et al., 1998), there was no relationship between patients' socio-demographic characteristics and their partners' experience of caregiver burden. The financial burden of caregiving was not explored by all the studies, but it emerged as an important finding in some studies. Jacobi et al. (2003) found that financial problems

resulted in a larger burden for caregivers when patients had limited mobility and problems with self-care activities.

Determining Patient Factors That Influence Caregiver Burden

Across studies it was generally found that the worse off patients were, the worse burden their partner caregiver felt. Patient's levels of pain and functional mobility affected caregiver burden levels (Reich et al., 2006). When comparing Osteoarthritis and Fibromyalgia caregivers, Reich et al. found that disability was positively correlated with partner supportiveness for osteoarthritis patients, but there was not a significant correlation for the fibromyalgia caregivers. This implies that the level of disability plays some role in how supportive caregivers are (Reich et al.). When patients had problems with self-care activities and activities of daily living, partners reported the largest levels of caregiver burden (Jacobi et al., 2003). High levels of patient dependency on partners contributed to negative caregiving experiences for partners (Nijboer et al., 1999).

The greater the disability of the patient, the greater the burden of caregiving partners experienced (Post et al., 2005), and this was particularly true when patient disabilities included cognitive impairment and psychological symptoms (Figved et al., 2007). In fact, mental symptoms in the patient were the most powerful and consistent determinants of both quality of life and caregiver distress (Figved et al.)

Determining Caregiver Factors That Influence Caregiver Burden

In some cases caregiver burden was less determined by patient factors than by partner factors. For example, Scholte op Reimer et al. (1998) found that partners' emotional distress, loneliness, disability, amount of informal care they provided, and unmet needs for psychosocial care and help with patients' activities of daily living were

the primary factors that revealed higher caregiver burden. In the end, burden was more related to emotional distress in the partner than in the workload they had as caregivers. (Scholte op Reimer et al.). Post et al. (2005) found that burden was highest for caregivers of spinal cord injured patients who provided much ADL support, who were older, female, caring for patients who had more severe disabilities, more recent injuries, and more psychosocial problems.

Often times partners providing care have medical issues and physical limitations of their own, so that both partners' and patients' health predicts burden for partners (Jacobi et al., 2003). Negative levels of caregiver burden were associated with partners' problems with mobility, pain and discomfort, and problems such as disrupted schedule, lack of family support, financial problems, and loss of physical strength (Jacobi et al.). Negative caregiving experiences were also associated with the couple having low income, living with only the patient, high involvement in caregiving tasks, and a distressed relationship (Nijboer et al., 1999).

Gender and age may play a role in the burden felt by caregivers. In a study of partners of spinal cord injured patients, Post et al. (2005) found that higher burden was experienced by individuals who were women, were older, whose partners had more severe disabilities, had recent spinal cord injury, and had more psychosocial problems. Conversely, in a study of partners of patients following coronary artery bypass surgery (Halm et al., 2007), findings emerged that men experienced a greater total caregiver burden.

Wright et al. (1999) found difficulty making any conclusion about the trajectory of depression for spouse caregivers of stroke patients. In their own study there was no

relationship between patient impairment characteristics and caregivers' depression one year after stroke, and this was supported in a study by Anderson, Linto and Stewart-Wynne (1995). However, Wright et al. point out that this was contradicted by findings of Carwath and Johnson (1987) who found that there were significant increases in depression when patients were more severely impaired by stroke. Wright et al.'s suggestion was then to make distinctions between caregivers of patients who made steady improvements, caregivers who adapted to patients' residual impairments, and caregivers who suffered negative emotional and physical health outcomes caring for patients with continuous decline.

Race was an interesting caregiver trait that emerged in Wright et al.'s (1999) study. African American caregivers had decreasing rates of depression over time while white caregivers continued to rise over the year of study. The authors were reluctant to pose firm conclusions because the sample of African Americans was small (4 couples), but supporting literature is cited and the idea caused the authors to wonder about a buffering effect in African American culture that allows acceptance and adjustment to spousal disability.

One of the most interesting findings in three of the studies was that relatively little caregiver burden was reported by the populations under study. Edwards and Ruettiger (2002) found that caregivers of patients with Parkinson's reported minimal burdens, measuring only an average of 23.6 out of a possible 88. Halm et al. (2007) found that burden levels were low to moderate for caregivers of patients who had undergone coronary artery bypass graft surgery.

How The Relationship Between Partners and Patients Was Affected

For fibromyalgia patients and their partners when uncertainty about the course of the illness was high, low levels of partner supportiveness to patients was related to increased report of caregiver burden, suggesting that when partners and patients felt uncertain about their future the partners felt a higher sense of burden and were less able to be supportive to their loved ones (Reich et al., 2006). For osteoarthritis patients higher support was related to higher relationship satisfaction when uncertainty was low (Reich et al.). The net result of these findings is that uncertainty in the course of the illness matters to patients, partners, and their relationship.

What Caregivers Need

Professional caregivers must include nonprofessional caregivers in care for their patients and special attention and support must be provided to the partners not just because they are providing much needed care, but also because they have needs themselves (Nijboer et al., 1999). Strategies are needed to help reduce the psychological, occupational and financial burden that caregivers experience. Strategies are also needed to address the disruption that caregiving leads to, and to help partners focus on the positive aspects of caregiving (Jacobi et al., 2003).

Respite for partners who are home providing care and are isolated is particularly needed, as is future attention to alleviating partner stress surrounding nursing home placement (Drentea et al., 2006). Early assessment of caregiver needs and interventions to support them will help caregivers improve their quality of life and increase their stamina to provide care to their loved ones (Wright et al., 1999). In short, spouses need to

be prepared for the course of caregiving that is appropriate to the illness involved (Halm et al., 2007).

Discussion

The preceding body of literature can help professional caregivers anticipate the needs of partner caregivers and the risk factors for partners as they become caregivers. For example, partners who have depression or anxiety, physical disabilities, relationship difficulties that precede the caregiving situation should be a red flag to professional caregivers that those partners need intervention and planning.

While each of these studies provide meaningful and valuable data, the majority of them have been done using quantitative methods, and the findings often leave the reader wishing to hear the patients themselves define ‘caregiver burden.’ Several of the studies were investigations and descriptions of what the caregivers’ burdens consisted of (Post et al., 2005; Jacobi et al., 2003; Scholte op Reimer et al., 1998), but all of them did so by offering researcher-conceived options of what caregiver burden meant to the researchers. This left no room for participants to point out experiences that had not been asked about.

For example, Jacobi et al.’s (2003) study of partners of rheumatoid arthritis patients assesses burden using several instruments. Having just read the study by Reich et al. (2006) that discusses the role of uncertainty in caregiver burden, the reader can’t help but wonder if uncertainty plays a role in caregiver burden for rheumatoid arthritis patients as well. Uncertainty might have emerged in Jacobi et al.’s study – and for that matter any of the studies reviewed here – if qualitative methods were used so that caregivers could describe their experience themselves.

Similarly, Nijboer et al.'s (1999) study of partners of cancer patients attempted to assess caregiver mental health using an instrument to measure depression and an instrument to measure quality of life, both variables that comprise the outcomes of caregiving on caregivers' mental health in their conceptual model. However, these two measurements alone would provide an incomplete picture of mental health. Including measurements for loneliness as Scholte op Reimer et al. (1998) did, or measurements for uncertainty as Reich et al. (2006) did might provide a more multifaceted picture of mental health.

Conclusion

This review revealed important trends in research on caregiver burden. Nursing has contributed the largest number of studies regarding the concept, as well as the greatest depth of study on caregiver burden among elders. In some cases nursing researchers have moved the science forward, moving beyond descriptive studies to intervention studies, as can be seen in Yin, Zhou, and Bashford's 2002 meta-analysis of interventions for family members caring for frail elderly. The focus in nursing on the concept of caregiver burden rather than on the illness that the care recipient is affected by is exemplified by Chang, Brecht, and Carter's (2001) study on social support and caregiver outcomes. In this study the illness appears to be nearly inconsequential to the examination of caregiver burden since it is not until page seven of the article that the reader learns that the sample is Alzheimer's patients. While nursing has been providing depth by focusing on elders, other disciplines including sociology, psychology, public health, and medicine have provided breadth to the study of caregiver burden by studying the concept in the context of a wider variety of illnesses.

Future research should focus on partners, not just spouses, more nonwhite racial and ethnic groups, more men, and should examine caregiver burden in the context of other illnesses where it has not yet been tested. The group of studies reviewed here has begun to capture the common qualities of the caregiver experience across illnesses. Once that has been done more broadly, researchers can begin to sort illnesses into groups of common caregiver experiences. This author anticipates that illnesses with high degrees of uncertainty will have common caregiver burden experiences, while illnesses with terminal prognoses will have a different caregiver burden experience, and illnesses with a high involvement in activities of daily living and high physical caregiver burden will have yet again a different experience.

Progress toward parsing out the different types of caregiver burden lies in experimentation with the concept in new areas—some of which may seem an unlikely fit for caregiver burden. For example, research has demonstrated that partners of depressed persons have increased risk of depression, anxiety, and psychological distress (Benazon, 2000; Spangenberg & Theron, 1999). This can be compared to Grunfeld et al.'s (2004) and Pirraglia et al.'s (2004) findings that caregivers of breast cancer patients and HIV patients (respectively) are at increased risk of depression and anxiety. In the end the support that caregivers need has to be gauged based on the type and phase of the illness trajectory (Wright et al., 1999).

Research has also demonstrated that poor coping and high stress in partners can cause poor emotional support to depressed patients, and this can aggravate the depression (Spangenberg & Theron, 1999). This cyclic exchange of burden between partners and patients can be likened to Reich et al.'s (2006) findings that when partners and patients

felt uncertain about their future the partners felt a higher sense of burden and were less able to be supportive to their loved ones.

Uncertainty is an additional common thread for caregivers of depression and caregivers of some other illnesses. For example, Reich et al.'s (2006) findings that uncertainty in the course of the illness matters to patients, partners, and their relationship may be similar to what occurs for partners of depressed persons. However, uncertainty has not yet been a focus of research on partners caring for depressed persons. These are three ways (increased rates of depression and anxiety among partners/caregivers, cyclic exchange of burden, and uncertainty) that caregiver burden for depression is similar to caregiver burden for other illnesses. However, many illnesses require partners to do considerable physical care and assistance with activities of daily living, and this is unlike depression.

The literature review of caregiver burden helps clarify the experience of caregivers, but even more it shows how broad and varied caregivers' experiences can be based on the illness with which their partners are affected. Comparison of caregiver burden with the experience of partners of depressed persons raises basic questions of what it means to provide care for a partner. Is living with and loving a partner during their depression really 'caregiving'?

A person with a depressed partner is not needed for help with activities of daily living and would perhaps be less likely to experience the financial and occupational effects of caregiving discussed here, but the psychological and social effects of caregiving discussed here may be completely applicable to persons with depressed

partners. Indeed, every suggestion made for what caregivers need in this paper would fit well with persons with depressed partners.

The questions that this literature review raises warrant future exploration to determine the connection between caregiver burden and the experience of individuals who have depressed partners as well as the experience of other illnesses that have not yet been explored through the lens of caregiver burden.

CHAPTER 3

METHOD

Introduction

The purpose of this study was to explore the experience of living with a partner who suffers from depression. An in-depth, phenomenologically-based interviewing method was used to ask open-ended questions so that the experience of living with a depressed partner was characterized by the participants (Seidman, 2006). Phenomenology is the study of lived experience as opposed to reality that is separate from an individual (van Manen, 1997). Phenomenologically-based inquiry asks ‘what is this experience like?’ and seeks to reveal meaning of experiences of everyday existence (Laverty, 2003). This interview method offers the researcher the ability to explore a participant’s experience from the participant’s point of view as much as possible. By asking open-ended questions the participant is invited to frame or explain the experience in his or her own way, choosing to emphasize or discuss what aspects of the experience matter to him or her most. The goal is to capture the experience and meaning of the participants’ every day world (Kvale, 2007).

Method

In-depth qualitative interviewing was chosen as the method for this study in an attempt to fill in the gap of what was previously known about individuals with depressed partners. There is an abundance of quantitative research on living with depressed partners/spouses that has asked pointed questions or used symptom checklists to capture participants’ specific levels of coping, anxiety, depression, marital distress, or marital

maladjustment. Such questions focused on individual variables, symptoms or concepts are informative, but without a broader understanding of the experience of living with a depressed partner, findings are limited in their clinical applicability.

As a reader of research in this area, it is striking that no previous studies had asked participants what the experience of living with a depressed partner is like *from their points of view*. Additionally, as a nurse practitioner providing care to individuals with depressed partners, it is clear that much is missing from the available research. The experience of living day-to-day with a depressed partner is not captured by discussions of isolated variables. Only a research method that allows individuals who live in this situation to describe it themselves can fill in the gaps so that a complete picture of the experience could be developed.

This detailed description of the experience was achieved by a series of two 90-minute interviews with each participant. The first interview began by establishing context for the experience under study by asking ‘Tell me about your life before the depression.’ The second question was ‘What is it like to live with a depressed partner?’ The second interview continued to explore the experience of living with a depressed partner and the meaning of this experience. Gentle probing questions were asked along the way to seek clarity or further depth, encouraging participants to describe in detail what they experience and how they feel. The goal of this interview method is to capture the experiences and lived meaning of participants’ everyday worlds (Kvale, 2007).

As a nurse researcher, and apparently the first nurse researcher to venture into a study of partners and depression, it was helpful to begin research in this area by asking open-ended questions. Because nurses tend to view humans holistically, with minds,

bodies, and spirits affected by health and illness, they bring a unique perspective to this area of study. By inviting participants to describe their experience in its entirety, the full breadth of what it means to live with a depressed partner was explored in this research.

Sample

The sample for this study was composed of community-dwelling individuals who currently live with depressed partners. Ten individuals responded to recruiting posters placed in community buildings throughout the Pioneer Valley in Massachusetts and the Upper Valley in New Hampshire and Vermont. Two volunteers were excluded because they did not fit inclusion criteria. Eight were enrolled in the study, seven of these were female. Ages ranged from 34 to 61. Participants had been with their partners for an average of 14 years. All of them were currently living with their partners. Two participants did not have children, four were raising young children, and one had an adult child. Levels of education for participants ranged, with one who completed high school, two who attended or completed college, and four who have additional or advanced degrees.

All depressed partners had been diagnosed with depression by a medical professional; four were diagnosed in the past 4 years and three were diagnosed more than 20 years ago. All the depressed partners had unipolar depression except one who had bipolar, with mania that was very well controlled for twenty years. All participants reported that it had been less than one year since their partners' last episode of depression and most had difficulty specifying how many episodes of depression there had been, though several participants described their partners' depression as "constant," "never-ending," or "chronic" with periods of "big bouts" or "exacerbations." When asked about

their partners' current level of depression on a scale of 0-10 (with 0 being no symptoms and 10 being the worst possible depression), three participants responded with the 2-3 range, two participants responded with the 7-8-9 range, and two reported 10.

Inclusion Criteria

To be included in the study, participants had to:

- be in middle adulthood (ages 20-65);
- be in a long-term (at least three years), cohabiting relationship with a partner who has been diagnosed with unipolar depression at least one year previous to enrollment in the study;
- have been present in their relationships while their partners suffered from at least one year of chronic or recurrent episodes of depression for which their partners sought medical or psychological treatment for diagnosed depression.

Participants' self-reports of their partners' diagnoses of depression was adequate (i.e., official records of the diagnoses of partners' depression were not sought). Lack of emphasis on the distinction between major depressive disorder and dysthymia was purposeful and was based on research that found no significant differences in quality of interpersonal relationships between patients with dysthymia and major depressive disorder (Zlotnick, Kohn, Keitner & Della Grotta, 2000). Additionally, any attempt to measure the level of depression in participants' partners would have interfered with the confidential nature of the participation in the research and the attempt to elicit candid responses without inhibition of the depressed partners' involvement in the study. It was anticipated that the screening questions, 'how many episodes of depression has your partner experienced since you have been together?' and, 'has your partner ever been

medicated for depression?’ would likely reveal any doubt that might exist about an actual diagnosis of the partners’ depression as opposed to simply a perception of depression by the nondepressed partner.

The goal of these inclusion criteria regarding length of relationship and chronic/recurrent form of depression was to recruit individuals whose lives have been significantly affected by their partners’ depression. Primary recruitment efforts focused on community advertisements in hopes that a less acute sample would volunteer as compared to the majority of studies reviewed in the literature review that recruited almost exclusively from psychiatric clinics. Participants’ partners were not interviewed or contacted. Participants were English-speaking and capable of giving informed consent.

Exclusion Criteria

Individuals were excluded from the study if:

- Their partner had not been diagnosed with depression by a healthcare professional;
- Their partner’s depression was comorbid with other major psychiatric illness (i.e. schizophrenia, untreated bipolar, etc.);
- Their relationship with their partner had ended or they were no longer living together;
- They were, themselves, currently inpatients in a psychiatric setting.

Procedure

Individuals who responded to public recruiting posters were contacted to determine their fit with inclusion criteria. Due to concerns about participants’ partners, care was taken in communications with participants while setting up interview times to

keep the participants' participation in the study confidential (i.e., at first contact the researcher asked the prospective participant how he/she would like to be reached by email or phone).

Individuals who fit the inclusion criteria were invited to participate and a first interview was arranged. A brief description of the study and the plan for two 90-minute interviews was given in the first contact, and again at the first interview. Informed consent was obtained at the beginning of the first interview. At the end of the first interview, a second interview was arranged to take place one to two weeks after the first interview.

Recruitment of Participants

A purposive sampling method was used. Participants were recruited entirely by advertisement in community publications (*Greenfield Recorder*, *Kids' Newspaper*) and posters at public locations throughout the Pioneer Valley in Massachusetts and the Upper Valley in Vermont and New Hampshire. Posters had pull-off tabs with contact information that individuals who were interested in participating in the study used to contact the principal investigator by phone or email. A sample recruitment poster can be found in the appendix.

Setting

Interviews were conducted in private conference rooms at Franklin Medical Center located in Greenfield, Massachusetts, in a classroom at the University of Massachusetts Amherst, in a coffee shop, in a workplace, and in town buildings in Vermont and Massachusetts.

Inclusion of Women, Minorities, and Children

Efforts were made to post recruitment posters in a variety of community locations to achieve demographic diversity of the sample. Women were the primary respondents to recruitment efforts and were the majority of participants in the study. This study did not include children.

Protection of Human Subjects

The purpose of the study was explained to each participant. Consent forms were explained and time was given for full reading of the consent forms by participants. A copy of the informed consent form can be found in the appendix. Once questions were answered and consent forms were signed, participants were interviewed. Participation in the study was voluntary. The study was reviewed by the Institutional Review Board (IRB) at the University of Massachusetts, Amherst.

Privacy during the interview was guarded by the use of private conference rooms or other locations for interviewing. Pseudonyms were used in all written materials to protect the identity of participants. Interviews were tape recorded with the knowledge and permission of participants. The tapes were coded for identification and transcribed by the researcher verbatim. Tapes, transcripts, and consent forms are kept locked in a cabinet accessible only by the principle investigator.

There was no anticipated risk of physical harm for participants. However, since discussing their partner's depression and reflecting on their lives may have caused some emotional difficulty for participants, a handout was given to participants. Appendix G is a copy of the handout that was given to each participant. It includes a list of local therapists and their phone numbers as well as a women's shelter and resource center, and a brief list of some online resources that participants may find helpful. (Advice for caregivers is at:

http://www.helpguide.org/elder/caring_for_caregivers.htm and advice for how to cope when a spouse is depressed is at: <http://ezinearticles.com/?How-to-Cope-When-Your-Spouse-is-Depressed&id=372411>)

Participants may have experienced positive benefits of involvement in this research such as appreciation of being able to tell their own stories to an attentive listener or satisfaction at knowing that their participation in the study may help others through the dissemination of research findings. Participants and others may benefit ultimately as readers of the research findings after they are published.

Data Collection

At the beginning of the first interview, informed consents were completed and demographic information was collected. Each participant was given the same explanation of the study purpose and assurance of confidentiality. Each participant was interviewed twice for approximately 90 minutes each time. A second interview was completed approximately one week after the first interview. The purpose of the second interview was to allow participants to revisit the question ‘what is it like to live with a depressed person’ after some time has passed since the first interview so that further meaning and depth of response could be gathered in the second interview. Interviews were audio-taped.

Interview Protocol

The first interview began with the question: ‘Tell me about your life prior to the depression.’ Once the participant had provided a general framework for understanding his or her life and current partnership, the research question was asked: ‘What is it like to live with a partner who is depressed?’ A protocol checklist can be found in the appendix

that was used by the researcher for each participant to keep track of the proper steps in the procedure for each stage of research.

Thirty-dollar gift certificates to a local supermarket or restaurant were given to participants as thanks for their time. Gift certificates were not mentioned on the recruitment posters but were explained in the first contact phone call or email. At the end of the first interview the researcher asked participants where they would like their gift certificate to be from. Gift certificates were given to participants at the end of the second interview.

Before transcription, pseudonyms were chosen for participants and for any family members who are referred to in the interviews. This method of substitution for actual names during transcription ensured that the all written materials in the transcript and data analysis phase used pseudonyms to protect participant confidentiality. All research reports or articles used pseudonyms.

Upon completion of the dissertation research, a public presentation will be delivered at the dissertation defense. This will include the researcher's summary of the study and findings as well as brief audio clips of interviews from participants who have consented to this use of their voice. Only audio clips that contain non-identifiable information will be used (i.e. no names, locations, etc.).

Presentation of findings similar to the dissertation defense may be made at nursing or other research conferences. Broader dissemination of research findings will be pursued through publication of one or more articles in nursing journals.

Benefits To Participants

Besides individual psychotherapy, there are few forums in today's world where people can discuss what it is like to live with a depressed partner and be fully listened to in a confidential forum. Therefore, with attention to interview method, participation in this research offered an opportunity for participants to express themselves fully and to be listened to attentively.

Data Analysis

An open coding method was used to group similar types of data or comments, meaning that the researcher read the transcript text with an open mind without preconceived concepts, instead making comparisons and asking questions while reading the transcript text (Gibbs, 2007). Because this study used a qualitative inquiry approach, special attention was paid to the meaning of participants' words and experiences. The coding process moved from descriptive codes to categorical codes and then to analytic codes (Gibbs). Groups of similar codes were grouped into themes. Codes and themes lead to findings discussed in detail with excerpts from the transcripts in the findings section of this research report.

The data analysis phase was concurrent with the data collection phase so that when saturation of data was reached, the data collection phase ended. Peer debriefing was used to verify data saturation and the appropriateness of ending the data collection phase.

Safeguards of Trustworthiness and Integrity of the Study

Several steps were taken to establish trustworthiness of the interview data, in keeping with the techniques described by Lincoln and Guba (1985), including credibility, transferability, dependability and confirmability. For a reader accustomed to quantitative

research, these concepts are, respectively, the qualitative equivalents for the terms internal validity, external validity, reliability, and objectivity.

Credibility and Dependability

Credibility, or the likelihood that the study will produce credible findings based on the data, was enhanced by three steps. First, the researcher attempted to identify her own biases and practiced vigilance to minimize intrusion of her own biases. These efforts were helpful to ensure that the findings were credible based on systematic analysis of participant interviews rather than a reflection of the researcher's own thoughts or agenda. Second, the researcher had prolonged engagement with participants and the data, making participants comfortably able to express their meaning, thereby assuring that the researcher had given adequate time and thought to the context, analysis, and findings that emerged in the study. Third, efforts were made to ensure that the participants' words are accurately interpreted by the researcher, a process called member validation (Kvale, 2007).

Building trust with participants was the first step toward creating an atmosphere in which honest and meaningful exchange of information could occur. Each interaction the researcher had with participants was seen as an opportunity to build trust with participants. Beginning with the first contact by telephone or email, the researcher tried to convey a calm, appreciative, and trustworthy attitude about participation in the research.

During the first interview time was spent building rapport before more sensitive questions were asked. The first interview question, 'tell me about your life before the depression' is designed to convey an appreciation for the breadth of participants' lives. Such a broad question also invited participants to tell the researcher about the parts of

their life that they want to convey, gave them time to get comfortable in the interview setting, and established a context for further discussion about their experience of living with a depressed partner. (Seidman, 2006)

Since the research questions were of a sensitive nature, the researcher was mindful of her tone of voice and body language during interviews. In the spring of 2008 three interviews were done as a pilot project for this study as part of a graduate course on qualitative interviewing, giving the researcher the opportunity to practice interview technique. These practice interviews also gave the researcher the opportunity to examine her own biases that may have come out in the course of interviews.

Further efforts to identify researcher bias included an interview of the researcher by another nurse practitioner using the same questions that were used with participants. The transcript was reviewed with the goal of identifying potential bias, but it was not coded and the content was not used in the data analysis for this study. The purpose of doing this was to aid the researcher in identifying her own assumptions and biases as well as to give the researcher an opportunity for direct expression and acknowledgement of her experience in the interview forum so that her experience will then be less likely to come out through indirect means during interviewing, coding, or analysis.

The researcher will have prolonged engagement with the subject matter through literature review and periodic reflective journaling. At the time of this writing, the researcher has already spent three and half years working with this research question (through literature reviews, journaling, discussions, concept analysis, and theory exploration). Prolonged engagement with the subject matter was furthered during the interviewing, transcription, coding, and analysis phases of the research. Journaling

documented methodological decisions and reasons for making them, as well as reflections on interview questions that have been effective and ineffective, or perceptions of the directions that interviews take that vary from what the researcher expected (Lincoln & Guba, 1985).

Prolonged engagement with participants during interviews helped create an environment in which participants were not rushed and had time to describe the experience of living with a depressed partner. Participants were interviewed twice for approximately ninety minutes each time. Ninety-minute interviews were intended to break through the expectations or clock-watching that one-hour interviews may invite, and establish an expectation of when the interview will end for participants (Seidman, 2006).

The practice of member checking was implemented in two different ways to verify that what the interviewer had heard and interpreted was what the participant meant. First, over the course of interviews the researcher periodically made summary statements and sought verification as to their accuracy from participants' points of view. Member checking in this manner was intended to minimize the researcher's assumptions about meanings by having the participant correct or clarify the researcher's perceptions by volunteering additional information (Lincoln and Guba, 1985).

The second method of member checking was done after interview data had been transcribed and coded. As Lincoln and Guba (1985) argue, if a researcher presents data as an adequate representation of participants' reality, participants ought to have the opportunity to react to that representation. Therefore, after coding, a summary of the major themes in the interview was sent to participants along with a thank you for their

participation. This letter encouraged participants to provide feedback if they did not agree with the themes extracted from their interviews. In every instance participants responded that the researcher's impressions and summary of interview themes were accurate.

Both of these methods of member validation put participants on record as agreeing or disagreeing with the correctness of the researcher's representation of their meaning. Once credibility had been established, and the quality of the study was clear through those methods, dependability had also been established. (Lincoln and Guba, 1985).

Transferability

Whereas quantitative researchers calculate external validity to gauge the generalizability of findings to other contexts, qualitative researchers aim to create 'thick description' to enable a reader to make judgments as to whether findings are transferable (Lincoln and Guba, 1985). Thick description refers to the ability of the data to support or demonstrate the researcher's findings. This is not reducible merely to quantity of participants or the number of times a concept is discussed across various interviews. Rather, it is reflected in the meaning or weight given to concepts across interviews.

Thick description was created in this study by in-depth interviews of 90 minutes each, twice with each participant. Since the data analysis and interview phases were concurrent, the researcher continued to recruit and interview until data saturation was reached, meaning that enough interviews had been done that new themes or essences were no longer emerging and that the data was repeating (Speziale & Carpenter, 2007). When the researcher perceived that data saturation had been reached she sought a second opinion from her dissertation chair before closure of the data collection phase to guard

against premature closure of the data collection phase of the study (Lincoln and Guba, 1985).

Reflective journaling, in which the researcher reflected on her own preconceptions, biases, and assumptions as described as a technique for establishing all four areas of trustworthiness by Guba and Lincoln (1985) was practiced in an ongoing manner in order to stay continually vigilant in preventing the encroachment of the researcher's own perspective. Dated notes on coding, researcher thoughts and decisions during the interview, transcription, and writing processes serve as an audit trail of the research process.

Confirmability

Confirmability involves attempts to ensure that all findings are grounded in the data. Documentation of each step of the research process serves as support for an argument of confirmability, and includes audio recordings of interviews, transcripts, coding, analysis, and reflective journaling. The last form of documentation is perhaps the most useful in confirmability because journaling records the reasoning behind choices made about method and analysis. Together, all of these efforts to assure confirmability of findings provide a path of decisions and findings that an auditor could backtrack through to determine if a particular finding could be logically arrived at based on interview data. This process created an audit trail. (Lincoln & Guba, 1985)

CHAPTER 4

RESULTS

Introduction

Themes that emerged in the coding process are presented here by major thematic headings and are described in further detail in their sub-themes. The four major themes include: identifying onset signals, trying to help, internal management of the diagnosis, and partnership disrupted: carrying on with life when one partner is depressed. To provide context for what it is like for the participants of this study to live with their depressed partners, we begin with participants' descriptions of the character and severity of their partners' depression.

Identifying Onset Signals

The Nature of Their Partners' Depression

Everyone who experiences depression seems to have his or her own particular kind of depression, and this was demonstrated by the seven participants in this study. Several participants described their partners' depression as low level – constantly increasing and decreasing waves of depression with occasional exacerbations of much greater severity. At times, it was hard for participants to tease out what behavior was depression and what was merely a 'bad day'; when depressed symptoms lasted for more than a few consecutive days, participants started to worry. For many of the participants, their partners' depression would occasionally reach serious levels, but generally the partner would receive medication before things reached such a point. For one participant, the partner's depression was characterized by a low level of depressed mood and self-

esteem issues at most times, with two clear episodes of increased depression that led to suicidal thinking. Two participants described a chronic level of alcohol and drug use among their depressed partners, which participants saw as their partners' ways of dealing with the depression. Six of the seven participants' depressed partners had an established medication regimen to implement when symptoms worsened.

Three participants described periods of time that their depressed partners experienced suicidal thinking. Two participants described times when their depressed partners were unable to get out of bed for days at a time. One participant's depressed partner would stay in bed most of the day, then rise and shower just before the participant arrived home from work as a sign to her that he was making an effort.

Several participants questioned whether there were any seasonal fluctuations for the partners, and at times either they or their partners believed that symptoms were worse in the winter. However, each of the participants ultimately remained baffled by the occurrence, unsure of whether sunlight, winter, or summer were relevant factors since the depressions occurred apparently without any pattern. It remained a nebulous factor for many of them. The most common factor identified among participants of what was behind an episode of depression was the partner's job, either because it was too stressful, not as fulfilling as they had hoped it to be, or difficult in some way.

Recognizing That Partners Are Depressed and Need Help

All the participants were able to describe a set of symptoms that raised concern in their minds that their partners were beginning episodes of depression, and it became easier for them to pick up on these signals the longer they were in the relationship. The behaviors that triggered concern for participants included: the partner isolating himself/

herself in a room with the door shut or by not engaging in his/her normal social activities, watching TV for hours on end; or by: demonstrating depressed mood, inability to laugh, increased anxiety and worry, increased irritability, dramatically decreased appetite, lethargy, or changed sleep patterns (staying up late into the night and sleeping late in the morning, or even sleeping all day).

Some participants describe a total lack of motivation by their partners to do daily tasks around the house and lethargy for getting anything done except comfort activities (e.g., reading, watching TV, drinking coffee, etc.) This often led to procrastination at work, not getting things done, and then feeling overwhelmed when things seemed in disarray. One participant explained that despite her depressed partner's inner feelings of anxiety, she was the one who seemed to be always tired, having headaches, and exhibiting slower body movements. Another participant explained that her husband became emotionally distant and 'grouchy,' and that during his last period of depression he was physically present, but in terms of emotional availability, "*he just sort of went away.*"

For some participants, an episode of marked irritability or rage would occur in their partners, causing the participant to retroactively examine the preceding weeks. In retrospect, they were generally able to see that things sneaked up on them and that their partners' typical depression symptoms had been increasing over the past weeks. One participant explained that when he sensed that his partner's symptoms were increasing and her depression was setting in, he tried to step out of his role as husband and ask himself, "*is this reasonable behavior?*"

The ability of participants to recognize the symptoms of on-setting depression depended significantly on the busyness of their own lives, (e.g., when they were busier with work or projects, they usually didn't realize as readily that a new bout of depression was setting in for their partners), as well as the length of their relationship and number of episodes of depression their partners had experienced (i.e., if the partners had been depressed many times, the participants were better at recognizing the onset symptoms than were couples who had not been together for as long or who had not experienced as many bouts of depression together).

With recognition of depression symptoms, a range of feelings were experienced by participants. For some it was dread, discouragement, and fear. One participant commented that when she started to see signs of depression, "*you get this pit in your stomach, like, 'what's going on'?*" Another participant explained, "*I hold my breath and hope that maybe it won't last that long, things might turn around on their own.*" Another participant described this recognition of new depression as, "*scary, anxiety-producing... 'cause I don't know how bad it's gonna get.*" Another participant described feeling helpless knowing that her partner was home in bed all day – not eating – while she was at work. Two participants who each owned businesses expressed fear for the success of those businesses and their family finances whenever they saw symptoms of depression in their partners. Another participant felt frustration when she saw her partner sinking into depression; she wanted him to take action to address the depression and told him, "*do something to address it: exercise, or therapy, or diet, or medication—something!*"

Some participants responded by withdrawing when they observed their partners sinking into depression, avoiding interactions that were likely to provoke the depressed

partners. They often responded with such actions as taking their children to do something, going to work early and/or staying late, or generally avoiding the depressed partner while making sure their children were all right. For one participant, this meant that she would stop sharing her problems or worries with her depressed partner because she saw that when she did, her partner thought that he was supposed to do something and became more agitated than she was about her own concern. She eventually began to believe that talking about her own concerns made things more complicated, so she turned to close friends instead. Some participants reported feeling helpless, “*scared to death*” of losing the depressed partner to a hospital or of losing their relationship. Another participant recalled thinking when the first depression presented itself in their relationship, “*my god, what have I attached myself to?*”

Once it became apparent to participants that their depressed partners were demonstrating symptoms of an onset/increase in depression, their task became communicating their observations with their partners. This communication could be very challenging. This phase of recognizing the symptoms and needing to tell the depressed partner was often lonely, because at such a point only the participants – and not their partners – had recognized the new onset of depression. For several participants, this was the most difficult phase because they saw the problem, felt fear or dread about the oncoming depression, and did not have the support of friends or family due to the need to protect the privacy of their depressed partners. This was true even for several participants who generally felt that they could discuss the depression with a few close friends or family members. It had been made clear to two participants that their depressed partners did not want them to talk to anyone else about the depression during this phase of new

onset. Protecting the depressed partners' privacy was an important theme that will be discussed in greater depth later in this paper.

Trying To Help: Balanced Partnership Transitions To Caregiving

Telling Partners They Need To Begin Or Resume Medication

For all of the participants, it was difficult to convey to their depressed partners that they saw the symptoms of depression worsening. This appeared to be a major break in the partnership/mutuality of the relationship, where two individuals were no longer working side-by-side on their shared tasks, but instead one partner was observing qualities in the other that were destructive to the individual and to their partnership, and expressing such had to be done carefully and thoughtfully. This was especially true when depressed partners were sensitive to criticism and were already not feeling positively about themselves.

For some participants, conveying to their depressed partner that they thought starting or restarting an antidepressant was needed simply required tact and good timing. The antidepressant had worked in the past and it was currently available, so it was often simply a matter of encouraging the depressed partner to start or resume taking it. But, how to put this into words to a loved one who is already depressed and irritable was a more difficult aspect. Some learned from experience to address the symptoms in a non-threatening, non-blaming way, phrased as, "*this is what I'm noticing; when was the last time you took your pills?*" One participant put the medication out with his depressed partner with her morning coffee or handed them to her, otherwise the depressed partner would forget to take them.

“It can be difficult, um, it takes so long for the antidepressants to kick in. And having had depression I know that you have to keep taking these meds every day and you don’t want to take them. Side effects aren’t always so great. At the same time, she has to want to take them herself and want to be compliant with the medication – I can’t make her take the medication. So, it’s fear, it’s helplessness, it’s, ‘oh my god what am I going to do if this gets worse?’”

For others, however, medication was not an established go-to remedy, making the task of discussing symptoms more difficult. Trying to get an already-depressed partner to make an appointment to talk to a health-care provider was very challenging. Additionally, when the primary care office was reached, there was typically a wait of two weeks or more to be seen by a provider, followed by another one-to-three weeks before effects of the antidepressant medication were seen. This seemed like an interminably long wait to the nondepressed partner. As one participant said, in her frustration that the process took so long to get medication, *“why hadn’t he called the seven times I’d asked him to? But, I didn’t call because I’m trying not to be his mother.”*

This comment illustrates the double dilemma that is unique to the situation of having a depressed partner. First, it was seen as difficult to care for an adult person that one loved and who was responsible for himself/herself; the nondepressed partner was unable to make him or her take medication and/or seek therapy, and the nature of the illness made the partners resistant to taking action. Second, the nature of the partner relationship had limitations for most people about how far one pushed to take care of a distressed partner. As one participant said, *“It’s not like he’s bleeding to death. What am I supposed to do? I can’t make the appointments for him and I can’t make him go.”*

The partner relationship, for some participants, required careful communication. A participant stated, *“Right now, we’re in an in-between time where I’m seeing the signals and she’s saying everything is fine. I accept what she says if she says she’s fine. I can’t tell her she’s depressed, I can only tell her what I’m seeing.”* He found that this approach usually caused his partner to reflect on what she was doing. This participant also found that, *“when bringing it up, timing is everything, so if I bring it up right when I have to leave for work and make a quick exit it can fester for the day.”* Another participant took great care in conveying her concern when she started to see that her partner was showing signs of a new depression setting in. Having experienced depression herself, and having had a friend tell her she needed to get some help, this participant was very sensitive to how it feels to hear this message, knowing that as a depressed partner, *“you’re fighting this battle with yourself.”* Talking about medication was a comfortable and acceptable starting point for her to begin to discuss the depression with her partner.

Two participants were very empathetic to their partners’ occasional need to take a “med-holiday” (i.e., a temporary break from taking the medication), and carefully pointed out the increased symptoms that they were seeing. One participant explained that he felt his partner was entitled to the break: *“I can totally relate to not wanting to take any kind of medication on a regular basis, so... I mean, it’s not like she gets suicidal or is gonna hurt the kids so ‘okay we’re going through a little swing here...’ God I can’t imagine medicating her into this even zombie, that would be pretty boring.”* Another participant described her observation that, *“if she doesn’t take her medication for a week, it starts showing in her behavior.”* She also commented that, *“I can totally see where she is coming from”* needing to take a “med-holiday” at times.

Another participant reported much more frustration and had a more directive/maternal role with her partner; she had no patience for her depressed partner lying in bed all day. With a sense of humor in her tone and word choice, but not in the message she was conveying, she told her depressed partner, “*get the fuck out of bed!*” Another participant expressed frustration that her partner took Prozac “*only when he felt like it*” and wouldn’t seek therapy, whereas she feels he needed more than what occasional Prozac use could provide him.

Three participants were health professionals, two of whom were mental-health providers. One depressed partner was able to listen to her partner’s observation of new depression symptoms because her partner was a nurse. Another participant who was a mental-health provider would, when observing symptoms of depression, address things very directly and compassionately, being careful not to be too provocative. She had benefited from her many years of living with other depressed family members and briefly experiencing her own depression, as well as decades of work in mental healthcare, where she developed excellent communication skills. She knew that when presenting her observations to her depressed partner, he might get angry or not respond well, but she also felt the need to be direct. Sometimes, she had to wait for a period of time so that she could be rational when discussing her concerns, having learned in the past that, “*if I’m careless he is – BOOM – nothing useful.*” Another participant who was a mental-health provider wondered if her knowledge simply made her partner’s depression seem more normal to her, making it harder for her to sort out what was normal and abnormal.

Medications and Therapies

Once the diagnosis of depression had been made, all seven depressed partners were prescribed antidepressants. A few participants believed that medication had always been helpful to their partners and improved symptoms within a few weeks after starting, restarting, or increasing dosages. The primary problem for these couples usually lay in getting the depressed partner to take the medication, or start it, or resume taking it. One participant recognized his good fortune in the fact that medications have always worked for his partner, acknowledging that his outlook on the depression would be much different if she had to be hospitalized.

One participant explained that her partner really didn't want to be on medication at first and still did not like taking medication, but since it helped, "*she's sort of adapted to that idea.*" However, another participant's depressed partner could not adapt to that idea. Her partner took an antidepressant for six months, during which time the participant felt that he was "*back to his old [nondepressed] self,*" acting up only once in a while. But, after the initial six months, he stopped taking the medication and has not taken it again since. Another participant described her partner's secretive nature regarding medication, that he will stop taking his antidepressant sometimes, wanting to control things on his own with yoga and other therapies. She was very frustrated by the lack of openness in his stopping medication:

"I realized it when I found like a full prescription bottle. We ended up talking about it in couple's therapy this week and he doesn't remember us talking... but recognized that I am part of the solution. And I will be involved in all future decisions. So

that felt good. And he's hooking me up with his psychiatrist so I feel like I want to be part of these decisions cause I live there."

One depressed partner's choice of treatment for years before he agreed to start medication was alcohol and marijuana. He explained to his nondepressed partner that he used these to 'exhale' and manage his depression and stress. She expressed frustration with this idea because she sees the alcohol and marijuana use as part of the problem and not a valid treatment. She explained her frustration:

"I said I still don't understand exactly what your concern is about antidepressants. And in my mind clearly you don't mind self-medicating. Pot is okay, alcohol is okay, so.... He'll take every herbal cold remedy in the world, our medicine cabinet has so many herbal remedies in it. He'll have any of that stuff but he's not gonna try medicine. I just don't understand what it is that you're concerned about. Well I'm worried it might work and then I'll take it forever. Oh my god you're not doing this because it might work?!"

Ultimately this struggle was resolved when the depressed partner made an appointment with his doctor, had an antidepressant prescription filled, and gave his partner a Valentine's Day card with the pharmacy receipt in it, stating that he had started the medication.

Taking Care of a Depressed Partner

Participants described ways that they tried to help their partners during periods of depression, or during times when things were well as a way of preventing future spells of depression. For many participants, one of the biggest ways that they believed they could help their partners was to support, facilitate, or encourage the use of medication, and this

is discussed in detail under the theme ‘medication and therapies.’ Assuming the role of doing this was comfortable for some participants and less comfortable for others.

One participant was pleased that, with her urging, her partner has started to plan more time off for herself as a way of preventing depression and burn-out. “*We’ve made adjustments in our lives, I’ve convinced her to take more days off so she gives herself a break. She used to just go and go and go, never taking days off, getting so burned and fried. Then depression rears its ugly head. It’s been better since we figured that out.*” The participant remained vigilant for signs that her depressed partner was unhappy or frustrated at work since those have been the times in the past when his depression worsened.

This participant’s adult child had also struggled with depression and she described how it was different to care for a child than a partner. She explained, “*you’re supposed to make sure your kid’s okay, you’re supposed to be watching out for them. So when I look at him different things go through my mind than when I look at [my partner]. She’s an adult with a certain level of responsibility for herself.*” This participant was also a nurse, so she had a clear idea of what it meant to be a caregiver in her professional life, and she did not consider herself in that role at home in relation to her depressed partner. As a nurse, “have you been taking your medication?” is one of the first questions she would ask when assessing a patient’s status. But, she explained that, as a partner, the symptoms of the depression sneaked up on her, and she got lost in the subjectivity of the relationship and filter of her role as a partner.

One participant opened all of her depressed partner’s medical mail and attended to it since his disorganization and feeling overwhelmed had led to loss of health insurance in

the past. This participant also described the tough love that she gave when she saw that her partner was very depressed: *“Those early times he wasn’t getting out of bed I was literally, bodily taking him out of bed, dragging him out of bed. And like saying you have to get out of bed. This is not a joke, you have to get out of bed right now. And he’d say ‘no’. I remember physically dragging him out of bed, and he was so mad at me, he did not want to be out of bed, and I’d say I’m sorry but you have to go outside right now. There is waning sunlight and you need to go outside and get some of it before the sun goes down. And like I forcibly put him out of the apartment.”*

Another participant attempted to take care of his partner by helping her identify her needs and take care of herself. His approach was, *“What do you need to take care of yourself? You need to ask for it because I can’t figure it out.”*

Another participant attempted to care for her partner by interrupting his self-damaging thoughts: *“the times when he has not gotten out of bed. Like I am riddled with the worry, and sometimes I’m at work and I’ll just have a sense that it’s one of those days and I’ll just call and let the phone ring and ring until he answers it. We didn’t used to have a house phone so he could just turn his cell phone off. But now we have a house phone and we don’t have an answering machine on it so I’ll just let it ring until he answers it. Cause he gets stuck in these like cycle of like, and that’s one of the things that are hard, his depression is all about feelings of shame that I’m a bad son, I’m a bad boyfriend, I’m a terrible person, he gets stuck in cycles of that, and I sometimes feel like if I can call and interrupt it, and I’m not sure I really can interrupt it, but if I sense that it might be one of those days I try to call.”*

Two participants have, at times, had the ability to talk to their depressed partners' psychiatrists, to convey what they were seeing at home and to kept abreast of what medication changes were being made. Both participants knew that ultimately the psychiatrist-patient relationship was one that they did not have unlimited access to, and might not have any access to if the patient or psychiatrist did not want the partner's involvement. This was a very challenging situation for one participant because she knew that her depressed partner was not getting out of bed, and she felt strongly that his therapist did not know how bad things had gotten. She explained: *"I don't know when I insisted on going to his therapy with him...like does your therapist know what's happening here? Does she have any idea? I just muscled my way in there because somebody needed to be like, I think his version of the truth is the truth to him, and there is no such thing as objective truth, but this lady needs to know these are the behaviors that are going on at home, like you're not getting out of bed... He doesn't see how bad things are when he's in it. I've empowered myself to attend his therapy a few times since then. Not often but when it gets to a critical place I have inserted myself in that way."*

One participant explained that when her depressed partner came home from his very stressful job and needed to talk, she would provide what he called *"the million dollar consult."* She listened closely and tried to help in ways that she could and took her role very seriously. She also took care of as many every-day and household tasks as possible as part of this partnership: *"Because he was so distressed and preoccupied with his distress about work, and really serious matters, that he didn't really have that much room, spiritually, emotionally, anyway, to deal with a lot of every day normal stress of*

living, and he made good money so a lot of that stuff I just took care of. I mean I was totally taking care of him spiritually.”

However, this participant also expressed frustration with the fact that there were limitations to what she could do, particularly when things were at their worst. When she saw that her partner was very distressed and needed help, she urged him to see a therapist, but she was keenly aware of the reality that she couldn't make appointments for him or force him to keep the appointments he had made. She also described that, in retrospect, she was aware that she had adapted to how distressed he had become. Finally when a supervisor insisted that her partner take a leave of absence, she felt validated once the severity of what was going on was perceived by others: *“It was in a sense validated by his supervisor saying something to him. Suddenly, he’s on emergency leave and all this stuff; I remember having a big leap into the compassion mode for a while. Just cause, like wow, I just didn’t realize it was that severe or that something could be done about it. Because I had talked to him a lot about we need to find you a doctor, let’s go to Boston, but I don’t know it wasn’t like a gaping wound where you say I don’t care if you don’t want to go to the hospital, you’re going!”*

Another participant explained that she frequently called home while at work to check on her depressed partner. She tried to be supportive, but not ‘bossy.’ This was sometimes challenging when her partner was depressed because of her extreme worry for him: *“You know like ‘you might feel better if you take a walk, have you eaten anything?’ ‘Cause I’ll come home and he’ll have eaten like a bowl of Cheerios and then another bowl of Cheerios. And that’s not helping to not have a proper meal either, so I encourage him to eat proper meals, I try to leave something in the fridge that is edible.”*

The question of who takes care of whom more had been an important factor for one participant. She explained that her depressed partner had told her that he felt guilty about his perception that she takes care of him more than he takes care of her. She acknowledged that she did often feel that she ‘took care of him,’ *“but he’s also taking care of me in a big way. Sometimes, he feels like it’s not a two way street, that I take more care of him than he takes care of me. But that really isn’t true. We’ve talked about it in therapy. Cause I cook and I do lots of other things. He works three days a week and I work a lot more than that. So, um, he was feeling like he wasn’t pulling his weight, and when it comes to housework he kind of isn’t, but he does a lot of other things. We made a list of all of the things we do in the house and outside of the house for our life and it really did. He takes care of the trash and the garden. So in terms of emotionally caring for me, he takes care of me, and the difference that’s made in my life, I’m gonna cry, I really felt very alone in the world before I met him.... So in terms of who’s supporting who or whatever, we’re supporting each other.”*

Conversely, other participants described less reciprocity in caring for one another. One participant described her feeling that she had a natural ability to handle more than her depressed partner does. But eventually she ended up feeling resentful that she was working more, taking care of the children more, handling more, and enabling him to handle less. She admitted that she had trouble putting her own needs first, so when she observed her depressed partner focusing so much on his own needs she was pleased because he needed to do this to treat his depression. However, she simultaneously felt *“pissed off”* that his needs were being met and hers were not because she was caring for

everyone in the family. When he stated that he was going to do something fun that she never had time to do she thought, “*fuck you!*” but never said it.

Feeling “Like It’s Too Much”

As participants described the effect of living with a depressed partner, some of them expressed feelings that, at times, it was “too much” for them. As one participant said, “*like every 6 months where I’m just like ‘what the fuck am I doing?’ It is more than I can handle; I did not bargain for this.*” She described feeling helpless when she realized that her partner had been in bed all day.

Another participant described feeling like life had become too heavy and that their family wasn’t having any fun. “*There have been moments where when he said he wasn’t going to take the antidepressants, that I should take antidepressants. Like how can I be here and not just get sucked into this?*” She also described that there are low moments sometimes: “*I do have moments of hopelessness, where I’m like ‘what am I doing here?’ What would divorce look like? Where are we gonna live?’ Oh my god.*”

Another participant spent an entire first interview of 90 minutes reporting very little difficulty with his partner’s depression. However, at the start of the second interview, he admitted bluntly that he realized he had spent the entire first interview protecting his partner and not saying the following truth: “*God, it really sucks some days living with somebody that’s depressed, and I hate to come home sometimes ’cause I don’t know what I’m gonna walk into. Or I think I’m gonna walk in to depression. So anyway, yes, in the most part I’m very, pretty mellow about the whole thing, but other times I’m pretty angry about having to cope with situations that I, um how shall I say, I’m the recipient of actions of the depression and I have absolutely have no control over it. And*

that part is difficult 'cause if your spouse is in a bad mood and you come home and, well, you can cope with that, but if you come home and she's just somewhere on the roller coaster, I have no idea where it's going to be."

Caregiver Burden

During each interview, the concept of 'caregiver burden' was explained and each participant was asked if he or she felt that this term described his or her experience. For the most part, all of the participants immediately said 'no', caregiver burden did not describe what they felt. They expressed discomfort with considering themselves to be their partners' caregivers and saw a clear distinction between what they did to care for their partners and what care is provided to a family member with cancer, Alzheimer's, or another terminal illness. One participant explained, *"No, having been the sole caretaker of my father through terminal illness, this is nothing compared to that, this is easy. I don't feel a caregiver's burden for a couple of reasons, one is the depression bouts are not really that severe, I've never been worried that she is going to harm the children or herself or do something totally dangerous or something like that. Also they tend to be fairly short periods, I mean a long one is like a couple of months long, and it's like 'okay what are you doing here?' and I'm standing there with medication saying 'here take this', that sort of thing. So no, in that sense I have not felt that kind of burden with her. "*

Another participant described feeling similarly after having seen a family member become a caregiver for an ill husband. *"I'm not aware of feeling that way [caregiver burden] at the time...it's probably a small component there but it's not huge... enough for me to say 'wow', but probably because she's not terribly functional... partners-- one*

picks up the load for a while. It's life. It is what it is. In a perfect world she wouldn't have it [depression]. But that's just the way it is."

Yet as much as they rejected the term, many participants were able to identify ways that caring for their depressed partners was burdensome at times.

Nearly all participants described ways that they pick up more of the workload around the house because of their partners' depression. One participant expressed anger at having to do *"all of the work."* *"I've taken on all of the responsibilities because he can't handle any problems. He drinks and then we all pay."* This participant also explained that she resents the lack of support that she gets from her partner's family, *"I've had to ask her would she come up and get him out of here for a little while. Just to see what it would be like. All of a sudden she goes "Well what can I do?" I gotta go to work and blah blah blah. Okay you asked me what you could do and you just don't help me out and follow through."*

For one participant with two young children, her depressed partner's increased need for sleep was one of the biggest sources of burden. She recognized that his insomnia was part of his depression so she regularly let him sleep in on weekends, but this left her feeling *"pissed off that I never get to sleep in."* She became weary of her partner's needs always coming first and her own habit of being quick to help him, to try to fix things, make things easier for him, and then became depleted of energy and resentful that no one was listening to her needs. She felt conflicted because she wanted her depressed partner to take care of himself by exercising or doing things that made him happy, but when he did those activities it left her with more of the parenting and household duties. She described feeling that rather than feeling caregiver burden related to her partner's

depression, she felt caregiver burden related to caring for her children because she was doing all of the work.

For another participant, keeping privacy about the diagnosis was the biggest burden. For still another the burden felt greatest when he had little flexibility at his workplace and a boss who was not understanding about what he was managing at home. Being able to arrive late at work or shift hours when needed was helpful to picking up extra tasks at home and not feeling that it was a burden. When things got to feel burdensome he admitted to drinking moderately in the evenings, jokingly saying that *“Yes, medicating myself is a pretty good treatment for my wife’s depression, I’ve found.”*

Another participant described how appreciative she was to have an understanding boss when things were difficult at home. *“There was a time last winter when he was just in a bad way, and it’s almost always the wintertime, and I was just like nearly barfing at work from worry. And she was like ‘hey what’ going on?’ and she was an extremely sympathetic ear. And she gets it, it’s such a pleasure having a boss that gets it. I am extremely distracted at work, what do they call that—presenteeism, when you’re present at work but not actually, you’re sort of absent. So I was totally a presenteeism person at work that day. And it was extremely valuable to me at work that day to have her, just telling her this is happening at home... But sometimes the burden is on, especially when I’m supposed to be doing something else. But it feels burdensome for short periods, not for long drawn-out periods that some people might struggle with.”*

One participant described her discomfort with becoming her depressed partner’s caregiver. She described feeling that she becomes his mother and she doesn’t want that role. It is a role that she cannot fill anyway. She knows that he needs to see a doctor but

he won't go and she can't make him go. *"And I'm just crying eventually. I just feel that whatever I do is wrong. If I try to help it's wrong. If I don't say anything it's wrong, if I just let you be depressed it's wrong, if I try to take some of the weight off you it's wrong, I know that when you said you didn't want to fill the prescription everything I said was pushing you away from what I wanted you to do at that moment."* In her frustration with taking care of her depressed partner and their children, she becomes exhausted and resentful, and just wants him to take care of her more.

Finally, one participant explained that she could see how caring for a depressed partner could be similar to the burden of caring for a family member with Alzheimer's, but it would be a suicidal depression that required more vigilant care. She also acknowledged that while she was caring for her depressed partner during an acute episode *"I didn't feel burdened by it but I probably was."*

Internal Management Of The Illness

Privacy

The matter of privacy was an important topic for most participants as they struggled to balance their own desire to talk with family or friends about what was happening in their home with their partner's need for privacy. Nearly all participants reported that they believed there was significant stigma about depression, and while it was very socially acceptable to come to work and mention the challenges of life when a partner has a physical illness or injury, that same acceptability does not exist when discussing the challenges of life when one's partner is depressed. For one participant the need to guard her partner's privacy was difficult; *"the people that I'm close to, I don't like to have to keep things private. Because it's how I cope, it's how you cope, you talk to*

other people about it. And at the same time, there is this other person that I love and if she wants me to keep quiet about it, that's what I need to do, but it's tough cause you can't say now how are things going and you're kind of like 'hmmm', you can't really say that she forgot to refill her prescription for a week. And so she's starting to back slide a little bit, had trouble over the weekend, that type of thing."

One participant described feeling torn about talking with friends regarding her partner's depression: *"It's so complicated. There are lots of times where I feel like I shouldn't say anything because it's his stuff, but it's affecting me."* This participant had received a number of explicit *"don't talk to other people"* messages from her partner, which made her feel conflicted and isolated. *"Well there are times where he has said 'please don't tell anybody, please don't tell your family'. It's like okay, that's an unfortunate request, so it was sort of a relief that he told my sister, and I had actually spilled the beans like a week or so before."*

One participant explained that she worried about being judged negatively if she discussed her partner's depression or that friends would want to avoid her family if they knew about the depression. The solution for her was to call friends who live far away or with whom she works, people that are not part of her partner's life. *"So I talk to people far away. But other times I don't want to talk about it, it feels boring, I don't even want it, whatever, he's depressed again. There's no new information. There's no new—alright now he's actually trying the medication!"*

Another participant described her habit of intense privacy, which was natural to her from her own family upbringing but was pronounced in her current situation because her partner is a community figure and protecting his privacy was important to them. So

when she needed to discuss her partner's depression with someone, she would call one of two confidantes in her life, far away, to whom she could tell everything. She discussed very little personal information with friends and acquaintances that lived nearby, but she often sought their company to avoid isolation. When asked if she would have liked to have shared more with the people nearby, she responded that she probably would not have benefited from doing so because she believed that not discussing her husband's depression was best for her, because discussing it would have disrupted her ability to deal with it. For her, intense privacy was a coping tool.

Two participants who no longer had loving partnerships with their depressed partners did not feel any need to protect their privacy. They spoke freely about it to their friends and were not afraid of people knowing about their problems. One of them, however, was very cautious during the interview and expressed worry that her partner might find out that she was talking about him, so privacy was an issue for her borne more from fear of his reaction rather than respect for his privacy. A third participant discussed her partner's depression openly with friends because she knew that her partner was very open about his depression and had never indicated any desire for her to be private about this issue.

Stigma

The level of privacy that participants and their depressed partners sought was linked to their feelings and perceptions of stigma about depression. As stigma was discussed in interviews, two types emerged: an inner stigma that either the participant or the depressed partner felt about acknowledging/accepting/recognizing depression, and a

separate outer stigma that was related to how participants and depressed partners perceived the outside world reacted to or viewed the depression.

Essentially, all participants reported feeling no stigma about depression as an illness, they simply saw it as an illness similar to diabetes, a chemical imbalance that could be managed. About half of participants reported that their depressed partners also felt no stigma within themselves about having depression, they generally accepted the illness matter-of-factly and treated it. The other half of participants described some difficulty for their depressed partners as they felt badly about themselves for having what they perceived as a personal flaw or weakness to need medication. One participant described a distinction she sees between shame and stigma. She explained that her partner felt no stigma about his illness and readily told people about it when he meets them, but feels a sense of shame about the effects of his illness on his relationships and how it has caused him to be (in his self perception) a bad husband, a bad boyfriend, etc.

Participants' perceptions of outer stigma, or how they perceive the world reacting to their partners' depression was somewhat different. While many participants themselves felt no stigma toward depression, they did feel that in society depression does have a stigma, and they maintained privacy specifically because of that. One participant explained that *“even being a nurse and having had depression myself, I wasn't terribly open with my family [about her partner's depression]...you know we tell patients that it's not a character flaw, it's a chemical imbalance, blah blah blah, but when you're dealing with it personally like that, whether it's yourself or somebody that you're intimate with, it doesn't feel like it's not [a character flaw], it feels like almost something to be embarrassed about, like oh my god they're gonna find out that she's depressed and that*

would be a horrible thing.” This participant’s partner struggled with the stigma of depression for years, not wanting anyone to know that she was seeing a therapist and taking ‘*happy pills*’ until her own father was depressed and divulging her experience with depression, therapy and medication was a way to try to help her father accept the idea and seek treatment. For her setting aside privacy and disregarding stigma was necessary to help a family member.

This uneasiness between knowing within oneself that depression is simply an illness like many others but worrying about how the outside world will react was aptly expressed by one participant: *“if it’s a biological switch in your brain, what is there to hide about it?”* This dichotomy was very real for participants whose depressed partners needed to miss work for periods of acute depression. As one participant said, *“It’s not like you can go to your employer with a level of comfort and say well I’m sorry I missed last week”*, as you might be able to do if it were a broken ankle instead of depression causing the absence from work. Several participants reported frustration about this double standard.

This dichotomy between inner acceptance of depression and fear of societal reaction was also clear for another participant. As a health professional, this depressed partner felt no stigma about depression within himself. However, it was very challenging for him to find psychiatric care that felt private because he knew everyone in the health care facility where he had to seek care (with psychiatric care being a limited resource in a rural setting), and this caused him to refuse to seek care for several years.

Isolation

When participants or their depressed partners felt inner stigma or perceived outer stigma there was a greater demand on participants to maintain privacy, and this often led to isolation. Several participants reported that their depressed partners felt an intense need for privacy as a new episode of depression was occurring, and this led to a brief period when participants and their depressed partners recognized that depression had set in and participants felt restricted in their ability to discuss their worries with anyone. This created a period of isolation for participants as they worried about their depressed partners, they recognized new onset or worsening of symptoms, but because they felt bound to protect their partners' privacy they did not discuss their concerns with anyone. As one participant described, "*it was very isolating. Cause you're kind of, it's you and her, she might have been starting the medication and you have this secret, there's something wrong and you can't share it. You can share a broken ankle but not 'Donna's depressed'.*" Another participant explained that, for her, this time period was fraught with fear more than isolation or loneliness: "*it's scary cause I don't know how bad it's gonna be.*"

As depressed partners sought treatment and as couples experienced more bouts of depression together over the years their depressed partners guarded their privacy less closely and participants felt that they were more allowed to discuss with friends and family what was going on. One participant reported that her friends have known them for years and have seen them through multiple bouts of depression and are now savvy enough to know when something is going on.

For another participant whose partner was chronically depressed but was not receiving treatment and symptoms were compounded by abundant alcohol use, his behavior was isolating more than the stigma about depression was. She felt estranged from friends because a lot of them no longer liked her depressed partner or could tolerate his behavior. She explains “*He’s lost us all our friends,*” and “*the kids are embarrassed to have people over.*” This participant described feeling very lonely at times: “*no one listens to my cries about how difficult it is.*” She feels particularly lonely at holiday times because she used to love having family gatherings but because of her depressed partner’s poor behavior they no longer do. She sees that the neighbors all have friends over but at her house they only have each other.

The depressed partners’ need for privacy caused some couples to live in more isolated areas. One participant reported that her depressed partner needed to escape from the world, flee from his situation, he needed isolation. And she didn’t mind that at the time, she was able to maintain friendships and fulfilling personal activities that kept her from feeling isolated. She recognized her own ability to adapt to situations that her partner needed. Conversely, another participant recognized her depressed partner’s desire for physical isolation and she felt that the isolation had a negative effect on them both. She became adamant about moving from their rural location into a city neighborhood where they were surrounded by people, and she feels that they have both benefited from having people around.

Supports for the Nondepressed Partner

For the six female participants in this study it was important to have friends to talk to about what was occurring at home related to their partner’s depression. Certainly

the level of privacy that the couple or participant or depressed partner felt was a factor in whether they chose to discuss their concerns openly, as discussed in the prior section on privacy. When asked if they had support from anyone outside of their partnership, most participants reported that they had a friend or friends they could talk to and that the support they received from friends was important, particularly if their friends had a similar situation at home.

One participant described the importance of being able to “*bitch*” about her partner and commiserate with her friends. When asked what it would be like if she couldn’t do that, she responded: “*It would be difficult, it would be more difficult, it would be isolating. It would probably increase my anxiety about it [the depression], I wouldn’t have an outlet. Um, I wouldn’t have somebody else say ‘yeah, yeah that happened with us too and things are okay now.’ It would increase my fear and my frustration a little bit.*”

One younger participant routinely sought the advice of an older friend whose husband also had depression, and this participant appreciated the directive advice of her older friend who had had similar experiences. This participant also had a supportive and understanding boss whom she could talk to. She described one such conversation: “*When he wasn’t getting out of bed I was like ‘what the fuck am I doing here?’ How did I end up in this? And she was like ‘well you have an option of getting out.’ And I said I don’t want that option. I prefer not to use that option. I think the most recent time I was at her kitchen table weeping openly about how I can’t do it ...*”

Two participants found it very helpful that their depressed partners had a lot of supports of their own, including a therapist, friends, and family members. One participant expressed her appreciation that her depressed partner had a therapist: “*She’s in therapy,*

there's someone else listening and asking about her meds. I'm not the only one."

Conversely, three participants expressed frustration that their depressed partners did not see a therapist or have another person to depend on.

Therapy or therapists were another source of support for participants. For some this was individual therapy and for some it was couples' therapy. As one participant said as she explained how helpful it was to have couples' therapy, "*I was having a hard time and couldn't handle it by myself.*" She explained that the therapist served as a mediator sometimes so that her concerns were heard and taken seriously. Another participant explained that couples therapy had helped both herself and her partner stop avoiding discussing the difficulties and bring things out in the open.

For the single male participant in this study there was no real need to talk about things, he only needed to make small comments at work like "*Oh man was I glad to get out of the house this morning.*" He described his lack of need to discuss it further: "*I love this woman, so she had a bad day. I don't need to process it, she just had a bad day.*"

Another participant very rarely spoke to anyone about her partner's depression. She preferred to cope by running, taking care of her animals, and always had good friends and acquaintances who she talked to about other things, thus getting a general kind of positive support without having to vent directly about what was going on at home. She had a nearby best friend who essentially understood what was going on and she had another dear, old friend farther away to whom she could tell everything. But for the most part *not* talking was a coping mechanism. As she said, "*maybe if I'd had this happy normal little life, not holding all this shit together [I would have talked to people more].*"

Partnership Disrupted: Carrying On With Life When One Partner Is Depressed

Effect On Employment

Among the practical aspects expressed of living with a depressed partner was the consideration of employment for the depressed partner and/or the participants and how their jobs might be affected by the presence of depression. For three couples the effect on employment was significant because the depressed partners' level of depression was so serious at times or so damaging as a chronic element that the depressed partner couldn't keep a job.

One participant who owned a business with her depressed partner described the transition from a partnership in their business years ago to their current arrangement in which she worked all but three days each year because she did not want her depressed partner to be taking care of customers. *"Ya know, people don't want to hear it, people want to come in, get their [purchase] and go home. They want to have a friendly face behind here [the counter], somebody who's smiling and happy not somebody who's ..and he walks around and lets everybody know he's miserable."* She described the fatigue of working so much to make up for his absence.

Another participant who owned a business with her depressed partner described the procrastination and overwhelmed feeling that her depressed partner experiences at work when depression is present. She finds it very challenging to run a business together with someone who is depressed. She has real fears about the business when he is depressed and explains, *"I haven't really said this to him, but people don't want to do business with someone who's depressed. You go out to their house for an assessment, part*

of why you choose this person over that is because you like them. You like their energy, you think they're going to do a good job."

Another participant described the poor work history that her depressed partner has because of his depression. At the time of the interview she was very pleased that he had been able to maintain a steady part time job for the prior two years, and she appreciated the role that the job played in making her partner get out of bed two days each week.

Three participants saw their depressed partners' jobs as one of the primary sources of stress that has lead to their bouts of depression. One participant commented that in two out of the four bouts of depression her partner has had, her partner was unhappy and frustrated with work. And the participant reported that most of her concerns and anxieties about her partner's depression stem from the extended work absences that occur when she is depressed, making her worry that her partner will lose her job.

One participant explained that her partner's stress, work load, and job burnout were huge factors in his depression. At one point, his supervisor forced him to take time off from work because of it. This recognition of the problem by his supervisor was a reality check for the participant, it helped her realize how bad things had gotten and how proficient she had become at adapting to the problems.

Raising Children

Four of the participants in this study were currently raising young children with their depressed partners. There was a range of experiences related to the effect that the depression had on child rearing practices.

For couples who had children, there was a shift in workload when one parent was depressed. Two participants reported that they assumed more of the child-rearing duties

when their partners were depressed. One participant described not having time to talk and work things out when having young children; that the time consuming nature of dinner and bedtime for children left little time to talk in depth with her partner at night.

Another participant described the ways that he ‘picked up the slack’ when his partner is depressed: *“her interaction with the kids tends to be loud and distant and shouted from the living room so I’m checking in, for me the alarm bells are going off, okay what’s going on here... I mean they’d come and hang out with me and just avoid her. Now I talk to, especially my son, the elder child, uh, I just talk to him and say ‘look this is not worth fighting about, you’ll lose the argument, this is just how mom is right now, she needs, she needs help without arguing.’ So as they get older then, well I haven’t talked to them about depression and everything else, I’ve tried to give them coping skills.”*

For one participant, the irritability that her partner displays when he is depressed makes every-day family life tense. For example, he was bothered by loud noises, so young children playing and having fun, or being rambunctious at the dinner table irritated him. The participant described feeling conflicted about whether to side with her children, whom she felt were doing nothing wrong, or with her partner, to whom she felt an obligation to support. She struggled with how to meet everyone’s needs when her children’s and her partner’s needs were competing. This irritability escalated at times to the point that she would not leave their two year old child at home with her depressed partner because he was so short tempered. This furthered her struggle as she put her young child’s needs before her own. She believed that she needed a break from the situation, but she didn’t feel that it was fair to leave their child with her partner. This led to a compound problem for her when she felt that her depressed partner was taking care

of his own needs and not the children's, leaving her feeling that she needed to take care of the children with her own needs unmet.

Another participant described the distress she felt about her children. Because she was at work much of every day and her depressed partner took care of the kids after school, she was resentful that she missed many of their activities. Further, she was frustrated that in the time that her partner spent with their children they took on their father's negative view of the world. She would have preferred to be caring for her children more but she felt that she had to adapt to the current arrangement. She explains that the children are the main thing keeping her in the marriage. She is sad that her kids don't have stable parents and "*are always afraid of what mood daddy is in today*", but she stays in the relationship because, "*if [her partner] gets stable the kids would be missing out.*"

For the other participant who no longer had a loving relationship with her partner, the feelings were similar. She explained feeling that she and her depressed partner were meant to have children together: "*that's what some couples do, they don't know they like each other for children but then when the children come, pop out, then you're glad you liked each other.*" She explained that even when she could not stand her partner and wanted to leave, she stayed and said she would always love him as the father of their child. She too was troubled when she saw her partner's depression "*rubbing off*" on their child, but she also thought that her partner was a good father at times. She thought of leaving, but explains that she did not have another good father figure to replace him with.

Two couples did not have children together. One partner explained that she had never wanted to have children and believed it would have been too much for them. Her

partner's job occupied so much of his energy that he did not have room left. Another participant – who was young – expressed feeling that she would have loved to have children, but her partner did not want to.

Communication

Several participants described ways that they communicated carefully with their depressed partners. One participant explained that, having had depression herself, she had great empathy for her partner and tried to communicate thoughtfully when she saw symptoms of depression that needed to be addressed. *“I know how it feels. I know it's a crappy feeling to have somebody say that to you.”*

For example, one participant explained that when she was upset about something she tried to wait until she had sorted out her feelings before discussing it with her partner: *“I think I have to just be honest with him about things, when things are feeling like that. Like I don't always take it to him right away, and this may be a part of our relationship that is a little unhealthy, but I am careful, I shield him from the worst of my feelings about things. I wait until I've sorted out my feelings. So that I only tell him what he needs to know.”*

Another participant was careful not to discuss her concerns or things that were worrying her with her depressed partner because it caused him so much upset that she then had to deal with his response. Instead, she made a habit of not talking to him about any things that were upsetting her. This was particularly true when she was worried about her partner's mental health. When she saw that he was becoming more distressed and depressed, she would be very careful to filter her concerns: *“... 'cause what would be*

coming up for me was outrage or hostility about the whole thing happening and he didn't need that."

Similarly, a third participant did not share her concerns with her depressed partner when she perceived that he was doing poorly. She explained that she knew she needed to talk to him more, but his depression made her feel that he could not handle the conversation. Therefore, their communication became dysfunctional as she feared making things worse. When she worried about the business that they ran together, she was unsure if she should share her worries with her partner, or if her worries would paralyze him.

For one participant the broken-down communication was the most troubling aspect of her partner's depression. She described feeling that she could handle his depression much better when he talked to her rather than put up "a wall" and communication between them broke down. *"When he would talk to me about the depression and what he felt I felt connected, closer to him. Then when he's not able to do anything about it I get frustrated and mad. But connected and that keeps, that's a much easier place to stay sustained than knocking your head and keep getting hurt and thinking why am I here? You don't care."*

Feelings Of Love

The degree to which partners felt isolated versus connected to their depressed partners seemed to be an important factor in whether their love survived the years with multiple spells of depression. When participants felt connected to what their depressed partners were going through they tried to help, and willingly picked up the life tasks that the depressed partner couldn't do at that time, talked and listened tirelessly, and generally did what they could to help their depressed partners through the tough time. However,

when partners felt estranged, isolated, or that they were doing the work of both partners, their relationships were strained.

Despite the trials of living with their partners' depression, most participants lovingly described their partners during these interviews without any prompting. Most of them described their partners' attributes and what originally attracted them to their partners and smiled while describing their first meeting and early years together. For most of them this love and recognition of their partners' good qualities kept the depression in perspective. This is illustrated by one participant's words:

“Yeah, I’m not going to get resentful about these things happening. It’s not like she’s this horrible person who’s trying to control my life by being depressed, it just doesn’t happen. She’s a wonderful person who occasionally gets depressed and that affects what we do. So uh, you know, she’s hung around with me long enough and taken care of me, so that’s a good deal.”

Most participants were also somewhat protective of their partners during the interviews, avoiding harsh descriptions and frequently following descriptions of problems with comments that expressed understanding of how hard it is to have depression. One participant commented that after the first 90-minute interview, he got to his car and realized that he had spent the entire interview time being protective of the woman that he loved, and he was reluctant to complain or delve into the problems that depression brings.

For two participants, their relationships with their depressed partners were no longer loving. Too many years of bad behavior on their partners' part, too many instances of roughness and domestic abuse, or too many changes had left them wanting their depressed partners to just leave and not come back. However, both of them expressed

love for their depressed partners as the fathers of their children. As one participant said, *“I love him because he’s my kids’ father, but I don’t want nothing to do with him. He’s icky and gross to me. I don’t want him around me. We don’t sleep in the same bed anymore. It used to be great, but it’s been a while since I’ve liked him. ... I was truly in love with him, and all of a sudden he changed and then we changed.”*

Sharing Affection

Either the depression or side effects of depression had a notable effect on the sexual relationship and the sharing of affection among partners for all participants in this study yet the change was seen in a variety of ways. For some the effect on the sexual relationship was recognized by both the participants and their depressed partners. In one case the depressed partner’s libido was decreased and the medication caused such a decrease in ability to reach orgasm that he would occasionally skip doses of medication to increase sexual function. This depressed partner had expressed feeling badly that his libido did not match his partner’s and he was not able to perform sexually as he would have liked because of medication side effects. This double effect of decreased libido and inability to perform as desired led to the depressed partner rarely initiating sex and this was hard for the participant, *“He doesn’t initiate sex, and that’s difficult as a person who wants to be wanted.”*

This participant struggled with feeling undesired, particularly because when the couple was first together the depressed partner had been the primary initiator of sex. But after recognizing that the lack of sex initiation by her depressed partner was more about his illness than about her, she was able to understand it, although it was still difficult at times. A similar frustration at feeling undesirable to the depressed partner was

experienced by another participant when she was pregnant. With an increased libido because of her pregnancy and an increased desire for closeness, it was hurtful to find her depressed partner uninterested in sex. and she felt rejected.

For another participant, the effect on sex was not related to medication (because the partner was not taking medication), but instead the decreased exchange of affection was more complicated and was wrapped up in the frustrations and stresses of all that was going on for the couple as symptoms of depression existed. Nondepressed partners recognized that they were picking up the slack while the depressed partner was retreating from family and work life and some were resentful about this.

One participant reported that during her partner's depression she was managing too much and she kept distant from her partner because she didn't want to act out '*being pissed off*', '*feeling outrage and hostility about the depression happening and he didn't need that.*' As she withdrew, so did her depressed partner.

As one participant explained, her partner's depression decreased her libido as much as it decreased his: "*I think that one of the main things that is attractive in a man is competence, so when he's sort of schlumping around... it's hard to want to respond if he makes a sexual overture... I thought, well the thing is, he has a choice, he can take the antidepressant and he's not interested in sex or he can not take it and I'm not interested in having sex with him.*"

This sentiment of frustration was exacerbated by the depressed partner '*stonewalling*' or failing to communicate when depressed. Increased communication between couples improved the sexual relationship. More openness and discussion of the

depressed partner's feelings made the nondepressed partner feel more loving and open to sharing affection.

For two participants the depressed partners' behavior was so poor because of depression that over the years they had disengaged from a habit of showing affection; they no longer slept together or expressed affection through touch or loving words. Both participants had suffered domestic abuse at the hands of their partners, so they neither felt desire or longing for their partner nor for sex or physical affection from any other man.

For other participants the notable decrease in demonstrated affection or sex was not problematic, it was simply a part of life that they could cope with—a trade off for an overall good life. The decreased affection when the partner was depressed was hard but it was accepted as part of an imperfect situation. Sharing affection with their children and pets through cuddling and hugging became a way to express affection that was not enacted in the partner relationship.

While the sexual relationship was diminished during spells of depression reported by most participants, the exchange of affection in other ways remained the same for some couples. Hand-holding, snuggling, sitting close while watching TV and hugging were all ways that affection continued to be expressed for some couples despite a disrupted sexual relationship.

Positive Effects

In the course of interviews participants were asked if there might be any positive effects of the depression. Most participants said 'no' right away, or commented that they never considered that there might be positive effects of the depression, but then thought for a moment and were able to come up with some things they thought were positive

effects of the depression. One participant felt that he had gained empathy and understanding of the many people around him in the world who might have depression and patience for why they may be acting oddly. Similarly, one participant who was also a mental health care provider felt that she had gained more compassion and empathy for the parents of mentally ill children that they care for lifelong.

One participant felt that the experience of watching his wife struggle with depression had given him an appreciation for how well she holds things together despite her depression. One participant responded that her partner, who was already introspective by nature, was forced by the depression to really look at his own poor behavior, including aspects of himself that she saw as more of his character than the depression itself.

The two participants who had particularly difficult experience, including poor treatment/abuse by their depressed partners, both described positive growth experiences for themselves. One felt that she had become stronger and more capable and wiser to the world. *“It’s amazing what you can get done because you have to.”* The other explained that she was stronger because of the adversity in her life brought by her partner’s depression and so is her son, of whom she is proud because he seems a little more mature than his friends because of all this.

Another participant felt that there aren’t any positive effects of depression for her or her partner. She sees that depression is neither good nor bad, *“it’s just part of life so get on with it.”*

CHAPTER 5

DISCUSSION

Introduction

As described in the literature review in chapter two, a variety of aspects of the experience of living with a depressed partner were known from previous research. It has been well documented that when one member of the couple is depressed, the other partner experiences anxiety, stress, depression, and difficulty coping (Halgin & Lovejoy, 1991; Coyne et al., 1987; Merikangas, Prusoff, Kupfer & Frank, 1985; Mitchell, Cronkite & Moos, 1983). It is also well known that nondepressed partners often pick up more parenting duties or increased responsibility for financial concerns (Coyne et al., 1987) and report feeling restricted and isolated (Halgin & Lovejoy, 1991).

There has been no discussion in previous research of the possible positive effects of the depression for individuals or couples, effects of depression on affection and sexuality, effects on raising children, discussion of the characteristics of the depression as it plays out in couple relationships, and limited discussion of moderately-depressed individuals (as opposed to severely depressed). There has previously been no research regarding how nondepressed partners feel about their quasi-caregiving role. Finally, while burden that nondepressed partners experience had been documented, there had been no previous attempts to explore the appropriateness of fit of the term ‘caregiver burden’ to the situation of living with/caring for a depressed partner. The goal of this study was to fill in these gaps as well as to provide context and breadth to what previous research has

shown; ultimately to provide clinicians with a better understanding of what it is like for individuals to live with a depressed partner.

The findings of this study support what has been shown in previous research and offer many previously unstudied facets of the experience of living with a depressed partner. First and foremost, this study concurred with previous research by demonstrating that individuals who live with depressed partners are profoundly affected by the depression, the change in their partner, and the change in their relationship. There are few findings of this study that are at odds with previous research. This section is a reckoning of previous research and findings of this study and is presented in two sections: findings of this study that support previous research and new findings of this study.

Findings of This Study that Support Previous Research

Certainly the findings from previous research documenting that nondepressed partners have excessively high levels of stress, and many experience depressive symptoms themselves (Coyne et al., 1987; Mitchell et al., 1983; Siegel et al., 2004) were supported by the findings of this study. All participants of this study described varying degrees of stress, fear, and worry that they felt related to their partner's depression. This supports the Spangenberg and Theron (1999) finding that 54% of individuals with depressed partners had some symptoms of depression and Coyne et al.'s (1987) finding that 40% of adults living with depressed partners had levels of psychological distress that made them suitable for therapeutic intervention.

This study supported previous findings that there is decreased expressed affection (Coyne et al., 2002), and increased conflict (Spangenberg & Theron, 1999; Benazon & Coyne, 2000; Siegel et al., 2004; Sandberg et al., 2002) when one partner is depressed.

Two couples experienced so much conflict and difficulty that they no longer had loving relationships (with essentially no expressed affection) with their partners, while four participants described fluctuating levels of conflict and generally lower levels of expressed affection when their partner was depressed. This was, for some, related to decreased libido for some and for others was related to increased frustration/irritability on the part of both partners, but generally concurred with Basco et al.'s finding of impaired capacity for intimacy caused by accumulation of marital problems characterized by emotional deprivation and unresolved tension.

There was one exception to this: one participant described no increased conflict during episodes of depression, and no decrease in expressed affection—in fact her partner's need for touch increased when she was depressed. It is possible that this exception is related to their being the only lesbian couple in the study, but based on the small sample size that is just conjecture—but may be a valuable question to be considered for future research.

One study by Merikangas et al., (1985) found that couples with one depressed member scored significantly worse in all areas of functioning, reported being generally unhappy in their marriages, and viewed their marriages as worse than most marriages they knew. This negative summary fits only two of the participants in this study, both of whom had suffered violence at the hands of their depressed partners and no longer loved their partners. Aside from those two participants, the other five participants in this study did not describe such generally negative outlooks on their partnerships and overall functioning. On the contrary, four of these five participants expressed statements that put the depression in the context of a generally good and functional relationship.

The difference in perspective between these four participants and the findings in Merikangas et al.'s (1985) study may be due to a greater severity of depression in that study (with samples that were recruited from in-patient psychiatric settings and were treated for major depression). However, it may also be due to a generally optimistic outlook that these four individuals displayed. There may also be added perspective that three of these four participants gained from having gone through divorces, as their current partnerships were second marriages for each of them.

A final and important finding of previous research that was supported by this study was the need for nondepressed partners to be involved in the psychological interventions that address their partners' depression (Harris et al., 2006). Three participants in the study expressed extreme frustration at not being able to participate in their partners' treatment or to get their partners to initiate treatment. Two participants found it essential to their relationships with their partners and also to effective management of crises that they have access to their partners' therapists/psychiatrists. This is very important because the structure of psychotherapeutic care today emphasizes patient motivation and privacy to such an extent that spouses/partners often feel that they have no access to the therapist.

New Findings of this Study

As was hoped in the planning of this study, the open-ended qualitative inquiry design of this study elicited many aspects of the experience of living with a depressed person that were not known from previous research. New findings in the first section, 'Identifying onset signals' include: a kind of personal expertise on their partners' depression, a struggle to maintain or regain perspective, fear about consequences of the

depression, the dilemma felt about guarding privacy, frustration felt by nondepressed partners, and careful communication about medication. New findings in the ‘Trying to help’ section include: love and empathy beneath the attempts to help, discomfort with the term ‘caregiver burden’ despite its accuracy in this context, disruption to the partnership that caregiving implies, and difficulties encountered by nondepressed partners who try to access or initiate healthcare for their depressed partners.

The third section of the findings, ‘Internal management of the diagnosis’ revealed new findings including: struggle with guarding privacy while needing to talk, fear of stigma, and coping by not talking and by seeking social isolation. And finally, new findings in the fourth section, ‘Partnership disrupted: Carrying on with life when one partner is depressed,’ included: job performance as a measure of depression severity, depressed individuals who run their own businesses, limited expression of worries to the depressed partner, and caring for children presents unique struggles and conflicts about sleep, workload, and household duties.

These findings are discussed in this section under the four thematic headings presented in the results chapter.

Identifying Onset Signals

Previous research has described the difficulty of living with a partner who is hopeless, lacks energy, feels worthless, worries excessively and lacks interest in every day activities (Coyne et al., 1987), and all of the previous research has been based on the Diagnostic and Statistical Manual of Mental Disorders criteria for diagnosing depression. However, in this study participants provided a separate list of characteristics that, to them, were indicators that their partners were becoming depressed. This is a set of

diagnostic criteria from people who are experts not in mental illness but experts on their partners. And while these are not clinically applicable observations, the nature of that expertise should not be overlooked.

Yet the expertise of nondepressed partners is complicated by their own proximity to the situation. They are active with their own jobs and life tasks, operating with the assumption that their partners can take care of themselves. One participant explained how this is different from caring for a child whom you are constantly assessing. Participants explained that they were simultaneously adapting to new conditions until something clearly abnormal occurred, causing them to try to regain perspective and ask “*is this normal behavior?*” Maintaining perspective when one’s partner’s behavior changes over weeks is not easy, as one participant pointed out; she saw her ability to constantly adapt to situations as an asset.

The fear described by some participants is a new concept that this researcher had not encountered in previous studies: fear of the unknown, fear of how bad things were going to get. Another facet of the experience of living with a depressed partner that had not been encountered in previous research was the dilemma that participants felt when they wanted to talk to family or friends but could not because of their partners’ desire for privacy. For the participants who felt this dilemma, keeping privacy meant waiting out a period of isolation while worrying about their partners’ increasingly severe symptoms.

Previous research had certainly documented the role of medication in treating depression, but the findings of this study that described the communication between partners about getting a medication started or restarted had not previously been addressed. Further, the level of frustration experienced by some participants about

seeking care, managing side effects, taking medication holidays, agreeing to take medication, and open and honest communication about the use of medication was also new information explained in such detail. Frustration emerges as a major component of what it is like to live with a depressed partner, and this frustration appears to stem, more than anything, from participants' ability to see the problem but not be able to get the depressed partner to do anything about it. These findings add much to a clinician's understanding of what occurs at home before a patient arrives for the clinic visit requesting medication or expressing concern about depression.

Trying To Help

We know from previous research that nondepressed partners attempt to help their depressed partners. Women have a stronger inclination to attend to the needs and desires of their partners (Eisenberg and Lennon, 1983), and women may be more likely to develop a sense of responsibility to those needs (Gilligan, 1982). However, partners of both sexes help each other in different ways. This study details the ways that participants try to help their depressed partners and how depressed partners react to that attempt to help, as well as their perception of when trying to help becomes burdensome. This study also reveals the love and empathy felt by some nondepressed partners that motivated their attempts to help. The understanding that some partners have for their depressed partners not wanting to be on medication was an aspect of this experience that was newly revealed in this study.

Previous research by Coyne et. al (1987) demonstrated that individuals living with depressed partners experience a formidable burden and their level of psychological distress is directly related to extent of their burden. This study explored the fit of the term

‘caregiver burden’, which is used in the context of many illnesses but not in depression, in the context of living with/caring for a depressed partner. It was demonstrated that participants did not identify with the term ‘caregiver burden’, though most of them could readily name ways that they take care of their depressed partners and ways that they occasionally feel burdened.

The distinction between *being* a caregiver and *giving care* stems from the partner relationship, in which the two members of the partnership are thought of as equals and in which caring for one another is expected. As equals it feels patronizing to think that one person is the other’s caregiver; it implies that the recipient of the care is incapable, and therefore the term ‘caregiver’ feels uncomfortable. And while the care that participants provide to their depressed partners may be necessary, this is seen as a temporary arrangement during crisis. There is also a sense of reciprocity in which the participant is giving care within the general expectations of the partnership, and that if the circumstances were reversed the depressed partner would do the same for them. This reciprocity is essential to the partnership and is partly what keeps participants from feeling like caregivers.

This partially explains the frustration experienced by participants when they wanted to be involved in therapy or at least in communication with their depressed partners’ therapist or psychiatrist. Here they were in a partnership, wanting to support their depressed partner in getting treatment and following through with treatment plans, but feeling cut out of the equation by the health care system. The reality of our mental health care system today is that providers generally want to see motivation and investment on the part of the client (the depressed partner), and therefore do not welcome

or allow partners to initiate appointments. This can be a catch-22 for a concerned partner who gets a depressed partner to the point of agreeing to therapy but who is still too unmotivated by depression or generally feeling too apathetic or withdrawn to make the call for an appointment himself. As one participant described, it made her feel like everything she did to try to help was wrong.

The term ‘caregiver’ also implies serious illness, usually one that is visible. The term brings to mind either an adult caring for a child or a an adult caring for another ill person who is in some way incapacitated, sick, or hurt. For example, a family member who has cancer or a serious chronic illness. None of these images matches with the depressed partner to whom participants provide a unique type of support or care.

However, participants’ resistance to the term ‘caregiver’ does not mean that they are not actually caregivers. In the strict sense of the term they are caregivers because they are giving care to their depressed partners. The term fits, though most participants do not identify with it themselves. It may be because society does not fully accept mental illness as a legitimate, acceptable illness that we are not fully comfortable with the thought of an individual caring for a depressed partner as a caregiver. Or it may be because in partnerships we strive to be essentially equal members with give and take, each caring for the other at different times and in different ways, and using the term ‘caregiver’ marks an imbalance that participants were uncomfortable naming.

One participant described yet another factor that is important about identifying caregiver burden: her lack of recognition of whatever burden she may have been experiencing because she was too busy coping to worry about that at the time. It may be that caregiver burden, if it is an appropriate term for this situation, feels more appropriate

to the outsider who can see the numerous ways the nondepressed partner is accommodating, adapting, and trying to offer care. But to the nondepressed partner currently caught in the situation of coping with a depressed partner who needs help, patience, and support, these feel like everyday requirements of their partnership.

In the end, 'caregiver burden' does technically capture the experience of individuals who live with depressed partners. However, the term is a poor fit because it implies a certain level of severity, a level of chronicity, and a level of care that does not match the experience of living with a depressed partner. Moreover, the participants in this study did not identify with the term, demonstrating its poor fit. A more accurate and suitable term is needed and will ideally acknowledge the challenge that individuals face as they transition from partner/equal to caregiver offering help that may not be wanted.

This study reveals that, especially for partners who are also raising small children, being a caregiver for a depressed partner can be exhausting and depleting. As one participant pointed out, her husband's depression was not depleting her, but his need to take care of himself was leaving her to do all of the parenting and household work alone, and this left her feeling resentful that she was taking care of everyone except herself.

Internal Management Of The Diagnosis

Social isolation was a concept that previous research on depressed spouses had identified. However, the complexities of how guarding a depressed partner's privacy plays out as a cause of social isolation had not, to this researcher's knowledge, been discussed in research before. The need to protect their partners' privacy just at the time that they most needed to talk to someone else about their worries presented a significant dilemma or awkward situation for several participants. Other participants had no qualms

discussing their concerns as needed and they consequently felt less social isolation caused by their partners' depression. Privacy and lack of discussing her concerns served as an effective coping mechanism for one participant. Social isolation, too, served as an effective coping mechanism for some depressed partners and for two participants this was remedied by instigating a move to a more populated area once the depression was past its acute phase, with the intention of decreasing isolation for both participants and their depressed partners.

The degree to which participants or their depressed partners felt a stigma about the diagnosis had also not been previously discussed in the context of previous research. It was the same participants who felt obligated to protect their partners' privacy as those who felt (or whose partners' felt) shame or stigma about the diagnosis. An important distinction though was that participants all felt no internal sense of shame or stigma about depression and viewed it very matter-of-factly, but several feared that society or family members would view things differently. Being able to discuss concerns and the existence of the depression was a major support to participants who had this freedom.

Partnership Disrupted: Carrying On With Life When One Partner Is Depressed:

Some of the many effects that partners' depression had on daily life were documented in previous research and were further expanded upon in this study. For example, it was known that communication about the depression was altered to spare the depressed partner from worsening symptoms, that nondepressed partners often assume social roles and external responsibilities, and often change occupations to secure additional income and assume decision making for major life events (Dudek et al.). However, each of these facets of daily life was affected in more than a single way.

Some participants noted that their depressed partners' job was the primary source of stress and therefore intimately involved in the source of the depression. And for other participants job performance/attendance was the ultimate measure of how depressed their partner had become. Indeed, some participants' fear at seeing on-setting depression symptoms was largely due to fear that the depressed partner would not be able to maintain work attendance or his job. Job security equates with financial security, and when depression threatened job attendance participants worried about the couple's/family's financial security. Job performance served as the validation of the severity of the depression for several participants as they saw partners lose their jobs or take forced leaves of absence.

Concern about the effects of the partner's depression on employment was most acutely felt by couples that owned businesses together. Certainly the increased level of concern is understandable, as the entire family's welfare depended on the success of the business, which was linked to the ability of both partners to fully participate. Considering the increased risk that owning a business has for a person with depression, it begs the question: is it wise for a person with serious depression to own a business? Yet there is an enticement to owning one's own business for a depressed partner because they can be isolated if they wish and they can do things on their own terms, including as it relates to their sleep. Perhaps there is an enticement for the nondepressed partner too because they want a job situation that will work and can be tailored to the depressed partner's skills. Not having a boss means having more flexibility and less conflict.

Participants honed their communication skills to maintain contact with their depressed partners, to avoid agitating them and increasing their distress, and to convey

the empathy and love that motivated their attempts to help. However, many attempts to manage communication with depressed partners as effectively as possible were ineffective as communication was often troubled for these participants. It was difficult for participants to strike the balance between being a partner who shared personal concerns and being a caregiver who sheltered a depressed partner from worries and even their own frustration and anger, making communication less open. The primary function of effective communication about the depression was that it kept couples on the same side, united against the depression, working to overcome it together. Whereas participants whose communication with their depressed partners broke down felt less connected to their partner and less able to help and less sure about their role and their closeness to their partners.

The effect of partners' depression on the love felt between partners or by nondepressed partners had not been discussed in previous research either. This study demonstrated that, for the five participants who continued to have loving relationships with their depressed partners, there was always a working partnership in more ways than just raising children together. For the two couples who no longer had loving relationships, the depression had caused years of poor behavior that had made mutual loving feelings and affection difficult or impossible for these two participants. In both cases the participants described that the depression had wrecked their partner and the poor behavior had wrecked their love.

Previous studies had documented the effect of living with a depressed person on families and children, and the common effect of the nondepressed partner picking up more of the parenting responsibilities when one partner is depressed (Benazon, 2000;

Coyne et al., 1987). However, the context of how that shift occurs has not been detailed in previous studies. This study demonstrates the frustration, exhaustion, and imbalance in workload that is experienced by individuals who are raising young children and caring for a depressed partner. Participants in this study explained the conflict they felt as they wanted their depressed partners to sleep and take care of themselves, knowing that as they did so it meant that they had to take on more parenting and household duties, leaving them feeling exhausted and resentful toward their depressed partners. Remarkably, even the most angry participants acknowledged the ability of their depressed partners to be loving and good parents even while they were frustrated with them as partners.

Reckoning Biases With Results

As part of the design of this study, the researcher made efforts to identify her own biases and to set aside her own expectations of what this study would discover in the hopes of maintaining open-ended questions and not directing participants' responses in any particular way. As discussed in the methods chapter, much reading had been done in the literature review, a pilot project had been done, and the researcher had discussed the experience of living with a depressed partner with patients in clinical settings. Based on these previous experiences and exposures, the following assumptions or suspicions were held by the researcher at the outset of this study:

- Assumptions (aside from the many findings from previous research laid out in the literature review):
 - Nondepressed partners have a largely unrecognized role as caregivers
 - It is difficult to live with a depressed partner
- Suspicions that this study would reveal:

- That burdens are greater for individuals who are raising children together
- That there is more anger and frustration on the part of nondepressed partners than previous research had reported.
- That privacy is an important issue for nondepressed partners
- That sexuality would be an area of distress, disappointment, or frustration for participants
- That there are some positive effects of living with a depressed partner that previous research had not captured or that the love present in these relationships is significant (why else would they still be in the partnership?)
- That there are not significant differences in experiences of married versus unmarried partners, nor among hetero versus homosexual couples.

Many of these assumptions and suspicions turned out to be validated by this study, but some of them were not as strongly validated or as completely on track as the researcher would have hypothesized prior to the study. For example, the assumption that it is difficult to live with a depressed partner was true for the most part, but two participants made it clear that they would not characterize their life or partnership as being damaged by the depression (though it is notable that both of these participants reported the lowest levels of current level of depression for their partners). Rather, these two individuals acknowledged that having their partner depressed was unfortunate and scary, frustrating, or even terrible at times, but it was simply part of life and they viewed the depression with a perspective of the entirety of life and relationships which they were generally content with.

Similarly, the researcher's suspicion that sexuality would be a troubling aspect of these partnerships was validated, but for most of the participants (in fact, 6 of the participants over age 35) the effect of medications or the illness on libido and the expression of affection were not excessively troubling. It was only the youngest participant (aged 34) that spoke freely and extensively about her frustrations related to her partner's altered sexual performance (or more accurately his feelings and perception of his altered performance and decreased desire to initiate sex). For the most part couples reported decreased affection and sex during depression, and this brought some frustration but it was not overly troubling for them. All participants were able to discuss sex in the interviews with some openness, but despite researcher efforts to be matter-of-fact about sex and its role related to depression, there may have been some reluctance to speak about sex at a deeper level that revealed problems, this is not known.

The positive effects of living with a depressed partner, which the researcher expected were present, were minor. Most participants rejected the idea or laughed when they were asked if there were any positive effects, but then each of them modified that initial response with some description of increased empathy, love, appreciation for their partner, or recognition of skills they had gained because they had taken on more in life and in their homes than they might have if their partners were not depressed. This was, then, a validation of the researcher's expectation, but the responses were not strongly voiced and would likely have not come up if the direct question had not been asked.

The remaining four suspicions were strongly validated: there were not significant differences in experiences of married versus unmarried partners, nor among hetero versus homosexual couples (though this statement must be modified by the small sample size

making comparisons between groups of limited significance). Based on the findings of this study, burdens are certainly greater for participants who are raising children together, though burdens were experienced by all participants. There was considerable anger or frustration voiced by all but one participant. Knowing the source of the anger and frustration provides more of a basis for understanding previous research findings that marriages of depressed individuals are characterized by decreased expressed affection (Coyne et al., 2002), and increased conflict (Spangenberg & Theron 1999; Benazon & Coyne, 2000; Siegel et al., 2004; Sandberg et al., 2002). Finally, privacy is a significant factor for couples and it is directly related to the extent of social isolation and support that nondepressed partners experience.

Implications for Nursing Practice

The ultimate goal of this study was to provide greater breadth and depth to the research previously available to clinicians. With the intent of contributing to the nursing discipline, this study's primary aim was to improve clinical care by nurse practitioners who have daily encounters with families in which one partner is depressed. However, the application of these findings is not limited to nurse practitioners. Indeed, given the prevalence of depression in society today, nurses, social workers, psychotherapists, physicians, and ministers might all benefit from the greater understanding of what it is like to live with a depressed partner that this study offers. Nurse Practitioners, and particularly Family Nurse Practitioners, were the primary audience for this study because they are ideally situated to attend to the family dynamics that affect patients' health.

For example, a Family Nurse Practitioner sees a 30 year-old woman for regular visits with primary complaints of poor sleep, high stress, abdominal discomfort, and back

pain. It would be standard as part of the Nurse Practitioner's health history interview to ask about the patient's mental health, history of depression, etc. It would also be standard as part of her social history to ask about her family, who is living in the home, her marital status, the ages of her children, etc. It would not be standard to ask about her partner's mental health, however this study points out that it probably ought to become standard. This study and previous research make it clear that if the patient is living with a depressed partner there are many reasons that she might be experiencing increased stress and poor sleep. The findings of this study encourage clinicians to think broadly about the effects of depression in the home, to ask more questions about sexuality, affection, sleep, workload at home, child rearing, stress load, job-related stress, supports the patient might have, and other important aspects of the experience of living with a depressed person that were revealed in this study.

This study encourages Nurse Practitioners and other clinicians to take what is known about side effects of antidepressants (specifically decreased libido or inhibited orgasm) and bring that knowledge into the patient visits with individuals who live with depressed partners. This study also encourages Nurse Practitioners and other clinicians to take what is known about caregiver burden and ask questions about the extent of burden experienced by their patients who live with depressed partners. As Family Nurse Practitioners our goal is to care for the whole patient in the context of their family unit, and to recognize that when one member of the family is affected by illness or injury there are waves of effect throughout the family unit.

Finally, this study encourages Nurse Practitioners and other clinicians, when they see depressed patients, to ask about their nondepressed partners. In many practices it

would even be appropriate to invite the nondepressed partner for evaluation based on their current experience of giving care and living with a depressed partner. This recognition of the caregiver role is important since the well-being of the caregiver affects two or more individuals: the depressed partner, the caregiver/nondepressed partner, and any children who are in the home.

Implications for Policy

As explained in the discussion of previous findings that were supported by this study, it is important for nondepressed partners to be involved in the psychological interventions to treat their depressed partners. Involvement in treatment will teach couples to consider the interactional nature of depression, teach the nondepressed partner what he or she can do to help effectively, and also give the nondepressed partner a voice when concerns about the severity of symptoms leave them feeling worried and isolated.

It is equally important, as demonstrated by this study, that nondepressed partners have some way to assist in the initiation of care. Psychiatry practices have, by necessity, developed policies that require the patient to set up their own appointments, but providers, particularly in family practice, would be able to reach out and make first contact with depressed patients more easily if they had flexibility to such policies. It would benefit providers, depressed patients, and nondepressed partners if partners had some way to help get care started and help keep it sustained in an appropriate way.

Limitations of this Study and Implications for Future Research

As an in-depth qualitative study, the sample for this study was limited. However, the findings provide breadth to our understanding of what it is like to live with a depressed partner, indicating future areas of study that could be done with either

qualitative or quantitative methods. As detailed in the literature review in chapter two, there have been important differences found in the ways men and women deal with the effects of a partner's depression. With limited male participation in this study these potential differences could not be discussed. Future study with more male participants would be beneficial. The issues raised by participants who were raising young children indicated a unique set of challenges, and this population warrants further study.

There is a historically significant reason to conduct further research on families with young children at this time. With the financial challenges that have occurred in the U.S. since 2008, there has been a large number of layoffs and higher rate of unemployment. Traditionally male-dominated industries were most affected by financial troubles, so men have been particularly hard hit by layoffs, suffering two-thirds of the 11 million jobs lost since the recession began in 2007 (Bennett & Ellison, 2010). This has led to the current two-thirds of American households with women as the breadwinner or co-breadwinner (Bennett & Ellison). With many men affected by unemployment, shifting career expectations, loss of their breadwinner status, and transitions to staying home to take care of children, there may be ramifications for depression and burden experienced by nondepressed partners.

Further limitations of this study are that participants were all white. Given the generally homogenous racial make-up of this region, this limitation was expected and as much diversity among the sample as could be achieved was: including participants from a variety of economic status and educational backgrounds, one participant who struggled with chronic mental illness herself, a male participant, a homosexual participant, and a partner who was not married. However, future studies that include greater diversity will

continue to add to the breadth of our understanding. Though the sample in this study was small, there did not appear to be significant differences in experiences between those who were married and unmarried. Therefore an implication for future research would be to continue to define inclusion criteria using “partner” rather than “spouse.”

A further limitation of this study is that any study of a partnership can only be a discussion of multiple constantly changing variables. In monogamous relationships individuals have no point of comparison to other partnerships. What may be felt as a problem attributable to depression may be a problem that is experienced in most partnerships and the presence of depression makes it appear to be the cause. It is not usual for qualitative studies to have controls, but there may be some value in conducting a study similar to this one with multiple couples who do not have depression included in the sample, simply as a point of comparison.

A final important limitation of this study that is inherent to its design is that it provides one side of the story that is really about a partnership. The focus of this study was on the nondepressed partner, but much of what was discussed was about communication and exchanges that involve both members of the couple. This was necessary to achieving uninhibited responses by participants, but it limits the ability to learn more about, for example, Spangenberg and Theron (1999) findings that poor coping and high stress in nondepressed partners can cause poor emotional support to their depressed spouses, and this can aggravate the depression or Miller et al.’s (2000) finding that a cyclic exchange of high stress by family members can increase depressive symptoms in partners.

Future research could further our knowledge by using quantitative studies and larger samples to investigate the findings that were unique to this study, including: frustration, anger, and fear felt by nondepressed partners, difficulties of child-rearing when one partner is depressed, and the effects on sexuality and affection expression, and the role of privacy and stigma as it relates to burden. One question which arose during the analysis of results was whether participants felt that therapy was helpful, and this would be a useful area of further research as well, particularly if comparisons of male and female responses to therapy are made.

CHAPTER 6

CONCLUSION

This research has demonstrated that living with a depressed partner is an experience that is, in some ways, similar to caring for a family member with other serious, chronic illnesses and in other ways a unique experience that is affected by the caregiver's partner relationship and societal acceptance of mental illness. There is a fine balance between maintaining a partnership when one partner is depressed and the transition into caregiving. This study explored this area of transition and the language used to describe this transition.

This study has filled in some gaps of the previous research available regarding depressed spouses. It has offered description and context for the daily consequences of depression in a partnership that will help nurse practitioners and other clinicians provide more thorough, understanding, and sensitive care to patients. Suggestions for policy implications and further nursing research have been made to bring the findings of this study another step closer to providing excellent care and appropriate policy for those who experience and are affected by depression.

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