

Living with Bipolar Disorder

The experiences of the persons affected and their family members, and the outcomes of educational interventions

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To my family, with ♥ and gratitude

ABSTRACT

Bipolar disorder has considerable consequences for the daily life and functioning of the person affected and their family. The aim of this study was to describe the experience of living with bipolar disorder from the view of the person affected and their family. A further aim was to analyze the outcomes of educational interventions for persons with the illness and their family members in outpatient mental health care.

In Papers I and II, qualitative interviews were conducted with persons diagnosed with bipolar disorder (n=18) and family members (n=17) focusing on their experiences of life with the illness. In Papers III and IV the outcomes of educational interventions for those affected (n=32) and the families (n=34) were followed-up and analyzed. Paper III included a comparative group (n=15) of persons with the illness only receiving standard treatment. Data were collected using a semi-structured interview (III) and self-assessment instruments (III-IV) on five occasions, starting before the intervention and ending at the two-year follow-up. Content analysis was applied to the qualitative studies, whereas descriptive and non-parametric statistical methods were used for the quantitative studies. The educational intervention was an existing health care intervention in a unit in outpatient mental health care services consisting of ten group-sessions with different topics related to living with bipolar disorder which the group discussed and reflected on. It is based on the assumption that communication, collaboration and discussion in these groups create interaction that facilitate development of knowledge about and capacity to manage living with the illness.

The results of this thesis showed that the whole lives of the family and the member affected were influenced. The process of integrating the illness challenged their pre-understanding, requiring reconsideration of self among the persons affected and confirmation of the correctness of the families' experiences. Uncertainty among persons with the illness concerning their own capacity and the limited life associated with the illness influenced their view of the future. The younger adults avoided planning or hoping for the future, and without hope of improvement it sometimes felt hard to continue. The families were strongly committed to the care for the member with the illness, but felt engaged in a lonely and burdensome struggle that diminished their chances of a normal life of their own. Hope for the future, sufficient social functioning and feeling part of society was prerequisites for a manageable life for these people. The educational interventions gave them opportunity to interact and learn together with mental health-care professional and other people within a constructive environment. The outcomes of the interventions showed that both persons with bipolar disorder and the family members increased their self-management ability as a result of their developed knowledge and their ability to meet the daily social concerns and stresses related to living with bipolar disorder improved.

This thesis contributes increased knowledge concerning what it means to live with bipolar disorder in the long-term and emphasis the importance of educational interventions with a person-centred view for person affected and family members developing their capacity to manage life. The overall support from mental health care has to be further developed and designed to meet all the specific and different needs of those persons and their families. To supplement the promising outcomes of the educational interventions more research is needed concerning increased self-management under different stages of the illness and life.

Keywords: adult, bipolar disorder, caring, educational intervention, family, follow-up studies, mental health services, psychiatric mental health nursing, self-management, young adult

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ORIGINAL PAPERS

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INTRODUCTION

The focus of this thesis is the persons diagnosed with Bipolar Disorder (BD), their family members and their experiences of living with the illness. In addition, the outcomes of educational interventions aimed at these persons are studied.

Variations in mood are a natural part of life. People experience these variations in unique individual ways and have different strategies for dealing with them. However, when the mood swings are manifested in extreme depressed or restless, euphoric states, over a period of time and in a way that differs strikingly from an individual's normal way of feeling, behaving and functioning in daily life, they can be symptoms of the mental illness called bipolar disorder (American Psychiatric Association 1994). BD is a recurring, episodic, but lifelong and severe mental illness affecting a person's mood. It was Emil Kraepelin (1856-1926) who first described the concept of manic-depressive illness as a single disease entity and included it in a disease model. However, melancholia was described in the literature as early as in the fourth and fifth centuries B.C., and the link between melancholia and mania was described in the second century A.D. (Goodwin & Jamison 2007). The illness manifests itself early in life and generally starts in teenage or young adulthood (Hirschfeldt, Lewis & Vornik 2003, Kessler *et al.* 2005). But it can take almost a decade for BD diagnosis to be established because of the complexity of the illness and the difficulties in identifying the course of the illness cycle's (Leverich *et al.* 2002). Epidemiological studies have reported the lifetime prevalence of BD, the total or average total number of persons at risk of developing BD in their lifetimes, to be around 2-4 % (Kessler *et al.* 2005, Merikangas *et al.* 2007). According to the World Health Organization (WHO 2008) there are 29.5 million persons in the world living with bipolar disorder and the illness is ranked as the seventh (males) and eighth (females) highest cause of disability worldwide. Their life is characterized by stress and limitations on psychosocial functioning as a result of the long-term changes caused by the condition (Lim *et al.* 2004). The negative impacts of the illness on the families' lives are considerable, even if some benefits can be derived from caring for the member with BD (Maskill *et al.* 2010).

The frequency of mental illness is increasing globally and causes great harm in life of the sufferings as well as for their families as well (WHO 2001). This fact alone justifies the support and treatment of those affected. The importance of both the person with mental illness and the family having an influence over their mental health care has been highlighted by the government in Sweden (Statens offentliga utredningar 2007) and that they should be able to live a life as normal as possible with opportunities to monitor and influence their life situation. Socialstyrelsen (2010a) emphasize the importance of gaining specific knowledge about the person and his/her environment, vulnerability and needs, but also about the opportunities for family and network to support recovery. These expectations that persons with BD and their families can assume responsibility for managing their life with the illness have challenged the understanding of healthcare professionals of how to support them in acquiring the necessary knowledge, skills, and social facilitation they need in order to succeed (Ryan & Sawin 2009). However, these concerns are not the primary focus for mental health care, which by tradition primarily have focused on treating the illness and controlling

the symptoms. The illness perspective, and interventions focusing on facilitating the daily management of the person affected and their family are still lacking in mental health care. Many of the needs that follow living with bipolar disorder still remain unnoticed. An important point for improvement is therefore to incorporate the assessment of advanced care needs of those living with the illness into the treatment process (Goossens *et al.* 2008a).

During my work as a psychiatric and mental health nurse (PMHRN) in in-patient and out-patient units for persons with affective disorders, I have met many people with BD and their families under various circumstances. Many of those I met were the same people who came to the hospital with recurrences of either depression or mania. I became affected by the complexity and instability that characterize these persons' daily life but also by their willingness to overcome their limitation.

In my work I sometimes felt that there was a gap between the support offered by healthcare and what they actually needed to be better able to manage their illness and living situation on their own. I asked myself what I as a nurse, could do to provide a better support. In 2001 I was a part of the development and start-up of a new out-patient-care unit focused on improving the care and support for these persons and their families needed to manage life with the illness in their normal living conditions. To meet these needs e.g group educational interventions for persons affected and their families were developed. The interventions were inspired by earlier positive experiences from similar nursing activities for persons living with other kinds of mental illnesses both within our psychiatric service and in other parts of Sweden. Inspiration was also drawn from some nursing interventions newly developed in the USA.

However, knowledge about the illness based on the experiences of those with BD and their families was still limited as were the outcomes of educational interventions. My foundation in nursing is that interaction and genuine care of a person affected by illness and their family can promote their growth (Mayeroff 1990) and facilitate their learning about how to manage their new life conditions.

In order to support a person so that they can manage self-care, an RN needs to have a holistic view that considers the person's total current situation, their experiences and interpretation of the situation (Berg, Hedelin & Sarvimäki 2005). This is even more important in light that persons with mental illness have difficulties verbalizing their problems (Skärsäter *et al.* 2003a, Svedberg, Jormfeldt & Arvidsson 2003). These experiences have strengthened me in my efforts to gain a richer understanding of what it means to live with the illness from the point of view of persons affected and their family, but also how mental health care can intervene and facilitate management of daily life in the long-term by these people themselves. There is a need for research that place greater consideration on the person-centred active processes in relation to becoming ill with BD (Perlick *et al.* 2004).

BACKGROUND

Persons affected by bipolar disorder

BD is an illness that has considerable consequences for the daily life and functioning of the person affected. The characteristics of BD are described in Table 1. Depending on how the illness manifests itself, the extent and recurrence of the symptoms, BD can be divided into different types. In this thesis BD refers to bipolar I disorder (BD I) and bipolar II disorder (BD II). Even if the cycles and manifestation of symptoms differ to a degree between BD I and BD II, the level of impairment in those persons affected is more similar than it is different (Ruggero *et al.* 2007). Persons with BD are affected by symptom of the illness for almost half of their lifetime (Judd *et al.* 2002, Judd *et al.* 2003). Recurrences of mood episodes in BD are frequent (Gitlin *et al.* 1995, Perlis *et al.* 2006), and depressive episodes in particular are prevalent and likely to recur in spite of guideline-based treatments (Perlis *et al.* 2006). The pharmacological treatment of persons with BD with mood stabilizers is an important part of treatment, however lack of compliance with treatment is a common problem (Colom *et al.* 2000, Reilly-Harrington & Sachs 2006). Suitable pharmacological treatment together with psychosocial interventions may nevertheless improve the level of functioning and reduce disability in bipolar patients (Beynon *et al.* 2008, Sanchez-Moreno *et al.* 2009). Only recently have personal experiences of living with BD come more into focus, but research is still limited and nursing interventions need to be developed, as has also have been reported by Goossens, van Achterberg and Knoppert-van der Klein (2007).

Experiencing an episode of major depression is characterized by significant impact of the individual's mental and physical health, their total function in and understanding of their world, distinct from grief or other understandable reactions to adversity or loss (Skärsäter 2002). An episode of mania is characterised by a powerful psychological and physical, fluctuating experience between being alive and mastery, and paralyzing anxious isolation and self-destructive forces (Karlsson 2004). For persons living with BD the illness is always present in life, intertwined with one's whole being, irrespective of mania or depression being present or not (Rusner *et al.* 2009). Previous research showed that persons with BD had difficulty handling stress and demands and that their lives were characterized by loss and limitations, in e.g. relationship and psychosocial functioning, as a result of long-term changes caused by the condition (Lim *et al.* 2004). As a consequence of this they could even feel isolated from and rejected by their families and society (Pollack & Aponte 2001). They had to cope with psychosocial impairments (Judd *et al.* 2008) that fluctuated in parallel with changes in affective symptom severity (Judd *et al.* 2005) for a great part of their lives. The consequences could be seen in impaired quality of life (Michalak *et al.* 2006) and social adjustment, with functional disruptions in the family environment (Cutler 2001, Dore & Romans 2001, Blairy *et al.* 2004, Sanchez-Moreno *et al.* 2009), work function (Blairy *et al.* 2004, Michalak *et al.* 2007, Sanchez-Moreno *et al.* 2009) and leisure activities, even after the remission of clinical symptoms (Blairy *et al.* 2004). However, they sought independence from their family as well as the financial and healthcare system (Michalak *et al.* 2006).

Another problem with functional impairment seen in these persons is that it can increase the speed at which further episodes of the illness recur (Weinstock & Miller 2008). Those afflicted attempted to find stability in mood as well as in life, but the only thing that they felt they could control was the symptoms, by means of pharmacological treatment. The fact that feelings, thoughts, and mood often change from day to day or week to week among those affected by BD, causes them to feel unstable and that they with little opportunity to influence or change the course of the illness (Lim *et al.* 2004). They struggled to disentangle experiences from what may have been symptoms of the illness, but how the illness affected their sense of self also influenced their self-identity (Michalak *et al.* 2006).

According to Pollack and Aponte (2001) the identification with or acceptance of BD is a lengthy process. Acceptance promotes compliance and self-management, which is a foundation for persons with BD being able to take more responsibility for their own care. However, denial and despair in relation to the illness, common in persons with BD, can be obstacles in this process. The acceptance of the illness and increased knowledge about BD was a foundation on which those affected could develop individual and context-adjusted strategies, e.g. managing stress and having a supportive network, in order to stay well and avoid new episodes (Russel & Browne 2005).

Table 1. Diagnostic criteria for major depression, hypomania and mania, in bipolar disorder types I and II, modified from the DSM-IV (American Psychiatric Association 1994)

Major Depressive Episode	Hypomanic or Manic Episode
Depressed mood	Inflated self-esteem or grandiosity
Diminished interest or pleasure in activities.	Reduced need for sleep (e.g., feels rested after only 3 hours of sleep)
Decrease or increase in appetite	More talkative than usual or pressure to keep talking
Insomnia or hypersomnia	Flights of ideas or subjective experience that thoughts are racing
Psychomotor agitation or retardation	Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
Fatigue or loss of energy	Increase in goal-directed activity or psychomotor agitation
Feelings of worthlessness or excessive or inappropriate guilt	Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., the individual engages in unrestrained buying sprees, sexual indiscretions, or foolish business investments)
Diminished ability to think or concentrate, or indecisiveness	
Recurrent thoughts of death (not just fear of dying)	

- The diagnosis of a *major depressive episode* requires the presence of at least five symptoms during a 2-week period, one of the symptoms being either (1) depressed mood or (2) loss of interest or pleasure, representing a clear change from previous functioning

- For a *manic episode* or a *hypomanic episode* there must have been a distinct period of abnormally and persistently elevated, expansive or irritable mood, lasting at least 1 week (manic episode) or 4 days (hypomania)

- Episodes of mania and depression characterize BD I, while episodes of hypomania and depression indicate BD II

The family view of bipolar disorder

In this thesis the term family is defined in accordance with Stuart (1991) who described the family as a system or unit where the members do not necessarily need to be related or live together, but they need to be committed and attached to each other, which include a future engagement among the members. From the perspective of being a family member of a person with BD, this commitment may entail a role that is hard to manage, with feelings of distress, burden (Dore & Romans 2001, Veltman, Cameron & Stewart 2002, Nehra *et al.* 2005, Chang & Horrocks 2006, Reinares *et al.* 2006, Perlick 2007, Wynaden 2007) and not having a life of ones own (Stjernswärd & Östman 2008), shaping their daily life. Despite this, family interventions and support are still lacking and many families' needs go unmet (Hill, Shephard & Hardy 1998, Östman, Hansson & Andersson 2000, Doornbos 2002, Jensen 2004, Rose, Mallinson & Walton-Moss 2004, van der Voort, Goosens & van der Bijl 2009).

Research focusing on the family perspective in relation to BD is still limited. According to Tranvåg and Kristoffersen (2008) families' experiences of a member contracting BD lead to a dramatic change in life, involving a number of illness-related and burdensome challenges. The distress the families experience seems to occur more often among those who report more consequences and are more passive in their management of the condition of the person with the illness (Goosens *et al.* 2008b). Studies have shown that these families experience such distress and a sense of burden that their own health and ability to function in life is affected (Dore & Romans 2001, Nehra *et al.* 2005, Reinares *et al.* 2006, Perlick *et al.* 2007) with both financial and legal implications (Dore & Romans 2001). These consequences can be manifested in terms of a reduced self-esteem and confidence (Perlick *et al.* 2007) and in anxiety and symptoms of depression (Hill *et al.* 1998, Perlick *et al.* 2007). These families also feel isolated and forced to sacrifice their social life more often than is the case with other mental illnesses (Östman, Wallsten & Kjellin 2005).

The research done on the family perspective of the illness BD, shows that their lives are negative influenced in terms of high stress and burden, ill health, impaired functioning and social life. In addition it is also implied that these consequences are more difficult for them to deal with when they do not feel able to manage the condition of the member who is ill. Further research is needed to increase understanding of the family's view of living with a member with BD and how their management of the situation can be strengthened.

Mental health care

The view of persons with mental illness and their family

Traditionally in mental health care the person affected by mental illness was in focus but the situation for the families was largely ignored (Jubb & Shanley 2002). From the late 18th and 19th centuries medical science started to interest itself in insanity, and in Sweden, asylums were built during this period for treating the mentally ill. This resulted in persons affected with BD and other mental illnesses being separated

from their families and society (Danielson 1983, Sjöström 1992). However, this trend ended in Sweden with the Mental Health Reform 1995, which sought to strengthen the rights of those affected by mental illness to function well and be a part of society. As a consequence the number of hospital sites decreased radically and the length of hospital stays was shorter. The greater part of health care was now provided by out-patient mental health care services, taking place in the home of the persons affected by mental illness, which raised the importance of the role of the family (Statens offentliga utredningar 1999). Supporting the family was now seen as a prerequisite for many of those with a mental illness being able to live a life outside institutions (Socialstyrelsen 1999), and research has highlighted the importance of supporting these families as part of the treatment and care process (Dixon *et al.* 2001, Rea *et al.* 2003, Jensen 2004).

The changes in health care contributed to an increased interest in the persons affected and their families taking more responsibility for care and treatment, and learning how to manage with the consequences of living with a mental illness on a more daily basis. Those affected by mental illness have traditionally been assigned a passive role in care and treatment, which may be a consequence of the strong biological view of mental illness seen in history. The unique knowledge, based on a person's own experiences of living with a mental illness for a long time, is seldom used when decisions about their care are taken. Yet the intention of society is that the person suffering from an illness should be involved in and have influence over their health, care and treatment (Socialdepartementet 2009, Socialstyrelsen 2010a). Accordingly, pedagogic processes as an integrated part of care and treatment are of increasingly importance in maintaining good health care that strengthens people with long-term mental illness and their families in managing living with the illness. Historically, in their roles as health counsellors, registered nurses have had a responsibility for educating persons affected by illness (Häggström 1999). The general interest in education in health care services has also increased in pace with the decline in funding (Svensk Sjuksköterskeförening 2007).

Persons with bipolar disorder and their families need of care and support

The considerable influence of BD on the person with the illness and their family members whole lives, give rise to a growing need for support for these individuals. They need support to strengthen their ability to manage the illness and its consequences in daily life and to promote their own wellbeing. Research also shows that there are a range of strategies that persons diagnosed with BD can learn and develop to stay well (Russel & Browne 2005, Murray *et al.* 2010). According to Corbin and Strauss (1988) persons living with a chronic illness, such as BD, not only have to participate in activities necessitated by the illness but also work with maintaining everyday life and dealing with an altered view of the future. To support all the needs of these persons health care has to employ a more holistic view that incorporates the person's own experience of the illness and whole life context in the care and treatment of them and their families, instead of focusing only on symptom management and preventing recurrences. Communicating about these experiences should be an integrated part of the care where the knowledge, understanding and insight of the person affected and their family are a condition for them to be involved in and be able to influence their

own health, care and treatment. The use of a more collaborative approach for these persons emphasizing that they are active co-managers of the illness and that successful outcomes are enhanced within a supportive social environment seems to be beneficial for this purpose (Bauer 2001, Sajatovic *et al.* 2005, Davies, McBride & Sajatovic 2008, Bauer, Biswas, & Kilbourne 2009). Surveys of patient organizations across Europe and the US reveal that there is a strong desire by those with BD for both self-help and psychological treatments in addition to pharmacotherapy (Hirschfeld *et al.* 2003, Morselli & Elgie 2003). Furthermore, systematic reviews about families affected by BD (Ogilvie, Morant & Goodwin, 2005, van der Voort, Goossens & van der Bijl 2005) show that they are in need of support and psychosocial interventions based on a greater understanding of their unique situations. There is a need for research that places more consideration on the person-centred active processes in relation to becoming ill with BD (Perlick *et al.* 2004).

Support and interventions in bipolar disorder

Supporting persons with BD and their families in finding ways to manage the condition in the long-term by themselves is about supporting a process that they initiate to bring order into their lives (Kralik *et al.* 2004). Recent national treatment guidelines recommend that structured psychological interventions (psychological therapy with psychosocial support, individual as well as family intervention including education) as well as promotion of a healthy lifestyle, relapse prevention and physical care should be offered to people with BD (American Psychiatric Association 2002, National Institute for Health and Clinical Excellence 2006, Yatham *et al.* 2006, Socialstyrelsen 2010b). Gaining knowledge about the illness is particularly important in bipolar disorder and educational interventions consisting of care based on the individual's need should be offered (Socialstyrelsen 2010b). Analogous to traditional patient education, which is entirely guided by health care professionals and focuses on disease-specific information and technical skills, educational interventions focus on supporting the individual in managing the condition by themselves and use more problem solving skills. The individual is here allowed to identify their problems and is provided with techniques to help them to make decisions, take appropriate actions, and adapt these actions as they encounter changes in circumstances or condition (D'Zurilla 1986).

Educational interventions in bipolar disorder

There has been an increasing interest in research into and development of different educational interventions for persons with BD, mostly in the USA and the western parts of Europe, but the outcomes measured in BD have to a majority been determined by the assessment of objectively clinical information, such as time to relapse and stay in hospital rates. The main focus for research into the outcomes of educational interventions for persons affected by BD (Perry *et al.* 1999, Colom *et al.* 2003a, Colom *et al.* 2003b, Lam *et al.* 2003, Colom *et al.* 2005, Bauer *et al.* 2006, Perlis *et al.* 2006) and their families (Miklowitz *et al.* 2003, Rea *et al.* 2003) has been on reducing the risk for recurrence of BD episodes, risk of hospitalization and/or compliance with pharmacological treatment. The studies have showed that educational interventions are an effective complement to pharmacological treatment in the treatment of BD, e.g. a new study by Colom *et al.* (2009) with a 5-year follow-up of persons with BD after they

received an educational intervention, showed a longer interval between recurrences, less time acutely ill and fewer days in hospitals. However, interventions focusing on outcomes in the person and their family's daily management of the illness and their stressful and burdensome situation are still scarce. Keck (2004) has suggested that it is more meaningful to measure functional outcomes of response to treatment for persons with BD, than scores on various psychiatric rating scales. In the few studies that include this perspective, positive outcomes have been seen in psychosocial (Patelis-Siotis *et al.* 2001) and social function (Perry *et al.* 1999, Lam *et al.* 2003, Bauer *et al.* 2006) and employment (Perry *et al.* 1999). Earlier studies of inpatients with BD, with the focus on their learning about the illness and how to manage it in daily life, indicate that these kinds of interventions are promising regarding improving their ability to manage the illness themselves (Pollack 1995, Pollack 1996a,b, Pollack & Aponte 2001). There are only a few studies made of educational interventions for family members of BD sufferers, all showing promising results on family attitudes towards the ill person, perceived burden and knowledge of the illness (Honig *et al.* 1997, Reinares *et al.* 2004).

From the studies already performed there are some aspects of educational interventions that seem to be important for their outcomes. These aspects concern the focus and content of the intervention, e.g. its length and the role of the persons affected and their family in the intervention. The most successful educational interventions in BD reported here, all included systematic, intensive, collaborative and interactive learning efforts. Whereas other interventions, with a less intensive or a more traditional and informative design, seem to yield poorer results. This can be exemplified by a study of Miklowitz *et al.* (2007) who compared the effects of a short three-session educational intervention with intensive psychotherapy (30 sessions over 9 months of interpersonal and social rhythm therapy, cognitive behaviour therapy, or family-focused therapy). The intensive psychotherapy showed effects in terms of better total functioning, relationship functioning, and life satisfaction among the persons with BD. In contrast, a long-term study of persons with BD who were offered education through a workbook and a videotape in combination with pharmacotherapy, showed no effect on the main outcome, recurrences (Perlis *et al.* 2006).

The educational intervention here reviewed was mainly performed by psychologist and psychiatrists whereas Pollack's studies of inpatients with BD are the only nursing interventions. Educational interventions can be carried out by different mental health-care professionals well experienced in the area. However, PMHRN's working in outpatient mental health care have the capacity and the ability to involve the whole family of the member with BD in the care and to support them in gaining this knowledge to facilitate their lives and manage the dilemmas (Goossens *et al.* 2008a, Psykiatriska Riksföreningen & Svensk Sjuksköterskeförening 2008).

For learning efforts such as in educational interventions, to be successful it seems important that they are based on well-planned and intensive efforts, with interactions between those with the illness, the families and healthcare professionals. However, in research into these interventions there is a need for more focus on psychosocial function outcomes.

RATIONALE OF THE STUDY

How these persons are able to come to terms with the condition and manage life and the stress it causes is a major concern in this study. There is a lack of knowledge about how persons with BD and their families' experience the condition and the long-term management of the stress it causes in their lives. Even though previous studies indicate promising results concerning educational interventions, there is a need to develop and study educational interventions in mental health care, performed by PMHRN's. To answer the needs of the persons affected and their families and to strengthen their ability to manage the situation, support and interventions have to be based on collaboration and interaction that give them the chance to learn and take responsibility for the illness. Knowledge about the condition and how to live with it is an important part of care, strengthening persons with BD and their families in finding a way in which to manage with the condition and their lives. However, there is still a lack of research into the outcomes of educational and family interventions. Developing and describing the outcomes of interventions that focus on strengthening the ability of these persons ability to perform self-management in daily life and to engage in mutual relationships with others is still needed.

AIMS OF THE THESIS

The aim of this study was to describe the experience of living with bipolar disorder (BD) from the view of the person affected and their family. A further aim was to analyze the outcomes of educational interventions for persons with the illness and their family members in outpatient mental health care.

This thesis comprises four papers with the following specific aims:

- | | |
|-----------|---|
| Paper I | To describe the meaning of living with BD from persons' view of the illness and the future. |
| Paper II | To elucidate what it means for family members to live with an adult person with BD, with reference to their views concerning the condition of the person affected and the future. |
| Paper III | To analyze the outcomes of an educational intervention for persons with BD on their subjective management of stress but also social and global functioning over a 2-year period. |
| Paper IV | To analyze the outcomes of an educational intervention for the family of the person with BD on their stress management, social function and carer situation over time through a two-year follow-up. |

THEORETICAL PERSPECTIVES

In this thesis it was studied what it means for the daily life of a person and his/her family to be affected by BD. BD is to be seen here as a long-term illness where the affected person and his/her family are forced to face life with the illness and to rely on their personal resources and their social context (Miller 1993). To understand this and to develop health care, it is not enough to have knowledge about the disease BD and its manifestations, the personal and family perspectives of the illness must also be understood. Furthermore, how these persons manage the illness or their role as family members in order to facilitate their daily life needs to be further investigated. Against this background the theoretical perspectives are used to distinguish between disease and illness, and to describe the essence of caring and learning in a social and cultural context, in person with long-term mental illness and their families.

Illness and disease

BD is termed a disease or a disorder, in the international classifications of diseases DSM-IV and ICD-10. To be diagnosed as having BD there must be several symptom of abnormal functioning that remain for a period of time. But even if a person exhibits the symptoms needed to meet the criteria for the diagnosis, it does not mean that the person experiences himself as having a disease or disorder. It is the personal experience of ill health that defines illness and that can be experienced even when no disease can be found (Boyd 2000). Disease is based on a biomedical perspective and can be defined as “any derivation from or interruption of the normal structure or function of a part, organ, or system of the body as manifested by characteristic symptoms and signs; the etiology, pathology, and prognosis may be known and unknown”. Whereas disorder is “a derangement or abnormality of function; a morbid physical or mental state” (*Dorland’s Illustrated Medical Dictionary* 2003, p. 547). Disease has also been described as a pathological process, a deviation from a biological norm (Boyd 2000). Illness is based on a more humanistic perspective and has been described as the human experience of loss or dysfunction whereas disease is the manifestation of aberration at tissue, cellular, or organ level (Benner & Wrubel 1989).

Another perspective of illness problems is described as the difficulties created by symptoms in daily life. Often illness is invisible to others and it cannot be objectively determined whether the experience is real or not (Kleinman 1988). Illness refers to how the person being ill, but also their family members or social network perceive, live with and respond to the symptoms of the illness and disability. However, a change in context, as when a person is confronted by a new and strange situation, such as an illness, can cause stress when their background and self-understanding are insufficient and they have to stop and reflect over the situation (Benner & Wrubel 1989). How someone attaches meaning to their illness experience, what resources are available and what they have to cope with arises out of the transaction of that individual’s personal/cultural meanings, social context and the situation of the illness. It is this perspective of BD that has been guiding this thesis.

Caring

This thesis has its foundation in caring science where the human being is seen as a whole. Caring science is basically humanistic in nature (Eriksson 2002). The human being is fundamental in Eriksson's theory and in suffering caring activities have a natural basis. Care for another human being can be based on natural assumptions and Mayeroff (1990) emphasised to care for another person is to support that person in growing and actualizing himself, a process that involves development of a trusting relationship. In this thesis such a relationship can be that one of a family member that is caring for a person with BD, or a mental healthcare professional caring for a person with BD and their family. To support another person in growing is to support them in taking responsibility for their own life and need to care. Growing includes learning that leads to re-creation of one's own person by integrating one's own values and ideals that are based on one's experiences and ideas, in contrast to conforming to prevailing values or rejecting them (Mayeroff 1990). Leininger (1981) described that care/caring is about those assistive, supportive, or facilitative acts for another person or group of persons with evident need to improve the condition or way of life of that person or group. It appears to be the heart of all healthcare services and at the centre of helping humankind in wellness, illness and stressful situations. In mental health care, nurses and other professionals have the possibility of facilitating and supporting those living with an illness and their families so that they can come to terms with their condition and manage the stress in terms of transferring knowledge and, in collaboration create tools in order to utilize their own ability. However, the essence of caring is the relation, between the healthcare professional and the persons affected by illness and their relatives (Morse *et al.* 1991).

Furthermore, according to Benner and Wrubel (1989) the main goal of the nursing care relationship is to assist and enhance the person's ability to develop into the persons they want to be. Healthcare professionals are responsible for giving knowledge to the person with an illness and their family, in order to support their understanding of the condition and their involvement in their care. To facilitate changes in lifestyle and health habits these efforts need to be integrated into a person's own cultural traditions and embedded in the person's social context. A person is a self-interpreting who is created, and creates itself, in relation to the context in which the person concerned functions during his/her life (Benner & Wrubel 1989). This also means that for healthcare professionals to be able to offer a more person-centered care the focus needs to be broadened with the patient seen as a person, with understanding of the individual's experience of illness, sharing power and responsibility, and a therapeutic alliance between the patient and the caregiver (Mead 2000).

Learning through social interaction

The socio-culture perspective is a theoretical way of describing the development of cognition and how people act in different circumstances, which has guided this thesis in understanding how adults and their families can learn about and increase their capacity to manage life with BD. In practice, a person acting on the basis of their

knowledge and experience and how they consciously or unconsciously perceive what the environment requires, permits, or makes possible in a given activity (Säljö 2000). People must be able to determine when a particular set of skills is relevant and productive, and how they works in different situations, this means e.g. that a family member with BD, needs to learn when and how they can use different skills/tools to manage a specific situation in an advantageous way. According to socio-cultural theory, a person's thinking is rooted in his or her culture and society (Vygotsky 1978). Adults form attitudes to gain control over their illness and to learning itself, which will influence the willingness and ability to learn, therefore the goal for educating efforts is to enable them to learn for themselves. These formed attitudes highlight the complex situation of learning among persons with an illness, thus their individual understanding of the condition must be considered (Friberg, Andersson & Bengtsson 2007). To facilitate for an adult person affected by BD and the family learning about how to live with the illness, healthcare professionals need to start by establishing what understanding of the illness these persons have, what they already know, and then organising the educational interventions in such a way that new matters are integrated into existing knowledge (Rogers 1989).

Vygotsky (1978) stated that cultural development appears twice: first, between people (interpsychological) and then inside the person (intrapsychological), this means that social interaction plays a fundamental role in this development. People develop their thoughts in their specific socio-cultural contexts by actively participating and communicating in social interactions. This means that the development of a person's thoughts about their illness is manifested both within the self and changed by the socio-cultural context over a lifetime. Furthermore, Vygotsky stated that the potential for a person's cognitive development depends upon the potential level of development which they can achieve through increased knowledge. There is a difference between the learner's current knowledge, a knowledge that the person has mastered on their own, and their potential level, what can be achieved through support or in collaboration. One essential feature of learning is that it creates a base for potential development; that is, learning awakens a variety of internal development processes that are able to operate only when the person is interacting with others in his environment and in cooperation with peers and family members and others in reliable relations, e.g. PMHRN's. However, people have different prerequisites for achieving this. Those with high intellectual or emotional barriers, e.g. persons affected by long-term mental illness, are in need of more support than others (Vygotsky 1978). The range of skill that can be developed through interactions and collaboration exceeds that which can be attained alone. Vygotsky believed that it is the dialogue that creates the real communication and that language is the paradigm for the relation between learning and development.

METHODS

Design

In order to develop understanding and support of persons with BD and their families a combination of different research methods was used to capture the experience of living with BD and its consequences for daily and future life, described from the point of view of these individuals (I-II). Furthermore, the outcomes of educational intervention focusing on increasing knowledge about how to manage a life with BD were studied (III-IV). In the first two studies (I-II) the design was descriptive and retrospective. Paper III and IV were follow-up studies with a longitudinal (III-IV) and comparative (III) design. The results were evaluated through qualitative (I-II) and quantitative (III-IV) analytical methods.

Table 2. Research design overview

Paper	I	II	III	IV
Design	Descriptive, retrospective, qualitative	Descriptive, retrospective, qualitative	Longitudinal, comparative, quantitative	Longitudinal, quantitative
Data Collection	Interviews	Interviews	Self-administered instruments, semi-structured interview	Self-administered instruments
Participants	Persons with BD (n=18)	Family members of persons with BD (n=17)	Intervention group - persons with BD (n=32) comparative group of persons with BD (n=15)	Intervention group - family members of persons with BD (n=34)
Analysis	Content analysis	Content analysis	Descriptive and analytical statistics	Descriptive and analytical statistics

Educational intervention

In Papers III and IV the educational intervention was an existing health care intervention in a unit in outpatient mental healthcare services. The intervention was developed to strengthen the participants' self-management skills to compensate for the lack of support and high stress perceived and identified among these individuals in existing research (as described earlier in this thesis). It is based on the assumption that communication, collaboration and discussion create interaction and facilitate the participants to learning so that they can develop their knowledge about and capacity to manage living with BD.

The intervention consisted of a mix of learning methods with some influences from the cognitive model (Beck *et al.* 1979), which focuses on the relation between thoughts, mood and behaviour. In the intervention session they were offered the possibility to socially interact with other persons affected respectively other family members with experiences of the illness, “experts from experience”, but also with healthcare professionals such as PMHRN in a collaborative and understanding environment. The interventions consisted of ten group-sessions which were held once a week at the same time in the same place in an outpatient mental healthcare unit. Every session had different topics related to living with BD which the group discussed and reflected on (see Table 3). The opportunity and time to share experiences, meeting others with similar experiences and learning strategies to managing life with the illness in a pleasant environment was an important part of the education, and has shown to be beneficial for people living with mental illness (Borge & Hummelvoll 2008).

Table 3. Topics in the educational interventions for persons with BD and families

Topics for the sessions	Persons with BD	Family
Manifestation of bipolar disorder	How do mania and hypomania affect you?	How do mania and hypomania affect the family?
Manifestation of bipolar disorder	How does depression affect you?	How does depression affect the family?
Treatment	What treatments can be used and how does they affect you?	What treatments can be used and what are the effects?
Why?	What makes you ill? Explanations and experiences	What explanations are there for the illness? Explanations and family experiences
Stress & Anxiety	How does it affect you? How can you help yourself?	How does it affect the member with the illness and yourself? What can you do?
The influence of our thoughts	How thoughts affect emotional experiences and behavior. How to manage: recognition, challenge and change	How thoughts affect emotional experiences and behavior. How to manage: recognition, challenge and change
Early warning signs	Learn to help yourself. How to manage: Identifying signs of new episodes of illness, action plan and involving the family	Learn to help the member with BD. Identifying warning signs of new episodes, action plan and family involvement
Life style questions	Destructive and beneficial habits. Finding new routines and a healthier behavior	Destructive and beneficial habits. Finding new routines and a healthier behavior
Sum up & repetition	Summing up and discussion about how to go forward	Summing up and discussion about how to go forward
Booster	Repetition and discussion about what has been learned	Repetition and discussion about what has been learned

In each intervention group two PMHRN's led the sessions. The group leaders were well experienced and trained in cognitive therapy. They were clear about the importance of confidentiality in the groups and sensitive to the participants' reactions, with no one being forced to speak and extra support given if needed. Every session lasted for two hours with a break in the middle. At the first session the PMHRN told the group about themselves and the participants were given time to get acquainted. The first eight sessions began with an introduction to the topic for the day and opened the way for reflective discussion based on the participants' own experiences and feelings. The last two sessions were used for repetition and rounding of the education. The intervention was informative, reflective, explorative and problem-based, and learning was strengthened through the ongoing dialogue between the PMHRN and the persons with the illness or the family members, but also between the individuals participating in the groups. In the informative parts simple words and phrases were used in combination with illustrative pictures, to support the participants' understanding. The participants also discussed and practised, e.g. through role-play or homework, how to manage situations they experienced or that could arise as a consequence of the illness. At the end of each session the participants had opportunity to narrate about their experiences. This was a way of summing up the session together in a positive manner. At the last session of the intervention the participants received a compendium including the introductions to the topics discussed during the education in order for them to use for own further training.

Participants and settings

All participants in Papers I and III were recruited from the outpatient mental health-care services in a county in the southern part of Sweden. They were all under the care of an outpatient mental healthcare unit and receiving the usual pharmacological treatment for BD. Criteria for inclusion (I & III) were: ≥ 18 years of age; diagnosed with bipolar I or II disorder in accordance with Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association 1994) by a board-certified psychiatrist; and able to understand, read, and speak Swedish. Exclusion criteria were being in an acute episode of BD or a current DSM-IV Axis I comorbidity (only in severe conditions).

The participants in Papers II and IV were all family members of persons treated at the unit for BD. In the recruiting process the family member was designated by the person with BD as a significant, influential person in his/her life. The inclusion criterion (II & IV) were: a significant member of the family (parent, partner, adult child or friend) of a person (older than 18 years) who had been diagnosed as having BD in accordance with the DSM-IV (American Psychiatric Association 1994) by a board-certified psychiatrist and receiving treatment within outpatient mental healthcare services.

The participants (n=18) in Paper I were recruited from six outpatient mental health-care units within the same county, five for adults and one for children and adolescents. The data-based medical record system of the outpatient mental healthcare services was used to identify persons with BD. For distribution of interviews with participants of different ages a purposeful selection of participants was made by the first author, in

accordance with the inclusion criteria. However, in two cases participants were identified by professionals from the child and adolescent psychiatric unit (I). The participants (n=17) in Paper II had all been identified as significant influential people by the participants in Paper I where 16 of the 18 participants diagnosed with BD stated that they had a family member the interviewer was allowed to contact for the study. One individual gave two family members. They were all included in Paper II.

Paper III included one intervention group (IG) and one comparative group (CG). The participants in the IG were recruited from the outpatient mental healthcare unit where the educational intervention was offered, and the CG from three others units. The author had several meetings with those in charge and the local mental health professionals in these units to inform them about the study, intervention and recruitment procedure. The participants in the IG were first indentified by the healthcare professionals in the outpatient mental healthcare unit in accordance with the inclusion criteria and then contacted by the author about the study. A total of thirty-six persons agreed to participate in the IG. The IG was offered the educational intervention consecutively divided into four groups (6-10 participants/group); one group every 6 months over a period of two years. The participants in the CG were identified by the author through the data-based medical records at the three other outpatients mental healthcare units. A consecutive selection was then made by the author to match the CG with the IG participants with regard to age, gender, place of residence and type of BD. Thirty-four persons with BD were invited to participate in the CG, 16 agreed to do so. The CG was not offered any intervention in addition to standard care. Three people dropped out of the IG after baseline assessment for personal reasons. One other person dropped out after the first half-year follow-up after the intervention (T³) because they felt uncomfortable about participating in the study any further. In the CG one person dropped out at the time of the baseline assessment because of not feeling sufficiently recovered. The total study sample consisted of 47 persons, with 32 participants in the IG and 15 in the CG.

In the study presented in Paper IV the participants in the educational intervention were recruited from the same outpatient mental healthcare unit where the educational intervention was offered. They were all identified by the healthcare professionals at the unit, in accordance with inclusion criteria, and contacted about the study by the author after approval had been received from the member treated for BD at the unit. Forty family members first agreed to participate in the study, however, six dropped out at baseline, five for personal reasons or no given reason and one from fear that data given would de misused. The total study sample consisted of 34 persons.

Data collection

The participants were first sent a letter providing information about the study. After a few days they were telephoned by the first author, and if they agreed to participate, a time and place was set for the interview or the baseline assessment, which were carried out in a place chosen by the participants, either in their home or a private room in the outpatient mental healthcare unit. Written informed consent was obtained at the time of the interview or baseline assessment.

Papers I and II

Persons diagnosed with BD (n=18) and their family members (n=17) were studied. The data collection was made during 2005. Data were collected by means of qualitative interviews which make it possible to capture, in their own words, how each interviewee viewed the world (Patton 2003). The interviews with the participants in the study lasted 51-97 minutes (median=63 minutes) (I) and 30-77 minutes (median=56 minutes) (II) and were conducted by the author. The interviews were transcribed verbatim, either by the author or a medical secretary experienced in transcribing research interviews. The interviewer had not previously met any of the participants.

Interviews

The use of qualitative methods (I-II) is called for when something is to be studied in depth and detail (Patton 2003). Qualitative methods allow the collection of larger amount of detailed data about small groups of people than do quantitative methods. The qualitative research interview is a method used to understand the world from the interviewed person's point of view, to develop meaning from human experiences, which allows their world to be revealed before it is explained scientifically (Kvale & Brinkmann 2009).

An interview guide, constructed by the team of authors, was used to ensure that the same topics were illuminated in all interviews and that the participants were asked to give their view of the illness and the future. The interviews were all conducted by the first author and performed in a conversational manner in a place chosen by the interviewee. The main questions (domains) were: What is your view of your illness? What is your view of the future? (I); and: What is your view of the condition of the person with the illness? What is your view of the future? (II). The questions were asked in a way that allowed the interviewee to speak freely about their experiences of the matter. Follow-up questions were used in order to extend the conversation within a domain, and to confirm that the questions were understood in the context of what was being said. In Paper I the interviews were limited to 18 because the author believed that all essential information and themes had been illuminated, patterns were repeating, and no new themes were emerging (Sandelowski 1986). In Paper II all the 17 family members available were interviewed. The interviews were all tape-recorded and transcribed verbatim the same day, with the exception of two interviews that could not be recorded due to a problem with the tape-recorder. These interviews were recorded by means of brief notes that were transcribed the same evening. The author and a medical secretary transcribed all the interviews and in order to avoid misinterpretation of the text, the author listened to all the recordings and checked them against the transcripts.

Papers III and IV

The data collection methods used in Papers III and IV are: a clinical face-to-face semi-structured interview (III) and self-assessment Questionnaires (III-IV) at baseline (T¹), immediately after the education ended (T²), six months after the education finished (T³) and one year and two years respectively after the education finished (T⁴ - T⁵). The same data collection method and time-frame was used for the comparative group (III) but without the educational intervention.

Instruments

The JCS-40 (Jalowiec, Murphy & Powers 1984, Jalowiec 1988) assesses the general coping behavior of the participants and is based on the Lazarus model of coping. JCS-40 is a 40-item questionnaire answered on a four-point scale. Each item is in the form a statement concerning a strategy used to handle stress. The questionnaire included statements concerning confrontive (Jalowiec 2003) (13 items), emotive (9 items) and palliative (14 items) coping styles. Higher sum scores indicate a more consistent use and lower scores less use of the coping styles to handle stress. Jalowiec (1988) has established construct validity for this three-factor structure and has reported values for internal consistency showing Cronbach's alpha values ranging from 0.70 to 0.85 for the three factors. The Swedish version of the instrument was used. Content validity have been supported by a group of 200 Swedish nurses (Klang, Björvell & Cronqvist 1996) and with Cronbach's alpha values for the three factors ranging from 0.80 for the confrontive, 0.72 for the emotive and 0.65 for the palliative (Gustafsson & Ahlström 2006).

Table 4. The instruments used in Papers III and IV over a time axis from baseline to the two-year follow-up

Instruments		At Baseline T ¹	At end of intervention T ²	After ½ year T ³	After 1 year T ⁴	After 2 years T ⁵
Paper III	Jalowiec Coping Scale (JLC-40)	X	X	X	X	X
	Sense of Coherence questionnaire (SOC)	X	X	X	X	X
	Social Adaptation Self-evaluation Scale (SASS)	X	X	X	X	X
	Global Functioning (GAF) (last few weeks)	X	X	X	X	X
	Knowledge Ladder (version of person affected)			X		
	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	X	X	X	X	X
Paper IV	Jalowiec Coping Scale (JLC-40)	X	X	X	X	X
	Sense of Coherence questionnaire (SOC)	X	X	X	X	X
	Social Adaptation Self-evaluation Scale (SASS)	X	X	X	X	X
	COPE index	X	X	X	X	X
	Knowledge Ladder (version of family member)			X		

The SOC is a questionnaire that provides a measure of the individual's capacity to manage stress and stay well (Antonovsky 1987). In the present study the Swedish version of SOC, with 29 items, was used. Variables are rated on a Likert-type seven-point scale. The sum of all variables provides a score ranging from 29 to 203. Higher scores indicate stronger SOC. Three components: Comprehensibility (11 items); Manageability (10 items), and Meaningfulness (8 items) are assessed in the questionnaire. The SOC instrument has shown acceptable validity and reliability with the Cronbach's alpha ranging from 0.70 to 0.95 in 124 studies using SOC 29 (Eriksson & Lindström 2005). In this study the Swedish version of SOC, with 29 items, was used. This version has shown acceptable validity and reliability with the Cronbach's alpha ranging from 0.79 to 0.90 (Langius, Björvell & Antonovsky 1992).

The SASS is an instrument that assesses the social functioning of the participant. It consists of 21 items measuring social motivation and behavior (Bosc, Dubini & Polin 1997). The questions are scored 0–3 and the total score range is 0–60 (questions 1 and 2 are mutually exclusive). The test has proved to have high test-retest reliability and to be sensitive to change with a Cronbach's alpha value of 0.74. The Swedish version of SASS was used in this study with a Cronbach's alpha value of 0.62.

The GAF self-report version measures the individual's psychological, social and occupational functioning (American Psychiatric Association 1994) that has proved to be useful for measuring outcome in psychiatric care (Ramirez, Ekselius & Ramklint 2008). It is answered on a 100-point scale with lower scores indicating worse functioning. The scale is judged to be a valid and reliable instrument with an overall correlation of 0.62 between self and expert ratings (Bodlund et al. 1994).

The participants' histories and course of BD episodes were verified and tracked through the structured clinical interview for DSM-IV Axis I Disorders (SCID-I) (First *et al.* 1994) and complemented with data from the participants' medical records. The SCID I is a semi-structured interview support for psychiatric diagnosis according to DSM-IV and consists of standardized diagnostic questions arranged in modules corresponding to each DSM-IV Axis I disorder.

The COPE index is a 15-item questionnaire that assesses the carer's subjective perceptions of the positive values and negative effects of their carer circumstances as well as the quality of support (McKee *et al.* 2003). Each question is answered on a four-point scale with the alternatives 'never', 'sometimes', 'often' and 'always'. For some of the questions there is also a 'not applicable' response. The questionnaire includes three components: positive value; quality of support; and negative impact. Higher sum scores indicate a higher negative effect, positive value, or quality of support. The COPE index has shown internal consistency with good to satisfactory Cronbach's alpha values ranging from 0.64 to 0.83 for the three factors solution (Balducci *et al.* 2008). The Swedish version of the instrument, also applied in the study by Balducci *et al.* (2008), was used.

One new instrument was developed the "knowledge ladder" to rate the persons subjective appreciation of whether the knowledge learned was useful in managing their

life with the illness or the situation of living with a person affected. Participants were asked to rate freely on a visual analogous scale in the form of a ladder, which was then converted into a 10-point scale for analysis. Higher score indicated more useful knowledge learned.

Sociodemographical data were obtained at every measurement occasion.

Data analysis

Qualitative content analysis

Qualitative content analysis was the chosen method (I-II) for analyzing the texts of the transcribed interviews so that meanings could be identified in the material. There is no single way of doing content analysis, which comprises many techniques and methods. There are many fluctuating approaches described in the literature. Krippendorff (2004) has described content analysis as a research technique that is used for making replicable and valid inferences from texts (or other meaningful matter) into the context of their use. Content analysis provides new insights but also increases a researcher's understanding of particular phenomena, or gives information concerning practical actions. He stated that what is different for this type of analysis is the recognition of meanings. According to Sandelowski (2000) qualitative content analysis is data derived as the coding process moves further into the domain of interpretation with an effort to understand the manifest as well as the latent content of data. However, it may be hard to define exactly how far one has moved into interpretation in an analysis.

The content analysis was found to be well suited providing new insights and increasing understanding of the particular phenomenon in view, which in this study was "living with bipolar disorder" from the experiences of persons affected by the illness (I) and their family members (II). The first qualitative analysis made in this thesis (I) was inspired of Krippendorff (2004), who has his basis in logical positivism, and allowed interpretations of the data while staying close to it. The other qualitative analysis made (II) was more interpretative, more into the domain of hermeneutics (Baxter 1991). The major differences in interpretation between the analyses were in the abstraction of codes and development of themes. The content analysis was applied to the transcribed data in several steps. After the transcribed interviews had been read through several times those parts of the text relevant to the research question (domain) were marked, condensed into meaning units, and abstracted into codes by the author and the co-researchers. Thereafter the codes were reread, discussed and compared (I-II). Finally the codes were grouped into six (I) and five (II) themes respectively.

Statistical methods

In Papers III and IV the statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS statistics 17.0 2008, Norusis 2010). Descriptive statistics were used to summarize the sociodemographic and clinical characteristics of the study participants. The non-parametric Wilcoxon's rank test was used because of the limited sample size and ordinal scale level of scores. Comparisons of means

within the groups were analyzed over time during the two-year follow-up. In Paper IV Friedman's test was applied when exploring development over time. A significance level of $p < 0.05$ was applied for all analyses and the p -value was reduced according to Bonferroni correction. Drop-out was registered and analyzed.

Ethical considerations

Ethical requirements concerning informed written consent, confidentiality and utility of data were met. The study was approved by the Regional Ethics Review Board in Lund (Dnr 298/2004). Interviewing persons and families living with such a severe illness as BD (I-II) can be distressing for them and require great effort. The interviewer was therefore attentive and sensitive to what took place during the interview. If it was necessary the interviewer allowed short breaks during the interview and after words the interviewees were asked about their impression of the interview. The interviewees said that they were eager to share their experiences and stressed the importance of helping others.

The participants (III-IV) had to answer a large battery of research questions, which can be demanding but none of the participants complained about it. The first author remained available to the participants at the time of the baseline assessment in order to give them support and familiarize them with the questions, if needed. Participating in an educational intervention group could be stressful in the beginning, because of the fear of being compelled to talk and that what is said will be circulated outside the room. The PMHRN leading the group was clear from the beginning that one only had to share what one wanted to and secrecy applied to everyone participating in the educational group sessions.

RESULTS

The results from this thesis are summarized and presented below, first from the perspective of the persons affected and then from that of the family members, under the headings: a struggle against uncertainty and limitation; a movement from powerlessness towards a more manageable life; and a strengthened self-management and outcomes for daily life.

A struggle against uncertainty and limitation

The persons affected with BD found it difficult to come to an understanding of their illness experience. Their striving for understanding meant they had to go through a demanding transition from uncertainty towards an insight concerning their shifting mood and the way they felt. It was difficult for them to distinguish between what was their own normal way of feeling and what was illness-related. Accepting that the illness was a long-term, fluctuating process required insight into this relation. This process was made even worse as the persons affected had to struggle simultaneously with their own and general prejudices surrounding being identified as an individual with a mental illness. Sometimes the acceptance of the condition was too burdensome and they reacted by denying it or simply became resigned. The persons with BD felt their lives constantly were interrupted by the illness as a result of the recurrent episodes of both depression and mania or hypomania. This gave rise to a feeling of being insecure in themselves, with a questioning of their own ability to function and of how they were perceived by others (I). This kind of interruption common among those with the illness limited their lives both functionally and socially. They also had little capacity to manage stress and stay well (III). They longed for a life without fear and limitations and sometimes the change from depression to mania felt liberating. But with an increased understanding they could start to relate socially to other persons with similar experiences and no longer had to feel alone with their illness (I).

A major concern for the family of the member with BD was that they felt they had to face change alone. They had to confront the unpredictable, rapid mood fluctuations and behaviour of the member of the family who was ill, which were not always visible to others. From the family's perspective they were left alone with their experience when no one else understood what was going on (II). The perceived low quality of support confirmed their solitary situation. They also felt that caring for the member with BD had a considerable negative effect on their own lives, whereas the positive value was limited (IV). Finally when the frustration and fears related to the change grew too strong, families felt a need to seek help from healthcare. It was a major concern for the families to find an acceptable explanation for the condition of the person who was ill, but this was a challenging process in which making sense of their experiences also raised doubts. Their normal and logical reasoning was sufficient to explain the condition or to distinguish between the symptoms of the illness and what was an ordinary variation in the life of the person who was ill. This could cause them to feel guilty as they started to question themselves and how they acted towards the person with the illness (II).

A movement from powerlessness towards a more manageable life

The persons affected by BD felt uncertain about the future course of the illness and their ability to manage employment, further education, relationships and financial matters, and that this was out of their power. Many of the younger adults (18-30 years old) did not dare to make plans or have dreams for the future, instead they avoided thinking about it, took one day at a time and only made short-term arrangement. One serious consequence of this uncertainty was that hope of being able to becoming well again was lost, and giving up and dying were sometimes the thoughts that were seen as the solution (I). However, those affected who were offered the educational intervention showed that they benefited from the support and knowledge they gained through a stable increase in their social functioning (III). Among the older adults (31-57 years old) suffering from BD strategies such as positive thinking, not giving up, and trying to make the best of the situation were commonly employed in managing the illness. Living with the illness was not only devastating, it could also contribute to personal growth in those affected, incorporating new perspectives on life with an understanding of how life can change. By developing individual strategies that included having someone to talk to, taking their medication, having time for themselves, planning better and having clear routines, they were able to adapt to a more peaceful daily life with less stress. Nevertheless in order to manage life with the illness they had to accept the illness, increase their knowledge about it and assume responsibility for managing it as a part of their life (I).

Among the family members there was a constant strong desire to support the person who was ill, but this commitment also meant bearing the burden of having to be in control, take responsibility and constantly worry about their future. This situation challenged their view of their own future, and they balanced between the need to be in control of the condition and, simultaneously, to be relieved of responsibility. The family members felt powerless in the face of the encroachment of the illness on their own daily life and they struggled to maintain normal family life. When family members became reconciled to the condition of the person with the illness, the abnormal became normal, and they were able to discern new perspectives (II). The educational intervention offered to the families proved beneficial for them in this struggle as they reported an increase in useful knowledge about managing life with the illness as a member of a family with a person with BD. Furthermore, the families seemed to be able to retain their daily social interactions on a “normal” level over time, which indicated that they did not have to give up their own social life (IV). In their struggle to maintain normality the family members also had to cope with other people’s lack of understanding and their own feelings of shame about the situation. It was a relief for them to be able to talk about the situation with other people, and it made their life easier to manage (II).

A strengthened self-management and outcomes for daily life

A hopeful future began to emerge when the persons affected by BD started to believe in their ability to influence their illness and live a manageable life, with feelings of wellbeing and being a part of society. The feeling of hope was accelerated by their acceptance that not only do they have to learn to live with BD but they also have to

assume responsibility for managing it, e.g. by obtaining support and knowledge about the illness (I). Those with BD who attended the educational intervention developed their skills, such as acquiring more effective ways of managing stress, and could thus better manage their life with the illness. This was made possible when they learned more about how to manage difficulties in daily life related to their condition. The way they managed stress shifted after the intervention in that they used less so-called palliative, or avoiding, behaviors and tended to use less emotive and more confrontive, or problem-solving, strategies. This means they shifted the way they managed stress away from efforts aimed at reducing the emotional discomforts related to their experience of the illness, and towards increased efforts to focus on removing the threats to their health. An increased overall capacity, in the long-term to manage stress and stay well (SOC) could also be confirmed among these persons (III). To set up goals and achieve a hopeful future was dependent on the person's will to fight the illness and their fears of it, but also on learning how to create a more peaceful life and handle the illness more independently. This could mean they had to change their old habits and patterns (I).

The efforts made by the families to resume and get on with their own lives provided the foundation for building hope for the future. To retain a positive attitude to the future and make life more manageable, the family members had to adapt their idea about what the future would be like in the current situation. They also had to find new perspectives on the current situation and make an acceptable agreement with themselves to limit their responsibility for the life of the person who was ill. They pointed out the importance, for feeling that there was hope, of future opportunities to meet with other people who had similar experiences. But they also needed to receive understanding from their colleagues, friends and relatives and support from the public health service (II). Even though the families receiving the group education had the capacity to manage stress and stay well, they seemed to benefit from the intervention in terms of them acquiring useful knowledge and an increasing comprehensibility of their life situation that continued throughout the follow-up period. Furthermore, the total use of stress-management strategies was reduced after participation in the intervention. A stable reduction over time was seen in their use of strategies focused on confronting or solving problems which they related to stress, whereas an immediate decrease was found in their so-called palliative, or avoiding, behavior (IV).

DISCUSSION

The meaning of living with BD from the experiences of the persons affected and their families were in this thesis found to be characterized as a struggling against uncertainty and limitation, and a movement from powerlessness towards a more manageable life. The outcomes of the educational interventions showed to strengthened self-management and outcomes for daily life. In the following discussion the prerequisites for and obstacles to integrating the illness into ordinary life will be highlighted. Furthermore, how the interactions and the social context interplay with these persons' self-management of their situation and, finally, the meaning of increased knowledge and a strengthened self-management will be discussed.

Integrating the illness into ordinary life

Bringing into light the illness perspective of a person with BD is a prerequisite for gaining an understanding of the difficulties that the illness creates in that person's daily life. This is of major importance as illness is often invisible to others and the truth of the experience can only be subjectively determined (Kleinman 1988). The meaning the person attaches to the illness experience and what resources he/she has available to manage it with are based on the transaction of that person's social context, personal/cultural meanings and the situation of the illness (Benner & Wrubel 1989). The interviews with the persons affected from BD revealed that they were struggling with uncertainty, moving towards an understanding of the complex and unpredictable illness and situation. The longing among the affected persons to be well and normal could lead to denial of that they had the illness, in order to be able to endure the situation without having to deal with it, instead of finding a way to wellness and normality based on their own premises. On the other hand, their inconsistency in developing an understanding of the illness could lead them suffer losses, such as reduced control over their life and future. Instead of developing a true understanding of self, they risked raising doubts about themselves and their abilities which could affect their self-confidence (Karlsson 2006) as well as their self-esteem and self-identity (Charmaz 1983), resulting in a diminished self. This consequence was seen very clearly among the younger adults who did not dare to have dreams and make plans for the future. They arranged their life by taking one day at a time as they were afraid of new failures and limitation to their life. Only living in the present can be a strong indicator of an inhibition to participation and engagement in the transition (Selder 1989) of learning to live with their illness.

According to Benner and Wrubel (1989) the inconvenience, or health worry, of experiencing interruption of ones daily life by illness disrupts meaning, understanding, and smooth functioning. A serious consequence seen in this study was that the future was seen as uncertain and hope of being able to becoming well again was lost, leading to thoughts about giving up where death was sometimes was seen as a solution. Delmar *et al.* (2005) described getting in harmony with oneself as a movement towards, and a form of acceptance of, living with a long-term illness. Some persons can achieve this level of acceptance, while for others the obstacles in everyday life make

this movement towards acceptance more difficult. Achieving harmony with oneself is conditioned by the existence of hope, the willingness to change one's situation and by the pressure of doubts on this hope; all important aspects of having a hopeful future among the persons with BD in this thesis. Doubts can shake hope so that instead of moving towards acceptance, the person drifts towards hopelessness and despair (Delmar *et al.* 2005). However, in this study when persons with BD became aware that they could positively influence their situation and gained knowledge about how to do it, they were able to discern a hopeful future and were motivated to continue and to struggle to manage their situation by themselves. This self-management required taking responsibility for one self. According to Delmar *et al.* (2005) self-responsibility and self-control are meaningful values in the activities and decisions of the daily life of a person with a long-term illness. Dignity and being respected as an individual are closely connected to being able to manage on one's own and be independent of others.

The family members felt powerless and alone in the face of the condition and the changes in the person who was ill and also of how their own life and mood were disrupted. Their uncertainty and insufficient knowledge about the illness and future outcomes made it difficult for them to balance their need to take care of and be responsible for the person with BD with their need to focus on or give priority to their own life. Their involvement included trying to compensate for the limitations in daily life placed on the member with the illness and to prevent the condition from being worse. This is in line with results about persons with major depression (MD) and their families described by Skärsäter *et al.* (2003 a,b) and Ahlström, Skärsäter and Danielson (2009, 2010), whose studies claim that they compensate for the inadequate contribution to the family of the member who is ill and take over tasks that he/she would normally have performed. The concept of uncertainty is useful in understanding the stress this creates in the persons affected as well as the family members and has been described as a dynamic state of inability to predict consequences which, in turn, leads to feelings of discomfort (Penrod 2001). This was a part of daily life for these families that they tried to manage in one way or another and constituted an obstacle to their moving on with their own lives, which became of secondary importance (Östman *et al.* 2005, Stjernswärd & Östman 2008). This can have unwanted consequences for the relationship between the family member and the person with the illness, transforming the dynamics of the relationship into one that could be characterized more as nurse–patient or parent–child in nature (Stjernswärd & Östman 2008).

The insight among family members that they could not control the illness allowed them to reduce their involvement without guilt. Strauss *et al.* (1984) have suggested that the basic strategy for coping with these kinds of issue was to live as normally as possible. In addition, being in harmony with oneself concerns learning to adjust and to deal with one's new situation. Once family members became reconciled to the illness there was a shift in what were experienced as abnormalities in their life towards accepting them as something normal. The families were able to discern possibilities and a hopeful future after having gained new perspective on their own life and the life of their member with BD.

Interactions and self-management

Results in this thesis show that the basis for self-management was taking responsibility for one self and that the self-management strategies employed were individual and focused on establishing a structure to reduce stress in daily life and having access to support when necessary. This thesis also highlights that including other people into one's life situation provides a foundation for self-management. When stress occurs (Lazarus & Folkman 1984) there is an ongoing interaction between the individual and the environment where both the personality of the individual and the characteristics of the environment play important roles in managing the various stressors. For mental health professionals it is important to be aware of the person's social learning conditions. People mainly learn about their responses to illness through experiences of trial and error in daily life (Kralik *et al.* 2004). This learning maintain people to make changes to their daily lives and their self-identity is reconstructed by exploring their personal limitations or boundaries. Self-management of long-term illness contain both structure and process, and it is the process of self-management that is central to the experience of moving from a stressful and uncertain life towards normality and the manageability of life with an illness or with a member of the family affected.

The self-management concept is primarily applied to the person living with a chronic illness but its application on family members is unclear. According to the results in this thesis family self-management is about coming to terms with the situation and actions taken to find a balance between being a member of a family where one person has a long-term mental illness and having a life of their own. In accordance with Pollack (1996a,b), there is a range of motivators and barriers concerning self-management efforts among persons with BD and their families. In this thesis those with BD and their families were shown to need supportive social interactions in order to be able to manage their stressful daily life more successfully, of these interactions infusing hope and increasing their understanding of the condition and of their lives were of major importance.

The development of ideas about the illness was both manifested within the person affected himself and changed by the socio-cultural context over his/her lifetime. This means that the person's context changes when confronted with the illness, and when the person lacks sufficient self-knowledge and background understanding he/she has to stop and reflect over the situation, which can cause them stress (Benner & Wrubel 1989). In this thesis those affected by BD tended to adopt a picture based on prejudices about mentally ill people in their social context, associated with poor functioning and being different from other people. This was a complication when they were trying to integrate the illness which was a part of their lives. Williams and Collins' (2002) have suggested that there in the desirable outcome of insight among persons with BD, there is a risk of undesirable identification with the patient role. There is a complex co-existence between 'living a life' and 'living an illness'. People with long-term illnesses make considerable efforts to integrate the illness into their life context and participate in a personally meaningful life. However, it is easy to be consumed with 'living an illness' as the daily tasks, the changing symptoms and the fluctuating emotions can be overwhelming (Whittemore & Dixon 2008) and the illness perceived

as out of their power to influence. This can prevent the possibility of developing potential new knowledge in terms of effective self-management efforts and belief in a hopeful future. In this thesis the quality of social interactions was shown to be important for the persons affected and their families in terms of the possibility of improving social support and facilitating develop their abilities. Receiving nurturance can to provide opportunities for increasing the capacity to manage stress and to promote wellbeing (Langeland & Wahl 2009). Among those with a major depressive disorder social support was a cornerstone in the restoration of their stress-management capacity and wellbeing (Skärsäter *et al.* 2005).

The uncertainty about the illness and future seen among the family members of persons with BD can be explained by the fact that their understanding of their lives before the condition, the current knowledge which the person could master on their own (Vygotsky 1978), were not applicable to their present life in a family where one member has BD. The families had little possibility to communicate with their environment about the condition of the member who was ill, on account of meeting incomprehension and prejudices about mental illness. This prevented them from shifting views on their situation and of reaching their potential developing level, which can be achieved through support or collaboration with others (Vygotsky 1978). This resulted among the family members in a questioning of self and their own pre-understanding with the added complications of self-blame and avoidance of social contacts. Furthermore, their experience of being alone in the situation could be strengthened and more doubts could be raised about the causes and outcomes of the illness. An understanding environment and supportive and collaborative encounters with healthcare professionals could induce these family members to talk about their concerns and feel that they are an important part of the care for the member who is ill, with a greater potential to develop understanding for their situation to a new level (Vygotsky 1978). But if the family members feel that they are not listened to in encounters with healthcare professionals this can constitute a further source of stress (van der Voort *et al.* 2009) in their already stressful situation (Östman & Kjellin 2002, Östman *et al.* 2005, Reinares *et al.* 2006) and can increase their loneliness. Research has highlighted the importance of a collaborative relationship with mental healthcare professionals that also incorporates the family and encompasses shared information, adjusted support and counselling, to increase manageability of their specific life situation (Norby, Kjønberg & Hummelvoll 2010).

As PMHRNs often support those with BD on a more daily basis, there are many possibilities for encounters with both the person with BD and the family and opportunities to acquaint themselves with these people's experiences of the condition from the perspective of daily life. This makes it possible for the PMHRN to identify matters and needs that should be the targets of a holistic mental health care. The role of PMHRN is importance as they are in a position to meet the needs of both the persons affected and their families, and enable them to learn how to manage the illness and its consequences which is a part of their lives. But this also requires that PMHRNs have the knowledge of both BD and learning processes in vulnerable adult persons and their families struggling to recover their life.

The meaning of increased knowledge and a strengthened self-management

From a socio-culture perspective (Vygotsky 1978) education about BD in relation to the participants' own experiences, and the interactions with the PMHRNs and the other participants were central for the learning process in the interventions offered to those with the illness and their families. The focus was to support self-management of the condition and life by enabling the participants to become aware and gain new knowledge, and improve skills that are both adaptable and beneficial to their lives.

The results in this thesis show that those affected who received the educational intervention gained knowledge that was helpful to them in managing their life with the illness. This is an important result as these persons often lack the ability to self-manage (Cutler 2001). However, the benefits of this development was not primarily seen in outcomes of their illness, as they still tended to show a high frequency of recurring BD episodes. The benefits were seen rather in the development of an improved capacity to manage stress and to function socially, sustained long after the intervention ended. These outcomes put life with the long-term changes caused by BD in a more favorable light, showing that it is possible to improve social limitations in social life (Blairy *et al.* 2004, Sanchez-Moreno 2009) and the ability to handle stress (Cutler 2001, Lim *et al.* 2004) as commonly seen among those affected after nursing interventions. A persons-centred care, as in this intervention, in mental health care requires that outcomes that are meaningful to both mental healthcare professionals and users of mental health services are taken into consideration. A study by Perry and Gilbody (2009) of user-defined outcomes in mental health care revealed a great emphasis on personal and social outcomes. The individual outcomes identified concerned *e.g.* changes in myself; believing in change; managing independently; social contact and connection with society; all of which were important outcomes confirmed among the persons with BD in this thesis.

Through participating in the educational intervention the families gained an increased competence and comprehension that was helpful for them in managing their daily life as carers of a member with BD, in spite of the very negative influences this role had on them. After the intervention family members showed a reduced need to use stress management strategies, which implies that their capacity to manage with the stress was strengthened. This could be a result of their experiencing less subjective stress related to their increased knowledge (Reinares *et al.* 2004) and awareness of the condition but also of a better comprehension of their life situation. This is an important result in light of the knowledge that even though families of persons with mental illness seem to grow accustomed to dealing with difficulties related to the illness, their distress or psychological problems appeared to increase over the years (Goossens *et al.* 2008b). The reduction shown in stress management in the family with a member with BD can be explained by the intervention facilitating their acquisition of knowledge about the condition of their member, which in turn could evoke feelings of hope, compassion and sympathy (Karp & Tanarugsachock 2000). In this scenario, actions taken to improve the family's ability to manage of the negative consequences of living with a member with the illness could provide them with opportunities to develop self-growth and a greater awareness of their own inner strengths.

Caring processes such as teaching self-management techniques, establishing and maintaining therapeutic alliances, educating both patient and family, according to Goossens *et al.* (2008a), all aim to benefit health status and social functioning and to reduced the levels of burden experienced by the persons affected and the family. But the way in which such action is performed play a crucial part for the whole family *e.g.* if information is insufficient in its performance and content it becomes incomprehensible (Ahlström 2009). In addition, if healthcare professionals lecture to much, considering themselves experts, it becomes undignifying (Svedberg *et al.* 2003). The caring relationship in which the nursing actions take place is a prerequisite for the success of the individual's ability to grow and integrate the illness into his/her daily life. The caring relationship between persons with long-term illness and their PMHRN needs to create conditions for a holistic view of care based on a mutual commitment and including their families. In this way the individual's dignity can be maintained and strength can be generated (Berg 2006) that in a family perspective also can be a strength the for the family with a person with BD.

One concern is the condition of the persons affected by BD and their families when entering the educational intervention. If the individuals are too overwhelmed by the consequences of the condition they might not have the ability to develop their potential knowledge. To offer an educational intervention at that time might not be appropriate. That is why it is important that the persons affected by the illness have started to recover before they engage in the intervention. Family members might need to have been given support of their own first. Professionals in mental health care need to be attentive to this and offer support that is appropriate at the time, for the individual.

METHODOLOGICAL CONSIDERATIONS

Studying the experiences of persons with BD and their family members in relation to their condition and measuring the outcome of an educational intervention required the use of a variety of research methods. The research question in each of the studies guided the choice of appropriate method. Qualitative interviews using an interview guide were employed as the means to obtain in-depth and comprehensive narratives of the participant's experiences (I-II). Quantitative methods were used to analyze the outcomes of the intervention through specifically selected instruments (III-IV). It was a strength of this study that different methods were used, as the results of the studies could complement each other. However, both qualitative and quantitative research approaches have their strengths, limitations and weaknesses (Polit & Beck 2004), which will be discussed below.

The sample consisted of persons diagnosed with BD, receiving care in an outpatient mental healthcare unit. However, even though the sample was consistent there were some problems in the recruitment processes to both studies that included persons with BD (I and III). The recruitment was hampered by the lack of a registered diagnosis in the medical data records used to identify participants with a BD diagnosis. This limited the number of potential participants particularly to the CG (III). Another concern of the CG was that almost half of those invited to participate in the study agreed to do so, which could be because they were recruited to a comparative group and not the intervention group who received the education. All the participants who were offered the educational intervention (III-IV) were recruited by the healthcare professional at the outpatient mental healthcare unit offering the intervention. One strength of the studies was that there was a wide distribution of participants, in terms of sex and age but also diagnosis of BD I or BD II and family relations. But in Study II where the recruitment of the family members was determined by the person with BD, an imbalance was seen in the distribution of the family relations. The fact that mothers were predominant could mean that experiences specific to other family relationships were not afforded sufficient attention in that study.

The dropout seen in Studies III and IV were within the limits of what can be expected in long-term follow-up studies. It was both beneficial and a limitation that the studies (I-IV) were carried out in the outpatient mental healthcare services in which the author had been active as a PMHRN. It made it easier for the author to gain access to the setting for the study and relations with key-members of the staff were already in place. The negative side was that to some extent it limited the potential study sample because some of those with BD and their families already had a relation with the author as a PMHRN and were therefore, not eligible for inclusion in the study.

Quality aspects concerning data collection and analysis in Papers I-IV will be discussed with reference to accepted quality criteria for validity and reliability, but in qualitative research other criteria need to be used.

The trustworthiness of research results in the qualitative studies (I-II) was established in accordance with standard criteria for qualitative research, credibility, dependabil-

ity, confirmability and transferability (Lincoln & Guba 1985, Leininger 1991, Patton 2003). The participants in the interview studies were themselves able to choose the place for the interview; this can constitute a limitation for the study as people assume different roles in different environments, but the benefit of them being able to choose the place themselves was that they could feel safe in the interview situation, which strengthened the quality of the narratives. According to Patton (2003) the credibility of qualitative methods depends largely on the skill, competence and accuracy of the person performing them.

Furthermore, it is the quality of the original interview which determines the quality of the subsequent analysis, how it is verified and reported (Kvale & Brinkmann 2009). The author was aware that his pre-understanding could influence the interpretation of the data. This was always taken into account in performing the studies and was discussed with the co-author. Dependability was increased by having two main guiding questions to ensure that the same domains were dealt with in all the interviews and through having discussion about similarities and differences in consistency and content over time. There was a risk that the choice of questions would not give the answers that fitted the aim of the studies, but the richness and depth of the narratives ensured satisfaction with the interviews. Numerous quotations from participants were also presented to support the interpretation. Confirmability was achieved through clear descriptions of the selection, context and the characteristics of participants as well as the processing of the data collection and analyse. This also facilitated transferability of the results to other persons with BD and their family members living in a similar context.

Quality aspects concerning data collection and analysis in Papers III-IV will be discussed by referring to the quality criteria of internal and external validity (Polit & Beck 2004). The internal validity concerns the degree to which one can infer that the educational intervention, rather than uncontrolled, other factors, is responsible for the effects measured. To rule out alternative explanations for the results the sample under study can be compared with another similar sample.

In Paper III we tried to obtain a sample for the CG that were as similar as possible to the IG in term of gender, age and illness, as it was not possible to recruit a sample large enough to match a control group. In the outpatient mental healthcare unit where the educational intervention was performed all those with BD at that time, in a condition to participate, were invited to join the intervention. This meant that the sample was not big enough to randomise participants to one of two groups. Instead the CG was recruited from other outpatient mental healthcare units. The fact that the participants in the IG and the CG (III) were recruited from different outpatient mental healthcare units could explain the socio-demographic differences at baseline. Another weakness was that there was possibly some differences in treatment culture and diagnostics even if the units were part of the same mental healthcare service in the same county. This, together with the difference seen at baseline between the groups, limited the possibility of drawing any clear conclusion. However, comparing changes in variables over time between the groups was beneficial as it was possible to see changes in the IG that were not seen in the CG and vice versa. In Paper IV no control or comparative group was possible, which was a limitation.

External validity concerns the degree to which the results of a study can be generalized to other settings or samples than the one studied (Polit & Beck 2004). The interpretation and generalization of Papers III and IV can be discussed. The sample sizes were small but it is difficult to know in advance how easy or hard it will be to recruit participants from a setting. In this case a longer study period or a multi-centre study would have been needed to recruit a bigger sample, but that was impossible to achieve within the frame for this thesis. The interventions studied in the thesis were also developed and a part of the existing treatment selections at only one specific outpatient mental healthcare unit. The fact that the affected persons had all been diagnosed by a psychiatrist in accordance with accepted criteria strengthened the generalization of the results found. The small sample sizes and the lack of a control group in Paper IV limits the possibility of generalizing the results, however, the negative long-term consequences seen in the family members of persons with BD emphasizes the need for further investigation in this area. On the other hand the follow-up of participants over a 2-year period strengthened the reliability of statements concerning the changes seen among the participants. The careful description of the contexts and characteristics of the participants in the papers (III-IV), as well as the process of data collection and analysis, mean that the results are transferable to persons with BD and family members in similar contexts.

Stress-management and social functioning are of importance for how well a person with BD and their family can manage the distress and burden brought by the illness to their lives. These areas were in focus for the intervention studies (III-IV). Behaviour changes take time and therefore following the outcomes of the interventions for a longer time was required. The follow-up period was set at two years, long enough to follow changes over time and short enough to limit, to a certain degree, the influence of other aspects of life on the areas in focus for the studies. However, there are surely many aspects of life that are not related to the illness and the intervention that influence the participants and that are impossible to control in a study. This highlights the importance of fulfilling the research quality criteria for internal and external validity. The instruments were identified based on earlier research in relation to important areas of the participant's daily life and which could constitute important health targets for an intervention. Other measurements may need to be added when measuring outcomes in order to be able to see the full potential of an educational intervention. All the instruments were well established and had been used in similar contexts, apart from the "knowledge ladder" which was constructed for this thesis by the author. There are some facts that need to be taken into consideration when using the instruments. In the GAF self-report version, those affected have been shown to rate themselves lower than professionals rate them, with those with mood disorders and depressive symptoms being more likely to rate themselves too low (Bodlund *et al.* 1994). A semi-structured interview SCID was used to measure and follow symptoms and recurrences in BD. One can discuss whether using medical record data or objective symptom scales would have been better for this purpose, but self-reports of those affected by an illness concerning their symptoms are reliable and a better predictor of outcomes than physicians' reports about the symptoms of the affected person (Dodd 2001).

CONCLUSION

The results of this thesis show that the whole lives of the person with bipolar disorder and their family were influenced by the illness. For these people trying to integrate the illness into their lives was an ongoing learning process, which meant that their pre-understanding was challenged, requiring reconsideration of self among the persons affected and confirmation of the correctness of the families' experiences. This resulted in uncertainty among those with the illness concerning their self-identification, own capacity and future life. Among the younger adults this prevented them from venture planning or hoping for the future, and could give rise to feeling that there was no point in going on with life. The situation of the family member was experienced as a lonely struggle, within a strong caring commitment towards the member with the illness, reducing their chances of a having a normal life of their own. Integrating the illness into ordinary lives of those affected and their families was facilitated by them learning more about how to manage a life with it, to remain hopes for the future, sufficient social functioning and support and a feeling of being part of society. The educational interventions gave them opportunity to interact and learn together with mental health-care professional and other people within a constructive environment. The outcomes of the interventions show that the persons with BD who received the intervention made greater improvements in their self-management ability than those in the comparative group did, in terms of long-term improvement in stress management and social functioning. Both the persons with the illness and the family members received knowledge about the illness useful in their daily life. There was a strong negative impact on the families as carers. However, as outcomes of the educational intervention they gained a strengthened self-manageability of dealing with stress and increase their comprehension of the situation. In addition, the outcomes of the educational interventions implies that the families were able to retrieve there social functioning whereas the persons with BD could start restore theirs.

Health care needs to apply a holistic view on these persons and use strategies that support the persons own growth and self-management, to reinforce and enable them to take greater control of their lives. These families and members with BD need to understand the illness and develop constructive strategies for managing the situation. Mediating hope and opportunity to discuss and to share experiences of the condition with healthcare professionals and other persons with the illness or family members are important and can be facilitated by trusting and collaborative relationships. Mental health care, as educational interventions, for these people need to be based on a genuine interest for their individual views of the illness and emphasize communication, dialog and mutual learning.

The results in this thesis have increased the understanding of what it means to live with BD from the persons-centred view of the person affected and their family members and what they need to be better able to manage the illness themselves. Educational interventions designed to meet the needs of these individuals give them the possibility to learn and develop their capacity to self-manage their lives in the long-term.

IMPLICATION AND FURTHER RESEARCH

The results provide further knowledge about the benefits of offering educational nursing interventions in groups to persons with mental disorders such as BD and their family. Educational interventions focusing on improving stress management and social functioning should be a part of all person-centred care for those with these types of illnesses and their families. This is one of the first nurse-led clinical studies to assess the long-term outcomes of an educational intervention focusing on persons with BD.

It is important that mental healthcare services is organized in a way that gives possibility to work health-promoting by strengthening self-management ability and social functions of persons with BD, and that also includes the whole family. A collaborative approach is necessary both between the professionals and the person affected together with his/her family, and also between different mental healthcare professionals.

Educational interventions could be performed by different mental healthcare professionals but PMHRN are especially well suited for this kind of intervention since they have obtained specialists status in psychiatric caring and are in a position where they meet and support these persons on a daily basis. However, both nursing students in basic training and on advanced level have to be given adequate time and support in their training to learn about and to develop their competence concerning education for both adults and young persons with long-term mental illnesses and their families.

More knowledge and understanding are needed about what living with BD means for those affected and their families in order to combat the prejudiced attitudes to BD that still exist in society. Efforts made by society are needed to help or give this people possibility of regaining a place in and feel part of society, *e.g.* through offering them the opportunity to participate in emotional support and self-help groups, meeting others in similar situations, but also through adjusting work to reduce stress.

The overall support from mental health care has to be further developed and designed to best meet all the different needs of persons with BD and their families. More research is required to identify the specific meanings and needs experienced by *e.g.* young adults with BD and their families as those have to struggle really hard to maintain some structure to their daily life and to manage remain hopes for the future. It should be evaluated what kind of support that best meet their needs and are most beneficial for their self-management under different stages of illness. More research is needed to supplement the promising outcomes, showed in this thesis, of educational interventions and to evaluate their benefits in other aspects concerning living with BD in the long-term perspective.

SVENSK SAMMANFATTNING

Att leva med bipolär sjukdom - Erfarenheter hos personer med sjukdomen och deras familjer, samt effekter av utbildningsinterventioner

Den psykiska ohälsan ökar och orsakar ofta stort lidande för dem som drabbas och deras familjer. Bipolär sjukdom eller manodepressiv sjukdom som den tidigare benämns beräknas, av Världshälsoorganisationen, utgöra en av de tio främsta orsakerna till funktionsnedsättning bland vuxna. Sjukdomen som karaktäriseras av återkommande svängningar i sinnestillståndet, med pendlingar mellan depression och hypomani/mani, drabbar oftast personer redan i sena tonåren eller i tidig vuxenålder. För den som insjuknat präglas ofta livet av återkommande symtom och sjukdomsepisoder vilka medför betydande funktionsnedsättningar, stress och lidande både för den drabbade likväl som för dennes familj. Sjukdomens komplexitet, oförutsägbarhet och skiftande uttryck gör den svår att förstå och är en betydande orsak till varför det kan ta upp till tio år innan rätt diagnos kan ställas och därmed behandling ges.

Av tradition har den psykiatriska vården tidigare fokuserats på den enskilda individen och dennes sjukdom. Dagens vård som huvudsakligen bedrivs i öppenvård har inneburit att personen själv tillsammans med sina familjer och närstående har fått ta ett allt större eget ansvar för sin psykiska hälsa. Detta ställer också andra krav på hälso- och sjukvården. För att kunna förbättra vården och stärka personer med bipolär sjukdom och deras familjer egen förmåga att hantera livet med sjukdomen, behöver vården anpassas och interventioner, såsom utbildnings interventioner, utvecklas utifrån deras specifika behov.

Syftet i denna avhandling var att beskriva personer med bipolär sjukdom och deras familj/närståendes erfarenheter av sjukdomen och dess konsekvenser i det dagliga livet. Därutöver har även betydelsen av utbildningsinterventioner i psykiatrisk öppenvård till dessa personer studerats.

Utbildningsinterventionerna som studerades utgjorde en del av den ordinarie verksamheten vid en psykiatrisk öppenvårdsmottagning och bestod av tio gruppträffar. Vid varje träff diskuteras och reflekteras kring olika ämnen relaterade till bipolär sjukdom. Interventionen hade ett person-centrerat fokus och baserades på antagandet att interaktion mellan deltagarna, och med psykiatrisjuksköterskorna i form av kommunikation, samarbete och diskussion, möjliggör utveckling av kunskap och kapacitet för att bättre kunna hantera livet med sjukdomen.

Intervjuer har genomförts med arton personer som med diagnostiserad bipolär sjukdom (studie I) och sjuutton familjemedlemmar (studie II) för att belysa deras erfarenheter utifrån hur de ser på sjukdomen och framtiden. För att undersöka betydelsen av utbildnings interventioner för dessa människor har också trettiofyra personer med bipolär sjukdom (studie III) och trettiofyra familjemedlemmar (studie IV) som genomgick en sådan utbildning vid en öppenvårdspsykiatrisk mottagning följts. En

grupp på femton personer med sjukdomen som endast erhöll sedvanlig behandling utgjorde en jämförelse grupp (III). Deltagarna fyllde i självskattningsinstrument vid fem tillfällen, första innan utbildning och sista 2 år efter, som belyste deras stresshanteringsförmåga, känsla av sammanhang och sociala funktion (III-IV). Personerna med sjukdomen skattade också sin globala funktionsförmåga medan symtom och nya återfall fångades genom en semistrukturerad intervju kompletterad med data från patientjournal (III). Familjernas upplevda påverkan av att vara familjestödjare åt persons med bipolär sjukdom undersöktes också (IV). Innehållsanalys användes som analysmetod av intervjuerna (I-II), medan beskrivande och icke-parametriska statistiska metoder tillämpades för data från interventionsstudierna (III-IV).

Resultaten av avhandlingen belyser en krävande process för att försöka förstå och acceptera de förändringar som drabbar personerna med sjukdomen, där deras okunskap och existerande fördomar om psykisk sjukdom försvårade processen. Det fanns en risk för att de begränsningar som de drabbade associerar med ett liv med bipolär sjukdom hindrar dem från att se de möjligheter som fanns till att leva ett tillfredställande liv med sin sjukdom. Den osäkerhet som fanns kring förmåga att hantera sjukdomen och styra över sitt liv påverkade också hoppet inför framtiden. Hos de yngre personerna kunde detta resultera i en vardag utan framförhållning och planer för framtiden, och hos några fanns ibland tankar om att ge upp livet. Familjemedlemmarna oroade sig för personen som var sjuk och beskrev ett starkt engagemang men också ansvar för att upprätthålla ett normalt familjeliv. Situationen tyngde dem och deras tillvaro kunde upplevas enslig, då de saknade förståelse från omgivningen och någon att dela sina erfarenheter med. Familjerna kände en maktlöshet inför hur deras tillstånd balanserade mellan en vilja att ha kontroll över dennes tillstånd men samtidigt att bli befriad från ansvar.

Personerna med bipolär sjukdom och deras familjers strävan mot hanterbar vardag underlättades av ökade kunskap om sjukdomen och dess konsekvenser, förhoppningar om att situationen kunde förbättras i framtiden och känsla av att vara en del av samhället. Ett stabilt socialt stöd gjorde det möjligt för dem att bli bekräftade i sin situation men också utveckla konstruktiva strategier att hantera konsekvenser av sjukdomen i form av svårigheter i vardagen. Utbildningsinterventionerna visade på lovande och långsiktiga resultat för personer med sjukdomen och deras familjemedlemmars förmåga att hantera en vardag med sjukdomen. Personer som vara drabbade av sjukdomen stärkte långsiktigt sin förmåga att hantera stress och sin sociala funktion. Dessutom utvecklade de strategier och kunskaper som de kunde använda i det dagliga livet för att hantera sjukdomen och integrera den som en del av livet. Familjemedlemmarna upplevde situationen mer begriplig och utvecklade kunskap som de direkt kunde applicera i sin vardag. Interventionen visade även nytta för dem i form av reducerad stress och bibehållna sociala funktioner.

Slutsatserna av denna avhandling visar att för att kunna möta de behov som finns hos dessa personer med bipolär sjukdom och deras familjer så behöver hälso- och sjukvården utgå från en helhetssyn som tar hänsyn till hur hela deras liv påverkas av sjukdomen. Både de drabbade och deras familjer behöver stöd för att återupprätta

och behålla viktiga vardagsfunktioner. Pedagogiska insatser utgör en allt viktigare del av psykiatrisk vård och bygger på samarbete och ett genuint intresse för personen med sjukdomen och familjens perspektiv på sjukdomen, där kommunikation, dialog och ömsesidigt lärande betonas. Den inom psykiatrisk omvårdnad specialistutbildade sjuksköterskan har de pedagogiska kunskaper som är nödvändiga för att stödja dessa personer och deras familjer till ökad kunskap och förmåga att själv klara hantera sjukdomen och sina liv, så kallad self-management. Men detta kräver också att den psykiatriska vårdorganisationen med utgångspunkt i en person-centrerad vård behöver vara organiserad på ett sätt som möjliggör hälsofrämjande insatser såsom utbildningsinterventioner. Forskning behövs som kan komplettera de i denna avhandling lovande resultaten av interventionerna för de med bipolär sjukdom och deras familjer, utifrån deras self-management förmåga under olika perioder av sjukdomen och varierande faser av livet.

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