**Informal caregivers’ learning experiences with self-management support of individuals living with bipolar disorder: A phenomenological study**

S. C. G. H. van den Heuvel \*, 1 , 2 , 3 , 4 MA RN, P. J. J. Goossens5 , 6 , 7 , 8 PhD MANP RN FEANS, C. Terlouw9 PhD, L. Schoonhoven10 PhD RN FEANS & T. van Achterberg11, 12, 13 PhD RN FEANS

1Lecturer and Researcher, Saxion University of Applied Sciences, Expertise Centre for Health, Social Care and Technology, Deventer, The Netherlands

2 Junior Researcher, Radboud university medical center, Radboud Institute for Health Sciences, IQ Healthcare, Nijmegen, The Netherlands

3 Junior Researcher, Dimence Group, Center for Mental Health Care, SCBS Bipolar Disorders, Deventer, The Netherlands

4 Junior Researcher, KU Leuven, Centre for Health Services and Nursing Research, Leuven, Belgium

5 Advanced Nurse Practitioner and Senior Researcher, Dimence, SCBS Bipolar Disorders, Institute for Mental Healthcare, Deventer, The Netherlands

6 Senior Researcher, Radboud university medical center, Radboud Institute for Health Sciences, IQ Healthcare, Nijmegen, The Netherlands

7 Senior Lecturer, GGZ-VS, Institute for the Education of Clinical Nurse Specialists in Mental Health, Utrecht, The Netherlands

8 Visiting Professor, University Centre of Nursing and Midwifery, Department of Public Health, Faculty of Medicine and Health Services, Ghent University, Ghent, Belgium

9 Emeritus Professor, Expertise Centre for Educational Innovations, Saxion University of Applied Sciences, Deventer, the Netherlands

10 Professor, Faculty of Health Sciences, University of Southampton, UK

11 Professor, KU Leuven, Department of Public Health and Primary Care, Academic Centre for Nursing and Midwifery, Leuven, Belgium

12 Visiting Professor, Radboud university medical center, Radboud Institute for Health Sciences, IQ Healthcare, Nijmegen, The Netherlands   
13 Visiting Professor, Uppsala University, Department of Public Health and Caring Sciences, Uppsala, Sweden.

SvdH: [s.c.g.h.vandenheuvel@saxion.nl](mailto:s.c.g.h.vandenheuvel@saxion.nl)

\* Corresponding author:

Handelskade 75

Post-box 501

7400 AM Deventer

The Netherlands

M: +31 (0)6 12 37 12 41

Co-authors:

PG: [p.goossens@dimence.nl](mailto:pgoossens@dimence.nl)

CT: [cees\_539@hotmail.com](mailto:cees_539@hotmail.com)

LS: [L.Schoonhoven@soton.ac.uk](mailto:Lisette.Schoonhoven@radboudumc.nl)

TvA: theo.vanachterberg@kuleuven.be

Silvio van den Heuvel (SvdH): designed the study, collected, analysed and interpreted data, and drafted the manuscript. Peter Goossens (PG): co-designed the study, peer-debriefing of analysed and interpreted data, and drafted the manuscript. Cees Terlouw (CT): co-designed the study, peer-debriefing of analysed and interpreted data, and drafted the manuscript. Theo van Achterberg (TvA): co-designed the study, and revised the article critically for important intellectual content. Lisette Schoonhoven (LS): revised the article critically for important intellectual content.

**Role of funding source**

Funding was received from the Dutch Ministry of Education, Culture and Science.

**Conflict of interest**

None to declare

**Acknowledgements**

We would like to thank Ciska Wilms of 4OfficeAssistance for transcribing the interviews verbatim.

ABSTRACT

BACKGROUND: The degree of informal caregiver involvement influences the self-management of individuals living with bipolar disorder (BD). OBJECTIVE: This paper aims to provide a description of informal caregivers' learning experiences in self-management support of BD in order to guide professionals in tailoring future psychosocial and psychoeducational interventions. DESIGN: In-depth open interviews with ten informal caregivers of patients with BD who followed treatment in the context of specialised outpatient bipolar care were conducted. RESULTS: Four learning phases emerged from the phenomenological analysis describing the informal caregivers learning process: (1) understanding bipolar disorder, (2) overcoming the dilemmas in self-management support for individuals living with BD, (3) dividing tasks and responsibilities and, (4) acquiring a personal definition of self-management support for individuals living with BD. CONCLUSION: By grasping the concept of BD, informal caregivers gradually learn how to overcome dilemmas resulting from living with someone with BD, and how to control the expression of emotions. They learn to reflect on the nature of conflicts, and how to share the responsibilities of illness-management with individuals living with BD and professionals. Mastering these skills eventually allows them to define and delimit their supporting informal caregiver role in the self-management of BD. PRACTICE IMPLICATIONS: Our findings provide information regarding the educational needs of informal caregivers in order to tailor counselling, and psychosocial and psychoeducational interventions in specialised outpatient care for individuals living with BD.

**Background**

Self-management of a chronic illness is one part of the treatment in the Chronic Care Model and part of the definition of health as stated by the World Health Organization (Huber et al., 2011; Wagner, Austin, & VonKorff, 1996). Self-management improves outcomes and reduces the costs of healthcare because the patients are actively involved in their treatment (Lorig & Holman, 2003; Newman, Steed, & Mulligan, 2004). The primary goal of self-management education is to increase the individual’s ability to overcome the negative consequences of living with a chronic condition and maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

Bipolar disorder (BD) is a chronic mental illness characterized by the extreme fluctuation of emotions, energy levels or activity patterns. In the European Union, BD has a prevalence rate of approximately 1% in people between 18–65 years of age (Pini et al., 2005). The morbidity of BD is substantial because of recurrent episodes that alternate between euthymic, (hypo)manic, or major depressive mood states, with frequent relapse rates up to 60% within two years and 75% in a five-year span (Judd et al., 2002). BD can be differentiated into two subcategories: 1) BD I when at least one manic episode, that is, an episode of persistently elevated mood with an abnormally high level of activity for most hours of the day and that exists for at least a week, has occurred in the illness history of an individual; or 2) BD II, when an individual suffers from one or more depressive episodes for at least two weeks, and these episodes are accompanied by at least one episode of hypomania, that is, milder features of mania that are not severe enough for acute hospitalization (American Psychiatric Association, 2013).

According to international multidisciplinary guidelines, the treatment of BD consists of pharmaceutical therapy (Bauer, Biswas, & Kilbourne, 2009; Kupka et al., 2015), psychosocial support (Crowe et al., 2010), psychoeducation (Colom et al., 2003; Colom & Lam, 2005), additional psychological therapy (Lam, Burbeck, Wright, & Pilling, 2009), and self-management education (Perry, Tarrier, Morriss, McCarthy, & Limb, 1999). Professional support in the self-management of BD entails teaching individuals living with BD to monitor mood and activity by utilizing a life chart and to efficiently counteract prodromal signs and symptoms using preset interventions from a relapse prevention plan (Daggenvoorde, Goossens, & Gamel 2013; Goossens, Kupka, Beentjes, & van Achterberg, 2010; van Bendegem, van den Heuvel, Kramer, & Goossens, 2014).

Although the term “self-management” may suggest that individuals living with BD are solely responsible for their outcomes (Janney, Bauer, & Kilbourne, 2014; Jones, Deville, Mayes, & Lobban, 2011; Trappenburg et al., 2013), numerous studies have shown that the active involvement of informal caregivers positively affects the course of BD (Miklowitz, 2007; Perlick et al., 2010; Scott, Colom, Pope, Reinares, & Vieta, 2012). However, caregiver involvement has an excessive cost. Being an informal caregiver of someone with BD is associated with high rates of emotional burden and experienced distress (Beentjes, Goossens, & Poslawsky, 2012; Jönsson, Wijk, Danielson, & Skarsater, 2011; Reinares et al., 2006). Also, providing informal care for someone with BD has a massive impact on relationships (Goossens, van Wijngaarden, der Klein, & van Achterberg, 2008; Granek, Danan, Bersudsky, & Osher, 2016) and can lead to serious mental problems (Perlick et al., 2016; Steele et al., 2010). Providing informal care for someone who has BD means balancing between competing needs and coping with feelings of being pulled on and rejected at the same time (Lewis, 2015; Rusner, Carlsson, Brunt, & Nystrom, 2013). Yet it is widely known that informal caregivers play a significant role in signaling the prodromal symptoms of upcoming episodes (Goossens et al., 2010). Often, the person with BD will find it difficult to recognize these changes, so having an external person who is able to observe any variations in behavior can be vital for successful early interventions (Regeer et al., 2015).

Teaching informal caregivers how to support individuals in coping with the consequences of living with BD is essential for the well-being of both the caregiver and individual with BD (Fiorillo et al., 2015; Miklowitz & Chung, 2016; Reinares et al., 2016). However, the literature on how informal caregivers learn to support individuals in self-managing BD is scarce. Therefore, the aim of this study was to describe how informal caregivers have learned to overcome the impact of emotional burden and experienced distress, and how they have developed a personal definition of efficient self-management support for individuals living with BD.

**Method**

*Research Design*

A modified descriptive phenomenological method based on the philosophical ideas of Edmund Husserl (1973, 1984) was chosen as the study design. Because descriptive phenomenology is a philosophical approach without a clear-cut qualitative methodology, it was modified into an inductive method of data collection and analysis to meet the criteria for empirical qualitative research (Dowling, 2007; Giorgi, 2005). In contrast to the original descriptive phenomenology, our approach used the concepts of the expansive learning theory (ELT) as a guiding interview tool to set the framework for the interview topics to prevent interviewees from narrating beyond the scope of the study’s aim (Engeström & Sannino, 2010). For data collection and analysis, we used a six-step inductive empirical method similar to a parallel study on learning experiences of individuals living with BD (van den Heuvel, Goossens, Terlouw, van Achterberg, & Schoonhoven, 2015).

*Sampling and recruitment*

From January 2012 until April 2013, we recruited Dutch participants involved in informal caregiving for persons diagnosed with BD I or II. Participants could be spouses, family members, or friends of the people with BD. The recruitment of the participants started by asking individuals living with BD who were part of a parallel study (van den Heuvel et al., 2015) to identify significant persons (the informal caregivers in this study) who supported them in self-management activities. No other inclusion criteria were set. Although our sample was collected based on convenience, we purposively searched for heterogeneity to meet the phenomenological principle of multiple perspectives (Husserl, 1973, 1984).

Ten informal caregivers, five being marital partners, two parents, one sister, one a close friend, and one a daughter, agreed to be interviewed. The mean age was 51.5 (SD=9.6) years. Seven respondents were female. The highest educational level was on academic level, the lowest vocational. The mean years of experience in informal caregiving was 11.5 (SD=12.5), the length was defined starting from the year in which the first symptoms occurred or when the relationship started. Socio-demographic data are presented in Table 1.

*Ethical considerations*

According to the principles of the Declaration of Helsinki (http://www.ccmo.nl), the Dutch *Central Committee on Research Involving Human Subjects* found no objections to this study. Nevertheless, ethical guidelines for research governance were followed, meaning that all the participants signed an informed consent form after they received written and spoken information before the interview started. The data gathered in this study were treated as confidential and processed anonymously.

*Data collection*

The interviewer (SvdH) collected data through in-depth and open face-to-face interviews (35–110 min.) with the informal caregivers separately from their loved ones, at a place of their convenience (at home or at the university). All interviews were digitally recorded and transcribed verbatim. The starting question was the following: What does self-management of BD mean to you? Subsequently, the interviewer prompted the interviewees’ answers with regard to self-management supporting activities. Additional questions were asked based on the central concepts of the ELT (Engeström & Sannino, 2010), which holds the premise that learning situations are activated in a collaborative network. These central concepts included themes about the division of family responsibilities, the supporting role of the informal caregiver during different stadia of the illness, and the way the caregivers coped while living with someone who has BD.

*Data analysis*

The analysis started with three analysts (SvdH, PG, and CT) separately reading the transcripts thoroughly to grasp the essence of the interviews. Summaries of the transcripts were sent to the respondents as a member check to verify that what they had said was well-interpreted. Aside from textual corrections, all respondents agreed with our interpretations. The first interpretations were entered in the *Atlas.ti 7* data analysis software packagecodebook (Friese, 2012), that is, without connecting the codes to the transcripts. Two analysts (PG and CT) hand-labeled a random selection of transcripts.

The interpretations of all analysts were compared and discussed in peer debriefing to increase the trustworthiness and reduce researcher bias; this was carried out until a consensus was reached about the meaning of the concepts. Concepts on which we agreed were also entered in the database codebook. After this step, the text fragments of the full transcripts in *Atlas.ti 7* were labeled. Codes that could not be labeled to a text fragment were considered to be a preliminary interpretation of the researcher and were therefore removed from the dataset.

This intermediate step was made to ensurethat inopportune ideas from the researchers’ natural attitude were disentangled conform the phenomenological methodology (Husserl, 1973, 1984). In the final step, the labels were inductively categorized based on similarity in meaning until a thorough “thick description” of learning experiences was reached. Two analysts (LS and TvA) supervised and reflected on the final themes that were composed during the analysis. New insights emerged from the analysis of each interview and from peer debriefing by the research team (SvdH, PG, CT, LS, and TvA) and the guiding topics of the aide memoire were adapted accordingly. This inductive methodology was used rigorously until no topics were added or replaced. At this point we decided that we had reached data saturation.

**Results**

Our phenomenological analysis provided a logical reconstruction of the learning experiences of informal caregivers (N = 10) when supporting individuals who were self-managing BD into four phases: *understanding bipolar disorder, overcoming the dilemmas in self-management support for individuals living with BD, dividing tasks and responsibilities,* and *acquiring a personal definition of self-management support for individuals living with BD.*

**Understanding bipolar disorder**

The first time informal caregivers were confronted with the symptoms of BD, they did not know how to interpret the odd behavior, which was utterly deviant from the normal characteristics of their beloved ones:

His behavior was abnormal, completely different from the modest person we knew before. He turned into being supercilious and overconfident, and later on, he became very timid and hesitant… until he was not able to do anything, anymore…

(Informal caregiver 8)

After the acute phase was over and a diagnosis had been given, most informal caregivers were eager to gather lots of information, primarily from the Internet, to grasp the abstract concept of “bipolar disorder.” This basic understanding of the course and nature of the illness allowed them to relabel what they had previously called “odd behavior” into the signs and symptoms of BD. Through their eagerness to learn about the nature of BD, informal caregivers felt confident about what was anticipated to be their supporting role by the time they joined the individual living with BD when visiting the appointed healthcare professional. However, informal caregivers reported that, to their surprise, individuals living with BD were not as willing to learn as much about the illness as they were. This difference in need for knowledge led to the caregivers’ assumption that the individual living with BD was non-compliant, not interested in his or her well-being, or did not comprehend the importance of knowing what to do to prevent a recurrent episode:

When the diagnosis of [name individual living with BD] was set, I immediately started reading lots of information about the illness. He avoided all conversations about the manic-depressive illness. He was convinced that he had recovered. So he was acting as if nothing had happened… But I, on the other hand, never stopped reading new information about the illness. I even joined the Dutch Bipolar Patient and Informal Caregiver Association.

(Informal caregiver 5)

Although informal caregivers had learned to recognize and efficiently respond to early signs and symptoms of BD, they also mentioned the difficulty of differentiating between the normal and abnormal behavior and activities of individuals living with BD:

When we read the information leaflet that summed up the features of BD, we recognized some things. However, when the first symptoms reoccurred, we did not recognize it as such at once. He [her father] just gradually started to behave differently. The symptoms appeared insidiously […] that is the elusiveness of this disease; you never know when an episode will recur. So, that is why… for instance if there is a sale at a store and he buys a thing or two… or more… I have to be alert. Just in case. You never know for sure.

(Informal caregiver 2)

**Overcoming the dilemmas in self-management support for individuals living with BD**

Most informal caregivers said that they found support and understanding from peers in sessions organized by the Dutch Bipolar Patient and Informal Caregiver Association when trying to comprehend the difficulties they faced. However, the dreadful stories of some peers also sketched a fearsome image of BD: an unpredictable mental illness. Along with their own insecurities, this induced a fear for future episodes:

I keep her in sight and see that she takes her medication on time, but I try to let it go sometimes… to let her decide on her own what to do on some occasions. It is hard to let go of her, just because I am afraid of a recurrent episode… that dormant fear is always there.

(Informal caregiver 9)

The dormant fear of a possible exacerbation and the assumptions that the individual living with BD lacked acknowledgement of having a chronic mental illness was the leitmotiv for informal caregivers to take the lead in delaying, or better, preventing a recurrent (hypo)manic or depressive episode for the sake of all stakeholders:

My mother was… or we all, were constantly on top of him… It must have felt quite oppressive for my father… that he might have thought that we should back off and leave him alone for a while… but my mother, she was all over him, telling… no, summoning him, to take the medication that he needed for his own sake…

(Informal caregiver 2)

However, these good intentions to take full control could lead to conflicts. Sometimes, the informal caregivers’ overprotective behavior fed the stubbornness of individuals living with BD, resulting in refusing any form of treatment, with recurrent episodes and rehospitalization as the outcome.

Another problem informal caregivers had to overcome was the moral dilemma of what to do when they received the early signals of a recurrent episode. Was it wise to confront the individual living with BD or inform professionals without permission of the individual when he or she was reluctant to take advice? Sometimes, informal caregivers were drawn into a mediating role that led to situations where they became caught in the crossfire of escalating conflicts between individuals living with BD and significant others. These dilemmas illustrate the demanding task of informal caregiving:

If you want to be an informal caregiver, I think you have to be sure about what you are up to because it comes with great responsibilities and demands a lot of the time. I do not always like it. I mean, we have a good understanding and a natural sister bond, but sometimes… it is emotionally very demanding. There are days on which I am the one who is caught in the crossfire between family quarrels.

(Informal caregiver 10)

**Dividing tasks and responsibilities**

Gradually, informal caregivers learned that self-management of BD does not entail them taking responsibility for the situation because decisively taking control sooner or later led to tension. Fortunately, for informal caregivers who were on the borderline of a burnout, most individuals living with BD responded emphatically to the signals of their exhausted partner by taking care of family matters:

My father died a few months ago and before that I took care of him…That was a very burdensome time. I felt exhausted and emotionally overwhelmed… I said to him I could not bear it anymore… and he understood that very well; he picked up the responsibilities I used to do and took care for our family… A year ago, I thought this was never going to happen anymore…

(Informal caregiver 3)

By this time, informal caregivers were more accustomed to the idea that the individual with BD should be intrinsically motivated to self-manage BD, and this should not be initiated by them. Instead, putting trust in their beloved’s capabilities to maintain their health induced a mutual confidence in the ability to cope with BD:

Even if things tend to go wrong with her, I am not scared because I have the confidence that I know what I have to do to regain control. That builds your confidence, knowing what to do… That is why I do not call the professionals each time she has a minor mood swing.

(Informal caregiver 7)

The sufficiency of self-management support to individuals living with BD increased with the wish of both to restore the reciprocity in their relationship. Open communication about the source of conflicts yielded the insight that mutual agreement had to be reached regarding the extent to which they both allowed this mental illness to disturb family living. Keeping balance in managing BD and the responsibilities of family life was often a trade-off, and had to be negotiated:

It was a good move to let her work at the kindergarten. It helped her a lot to get around people again.

At first, she found it quite exhausting, but she learned to take breaks and balance her activity level. We often discuss whether or not she should do something. It is all about finding a balance in activities and responsibilities; if you do one thing, you have to keep in mind that another thing has to go.

(Informal caregiver 6)

**Acquiring a personal definition of self-management support for individuals living with BD**

Over time, informal caregivers acquired a keen eye for recognizing the signs and signals of a prodromal phase of an episode, even before the individual living with BD noticed it. However, reflections on previous phases made them aware that these differences in insights were often the source of many conflicts and, that it was better to bring up the urgency of the message without being emotionally drawn into a discussion. Some informal caregivers found a creative way to avoid conflicts through communication with “code words” or “red flags” without an emotional connotation:

Usually, I can tell by the sound of her voice what her current mood is. If I, for example, ask her what she is up to and she tells me that she has lots of things going on or planned, I tell her that I have the *feeling* that you are a little too “jumpy”… we use that expression instead of the term “hypomania” because it does not have that pathological connotation about which she is so sensitive. We have chosen to use this kind of expression as a code word. My sister immediately recognizes the red flag without confronting her with her illness, and therefore she is willing to let, or do, things to counteract a mood swing.

(Informal caregiver 10)

Overall, informal caregivers gradually learned that self-management support meant, moderating their intrusiveness. They learned that providing positive feedback to the individual living with BD, and stepping back when things went well, in itself is a self-management promoting activity. Informal caregivers grasped that individuals living with BD needed to be empowered by putting trust in their good intentions and capabilities to self-manage BD. Because, trust in knowing what to do could restore the long-lost self-esteem of both the individual with BD and the informal caregiver:

What you should preserve is confidence, self-esteem… nothing is more disastrous for someone’s confidence than not being able to trust your own mind anymore… that must be horrifying… I consider it of utmost importance that an individual’s confidence is restored… by picking up small activities and responsibilities… just to let her know, that she is able to do things again, step by step… looking for strongholds, that is self-management support.

(Informal caregiver 7)

**Discussion**

According to our findings, the learning process of informal caregivers started with an endeavor to comprehend the concept of BD. This learning strategy provided the basic knowledge with which to fulfil a supporting role, which seems a successful effort that indeed reduces the number of early relapses of (hypo)manic and/or depressive episodes (Perlick et al., 2010). However, we found that gaining basic knowledge with which to comprehend BD also had its downsides. Collecting information about the features of BD did not immediately yield insight into the differences between pathological and normal behavior of individuals living with BD. It also unintentionally created a gap in knowledge, acceptance, and motivation between informal caregivers and individuals living with BD that led to distress, mutual incomprehension, and conflicts in the first phase of this learning process. Seeking help from peers led to more recognition and support from other informal caregivers, but also had the adverse effect of hearing about negative experiences that created a horrible image of an unpredictable disease with a high rate of recurrent episodes that were impossible to control (Jönsson, Skarsater, Wijk, & Danielson, 2011; Jönsson, Wijk, et al., 2011).

It is well-known that close informal caregiver involvement increases the complexity of the caring process for all stakeholders (Chatzidamianos, Lobban, & Jones, 2016; Peters, Pontin, Lobban, & Morriss, 2011). We believe that this complexity of care delivery can be explained by the asynchrony of differentiated learning phases between informal caregivers and individuals living with BD (van den Heuvel et al., 2015). In the present study, we found that the more the informal caregivers were involved in the treatment of the individual living with BD, the more it seemed to them that the individuals living with BD became reluctant to accept help. These findings are in line with literature that reports disenfranchised feelings about caregivers’ contributions to care for individuals living with BD and high rates of perceived burden of informal caregivers because of the consequences of recurrent episodes, frequent hospitalizations, and lack of commitment or non-adherence to treatment by the individuals living with BD (Beentjes et al., 2012; Reinares et al., 2006; Lewis, 2015). Some informal caregivers who were a parent or child were closely involved and highly alert to prodromal symptoms because of their dormant fear of a recurrent episode. In contrast, the informal caregivers who were somewhat more distantly related, such as siblings or friends, were the ones who found an efficient definition of self-management support by balancing between being there for an individual living with BD and meeting their own needs.

The learning phase wherein daily tasks were divided was the tipping point where informal caregiver involvement was tempered and individuals living with BD started taking on more family responsibilities. Our findings are in line with the literature that shows that informal caregivers look for a balance between self-effacement (putting the needs of others first) and self-fulfillment (putting the needs of themselves first) to prevent being brought down by the burden caused by living with someone with BD (van der Voort, Goossens, & van der Bijl, 2009). Informal caregivers are always a step ahead in recognizing prodromal symptoms, almost like a seismograph, before the individual who lives with BD notices the signs (Rusner et al., 2013). So when the informal caregivers opt for self-effacement, the individual living with BD interprets this help as meddling and becomes reluctant to accept it. Our results show that this often culminates in an absolute need for the informal caregiver to gain control. However, informal caregivers often feel one step behind the needs of the individual living with BD, so when the informal caregivers aim for self-fulfillment, individuals living with BD tend to feel abandoned, especially when a prodromal phase of a recurrent episode has occurred (van den Heuvel et al., 2015). Therefore, informal caregivers end up in a paradoxical situation on account of an attract–repel attitude of the individual living with BD (Rusner et al., 2013; van der Voort et al., 2009).

Despite good intentions, overprotectiveness and taking control worked against the situation and led to conflicts. Studies have confirmed that the high expression of emotions and a criticizing or uninterested attitude on the part of informal caregivers are detrimental to effective outcomes in the treatment of BD (Granek et al., 2016; Miklowitz, 2007; Scott et al., 2012). The consequences of emotional over-involvement and high expression of emotions in the (non)verbal communication of informal caregivers are recognized as a negative moderator of outcomes in the treatment of BD (Fredman, Baucom, Boeding, & Miklowitz, 2015; Kim & Miklowitz, 2004; Leff & Vaughn, 1985). Informal caregivers in our study learned that escalating conflicts fed the stubbornness of individuals living with BD, who then boycotted all forms of treatment as a means of protest, thus leading to more recurrent episodes over time (Miklowitz et al., 2009; Miklowitz & Chung; 2016; Reinares et al., 2016).

Later on in the learning process, informal caregivers became aware that efficient support of individuals in self-managing BD meant confining their emotional overreactions and learning to communicate in a non-confrontational style to avoid disagreement and a high expression of emotions. For instance, by using a code word to warn the individual living with BD about an upcoming prodromal sign without becoming too emotionally involved. Open communication, mutual trust, and reciprocity restored the relationship between informal caregiver and the individual living with BD. Informal caregivers eventually understood that efficient support in the self-management of BD meant resisting what the French philosopher Emmanuel Levinas (2012) called “the endless responsibility that goes out from the compelling call expressed in the face of a needing person.” Instead of primarily responding to upcoming episodes with emotional over-involvement, informal caregivers learned to reframe the “call for help” of an individual living with BD as the need to help them overcome their perceived helplessness.

*Strengths and limitations of the study*

Qualitative research has its limitations when it comes to the validity and reliability of a study’s results; therefore, different criteria are formulated that are more applicable to this approach to ensure its scientific rigor (Lincoln & Guba, 1985). By using a phenomenological method of open interview techniques guided by a topic list and an inductive data analysis, the replicability of this study became limited. However, to increase the trustworthiness of our results, we audited our process by using a logbook of field notes, performed peer debriefing and researcher triangulation, and used a computer-assisted qualitative data analysis software package.

Our recruitment strategy led to a convenience sample of informal caregivers that does not ensure the preferable “variation of perspectives” of a phenomenological approach, so our description of the views on self-management support for individuals living with BD might not be as “dense” as it could have been if the sample were purposively set (Husserl, 1973, 1984). However, we increased the rigor of our phenomenological content analysis by using a constant stepwise approach until data saturation has been reached. We considered the data to be saturated when no new topics were heard during the interviews.

Although our results are limited to the context of the Dutch healthcare system, the insights into learning how to support self-management as an informal caregiver might be transferable to similar situations, settings, and practices. To guarantee the authenticity of our study’s results, informal caregivers’ learning processes were affirmed by the original citations of respondents. Confirmability was achieved by sending respondents written summaries of the transcripts as a member check.

*Conclusions and relevance for clinical practice*

We have logically reconstructed that informal caregivers learn in phases, first by comprehending the concept of BD, then overcoming the dilemmas stemming from living with someone with BD, next to gradually understanding the devastating results of emotional over-involvement and high expression of emotions and solving this by a division of responsibilities, and finally, later knowing how to define and delimit their supporting role in the self-management of BD. We want to emphasize that there is no “final phase” in this learning process because learning requires lifelong maintenance. The different phases in this learning process are not chronological, but instead are intertwined and sometimes co-existing. The learning phase of an informal caregiver depends on what outcomes his or her supporting actions sort and, on the episodic fluctuations of the individual living with BD. Our findings indicate that self-management support for individuals living with BD is a cyclic process that evolves over time and comes with a changing attitude toward a measure of informal caregiver involvement that is appropriate for the learning phase of the self-management of the individual living with BD.

In our opinion, professionals should recognize the differences in the educational needs of both individuals living with BD and informal caregivers. The learning processes of both occur in a temporal asynchrony that can easily grow into a source of conflict that ultimately leads to a vicious circle of triggering recurrent episodes. Further research is needed to specify the didactical professional role required for each phase in the learning process of individuals living with BD and their informal caregivers. Nevertheless, based on our findings, we advise professionals to aim their actions toward guiding the flow of information and correcting misunderstandings when informal caregivers are learning to comprehend BD. In the next learning phase, professionals should focus on the relationship between the informal caregiver and the individual living with BD to support them in overcoming the dilemmas of caregiving. When responsibilities are shifting, professionals could teach informal caregivers how to cope with insecurities and support individuals living with BD through positive reinforcement.

Informal caregivers can be advised to share the information that they had gathered from the internet with a professional to verify the reliability of the content. However, they should also be warned about the pitfall that gaining knowledge about the illness does not automatically entail that one knows what to do in particular cases. The features of the illness often vary per person. Therefore, informal caregivers have to be taught how to recognize the early signs and symptoms of an upcoming episode, and how they can learn to differentiate between pathological features and normal behavior. Another important message for informal caregivers is that the persons diagnosed with BD are not always willing to accept the diagnosis, and sometimes even opposite against treatment. For this reason it is best for them to avoid talking about behavior in pathological terminology. Instead, it is more efficient for informal caregivers to use a code word to warn the person with BD about a red flag. For instance, using the phrase “Maybe it is better to visits some friends because you look so lonely.”, instead of using words with a pathological connotations such as “depressive”, “down” or “passive”. With this kind of non-confrontational communication strategy the informal caregiver avoids that he might get drawn into a discussion about the current health status of a person with BD.

Although, peer support is helpful, informal caregivers should be warned about the downside of hearing about negative experiences. Self-management support does not entail taking over matters. The protective behavior of informal caregivers is a quite understandable natural reaction, considering the consequences of a manic or depressive episode for all stakeholders. However, it is important for them to know that this reflex of taking full control, no matter the goodness of intention, is often the source of conflict and even increase recalcitrant behavior. Therefore, it is advisable to teach informal caregivers to search for a common ground, instead, which often can be found in the mutual wish to restore the default in the relationship. Open communication about who takes care of what applies to all stakeholders involved. Listening to each other’s preferences is the starting point of realizing a personal definition of self-management (support).

The increased attention toward the self-management of chronic illnesses entails that informal caregivers must be properly equipped to address the demands of efficient self-management support for individuals living with BD. Psycho-educational programs wherein both individuals living with BD and informal caregivers can partly deliver the knowledge that is necessary to cope with the negative consequences of BD. However, to develop and refine the supporting skills informal caregivers require, more attention should be given to self-management support for individuals living with BD by inserting the above as a routine part in the conversation during consultations.

**References**

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*  (5th ed.). Arlington, VA: American Psychiatric Publishing.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling, 48*(2), 177-187. doi:10.1016/s0738-3991(02)00032-0

Bauer, M. S., Biswas, K., & Kilbourne, A. M. (2009). Enhancing Multiyear Guideline Concordance for Bipolar Disorder Through Collaborative Care. *American Journal of Psychiatry, 166*(11), 1244-1250. doi:10.1176/appi.ajp.2009.09030342

Beentjes, T. A., Goossens, P. J., & Poslawsky, I. E. (2012). Caregiver burden in bipolar hypomania and mania: a systematic review. *Perspectives in Psychiatric Care, 48*(4), 187-197. doi:10.1111/j.1744-6163.2012.00328.x

Chatzidamianos, G., Lobban, F., & Jones, S. (2015). A qualitative analysis of relatives', health professionals' and service users' views on the involvement in care of relatives in Bipolar Disorder. *BMC Psychiatry, 15*, 228. doi:10.1186/s12888-015-0611-x

Colom, F., & Lam, D. (2005). Psychoeducation: improving outcomes in bipolar disorder. *European Psychiatry, 20*(5-6), 359-364. doi:10.1016/j.eurpsy.2005.06.002

Colom, F., Vieta, E., Martinez-Aran, A., Reinares, M., Goikolea, J. M., Benabarre, A.,Torrent, C., Comes, M.,  
Corbella, B., Parramon, G., & Corominas, J. (2003). A randomized trial on the efficacy of group psychoeducation in the prophylaxis of recurrences in bipolar patients whose disease is in remission. *Archives of General Psychiatry, 60*(4), 402-407. doi:10.1001/archpsyc.60.4.402

Crowe, M., Whitehead, L., Wilson, L., Carlyle, D., O'Brien, A., Inder, M., & Joyce, P. (2010). Disorder-specific psychosocial interventions for bipolar disorder-A systematic review of the evidence for mental health nursing practice. *International Journal of Nursing Studies, 47*(7), 896-908. doi:10.1016/j.ijnurstu.2010.02.012

Daggenvoorde, T. H., Goossens, P. J., & Gamel, C. J. (2013). Regained control: a phenomenological study of the use of a relapse prevention plan by patients with a bipolar disorder. *Perspectives in Psychiatric Care, 49*(4), 235-242. doi:10.1111/ppc.12009

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*(1), 131-142. doi:10.1016/j.ijnurstu.2005.11.026

Engeström, Y., & Sannino, A. (2010). Studies of expansive learning: Foundations, findings and future challenges. *Educational Research Review, 5*(1), 1-24. doi:10.1016/j.edurev.2009.12.002

Fiorillo, A., Del Vecchio, V., Luciano, M., Sampogna, G., Sbordone, D., Catapano, F., De Rosa, C. Malangone, C.,Tortorella, A., Veltro, F., Nicolo, G., Piselli, M., Bardicchia, F., Ciampini, G., Lampis, D., Moroni, A., Bassi, M., Iapichino, S., Biondi, S., Graziani, A., Orlandi, E., Starace, F., Baronessa, C., Carra, G., & Maj, M. (2016). Feasibility of a psychoeducational family intervention for people with bipolar I disorder and their relatives: Results from an Italian real-world multicentre study. *Journal of Affective Disorders, 190*, 657-662. doi:10.1016/j.jad.2015.10.060

Fredman, S. J., Baucom, D. H., Boeding, S. E., & Miklowitz, D. J. (2015). Relatives' emotional involvement moderates the effects of family therapy for bipolar disorder. *Journal of Consulting and Clinical Psychology, 83*(1), 81-91. doi:10.1037/a0037713

Friese, S. (2012). *Qualitative Data Analysis with Atlas.ti*. Hannover: SAGE Publications Ltd

Giorgi, A. (2005). The phenomenological movement and research in the human sciences. *Nursing Science Quarterly, 18*(1), 75-82. doi:10.1177/0894318404272112

Goossens, P. J. J., Kupka, R. W., Beentjes, T. A. A., & van Achterberg, T. (2010). Recognising prodromes of manic or depressive recurrence in outpatients with bipolar disorder: A cross-sectional study. *International Journal of Nursing Studies, 47*(10), 1201-1207. doi:10.1016/j.ijnurstu.2010.01.010

Goossens, P. J. J., van Wijngaarden, B., der Klein, E., & van Achterberg, T. (2008). Family caregiving in bipolar disorder: Caregiver consequences, caregiver coping styles, and caregiver distress. *International Journal of Social Psychiatry, 54*(4), 303-316. doi:10.1177/0020764008090284

Granek, L., Danan, D., Bersudsky, Y., & Osher, Y. (2016). Living with bipolar disorder: the impact on patients, spouses, and their marital relationship. *Bipolar Disorders, 18*(2), 192-199. doi:10.1111/bdi.12370

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., van der Meer, J. W. M., Schnabel, P., Smith, R., van Weel, C., & Smid, H. (2011). How should we define health? *British Medical Journal, 343*. doi:10.1136/bmj.d4163

Husserl, E. (1973). *Die Idee der Phänomenologie. Fünf Vorlesungen* [The idea of phenomenology, Five lectures]. The Hague, The Netherlands: Biemel, W., & Nijhoff, M.

Husserl, E. (1984). *Logische Untersuchungen*, Band I & II [Logical Investigations part I and II]. The Hague, The Netherlands: Nijhoff, M., & Kluwer Academic Publishers.

Janney, C. A., Bauer, M. S., & Kilbourne, A. M. (2014). Self-management and bipolar disorder--a clinician's guide to the literature 2011-2014. *Current Psychiatry Reports, 16*(9), 485. doi:10.1007/s11920-014-0485-5

Jones, S., Deville, M., Mayes, D., & Lobban, F. (2011). Self-management in bipolar disorder: the story so far. *Journal of Mental Health, 20*(6), 583-592. doi:10.3109/09638237.2011.600786

Jönsson, P. D., Skarsater, I., Wijk, H., & Danielson, E. (2011). Experience of living with a family member with bipolar disorder. *International Journal of Mental Health Nursing, 20*(1), 29-37. doi:10.1111/j.1447-0349.2010.00704.x

Jönsson, P. D., Wijk, H., Danielson, E., & Skarsater, I. (2011). Outcomes of an educational intervention for the family of a person with bipolar disorder: a 2-year follow-up study. *Journal of Psychiatric and Mental Health Nursing, 18*(4), 333-341. doi:10.1111/j.1365-2850.2010.01671.x

Judd, L. L., Akiskal, H. S., Schettler, P. J., Endicott, J., Maser, J., Solomon, D. A., Leon, A. C., Rice, J. A., & Keller, M. B. (2002). The long-term natural history of the weekly symptomatic status of bipolar I disorder. *Archives of General Psychiatry, 59*(6), 530-537. doi:10.1001/archpsyc.59.6.530

Kim, E. Y., & Miklowitz, D. J. (2004). Expressed emotion as a predictor of outcome among bipolar patients undergoing family therapy. *Journal of Affective Disorders, 82*(3), 343-352. doi:http://dx.doi.org/10.1016/j.jad.2004.02.004

Kupka, R.W., Goossens, P.J.J., van Bendegem, M., Daemen, P., Daggenvoorde, T., Daniels, M., Dols, A., Hillegers, M., Hoogelander, A., ter Kulve, E., Peetoom, T., Schulte R., Stevens A., & van Duin, D. (2015). *Richtlijn Bipolaire Stoornissen van de Nederlandse Vereniging voor Psychiatrie* [The Dutch Society for Psychiatry Multidisciplinair Guideline for the Treatment of Bipolar Disorder]. Utrecht: De Tijdstroom.

Lam, D. H., Burbeck, R., Wright, K., & Pilling, S. (2009). Psychological therapies in bipolar disorder: the effect of illness history on relapse prevention - a systematic review. *Bipolar Disorders, 11*(5), 474-482. doi:10.1111/j.1399-5618.2009.00724.x

Leff, J., & Vaughn, C. (1985). *Expressed emotion in families: Its significance for mental illness*. New York: The Guilford Press.

Levinas, E. (2012). *Totaliteit en Oneindigheid* [Totality and Infinity]. Amsterdam: Boom.

Lewis, L. F. (2015). Balancing Competing Needs: A Meta-Ethnography of Being a Partner to an Individual With a Mood Disorder. *Journal of the American Psychiatric Nurses Association, 21*(6), 417-427. doi:10.1177/1078390315620611

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. doi:10.1207/s15324796abm2601\_01

Miklowitz, D. J. (2007). The Role of the Family in the Course and Treatment of Bipolar Disorder. *Current Directions in Psychological Science, 16*(4), 192-196. doi:10.1111/j.1467-8721.2007.00502.x

Miklowitz, D. J., Axelson, D. A., George, E. L., Taylor, D. O., Schneck, C. D., Sullivan, A. E., Dickinson, L. M., & Birmaher, B. (2009). Expressed emotion moderates the effects of family-focused treatment for bipolar adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 48*(6), 643-651. doi:10.1097/CHI.0b013e3181a0ab9d

Miklowitz, D. J., & Chung, B. (2016). Family-Focused Therapy for Bipolar Disorder: Reflections on 30 Years of Research. *Family Process*. doi:10.1111/famp.12237

Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet, 364*(9444), 1523-1537. doi:10.1016/s0140-6736(04)17277-2

Perlick, D. A., Berk, L., Kaczynski, R., Gonzalez, J., Link, B., Dixon, L., Grier, S., & Miklowitz, D. J. (2016). Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. *Bipolar Disorders, 18*(2), 183-191. doi:10.1111/bdi.12379

Perlick, D. A., Miklowitz, D. J., Lopez, N., Chou, J., Kalvin, C., Adzhiashvili, V., & Aronson, A. (2010). Family-focused treatment for caregivers of patients with bipolar disorder. *Bipolar Disorders, 12*(6), 627-637. doi:10.1111/j.1399-5618.2010.00852.x

Perry, A., Tarrier, N., Morriss, R., McCarthy, E., & Limb, K. (1999). Randomised controlled trial of efficacy of teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment. *British Medical Journal, 318*(7177), 149-153.

Peters, S., Pontin, E., Lobban, F., & Morriss, R. (2011). Involving relatives in relapse prevention for bipolar disorder: a multi-perspective qualitative study of value and barriers. *Bmc Psychiatry, 11*. doi:10.1186/1471-244x-11-172

Pini, S., de Queiroz, V., Pagnin, D., Pezawas, L., Angst, J., Cassano, G. B., & Wittchen, H. U. (2005). Prevalence and burden of bipolar disorders in European countries. *European Neuropsychopharmacology, 15*(4), 425-434. doi:10.1016/j.euroneuro.2005.04.011

Reinares, M., Bonnín, C. M., Hidalgo-Mazzei, D., Sánchez-Moreno, J., Colom, F., & Vieta, E. (2016). The role of family interventions in bipolar disorder: A systematic review. *Clinical Psychological Review, 43*, 47-57. doi:10.1016/j.cpr.2015.11.010

Reinares, M., Vieta, E., Colom, F., Martinez-Aran, A., Torrent, C., Comes, M., Goikolea, J. M., Benabarre, A., Daban, C., & Sanchez-Moreno, J. (2006). What really matters to bipolar patients' caregivers: sources of family burden. *Journal of Affective Disorders, 94*(1-3), 157-163. doi:10.1016/j.jad.2006.04.022

Regeer, E. J., Kupka, R. W., Have, M. T., Vollebergh, W., & Nolen, W. A. (2015). Low self-recognition and awareness of past hypomanic and manic episodes in the general population. *International Journal of Bipolar Disorders, 3*(1), 22. doi:10.1186/s40345-015-0039-8

Rusner, M., Carlsson, G., Brunt, D., & Nystrom, M. (2013). Towards a more liveable life for close relatives of individuals diagnosed with bipolar disorder. *International Journal of Mental Health Nursing, 22*(2), 162-169. doi:10.1111/j.1447-0349.2012.00852.x

Scott, J., Colom, F., Pope, M., Reinares, M., & Vieta, E. (2012). The prognostic role of perceived criticism, medication adherence and family knowledge in bipolar disorders. *Journal of Affective Disorders, 142*(1-3), 72-76. doi:10.1016/j.jad.2012.04.005

Steele, A., Maruyama, N., & Galynker, I. (2010). Psychiatric symptoms in caregivers of patients with bipolar disorder: A review. *Journal of Affective Disorders, 121*(1-2), 10-21. doi:10.1016/j.jad.2009.04.020

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: One size does not fit all. *Patient Education and Counseling, 92*(1), 134-137. doi:10.1016/j.pec.2013.02.009

van Bendegem, M. A., van den Heuvel, S. C., Kramer, L. J., & Goossens, P. J. (2014). Attitudes of Patients With Bipolar Disorder Toward the Life Chart Methodology: A Phenomenological Study. *Journal of the American Psychiatric Nurses Association*. doi:10.1177/1078390314558420

van den Heuvel, S. C., Goossens, P. J., Terlouw, C., Van Achterberg, T., & Schoonhoven, L. (2015). Identifying and describing patients' learning experiences towards self-management of bipolar disorders: a phenomenological study. *Journal of Psychiatric and Mental Health Nursing, 22*(10), 801-810. doi:10.1111/jpm.12243

van der Voort, T. Y. G., Goossens, P. J. J., & van der Bijl, J. J. (2009). Alone together: A grounded theory study of experienced burden, coping, and support needs of spouses of persons with a bipolar disorder. *International Journal of Mental Health Nursing, 18*(6), 434-443. doi:10.1111/j.1447-0349.2009.00634.x

Wagner, E. H., Austin, B. T., & VonKorff, M. (1996). Organizing care for patients with chronic illness. *Milbank Quarterly, 74*(4), 511-+. doi:10.2307/3350391

Table 1: Demographic characteristics of interviewed informal caregivers

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Informal Caregiver | Sex | Age | Educational background | Status | Relation to patient in years | Years of caregiving | Patient\* | Sex | Age | Educational background | Diagnosis | Year of diagnosis (first symptoms occurred) |
| 1 | F | 58 | Vocational | Married | 5 years of marriage | 5 years | 1 | M | 59 | Vocational | BD II | 2008 (1976) |
| 2 | F | 47 | Academic master | Married | Daughter | 2 years | 3 | M | 65 | Vocational | BD I | 2010 (2010) |
| 3 | F | 53 | Bachelor | Married | 21 years of marriage | 3 years | 4 | M | 50 | Bachelor | BD II | 2009 (2009) |
| 4 | F | 46 | Bachelor | Single | Friend for 5 years | 5 years | 2 | F | 40 | Bachelor | BD I | 2007 (1997) |
| 5 | F | 63 | Bachelor | Married | 40 years of marriage | 38 years | 5 | M | 64 | Bachelor | BD I | 2008 (1974) |
| 6 | M | 46 | Bachelor | Married | 23 years of marriage | 19 years | 9 | F | 43 | Bachelor | BD II | 1998 (1993) |
| 7 | M | 65 | Vocational | Married | 40 years of marriage | 28 years | 10 | F | 64 | Vocational | BD II | 2002 (1984) |
| 8 | M | 57 | Bachelor | Married | Father | 2 years | 11 | M | 24 | Bachelor | BD II | 2010 (2010) |
| 9 | F | 47 | Vocational | Widow | Mother | 6 years | 14 | F | 23 | Lower vocational | BD I | 2009 (2007) |
| 10 | F | 33 | Academic master | Married | Sister | 7 years | 15 | F | 29 | Academic Master | BD II | 2006 (2006) |

\* Number of patient corresponds to dataset of parallel study (van den Heuvel et al., 2015)