

FEATURE ARTICLE

Alone together: A grounded theory study of experienced burden, coping, and support needs of spouses of persons with a bipolar disorder

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ABSTRACT: *Bipolar disorder is a chronic and severe mental disorder. Little is known about the experiences of the spouses of such patients. A grounded theory study was undertaken to examine the burden for spouses living with a partner with a bipolar disorder and to explore how they cope and what support they need. Fifteen spouses and ex-spouses were interviewed; they experienced heavy burden and found themselves to be ‘alone together.’ Their coping process is found to involve appraisal of the situation and attempts to achieve a balance between self-effacement and self-fulfilment. While support can clearly reduce experienced burden, the spouses surprisingly receive virtually no professional support. A theory is developed that constitutes a starting point for the development of adequate support for spouses.*

KEY WORDS: *bipolar disorder, burden, support needs, caregiver, coping.*

BACKGROUND

Bipolar disorder is a severe and chronic mental illness with lifetime prevalence rates estimated to be 1.5–2% in the European Union (Pini *et al.* 2005). The disorder is characterized by manic episodes alternating with depressive episodes, mixed episodes, and euthymic episodes (American Psychiatric Association 2000). It is reported that 75% of patients also experience functional disabilities between episodes (Rea *et al.* 2003), which can lead to decreased social functioning, diminished career prospects, and financial dependence. An increased risk of aggression has been found to occur during manic episodes (Feldmann 2001; Ogilvie *et al.* 2005). The lifetime risk of suicide is increased for people affected by a bipolar dis-

order, with an estimated nine times higher incidence of suicide risk than among the general population (Dutta *et al.* 2007). These factors all place a severe burden on the caregivers of these patients (Chadda *et al.* 2007; Chakrabarti & Gill 2002; Nehra *et al.* 2005; Perlick *et al.* 2005), which can lead to psychological distress for the caregivers (Goossens *et al.* 2008; Perlick *et al.* 2007).

To provide patients with a bipolar disorder appropriate evidence-based care, guidelines have been developed, such as the American Psychiatric Association (American Psychiatric Association 2002) and Canmat guidelines (Yatham *et al.* 2005). These guidelines are aimed mainly at medication, psychotherapy, and psychoeducation (Regeer *et al.* 2004). During the past few decades, treatment and care have been increasingly provided outside psychiatric institutions, which means that the provision of informal care given by non-professionals for these patients has expanded greatly (Cuijpers & Stam 2000). Family members, such as spouses, have thus become more important in care. Research has shown that providing support to those involved with patients with severe

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mental disorders should constitute a substantial part of treatment and care (Rea *et al.* 2003). Given that nursing care is aimed at the consequences of illness, providing care for caring family members can be considered part of the nursing task (Dutch Nursing Association 2004). It is therefore essential that nurses have knowledge of the needs and experiences of caregivers in order to provide the appropriate support. In a recent systematic review on burden, coping, and the support needs of caregivers for those with a bipolar disorder (van der Voort *et al.* 2007), caregivers were found to frequently experience severe burden; for example, disruption of household activities, leisure time, and career, strained family relations and reduced social support, reduced mental health, subjective distress, and burnout. Further research is needed to explore how professionals can provide support for the caregivers of patients with a bipolar disorder. The concepts of caregiver burden and caregiver-coping mechanisms in dealing with the burden need more exploration. Additional research is needed to identify just how adequate illness perceptions and effective coping mechanisms can best be promoted on the part of caregivers.

The purpose of this research is to provide greater insight into experienced burden, coping mechanisms, and the support needs of these spouses. Therefore, the research questions are: Which burdens do spouses of people with a bipolar disorder experience by living with a spouse with a bipolar disorder? How do they cope? What support do they need?

METHOD

Design

In a qualitative study undertaken in the Netherlands, the grounded theory method, as developed by Glaser and Strauss, is used (Strauss & Corbin 1998). This research method is considered suitable for our research purposes as it addresses the behaviour, experiences, and feelings of humans. Using this method provides a good starting point for the examination of a phenomenon about which little is known and can lead to the development of theory based on data. Finally, it can produce practical advice about the support needs of spouses of persons with a bipolar disorder.

Sampling

To recruit participants, a pamphlet was developed with a concise overview of the research and an outline of the inclusion criteria. Caregivers were invited to participate in the study during the annual meeting for the spouses of patients with a bipolar disorder, organized by the Dutch

Society for Manic Depressives and Caregivers. This society, run by volunteers, provides members with information and support by publishing a journal and organizing meetings for members. Spouses of people with a bipolar disorder were required to meet the following criteria for inclusion in the study: the relationship duration is at least 5 years, the spouse lives with the patient, the patient has been diagnosed as having a type I or II bipolar disorder according to DSM IV (American Psychiatric Association 2000), the patient has suffered at least three episodes in the past with at least one episode in the previous year, the spouse speaks and understands Dutch, the spouse is older than 21 years of age.

In keeping with the grounded theory methodology, during the study, the question of why some spouses stayed while others gave up and left their partners arose. It was therefore decided that ex-spouses should be invited to participate. This was done via an online advertisement posted on a website for single parents and via newspaper advertisements. The ex-spouses were required to have had a relationship with the patient for at least 5 years and divorced for no more than 15 years. The rationale for this choice was that while ex-spouses were hard to find, there was an increased risk of the ex-spouse not remembering what the relationship was like if the period of separation was too long. In summary, purposive and theoretical sampling was undertaken. Participants were informed orally, as well as in writing, about the aims and the method of the study, and informed consent was obtained, with all participants signing the form.

Data collection and analyses

The collection and analyses of the data occurred simultaneously. Data were collected via an interview with the spouses in their homes. The interviews were semistructured, audio recorded, and transcribed verbatim. The constant comparison method (Strauss & Corbin 1998) was used: Transcriptions were analyzed immediately after their completion, and the results were used to guide the course of subsequent interviews and the selection of topics to be further addressed. The researcher took notes throughout the entire study and kept logbooks. Thoughts, decisions, and emerging questions were all recorded and served as additional data. Data collection continued until saturation was reached, which meant that no new concepts arose from the data (Strauss & Corbin 1998). The data were systematically analyzed and interpreted according to the coding techniques developed by Strauss and Corbin (1998), and with help of MaxQDA (VERBI Software, Berlin, Germany), a software program designed to analyze and edit qualitative data. During the interpretation and

coding process, the following questions were asked: What makes this spouse feel so lonely? Which factors influence this feeling of loneliness? What are the consequences of this loneliness? What factors appear to help the spouse cope? The core category developed gradually, and slowly, more insight appeared in the experiences of these spouses and the theory emerged.

Trustworthiness of the data

The methodological quality of the data was checked and maximized in several ways using the criteria of Lincoln and Guba (1985). Credibility of the data collection was enhanced by interviewing the participants in their own houses. The researcher was a registered nurse with 30 years' experience in mental health care who was trained in qualitative interview techniques. The study was performed as part of a Master of Science degree in nursing. Audio recording of the interviews and verbatim transcription also enhanced the credibility and the chance of false registration of the data was avoided. The content of all the transcripts was checked by the researcher. Four full transcriptions, randomly selected, were compared to the recording to verify that the transcription matched the original. Member checks were performed during the interviews. Interpretations by the researcher of data from earlier interviews with other participants were presented to the participants and they were asked to react. Emerging interpretations were also presented to the participant during the interview itself. Participants were further asked to inspect the transcripts of their interviews together with the interpretations provided by the interviewer. Nine responded and agreed with the interpretations of the researcher; the other six did not respond. The reason for not responding was unknown to the researcher. Partial triangulation of researchers was accomplished on two occasions by having two additional researchers independently analyze two interviews and discuss the results together. Logbooks were maintained throughout the entire study, which increased dependability. The detailed description of the method and conduct of the research in the research report also increased the dependability and transferability of the results, as reporting makes replication possible (Strauss & Corbin 1998). Finally, the confirmability was maximized with the provision of 'thick description', where numerous citations of participants are presented, which allows readers to check the interpretations being made themselves.

Ethical considerations

All of the participants volunteered to participate in the study, and no connections existed between the researcher

and mental health workers who might provide care for the spouses. No permission was needed from the Dutch Medical Ethical Committee because the participants were healthy people with no specific vulnerability who volunteered to participate. Anonymity of the participants was guaranteed. The participants were told that the answering of questions was completely voluntary and that they could terminate the interview at any point without consequences. The researcher was aware that the interview could be quite emotional for the participants and was alert to such indications. A psychiatrist was available to answer questions on the part of the participants or provide support. However, none of the participants made use of the psychiatrist.

RESULTS

Participants

All 15 respondents met the inclusion criteria as formulated. Information on the sociodemographic characteristics are presented in Table 1.

Core concepts

Most of the spouses experienced heavy burden and difficulties with coping. The core category in this burden and in the process of coping was feeling 'alone together': The healthy partners felt alone, although they live with their partner. This feeling was reported to be experienced by many spouses during not only manic and depressive episodes of their partners, but continuously. In Figure 1, an image representing the experience of living with a person who has a bipolar disorder is presented. The concepts used in this model to explain this experience are accounted for in the following part of this article.

Burden

The main burden that spouses experienced was related to not being able to share several important aspects of daily life with the spouse who had a bipolar disorder. The

TABLE 1: Sociodemographic characteristics of the participants

	Spouses <i>n</i> = 11	Ex-spouses <i>n</i> = 4
Sex	6 female, 5 male	3 female, 1 male
Age (years)		
Range	30–60	34–53
Median	42	37
Duration of relationship (years)		
Range	6–30	8–30
Median	8	9

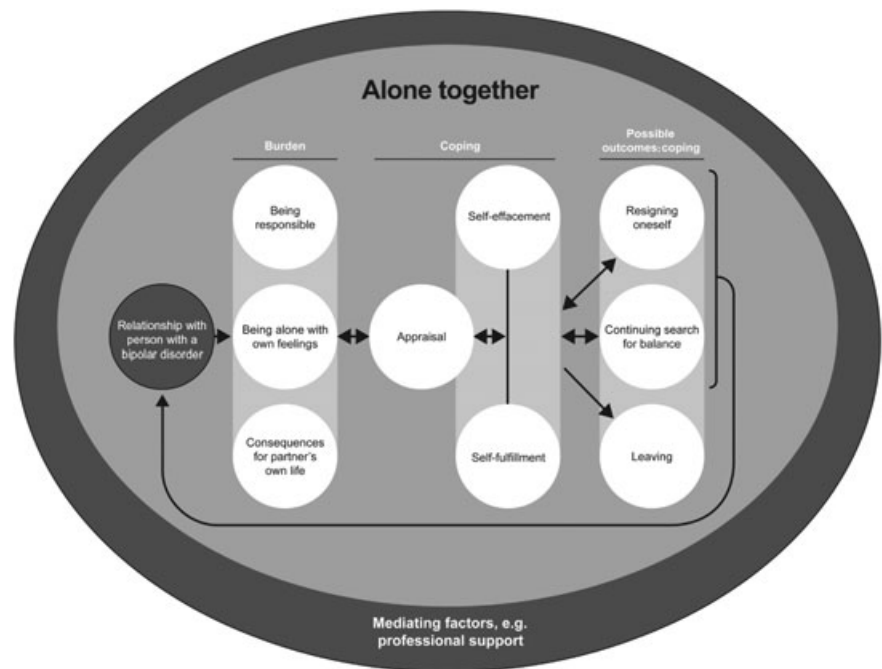


FIG. 1: *Experience of living with a person with a bipolar disorder.*

resulting loneliness was described in three categories of experienced burden: being solely responsible, being alone with one's feelings, and consequences for the life of the healthy spouse.

Participants stated that they felt responsible for the household and raising the children, as well as for dealing with the disease. They made sure that the partner took their medicine, and noticed changing behaviour and symptoms.

It is just, uh, just so difficult to feel that if I happen to make a mistake that everything is going to collapse . . . he is normally not really there and that is very difficult for me. This responsibility is very heavy. Yes . . . (woman, age 30, two children)

The participants said they felt alone with their emotions about the illness and had feelings of guilt and anger. They said that they were constantly caring about their partner, that there was an absence of sex and intimacy, and there were doubts about the future.

It is not possible to be in contact with him, no. No matter how hard you want to. No matter how much you fight for it. No, that is the worst of it, I think. That causes so much grief and pain . . . The being alone . . . (woman, age 49)

Participants spoke of the consequences on their own lives, such as being forced to quit a job, perform new roles in the relationship, and being exhausted.

. . . [I was in the] highest level in business and I had to travel around the world for this job. I had to give it all up, because you never know how things are going at home. Being away that long is not possible any more . . . (male, age 42, two children)

Appraisal

Healthy spouses were learning to cope with their partners who had a bipolar disorder and the consequences of the disorder. Here, being 'alone together' could be recognized. The development of coping was not linear and was characterized by alternations between different strategies. The healthy spouses became increasingly aware of the situation they were in and gradually began to appraise the situation. Initially, the spouse tried to understand the behaviour of the patient and wondered if it was the individual himself/herself who was behaving in such a manner or if it was the disorder causing the behaviour.

. . . It is your own responsibility . . . although you are as mad as you are, you are still responsible for your actions . . . I can take his illness into account, oh, look how pitiful he is, but he is still responsible for what he is doing. (woman, ex-spouse, age 38)

The spouse also tried to find out if it was possible to influence the behaviour.

... He was so depressed all day, and after he was gone, I felt so sad... everything you try to do, it is of no use... (woman, ex-spouse, age 51, two children)

The healthy spouses eventually reflected upon their own position in the relationship. This growing awareness sometimes developed slowly and gradually, and in other cases appeared very sudden. By appraising the situation, the healthy spouse acquired an opinion or view on it, which influenced the experienced burden. Feeling 'alone together' was present in this process again.

So in this way I learnt a lot about it, and yes, I can use this quite well. So I do not get alarmed about it, like what is happening now? So I can handle this properly all the same. (male, age 42, two children)

Self-effacement versus self-fulfilment

Several coping strategies were used by spouses, of which the initial phase was appraisal. The next step was searching for a balance between self-effacement (putting the needs of others first) and self-fulfilment (putting one's own needs first). This search for balance was again characterized by feeling lonely. In most cases, the spouses were already putting their needs aside before they were even aware of it. It was like an instinctive reaction. In general, a process of learning started and an increasingly more conscious search for an acceptable balance could be seen to occur, mostly aimed at increasingly self-fulfilment.

Yes, yeah, in the beginning of our relationship, I adapted completely to him, but you cannot keep doing this... because you are a person too. You are putting yourself completely aside. So, yes, where am I? Where is my own value? So you start looking, you start searching for a balance... (woman, age 49)

Self-effacement implies that the other is considered more important than oneself. It is striking that six of the 15 participants stated that they were inclined to put themselves second. Such self-effacement appeared to be a personal characteristic that the spouses became increasingly aware of. Taking one's own needs more into consideration was sometimes the result of a decision taken at a specific moment, when the burden rose. In other cases, it was the result of a slow, ongoing process, which gradually had to be changed. In all cases, the decision to start coping differently was a matter of appraisal of the situation, which led to decisions about one's own position. Three of the four spouses who were divorced mentioned that, in retrospect, they should have paid greater attention to their own needs.

Three types of activities were described by participants to start taking their own needs more into consideration.

These activities can be interpreted as attempts to compensate for the loneliness being experienced in the relationship. The first activity we found was that some of the spouses tried to restore contact with their partner and share their feelings with them.

Well I can share some things with her, but she had been admitted several times... She is also very egocentric... She says: be glad you do not have this disease! Because that is much worse! (male, age 57, one child)

A second activity was trying to find support, where the participants spoke with others about their experiences and feelings or sought care and support from family, friends, and professionals.

... And then, I went to my sister and I cried my heart out, and afterwards we talked pleasantly and we went for a nice walk there, and then I returned home, and then I was able to put up with it again. (woman, age 30, two children)

A third activity aimed at increasing the personal space of the spouse was to withdraw from the problematic situation by working or relaxing inside or outside the house.

Take some time for myself. Reading a bit, doing some things on the computer, just doing something for myself... these are things that give me some rest... (male, age 42)

Almost all of the participants who were still together with the spouse who had a bipolar disorder at the time of this study recalled having moments in which they considered divorce. All of the participants appeared to shift continuously between the different ways of coping and experienced fluctuating amounts of burden and loneliness.

That is the illness and when I look at her and I see her lying asleep: This is the woman I love. I know she has got this disease, and I accept it because it is just there... Yes, one moment I was ready to quit... out of anger... I even said once: 'Get out! Out of this house now! I throw your things out and you go now!' (same male, age 42)

Alternately, the participants put their needs aside; they appraised the situation, as well as tried to take their own needs more into consideration. This capricious process, which often evolved towards greater consideration of one's own needs, was also frequently accompanied by feelings of guilt. Some of the spouses decided to focus on their own needs and decided not to feel guilty about this.

Those spouses who decided to leave (i.e. divorce) mentioned that the burden became too heavy at a certain point and that other coping strategies were no longer effective. The exhaustion and loneliness became

unbearable, and protective factors were either too weak or completely absent. Social support, such as practical help or understanding from family or friends, was hardly available for the four interviewed ex-spouses.

... Neither my own family, nor his family, nor friends. They all let me down. One reason for that was that he was always the nice, sporty, hard-working guy for the outside world... No one realized how difficult it all was for me... (woman, ex-spouse, age 57, three children)

The sharing of feelings with the spouse with a bipolar disorder was also virtually impossible in these cases. Some of the participants were completely self-effacing in light of their spouse's disorder. In other cases, the spouse with a bipolar disorder had serious symptoms almost continuously and a total lack of insight into the disease.

Interviewer: Were you two able to talk about your experiences?

Participant: No that was very difficult, very difficult. I think he was not able to get into details. That is really difficult, to talk with him... (woman, ex-spouse, age 51, two children)

Another factor that contributed to the decision to leave involved feelings of being 'dragged along' with the disease and not knowing what to do to cope. Three of the four divorced participants stated that by the time they realized what was going on (i.e. the extent of their self-effacement), they were too exhausted to change things and try to start putting their own needs first.

I only thought about her, if she was doing all right... I did not think of myself... One is too empty for that, you cannot think of yourself... one is far too empty for that... (male, ex-partner, age 35)

Mediating factors

Several factors mediated the experienced burden, as well as the extent of successfully coping with the situation. Characteristics of the person with a bipolar disorder, such as the ability to take the feelings of the spouse seriously, can be of help for the spouse. Characteristics of the healthy spouse, such as having the capacity to persist during difficult periods or recover after a particularly difficult period, also help in the coping process. Environmental characteristics, such as external support, also assist in the coping process.

More factors served a protective function for the participant and diminished the loneliness experienced – at least temporarily. The more of these factors present, the better the spouses were able to cope with the situation: having a sense of humour, loving the spouse (or the

memory of loving them), being able to share feelings with them, and experiencing positive things in the relationship.

You love someone or you do not love someone, and when you do, you just take things as they are. That probably was my moving spirit. Yes. (male, age 57, one child)

... And that makes a big difference, I think... Whether he ignores my feelings or takes them seriously. He takes me seriously then. (woman, age 51)

As already mentioned, social support was often lacking, which could be caused by the stigma that accompanies mental illness; this was often felt by the spouses of those affected.

Yes, even in the family they find it hard to handle... yes. They sometimes do not dare visit us... then I think, yes, I feel sorry about this... But anyway... Most of them do know they (these patients) have it in periods... but seriously trying to talk about it or understand what the problems are... all that is not so easy...! (male, age 42, two children)

Resignation

Outcomes of the described processes differed. Some of the spouses could be seen to clearly resign themselves to the situation, which can actually be understood as an active choice and a step towards to self-fulfilment.

You can feel very sad about it or feel bad and helpless, but you can also accept it. So be it. So be it. I am not going to let it drive me crazy. Because that is not good; that is not good for me. (woman, age 60, two children)

For other spouses, a more extreme form of self-fulfilment manifested itself, namely ending the relationship and leaving.

... And when I finally began to realize, then... I realized that I am a person worth being me... and he, he is not well, he has got a disease... then I understood a little bit more. But by then, I was so exhausted and I was so fed up... (woman, ex-spouse, age 38)

A third group of spouses continued to search for a satisfying balance between self-effacement and self-fulfilment and experienced fluctuating amounts of burden in connection with the disorder of the partner.

... Last year I said: 'You do what is necessary and accept support for the family, or I get the children and leave'... that is what I said actually, and since then, we have a professional worker who helps with the children and the household and now these things are going well. (male, age 36, two children)

Support needs

The most striking finding in the present study was that many of the participants did not have any professional support. Those participants who mentioned the availability of professional support described it as obviously being aimed at the patient and not at themselves.

No I noticed that this psychologist is strongly on principle, 'Okay, I am the psychologist of your partner and if you want to come too you need to make an separate appointment all the same.' (male, age 42)

Many of the spouses expressed a desire for professional support, but seemed unaware of the existing possibilities. A remarkable finding was that the process of searching for professional support was often characterized as a new source of stress, which increased the level of experienced burden for them.

And then you think about the support you can expect from the medical world: it is not much they have to offer. They hardly are giving any support. In the end, you are the only one, you are responsible, you have to drag her to them every time and it does not do any good (male, age 57, one child)

According to the participants, professional support should serve two purposes. First, it should reduce the experienced burden, diminish loneliness, and mobilize protective factors. Second, support should promote successful coping, which means helping the spouse adequately appraise the situation and find a suitable balance between self-effacement and self-fulfilment. The spouses stated they needed someone to listen to their story. They said they needed information about the disorder, help with understanding what behaviour can be caused by the disorder, and help with appraisal of their own situation.

... I think that professionals should try to get in contact with partners, but I think the psychiatrist should invite [the] partner or children for a meeting anyhow and ask how they are doing, then they get information some patients do not give. (woman, age 60, two children)

... But never advice, no. Being a partner, you have to manage by yourself... What we need is a professional who visits you at home and who knows about your situation, who talks with you about how can you handle this and this... (woman, age 51, two children)

The longevity and continuity of the support are more important than intensity. The participants said that the daily lives of both spouses needed to be the topic of meetings between both spouses and a professional and

include topics, such as how to share responsibilities and tasks. The spouses reported needing professional help in the process of finding a suitable balance between self-effacement and self-fulfilment. The professional should help the spouses increase their awareness of their personal situation, search for additional support from within their social network, and if necessary, find a means to establish or expand a network. Practical advice for relaxing, work, education, or maintaining contact with others can be an important source of support.

DISCUSSION

The current study is the first, to our knowledge, to examine the consequences of bipolar disorder for spouses of such individuals in a qualitative manner. Karp and Tanarugsachock (2000) describe a process of 'emotion management' of caregivers of persons with a mental illness and mention, for example, the creation of greater personal space by withdrawing from caregiving tasks without feelings of guilt. The use of such a coping strategy is confirmed by the results of the present study.

Indications are found that caregivers who live with the person with a bipolar disorder experience a heavy burden (Gonzalez *et al.* 2007; Goossens *et al.* 2008, Post 2005). Perlick *et al.* (2007) found that the majority of caregivers experience a moderate level of burden, not only during manic or depressive episodes, but continuously. This burden is associated with symptomatic behaviour, decreased performance of tasks by the person being cared for, and negative consequences for family and household. These findings are confirmed by the present findings: the participants experienced a continuous burden.

In both previous research and the present study, an association appears to exist between how caregivers appraise the situation and the burden they experience (Chakrabarti & Gill 2002; Greenberg *et al.* 1997; Karp & Tanarugsachock 2000; Perlick *et al.* 1999). The conviction that people with a bipolar disorder are actually able to control their mental illness has been found to be associated with higher levels of not only burden, but also dissatisfaction with the relationship (Lam *et al.* 2005).

The 'stress, appraisal, and coping theory' developed by Folkman and Lazarus (Folkman *et al.* 1986) is a well known and accepted theoretical framework, suitable for all of the situations in which people handle stress. In the present study, the newly-developed theory can be seen as a specialized example of this model. One aspect is added to the model of Folkman and Lazarus: in the new theory, one phenomenon is playing an important role in all other elements ('alone together').

The most striking finding in the present study was the lack of support received by the participants by acquaintances and mental health services. Possible causes of this may lie in the mental health services, the participants themselves, and in society. Mental health services have been described as inaccessible, and the search for professional support has been reported by caregivers as an additional stressor (Rose 1998; Veltman *et al.* 2002). The results of the present study show that mental health services do not perform well when it comes to assessing the needs of spouses, provision of information, or making the possibilities for support sufficiently apparent. This provides a possible explanation for the fact that so many spouses lack support. A second explanation is that these spouses tend to be self-effacing and therefore do not seek help for themselves. A third explanation is related to heavy burden, which is found to literally drag the healthy spouse down. That is, the constant call upon spouses is so great that they simply lack the energy to acquire support for themselves. The lack of understanding and social stigma still surrounding mental disorder in society today (Struening *et al.* 2001) also presumably contributes to the lack of support experienced by the spouses of individuals with a bipolar disorder.

Limitations

The current research has several possible limitations. Eleven of the 15 participants were recruited via the Society for Manic Depressives and Caregivers for practical reasons, although this limits the transfirmability of the results. Membership of such an organization can be assumed to increase the amount of relevant knowledge and sources of support. In general, the characteristics of family association members have been found to differ from the characteristics of non-members (Kaas *et al.* 2003; Marshall & Solomon 2000; Schene & van Wijngaarden, 1994).

One of the criteria for inclusion in the present study was that the patient had a type I or II bipolar disorder diagnosis according to DSM IV (American Psychiatric Association 2000). The presence of such a diagnosis was specified by the participating spouse and not the researcher, which means that the information might not always be correct.

The interviews with the ex-spouses were difficult to interpret, as divorce is generally a swift process with emotional reactions. Therefore, it was hard to distinguish if what is reported about the relationship is due to the disorder or to the fact that the relationship did not work out.

While the member checks showed that the participants could see their own experiences reflected in the interpre-

tations provided, these results might reflect a predisposition on the part of the participants to supply the answers that they thought the investigator might want to hear. All of the participants, for example, applauded the opportunity to relate their stories and were all positive about the research being undertaken, which may have made it hard to be critical.

Implications for nursing practice

Psychiatrists are usually the first individuals to meet the patient with the bipolar disorder and their spouse. If the spouse is not present, he/she should actively be invited for future appointments with the psychiatrist. The couple should be advised to utilize long-term support services. These services have preventive elements and are aimed at the consequences of the patient's disorder on all aspects of daily life, so the mental health nurse will be the one to provide such services. The support should be aimed at diminishing feelings of being 'alone together' on the part of the healthy partner. The nurse should offer systematic support for the different elements outlined in the model (Fig. 1) and adapt the support to the phase in which the couple finds itself. Individual treatment or relationship therapy may also be necessary. Interventions aimed at strengthening the healthy spouse's informal support network might be needed. Emotional support, as well as practical support and psychoeducation, might be useful, and explicit help with finding a suitable balance between self-effacement and self-fulfilment will also often be called for.

When interventions have been formulated in detail, existing guidelines can be expanded and refined. In this way, the quality of the support provided by nurses for spouses of persons with a bipolar disorder can be improved.

CONCLUSIONS

In this qualitative research, analysis of the results has led to developing a theory, which forms an extension to the existing stress-coping theory of Folkman *et al.* (1986). This new theory provides a credible depiction of the experiences of spouses of people with a bipolar disorder in the Netherlands. Spouses experience a heavy burden that is characterized by being 'alone together'. In their attempts to cope, they appraise the situation and try to find a balance between self-effacement and self-fulfilment. In all elements of this process, feelings of being 'alone together' prevail, and professional support should be aimed at all of the elements in the presented model (Fig. 1). This support is lacking. The described process

provides a starting point to develop adequate support for spouses. Practical recommendations based on this theory can be made.

It is clear that living with a person with a bipolar disorder places an immense burden on the spouse and can lead to feelings of being 'alone together'. Support can make the difference.

REFERENCES

- American Psychiatric Association (APA) (2000). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edn. Washington: American Psychiatric Press.
- American Psychiatric Association (APA) (2002). Practice guideline for the treatment of patients with a bipolar disorder (revision). *American Journal of Psychiatry*, *159*, 1–50.
- Chadda, R. K., Singh, T. B. & Ganguly, K. K. (2007). Caregiver burden and coping: A prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Social Psychiatry and Psychiatric Epidemiology*, *42* (11), 923–930.
- Chakrabarti, S. & Gill, S. (2002). Coping and its correlates among caregivers of patients with bipolar disorder: A preliminary study. *Bipolar Disorders*, *4* (1), 50–60.
- Cuijpers, P. & Stam, H. (2000). Burnout among relatives of psychiatric patients attending psycho educational support groups. *Psychiatric Services*, *51*, 375–379.
- Dutch Nursing Association (AVVV) (2004). *Concept beroepsdeelfprofiel GGZ verpleegkunde*. Utrecht: Dutch Nursing Association.
- Dutta, R., Boydell, J., Kennedy, N., van Os, J., Fearon, P. & Murray, R. M. (2007). Suicide and other causes of mortality in bipolar disorder: A longitudinal study. *Psychological Medicine*, *37* (6), 839–847.
- Feldmann, T. B. (2001). Bipolar disorder and violence. *Psychiatric Quarterly*, *72* (2), 119–129.
- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A. & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, *50*, 992–1003.
- Gonzalez, J. M., Perlick, D. A., Miklowitz, D. J. et al. (2007). Factors associated with stigma among caregivers of patients with bipolar disorder in the STEP-BD study. *Psychiatric Services*, *58*, 41–48.
- Goossens, P. J. J., van Wijngaarden, B., Knoppert-van der Klein, E. A. M. & van Achterberg, T. (2008) Family caregiving in bipolar disorder: Caregiver consequences, coping styles and distress. *International Journal of Social Psychiatry*, *54*, 303–316.
- Greenberg, J. S., Kim, H. W. & Greenley, M. S. S. W. (1997). Factors associated with subjective burden in siblings of adults with severe mental illness. *American Journal of Orthopsychiatry*, *67*, 231–241.
- Kaas, J. M., Lee, S. L. & Peitzman, C. (2003). Barriers to collaboration between mental health professionals and families in the care of persons with serious mental illness. *Issues in Mental Health Nursing*, 741–756.
- Karp, D. A. & Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qualitative Research*, *10*, 6–25.
- Lam, D., Donaldson, C., Brown, Y. & Malliaris, Y. (2005). Burden and marital and sexual satisfaction in the spouses of bipolar patients. *Bipolar Disorders*, *7*, 431–440.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- Marshall, T. B. & Solomon, P. (2000). Releasing information to families of persons with severe mental illness: A survey of NAMI members. *Psychiatric Services*, *51*, 1006–1011.
- Nehra, R., Chakrabarti, S. & Kulhara, R. (2005). Caregiver-coping in bipolar disorder and schizophrenia: A re-examination. *Social Psychiatry Epidemiology*, *40*, 329–336.
- Ogilvie, A. D., Morant, N. & Goodwin, G. M. (2005). The burden on informal caregivers of people with bipolar disorder. *Bipolar Disorders*, *7* (1), 25–32.
- Perlick, D. A., Clarkin, J. F., Sirey, J., Greenfield, P., Struening, S. & Rosenheck, R. (1999). Burden experienced by caregivers of persons with bipolar affective disorder. *The British Journal of Psychiatry*, *175* (7), 56–62.
- Perlick, D. A., Hohenstein, J. M., Clarkin, J. F., Kaczynski, R. & Rosenheck, R. A. (2005). Use of mental health and primary care services by caregivers of patients with bipolar disorder: A preliminary study. *Bipolar Disorders*, *7*, 126–135.
- Perlick, D. A., Rosenheck, R. A., Miklowitz, D. J. et al. (2007). Prevalence and correlates of burden among caregivers of patients with bipolar disorder enrolled in the Systematic Treatment Enhancement Program for Bipolar Disorder. *Bipolar Disorders*, *9*, 262–273.
- Pini, S., de Queiroz, V., Pagnin, D. et al. (2005). Prevalence and burden of bipolar disorders in European countries. *European Neuropsychopharmacology*, *15*, 425–434.
- Post, R. M. (2005). The impact of bipolar depression. *Journal of Clinical Psychiatry*, *66* (5), 5–10.
- Rea, M. M., Miklowitz, D. J., Thompson, M. C., Goldstein, M. J., Hwang, S. & Mintz, J. (2003). Family-focused treatment versus individual treatment for bipolar disorder: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology*, *71*, 482–492.
- Regeer, E. J., ten Have, M., Rosso, M. L., Vollebergh, W. & Nolen, W. A. (2004). Prevalence of bipolar disorder in the general population: A Reappraisal Study of the Netherlands Mental Health Survey and Incidence Study. *Acta Psychiatrica Scandinavica*, *110*, 374–382.
- Rose, L. (1998). Benefits and limitations of professional-family interactions: The family perspective. *Archives of Psychiatric Nursing*, *XII* (3), 140–147.
- Schene, A. H. & van Wijngaarden, B. (1994). Consequenties van psychotische stoornissen voor familieleden; de aard en ernst nader onderzocht. *Tijdschrift voor Psychiatrie*, *36*, 1.

- Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research*, 2nd edn. Newbury Park, CA: SAGE Publications.
- Struening, E. L., Perlick, D. A., Link, B. G., Hellman, F., Herman, D. & Sirey, J. A. (2001). Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services*, 1633–1638.
- Veltman, A., Cameron, J. I. & Stewart, D. E. (2002). The experience of providing care to relatives with chronic mental illness. *The Journal of Nervous and Mental Disease*, 190, 108–114.
- van der Voort, T. Y. G., Goossens, P. J. J. & van der Bijl, J. J. (2007). Coping, burden and needs for support of caregivers of persons with a bipolar disorder: A systematic review. *Journal of Psychiatric and Mental Health Nursing*, 14, 679–687.
- Yatham, L. N., Kennedy, S. H., O'Donovan, C. *et al.* (2005). Canadian Network for Mood and Anxiety Treatments (CANMAT) Guidelines for the management of patients with bipolar disorder: Consensus and controversies. *Bipolar Disorders*, 7 (Suppl. 3), 5–69.

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