

# **Nursing care for outpatients with bipolar disorders: A study of current practice, care needs, coping and quality of life**

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# **Nursing care for outpatients with bipolar disorders: A study of current practice, care needs, coping and quality of life**

een wetenschappelijke proeve  
op het gebied van de Medische Wetenschappen

## **Proefschrift**

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## **Chapter 1**

### **Introduction**

The first descriptions of bipolar disorder go back to the times of the ancient Greeks (Marneros & Angst, 2000). Aretaeus of Cappadoci (circa AD 150) explicitly stated the connection between the two major mood states; the raving madness with exalted mood, and melancholia (Adams, 1856). 17 centuries later, the connection between mania and melancholia was rediscovered in Falret's "folie circulaire" (Falret, 1854) and Baillarger's "folie á double forme" (Baillarger, 1854). It was Kraepelin who, at the turn of the 19<sup>th</sup> century, established manic-depressive illness as a disease entity (Kraepelin, 1921).

### Diagnosis and epidemiology

Nowadays, as can be seen in table 1, different forms of the disease, all named bipolar disorder, are described in the DSM IV taxonomy (APA, 1996).

Bipolar disorder is a recurrent and long term mental illness that can seriously affect the lives of patients and their relatives. It is characterized by the alternating occurrence of manic, hypomanic, depressive and mixed episodes. Bipolar disorder has been ranked ninth among the worldwide causes of non fatal disease burden for people of all ages and ranked fifth for people between 15 and 44 years of age (World Health Organisation, 2001). The disorder is sometimes difficult to diagnose, particularly as symptoms may be confused with other psychiatric disorders. Bipolar disorder has life time prevalence rates estimated to be 1.5 – 2.0% in the European Union (Pini et al., 2005). The prevalence rate may rise to 5 % or higher with sensitive detection of hypomania (Angst & Cassano, 2005; Angst, 2007).

**Table 1: Bipolar disorder according DSM-IV**

|  |  |
|--|--|
| Bipolar I Disorder                       | Characterized by the occurrence of one or more manic or mixed episodes. Although the occurrence of a depressive episode is not required, almost all patients experience them, in fact, depressive episodes are more common than manic episodes   |
| Bipolar II Disorder                      | Characterized by the occurrence of one or more major depressive episodes accompanied by at least one hypomanic episode. Mood symptoms must cause clinically significant distress or impairment in social, occupational, or other areas of functioning  |
| Cyclothymia                              | Characterized by the presence of numerous periods with hypomanic symptoms and numerous periods with depressive symptoms that do not meet criteria for major depressive disorder for at least 2 years. During this 2-year period, the person has not been without the symptoms for more than 2 months at a time. No major depressive-, manic-, or mixed episode has been present during the first 2 years of the disturbance  |
| Bipolar Disorder Not Otherwise Specified | Is a mood disorder with bipolar features that fits no other category.<br>Examples: <ul style="list-style-type: none"> <li>• Very rapid alternation (days) between manic and depressive symptoms that do not meet duration criteria</li> <li>• Recurrent hypomania without intercurrent depressive symptoms</li> <li>• Manic or mixed episodes superimposed on delusional or psychotic disorder</li> <li>• Unable to determine if bipolar disorder is primary, substance induced or related to a medical condition</li> </ul> |

## **Treatment**

Treatment is largely symptomatic and aimed at the prevention of subsequent episodes and, when an episode does occur, reduction of its impact to the greatest degree possible. Three stages of treatment can be differentiated. The first is the acute treatment of an episode. The goal of the acute treatment stage is to induce remission of the symptoms of (hypo)mania or depression. The second stage is continued treatment with a focus on the prevention of acute symptoms. The third stage is prophylactic treatment after full recovery from an episode with the prevention of future occurrence as the primary goal (Kupka & Nolen, 1999).

## **Consequences**

When a bipolar disorder is not adequately treated, it can have major consequences for both patients and community (Kupka et al., 1999). Bipolar disorder is associated with a significantly higher suicide risk when compared to other psychiatric disorders (Goodwin & Jamison, 2007; Joukamaa et al., 2001; Sharma & Markar, 1994; Ten Have et al., 2002). Patients with a bipolar disorder also score significantly lower with respect to quality of life, mental health, emotional role, and social functioning (Ten Have et al., 2002). Goodwin and Jamison (2007) report a high use of alcohol and drugs among patients with a bipolar disorder.

## **Outpatient care**

The Dutch Nemesis study (Ten Have et al., 2002; Regeer et al., 2002) found that 56% of respondents with a bipolar disorder turn to a mental health organization for help. For 97% of these respondents requesting help, care was provided — to at least some extent — in an ambulatory care setting. One particular characteristic of the ambulatory treatment of patients with bipolar disorder is that it is a long-term process with an organization and duration of treatment that is very comparable with that required for the outpatient treatment of chronic conditions such as diabetes and epilepsy. Whereas the treatment for bipolar disorder was mostly provided by psychiatrists in the past, community psychiatric nurses (CPN) are increasingly being involved in the provision of care for this group of patients.

For some years, considerable attention has been paid to the development and implementation of mental health care programs in the Netherlands. The content and organization of health care for specific target groups are described in these programs. The mental health programs are also intended to provide a frame of reference for mental health care professionals in the delivery of mental health care

and to serve as a framework in the discussion of individual treatment plans (De Boer, 2001). Examination of mental health care programs provided by a number of different organizations has shown that within these programs the professional contributions of nurses are not at all, or only very briefly described. This can also be observed in existing guidelines for mental health care. The available guidelines for the treatment of bipolar disorders provide good quality information on pharmacotherapy, psycho-education, and psychotherapeutic interventions but do not reflect the role of the mental health nurse in the care and treatment process, nor the nurses' contribution to it (APA, 2002; Nolen et al., 2001). The establishment of a body of knowledge pertaining to the nursing of patients with a bipolar disorder is therefore vital for the development of integrated evidence-based treatment.

### **Aim of this thesis**

The general aim of this thesis is to establish a body of knowledge for the nursing of outpatients with a bipolar disorder. This general aim is specified in two sub-aims:

1. To describe what is known in literature about nursing patients with a bipolar disorder and what nurses actually do in daily practice while nursing outpatients with a bipolar disorder.
2. To provide information on care needs, coping styles, psychopathological symptoms, quality of life, and caregiver consequences in outpatients with a bipolar disorder to nurses that can support them in their critical decision making process while planning, conducting and evaluating the nursing care.

### **Outline of this thesis and research methods**

In this thesis four studies are reported in six chapters;

1. The first study, chapter 2 of this thesis, is a literature review carried out to identify the nursing processes described in the international literature and to investigate whether these nursing processes are supported by evidence. The aim of this study was to provide the research team with information on what was known and what was unknown prior to outlining the further studies. We used for a sensitive literature search method. Not only scientific papers were included in the review, descriptive reports by practicing nurses were included as well. This was done because we assumed that little research was done on this subject. Prior to this study the main researcher (PG) followed an intensive course on

literature review methodology at the EMGO institute, a research school, part of the VU University, Amsterdam.

2. The second study, chapter 3 of this thesis, focuses on the actual practice of CPNs in the Netherlands. A qualitative study among 23 CPNs working at 20 outpatient clinics across the Netherlands was carried out using semi-structured interviews and additional focus group interviews. The semi structured interviews were done using a topic list. This topic list was based on the results of the literature review (chapter 2) and the researchers' experiences in nursing outpatients with a bipolar disorder. The focus groups were performed to provide more in-depth information with the findings of the individual interviews. A group possesses the capacity to become more than the sum of its parts, to exhibit a synergy that individuals alone do not poses (Krueger & Casey, 2000). Also, the advantage of a focus group is that it has been shown to produce results at a reasonable price (Krueger & Casey, 2000). A major disadvantage of focus groups is group think, a process that occurs when one or two members of the group will dominate others into subscribing to a dominant view (Morse & Field, 1996). Performing interviews with individual CPNs prior to the focus groups gave us the means to address all ot the individuals ideas during the group sessions. Also, we arranged for the group leader of the focus group to create an environment that encouraged participants to share perceptions without pressuring participants to vote or to reach consensus and prevented the occurrence of dominant opinions from one or two participants (Krueger & Casey 2000). The second author of the chapter (TB) followed training in focus group methodology prior to the start of this study and acted as the chair, while the first author (PG) acted as the researcher on this project. The third author, (JdL) was asked to join the research team because of her expertise in qualitative research methodology and her membership of the Dutch Qualitative Research Method Group.
3. The third study is a cross sectional survey of bipolar disorder patients using questionnaires. We considered asking patients cared for by the CPNs involved in our previous (second) study, as this would facilitate comparisons of patients' and CPNs views. However, as interviewing patients at 20 outpatients clinics was not feasible from a practice perspective, we chose to perform interviews with patients at five outpatient clinics in the Netherlands. This guaranteed some generalizability across centres, but hindered direct comparison of the views of CPNs (second study, chapter 3) as a consequence. At the five outpatient clinics, 157 outpatients with a bipolar disorder were questioned on several aspects of

living with this chronic disease. The results were reported in 3 articles presented in chapters 4, 5, and 6 of this thesis;

- a. In chapter 4, care needs of outpatients with a bipolar disorder were examined because these needs provide key information for the nursing process. Nurses perform their interventions based on desired outcomes in relation to patient problems and patient needs. No studies on care needs of outpatients with a bipolar disorder were known to the researchers. The research team identified two relevant questionnaires for the measurement of care needs. The Camberwell Assessment of Needs (CAN) (Phelan, et al., 1995), a frequently used 27 item questionnaire and the Care Needs Questionnaire (CNQ) developed in the Netherlands by Kroon and colleagues (Kroon, 2003). Finally, the 42 item CNQ was preferred because of its Dutch origin, good clinimetric properties and its easy use. After this choice was made, dr. Kroon was asked to join the research team on this topic.
- b. In the second study (chapter 3), we identified the patient problems reported by Dutch CPNs. Most of these problems could be linked to problems in coping with the consequences of problems and unpleasant events. Coping styles of outpatients with a bipolar disorder were therefore examined using the Utrecht Coping List (UCL) (Schreurs et al., 1993) and reported in chapter 5 of this thesis. Results on coping styles were separately reported as the research team believed that knowledge of coping styles could support practising nurses during their clinical decision making processes when planning, conducting and evaluating the nursing care.
- c. In chapter 6 the results of a study into a broad set of patient reported residual and subsyndromal psychopathological symptoms and their relationship with the patients' perceived quality of life are reported. This part of the third study was undertaken because, during our clinical work, we observed patients' ongoing troubles with various symptoms. The Symptoms Checklist 90 (SCL-90) (Ardinell & Ettema, 2005), a 90 items questionnaire, was used to collect the data because of its broad scope on psychopathological symptoms. Again, we proposed that this questionnaire could provide valuable information for practising nurses, to guide them in their clinical decision making process. Data on quality of life were collected using the World Health Organisation Quality of Life Bref (WHOQOL-bref) (The WHOQOL group, 1998) and correlations were calculated to reveal the consequences of patients' suffering from psychopathological symptoms. The results are discussed and implications for clinical practice are given in chapter 6.

4. The fourth study is a cross sectional study on caregiver consequences, caregiver coping styles and caregiver distress. This study was performed because of the importance of the involvement of the patients' supportive system in the treatment process, and because evidence exists that caregiver distress hinders the treatment process of the patient. The respondents were 115 family caregivers of the respondents in the third study. In chapter 7, we report the results and conclusions from this study. Caregiver consequences were examined using the Involvement Evaluation Questionnaire (IEQ) (Schene & Van Wijngaarden, 1992). Coping styles were examined using the UCL (Schreurs et al., 1993) and caregiver distress was assessed with the Dutch version of the 12 item General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988). Dr. Van Wijngaarden was asked to join the research team on this topic because of his expertise in research in the area of caregiver consequences. Recommendations for future research on this rather unexplored topic are given.

In Chapter 8, the main conclusions from these studies are summarised and discussed. In addition we discuss future implications in relation to the changing role of the psychiatric and mental health nurse.

### **Advantages of the research approach**

Each of the four studies adds to the others and together they are a coherent amount of research.

The choice to include non scientific papers in the literature review will reveal a broader scope on the described nursing processes as we assumed that little research was done. Although these papers have little scientific value, this approach will make it possible to synthesize and describe what it is what nurses are doing while nursing patients with a bipolar disorder.

In the second study we will use qualitative methods to distract knowledge from the participating nurses. It is known that triangulation of research methods supports validity of findings. Therefore we will combine individual interviews with focus group interviews to analyse the findings in dept.

The two cross sectional studies have a very structured approach. We assume that it will be possible to include many respondents in a rather short time span because our resources are limited. By using a multi centre study approach in five outpatient clinics in different areas in the Netherlands, we assume that results can be generalised to other outpatient clinics in the Netherlands.

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## **Part I**

**State of the art and current practice of community practice nurses in nursing outpatients with a bipolar disorder**



## **Chapter 2**

### **Nursing processes used in the treatment of patients with bipolar disorder**

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**Abstract**

Psychiatric nurses are increasingly being involved in the provision of care for outpatients with bipolar disorder. The establishment of a body of knowledge for the nursing of these patients is vital for the development of integrated evidence-based treatment.

The literature for the period January 1980 to January 2006 is reviewed. A sensitive literature search included not only the nursing care based on research results but also nursing care based on experiences acquired by practicing nurses.

The results show that formal research on the nursing of patients with a bipolar disorder is remarkably limited. Three quantitative studies were identified in five articles and six qualitative studies addressing a broad range of topics. The remainder of articles meeting the inclusion criteria contained mostly descriptive reports.

An overview is presented of the nursing processes used during the euthymic stage of a bipolar disorder and during an acute episode of (hypo)mania. No specific nursing processes for acute episodes of bipolar depression are described in the literature. The results show hardly any evidence for the described nursing processes.

## 1. Introduction

A bipolar disorder is characterized by the alternating occurrence of manic, hypomanic, depressive, and possibly mixed episodes. It is a serious, widespread psychiatric disorder of a chronic nature and ranked as the world's eighth greatest cause of medical disability (Murray & Lopez 1996). The Dutch Nemesis study (Ten Have et al., 2002; Regeer et al., 2002) reported a lifetime prevalence of 1.9% and a 12-month prevalence of 1.1%. This means that about 2% of all Dutch adults will at one time in their life experience a manic or hypomanic episode. Treatment is largely symptomatic and aimed at the prevention of subsequent episodes and, when an episode does occur, reduction of its impact to the greatest degree possible. Three stages of treatment can be differentiated. The first is the acute treatment of an episode. The goal of the acute treatment stage is to induce remission of the symptoms of (hypo)mania or depression. The second stage is continued treatment with a focus on the prevention of acute symptoms. The third stage is prophylactic treatment after full recovery from an episode with the prevention of future occurrence as the primary goal (Kupka & Nolen, 1999).

When a bipolar disorder is not adequately treated, it can have major consequences for both patients and community (Kupka & Nolen, 1999). Bipolar disorder is associated with a significantly higher suicide risk when compared to other psychiatric disorders (Goodwin & Jamison, 1990; Joukamaa et al., 2001; Sharma & Markar, 1994; Ten Have et al., 2002). Patients with a bipolar disorder also score significantly lower with respect to quality of life, mental health, emotional role, and social functioning (Ten Have et al., 2002). Goodwin and Jamison (1990) report a high use of alcohol and drugs among bipolar patients.

In the United Kingdom, the economic consequences of bipolar disorder amount to as much as 199 million pounds Sterling per year. Hospitalization costs constitute 35% of this amount. When added to the indirect costs, bipolar disorder costs the British some 2 billion pounds on an annual basis (Das Gupta & Guest, 2002). The available guidelines and protocols for the treatment of bipolar disorders provide good information on pharmacotherapy, psycho-education, and psychotherapeutic interventions. The Dutch Nemesis study (Ten Have et al., 2002; Regeer et al., 2002) found 56% of respondents turn to a mental health organization for help. For 97% of respondents requesting help, care was provided — to at least some extent — in an ambulatory care setting. One particular characteristic of the ambulatory treatment of patients with bipolar disorder is that it is a long-term process with the organization and duration of treatment very comparable to that required for the outpatient treatment of such chronic conditions

as diabetes and epilepsy. Although the treatment for bipolar disorder was mostly provided by psychiatrists in the past, community psychiatric nurses (CPN) are increasingly being involved in the provision of care for this group of patients. The actions of CPNs are largely based on their experiences and decisions made during multidisciplinary consultations. The methods used by CPNs often differ from one setting to another, which means that the quality of care provided may vary from one institution to the next and that a general level of care quality is not guaranteed.

For some years, considerable attention has been paid to the development and implementation of mental health care programs in the Netherlands. The content and organization of health care for specific target groups are described in these programs. The mental health programs are also intended to provide a frame of reference for mental health care professionals in the delivery of mental health care and serves as a framework in the discussion of individual treatment plans (De Boer, 2001). Examination of mental health care programs provided by a number of different organizations has shown the professional contributions of nurses to not be described at all or only very briefly. This can also be observed in existing psychiatric guidelines, which in the absence of usable nursing research evidence, revert back to existing consensus documents. The establishment of a body of knowledge pertaining to the nursing of patients with a bipolar disorder is therefore vital for the development of integrated evidence-based treatment.

In the present paper, the nursing care of patients with a bipolar disorder is examined. In light of the fact that nursing is a largely experience-based profession, a sensitive literature search was undertaken: Not only those practices revealed by scientific research but also the reports of actual practicing nurses were considered.

## **2. Method**

A systematic search of the following databases was conducted for the period January 1980 to January 2006: Medline, EMBASE, Psychlit, CINAHL, INVERT, Cochrane Controlled Trials Register, and Cochrane Database of Systematic Reviews. Key search terms were: bipolar disorder or manic-depressive disorder or manic or mania or bipolar depression and nursing. Reference lists from relevant publications revealed by the aforementioned search were also investigated. English, Dutch, and French articles were included when a discussion of bipolar disorder and the nursing of such was clearly recognizable (i.e., the diagnosis and/or problem, nursing objectives, actions, and interventions or elements of

these). No special requirements were imposed with regard to the design of the studies; both quantitative and qualitative studies were considered in the review.

### **3. Results**

The systematic search produced 1230 admissible abstracts. These abstracts were examined by the first and second authors separately, and 80 articles were then ordered for closer examination. Of these 80 articles, 11 could not be found; 10 did not concern bipolar disorder; and 34 were not about nursing or nursing processes. Twenty-five articles were included in our review. There was a virtual absence of formal research on nursing practices for patients with bipolar disorder. Only 3 quantitative studies in five reports (see Table 1) and six qualitative studies addressing a broad range of topics (see Table 2) could be identified. The majority of articles meeting the criteria for inclusion in our review were thus descriptive reports of practicing nurses (see Table 3).

#### **3.1 The quantitative studies**

As can be seen from Table 1, all but one of the three quantitative studies reported in five articles followed only a quasi-experimental design due to the absence of a control group or no random assignment to the treatment and control groups. Shea et al. (1997) and Bauer et al. (1997) examined the impact of easy access to ambulatory care for outpatients with bipolar disorder on the care process and outcomes defined in terms of patient satisfaction, intensity of medication treatment, and amount and patterns of service use. The ambulatory care program developed by Bauer et al. (1997) and Shea et al. (1997) included the administration of medication according to treatment algorithms, the provision of standardized psycho-education, and easy access to a nurse to enhance continuity of care. The nurse worked with each patient to establish better coping responses and develop an action plan for crisis. At the time of the study, the program included two nurse specialists and a psychiatrist who dedicated a quarter of his time to the program. Patients showed significant increases in care satisfaction, increases in the intensity of medication treatment, and decreases in the use of costly mental health services. A multi-site randomised controlled trial with an additional 330 patients involved in the ambulatory care program has also been undertaken (Bauer, 2001), However the results of this trial were not available at the time of this review.

**Table 1: The quantitative studies**

| Author/yr              | Design<br>n= ....   | Program  | Nursing processes  | Outcome   |
|------------------------|---|--|--|---|
| Shea et al.<br>1997    | Quasi-experimental  | Multidisciplinary care program for outpatients, staffed by 2 specialized nurses and a psychiatrist . | Case management  | Significant increases in satisfaction with care   |
| Bauer et al.<br>1997   | pretest-posttest design<br>n=73   |  | Psycho-education<br>Easy access to nurse<br>Coping strategies<br>Action plan for crisis            | Increases in intensity of medication treatment<br>Significant decreases in emergency department use, psychiatric triage, and hospitalization days |
| Pollack et al.<br>1999 | Quasi-experimental non-equivalent comparison group design<br>n=110                        | Two models of group therapy conducted by trained nurse for inpatients with BD:<br>Interactional      | SM: understanding BD; relating to others, managing daily life, relating to self, living in society | No significant difference in patient satisfaction   |
| Pollack et al.<br>2001 | Quasi-experimental non-equivalent comparison group design with repeated measures<br>n=122 | model (IM) versus self-management model (SM)   |  | No significant differences in: perceived mood states<br>difficulties with symptoms and functioning<br>coping resources<br>patient satisfaction    |
| Dogan et al.<br>2003   | Pretest–posttest experimental design,<br>n=30   | 3-session education program for outpatients  | Psycho-education on disorder and medication  | Significant increase in medication knowledge,<br>decrease in symptom level,<br>increase in quality of life.<br>More regular medication use        |

In another quantitative study, two models of group therapy for inpatients with bipolar disorder were compared to each other with the expectation that participants treated according to the self-management group model (SM) would produce better outcomes than participants treated according to the interactional group model (IM) (Pollack & Cramer, 1999; Pollack et al., 2001). The SM was actually developed as a result of patient responses to the IM that was currently in use (Pollack, 1995a). The SM includes review and discussion of the self management of bipolar disorder, understanding bipolar disorder, relating to others, managing daily life, relating to the self, and living in society. In the first article (Pollack & Cramer, 1999), only patient satisfaction was reported and no significant differences were found. In the second article (Pollack et al., 2001), patient outcomes in terms of perceived mood states, difficulties with symptoms or functioning, coping resources, and patient satisfaction were examined on three occasions: before participation (T1), after participation in the last group session, just before discharge from the hospital (T2), three months after discharge (T3). No

significant total score differences were found for the two groups on any of the three measurement occasions.

In Turkey, the effects of patient education related to lithium therapy on quality of life judgments, symptom levels, and compliance with medication regimens was investigated using a pretest-posttest quasi-experimental design (Dogan & Sabanciogullari, 2004). A randomly selected study group (n=30) was presented a brief three-session education program regarding with bipolar disorder and lithium therapy by a nurse. The control group received care as usual. At the end of a three-month period, a significant increase in knowledge of medication, a significant decrease in symptom levels, and a significant increase in quality of life were observed for the study group. More regular medication use was also observed for the study group. Due to the small number of patients included in the study, external validity was low. The findings cannot be generalized, and the authors recommend further study with larger numbers of subjects followed across a longer period of follow-up time.

### **3.2 The qualitative studies**

Driven by the lack of attention given to the care of patients with a bipolar disorder by the nursing profession, Pollack published 12 articles between 1990 and 2001. Four of the studies met the criteria for inclusion in the present review and are informative with respect to the factors on which nurses could base their interventions (Pollack, 1993; Pollack, 1995b; Pollack, 1996a; Pollack, 1996b).

In 1993, Pollack reported the results of an exploratory content analysis of content and process issues raised by 65 inpatients with a bipolar disorder attending 40 short-term group therapy sessions. Five core areas emerged: understanding the disorder, relating to others, managing daily life, relating to the self, and living in society. "Guidance," "universality," and "self-understanding" were most frequently mentioned when the inpatients were asked to identify the group event that was personally most important to them.

In other research, Pollack examined the informational needs of patients hospitalized for a bipolar disorder (Pollack, 1995b) and information-seeking motivators and actions of such a group of inpatients (Pollack, 1996b). Semi-structured interviews were undertaken with 33 inpatients with bipolar disorder. The five areas of concern identified previously (Pollack, 1993) and a sixth area pertaining to self-management of the disorder were addressed during interviews. Twenty basic informational needs were identified from which various needs show overlap in several areas. The most frequently reported informational needs were:

how to obtain support (6 areas); how to obtain therapy (6 areas); symptom management (5 areas); resource books (4 areas); basic information about the disorder (4 areas); stress management (3 areas); time management (3 areas); how to improve interpersonal skills (3 areas); how to live with bipolar disorder (2 areas); and medication information (2 areas). Nine needs were identified in only one of the areas on how to: overcome denial, integrate treatments, stay focused, make decisions, manage finances, manage life, deal with guilt, educate others about the disorder and improve self-concept (Pollack, 1995b). In the article reporting information-seeking motivators and actions (Pollack, 1996b), a broad range of motivators and actions are identified. Responses regarding information-seeking motivators reveal a group of patients striving to stabilize themselves and their lives with a clear desire for normalcy. The reported information-seeking actions reflect a willingness to learn from others; a desire to learn more about the perceived benefits of groups and reading; and an understanding of personal responsibility for getting information needs met.

In 1996, Pollack published another article on how the same sample of patients hospitalized for a bipolar disorder managed their illness (Pollack, 1996a). Findings with regard to three areas of particular relevance are reported: factors that participants believe to affect their self-management; patient-initiated self-management interventions; and information believed to be important for other people with the disorder. Patients identified a multitude of barriers to successful self-management. These included internal barriers such as denial, fears, ignorance, medication abuses, depression, instability, shame, no self-interest, and so forth. They also included external barriers such as family attitudes, medication side-effects, having freedom taken away, stigmatization, and so forth. In addition to the aforementioned barriers, many other factors were also reported to affect the self-management process. Among the factors reported to contribute to successful self-management were: following professional advice, talking with people, taking medication, setting goals, following schedules, staying active, seeking information, group therapy, and hospitalization. Among the factors reported to contribute to unsuccessful self-management were: denying the problem, overextending themselves, doing street drugs, self-starting or self-stopping of medication, watching TV all the time, and getting angry. A large set of self-management interventions was found to be initiated by the patients themselves.

**Table 2: The qualitative studies**

| Author /year           | Research purpose  | Method  | Results  |
|------------------------|---|---|--|
| Pollack 1993           | What content topics do patients raise in group sessions?<br>What group processes do patients identify as personally most significant?<br>n=65   | Content analysis of group for inpatients with BD                    | Content topics: <ul style="list-style-type: none"> <li>• Understanding BD</li> <li>• Relating to others</li> <li>• Managing daily life</li> <li>• Relating to self</li> <li>• Living in society</li> <li>• Group process events: <ul style="list-style-type: none"> <li>• Guidance</li> <li>• Universality</li> <li>• Self-understanding</li> </ul> </li> </ul>  |
| Pollack 1995b          | To identify information needs of inpatients with BD<br>n=33   | Semi-structured interviews  | 20 information needs were identified in 6 areas. Various needs overlapped.   |
| Pollack 1996a          | To identify Information-seeking motivators and actions<br>n=33  | Semi-structured interviews  | A broad rang of motivators and actions is described. <ul style="list-style-type: none"> <li>• The reported motivators reveal a group of patients striving to stabilize themselves and their lives with a desire for normalcy.</li> <li>• The reported actions to seek information indicate a willingness to learn from others, recognition of the perceived benefits of groups and reading, and an understanding of personal responsibility in getting informational needs met.</li> </ul> |
| Pollack 1996b          | Inpatient self-management of BD<br>n=33 <ul style="list-style-type: none"> <li>• Factors that affect self-management</li> <li>• Patient-initiated self-management interventions</li> <li>• Information believed by participants to be important for other people with BD</li> </ul> | Semi-structured interviews  | Very large set of affecting factors, self- management interventions, and information for other people with BD reported in the article  |
| Hill et al. 1996       | Broad survey to audit the services, activities, and structure of the MDF organization and to gain information on the views of people with BD and their caregivers. Findings of particular relevance for mental health nurses are reported in this article.                          | Descriptive research using questionnaires n=1979 and 6 focus groups | Four key areas in which CPN can play a major role <ul style="list-style-type: none"> <li>• Assessment of suicide risk</li> <li>• Support for self-management</li> <li>• Psycho-education</li> <li>• Support for caregivers</li> </ul>  |
| Hummelvoll et al. 2002 | To illuminate nursing perceptions of individuals suffering from mania and how this influences the provision of nursing care   | Participatory inquiry, content analysis, and focus groups           | 3 nursing strategies are reported <ul style="list-style-type: none"> <li>• Form supportive circle around patient</li> <li>• Set firm limits</li> <li>• Build relationships and communication</li> </ul>  |

Nurses can thus empower patients with a bipolar disorder to perform these interventions and provide information needed for patients to learn to manage their illness.

In 1994, a British self-help organization for individuals with bipolar depression, the Manic Depression Fellowship (MDF), initiated a study of the nature of the needs of its members (Hill & Shepherd, 1996). A questionnaire was returned by 1979 individuals, and six focus groups were later organized to supplement the questionnaire results. Hill and Shepherd (1996) report those findings of particular relevance for mental health nurses. More specifically, they identify four key areas in which CPNs can play a major role: assessment of suicide risk; support of self-management efforts; provision of information on the MDF and/or other services available in the community; and support for caregivers.

Finally, the aim of the study by Hummelvoll and Severinsson (2002) was to illuminate nursing staff perceptions of patients suffering from mania and how these perceptions influence the provision of nursing care. A participatory inquiry design was followed with focus group interviews undertaken to collect the relevant data. Qualitative content analyses were applied to the interview data, and four underlying themes could be identified. One of the four main themes was nursing strategies to adopt with patients suffering from mania. Three nursing strategies were reported: forming a supportive circle around the patient to provide an impression of security, support, and structure; setting firm limits for the patient to establish structure, predictability, and security; and the building of relationships and communication.

### **3.3 Descriptive reports**

As outlined in Table 3, the majority of the articles included in the present review involved nurses describing their experiences with the care of bipolar patients. Although the descriptive reports have no level of evidence, the reported experiences should not be ignored as they describe exactly what practicing nurses do when they care for patients with a bipolar disorder in particular. Four key areas could be identified within the descriptive reports.

#### **3.3.1 Management of the nursing process**

In three articles, nursing assessment of bipolar disorder is mentioned. Tugrul (2003) writes that bipolar disorder is frequently underdiagnosed because most patients are more likely to seek help when they are depressed or feel “bad”. Nurses can play a critical role in the detection of symptoms of the disorder through

a mental status examination to screen for and assess signs of (hypo)mania. It is also suggested that clinical and self-assessment tools may be of help. Cole (1999) provides more specific information for the assessment of bipolar patients. The nurse should obtain a detailed history of mood instability and mood swings, stress factors, life events, alcohol and drug use, money spending patterns, and possibly promiscuous behavior. In the article by Buckwalter and Kerfoot (1982), the emergency department nursing care for a manic patient is described, and it is stated that one of the most helpful and efficient techniques is to interview family members for diagnostic details.

The use of a written contract/care plan involving explanation of the care policy to manage the manic behavior of patients in a psychiatric ward is described in a 1987 study (Brenners et al., 1987). The use of care management is also described in two very recent articles (Aillon et al., 2003; Foley, 2004). In both articles, the implementation of the collaborative practice model for bipolar disorder — as developed by Bauer (1997, 2001) — is described. One of the key issues within this model is the role of the nurse as case manager who thus evaluates patient symptoms, adverse events, and treatment response. Femolant et al. (1997) are the only authors to mention the role of the nurse in the follow-up period after discharge from a hospital

### 3.3.2 *Safety interventions*

Most of the safety interventions focus on the protection of the manic patient and his or her environment. Manic patients are extremely sensitive to both external and internal stimuli, and the most effective technique to deal with manic patients is therefore to reduce environmental stimuli and promote the establishment of a quiet, controlled, and structured environment (Buckwalter & Kerfoot, 1982; Brenners et al., 1987; Cole, 1999; Strong, 2004). In cases of real danger or when the patient threatens to use physical force, the following interventions are recommended to reduce safety risks: protection (Femolant et al., 1997), permanent observation (Cole, 1999), isolation (Gartside, 1980; Buckwalter & Kerfoot, 1982), or even seclusion (Brenners et al., 1987). Nursing care for a patient in the stage of acute (hypo)mania should be calm, supportive, and neutral but firm (Buckwalter & Kerfoot, 1982; Cole, 1999). The nurse must set clear and consistent limits, restrict activities, and reduce external stimulation (Buckwalter & Kerfoot, 1982; Brenners et al., 1987; Cole, 1999). A token economy system can help modify patient behavior (Gough, 1981). It is also recommended that risk assessment be undertaken to avoid suicide or self-inflicted harm (Gournay &

Ritter, 1996) and that an action plan be formulated in case of crisis (Aillon et al., 2003).

### *3.3.3 Pharmacological interventions*

Mood stabilizers such as lithium, carbamazepine, valproate, lamotrigine, or some antipsychotics are recommended treatment for bipolar disorder today (Nolen et al., 2001). Nursing interventions with regard to medication use are focused on the observation of treatment effectiveness and/or any side effects (Gartside, 1980; Femolant et al., 1997; Tugrul, 2003) and further on education with regard to and supervision of medication use (Brenners et al., 1987; Gournay & Ritter, 1996). In the case of lithium use, nurses should perform interventions related to the prevention of lithium toxicity such as the checking of lithium blood levels, daily weighing of patients, and observation for adequate fluid intake (Dixon, 1981).

### *3.3.4 Self-management interventions*

When the symptoms of an acute episode of (hypo)mania or depression are in remission, efforts should be taken to prevent the occurrence of new acute symptoms or episodes (Kupka & Nolen, 1999). The patient and his or her family must learn to cope with the disease. The nurse can teach self-management techniques to patients, patient's family and close friends. Psycho-education is mentioned by most of authors as a teaching technique to be conducted individually, with relatives, or in patient groups. In these sessions, attention can be paid to the impact of the illness and the treatment options (Morrissey, 1998), the use of pharmacology (Brenners et al., 1987; Gournay & Ritter, 1996), identification of a symptoms profile (Foley, 2004), identification of vulnerability factors (Gournay & Ritter, 1996), identification and anticipation of triggers (Gournay & Ritter, 1996), life stressors, potential relapse patterns (Foley, 2004), and learning of alternative coping strategies (Pollack, 1990; Aillon et al., 2003). In group sessions, patients can share information with others (Pollack, 1990) and also attain support for the organization of his or her daily life and maintenance of lifestyle regularity (Pollack, 1990; Femolant et al., 1997). The development of a close therapeutic relationship with patients and their support system (Morrissey, 1998) along with easy access to the nurse (Aillon, 2003; Foley, 2004) are stated to be necessary factors at this stage in the treatment process.

**Table 3: Descriptive reports**

| Author/yr              | Subject  | Identified nursing processes  |
|------------------------|--|---|
| Gartside 1980          | Case study describing the story of a BD inpatient and the care she received                  | <ul style="list-style-type: none"> <li>• Containing the patient to reduce risk of harm to herself.</li> <li>• Observation on medication use</li> </ul>  |
| Gough 1981             | A student nurse describes her experiences with one difficult BD inpatient                    | Token economy system to modify behavior   |
| Dixson 1981            | Nursing interventions related to lithium therapy   | <ul style="list-style-type: none"> <li>• Prevention of lithium toxicity</li> <li>• Checking the lithium blood level</li> <li>• Weighed daily</li> <li>• Observation of adequate fluid intake</li> </ul>   |
| Buckwalter et al. 1982 | Describes a manner to manage a manic patient in a emergency department                       | <ul style="list-style-type: none"> <li>• Limit setting</li> <li>• Restriction of activity</li> <li>• Reduction of external stimuli</li> <li>• Promotion of a quiet controlled environment</li> <li>• Calm, supportive, and firm approach</li> <li>• Isolation when the patient uses physical violence</li> <li>• Family assessment for diagnostic details</li> <li>• Support for the family</li> </ul>  |
| Brenners et al. 1987   | Describes manner to manage a manic patient using a care plan on a psychiatric ward           | <ul style="list-style-type: none"> <li>• Reduce stimulation by confining patient to room with supervised breaks</li> <li>• Use a written contract or care plan that explains the care policy</li> <li>• Seclusion when the patient becomes threatening</li> <li>• Structured environment</li> <li>• Weaning from isolation when mania appears to subside</li> <li>• Pharmacological interventions with education and supervision</li> <li>• Teaching self-management strategies to patient, patient's family, and close friends of patient</li> </ul> |
| Pollack 1990           | Describes the content of group therapy conducted by mental health nurses                     | Group therapy for inpatients with BD and following goals: <ul style="list-style-type: none"> <li>• Share information</li> <li>• Cope with bipolar disorder</li> <li>• Improve interpersonal relationships</li> </ul>  |
| Gournay et al. 1996    | Describes the role of the nurse in the management and treatment of BD patients               | <ul style="list-style-type: none"> <li>• Identification and reduction of vulnerability factors</li> <li>• Maximize patient social support</li> <li>• Identification and anticipation of triggers</li> <li>• Pharmacological interventions with education and supervision</li> <li>• Risk assessment to prevent suicide and self-harm</li> </ul>   |
| Fembolant et al. 1997  | Case studies describing the stories of three BD patients and the care they received          | <ul style="list-style-type: none"> <li>• Observation of treatment effectiveness and any side-effects of medication</li> <li>• Support daily life</li> <li>• Protection in case of danger</li> <li>• Follow-up after discharge from the hospital</li> </ul>  |
| Morrissey 1998         | Describes impact of BD diagnosis and particularly the implications for mental health nurses. | <ul style="list-style-type: none"> <li>• Inform, educate, and support the patient, partner, and family</li> <li>• Address the impact of the diagnoses on client, partner, and family</li> <li>• Education and consultation in relation to treatment options</li> <li>• Develop a close therapeutic relationship</li> </ul>  |

| Author/yr          | Subject  | Identified nursing processes  |
|--------------------|--|---|
| Cole 1999          | Describes nursing assessment and intervention for patients with BD   | <ul style="list-style-type: none"> <li>• Assessment of mood swings, stress, life events, alcohol and drug use, money spending patterns, promiscuous behavior</li> <li>• Set firm, clear, and consistent limits</li> <li>• Structured environment</li> <li>• Permanent observation in case of danger</li> <li>• Supportive yet neutral approach</li> </ul> |
| Aillon et al. 2003 | Reports on the implementation of a care program for BD patients based on Bauer and Shea (1997)   | <ul style="list-style-type: none"> <li>• Case management</li> <li>• Psycho-education</li> <li>• Easy access to nurse</li> <li>• Coping strategies</li> <li>• Action plan for crisis</li> </ul>  |
| Tugrul 2003        | The nurse's role in the assessment and treatment of BD   | <ul style="list-style-type: none"> <li>• Recognition and assessment of BD</li> <li>• Managed treatment</li> <li>• Education of patients and their families</li> </ul>   |
| Foley 2004         | Describes the nursing role in a nurse- driven unit using the collaborative practice model for treatment of BD based on Bauer and Shea (1997) | <ul style="list-style-type: none"> <li>• Evaluation of symptoms, adverse events and response to treatment</li> <li>• Patient education about illness and treatment</li> <li>• Group classes to assist patient to identify their personal symptoms profile, common life stressors, and potential relapse patterns.</li> </ul>                              |
| Strong 2004        | Overview of the role of antipsychotic medications in treating bipolar disorder   | <p>Nursing goals of patients experiencing a manic or mixed episode initially include:</p> <ul style="list-style-type: none"> <li>• Injury prevention</li> <li>• Maintenance of a safe environment</li> <li>• Assistance to meet basic physiologic needs</li> <li>• Return to normal levels of psychosocial functioning</li> </ul>                         |

#### 4. Discussion

Although the literature search was conducted in a systematic and sensitive manner, it is possible that certain publications may not have been found because they qualify as “grey literature,” which includes various theses. The number of publications in indexed journals was found to be very limited. The strategy we used to identify publications for inclusion in the present review can be qualified as thorough. There was a clear list of pre-set criteria; searches were performed on multiple databases; and abstracts were independently judged by both the first and second authors. Not only quantitative but also qualitative and descriptive reports were considered for selection and inclusion in the review.

Results provide an overview of nursing processes employed during the euthymic (i.e., neutral) stage of a bipolar disorder and during acute episodes of (hypo)mania. No descriptions of the nursing processes specifically employed during acute episodes of bipolar depression were encountered in the relevant literature. It is possible that nurses do not differentiate between bipolar and unipolar depression. All the nursing processes described in the literature are recognizable in Dutch mental health care except for one. Dutch nurses are not

allowed to check lithium blood levels as described by Dixson (1981). Only medical doctors are allowed to do this in the Netherlands. The results of the present review also provide very little evidence for the effectiveness of the described nursing processes. The poor level of evidence is obviously due to the very limited number of research studies. Those studies that have been performed also suffer from a number of methodological shortcomings such as small sample sizes, nonhomogenous samples, lack of control, lack of randomization, and lack of contrast between the experimental and control interventions. The results of the quantitative studies cannot be compared to each other because the samples were not homogenous and different outcomes were investigated. Further meta-analysis of the quantitative findings is therefore not feasible. The described quantitative studies concern a combination of therapies and interventions. It is not clear which interventions contributed to the effects.

Almost all of the articles included in the present review mention psycho-education as a relevant nursing process. In all four of the quantitative studies, psycho-education was investigated. The results of the qualitative studies performed by Pollack provide more specific information on the topics included in a psycho-educational program (Pollack, 1993; Pollack, 1995b; Pollack, 1996a; Pollack, 1996b). Research on the effectiveness of psycho-education provided by professionals other than nurses suggests a higher level of evidence. Van Gent (2000) investigated the effects of psycho-education and found patients to report fewer psychosocial problems. Significant decreases in non-compliance and hospitalization rates were also found. When Honig (1997) performed a controlled study of a family psycho-educational intervention, the key relatives of patients in the treatment group showed a significant change from high to low levels of expressed emotion. In addition, those patients living with key relatives with low levels of expressed emotion were generally found to have a significantly lower number of hospital admissions than those patients living with relatives with high levels of expressed emotion. Recent studies in Spain also show group psycho-education to constitute an effective intervention to prevent recurrence and relapse in pharmacologically treated patients with bipolar I and II disorder (Colom et al., 2003a; Colom et al., 2003b). Psycho-education for caregivers of bipolar patients has further been shown to improve caregiver's knowledge of the illness, reduce their distress or subjective burden, and alter their beliefs about a possible link between previous disruptions in their lives and the patient's illness (Reinares et al., 2004).

Additional nursing research should be conducted to further assess the care needs of patients with a bipolar disorder. Given the general lack of publications, a broad survey should be undertaken to investigate the daily practices of nurses working with bipolar patients. Which interventions do they use and when? What goals do they set when nursing bipolar patients? What are the critical decision points during the nursing process? What information do nurses use to make these decisions, and how do they obtain this information? And how do nurses evaluate the outcomes of their decisions with respect to patients with a bipolar disorder?

The results of these studies should be used to develop a nursing program that can be individualized for each patient. Results of studies reviewed here can also be used as the building blocks for such a nursing program. The most promising nursing processes for the care of patients with a bipolar disorder appear to be: a specific bipolar disorder nursing assessment; concrete formulation of both care and crisis plans; protection; psycho-education measures, and other measures aimed to enhance self-management and treatment compliance; support for the patient, caregivers, family, and friends; observation of treatment effectiveness and any side-effects of medication; and easy access to nurse as case manager. The nursing program should be carried out as part of a multidisciplinary approach to the treatment and care of patients with a bipolar disorder. After the implementation of such a program, a follow-up study should be undertaken to investigate the effects of the nursing program on the well being of bipolar patients.

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## **Chapter 3**

### **The nursing of outpatients with a bipolar disorder: What nurses actually do**

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**Abstract**

This qualitative study was undertaken to gain insight into the daily practice activities of community psychiatric nurses (CPNs) involved in the nursing of outpatients with bipolar disorders in the Netherlands.

Semi-structured interviews were undertaken with 23 CPNs and additional focus group interviews were conducted. Information was gained on the problems encountered by the patients with a bipolar disorder, desired outcomes, interventions used, and the role of the CPNs in the treatment of these outpatients.

One of the main conclusions is that a systematic approach to the nursing process is simply lacking. Recommendations for improvement are therefore presented in closing.

## 1. Introduction

Bipolar disorder is a complex and chronic psychiatric condition with an estimated lifetime prevalence rate of 1.5 – 2% of the population in the European Union (Pini et al., 2005). The disorder is characterized by the alternating occurrence of (hypo)manic, depressive, and sometimes mixed episodes. Bipolar disorder is associated with a considerable degree of illness-related morbidity (Post et al., 2003) and also constitutes a major social and occupational burden for both the patient and his or her family (Abood et al., 2002; Bowden., 2005; Pini et al., 2005; Vornik & Hirschfeld, 2005). The Dutch Nemesis study (Regeer et al., 2004; Ten Have et al., 2002) found 56% of respondents turn to a mental health organization for help. For 97% of the respondents requesting help, care was provided — to at least some extent — in an outpatient care setting. Community psychiatric nurses (CPNs) are increasingly being involved in the provision of care for such a group of patients. And for some years now, considerable attention has been paid to the development and implementation of mental health care programs in the Netherlands. Both the content and organization of the health care for specific target groups are described in these programs (de Boer, 2001).

Closer examination of the mental health care programs recently provided by a number of different organizations showed a description of the professional contributions of nurses to only exist in a very brief form or simply not all. In 2006, a review of the literature was further undertaken to identify those nursing processes used in the treatment of patients with a bipolar disorder (Goossens et al., 2007). The number of publications in indexed journals that met the criteria for inclusion in this review was found to be very limited. Most of the articles were descriptive reports written by practicing nurses. Only a few articles involved actual research reports. The most promising nursing processes identified in the review concerned the following: specific bipolar disorder nursing assessment, concrete formulation of both care and action plans; establishment and maintenance of a therapeutic alliance; education of patient and family; enhancement of treatment compliance; enhancement of self-management techniques; promotion of awareness of stressors, regular patterns of activity, and sleep; help to anticipate and address early signs of relapse; and monitoring of treatment response.

In addition to the results of the aforementioned review, insight into the daily practices of CPNs working with patients with a bipolar disorder is critical for the description of the nursing contribution to the relevant mental health programs and the further development of integrated evidence-based treatment. For this reason, the aim of the present study was to investigate the daily practices of nurses

working with bipolar disorder outpatients. Four research questions were addressed.

1. What problems do nurses identify for outpatients with a bipolar disorder and what are the specific signs and symptoms of these problems?
2. What are the desired outcomes identified for the nursing of outpatients with a bipolar disorder?
3. Which interventions are used for the nursing care of outpatients with a bipolar disorder?
4. How do nurses perceive their contribution to the treatment of outpatients with a bipolar disorder?

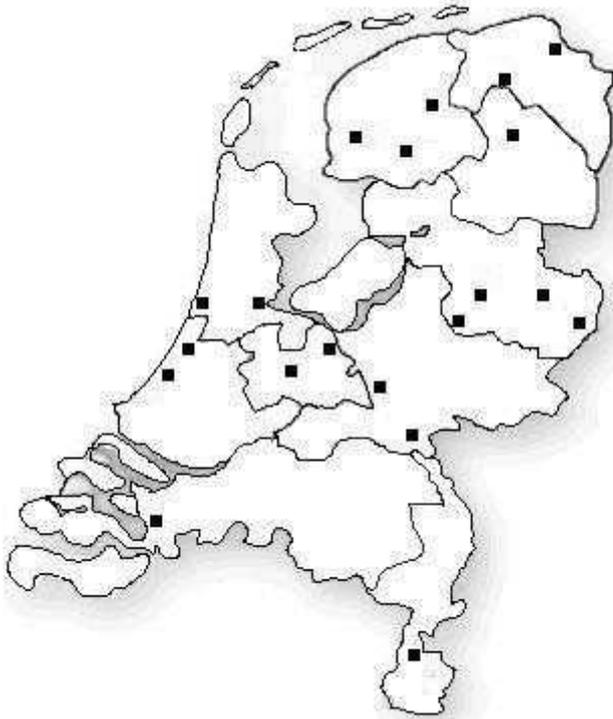
## **2. Methodology**

A qualitative approach was adopted. In addition to investigation of the actual nursing process, respondents were asked to mention any concerns and reflect more generally upon the nursing process for patients with a bipolar disorder. Semi-structured individual interviews and focus group meetings were held for this purpose.

### **2.1 Data Collection**

#### *2.1.1 Semi-structured Interviews*

A total of twenty-three CPNs from twenty mental health organizations were interviewed at the work place. The organizations were distributed throughout the Netherlands (Figure 1). Three of the interviews were actually held with two CPNs working closely together within the same organization. Sixteen of the CPNs were recruited from the Dutch Lithium Plus Working Group (Li+WG), a national network of professionals concerned with the treatment of bipolar disorder patients. The other seven CPNs were recruited via snowball sampling (Polit & Beck, 2004). A second interviewer was present at four of the twenty interviews. The interviews were semi-structured; that is, a topic list was used to obtain the data (Table 1). More specifically, the nurses were asked to compose a hierarchical list of problems encountered by their patients, desired nursing outcomes, and interventions used. In addition, the CPNs were asked to indicate if and why the nursing professional has value for the outpatient treatment of individuals with a bipolar disorder.

**Figure 1: Demographic distribution of the organizations across the Netherlands****Table 1: List of Topics Used in Semi-structured Interview****Organizational topics**

- Respondent's name and function
- Respondent's level of education and training
- Structure of the multidisciplinary team
- Level of specialization within the multidisciplinary team
- Education policy within the multidisciplinary team
- What to do in case of patient crisis
- External contact with patient associations, research organizations, etc.

**Patient care topics**

- Organization of treatment and care
- Methods of treatment and care currently in use (e.g., life chart, action plans, psycho-education groups)
- Process of critical thinking and clinical judgment
- Top five problems, outcomes, and interventions
- Use of nursing plans (e.g., NANDA taxonomy, NIC, NOC)
- Evaluation of care

**2.1.2 Focus Group Meetings**

Three focus group meetings were held in different parts of the Netherlands. The dates and places for the meetings were communicated to the 23 CPNs who were interviewed. Fourteen of the CPNs participated in the focus group meetings in the end. Two meetings with five participants and one meeting with four participants

were held. The researcher, a secretary, and a group leader who followed a two day training on focus group methods prior to participation in the present study were present at each meeting. The focus group meetings were audio recorded and transcribed. During the focus group meetings, the participants were asked to discuss the top five problems, outcomes, and interventions revealed by the interviews and to evaluate them in terms of signs and symptoms, indicators, and activities. Another topic for discussion was the role of the nurse in the treatment of bipolar disorder patients.

The participants in the focus groups were informed about the discussion topics prior to the meetings. The transcriptions of the meetings were compared to the original recordings and sent to the participants for validation and comments.

## **2.2 Data analyses**

### **2.2.1 Semi-structured Interviews**

Content analyses were conducted on the interview data. Analyses took place after the last interview was held. On each topic, notes made by the interviewer were typed out unabridged. Two researchers independently divided the interview into segments and assigned a code to each interview segment. The assigned codes were compared and discussed. Those segments with identical or similar codes were next grouped to derive central notions and these were thoroughly worked out in search for categories. The hierarchical orders for the relevant problems, outcomes, and interventions were determined in the following manner. Per interview, that problem, outcome, or intervention judged to be most important by the respondent in the interview was assigned five points; that problem, outcome, or intervention judged to be second most important was assigned four points; and so forth. The values assigned per problem, outcome, or intervention were then summed respectively and divided by the total number of participants mentioning that particular problem, outcome, or intervention. The rank orderings of the different categories were then identified.

### **2.2.2 Focus Group Meetings**

The data for a focus group was analyzed prior to the conduct of the next focus group and compared to the data from a previous group when available. This method of analysis improves data collection because it indicates which particular items may require more information and thus greater attention in future meetings. The data were analyzed using a so-called "long-table approach" (Krueger & Casey, 2000). The written transcripts of the focus group meetings were copied

onto colored paper, marker pens and scissors were distributed, and three colleagues (i.e., two researchers and a clinical nurse specialist) assisted the researcher in the analyses of the transcripts. More specifically, the transcript of a focus group meeting was distributed to the analysts with the request that each analyst read the transcript several times to get the whole scope of the interview and then mark those statements judged to contain information of particular relevance. After this, the group of analysts met and the marked passages were evaluated and discussed. When no consensus could be achieved with regard to the importance or relevance of a particular statement, the statement was omitted for any further analysis. The remaining statements were literally cut out and placed on one or the other sheet of paper representing a particular problem, outcome, or intervention (one sheet per category). The focus group analyses continued in such a manner until consensus was attained on the interpretations of the different statements within each category.

### **3. Results**

Twenty of the 23 CPNs were trained at a bachelor level and three at a master's level. Five of the CPNs worked within a team that specialized in bipolar disorder. Seven worked with patients with all types of mood disorders. Two of the CPNs only saw bipolar patients for consultation with regard to their use of a mood stabilizer. And nine of the CPNs worked in a general outpatient clinic but were specialized in bipolar disorders and therefore all patients assigned to them were diagnosed with bipolar disorder.

Eight of the 20 participating organizations actually described their treatment policies in mental health care programs. Five of the organizations conducted routine outcome measurement using the Beck Depression Inventory, the Hamilton Depression Rating Scale, or Life Charts. Five of the organizations held regular multidisciplinary evaluations of a patient's treatment plan; the other fifteen organizations undertook only ad hoc evaluations. Six of the 20 organizations measured patient satisfaction.

None of the CPNs reported use of the North American Nursing Diagnosis Association (NANDA) taxonomy, the Nursing Intervention Classification (NIC), or the Nursing Outcome Classification (NOC). Similarly, none of the CPNs reported use of nursing care plans. In Table 2, a list of the patient problems, desired outcomes, and current interventions mentioned by the nurses in the interviews is presented.

**Table 2: Overview of patient problems, desired outcomes, and current interventions mentioned in interviews with CPNs**

|    | Patient problems                         | Desired outcomes                       | Current interventions                         |
|----|--|--|---|
| 1  | Nonacceptance of disease                 | Euthymic mood state                    | Nurse accessibility                           |
| 2  | Social problems                          | Self-management of disease             | Information and education                     |
| 3  | Work-related problems                    | Quality of life                        | Support and counseling                        |
| 4  | Relational problems                      | Acceptance of having a chronic disease | Action plans                                  |
| 5  | Mood instability                         | Understanding the disease              | Monitoring of medication use                  |
| 6  | Problems with daily activities           | Treatment adherence                    | Life charts                                   |
| 7  | Integration of the disease into the self | Healthy structure for daily activities | Family counseling                             |
| 8  | Social isolation                         | Social competence                      | Promotion of contact with other patients      |
| 9  | Stigmatization                           | Trust in treatment                     | Enhancement of motivation for treatment       |
| 10 | Uncertainty                              | Proper diagnosis                       | Enhancement of structure for daily activities |
| 11 | Insufficient knowledge of the disease    |  | Monitoring of symptomology                    |
| 12 | Medication-related problems              |  | Enhancement of problem-solving skills         |
| 13 | Financial problems                       |  | Interventions in case of crisis               |
| 14 | Mourning about health loss               |  | Prevention                                    |
| 15 | Low self-esteem                          |  | Cognitive-behavioral therapy                  |
| 16 | Life events                              |  | Education of others                           |
| 17 | Addictions                               |  | Counseling for work resumption                |
| 18 | Sleep disorders                          |  | Counseling in case of pregnancy               |
| 19 | Housing problems                         |  |   |
| 20 | Anxiety                                  |  |   |
| 21 | Stress                                   |  |   |
| 22 | Treatment nonadherence                   |  |   |

### 3.1 Top five problems

#### *Nonacceptance of disease*

The nurses report nonacceptance of the disease particularly by those patients who have not given up hope of being cured. These patients are convinced that their condition is of a temporary nature despite doctors and nurses telling them that they have a chronic condition. Other symptoms reported by the nurses are: Patients not showing up for appointments, neglect of treatment advice, nonuse of prescribed medication, claims that complaints are not related to bipolar disorder but some other condition.

*Patients tell me: "It's going really well, why should I take medication?"*

#### *Social problems*

Problems on the social front are seen by the nurses to be a major consequence of the disease: loss of income, loss of self-esteem, loss of meaningful contacts, loss of housing. Patients with a bipolar disorder experience shame, a loss of face, debt,

stigmatization, and incomprehension. Several of the nurses report that the social roles of the patients change during the course of the disease with avoidance of social situations as a consequence. Another etiological factor reported by several of the nurses is that people do not dare to talk to patients because they do not know how to cope with a patient.

### *Work-related problems*

Work-related problems are often seen in patients with a bipolar disorder. The nurses state that these problems are often caused by a reduced capacity to concentrate, an inability to plan, stress intolerance, and reduced energy levels. Several of the nurses also stated that patients with a bipolar disorder often work below their level of intelligence, which can be experienced as humiliating. Working in shifts is also frequently reported as problematic due to the patient need for daily structure. Fear of stigmatization is reported as a reason for not telling colleagues about one's condition, which can further frustrate patients, lead to overburdening, and result in a loss of work in the end.

*Patients often ask me to help them write a letter to social institutions because they are afraid of losing their sickness benefits or being forced into a job that they know they cannot handle.*

### *Relational problems*

The nurses report that a shift of roles within the relationship can lead to major problems. Initial concern about the patient can change into apprehension or a critical attitude. High levels of expressed emotion are reported. Adultery and heightened sexual arousal during manic episodes and loss of libido during depressive episodes or due to medication are often mentioned as a source of relational problems. Other symptoms are: broken trust, loneliness, feeling ignored by partner, loyalty conflicts, and neglect of the disease by the partner. Divorce is frequently reported.

*Partners tell me that they find it really hard to stick to their marriage vows: For better and for worse.*

### *Mood instability*

Changes in patient behavior reflect mood instability and are reported by the nurses to be a major problem for patients: changes in patterns of sleep, changes in energy levels, and changed levels of activity with overloaded calendars and lots of cancellations in cases of (hypo)mania and empty calendars in cases of

depression. The nurses report paying close attention to nonverbal signs and symptoms. Is there a twinkle in the eyes of the patient? Is the patient restless or look depressed? Does the patient make his or her presence obvious or sneak in? Is the speech of the patient faster, slower, louder, or quieter than normal? Is the patient's handshake strong or weak? Other symptoms involve the patient's outward appearance. What is the state of personal hygiene? Is the patient dressed with care, eccentrically, or sloppily? When the patients carry a number of bags with them, the nurses state that they are aware of (hypo)mania.

### **3.2 Top five outcomes**

*Euthymic mood state* is the major desired outcome set by the nurses for their patients. Evaluation of this involves assessment of—among other things—mood state, sleeping behavior, weight gain or loss, medication use, and the occurrence of life events. Other indicators used to assess mood state are the serum levels of medication in the patient's blood, nonverbal signs, and the pattern of daily activities.

*Patients often tell me that they have gradually discovered the importance of a regular daily pattern for their lives.*

*Self-management* is also a desired outcome and defined as the individual's ability to integrate the disease into his or her daily life activities. The majority of the nurses reported evaluation of self-management in terms of the ability of the patient to recognize early signs or symptoms of an episode of (hypo)mania or depression and his or her ability to cope with these early warning signs. Another reported indicator is the ability of the patient to recognize his or her vulnerabilities and undertake the actions needed to cope with these vulnerabilities.

*When a patient has read about the disease and says "hey, that's a lot like me...", then you know that they're on the right road.*

*Quality of life* is yet another desired outcome and defined by the participants in the focus groups as the ability of a patient to fulfill various social roles. This ability may be assessed indirectly via evaluation of patient satisfaction level with daily activities, patient self-esteem, and the feel-good level of the patient.

Both *acceptance of having a chronic disease* and *understanding of the disease* are also identified as desired outcomes. These outcomes are typically evaluated in terms of self-management abilities, the capacity of the patient to recognize

problems/vulnerabilities, and the patient's ability to cope with the consequences of having such a condition and thereby avoid episodes of (hypo)mania and depression to the greatest extent possible.

### **3.3 Top five interventions**

#### *Nurse accessibility*

All of the nurses spoke of approachability and accessibility as the most common intervention. Given that mood swings can occur within a very brief time span, contact with the nurse should be possible within a very few hours. This contact can occur via the telephone, face to face, or via email.

*Knowing the importance of quick action, I keep space in my daily calendar.*

The nurses emphasize the importance of taking time to see the patient and mention a half hour as the minimum. Continuity in the patient-nurse relationship is of critical importance. The nurses observe that the patient-nurse relationship is not only a therapeutic relationship but also a matter of trust. Patients should feel free to talk about fears and uncertainties, ask questions, and tell their stories. According to the nurses, they need to be open, interested, and concerned. The nurses should speak to the patient as an equal and use clearly understandable language. The nurses report widespread use of self-disclosure to normalize the experiences of the patient. The contact with patients should be safe and secure; nurses should not judge their patients but, try to fit the perceptions of the patient. In other words, the nurse must be trustworthy, reliable, even-minded, and calm.

#### *Information and education*

All of the nurses were familiar with the Maastricht model for group psycho-education training (Hofman et al., 1992). This model is widely used in the Netherlands. In six sessions, patients and their close relatives are taught about: bipolar disorder; symptoms of the disorder; characteristics, course, and outcomes; psychopharmacology; psychotherapy; life charts; action plans; self-reports; legal issues; how to obtain information; and contact with patient associations. The nurses further mentioned addition of the following issues to the model: work-related problems; medical examination for social benefits; returning to work; bipolar disorder and pregnancy; and suicide. Two of the 20 organizations for which the nurses worked had actually developed their own group model while one of the organizations provided no such psycho-education.

*I think this training is an easy way to get the partner involved.*

All of the nurses reported face-to-face provision of information to patients and their relatives. Brochures are frequently distributed, and the nurses observe that such information must be provided on a regular and repeated basis: but not all at once.

#### *Support and counseling*

The nurses stated that they often help patients to structure their daily lives. Life style advice is also sometimes provided. The nurses may, for example, motivate the patient to be more active or to slow down, depending on the mood state.

*I often advice patients to lengthen their lunch break and get more and longer coffee breaks.*

Patients may be helped to order their thoughts, and advice on problem-solving possibilities and strategies may be provided. The nurses also coordinate care at times and, if necessary, consult with or call in other professionals.

#### *Action plans*

In 85% of the 20 organizations, the nurses help patients with the development of an action plan. Triggers, stressors, vulnerabilities, protective factors, early warning signs of instability, and interventions to regain stability are also described in the action plan. The nurses state that these action plans provide a basis for teaching the patient disease-related self-management techniques. The nurses also state that a useful means to identify the most relevant interventions is to consider the details of the most recent relapses. The Life Chart Method (Denicoff et al., 2000), which was actually number six on the intervention list, is reported to be of great value for this purpose. Questions included: Under what circumstances did the relapses occur? What were the first signals for the patient or relative? What did the patient do to prevent further mood instability or gain stability and was this successful? Helping the patient formulate an action plan is a standard intervention in most of the organizations. Some of the nurses stated that every patient should have an action plan. The nurses all agreed that an action plan can help other health care professionals in case of patient crisis. The nurses also all agreed that an action plan empowers patients and thereby helps them better cope with their disorder by making them a partner in the treatment. Action plans require regular review and revision. Every new relapse (or near relapse) provides information for the future prevention of possible relapse.

*Patients tell me that they get a feeling of autonomy and having a greater grip on the situation with an action plan.*

### *Monitoring of medication use*

All of the nurses carefully monitor the serum levels for mood stabilizers. They state that they know exactly what the serum levels should be and therefore request regular testing. The nurses ask about the side effects of the medication being used, and some report using a checklist for this purpose.

*I think that I have to ask about these side effects. Patients often don't report them.*

All of the nurses further reported advising other medical professionals with regard to medication changes. Sometimes the medical professionals, nurses, and patients jointly develop self-medication strategies, which are then described in the action plan. The nurses are frequently asked to then guide the patient. In some cases, the nurses deliver a weekly box of medication in order to promote adherence. The involvement of nurses in the prescription of medication and monitoring of effects/side-effects clearly differed across the 20 organizations. In some of the organizations, the nurse actually conducts the assessment and is involved in the choice of mood stabilizer although this is not common.

### **3.4 The nurse's role in the treatment of bipolar disorder patients**

The nurses whom we interviewed stated that the care for outpatients with a bipolar disorder is definitely within the scope of their tasks. The nurses reported being educated and trained on a broad spectrum of somatic, psychological, and social problems. The nurses further observed that patients may be more open to a nurse than to a psychiatrist. The nurses argue that they are on a more equal level than their medical colleagues and that the focus of many medical professionals is often predominantly biological. The nurses also observed that they are in a position to spend more time with the patient than other medical professionals. In fact, the nurse is often a continuous factor in the extended treatment of a patient, knows the patient inside and out, and is very capable of predicting instabilities that can lead to episodes of (hypo)mania or depression.

## **4. Discussion**

This study involved 23 CPNs who were carefully selected on their depth of knowledge and broad experience in nursing bipolar disorder patients. It should be noted that, although the nurses came from organizations distributed across the Netherlands, the present sample is not necessarily representative of the Dutch population of CPNs. Furthermore, the data were all self-reported, which raises the risk of a social-desirability bias. In future research, additional evidence of the identified problems, desired outcomes, and current interventions should therefore

be sought in actual nursing records. Unfortunately, none of the CPNs used nursing care plans.

The use of semi-structured interviews and focus groups involving multiple organizations helped us gain a thorough and fully contextualized picture of the outpatient nursing process for patients with a bipolar disorder. The present findings provide a clear overview of what CPNs encounter during the daily practice of nursing such outpatients. The results presented in this paper give no indications about the quality of the nursing care provided by the CPNs. Inspection of Table 2, moreover, reveals a few remarkable findings. A stable euthymic mood state is mentioned as the number one desired outcome while mood instability, in contrast, is ranked as only the fifth patient problem. This may be explained by the fact that nurses do not focus on the disease itself but on the consequences of the disease for the daily life of the patient. A prominent position is assigned to social problems, work-related problems, and relational problems, for example. A stable euthymic mood state is an important precondition for daily functioning of the patient and most of the nursing interventions. Similarly, a stable euthymic mood state may constitute a protective factor for other disease-related problems and therefore elicit considerable attention from CPNs to prevent further destabilization of the patient.

Treatment nonadherence is ranked last on the list of 22 patient problems noted by the nurses despite the fact that strong evidence shows nonadherence in the treatment of bipolar disorder patients to be the most frequent cause of episode recurrence (Colom & Vieta, 2002; Colom et al., 2000; Sajatovic et al., 2006; Scott & Pope, 2002). This finding can probably be explained by the fact that noncompliant patients rarely appear in the case loads of CPNs. It is well-documented, for instance, that many bipolar disorder patients avoid or withdraw from further treatment following acute episodes of either depression or (hypo)mania (Ten Have et al., 2002). According to recent publications, moreover, cognitive impairment in the form of problems with decision making, planning, verbal memory, working memory, attention/mental control, and the acquisition of information is now recognized as a problem bipolar disorder patients could encounter (Martinez-Aran et al., 2004; Murphy et al., 2001; Robinson & Ferrier, 2006). It is therefore remarkable that only a few of these problems were mentioned by the nurses whom we interviewed as the problems could underlie other problems and should therefore not be neglected in the nursing process or clinical judgments.

In closing, one of the main conclusions to be drawn on the basis of the present study results is the general lack of a systematic approach to the nursing activities

of CPNs. It is therefore recommended that CPNs perform more structured clinical judgment processes by conducting systematic nursing assessments, formulating nursing diagnoses and desired nursing outcomes, and making choices of nursing interventions. Regular evaluation of outcomes with both the patient and a multidisciplinary team of professionals is also clearly necessary to improve patient outcomes in cases of a bipolar disorder. Comparing the results of this study with the results of the before mentioned review on nursing processes used in the treatment of patients with a bipolar disorder (Goossens et al., 2007), the conclusion can be drawn that, despite the lack of a structured method in carrying out the nursing process, CPNs in the Netherlands are using all but two of the most promising nursing processes identified in the review. The two nursing processes that are not performed by the Dutch CPNs are the use of a specific bipolar nursing assessment and the formulation of a nursing care plan. The nursing processes that aim to benefit the patient health status and social functioning and decrease the level of burden experienced by the patient and his family such as the use of action plans in teaching the patient self-management techniques, the establishment and maintenance of a therapeutic alliance, education of both patient and family can all be identified in table two. This implies that CPNs cover the most relevant issues in care for patient with a bipolar disorder.

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## **Part II**

### **Supportive information for nurses' clinical decision making process**



## **Chapter 4**

### **Self reported care needs of outpatients with a bipolar disorder in the Netherlands: a quantitative study**

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**Abstract**

The care needs of patients with a bipolar disorder have not been studied to date. In the present research, the care needs, care received and unmet care needs for a population of outpatients with a bipolar disorder in the Netherlands are described. The participants (n=157) completed the Need for Care Questionnaire and a questionnaire addressing various demographic and clinical characteristics. The results show the care needs to mainly involve the domains of psychological help, psychiatric help and social functioning. Unmet needs are frequently reported for all domains and found to be particularly frequent for needs on social functioning. Some significant associations between source of income, number of hospitalizations and involvement of Community Psychiatric Nurses, on the one hand, and reported care needs, on the other hand, are identified and discussed. Incorporation of needs assessment into the treatment process is recommended in the form of structured questionnaires which can also then be used to guide and evaluate the treatment process. Future research should focus on the identification of the specific risk factors for particular care needs and thereby work to minimize the occurrence of such risk factors and promote early intervention efforts to reduce the burden on patients and their relatives.

## 1. Introduction

Bipolar disorder or manic-depressive illness is a chronic and severe psychiatric condition characterized by an alternation between episodes of mania (or hypomania), depression and sometimes a mixture of the two with an estimated lifetime prevalence rate of 1.5% to 2% for the European Union (Pini et al., 2005). Patients with a bipolar disorder show considerable illness-related morbidity (Post et al., 2003), and the disorder significantly influences the well-being of the patient and his or her social, occupational and general functioning (Post et al., 2003; Vornik & Hirschfeld, 2005; Mitchell et al., 2004; Sajatovic, 2005). Health-related quality of life (HRQoL) impairments among patients with a bipolar disorder are greater than among the general population and comparable to or greater than among patients with chronic nonmental health-related disorders. When compared to other psychiatric disorders, the HRQoL ratings for patients with a bipolar disorder are similar to those for patients with a unipolar depression but higher than for patients with schizophrenia. Impairments continue in patients with a bipolar disorder even when they are free of symptoms and thus in a stable euthymic mood state (Dean et al., 2004).

A strong predictor of a lower quality of life among people with a severe mental illness is the presence of unmet care needs (Wiersma, 2006; Wiersma & Van Busschbach, 2001). Within the domain of health care, a “need” is defined as a lack of health or welfare or a lack of access to care (Brewin, 1992). In the present study, “need” is also understood to be the psychosocial dysfunction which can arise as a consequence of a bipolar disorder. Nurses try to meet those needs which fall within the scope of the nursing process via assessment (i.e., identification and clarification of care needs and underlying problems), definition of the nursing diagnosis, description of the desired outcome, planning and conduct of nursing interventions and regular evaluation of client outcomes. When a literature search was undertaken to identify studies which assessed the care needs of patients with a bipolar disorder, however, only six articles were encountered. The search was conducted using Medline, Psychinfo, Embase Psychiatry and Cinahl, and it included the following terms: bipolar disorders, manic depressive illness, need(s) for care, need(s) of care and care needs. Three of the studies addressed only the information needs of patients with a bipolar disorder (Pollack, 1995a, 1995b, 1996); two of the studies addressed mental health problems in general and were therefore not specific to a bipolar disorder (Chadda et al., 2000; Birch et al., 2005); and the reference for one study was incomplete and therefore not usable. In the practice guidelines for the treatment of patients with a bipolar disorder

(American Psychiatric Association, 2002), specific attention is paid to the evaluation and management of functional impairments. However, no information is provided on just how the impairments should be assessed or the care needs associated with the impairments.

## **2. Study objectives**

The purpose of the present study was therefore to identify the self-reported care needs and unmet care needs for a population of outpatients with a bipolar disorder in the Netherlands. In addition, the associations between these care needs and particular demographic and clinical characteristics were explored.

## **3. Methods**

A cross-sectional research design was employed, and the study was conducted at five psychiatric outpatient clinics in the Netherlands. The subject selection criteria included: psychiatric outpatient diagnosed with a bipolar disorder using the DSM-IV criteria (American Psychiatric Association, 2005), older than 18 years of age and able to complete an interview.

## **4. Procedure**

Between April 2005 and April 2006, outpatients with a bipolar disorder were asked to participate in the study by their psychiatrist or community psychiatric nurse (CPN) after they verified that the patient was sufficiently stable to do this. The study aims and methods were briefly described to the patients by the psychiatrist or the CPN. When a patient indicated an interest in participation, a written permission to pass the patient's name, address and telephone number on to the researchers was attained. A written description of the study was then sent to the patient's home address, and he or she was contacted one week later by telephone. The researcher again explained the aims of the study, data collection methods and procedures to the patient and, when the patient agreed to participate, an appointment was made at the outpatient clinic where the patient was being treated. The session was conducted by the researcher or a trained research assistant and initiated by again informing the patient about the purpose of the study and assuring anonymity and confidentiality. The study was approved by a regional medical ethics committee certified by the Netherlands Central Committee on Research involving Human Subjects ([www.ccmo.nl](http://www.ccmo.nl)), as well as by the ethical committees of the participating institutes. All of the participating patients

signed an informed consent form prior to the start of data collection which was done using structured questionnaires.

## 5. Measures

Two questionnaires were administered during the session with the patient: (1) a self-constructed questionnaire to gather demographic and clinical data and (2) the Need for Care Questionnaire (NCQ). The NCQ includes 42 items comprising 7 scales and was recently developed in the Netherlands by Kroon and colleagues (Kroon, 2003). The scales are: psychological help and exploration (6 items); psychiatric help, including the need for protection (6 items); social functioning (10 items); daily living activities (6 items); housing and household skills (7 items); financial and administrative skills (4 items); and addiction (3 items). The Cronbach's alphas of these scales have been found to be  $>0.60$  to  $>0.80$  and, when the item scores are summed across all the scales, the total score has been found to have a Cronbach's alpha of 0.89. This indicates that the NCQ is internally consistent, that all the instrument's subparts are measuring the same concept.

The NCQ items all have the following format.

1. Do you receive help or guidance with...(item)?
2. Do you, yourself, think that you need help or guidance with...(item)?  
If yes, would you like:
  - more help or guidance (than you now receive)
  - the same amount of help or guidance
  - less help or guidance
3. Do you receive the suitable help or support with this
  - not applicable (I do not receive help or guidance)

Three scores can be calculated per item; help received, perceived need for care and unmet care needs. A need for care is unmet when the patient reports a need for care but help or guidance is simply not supplied, insufficient help or care is supplied or the supplied help or guidance is perceived as unsuitable. Two versions of the NCQ exist: one for patients and one for professionals. Given the aims of the present study, only the version of the NCQ for patients was used.

## 6. Statistical analyses

The frequency of received help, care needs and unmet needs were calculated per item and per scale. Unmet needs were only calculated for those patients who reported a need for care.

To explore the associations between care needs, demographic characteristics and clinical characteristics, the following tests were conducted: chi-squared tests, independent-samples t-tests or Mann-Whitney tests depending on the level of measurement and size of the sample (Altman 1991). All of the data were analyzed using SPSS 14.0.

## **7. Results**

### ***7.1 Demographic and clinical characteristics***

Of the 201 patients who initially showed an interest in study participation, 158 participated in the end (79%). Various reasons were provided for declining to participate: fear of destabilization, depressed or (hypo)manic mood state at the time of the appointment, hospitalization, unwilling to travel, nonmental illness at the time of the appointment, “talked out of participation by relatives,” or just not showing up for the appointment.

One patient declined to participate further during the interview itself which meant that this data was omitted from any further analysis. An overview of the demographic and clinical characteristics of the participants is presented in Table 1.

More females participated in the present study than males, and the majority of the participating patients had a euthymic mood state at the time of questionnaire administration. Of the 157 participants, 140 reported their mood state to be between 40 and 60 along a scale of 0 (= severe depressive mood state) to 100 (= severe manic mood state); 92 patients reported a mood state of 50. Some 75% of the participants lived with a partner, children or relatives. Despite the relatively high level of education characterizing the patients, only 42% of them had a job.

More than 50% of the patients had regular contact with a CPN in addition to a psychiatrist. Almost all of the patients used mood stabilizers, and lithium was used most commonly by these patients. Use of the psychosocial treatment modules, such as group psychoeducation and different forms of psychotherapy, during the maintenance phase of treatment and thus as recommended by practice guidelines (American Psychiatric Association, 2002) was uncommon. The same holds for the use of relapse prevention techniques such as the formulation of life charts or action plans.

**Table 1: Demographic and clinical characteristics**

|  |             |             |
|--|-------------|-------------|
| Female   | 65%         |             |
| Age  | Mean 47.24  | SD 11.776   |
| Living alone   | 24.2%       |             |
| Income   |             |             |
| • None   | 11.5%       |             |
| • Employed   | 35.3%       |             |
| • Self-employed  | 7.6%        |             |
| • Social welfare   | 39.7%       |             |
| • Retired  | 8.9%        |             |
| Education  |             | certificate |
| • Middle school  | 56.4%       | 77.5%       |
| • High school  | 36.9%       | 82.0%       |
| • University   | 20.4%       | 62.5%       |
| Diagnosis  |             |             |
| • Bipolar 1  | 66.9%       |             |
| • Bipolar 2  | 25.5%       |             |
| • Bipolar NOS  | 7.6%        |             |
| Mood state during the interview along a scale of 0 -100          | Mean: 50.46 | SD 8.726    |
| Number of episodes during the last year                          |             |             |
| • (Hypo)mania  | Mean: 1.32  | SD 5.180    |
| • Depression   | Mean: 1.25  | SD 3.133    |
| Number of hospitalizations during life                           |             |             |
| • Due to (hypo)mania   | Mean: 1.01  | SD 2.263    |
| • Due to depression  | Mean: 1.15  | SD 1.537    |
| Number of consultations with psychiatrist during last six months | Mean: 3.72  | SD 4.005    |
| CPN involvement in treatment                                     | 56.1%       | n=88        |
| Number of consultations with CPN during last six months (n=88)   | Mean: 5.39  | SD 5.102    |
| Mood stabilizer use  |             |             |
| • None   | 4.4%        |             |
| • Lithium  | 78.0%       |             |
| • Carbamazepine  | 10.1%       |             |
| • Valproate  | 10.1%       |             |
| • Antipsychotic medication                                       | 17.6%       |             |
| • Lamotrigine  | 6.3%        |             |
| Psychosocial treatment modules (present and past)                |             |             |
| • Group psycho-education   | 17.8%       |             |
| • Cognitive behavioural therapy                                  | 17.2%       |             |
| • Interpersonal psychotherapy                                    | 5.7%        |             |
| • Family focused therapy   | 4.5%        |             |
| Relapse prevention techniques                                    |             |             |
| • Life chart   | 28.7%       |             |
| • Action plan  | 37.6%       |             |

## 7.2 Received help, care needs and unmet needs

Of the 157 participants, 125 reported one or more care needs and 32 reported no care needs whatsoever. The specific NCQ results are presented in Table 2. As can be seen, the total scale score for received help was 9.5% while the total scale score for reported care need was 12.5%. This suggests that only a 3% lack of care occurred.

**Table 2: Received care, care needs and unmet care needs per item, scale and total**

| <b>Need scale</b>                          | <b>Care received</b><br>% (n) | <b>Need for care</b><br>% (n) | <b>Unmet need*</b><br>% (n) |
|--|-------------------------------|-------------------------------|-----------------------------|
| <b>Psychological help and exploration</b>  | <b>25%</b>                    | <b>30%</b>                    | <b>34.6%</b>                |
| Clarification of problems                  | 32.1% (52)                    | 33.1% (53)                    | 28.8% (15)                  |
| Discovery of what you want in life         | 14.6% (23)                    | 21.7% (34)                    | 47.1% (16)                  |
| Gaining more self-confidence               | 22.6% (36)                    | 29.6% (47)                    | 40.4% (19)                  |
| Learning to express feelings               | 14.0% (22)                    | 21.0% (33)                    | 48.5% (16)                  |
| Talking about life experiences             | 38.2% (60)                    | 43.3% (68)                    | 26.5% (18)                  |
| Determination of which help is best        | 27.4% (43)                    | 30.6% (48)                    | 29.2% (14)                  |
| <b>Psychiatric help</b>                    | <b>19.8%</b>                  | <b>25.0%</b>                  | <b>35.5%</b>                |
| Coping with grief or setbacks              | 28.0% (44)                    | 35.0% (55)                    | 29.1% (16)                  |
| Coping with hearing voices, sadness, fear  | 15.3% (24)                    | 19.7% (31)                    | 38.7% (12)                  |
| Coping with unexpected situations          | 14.0% (22)                    | 19.7% (31)                    | 48.4% (15)                  |
| Coping with sudden anger towards others    | 1.9% (3)                      | 8.9% (14)                     | 85.7% (12)                  |
| Feeling that you want to harm yourself     | 8.3% (13)                     | 9.6% (15)                     | 43.8% (7)                   |
| Timely indication of early warning signs   | 51.6% (81)                    | 57.3% (90)                    | 24.2% (22)                  |
| <b>Social functioning</b>                  | <b>6.2%</b>                   | <b>10.4%</b>                  | <b>56%</b>                  |
| Contact with others                        | 1.9% (3)                      | 5.7% (9)                      | 66.7% (6)                   |
| Contact with other patients                | 4.5% (7)                      | 4.5% (7)                      | 42.9% (3)                   |
| Coping with loneliness                     | 6.4% (10)                     | 12.7% (20)                    | 65.0% (13)                  |
| Filling up your spare time                 | 5.1% (8)                      | 7.6% (12)                     | 50.0% (6)                   |
| Standing up for yourself                   | 12.7% (20)                    | 22.3% (35)                    | 51.4% (18)                  |
| Daily activities                           | 5.7% (9)                      | 6.4% (10)                     | 27.3% (3)                   |
| Coping with quarrels and conflicts         | 8.9% (14)                     | 16.6% (26)                    | 57.7% (15)                  |
| Contact with family                        | 5.1% (8)                      | 7.0% (11)                     | 63.6% (7)                   |
| Sexuality                                  | 0.0%                          | 7.6% (12)                     | 100% (12)                   |
| Work                                       | 12.1% (19)                    | 14.0% (22)                    | 40.9% (9)                   |
| <b>Daily living activities</b>             | <b>0.6%</b>                   | <b>1.1%</b>                   | <b>54.4%</b>                |
| Washing yourself                           | 0.0%                          | 0.0%                          | 0.0%                        |
| Dressing yourself                          | 0.0%                          | 0.0%                          | 0.0%                        |
| Appearance                                 | 0.0%                          | 0.6% (1)                      | 0.6% (1)                    |
| Eating                                     | 0.6% (1)                      | 1.3% (3)                      | 66.6% (2)                   |
| Handicaps                                  | 3.2% (5)                      | 3.8% (6)                      | 33.3% (2)                   |
| Incontinence                               | 0.0%                          | 0.6% (1)                      | 0.6% (1)                    |
| <b>Housing and household skills</b>        | <b>4.6%</b>                   | <b>5.8%</b>                   | <b>40.6%</b>                |
| Shopping                                   | 3.2% (5)                      | 1.3% (2)                      | 0.0%                        |
| Travelling by car, bus or train            | 0.0%                          | 3.8% (6)                      | 100% (6)                    |
| Regular intake of medication               | 7.0% (11)                     | 6.4% (10)                     | 10.0% (1)                   |
| Cooking                                    | 1.9% (3)                      | 3.2% (5)                      | 60.0% (3)                   |
| Going to bed and arising on time           | 3.2% (5)                      | 5.1% (8)                      | 37.5% (3)                   |
| Finding your way around the neighbourhood  | 1.9% (3)                      | 1.3% (2)                      | 0.0%                        |
| Cleaning house                             | 15.3% (24)                    | 19.7% (31)                    | 40.6% (13)                  |
| <b>Financial and administrative skills</b> | <b>6.2%</b>                   | <b>9.7%</b>                   | <b>37.7%</b>                |
| Social agencies                            | 3.8% (6)                      | 5.7% (9)                      | 22.2% (2)                   |
| Management of finances                     | 8.9% (14)                     | 14.0% (22)                    | 36.4% (8)                   |
| Filling in forms and answering letters     | 8.9% (14)                     | 11.5% (18)                    | 33.3% (6)                   |
| Management of housekeeping money           | 3.2% (5)                      | 7.6% (12)                     | 58.3% (7)                   |
| <b>Addiction</b>                           | <b>2.1%</b>                   | <b>2.3%</b>                   | <b>45.4%</b>                |
| Gambling                                   | 0.0%                          | 0.0%                          | 0.0%                        |
| Non-prescription medicines and drugs       | 4.5% (7)                      | 3.8% (6)                      | 16.6% (1)                   |
| Alcohol                                    | 1.9% (3)                      | 3.2 (5)                       | 80% (4)                     |
| <b>Total scale score</b>                   | <b>9.5%</b>                   | <b>12.5%</b>                  | <b>40.2%</b>                |

\* Unmet needs are calculated for only those patients who report a need for care

However, when the self-report of unmet needs (i.e., no help or guidance, insufficient help or guidance or unsuitable help or guidance) is examined, a very different picture presents itself. Within the group of patients reporting a need for care, 40.2% of their needs remain unmet. Patients frequently reported a shortage of help or guidance or no help or guidance. The highest numbers of care needs were reported for the domains of psychological help (30%) and psychiatric help (25%). Fewer care needs were reported for the domains of social functioning (10.4%), financial and administrative skills (9.7%), housing and household skills (5.8%), addiction (2.3%) and daily living activities (1.1%). The five items with the highest frequency of reported care need were: timely indication of early warning signs, (57.3%), coping with grief or setbacks (35%), talking about life experiences (33.1%), identification) of which help or guidance is best (30.6%) and gaining more self-confidence (29.6%).

While the differences between the reported need for care and reported receipt of care were small for these items, a mismatch nevertheless appears to occur in many cases. That is, the high numbers of unmet needs for these items show the help received to simply not meet the needs of the particular patient on many occasions. High scores for unmet needs also occurred for a number of the other NCQ items and, for some of these items, virtually no help or guidance was reported whatsoever: 100% unmet needs for sexuality (n=12) and 85.7% unmet needs for suddenly getting angry at others (n=12). Finally, 68 or 56% of the 157 patients indicating a need for help or guidance on one or more of the items concerned with social functioning reported the need being unmet.

### ***7.3 Associations between care needs, demographic data and clinical characteristics***

The results of the analyses of the associations between the demographic characteristics, clinical characteristics and reported care needs of the patients are presented in Table 3. No significant differences were found at a general scale level between those patients reporting care needs and those patients reporting no care needs. However, for two of the seven scales, statistical analysis was not possible because too few patients reported care needs. Only 11 patients reported care needs for the daily living activities scale and 10 patients for the addiction scale.

**Table 3: Care versus no care need, demographic characteristics and clinical characteristics per care need scale and for total**

|  | Psychological help |                      |              | Psychiatric help   |                      |               | Social functioning |                      |              |
|--|--------------------|----------------------|--------------|--------------------|----------------------|---------------|--------------------|----------------------|--------------|
|  | Care need<br>n=88  | No care need<br>n=69 | P            | Care need<br>n=107 | No care need<br>n=50 | P             | Care need<br>n=68  | No care need<br>n=89 | P            |
| Sex (females): n.                      | 61 69.3%           | 41 59.4%             | 0.197        | 73 68.2%           | 29 58%               | 0.211         | 46 67.6%           | 56 62.9%             | 0.539        |
| Age: mean (s.d)                        | 47.8 (11.8)        | 46.4 (11.6)          | 0.477        | 46.8 (11.2)        | 47.9 (12.9)          | 0.590         | 46.7 (11.7)        | 47.6 (11.8)          | 0.624        |
| Household (single): n                  | 26 29.5%           | 12 17.4%             | 0.078        | 28 26.2%           | 10 20.0%             | 0.411         | 18 26.5%           | 20 22.5%             | 0.562        |
| Income: n.                             |                    |                      |              |                    |                      |               |                    |                      |              |
| • None                                 | 11 12.5%           | 7 10.1%              | 0.646        | 10 9.3%            | 8 16.0%              | 0.233         | 7 10.3%            | 11 12.4%             | 0.687        |
| • Employed                             | 27 30.7%           | 28 40.6%             | 0.215        | 38 35.5%           | 17 34.0%             | 0.822         | 20 29.4%           | 35 39.3%             | 0.179        |
| • Self-employed                        | 3 3.5%             | 9 13.0%              | <b>0.024</b> | -                  | -                    | -             | 3 4.4%             | 9 10.1%              | 0.183        |
| • Social welfare                       | 41 46.6%           | 21 30.4%             | <b>0.034</b> | 46 43.0%           | 16 32.0%             | 0.175         | 34 50.0%           | 28 31.5%             | <b>0.015</b> |
| • Retired                              | 8 9.1%             | 6 8.7%               | 0.931        | -                  | -                    | -             | 7 10.3%            | 7 7.9%               | 0.597        |
| • Middle school: n.                    | 49 55.7%           | 39 56.5%             | 0.980        | 59 55.1%           | 29 58.0%             | 0.783         | 37 54.4%           | 51 57.3%             | 0.795        |
| • High school: n.                      | 34 38.6%           | 24 34.8%             | 0.620        | 38 35.5%           | 20 40.0%             | 0.587         | 26 38.2%           | 32 36.0%             | 0.769        |
| • University: n.                       | 17 19.3%           | 15 21.7%             | 0.709        | 22 20.6%           | 10 20.0%             | 0.935         | 13 19.1%           | 19 21.4%             | 0.731        |
| Diagnosis (bipolar 1): n.              | 62 70.5%           | 43 62.3%             | 0.233        | 74 69.2%           | 31 62.0%             | 0.352         | 49 72.1%           | 56 62.9%             | 0.107        |
| Mood state: mean (s.d.)                | 50.2 (9.57)        | 50.7 (7.57)          | 0.764        | 50.6 (9.00)        | 50.1 (8.18)          | 0.770         | 49.0 (9.60)        | 51.5 (7.80)          | 0.073        |
| Number of episodes (last year)         |                    |                      |              |                    |                      |               |                    |                      |              |
| • (Hypo)mania: mean (s.d.)             | 1.86 (6.72)        | 0.64 (1.68)          | 0.142        | 1.57 (6.20)        | 0.80 (1.37)          | 0.387         | 1.06 (1.84)        | 1.53 (6.70)          | 0.575        |
| • Depression: mean (s.d.)              | 1.60 (3.78)        | 0.80 (1.96)          | 0.110        | 1.40 (3.46)        | 0.92 (2.24)          | 0.371         | 1.31 (1.75)        | 1.20 (3.87)          | 0.834        |
| Number of hospitalizations during life |                    |                      |              |                    |                      |               |                    |                      |              |
| • Due to (hypo)mania: mean (s.d.)      | 1.37 (1.58)        | 0.87 (1.44)          | <b>0.043</b> | 1.25 (1.53)        | 0.94 (1.53)          | 0.249         | 1.31 (1.53)        | 1.02 (1.53)          | 0.252        |
| • Due to depression: mean (s.d.)       | 1.16 (2.56)        | 0.83 (1.81)          | 0.360        | 1.08 (2.51)        | 0.86 (1.61)          | 0.564         | 1.37 (2.87)        | 0.74 (1.60)          | 0.085        |
| CPN involvement in treatment           | 57 64.8%           | 31 44.9%             | <b>0.013</b> | 68 63.6%           | 20 40.0%             | <b>0.006</b>  | 43 63.2%           | 45 50.6%             | 0.113        |
| Number of personal contacts (1/2 yr)   |                    |                      |              |                    |                      |               |                    |                      |              |
| • Psychiatrist: mean (s.d.)            | 4.28 (4.32)        | 3.01 (3.46)          | <b>0.050</b> | 4.07 (4.08)        | 2.98 (3.75)          | 0.114         | 4.36 (4.06)        | 3.24 (3.91)          | 0.083        |
| • CPN (n = 88): mean (s.d.)            | 6.14 (4.88)        | 4.00 (5.28)          | 0.060        | 5.75 (4.89)        | 4.15 (5.72)          | <b>0.014*</b> | 6.70 (5.33)        | 4.13 (4.58)          | <b>0.018</b> |
| • Group psycho-education: n.           | 16 18.2%           | 12 17.4%             | 0.898        | 18 16.8%           | 10 20.0%             | 0.628         | 12 17.7%           | 16 18.0%             | 0.957        |
| • Cognitive Behaviour Therapy: n.      | 15 17.4%           | 12 17.4%             | 0.955        | 17 15.9%           | 10 20.0%             | 0.525         | 12 17.7%           | 15 16.9%             | 0.896        |
| • Life chart: n.                       | 25 28.4%           | 25 36.2%             | 0.937        | 31 29.0%           | 14 28.0%             | 0.900         | 20 29.4%           | 25 28.1%             | 0.856        |
| • Action plan: n.                      | 32 36.4%           | 27 39.1%             | 0.722        | 40 37.4%           | 19 38.0%             | 0.941         | 27 39.7%           | 32 36.0%             | 0.631        |

**Bold: p ≤ 0.050** \* Mann Whitney test

|  | Housing and household skills |                       |       | Financial and administrative skills |                       |              | Total              |                      |        |
|--|------------------------------|-----------------------|-------|-------------------------------------|-----------------------|--------------|--------------------|----------------------|--------|
|  | Care need<br>n=48            | No care need<br>n=109 | P     | Care need<br>n=39                   | No care need<br>n=118 | P            | Care need<br>n=125 | No care need<br>n=32 | P      |
| Sex (females): n                       | 33 68.8%                     | 69 63.3%              | 0.510 | 25 64.1%                            | 77 65.3%              | 0.896        | 82 65.6%           | 20 62.5%             | 0.743  |
| Age: mean (s.d)                        | 49.4 (12.6)                  | 46.2 (11.3)           | 0.117 | 45.1 (10.7)                         | 47.9 (12.0)           | 0.193        | 48.2 (11.8)        | 44.1 (11.2)          | 0.097  |
| Household (single): n                  | 9 18.8%                      | 29 26.6%              | 0.290 | 12 30.8%                            | 26 22.0%              | 0.270        | 29 23.2%           | 9 28.1%              | 0.562  |
| Income: n.                             |                              |                       |       |                                     |                       |              |                    |                      |        |
| • None                                 | 2 4.2%                       | 16 14.7%              | 0.057 | -                                   | -                     | -            | -                  | -                    | -      |
| • Employed                             | 14 29.2%                     | 41 37.6%              | 0.289 | 13 33.3%                            | 42 35.6%              | 0.772        | 43 34.4%           | 12 37.5%             | 0.766  |
| • Self-employed                        | -                            | -                     | -     | -                                   | -                     | -            | -                  | -                    | -      |
| • Social welfare                       | 23 47.9%                     | 39 35.8%              | 0.123 | 21 53.8%                            | 41 34.8%              | <b>0.025</b> | 51 40.8%           | 11 34.4%             | 0.486  |
| • Retired                              | -                            | -                     | -     | -                                   | -                     | -            | -                  | -                    | -      |
| • Middle school: n.                    | 29 60.4%                     | 59 54.1%              | 0.381 | 21 53.8%                            | 67 56.8%              | 0.870        | 67 53.6%           | 21 65.6%             | 0.238  |
| • High school: n.                      | 16 33.3%                     | 42 38.5%              | 0.534 | 18 46.2%                            | 40 33.9%              | 0.169        | 45 36.0%           | 13 40.6%             | 0.629  |
| • University: n.                       | 8 16.6%                      | 24 22.0%              | 0.443 | 10 25.6%                            | 22 18.6%              | 0.347        | 24 19.2%           | 8 25.0%              | 0.467  |
| Diagnosis (bipolar 1): n.              | 32 66.7%                     | 73 67%                | 0.961 | 25 64.1%                            | 80 67.8%              | 0.770        | 83 66.4%           | 22 68.8%             | 0.939  |
| Mood state: mean (s.d.)                | 48.5 (9.16)                  | 51.3 (11.3)           | 0.068 | 48.2 (8.97)                         | 51.1 (8.55)           | 0.072        | 50.75 (8.87)       | 49.31 (8.16)         | 0.407  |
| Number of episodes (last year)         |                              |                       |       |                                     |                       |              |                    |                      |        |
| • (Hypo)mania: mean (s.d.)             | 1.17 (2.36)                  | 1.39 (6.02)           | 0.801 | 0.82 (1.14)                         | 1.49 (5.93)           | 0.485        | 1.49 (5.76)        | 0.69 (1.28)          | 0.437  |
| • Depression: mean (s.d.)              | 1.44 (2.70)                  | 1.17 (3.31)           | 0.617 | 1.10 (1.42)                         | 1.30 (3.53)           | 0.739        | 1.34 (3.33)        | 0.88 (2.16)          | 0.452  |
| Number of hospitalizations during life |                              |                       |       |                                     |                       |              |                    |                      |        |
| • Due to (hypo)mania: mean (s.d.)      | 0.98 (1.08)                  | 1.22 (1.70)           | 0.282 | 1.11 (1.64)                         | 1.16 (1.50)           | 0.843        | 1.12 (1.47)        | 1.25 (1.77)          | 0.676  |
| • Due to depression: mean (s.d.)       | 1.27 (1.96)                  | 0.90 (2.38)           | 0.344 | 1.58 (3.64)                         | 0.83 (1.56)           | 0.226        | 1.05 (2.39)        | 0.88 (1.66)          | 0.701  |
| CPN involvement in treatment           | 31 64.6%                     | 57 52.3%              | 0.153 | 27 69.2%                            | 61 51.7%              | 0.056        | 74 59.2%           | 14 43.8%             | 0.116  |
| Number of personal contacts (1/2 yr)   |                              |                       |       |                                     |                       |              |                    |                      |        |
| • Psychiatrist: mean (s.d.)            | 3.98 (3.77)                  | 3.61 (4.11)           | 0.595 | 4.29 (4.13)                         | 3.53 (3.96)           | 0.313        | 3.85 (3.72)        | 3.22 (4.51)          | 0.431  |
| • CPN (n = 88): mean (s.d.)            | 5.94 (4.93)                  | 5.09 (5.20)           | 0.460 | 6.26 (5.09)                         | 5.00 (5.09)           | 0.063*       | 5.54 (4.78)        | 4.57 (6.69)          | 0.065* |
| • Group psycho-education: n.           | 10 20.8%                     | 18 16.5%              | 0.515 | 12 30.8%                            | 16 13.6%              | <b>0.015</b> | 20 16.0%           | 8 25.0%              | 0.235  |
| • Cognitive Behaviour Therapy: n.      | 8 16.7%                      | 19 17.4%              | 0.907 | 9 23.1%                             | 18 15.3%              | 0.262        | 21 16.8%           | 6 18.8%              | 0.796  |
| • Life chart: n.                       | 15 31.3%                     | 30 27.5%              | 0.634 | 16 41.0%                            | 29 24.6%              | <b>0.049</b> | 34 27.2%           | 11 34.4%             | 0.423  |
| • Action plan: n.                      | 18 37.5%                     | 41 37.6%              | 0.989 | 15 38.5%                            | 44 37.3%              | 0.896        | 44 35.2%           | 15 46.9%             | 0.224  |

**Bold:** p ≤ 0.050 \* Mann Whitney test

Within the specific NCQ scale of psychological help and exploration, significant differences were detected for the care needs of those patients who are self-employed and those patients on welfare. Self-employed patients were represented least in the group of patients reporting a need for such help while patients on welfare were represented most in this group. A significant association between the number of admissions to a mental health institution on account of (hypo)mania and the frequency of reported care needs was also detected for the psychological help scale. Similarly, CPNs and psychiatrists were significantly more involved in the treatment of patients reporting psychological care needs than in the treatment of patients reporting no such needs.

For the psychiatric help scale, significant associations were detected between the involvement of CPNs in treatment and personal contact with a CPN, on the one hand, and reported care needs of the patients, on the other hand.

With regarding to social functioning, patients on welfare reported a significantly greater need for care. Those patients reporting more of a need for care in the domain of social functioning also reported more frequent contact with a CPN than those patients reporting less of a need for care in the domain of social functioning.

For housing and household skills, no significant associations between the care needs of the patients and their demographic or clinical characteristics were found.

A significant difference between the need for help or guidance with regard to financial and administrative skills versus no such need was detected for those patients on social welfare in particular. Similarly, a greater need for help or guidance with regard to financial and administrative skills significantly related to greater participation in group psycho-education and greater use of a life chart methodology to help prevent relapse.

## **8. Discussion**

To our knowledge, this is the first study to quantitatively examine the care needs of a population of outpatients with a bipolar disorder. When the results are compared to those for a population of patients suffering from severe mental illness and receiving long-term hospital or outpatient care (Kroon, 2003), relatively fewer care needs are reported by our population of outpatients with a bipolar disorder (12.5% versus 39%). It can be asked, of course, if our sample is representative of the population under investigation. It is possible, for example, that only patients with a stable mental condition and euthymic mood state were approached by the psychiatrist or CPN for participation in the present study. Patients with a high illness burden may not choose to participate in the study due to a fear that an

interview could destabilize their mood and also may be talked out of participation by relatives for a similar reason.

Our study sample was drawn from a population of outpatients, which means that the present results do not necessarily apply to all individuals living with a bipolar disorder. It is well-documented, for example, that many patients with a bipolar disorder withdraw from treatment or do not pursue further treatment following acute episodes of depression or (hypo)mania (Ten Have et al., 2002). Only those patients who are highly motivated for treatment maintenance thus become outpatients and may have participated in the present study. The use of a quantitative design results in a clear overview of the findings. It can be asked, if the use of a qualitative design could have revealed more in depth information about underlying factors influencing the care needs and the fulfilment of them.

The number of respondents reporting care needs for substance abuse and addiction was relatively low in the present study while substance abuse and particularly alcohol problems are quite common among patients with a bipolar disorder (Lawson & Bland, 2004). Many such patients use alcohol and/or drugs as self-prescribed medication while they are untreated (Ten Have et al., 2002). It is also possible that such patients do not report problems with substance abuse or addiction simply because they do not perceive their use of alcohol and/or drugs as problematic. Nurses appear to be particularly involved in the treatment of outpatients with care needs in the domains of psychological and psychiatric help but also in the domain of financial and administrative skills although the latter domain did not show clearly significant results. No other significant differences for the involvement of nurses were found although the constituent items for the other scales certainly fall within the scope of community psychiatric nursing.

It should be noted that we performed multiple tests and calculated the statistical significance of 134 comparisons. The conduct of multiple tests increases the risk of chance significance. We identified 12 significant associations using a probability level of 0.05 or less. When a total absence of associations between the various demographic, clinical and care variables is assumed, the conduct of 134 tests can be expected to produce six or seven chance findings with a significant level of 0.05 or less. When a stricter significance level of 0.01 or less is applied to our data, only one significant difference is detected, which is comparable to what one can expect to find on the basis of chance. This means that the results of our exploratory analyses should be treated with utmost care and attempts to validate the findings should certainly be made in future studies.

## 9. Conclusions

The results of the present study show the care needs of outpatients with a bipolar disorder to mainly occur in the domains of psychological help, psychiatric help and social functioning. Closer inspection of the items constituting these scales shows most of them to address coping with the consequences of the disease or the skills needed for self-management of the disease. A very important skill for patients with a bipolar disorder, for example, is to identify early warning signs and thereby prevent mood destabilization and relapse. And help with this item is by far the most frequently reported care need. Life charts and action plans (Denicoff et al., 2000; Goossens et al., 2008) are among the most important relapse prevention techniques but reported to be used by only 28.7% and 37.6% of the outpatients, respectively.

Unmet needs were frequently reported for all of the scales and almost all of the items in this study. It is possible that the care needs of outpatients go largely unmet because little attention is paid to the structured assessment of their needs during treatment. That is, many of the needs of the patient with a bipolar disorder remain unnoticed. An important point for improvement is therefore to incorporate the assessment of patient care needs into the treatment process. Identification of individual needs on the basis of such standardized questionnaires as the NCQ, which is only available in Dutch at this moment, or the Camberwell Assessment of Needs (CAN) (Phelan et al., 1995) can be of great value. The results of such an assessment can help tailor the CPN's involvement in the treatment process more to the actual needs of the patient. CPNs should regularly evaluate the status of the patient's needs. The results of repeated assessment can be considered an outcome indicator and thus used to evaluate the quality of the care provided (Wiersma, 2006).

The results of the present exploratory analysis of the relations between various demographic characteristics, clinical characteristics and the care needs of outpatients with a bipolar disorder revealed very few findings of relevance for the treatment process. The only clear conclusion is that patients on social welfare and patients with a higher number of hospitalizations due to (hypo)mania appear to have 1) relatively greater care needs and 2) relatively greater involvement of the CPN in the treatment process.

**10. Future research**

Future research should focus on the identification of specific risk factors for the occurrence of particular care needs. CPNs should then be informed about such risk factors in order to help prevent their occurrence and intervene when they do occur. Studies using mixed methods with patients who have recently been diagnosed as having a bipolar disorder can also provide insight into the emergence of particular care needs and those factors which appear to play a role in the emergence of such care needs during the illness process.

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## **Chapter 5**

### **Coping styles of outpatients with a bipolar disorder**

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**Abstract**

Patients with a bipolar disorder need to cope with the problems they encounter, the consequences of their disease, and unpleasant events in order to stay well. This study was undertaken to gain greater insight into the coping styles of outpatients with a bipolar disorder when confronted with problems and unpleasant events. The participants (n=157) completed the Utrecht Coping List and a questionnaire addressing various demographic and clinical characteristics. The results showed outpatients with a bipolar disorder to have a less active reaction pattern and more avoidant coping style than people from the general population.

## 1. Introduction

Patients with a bipolar disorder must overcome many challenges in order to lead a healthy and stable life. Bipolar disorder is a complex and chronic psychiatric illness characterized by alternations of depressive, (hypo)manic, and possibly mixed episodes with lifetime prevalence rates estimated to be 1.5% to 2% for the European Union (Pini et al., 2005). The objectives of therapy in cases of bipolar disorder are generally to alleviate the acute episodic symptoms, restore psychosocial functioning, and prevent recurrence to the greatest extent possible (Scott & Colom, 2005). A combination of pharmacological treatment strategies and psychosocial interventions has been recommended in recent studies (Bernhard et al., 2006; Miklowitz, 2006; Scott et al., 2005). Patients with a bipolar disorder and their relatives are confronted with a lifelong disease that has significant ramifications for their lifestyles. Bipolar disorder is associated with a considerable degree of illness-related morbidity, profound suffering, occupational impairments, and social burden (Abood et al., 2002; Vornik & Hirschfeld, 2005; Bowden, 2005; Depp et al., 2006; Sajatovic, 2005). The patient and family are faced with a situation in which they need to develop strategies to stay well and avoid relapses of (hypo)mania and depression (Russell & Browne, 2005).

Bipolar disorder can be compared to other long-term illnesses such as diabetes or arthritis in that patients must be prepared to cope with the illness via the application of various self-management techniques (Finkelman, 2000; Barlow et al., 2002). Early recognition of the symptoms of episode along with the development and use of action plans are among the self-management techniques already documented for patients with a bipolar disorder (Goossens et al., 2008; Morris, 2004; Perry et al., 1999). In the development of action plans, patients learn to assess their own behavior, recognize prodromal symptoms, and take actions in order to prevent the occurrence of acute episodes of depression and/or (hypo)mania. The use of action plans are examples of so-called problem-focussed coping strategies as defined by Lazarus et al. (1980). Problem-focussed coping strategies are actions to identify or change the effects of events, stress, illness, or the cognitive activities generated by events, stress, or illness. In contrast, emotion-focussed coping strategies are actions to change or control the feelings and emotional states generated by events, stress, or illness (Lazarus et al., 1980).

Coping is a complex process. It is variously described as a situational and as a trait-like response, as a response to stress and as a disposition to respond to change. (Beutler & Moos, 2003; Meijer et al., 1992; Lazarus et al., 1980). While Scheurs et al. (1993) refer to coping as a personality style, this does not mean that

coping strategies are static characteristics of the individual. People may have preferences for a particular forms or mixture of forms for coping, in most circumstances or situations; the coping style. *Ineffective individual coping*, a nursing diagnosis accepted by the North American Nursing Diagnosis Association (NANDA) in 1978 and revised in 1998, is then defined as an impairment of adaptive behaviours and problem-solving abilities of a person in meeting life's demands and roles. Ineffective individual coping has been found to be associated with decreased psychological well-being and social functioning (Mcfarland & Mcfarlane, 1997).

In the research literature, only four publications on the coping strategies of patients with a bipolar disorder were found. In 1997, a paper was published on prodromes, coping strategies, insight, and social functioning in patients with a bipolar affective disorder. The authors concluded that social functioning related to level of insight, how well the patients (n=40) coped with the prodromes of mania, and if the patients could detect the prodromes of depression or not (Lam & Wong, 1997). In 2001, the same authors published a second paper on the same 40 patients as in the 1997 study. The authors concluded that the patients with a bipolar disorder were able to reliably report prodromal symptoms and that those patients who reported the use of behavioral coping strategies while experiencing prodromal symptoms reported significantly fewer manic episodes or depressive relapses (Lam et al., 2001). In 2005, the same authors published a review article in which it was concluded that empirical evidence clearly exists for the beneficial effects of psychosocial interventions with elements that promote the early detection of prodromes and adaptive coping in cases of bipolar disorder (Lam & Wong, 2005). In the fourth publication on the coping of patients with a bipolar disorder (n=32), coping and adherence to medication regimes were examined. Both acceptance and denial as coping strategies were found to relate to adherence. Low levels of acceptance and high levels of denial appeared to undermine adherence to medication regimes (Greenhouse et al., 2000).

All of the above studies had small sample sizes and a limited focus on patient coping. No comprehensive studies of patients with a bipolar disorder and their coping styles when confronted with daily life problems or problems directly related to the disorder were found. The aim of the present study was therefore to identify the coping styles used by outpatients with a bipolar disorder when they encounter problematic situations. An additional aim of the present study was to investigate the possible associations between various demographic and clinical characteristics of the study population and reported coping styles.

## **2. Methods**

The present study followed a quantitative cross-sectional research design. That means that data were collected at one moment in time.

### **2.1 Subjects**

The subject selection criteria included: psychiatric outpatient diagnosed with a bipolar disorder using the DSM-IV criteria (American Psychiatric Association, 2005), older than 18 years of age, and able to complete an interview. Two norm groups were used to compare the results with. These were obtained from the publisher of the Utrecht Coping List (UCL). The first norm group (n=1493) consists of 1075 male employees of the Dutch Railway Association and an a-selective sample from the male Dutch population. The age varies between 23 and 65 with an average of 43. The second norm group (n=712) consists of a sample of female Dutch nurses with a average age of 30 and an a-selective sample from the female Dutch population with an average age of 47. The second norm group varies in age between 18 and 65 years.

### **2.2 Setting**

The study was conducted at five psychiatric outpatient clinics in the Netherlands.

## **3. Procedure**

Between April 2005 and April 2006, outpatients with a bipolar disorder were asked by their psychiatrist or community psychiatric nurse (CPN) to participate in the present study. This was done following verification by the psychiatrist or CPN, that the patient was sufficiently stable to do this. This means that the mood state of the patient should have been stable, and that the patient had recently (prior 4 weeks) not suffered from a severe episode of mania or depression. The study aims and methods were briefly described to the patients and, when a patient indicated an interest in participation, written permission to pass the patient's name, address, and telephone number on to the researchers was attained. A written description of the study was then sent to the patients home address, and he or she was contacted one week later by telephone. The researcher again explained the aims of the study, data collection methods, and procedures to the patient and, when the patient agreed to participate, an appointment was made at the outpatient clinic where the patient was being treated. The session was conducted by the researcher or a trained research assistant and initiated by again informing the patient about the purpose of the study and assuring anonymity and confidentiality.

The study was approved by a certified medical ethics committee and by the institutional review board from the five participating organizations. All of the participating patients signed an informed consent form prior to the start of data collection, which was done using structured questionnaires.

#### **4. Measures**

Participants were asked to complete two self-administered questionnaires for the measurement of coping styles and the collection of information on various demographic and clinical characteristics.

##### **4.1 Coping styles**

Coping style was measured using the Utrecht Coping List (UCL) (Schreurs et al., 1993). The 47-item UCL is a sensitive multidimensional self-report inventory used to measure coping with problems and unpleasant events. The items of the UCL are descriptions of possible reactions to a problematic or unpleasant event. The respondent is asked to indicate along a 4-point rating scale whether he or she would generally use this response when confronted with a problematic or unpleasant event (1 = rarely or never; 4 = very often). The items are grouped into seven subscales: (1) active approach; disentangling the situation and purposefully working to solve the problem, (2) palliative reaction; seeking of distraction to not have to think about the problem, (3) avoidance; leaving the problem to what it is or running away from it, (4) seeking social support; seeking comfort and understanding from others, (5) passive reaction pattern; being totally overwhelmed by the problem, (6) expression of emotions; showing irritation and anger about the problem, and (7) reassuring thoughts; using comforting thoughts. The subscale scores are obtained by calculating the mean scores. These mean score are to be compared with scores from norm groups. It is well-documented that coping styles differ depending on such demographic factors as gender (Schreurs et al., 1993). The norm groups for the general population are therefore divided into male and female, and the study results will be presented with respect to this distinction. Internal consistency of the UCL is calculated in several occasions. Chronbach's Alpha between .67 and .82 for the seven UCL subscales were found and can be qualified as good. Construct validity of the UCL was studied by comparing the results with the results of 23 different well validated tests. Predictive validity of the UCL is described by Schaufeli & Van Dierendonk (1992). Self-efficacy, negative affect and neuroticism are strongly associated with the use of the passive reaction pattern coping style. Avoidance as a coping style leads to mental health problems

and decrease of self efficacy while coping styles active approach and seeking of social support leads to increase of self efficacy and positive affect (Schaufeli & Van Dierendonk, 1992). Validity of the Dutch version of the UCL can thus be qualified as good (Schreurs et al., 1993).

#### **4.2 Demographic and clinical data**

Information on a broad set of demographic and clinical characteristics was gathered using a researcher constructed questionnaire based on clinical knowledge, experience and literature.

Mood state was assessed using a Visual Analogue Scale which is part of the Life Chart Methodology (Denicoff et al., 2000). The Visual Analogue Scores can range from 0 (= severe depressive mood state) to 100 (= severe manic mood state). The mood state of the individual outpatient was defined as depressed, euthymic or (hypo)manic when his or her Visual Analogue Score fell between 0 - 40, 41 - 59 or 60 - 100, respectively. The patient's DSM-IV diagnosis was retrieved from patient records.

### **5. Analyses**

In order to examine the coping styles of the outpatients with a bipolar disorder, the average scores per subscale of the UCL were calculated stratified per gender. To compare the outpatient results to those for the norm groups, one sample t-tests were conducted. To explore the possible associations between the number of depressive or (hypo)manic episodes experienced during life and coping style, the following subgroups of patients were created: patients who experienced 1 to 4 (hypo)manic episodes, patients who experienced 5 to 9 (hypo)manic episodes, patients who experienced more than 10 (hypo)manic episodes, patients who experienced 0 to 4 depressive episodes, patients who experienced 5 to 9 depressive episodes, and patients who experienced more than 10 depressive episodes. In these subgroups depressive and (hypo)manic episodes were mutually exclusive. In order to explore the possible associations between the number of years diagnosed with a bipolar disorder and coping style, three subgroups of patients were created: patients diagnosed between 2001 and 2006 (n=43), patients diagnosed between 1996 and 2001 (n=33), and patients diagnosed before 1996 (n=7). The possible relations between — on the one hand — the number of (hypo)manic or depressive episodes experienced during life, the number of years living with the disease, specific DSM IV axis 1 diagnosis, and highest level of education and — on the other hand — coping style were explored

in one-way analyses of variance (ANOVA) conducted using the Bonferroni t-procedure. Finally, independent sample T-test were calculated to determine the associations of admission to a mental health hospital, the presence of an action plan, participation in psycho-educational courses, and living alone with coping style. The data were processed using the Statistical Package for the Social Sciences (SPSS 14.0 for Windows).

## **6. Results**

Of the 201 patients who initially showed an interest in study participation, 158 participated in the end (79%). Various reasons were provided for nonparticipation: fear of destabilization, depressed or (hypo)manic mood state at the time of the appointment, hospitalization, unwillingness to travel, nonmental illness at the time of the appointment, talked out of participation by relatives, or just not showing up for the appointment. One patient declined to participate further during the interview itself. This meant that this data was omitted from any further analysis.

### ***6.1 Demographic and clinical characteristics of the patients***

An overview of the demographic and clinical characteristics of the participants is presented in Table 1. More females (65%) participated in the present study than males. Some 75% of the participants lived with a partner, children, or relatives. For 15% of the participants, elementary school was the highest level of education. Almost 45% had attended high school or college. The majority of the participating patients had a euthymic mood state at the time of questionnaire administration. Of the 157 participants, 20 reported a depressed mood state, 105 reported a euthymic mood state and 29 reported a (hypo)manic mood state. Seventy-one% of the participants had been admitted to a mental health institution on at least one occasion in their lives. Almost all of the participants used mood stabilizers, with lithium used most commonly. Use of psychosocial treatment modules during the maintenance phase of treatment as recommended by practice guidelines (American Psychiatric Association, 2002) was uncommon. Only 51% of all the patients had an action plan or were developing an action plan.

**Table 1: Demographic and clinical characteristics N = 157**

|   |       | mean  | sd     |
|---|-------|-------|--------|
| Female  | 65%   |       |        |
| Age   |       | 47.24 | 11.776 |
| Living alone  | 24.2% |       |        |
| Highest level of education                          |       |       |        |
| • Elementary school (n=24)                          | 15.3% |       |        |
| • Middle school (n=61)                              | 38.9% |       |        |
| • High school (n=40)                                | 25.5% |       |        |
| • College (n=32)                                    | 20.4% |       |        |
| Diagnosis   |       |       |        |
| • Bipolar I   | 66.9% |       |        |
| • Bipolar II  | 25.5% |       |        |
| • Bipolar NOS                                       | 7.6%  |       |        |
| Number of (hypo)manic episodes during life:         |       |       |        |
| • 1 to 4 (n=88)                                     | 56,1% |       |        |
| • 5 to 9 (n=32)                                     | 20,4% |       |        |
| • 10 or more (n=37)                                 | 23,6% |       |        |
| Number of depressive episodes during life:          |       |       |        |
| • 0 to 4 (n=70)                                     | 44.6% |       |        |
| • 5 to 9 (n=27)                                     | 17.2% |       |        |
| • 10 or more (n=60)                                 | 38.2% |       |        |
| Mood stabilizer use                                 |       |       |        |
| • None  | 4.4%  |       |        |
| • Lithium   | 78.0% |       |        |
| • Carbamazepine                                     | 10.1% |       |        |
| • Valproate   | 10.1% |       |        |
| • Antipsychotic medication                          | 17.6% |       |        |
| • Lamotrigine                                       | 6.3%  |       |        |
| Number of hospitalizations during life              |       | 2.10  | 2.651  |
| Psychosocial treatment modules (present and past)   |       |       |        |
| • Group psycho-education (n=28)                     | 17.8% |       |        |
| • Cognitive behavioral therapy (n=27)               | 17.2% |       |        |
| • Interpersonal psychotherapy (n=9)                 | 5.7%  |       |        |
| • Family focused therapy (n=6)                      | 4.5%  |       |        |
| Relapse prevention techniques                       |       |       |        |
| • Life chart (present and past)                     | 28.7% |       |        |
| • Action plan (present, past, or under development) | 51%   |       |        |

## 6.2 Coping Styles

As can be seen from Table 2, the coping styles of outpatients suffering from a bipolar disorder clearly differ from the coping styles of the norm groups when confronted with problems or unpleasant events. With the exception of reassuring thoughts, the mean scores on the different coping styles for the male subpopulations differed significantly. The female subpopulations differed significantly with respect to active approach, avoidance, passive reaction pattern, and reassuring thoughts. Both the male and female patients use a less active approach to solve the problems they confront than the male and female norm groups. Male outpatients show a significantly more palliative reaction than the

male norm group, which means that they tend to undertake activities to divert themselves from the problems confronting them. Both the male and female outpatients reported avoidance significantly more frequently than their respective norm groups. Similarly, both the male and female outpatients reported a significantly more passive reaction pattern than their respective norm groups. The male outpatients also produced lower scores for the expression of emotions than the male norm group while the female outpatients produced significantly lower scores for reassuring thoughts than the female norm group.

Whereas most of the above differences show less favourable scores for the outpatients, male outpatients with a bipolar disorder nevertheless reported actively seeking social support more than the men in the norm group.

**Table 2: Coping styles**

|                          | Outpatient males<br>(n=55)    |     | Norm group males between 19 and 65 years<br>(n=1493)  |     |        |
|--------------------------|-------------------------------|-----|---|-----|--------|
|                          | mean                          | sd  | mean  | sd  | p      |
| active approach          | 16.4                          | 3.4 | 18.3  | 3.5 | .000*  |
| palliative reaction      | 16.7                          | 3.7 | 15.5  | 3.6 | .018** |
| avoidance                | 16.0                          | 3.3 | 14.8  | 3.3 | .008*  |
| seeks social support     | 13.2                          | 3.4 | 11.3  | 3.0 | .000*  |
| passive reaction pattern | 13.0                          | 4.0 | 10.7  | 2.9 | .000*  |
| expression of emotions   | 5.4                           | 1.4 | 6.2   | 1.7 | .000*  |
| reassuring thoughts      | 11.1                          | 2.6 | 11.6  | 2.5 | .184   |
|                          | Outpatient females<br>(n=102) |     | Norm group females between 19 and 65 years<br>(n=712) |     |        |
|                          | mean                          | sd  | mean  | sd  | p      |
| active approach          | 16.4                          | 3.3 | 19.3  | 5.1 | .000*  |
| palliative reaction      | 17.3                          | 3.4 | 17.3  | 6.1 | .830   |
| avoidance                | 16.0                          | 3.4 | 15.2  | 6.0 | .010*  |
| seeks social support     | 14.2                          | 3.4 | 14.5  | 4.9 | .546   |
| passive reaction pattern | 12.9                          | 4.0 | 10.9  | 5.4 | .000*  |
| expression of emotions   | 6.1                           | 1.6 | 6.4   | 2.3 | .071   |
| reassuring thoughts      | 11.5                          | 2.3 | 12.1  | 3.8 | .031** |

\* mean difference is significant at .01 level (two-tailed)

\*\* mean difference is significant at .05 level (two-tailed)

### **6.3 Demographic and clinical characteristics in relation to coping style**

No significant differences in coping styles were found between those patients who had been admitted to a mental health hospital on at least one occasion and those patients who had not. Similarly, no significant differences in coping style were found between patients who were living alone versus living with others or those patients with DSM IV axis 1 diagnoses along the bipolar disorder spectrum.

**Table 3: Relations between coping style and number of (hypo)manic or depressed episodes during course of outpatient's life (ANOVA analysis used)**

| Coping style             | Number of (hypo)manic episodes during life |      |                   |     |                       |     |        |
|--------------------------|--|------|-------------------|-----|-----------------------|-----|--------|
|                          | 1 to 4<br>(n= 88)                          |      | 5 to 9<br>(n= 32) |     | 10 or more<br>(n= 37) |     |        |
|                          | mean                                       | sd   | mean              | sd  | mean                  | sd  | p      |
| active approach          | 16.6                                       | 3.5  | 16.4              | 3.2 | 16.0                  | 3.3 | .706   |
| palliative reaction      | 16.8                                       | 3.3  | 17.0              | 3.0 | 18.0                  | 4.1 | .195   |
| avoidance                | 15.5                                       | 3.1  | 16.6              | 3.4 | 16.9                  | 3.8 | .063   |
| seeks social support     | 14.1                                       | 3.6  | 13.3              | 3.3 | 13.9                  | 2.9 | .524   |
| passive reaction pattern | 12.1                                       | 3.5  | 12.5              | 3.7 | <b>15.2</b>           | 4.4 | .000*  |
| expression of emotions   | 5.6  | 1.5  | 6.1               | 1.4 | 6.1                   | 1.8 | .176   |
| reassuring thoughts      | 11.3                                       | 2.6  | 12.1              | 1.7 | 11.0                  | 2.4 | .141   |
|                          | Number of depressed episodes during life   |      |                   |     |                       |     |        |
|                          | 0 to 4<br>(n= 70)                          |      | 5 to 9<br>(n= 27) |     | 10 or more<br>(n= 60) |     |        |
|                          | mean                                       | sd   | mean              | sd  | Mean                  | sd  | p      |
| active approach          | 17.1                                       | 3.2  | 16.8              | 2.8 | 15.4***               | 3.5 | .014** |
| palliative reaction      | 16.9                                       | 3.3  | 16.6              | 2.7 | 17.6                  | 3.9 | .424   |
| avoidance                | 15.7                                       | 3.0  | 15.2              | 3.3 | 16.8                  | 3.7 | .066   |
| seeks social support     | 14.0                                       | 3.8  | 14.0              | 3.0 | 13.6                  | 3.1 | .750   |
| passive reaction pattern | 11.6                                       | 3.3  | 12.1              | 3.5 | <b>14.9</b>           | 4.1 | .000*  |
| expression of emotions   | 5.8  | 1.55 | 6.1               | 1.3 | 5.8                   | 1.7 | .546   |
| reassuring thoughts      | 11.7                                       | 2.4  | 11.7              | 2.2 | 10.9                  | 2.3 | .094   |

\*.  $p \leq .01$ \*\*.  $p \leq .05$ **Bold:** The mean difference is significant at the .05 level

\*\*\*. The mean difference is significant at the .05 level with the mean difference of the 0 to 4 group but not with 5 to 9 group

The use of an active coping style differed significantly for patients with an action plan ( $n=80$ ) versus patients with no such plan ( $n=77$ ) ( $16.9 \pm 3.2$  vs.  $15.8 \pm 3.4$ ;  $p=.047$ ).

Patients who followed a group psycho-education course ( $n=28$ ) are using a more passive coping style than those patients who did not follow such a course ( $n=129$ ). The difference is found to be statistically different ( $14.4 \pm 3.3$  vs.  $12. \pm 4.0$ ;  $p=.031$ ). Similarly, patients who had received cognitive behavioral therapy ( $n=27$ ) in the past or currently use a significantly more avoidant coping style than patients who had not received such therapy ( $n=130$ ) ( $17. \pm 3.1$  vs.  $15.5 \pm 3.3$ ;  $p=.013$ ). These patients also use a significantly more passive coping style ( $14.6 \pm 3.3$  vs.  $12.6 \pm 4.0$ ;  $p=.019$ ). The use of a more active coping style also differed significantly for patients with a college education versus patients with only an elementary education ( $17.93 \pm 2.9$  vs.  $15.16. \pm 3.2$ ;  $p=.014$ ).

When the coping style results were examined with respect to the number of depressive or (hypo)manic episodes experienced by the outpatients during the life course (Table 3), some clearly significant differences were discovered. For an

active coping style, the group of patients who had suffered 10 or more depressive episodes differed significantly from the group of patients who had suffered 0 to 4 depressive episodes (but not the group of patients who had suffered 5 to 9 episodes). Within the groups of patients who had suffered 10 or more depressive or 10 or more (hypo)manic episodes, those patients who had suffered relatively fewer depressive or (hypo)manic episodes showed less of a preference for a passive coping style ( $p \leq .01$ ). Only one significant difference was further found between coping style and the number of years since diagnosis with a bipolar disorder. Patients who were diagnosed between 2001 and 1996 showed a greater preference for an avoidant coping style than patients diagnosed between 2006 and 2001 ( $17.1 \pm 3.9$  vs.  $15.1 \pm 2.9$ ;  $p = .026$ ).

## 7. Discussion

To our knowledge, this is the first study to quantitatively examine the coping styles of a population of outpatients with a bipolar disorder. The results should nevertheless be considered in light of some possible methodological limitations. While the use of the psychometrically sound UCL to measure coping styles and a sufficiently large sample size make this study thorough, it should be mentioned that all of the data were self-report data, which increases the risk of social-desirability bias. It is also possible that the mood states of the different patients at the time of data collection may have influenced the results. Although the patients were explicitly instructed to report how they would react in general when problems or unpleasant events would occur, the participants with a (hypo)manic mood state at the time of data collection could overestimate their coping abilities while the participants with a depressed mood state at the time of data collection could possibly underestimate their coping abilities. Furthermore, the question of whether our sample is representative of the population under investigation can be raised. It is possible, for example, that only patients with a good mental condition and euthymic mood state were approached by the psychiatrist or CPN to participate in the present study. Patients with a high illness burden may have opted not to participate in the present study due to a fear that such participation and an interview would destabilize their mood state, or relatives may have discouraged from participation for similar reasons. Our study sample was drawn from a population of clinic outpatients, which means that the present results do not necessarily apply to all individuals living with a bipolar disorder. It is well-documented, for example, that many people with a bipolar disorder do not pursue further treatment following acute episodes of depression or (hypo)mania (Ten

Have et al., 2002). Only those patients who are highly motivated for treatment maintenance may continue with outpatient treatment and thus may have participated in the present study.

Coping is known to be a complex process that includes assessment of all factors influencing a problematic situation, including one's own role within the situation. Depending on the strengths and limitations of the person involved, particular response choices must be made. Mostly, a mixture of behaviours is needed. The next step in the coping process is evaluating the situation and if necessary, intervening again until the problem or situation is solved or bearable (Roodbol & Rutgers, 2005). Although the results of the present study show that patients who had experienced 10 or more acute episodes of depression and/or 10 or more episodes of (hypo)mania during the course of their lives to report the use of a passive coping style significantly more often than patients who had experienced fewer acute episodes of depression and/or (hypo)mania, causal claims cannot be made. Is it the lack of sufficient problem-solving skills that allow problems of patients to overwhelm them and thereby induce additional acute episodes of depression or (hypo)mania? Or have those patients who have experienced numerous acute episodes loss of self-esteem and given up hope?

The study results show that outpatients who use or used an action plan uses a more active coping style. According to the study of Schaufeli & van Dierendonk (1992) on the predictive validity of UCL, these patients could have increased self efficacy and increased positive affect. In the study of Perry et al. (1999), it was found that using an action plan significantly increased time to the next manic relapse, improved social functioning and performance to employment but did affect depressive relapses.

In our study, we found that those patients who had CBT used more passive and avoiding coping styles. We did not find a logical explanation for this in our analysis. Maybe, only patients who already use a passive and avoiding coping style were referred to this psychotherapy and perhaps, the CBT had no effect on the coping style.

In order to use the different coping styles in a mixture that is adapted to the problem and the context in which the problem occurs, patients need to master the required skills such as; disentangling the problematic situation, remaining calm, asking for support, and making deliberate choices. Nurses should support the patient in obtaining these skills. In an earlier study of what CPNs actually do during the nursing of outpatients with a bipolar disorder in the Netherlands (Goossens et al. 2008), the nursing process as carried out by the CPNs was found to lack a

systematic approach. Nevertheless, when the problem of ineffective coping was addressed, the following nursing interventions and activities were found to be most promising. In general, a long term and close therapeutic relationship (characterized by an open, interested, and concerned but empowering attitude on the part of the nurse) should be established with the patient and his or her relatives along with adequate accessibility. Nurses should also provide information and education on the disorder, incrementally. At the same time, the nurses should provide support for the development of adequate problem-solving strategies and teach the patient how to develop and use an action plan and also evaluate this regularly. An example of a specific supportive nursing intervention for developing skills can be found in the area of teaching contra behaviour. This means that patients with a depressed mood state are encouraged to behave as if they were hypomanic and vice versa. Nurses should address the patient as an equal, use clear and understandable language, and avoid judging the patient. The nurse should also try to match the perceptions of the patient. The nurse should know the strengths and weaknesses of her patients and also their support systems in order to appropriately advise them with regard to learning how to cope with particularly problematic and/or unpleasant situations (conflicts, bad luck etc) .

## **8. Conclusions**

In the present study, the coping styles used by outpatients with a bipolar disorder in the Netherlands were examined. The outpatients were generally found to report using a less active, more passive, and more avoidant coping style when confronted with problems or unpleasant events than people in the general population. In addition, the coping styles of the outpatients also differed somewhat from the normal population depending on gender. Male outpatients were better able to undertake activities to provide diversion (a palliative reaction), openly express their emotions, and seek social support than the males in the norm group. Female outpatients, in contrast, tended to use fewer reassuring thoughts than the females in the norm group. Although causality cannot be assumed, active coping styles appear to occur relatively more often in patients who already have or are developing action plans to cope with the prodromal symptoms related to their disorder and in patients with higher educational levels. A passive coping style, in contrast, appears to be related to frequent acute episodes of depression and/or (hypo)mania.

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## **Chapter 6**

### **Self-reported psychopathological symptoms and quality of life in outpatients with a bipolar disorder**

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**Abstract**

*Background:* Growing evidence exists that patients with a bipolar disorder in a euthymic mood state can suffer from subsyndromal or residual symptoms of depression or hypomania causing considerable burden and functional impairment. This study was undertaken to gain insight into the broader spectrum of psychopathological symptoms and quality of life associated with a bipolar disorder.

*Method:* Participants (n=157) completed the SCL-90, the WHOQOL-Bref and a questionnaire addressing demographic and clinical characteristics.

*Results:* Outpatients with a bipolar disorder reported more symptoms of psychopathology than the general population but a comparable number of symptoms to patients visiting their general practitioner. Outpatients with a bipolar disorder reported fewer symptoms of psychopathology than psychiatric outpatients in general. Relative to the general population, a significantly lower quality of life was reported. The number of symptoms of psychopathology also showed consistently negative correlations with the quality of life for the outpatients.

*Conclusions:* Outpatients with a bipolar disorder suffer from a broad range of psychopathological symptoms which greatly impact their lives. The more psychopathological symptoms reported, the lower the quality of life. Symptoms of depression appear to be the most important cause of a decreased quality of life for outpatients living with a bipolar disorder.

## 1. Introduction

Bipolar disorder, which is also known as manic depressive illness, is a recurrent and long term mental illness which can seriously affect the lives of patients and their relatives. It is characterized by the alternating occurrence of manic, hypomanic, depressive, and possibly mixed episodes. Bipolar disorder has been estimated to have a life time prevalence rate of 1.5 – 2.0% in the European Union (Pini et al., 2005). The prevalence rate may rise to 5% or higher with more sensitive detection of hypomania (Angst, 2007; Angst & Cassano, 2005). Although in remission, patients may suffer from subsyndromal or residual symptoms (Gitlin et al., 1995). And while subsyndromal hypomanic symptoms appear to enhance functioning, subsyndromal depressive symptoms can lead to impairment and disability (Altshuler et al., 2006; Judd et al., 2005; Lim et al., 2004).

It is well-documented that bipolar disorder greatly impacts quality of life (QOL) (Hakkaart et al., 2004; Michalak et al., 2006; Michalak et al., 2005; Sierra et al., 2005). The World Health Organization defines QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to the goals, expectations, standards, and concerns (The WHOQOL group, 1994). The QOL ratings for patients with a bipolar disorder are similar to those for patients with a unipolar depression but higher than for patients with schizophrenia. (Dean et al., 2004; Michalak et al., 2005; Sierra et al., 2005). Patients with a bipolar disorder, moreover, can have QOL impairments even when they are symptom free and in a stable euthymic mood state (Fagiolini et al., 2005; Robb et al., 1997). The QOL impairments under such circumstances clearly exceed those for the general population and are often comparable to or greater than the QOL impairments associated with other chronic nonmental health-related disorders.

When Vojta et al. (2001) investigated the self-reported QOL for 86 outpatients with a bipolar disorder across mood states, the QOL during a (hypo)manic episode was significantly less or equal to the QOL during euthymia; however, the self-reported QOL during a depressive or mixed episode was significantly less than the QOL during a (hypo)manic or euthymic mood state. The authors thus conclude that while (hypo)mania can be associated with a reduced QOL and the subjective suffering associated with (hypo)mania should therefore not be underestimated, depressive symptoms contribute most to a poor QOL for patients with a bipolar disorder (Vojta et al., 2001).

In a more recent study of the QOL for 60 patients with a bipolar depression which was either in remission or not, bipolar depression and residual symptoms of

depression negatively correlated with reported QOL (Gazalle et al., 2006). That is, when the number of symptoms increase, reported QOL decreases.

Apart from the associations between patient QOL and hypomania, bipolar depression and residual symptoms of hypomania or bipolar depression in particular, very little is known about the other psychopathological symptoms which outpatients with a bipolar disorder may suffer and just how these symptoms impact their QOL. Two goals were therefore identified for the present study.

- To explore the psychopathological symptoms and QOL in outpatients with a bipolar disorder.
- To identify the associations between self-reported symptoms of psychopathology, the QOL and the clinical characteristics of a population of outpatients with a bipolar disorder.

## **2. Methods**

The present study was conducted at five psychiatric outpatient clinics in the Netherlands. A cross-sectional research design was employed. The subject selection criteria included: psychiatric outpatient diagnosed with a bipolar disorder using the DSM-IV criteria (APA, 1996), patient older than 18 years of age and patient able to complete an interview.

## **3. Procedure**

Between April 2005 and April 2006, outpatients with a bipolar disorder were asked to participate in the study by their psychiatrist or community psychiatric nurse (CPN). This was done following verification by the psychiatrist or CPN, that the patient was sufficiently stable to do this. This means that the mood state of the patient should have been stable, and that the patient had recently (prior 4 weeks) not suffered from a severe episode of mania or depression. The study aims and methods were briefly described to the patients and, when a patient indicated an interest in participation, written permission to pass the patient's name, address and telephone number on to the researchers was obtained. A written description of the study was then sent to the patient's home address, and he or she was contacted one week later by telephone. The researcher again explained the aims of the study, the data collection methods and the procedures to the patient and, when the patient agreed to participate, an appointment was made at the outpatient clinic where the patient was being treated. The session was conducted by the researcher or a trained research assistant and initiated by again informing the patient about the purpose of the study and assuring anonymity and confidentiality.

The study was approved by a certified medical ethics committee and by the institutional review boards from the five participating organizations. All of the participating patients signed an informed consent form prior to the start of data collection.

Data on the perceived symptoms of psychopathology, patient QOL and various demographic and clinical characteristics were collected using a number of structured questionnaires.

## **4. Measures**

### **4.1 Symptoms**

Perceived symptoms of psychopathology were measured using the Dutch version of the Symptoms Checklist-90 (Ardinell & Ettema, 2005). The 90-item SCL is a sensitive multidimensional self-report inventory which addresses the majority of complaints reported by psychiatric outpatients by having respondents rate each item along a five-point rating scale ranging from 1 (=totally not) to 5 (=very much). The items are grouped into eight dimensions: (1) anxiety, (2) phobic anxiety, (3) depression, (4) somatization, (5) insufficiency of thinking and acting, (6) paranoid ideation and interpersonal sensitivity, (7) hostility and (8) sleep difficulty. Nine of the 90 items are not included in one of the aforementioned dimensions of psychopathology but nevertheless included in the total SCL score which is referred to as 'psycho-neuroticism' and reflects the general level of psychological dysfunction within a recent time frame.

SCL-90 scores for different Dutch-speaking norm groups including psychiatric outpatients, patients consulting their general practitioner and the general population are available. The reliability and validity of the Dutch version of the SCL-90 have been further shown to be good (Ardinell & Ettema, 2005).

### **4.2 Quality of Life**

Patient QOL was measured using the Dutch version of the World Health Organization's Quality of Life assessment instrument – bref (WHOQOL-Bref). The WHOQOL-Bref is a 26-item abbreviated version of the WHOQOL-100 (The WHOQOL Group, 1998). The instrument includes 24 items grouped into four domains (i.e., physical health, psychological health, social relationships and environment) and 2 items addressing overall QOL and general health facet of QOL. The WHOQOL-Bref is a self-report inventory in which respondents are asked to rate the individual items along a 5-point Likert scale. The domain scores for the WHOQOL-Bref have been shown to correlate highly with the domain scores

for the WHOQOL-100 (The WHOQOL Group, 1998). In 2005, adequate psychometric properties were reported for the WHOQOL-Bref when administered to a population of 533 Dutch adult psychiatric outpatients (Trompenaars et al., 2005). And the data for 630 adults from the general Dutch population were obtained from the Dutch WHOQOL Group at the Tilburg University, The Netherlands, for reference purposes

### **4.3 Demographic and clinical data**

Information on a broad set of demographic and clinical variables was gathered using a specially constructed self-report questionnaire. In addition mood state was assessed using a Visual Analogue Scale which is part of the Life Chart Methodology (Denicoff et al., 2000). The Visual Analogue Scores can range from 0 (= severe depressive mood state) to 100 (= severe manic mood state). The mood state of the individual outpatient was defined as depressed, euthymic or (hypo)manic when his or her Visual Analogue Score fell between 0 - 40, 41 - 59 or 60 - 100, respectively.

## **5. Statistical analyses**

To explore psychopathological symptoms and QOL of the outpatients studied here, the total scale scores and scores per dimension of the SCL 90 and domain of the WHOQOL-Bref were calculated. To compare the outpatient scores on the WHOQOL-Bref to the general Dutch population scores on the WHOQOL-Bref, t-tests for independent groups were conducted.

To provide information on the associations between self-reported psychopathological symptoms and QOL, Pearson correlations were calculated between the overall SCL90 scale scores, the dimensional SCL-90 scores, the overall WHOQOL-bref score and the four WHOQOL-bref domain scores.

Several statistical analyses were further performed to reveal major associations between the clinical characteristics of the population of outpatients with a bipolar disorder studied here, their self-reported psychopathological symptoms and their QOL. In order to explore the relations between mood state, on the one hand, and the SCL-90 and WHOQOL-bref scores of the outpatients, on the other hands, the outpatients were grouped according to their mood state: outpatients with a depressive mood state (Visual Analogue Scale score of 0 to 40), outpatients with a euthymic mood state (score of 41 to 59) and outpatients with a (hypo)manic mood state (score of 60 to 100). To identify the associations between perceived

symptoms, QOL and the patients' diagnoses and mood states, a series of one-way analyses of variance were conducted with a Bonferroni t-procedure.

The data were processed using the Statistical Package for the Social Sciences (SPSS 14.0 for Windows)

## **6. Results**

Of the 201 outpatients who initially showed an interest in study participation, 158 participated (79%). Various reasons for declining to participate were given: fear of destabilization, depressed or (hypo)manic mood state at the time of the appointment, hospitalization, unwillingness to travel, non-mental illness at the time of the appointment, 'being talked out of participation by relatives' or just not showing up for the appointment. One patient declined to participate further during the interview itself, and these data were therefore omitted from any further analyses.

### ***6.1 Demographic and clinical characteristics***

An overview of the demographic and clinical characteristics of the present sample of Dutch outpatients with a bipolar disorder is presented in Table 1.

Two-thirds of the patients was female, and the majority of the participating outpatients had a euthymic mood state at the time of questionnaire administration. Of the 157 participants, 20 reported a depressed mood state, 105 reported a euthymic mood state and 29 reported a (hypo)manic mood state. About 75% of the participants lived with a partner, children or relatives. Despite the relatively high level of education characterizing the outpatients, only 42% of them were employed.

**Table 1: Demographic and clinical characteristics of Dutch sample of outpatients with a bipolar disorder (n=157)**

|   |       | Mean        | SD     |
|---|-------|-------------|--------|
| Female                                  | 65%   |             |        |
| Age                                     |       | 47.24       | 11.776 |
| Living alone                            | 24.2% |             |        |
| Income                                  |       |             |        |
| • none                                  | 11.5% |             |        |
| • employed                              | 35.3% |             |        |
| • self-employed                         | 7.6%  |             |        |
| • social welfare                        | 39.7% |             |        |
| • retired                               | 8.9%  |             |        |
| Education                               |       | certificate |        |
| • middle school                         | 56.4% | 77.5%       |        |
| • high school                           | 36.9% | 82.0%       |        |
| • college                               | 20.4% | 62.5%       |        |
| Diagnosis                               |       |             |        |
| • Bipolar I                             | 66.9% |             |        |
| • Bipolar II                            | 25.5% |             |        |
| • Bipolar NOS                           | 7.6%  |             |        |
| Mood state during the interview         |       | 50.46       | 8.726  |
| • depressed (VAS score 0 – 40, n=20)    | 12.7% | 34.50       | 7.237  |
| • euthymic (VAS score 41 – 59, n=108)   | 68.8% | 50.06       | 1.768  |
| • (hypo)manic (VAS score 60-100, n=29)  | 18.5% | 62.93       | 5.750  |
| Number of episodes during the last year |       |             |        |
| • (hypo)mania                           |       | 1.32        | 5.180  |
| • Depression                            |       | 1.25        | 3.133  |
| Number of hospitalizations during life  |       |             |        |
| • due to (hypo)mania                    |       | 1.01        | 2.263  |
| • due to depression                     |       | 1.15        | 1.537  |

## 6.2 Perceived symptoms of psychopathology and QOL

The outpatients with a bipolar disorder studied here reported more symptoms of psychopathology than the general Dutch population but a comparable number of symptoms to Dutch individuals visiting their general practitioner. Compared to psychiatric outpatients in general, however, the outpatients with a bipolar disorder reported relatively fewer symptoms of psychopathology (Table 2).

When the results were examined more closely at the item level, the 10 items (i.e., symptoms of psychopathology) with the highest sum scores for the outpatients with a bipolar disorder were: trouble remembering things; worrying too much about things; concentration difficulties; trouble falling asleep; feeling low in energy; feeling critical of others; feeling tense; feeling worried about sloppiness or carelessness; restless or disturbed sleep; and loss of sexual interest or pleasure.

**Table 2: Overview of symptoms of psychopathology reported by different groups of individuals in the Netherlands**

| Total SCL-90 score and eight dimension scores     | Outpatients with a bipolar disorder |       | Psychiatric outpatients in general | Individuals visiting general practitioner | General Dutch population |
|---|-------------------------------------|-------|------------------------------------|---|--------------------------|
|   | mean                                | SD    | norm value range                   | norm value range                          | norm value range         |
| Psycho Neuroticism                                | 141.29                              | 48.45 | 193-214                            | 149-166                                   | 113-123                  |
| • Anxiety   | 15.91                               | 6.91  | 22-28                              | 15-20                                     | 12-14                    |
| • Phobic anxiety                                  | 9.31                                | 3.99  | 12-16                              | 9-11                                      | 7-8                      |
| • Depression                                      | 27.21                               | 12.10 | 39-47                              | 27-33                                     | 20-23                    |
| • Somatization                                    | 17.61                               | 6.46  | 23-29                              | 19-24                                     | 15-19                    |
| • Insufficiency of thinking and acting            | 16.56                               | 7.10  | 19-24                              | 14-18                                     | 11-14                    |
| • Paranoid ideation and interpersonal sensitivity | 27.42                               | 10.14 | 35-42                              | 26-30                                     | 22-26                    |
| • Hostility                                       | 8.07                                | 2.88  | 10-13                              | 8-10                                      | 7-8                      |
| • Sleep difficulty                                | 5.95                                | 3.20  | 7-9                                | 5-7                                       | 4-5                      |

As can be seen from Table 3, the QOL scores for the group of outpatients with a bipolar disorder differed significantly from the QOL scores for the general Dutch population. The group of outpatients with a bipolar disorder scored consistently lower in QOL. Significant differences were detected for three of the four QOL domains, namely: physical health, psychological health and social relationships. The scores for the environmental domain differed slightly but not significantly.

**Table 3: Comparison of overall and domain-specific WHOQOL-Bref quality of life scores for outpatients with a bipolar disorder versus general Dutch population**

|                      | Outpatients with a bipolar disorder (n=157) |      | General Dutch population (n=630) |      | p      |
|----------------------|---|------|----------------------------------|------|--------|
|                      | mean  | SD   | mean                             | SD   |        |
| Overall QOL          | 3.75  | 0.86 | 3.98                             | 0.80 | .001*  |
| Physical Health      | 13.93                                       | 2.81 | 15.54                            | 2.74 | .000*  |
| Psychological Health | 14.17                                       | 2.59 | 14.66                            | 2.24 | .021** |
| Social relationships | 13.99                                       | 2.92 | 15.19                            | 2.95 | .000*  |
| Environment          | 15.69                                       | 2.20 | 15.92                            | 2.18 | .202   |

\* Mean difference significant at the .001 level (2-tailed).

\*\* Mean difference significant at the .05 level (2 tailed).

### **6.3 Associations between reported symptoms of psychopathology, quality of life and clinical characteristics for a population of outpatients with a bipolar disorder**

In Table 4, the correlations between the different SCL-90 scores and the different WHOQOL-Bref scores for the outpatients with a bipolar disorder are presented. As can be seen, all of the dimension/domain scores and all of the overall scores correlated significantly with each other at a .01 level (two tailed).

**Table 4: Correlations between SCL-90 and WHOQOL-Bref scores for population of outpatients with a bipolar disorder**

|                      | Anxiety | Phobic anxiety | Depression | Somatization | Insufficiency of thinking and acting | Paranoid ideation and interpersonal sensitivity | Hostility | Sleep difficulty | Psycho-neuroticism |
|----------------------|---------|----------------|------------|--------------|--------------------------------------|---|-----------|------------------|--------------------|
| Physical health      | -.416*  | -.525*         | -.727*     | -.607*       | -.713*                               | -.593*  | -.442*    | -.632*           | -.757*             |
| Psychological health | -.659*  | -.468*         | -.702*     | -.468*       | -.676*                               | -.549*  | -.417*    | -.490*           | -.686*             |
| Social relationships | -.448*  | -.318*         | -.585*     | -.436*       | -.473*                               | -.430*  | -.289*    | -.424*           | -.545*             |
| Environment          | -.407*  | -.386*         | -.460*     | -.473*       | -.481*                               | -.471*  | -.252*    | -.323*           | -.516*             |
| Overall QOL          | -.417*  | -.351*         | -.665*     | -.408*       | -.490*                               | -.382*  | -.264*    | -.377*           | -.560*             |

\* Correlation is significant at the 0.01 level (2-tailed)

The strongest (negative) correlations occur between the depression dimension of the SCL-90 and all of the QOL scores with the exception of the environment domain. No statistically significant differences between the specific diagnostic groups revealed themselves for self-reported symptoms of psychopathology or quality of life (Table 5). When the self-reported symptoms of psychopathology or quality of life are examined in relation to the mood state of the patients at the time of questionnaire administration, statistical differences were found at a level of .01 for all of the different dimensions of psychopathology and domains of QOL with the exception of only 'paranoid ideation and interpersonal sensitivity' which shows differences at a .05 level of significance. The results of the Bonferroni-t procedure showed us that in all dimensions of psychopathology and domains of QOL, the depressive mood state group differs statistically significant at a .05 level from both the euthymic and the (hypo)manic mood state groups. The difference between the depressed mood state group and euthymic mood state group for the 'hostility' dimension of the SCL-90 proved significant at a .05 level while the difference between the depressed mood state group and the (hypo)manic mood state group for this dimension was non-significant.

**Table 5: Overview of self-reported symptoms of psychopathology and quality of life according to specific diagnosis and mood state of outpatients with a bipolar disorder**

|                           | Mood state         |       |                    |       |                     |       |                   |       |                   |       |                     |       |        |
|---------------------------|--------------------|-------|--------------------|-------|---------------------|-------|-------------------|-------|-------------------|-------|---------------------|-------|--------|
|                           | Diagnosis          |       |                    |       |                     |       | Mood state        |       |                   |       |                     |       |        |
|                           | Bipolar I<br>n=105 |       | Bipolar II<br>n=40 |       | Bipolar NOS<br>n=12 |       | Depressed<br>n=20 |       | Euthymic<br>n=108 |       | (Hypo)manic<br>n=29 |       |        |
|                           | mean               | SD    | mean               | SD    | mean                | SD    | mean              | SD    | mean              | SD    | Mean                | SD    | p      |
| SCL-90                    |                    |       |                    |       |                     |       |                   |       |                   |       |                     |       |        |
| Psycho-neuroticism        | 139.00             | 45.76 | 146.50             | 54.97 | 144.00              | 51.18 | <b>196.85</b>     | 47.63 | 131.00            | 43.78 | 141.31              | 40.00 | .000*  |
| Anxiety                   | 15.45              | 6.33  | 16.97              | 8.38  | 16.41               | 6.55  | <b>22.95</b>      | 8.82  | 14.68             | 6.14  | 15.65               | 5.31  | .000*  |
| Phobic Anxiety            | 9.17               | 3.78  | 9.55               | 4.56  | 9.75                | 4.24  | <b>13.20</b>      | 5.51  | 8.56              | 3.06  | 9.41                | 4.42  | .000*  |
| Depression                | 26.67              | 11.16 | 28.65              | 14.00 | 27.08               | 11.33 | <b>45.20</b>      | 13.81 | 24.40             | 9.77  | 25.24               | 7.43  | .000*  |
| Somatization              | 17.01              | 5.47  | 18.60              | 7.96  | 19.58               | 8.52  | <b>23.10</b>      | 8.35  | 16.62             | 5.88  | 17.55               | 5.25  | .000*  |
| In. thinking, acting      | 16.20              | 6.59  | 17.37              | 8.10  | 17.08               | 8.24  | <b>23.25</b>      | 8.24  | 15.27             | 6.51  | 16.75               | 5.88  | .000*  |
| Paranoid ideation         | 27.53              | 10.06 | 27.55              | 10.55 | 26.00               | 10.17 | <b>34.15</b>      | 10.72 | 25.81             | 9.79  | 28.75               | 9.18  | .002** |
| interpersonal sensitivity |                    |       |                    |       |                     |       |                   |       |                   |       |                     |       |        |
| Hostility                 | 7.88               | 2.82  | 8.47               | 3.01  | 8.50                | 3.00  | 9.95***           | 3.28  | 7.54              | 2.39  | 8.72                | 3.62  | .001*  |
| Sleeping difficulty       | 5.71               | 2.911 | 6.50               | 3.66  | 6.25                | 3.98  | <b>8.60</b>       | 3.28  | 5.39              | 2.84  | 6.20                | 3.55  | .000*  |
| WHOQOL-Bref               |                    |       |                    |       |                     |       |                   |       |                   |       |                     |       |        |
| QOL                       | 3.74               | .83   | 3.73               | .98   | 3.83                | .83   | <b>2.85</b>       | .98   | 3.84              | .78   | 4.00                | .70   | .000*  |
| Physical health           | 14.11              | 2.58  | 13.38              | 3.21  | 14.23               | 3.34  | <b>10.68</b>      | 1.81  | 14.42             | 2.68  | 14.36               | 2.37  | .000*  |
| Psychological health      | 14.13              | 2.65  | 14.10              | 2.47  | 14.83               | 2.52  | <b>11.73</b>      | 2.31  | 14.51             | 2.60  | 14.62               | 1.71  | .000*  |
| Social relationships      | 14.18              | 2.74  | 13.53              | 3.16  | 13.88               | 3.61  | <b>11.26</b>      | 3.07  | 14.25             | 2.70  | 14.89               | 2.59  | .000*  |
| Environment               | 15.50              | 2.12  | 16.15              | 2.35  | 15.87               | 2.33  | <b>13.85</b>      | 2.41  | 16.00             | 2.12  | 15.79               | 1.79  | .000*  |

\* P ≤ 0.01

\*\* P ≤ 0.05

Bold: Mean difference between outpatients with a depressed mood state versus an euthymic or a (hypo)manic mood state is significant at the .05 level.  
 \*\*\* Mean difference between outpatients with a depressed mood state versus an euthymic mood state but not a (hypo)manic mood state is significant at the .05 level

## 7. Discussion

To our knowledge, this is the first study to quantitatively examine a broad set of psychopathological symptoms and their relations to the perceived QOL in a population of outpatients with a bipolar disorder. When the self-reported symptoms of psychopathology for the Dutch outpatients with a bipolar disorder were compared to those for the general Dutch population and individuals visiting their general practitioner in the Netherlands, the outpatients reported greater psychopathological symptoms than the general Dutch population but not individuals visiting their general practitioners. The present population of outpatients with a bipolar disorder reported fewer psychopathological symptoms when compared to a population of psychiatric outpatients in general. Overall QOL scores and scores for three of the four QOL domains were significantly lower for the outpatients with a bipolar disorder when compared to the general Dutch population. Negative correlations between the number of symptoms of psychopathology and the QOL scores for the outpatients were also consistently found. The specific DSM-IV axis 1 diagnosis for the outpatients studied here, however, did not show significant differences in either the number of symptoms of psychopathology or the QOL reported by the outpatients. Patients with a depressive mood state at the time of questionnaire administration reported more symptoms of psychopathology and a lower QOL than patients with a euthymic or (hypo)manic mood state at the time of questionnaire administration.

The present results confirm the suggestion that symptoms of depression may be the most important cause of a decreased quality of life for individuals living with a bipolar disorder. The present results further supplement our current understanding of the associations between bipolar disorder and quality of life in the following manner. First, patients in an euthymic state at the time of questionnaire administration reported more symptoms of psychopathology than just the subsyndromal symptoms mentioned in the literature and the introduction to this study. Second, not only the residual symptoms of depression but all of the reported symptoms of psychopathology were found to contribute to a decreased QOL for the outpatients with a bipolar disorder studied here. Even in the group reporting a (hypo)manic mood state at the time of questionnaire administration, moreover, considerable psychopathology was detected, which suggests that the benefits of a hypomanic mood state or residual symptoms of (hypo)mania reported in the research literature (Altshuler et al. 2006) may be small at best and certainly not outweigh the burden caused by these residual symptoms.

The present results should be interpreted in light of some potential methodological limitations. While the use of instruments which are known to have good psychometric properties to measure the symptoms of psychopathology and the quality of life for psychiatric outpatients and the size of the sample make this study thorough, the data were nevertheless all self-reported which raises the risk of a social-desirability bias. Whether our sample is representative of the more general population of outpatients with a bipolar disorder is also very much the question. It is possible, for example, that only patients with a good mental condition and/or euthymic mood state were approached by the psychiatrist or CPN for participation in the present study. Patients with a high illness burden may have refused to participate in this study due to a fear of mood destabilization or talked out of participation by relatives for a similar reason. The present sample was also clearly drawn from a population of outpatients which means that the present results do not necessarily apply to all individuals living with a bipolar disorder. It is well-documented, for instance, that many patients with a bipolar disorder completely withdraw from treatment following acute episodes of depression or (hypo)mania (ten Have et al., 2002) and therefore do not qualify as outpatients. Only those patients who are highly motivated for treatment maintenance thus become outpatients and may thus have participated in the present study. The results of the study might have been confounded by comorbid mental illnesses or comorbid somatic illnesses.

Further, the results for our study sample were compared to the results for already existing norm groups. The norm groups involved large samples drawn from the general Dutch population and were used with the permission of the copyright owners. Unfortunately, we do not know if the demographic characteristics of the norm group were comparable to the demographic characteristics of our sample because this information was not available for us.

## **8. Implications for practice**

Despite the possible methodological shortcomings alluded to above, the present results have two major implications for clinical practice. To start with, in the treatment of patients with a bipolar disorder, we should not settle for treatment response in terms of reduced manic or depressive episodes but strive for full remission of all symptoms. The reduction of subsyndromal symptoms and other concomitant symptoms of psychopathology can positively affect the patient's quality of life, but this requires a highly structured treatment process with a clearly multidisciplinary approach to diagnosis, identification of treatment objectives and

choice of intervention. Regular evaluation of patient progress should also constitute a critical part of this treatment process. To monitor the effects of treatment on subsyndromal or residual symptoms, the SCL-90 questionnaire could be regularly administered. The second implication for clinical practice is the risk of 'invisibility' for the bipolar patient with a euthymic mood state in a thriving psychiatric outpatient clinic. Compared to the other patients, they may report fewer symptoms of psychopathology and when they are not articulate there is a risk that complaints are not mentioned and that they receive little or no help with their functional impairments and decreased QOL.

The results of the present study confirm the conclusions drawn in all of the other studies which we know of on the QOL in individuals living with a bipolar disorder: QOL is markedly impaired in patients with a bipolar disorder even when they report being in a euthymic mood state (Michalak et al., 2005; Robb et al., 1997; Sierra et al., 2005). The present results also confirm two of the other conclusions drawn in recent studies. First; the existence of debilitating subsyndromal symptoms in patients with a bipolar disorder (Altshuler et al., 2006; Judd et al., 2005). Second, the finding that depressive symptoms appear to be the primary determinants of the reduced QOL associated with living with a bipolar disorder (Gazalle et al., 2006; Vojta, et al., 2001).

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## **Chapter 7**

### **Family caregiving in bipolar disorder: caregiver consequences, coping styles and distress**

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**Abstract**

*Aims:* In this study, the consequences of caring for an outpatient with a bipolar disorder are examined along with the distress experienced and coping styles of family caregivers.

*Methods:* 115 family caregivers were asked to complete the Involvement Evaluation Questionnaire (IEQ) to assess caregiver consequences, the Utrecht Coping List (UCL) to determine coping style and the General Health Questionnaire (GHQ-12) to measure distress. The associations between the various scale and subscale scores were then explored.

*Results:* Caregiver consequences were minimal although some 30% of the caregivers reported distress. Male caregivers adopted a more avoidant coping style and undertook more activities to attain distraction. Female caregivers employed a less active coping style and sought less social support. Significant correlations of the IEQ overall score with the subscales of “tension” and “worrying” and also the UCL subscales of “palliative reaction pattern” and “passive reaction pattern” were found. Greater distress appeared to occur for those caregivers who report greater consequences and for those who employ a more avoidant and/or passive coping style.

*Conclusion:* Clinicians should assess symptoms of caregivers distress. When distress is detected, efforts should be undertaken to provide greater support and teach the caregiver to cope more effectively with the consequences of caring for an outpatient with a bipolar disorder.

## 1. Introduction

Both patients with a bipolar disorder and their relatives are confronted with a lifelong disease with significant lifestyle consequences. Bipolar disorder is associated with a considerable degree of illness-related morbidity, psychological suffering, occupational impairment and social burden (Depp et al., 2006; Bowden, 2005; Sajatovic, 2005; Vornik & Hirschfeld, 2005; Abood et al., 2002). In earlier years, patients with a severe mental illness were often committed to mental institutions for long-term care. As a result of deinstitutionalization movement, however, treatment and patient care have gradually shifted to outpatient hospitals (Baronet, 1999) and there has been an increase in informal care tasks provided by family members (Van Wijngaarden et al., 2002; Cuijpers & Stam, 2000).

Given increased caregiver tasks, increased caregiver burden or “the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient’s significant other(s), e.g. members of the household and/or the family” (Platt, 1985) has also been reported in several studies since the 1950s. Most of the studies have concerned schizophrenia (Van Wijngaarden et al., 2002). In a recent review Ogilvie et al. (2005) reported that, although there is a lack of relevant literature on caregiver burden in bipolar disorder, available data suggest that caregiver burden is high (Ogilvie et al., 2005). Unfortunately, the majority of the included studies involve a small sample size (Rose et al., 2006; Walton-Moss et al., 2005; Dore & Romans, 2001; Rose, 1998), self-constructed and thus unvalidated measurement instruments (Hill et al., 1998; Chakrabarti et al., 1992) and/or respondents with psychiatric diagnoses other than bipolar disorder (Rose et al., 2006; Walton-Moss et al., 2005; Rose, 1998; Mueser et al., 1996; Chakrabarti et al., 1992).

In two comprehensive studies of the caregiver burden specifically associated with a bipolar disorder, large sample sizes, sound research designs and instruments with clearly acceptable psychometric properties were utilized (Perlick et al., 2007; Perlick et al., 1999). In the 2007 study, 89% of the family caregivers for 500 patients with a bipolar disorder reported a significant burden in connection with the following: problematic patient behaviour, role dysfunction and disrupted household routines. Caregiver burden scores also correlated significantly with caregiver health problems, caregiver mental health problems and caregiver financial problems (Perlick et al., 2007). In the 1999 study, the widespread burden on the caregivers for 266 patients with a bipolar disorder was found to be influenced by caregiver beliefs regarding the illness. Caregiver belief that he or she can control the patient’s illness behaviour was associated with decreased

levels of burden while caregiver awareness of the severity of the patient's illness and perceptions of illness symptoms as being under control by the patient were associated with increased levels of burden (Perlick et al., 1999).

Both of the preceding studies were conducted in the USA which limits their generalizability to other cultures with different forms of health care delivery, different degrees of health care and different health care beliefs. Health care beliefs are obviously related to the coping strategies adopted by family caregivers and may therefore influence just how family members deal with the consequences of caring for a patient with a bipolar disorder. Coping refers to the person's cognitive and behavioural efforts to manage the internal and external demands of the person-environment interaction which may be appraised as exceeding or taxing the caregiver's resources at times (Lazarus et al., 1980). Coping style refers to a preference for a particular form of coping or mixture of coping forms in most circumstances or situations (Schreurs et al., 1993). And caregiver distress can thus be seen, within the present context, as the outcome of attempts to cope with the consequences of caring for a relative with a psychiatric disorder.

Only two studies have — to our knowledge — specifically examined caregiver coping in connection with a bipolar disorder. The results of these studies which were both conducted in India, however, cannot be generalized to the western world due to major cultural differences (Nehra et al., 2005; Chakrabarti & Gill, 2002).

In other research, Perlick et al. (2001) found high caregiver burden to predict adverse clinical outcomes among patients with a bipolar disorder (Perlick et al., 2001). High caregiver burden also appears to increase the use of health care services by caregivers and health care costs (Perlick et al., 2005). On the behalf of not only the health status of the patient but also the family caregiver, thus, clearly effective and clinically viable interventions specifically aimed at coping with the burden of caring for a patient with a bipolar disorder should thus be developed (Ogilvie et al., 2005). Along these lines, Reinares et al. (2004) examined the impact of a psycho-educational family intervention programme for the caregivers of stabilized bipolar patients and found the intervention to reduce stress and alter the beliefs of the caregivers with regard to the link between disruptions in their lives and the patient's illness (Reinares et al., 2004). The sample size was rather small (n=45), however, which means that replication is needed.

In sum, little is known about the consequences of family care for patients with a bipolar disorder, the degree of distress experienced by family caregivers or the coping styles used by family members to deal with the consequences of caring for

a patient with a bipolar disorder. The aims of the present study were therefore as follows:

1. to identify the consequences of bipolar disorder for caregivers;
2. to identify the coping styles used by the caregivers for outpatients with a bipolar disorder;
3. to identify the level of caregiver distress; and
4. to explore the relationships between experienced consequences, coping style and caregiver distress.

## **2. Methods**

The present study was conducted in five psychiatric outpatient clinics in the Netherlands using a cross-sectional research design. The criterion for subject selection was: Informal caregiver for a psychiatric outpatient with a DSM-IV diagnosis of bipolar disorder (American Psychiatric Association, 2005). "Informal caregiver" was defined as "the person who, in the perception of the patient, is an important person in his or her life, who is not a professional and who delivers significant support and care for the patient."

### **2.1 Procedure**

Between April of 2005 and April of 2006, outpatients with a bipolar disorder were asked to participate in the present study by their psychiatrists or community psychiatric nurses (CPNs). The aims of the study and methods were briefly described to the patients and, when a patient indicated that his or her informal caregiver would probably be willing to participate in the study, written permission to pass the patient's name, address and telephone number on to the researchers was obtained. A description of the study was then sent to the patient's home address and, one week later, direct contact was sought via the telephone. The researcher again explained the aims of the study, the data collection methods and the relevant procedures to the patient and caregiver. When agreement to participate in the present study was obtained from the patients and caregiver, an appointment was made with the patient and his or her caregiver at the outpatient clinic responsible for the patient's treatment.

The session with the patients and family caregiver was conducted by the researcher or a trained research assistant and initiated by again informing the participants about the purpose of the study and assuring them of complete anonymity and confidentiality. The study was approved by a certified medical ethics committee and by the institutional review boards for the five participating

institutions. All of the participants signed an informed consent form prior to the start of data collection.

## **2.2 Measures**

The caregivers were asked to complete three questionnaires to assess (1) the perceived caregiver consequences of having a relative with a bipolar disorder, (2) caregiver coping style and (3) caregiver distress.

The patients were asked to provide demographic data and some information on the clinical characteristics of their illness.

### **2.2.1 Caregiver consequences**

The caregiver consequences of having a relative with a bipolar disorder were assessed using the Involvement Evaluation Questionnaire (IEQ) (Schene & van Wijngaarden, 1992). The IEQ has a modular structure, and the core module involves a 31-item questionnaire with the following four subscales: (1) *tension* or interpersonal strain between patient and caregiver (9 items); (2) *supervision* including caregiver need to protect patient from dangerous acts (6 items); (3) caregiver *worry* (6 items); and (4) caregiver *urging* or activation of patient (8 items). All of the items are rated by the caregiver along a 5-point Likert scale (1 = never, 5 = always). A 27-item overall consequences score can also be computed. And four additional items are included but not subsumed under one of the subscales: getting used to problems of patient, perceived ability to cope with patient's disorder, changes in patient/caregiver relationship since the onset of mental health problems and caregiver ability to pursue own interests and activities during the past four weeks.

Three other IEQ modules were used in the present research. The first involved 15 socio-demographic and contact variables such as the age, sex, household composition and the amount of contact between the patient and the caregiver. The second module involved 3 items addressing the caregiver's utilization of professional help. The third module involved 9 items addressing the consequences of the mental health problem for the patient's children. The time frame for responding was four weeks prior to assessment.

The Dutch version of the IEQ has been validated in studies among the caregivers for patients with schizophrenia and patients with a depressive disorder. The IEQ has proved valid (Van Wijngaarden et al., 2000) and also sensitive to changes over time (Stam & Cuijpers, 2001).

### 2.2.2 Caregiver coping style

Caregiver coping style was measured using the Utrecht Coping List (UCL) (Schreurs et al., 1993). The 47-item UCL is a sensitive multidimensional self-report inventory used to measure coping with problems and unpleasant events. The items are descriptions of possible reactions to a problematic or unpleasant event. For each of reaction, the respondent is asked to indicate along a 4-point rating scale whether he or she would generally adopt this response when confronted with a problematic or unpleasant event (1 = rarely or never; 4 = very often). The items are grouped into seven subscales: (1) active approach, disentangles situation and purposefully works to solve problem; (2) palliative reaction, seeks distraction in order to not have to think about problem; (3) avoidance, leaves the problem as it is or runs away from it; (4) seeks social support, seeks comfort and understanding from others; (5) passive reaction pattern, is totally overwhelmed by the problem; (6) expression of emotions, shows irritation and anger about problem; and (7) reassuring thoughts, entertains comforting thoughts. The subscale scores consist of the mean scores, which can then be compared to the mean scores for various norm groups. Coping styles have been shown to differ depending on such demographic factors as gender (Schreurs et al., 1993). The norm groups for the general population have therefore been divided into male and female, and the study results will be presented with respect to this distinction. The internal consistency of the UCL was calculated on several occasions. Cronbach's Alphas of .67 to .82 were found for the seven UCL subscales and can thus be qualified as good. The construct validity of the UCL was also studied by comparing the present results with the results of 23 well-validated tests. The predictive validity of the UCL has been further described by Schaufeli and Van Dierendonck (1992). Decreased self-efficacy, negative affect and neuroticism are strongly associated with the use of a passive coping style. Avoidance as a coping style leads to mental health problems and decreased self-efficacy while an active coping style and the seeking of social support lead to increased self-efficacy and positive affect (Schaufeli & Van Dierendonck, 1992). The validity of the Dutch version of the UCL can thus be qualified as good (Schreurs et al., 1993).

### 2.2.3 Caregiver distress

Caregiver distress was assessed using the Dutch version of the 12-item General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1988). This instrument is an abbreviated version of the 60-item GHQ as developed by Goldberg to study psychiatric distress in primary care and community settings (Goldberg, 1978). The

GHQ assesses whether the respondent considers him/herself (1) better, (2) the same, (3) worse or (4) much worse than “usual” on 12 items. The number of items for which a score of 3 or 4 is provided (i.e., the respondent negatively differs from his/her “usual” self) constitutes the GHQ score, and those individuals with a GHQ score of 3 or more are considered distressed.

#### 2.2.4 Patient measures

Such demographic and clinical information as patient age, patient gender, number of (hypo)manic or depressed episodes during the last year and number of hospitalizations during life span was gathered via a self-constructed questionnaire. Mood state was assessed using a Visual Analogue Scale which is part of the Life Chart Methodology (Denicoff et al., 2000). The Visual Analogue Scores can range from 0 (= severe depressive mood state) to 100 (= severe manic mood state).

### 3. Analyses

In order to examine the *consequences* of caring for a patient with a bipolar disorder, the average IEQ subscale scores and overall IEQ scores were calculated. In order to examine the caregiver consequences on item level, the item scores were dichotomized to 0 (= “never” or “sometimes”) and 1 (= “regularly,” “often” or “always”). The percentage of cases in which a particular item applied at least “regularly” during the past four weeks was then computed.

To assess the *consequences* for the patients’ *children under the age of 16 years*, the percentage of cases in which the caregiver reported the occurrence of behavioural problems in the children was computed.

In order to examine caregiver *coping style*, the average scores for the UCL subscales were calculated. To compare the caregivers results to those of the norm groups, one sample t-tests were conducted per gender.

The *caregiver distress* scores were calculated using the conventionally binary GHQ scoring method (see Measures above).

To explore the possible relations between caregiver consequences and coping styles, Pearson correlations were calculated between the IEQ subscales, the overall consequences scale and the UCL subscales. To explore the possible relations between caregiver consequences, caregiver coping style and caregiver feelings of distress, two groups were formed: Caregivers reporting distress (i.e., a GHQ score  $\geq 3$ ) and caregivers reporting no distress (i.e., a GHQ score  $< 3$ ). Independent sample T-tests were then conducted for caregiver consequences and

caregiver coping style, respectively, using the Statistical Package for the Social Sciences (SPSS 14.0 for Windows).

#### 4. Results

Of the 157 outpatients who initially indicated an interest in study participation, the caregivers for 115 patients participated in the end (73%). Various reasons were provided for caregiver nonparticipation: an unwillingness to participate, unwillingness to travel, illness at the time of appointment or just not showing up for the appointment.

##### 4.1 Demographic and clinical characteristics of caregivers and patients

An overview of the demographic and clinical characteristics of both the caregivers and the patients is presented in Table 1.

**Table 1: Demographic characteristics of patients and caregivers (n=115)**

|   | %     | mean  | sd    |
|---|-------|-------|-------|
| Patient gender = female                                     | 64%   |       |       |
| Caregiver gender = female                                   | 46%   |       |       |
| Patient age   |       | 46.57 | 11.44 |
| Caregiver age   |       | 47.26 | 11.37 |
| Duration of illness   |       |       |       |
| • < 3 years   | 1.8%  |       |       |
| • 3 - 10 years  | 20.5% |       |       |
| • > 10 years  | 64.3% |       |       |
| • unknown   | 13.4% |       |       |
| Relation of caregiver to patient:                           |       |       |       |
| • Partner   | 72.2% |       |       |
| • Parent  | 7.8%  |       |       |
| • Child   | 3.5%  |       |       |
| • Sibling   | 7.8%  |       |       |
| • Friend  | 8.7%  |       |       |
| Living in the same house: yes                               | 78.3% |       |       |
| Hours of contact per week                                   |       |       |       |
| • < 8   | 19.2% |       |       |
| • 9 - 16  | 4.3%  |       |       |
| • 17 - 32   | 11.3% |       |       |
| • > 32  | 65.2% |       |       |
| Patient's mood state at time of assessment: Scale of 0 -100 |       | 50.73 | 8.80  |
| Number of episodes during the last year:                    |       |       |       |
| (Hypo)mania   |       | 0.93  | 2.03  |
| One or more   | 44.8% |       |       |
| Depression  |       | 1.00  | 2.36  |
| One or more   | 36.2% |       |       |
| Number of hospitalizations during life due to:              |       |       |       |
| (Hypo)mania   |       | 1.24  | 1.60  |
| One or more   | 36.2% |       |       |
| Depression  |       | 0.97  | 2.36  |
| One or more   | 56.9% |       |       |

Slightly more male caregivers participated in the present study than female caregivers; 64% of the patients was female. For the majority of the patients, the illness had a duration of more than 10 years. The caregiver was the patient's partner in most (i.e., 72.2%) of the cases, and some 78% of the caregivers lived in the same house as the patient. In 65% of cases, there was more than 32 hours of contact with the patient per week.

The majority of the patients reported a euthymic mood state at the time of questionnaire administration. During the year prior to assessment, 45% of the patients reported at least one acute episode of (hypo)mania and 36% reported at least one acute episode of depression. More patients were admitted to a mental health institute on at least one occasion during their lives due to depression than (hypo)mania (i.e., 57% vs. 36%, respectively).

#### **4.2 Consequences for caregivers and children**

The IEQ subscale scores and overall scores are presented in Table 2 along with the ranges of possible scores. As can be seen, the consequences of caring for a patient with a bipolar disorder are reported to be relatively few by the caregivers in the present study.

**Table 2: Caregiver consequences**

| IEQ scales    | mean  | sd   | Score range |
|---------------|-------|------|-------------|
| Tension       | 3.88  | 3.21 | 0-36        |
| Supervision   | 1.29  | 1.89 | 0-24        |
| Urging        | 3.88  | 3.22 | 0-32        |
| Worrying      | 3.54  | 2.87 | 0-24        |
| Overall score | 11.67 | 7.93 | 0-118       |

Examination of the item level scores showed the most frequently reported consequences for the caregivers to be tensions regarding one's own future (17% of cases), the need to encourage the patient to undertake activities (16%) and the need to carry out tasks normally done by the patient him/herself (15%). Other consequences reported in more than 10% of the cases studied here were worries about the patient's general health and future, ensuring that the patient attains sufficient sleep, annoyance by patient's behaviour, feeling burdened by patient's mental health problems, ensuring medication intake and worries about patient finances.

A number of consequences simply did not occur or occurred only rarely. None of the caregivers, for example, reported feeling threatened by the patient. Only one caregiver reported thinking of moving out during the past four weeks, reported

guarding the patient from self-inflicted harm, reported having to help the patient take proper care of him/herself or reported having to guard the patient from illegal drug use. Since the onset of the patient's illness, 38% of the caregivers reported changes in their relationship with the patient. Some 43% of the caregivers reported "often" having time to pursue their own interests and activities.

A total of 30 patients (or 26% of the patients) had children under the age of 16, and the following was found when the caregivers were asked to report on any problems observed in the children's behaviour. Difficult behaviour was reported most often (63%) and followed by sleeplessness on the part of the children (50%) and a loss of appetite (40%). Almost one fifth of the children had to stay with relatives or friends at times (23%), played less with friends than usual (20%), showed a fear of the patient (17%) or felt ashamed (17%).

### **4.3 Caregiver coping styles**

As can be seen from Table 3, the coping styles of the caregivers differ only slightly from the coping styles of the general population when confronted with problems or unpleasant events. Male caregivers report a palliative reaction significantly more often than the norm group of males between 19 and 65 years of age, which means that the male caregivers undertake activities to divert themselves from the problems confronting them more frequently than the norm group males. Male caregivers also report significantly more avoidance than the male norm group, which means that the male caregivers tend to ignore the problems confronting them and adopt a "wait and see" attitude more often than the norm group males. Female caregivers report a significantly less active coping style and seek less social support than the females in the norm group.

In addition to these UCL results, the two coping items from the IEQ showed the following: 51% of the caregivers indicated being (quite) accustomed to the problems of the relevant patient with a bipolar disorder and 55% indicated being able to cope with the patient's problems.

### **4.4 Caregiver feelings of distress and utilization of health care services**

As mentioned in the Methods, a GHQ-12 score of three or higher indicated caregiver feelings of distress during the past four weeks. This was found to be the case for 31% of the caregivers. On an item level, 33% of the caregivers reported feeling greater strain than usual, 27% reported less of an ability to enjoy their day-to-day activities than usual, 27% felt (much) more depressed than usual and 22% felt (much) more of an inability to overcome difficulties than usual.

**Table 3: Overview of caregiver coping styles**

| UCL subscale             | Male caregivers (n=62) |     |       | Norm group of males 19 to 65 years (n=1493) |     |       | Female caregivers (n=53) |     |        | Norm group of females 19 to 65 years (n=712) |     |        |
|--------------------------|------------------------|-----|-------|---|-----|-------|--------------------------|-----|--------|--|-----|--------|
|                          | mean                   | sd  | p     | mean  | sd  | p     | mean                     | sd  | p      | mean   | sd  | p      |
| Active approach          | 18.5                   | 3.1 | .473  | 18.3  | 3.5 | .473  | 17.4                     | 3.3 | .000*  | 19.3   | 5.1 | .000*  |
| Palliative reaction      | 16.6                   | 2.7 | .002* | 15.5  | 3.6 | .002* | 16.5                     | 3.2 | .115   | 17.3   | 6.1 | .115   |
| Avoidance                | 16.3                   | 3.5 | .000* | 14.8  | 3.3 | .000* | 15.2                     | 3.1 | .901   | 15.2   | 6.0 | .901   |
| Seeks social support     | 11.7                   | 2.7 | .197  | 11.3  | 3.0 | .197  | 13.3                     | 3.4 | .018** | 14.5   | 4.9 | .018** |
| Passive reaction pattern | 11.2                   | 3.0 | .153  | 10.7  | 2.9 | .153  | 11.5                     | 3.1 | .159   | 10.9   | 5.4 | .159   |
| Expression of emotions   | 5.8                    | 1.5 | .115  | 6.2   | 1.7 | .115  | 6.0                      | 1.5 | .108   | 6.4  | 2.3 | .108   |
| Reassuring thoughts      | 11.9                   | 2.2 | .398  | 11.6  | 2.5 | .398  | 12.0                     | 2.4 | .813   | 12.1   | 3.8 | .813   |

\* Mean difference significant at .01 level (two-tailed).

\*\* Mean difference significant at .05 level (two-tailed).

Despite these results, 81% of the caregivers indicated that they felt reasonably happy. Some 24% of the caregivers reported the receipt of help from their general practitioner for experienced distress. Some 17% consulted a social worker or a psychiatrist with regard to the distress being experienced. And some 20% of the caregivers used prescription medication.

#### **4.5 Caregiver consequences in relation to caregiver coping style**

In Table 4, the correlations between — on the one hand — the IEQ subscale results and the overall IEQ results (i.e., caregiver consequences) and — on the other hand — the UCL subscales (i.e., caregiver coping style) are presented. As can be seen, the UCL palliative and passive reaction patterns correlate weakly but significantly with almost all of the IEQ overall scores and subscale scores.

**Table 4: Correlations between caregiver consequences as measured by the IEQ and caregiver coping style as measured by the UCL**

|                          | Tension | Supervision | Urging | Worrying | Overall score |
|--------------------------|---------|-------------|--------|----------|---------------|
| Active approach          | -.130   | .172        | -.021  | -.75     | -.039         |
| Palliative reaction      | .314**  | .201*       | .230*  | .294**   | .343**        |
| Avoidance                | .277**  | .025        | .092   | .130     | .173          |
| Seeks social support     | -.130   | -.006       | -.047  | .055     | .038          |
| Passive reaction pattern | .399**  | .063        | .212*  | .259**   | .318**        |
| Expression of emotions   | .189*   | .059        | .125   | .040     | .139          |
| Reassuring thoughts      | .011    | -.005       | -.028  | .144     | .029          |

\*\* Correlation significant at the .01 level (2-tailed).

\* Correlation significant at the .05 level (2-tailed).

#### **4.6 Caregiver consequences and coping style in relation to caregiver distress**

As can be seen from Table 5, a number of significant differences manifested themselves for caregivers experiencing distress versus caregivers not experiencing distress. Statistically significant differences between the two groups were found for the overall IEQ scores and all but one of the IEQ subscores. Those caregivers who reported feelings of distress also appeared to be more tense and have more worries but also more frequently urged the patient to undertake activities. All of these differences were significant at a 0.01 level. With respect to caregiver coping style, those caregivers reporting feelings of distress reported the avoidance of the problems and unpleasant events confronting them more often than those caregivers not reporting feelings of distress ( $p < 0.05$ ); those caregivers reporting feelings of distress also showed a more passive style of coping (i.e.,

passive reaction pattern) ( $p < 0.01$ ) than those caregivers not reporting feelings of distress.

**Table 5: Overview of caregiver consequences and coping styles in relation to experienced distress**

|                      | No distress<br>(n=80 caregivers) |      | Distress<br>(n=35 caregivers) |      | P value |
|----------------------|----------------------------------|------|-------------------------------|------|---------|
|                      | mean                             | sd   | mean                          | sd   |         |
| Tension              | 2.70                             | 2.02 | 6.48                          | 3.75 | .000**  |
| Supervision          | 1.12                             | 1.58 | 1.66                          | 2.45 | .169    |
| Urging               | 3.22                             | 2.33 | 5.45                          | 4.35 | .008**  |
| Worrying             | 2.46                             | 2.10 | 5.60                          | 3.16 | .000**  |
| Overall score        | 8.93                             | 5.21 | 17.47                         | 3.14 | .000**  |
| Active approach      | 18.31                            | 3.32 | 17.47                         | 3.14 | .215    |
| Palliative reaction  | 16.14                            | 2.92 | 17.50                         | 2.90 | .026*   |
| Avoidance            | 15.50                            | 3.39 | 16.58                         | 3.40 | .125    |
| Seeks social support | 12.57                            | 2.78 | 12.11                         | 3.98 | .550    |
| Passive reaction     | 10.49                            | 2.52 | 13.26                         | 3.36 | .000**  |
| Expression emotions  | 5.84                             | 1.53 | 6.26                          | 1.54 | .188    |
| Reassuring thoughts  | 12.03                            | 2.19 | 11.73                         | 2.45 | .518    |

\*\* Mean difference is significant at the .01 level (2-tailed).

\* Mean difference is significant at the .05 level (2-tailed).

## 5. Discussion

In the present study, the consequences of caring for an outpatient with a bipolar disorder were examined for 115 informal caregivers in addition to the coping styles used by the caregivers to deal with the consequences of this severe mental illness and the distress they experienced. At the time of questionnaire administration, most of the patients in our sample were in a stable euthymic mood state. The results concern the four-week period prior to questionnaire administration and showed the caregiver consequences during this period to be rather few although more than 30% of the caregivers reported psychological distress. For children under 16 years of age, the consequences appeared to be much more prominent. Problematic behaviour was reported by the caregivers for a large percentage of these children.

With respect to the coping styles of the caregivers, male caregivers reported using a more avoidant coping style and undertook more activities to provide distraction than males in the general population. Female caregivers, in contrast, tended to adopt a less active coping style and seek less social support in dealing with the problems and unpleasant events confronting them than females in the general population. Clearly significant associations were found between the IEQ overall scores and the subscales of tension and worrying, on the one hand, and the UCL subscales of palliative reaction pattern and passive reaction pattern, on

the other hand. Feelings of distress appeared to occur more often for caregivers who reported greater consequences of caring for a relative with a bipolar disorder and caregivers who tended to use a more avoidant coping style or passive coping style although causality cannot be assumed.

In their studies, Perlick et al. (1999, 2007) reported widespread burden among the caregivers for patients with a bipolar disorder. These results clearly differ from the results of the present study, but this can be explained by the strongly differing research designs. In our study, a cross-sectional research design was used, which means that the data was collected at a single point in time and covered a maximum of four weeks prior to questionnaire administration. In the 1999 Perlick et al. study, a longitudinal prospective research design was used in which data was collected across a period of 15 months. In the 2007 Perlick et al. study, retrospective data was collected for the six-month period prior to questionnaire administration which was undertaken four weeks after enrolment of the patient in the Step-BD treatment program (Perlick et al., 2007). Another explanation for the discrepancies in the burden scores across the different studies may lie the severity of the symptomatology. In the 2007 study by Perlick et al., 23.7% of the patients were in full remission while most of our patients were simply in a stable euthymic mood state at the time of questionnaire administration. Along these lines, Perlick et al. (1999) reported higher levels of caregiver burden in cases of patient hospitalization and in cases of more severe symptomatology which suggests that the level of caregiver burden is sensitive to mental health crises or pending mental health crises on the part of patients. Our finding of relatively few caregiver consequences when the patient is in a euthymic mood state provide support of the above suggestion. In the 2007 Perlick et al. study, caregiver distress was measured using the Center for Epidemiological Studies of Depression Scale (CES-D) (Radloff, 1977) and 22.5% of the caregivers produced a mean score of 16 or greater, which showed them to be distressed. In our study, 30% of the caregivers were found to be distressed. Psychological distress thus appears to be clearly different or follow a different course than caregiver consequences. While caregivers appear to grow accustomed to dealing with the consequences of a major mental illness, the level of distress or psychological problems may nevertheless increase over the years. This finding is important for, as stated in the introduction, high levels of caregiver burden or distress predict adverse clinical outcomes for patients (Perlick et al., 2001). Low caregiver distress may thus constitute a protective factor for acute episodes of patient depression or (hypo)mania. And in order to minimize caregiver distress, interventions to

empower the caregiver to cope with the consequences of caring for a patient with a major mental illness and stimulate the adoption of a less passive coping style should be undertaken. The psycho-educational family interventions as developed by Reinares et al. (2004) might be an effective intervention to obtain this outcome. When we compare the results of the present study to the results of studies using the IEQ to assess the caregivers of patients with schizophrenia or depression (Van Wijngaarden et al., 2004; Van Wijngaarden et al., 2000), the IEQ caregiver consequences in our study are found to be remarkably low. In schizophrenia and depression the caregiver consequences are found to be very similar. This discrepancy between our findings and the findings of these studies can be explained by the nature of the diseases being studied. During the euthymic phase of a bipolar disorder, residual and subsyndromal symptoms can still be present (Marangell, 2004), cause functional impairments (Altshuler et al., 2006) and clearly affect the patient's quality of life (Gazalle et al., 2006). Patients with a bipolar disorder and their families can nevertheless live a rather stable and healthy life as long as the patient adheres to treatment regimes and has learned to manage his or her symptoms (Sierra et al., 2007; Morriss, 2004; Perry et al., 1999). In our study, 81.4% of the caregivers indeed reported feeling reasonably happy and some 50% of the caregivers reported being used to the mental health problems and able to cope with them.

While the use of psychometrically sound measurement instruments and a sufficiently large sample size make the present study thorough, it should be mentioned that all of the data were self-report data which increases the risk of a social-desirability bias. The question of whether the present sample is representative of the population under investigation can also be raised. It is possible, for example, that only patients with a good mental condition and euthymic mood state were approached by the psychiatrist or CPN to participate in the present study. Patients with a high illness burden may opt to not participate due to a fear of mood destabilization or caregivers may opt not to participate for similar reasons. Our study sample was drawn from a population of outpatients, which means that the present results do not necessarily apply to all individuals living with a bipolar disorder. That is, it is well-documented that many people with a bipolar disorder drop out of treatment following acute episodes of depression or (hypo)mania (Ten Have et al., 2002). Only those patients who are highly motivated for treatment maintenance may thus become outpatients and thus have participated in the present study.

In order to gain greater insight into caregiver consequences and caregiver distress when caring for an outpatient with a bipolar disorder, future research should use the IEQ to examine caregivers when the patients are suffering from an acute episode of bipolar depression or (hypo)mania. Many of the participants in the present study assured us that the results would have been quite different if they had completed the questionnaire during an acute episode of bipolar depression or (hypo)mania on the part of the outpatient. Although the majority of the caregivers reported feeling reasonably happy, a topic in need of further exploration is the impact of caregiver consequences and caregiver distress on the daily functioning of caregivers and their quality of life. Studies along these lines are not known to us.

In conclusion, clinicians should pay attention to signs of caregiver distress and stress on the part of the children of patients with a bipolar disorder. When distress is detected, efforts should be undertaken to support the caregiver and, if present, the children of the patient. The specific skills needed to cope with the consequences of the bipolar disorder should be taught. Support groups should be organized for the caregivers of patients with a bipolar disorder. And psycho-education following the "Maastricht protocol" should be available for both patients and relatives (Hofman et al., 1992). Group-based psycho-education courses have been shown to decrease the level of caregiver expressed emotion (EE), and patients living with low EE caregivers have been shown to have a significantly lower number of hospital admissions than patients living with high EE caregivers (Honig et al., 1997). The children of patients with a bipolar disorder are also at risk for the development of mood disorders (Reichart et al., 2007) and bipolar disorder is known to run in families which makes it important that the children of patients with a bipolar disorder be monitored. The General Behavior Inventory (GBI) can be used for this purpose (Reichart et al., 2005). And, in the Netherlands, several interventions are currently being undertaken by mental health organizations to provide support for the children of parents with psychological problems in particular. The most current intervention involves group prevention courses aimed at the exchange of experiences, the provision of information on specific illnesses and the advising of children on how to deal with the behaviour of an impaired parent (Netherlands Institute of Mental Health and Addiction, 2002).

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## **Chapter 8**

### **Conclusions and discussion**

The general aim of this thesis was to establish a body of knowledge for the nursing of outpatients with a bipolar disorder. The thesis was divided into two parts for this purpose.

In the first part of the thesis, the state of the art in the relevant nursing literature and the current practices of nurses caring for outpatients with a bipolar disorder were considered. The literature was systematically searched for nursing care based upon empirical results and nursing care based upon the experiences of practising nurses. In a qualitative research design which included semi-structured interviews and supplemental focus group interviews, the daily practices of community psychiatric nurses (CPN) were also investigated.

In the second part of the thesis, information was gathered to support nurses in their critical decision-making processes during the planning, conduct and evaluation of the nursing care provided for outpatients with a bipolar disorder and their family caregivers. Four studies were undertaken in the following domains: 1) the care needs of outpatients with a bipolar disorder, 2) the coping styles of outpatients with a bipolar disorder, 3) self-perceptions of psychopathological symptoms and quality of life for outpatients with a bipolar disorder and 4) family caregiver consequences, caregiver coping and caregiver distress.

In this final chapter, a number of conclusions based upon the main results are presented and discussed. The strengths and weaknesses of the present research are outlined, implications for actual practice and the development of nurses' roles are considered, and suggestions for future research are presented.

### **Main findings regarding state of the art and current nursing practices**

One of the main conclusions provided by our systematic review of the literature in Chapter 2 is that formal research on the nursing of patients with a bipolar disorder is remarkably limited. The majority of articles meeting the inclusion criteria involved descriptive reports. It was nevertheless possible to present an overview of the nursing processes provided during the euthymic stage of a bipolar disorder and during an acute episode of (hypo)mania. The specific nursing processes during an acute episode of bipolar depression, however, were not described in the literature. The most promising nursing processes identified in the literature for the care of patients with a bipolar disorder appeared to be as follows: a specific bipolar disorder nursing assessment; concrete formulation of both care and crisis plans; the offering of protection; the provision of psycho-education and other measures aimed at the enhancement of self-management skills and treatment compliance; provision of support for the patient, caregivers, family and friends; observation of

treatment effectiveness and any side-effects of medication; and easy access to the nurse as case manager. The review results provided very little evidence regarding the efficacy of the various nursing processes.

In July 2006, when chapter 2 of this thesis was accepted for publication in the *'International Journal of Psychiatric and Mental Health Nursing'*, the results of the multi-site randomized controlled trial that was described by Bauer et al. (2001) were published (Bauer et al., 2006). In this study, a collaborative care program for bipolar disorder, described and evaluated in a 1997 publication by the same group (Bauer et al., 1997), was examined with a more powerful research design (RCT instead of pretest-posttest). Patients in the intervention group showed a significant reduction in the duration of an affective episode, including a reduction in the duration of manic episodes, and a non-significant reduction in duration of depression. Treatment in the intervention group significantly improved overall social functioning, including work and parental and extended family roles. Mental, but not physical quality of life was significantly improved among participants in the intervention group and treatment satisfaction in this group was higher. Hospitalisation rates were lower for the intervention group in years 2 and 3. The collaborative care program was a combination of therapies and interventions provided by psychiatrists and nurses and it was not clear which interventions contributed to the effects.

The qualitative study of current nursing practices for outpatients with a bipolar disorder reported in Chapter 3, showed non-acceptance of the disease to be the most common problem which nurses see. Maintenance of an euthymic mood state was the most desired outcome, and nurse accessibility constituted the most common nursing intervention. This finding was supported by the study of Adams et al. (2003), who found that nurse accessibility, continuity and respect are highly valued features of CPNs and CPN services in patients with enduring mental disorders.

The nursing process as it is currently conducted by the nurses lacks a systematic approach. It can nevertheless be concluded that CPNs in the Netherlands use all but two of the most promising nursing processes mentioned in the review. Dutch CPNs do not undertake a specific bipolar disorder nursing assessment and do not formulate a nursing care plan, which shows the decisions made during the nursing process to be largely ad hoc and based upon the experiences of the particular CPN. Thus, a generally sufficient level of quality cannot be guaranteed.

### **Main findings regarding supportive information for critical decision-making processes**

In Chapter 4, the results of a study of the care needs of outpatients with a bipolar disorder are presented. Care needs were mainly reported in the domains of psychological help, psychiatric help and social functioning. Closer inspection of the items constituting these scales, however, showed the majority of the items to address coping with the consequences of the disease or the skills needed for self-management of the disease. A very important skill for patients with a bipolar disorder, for example, is to recognize early warning signs and undertake measures to prevent mood destabilization and relapse. Help with this aspect of coping with the disease is by far the most frequently reported care need. While life charts and action plans are among the most important relapse prevention techniques available to outpatients with a bipolar disorder, only 28.7% and 37.6% report using the respective techniques. Unmet needs are frequently reported for all of the scales and almost all of the items in this particular study. It is thus possible that the care needs of outpatients go largely unmet because little attention is paid to the structured assessment of their needs during treatment. That is, many of the needs of the patient with a bipolar disorder go largely unnoticed. Thus, an important point for improvement is incorporation of assessment procedures to evaluate the care needs of patients during the treatment process.

In Chapter 5, the results of a study of the coping styles of outpatients with a bipolar disorder are reported upon. The patient's coping style consists of those patient characteristics which contribute to efforts to adapt to living with a severe chronic mental illness. The outpatients with a bipolar disorder in this study generally reported using a less active, more passive and more avoidant style of coping when confronted with problems or unpleasant events than people in the general population. Although causality cannot be assumed, more active coping styles in which the patients disentangle the problematic situation and intentionally work to solve the problems appear to occur relatively more often among patients with higher educational levels and among patients who already have or are currently developing an action plan to cope with the prodromal phase of disease relapse (i.e., early warning signs). A passive coping style in which the patient is overwhelmed by the problem and unable to solve the relevant problems appears to be associated with the frequent occurrence of acute episodes of depression and/or (hypo)mania although causality again cannot be assumed.

In Chapter 6, the results of a study of the reported psychopathological symptoms and quality of life (QOL) for outpatients with a bipolar disorder in the

Netherlands are presented. Outpatients with a bipolar disorder experience more psychopathological symptoms when compared to individuals in the general population but not when compared to patients visiting their general practitioner. Compared to psychiatric outpatients in general, the population of outpatients with a bipolar disorder in the present study reported fewer psychopathological symptoms. As might be expected, the overall QOL scores were significantly lower for the outpatients with a bipolar disorder than for the general population. The more psychopathological symptoms reported, the lower the QOL score. Patients with a depressive mood state during the interview reported significantly more psychopathological symptoms and lower QOL than patients with a euthymic or (hypo)manic mood state during the interview. It can thus be hypothesized that symptoms of depression are the most important cause of a reduced quality of life for individuals living with a bipolar disorder. However, those patients who reported euthymia also reported psychopathological symptoms, and not only depressive subsyndromal symptoms, which all contributed to reports of a reduced QOL.

In Chapter 7, the consequences of bipolar disorder for the caregivers of outpatients with a bipolar disorder, the coping styles of these caregivers and the distress experienced by the caregivers for outpatients with a bipolar disorder are examined. The results show relatively few consequences for the caregivers of outpatients with a bipolar disorder during a period of 4 weeks prior to the time of assessment although more than 30% of the caregivers reported psychological distress. The consequences for the children under the age of 16 of outpatients with a bipolar disorder appear to be much more eminent. With respect to the coping styles of the caregivers, male caregivers are generally found to report using a more avoidant coping style and undertaking more activities to provide distraction than males in the general population. Female caregivers, in contrast, generally report the use of a less active coping style and the pursuit of less social support than females in the general population. Finally, feelings of distress were reported more often by caregivers who reported relatively greater consequences of the disease for themselves, a relatively more avoidant coping style and a relatively passive pattern of reacting to problems.

### **Main conclusions**

The nursing care for outpatients with a bipolar disorder is not evidence-based and not conducted in a systematic manner by Dutch CPNs. Nursing care plans are not utilized and many of the care needs of outpatients with a bipolar disorder go largely unnoticed and thus unmet.

A promising intervention for the nursing of outpatients with a bipolar disorder is certainly the use of an action plan to prevent relapse and thus the occurrence of acute episodes. Patients who are using or have used an action plan tend to adopt more active coping styles which can foster increased self-efficacy and levels of positive affect. The provision of support for the development and maintenance of an action plan is therefore one of the key interventions for CPNs caring for outpatients with a bipolar disorder.

Outpatients with a bipolar disorder typically suffer from a broad range of psychopathological symptoms and experience a decreased quality of life relative to the general population. The greater the number of symptoms and particularly symptoms of depression, the lower the QOL score. And although 30% of the caregivers for outpatients with a bipolar disorder report psychological distress, the consequences for the caregivers appear to be relatively limited. The consequences for the children of outpatients with a bipolar disorder, however, appear to be larger.

CPNs can play a major role in helping outpatients with a bipolar disorder maintain a euthymic mood state. However, even when the patient is in a stable mood state, attention must be paid to the remainder of the patient's care needs and to efforts to improve the patient's quality of life as well.

### **Strengths and limitations of the present study**

#### *Representativeness of the study populations*

In Chapter 3, just how the nursing respondents were selected with respect to the depth of their knowledge and breadth of their experience with caring for patients with a bipolar disorder was described. Although the nurses came from organizations distributed throughout the Netherlands, the study sample is not necessarily representative of the Dutch population of CPNs. In fact, a positive bias can be assumed in light of the high level of specialization characteristic of the nurses caring for outpatients with a bipolar disorder.

The population of outpatients with a bipolar disorder investigated in Chapters 4, 5 and 6 consisted of a large convenience sample of outpatients from five outpatient clinics in the Netherlands. Structured interviews were not undertaken to ascertain the diagnosis of bipolar disorder as the patients had long treatment relationship with the psychiatrist and/or CPN. Questions were asked about the occurrence of depressive and (hypo)manic episodes in connection with the patient's illness history, however, and this could have introduced some selection bias. It can certainly be asked if our sample of outpatients with a bipolar disorder is

representative of the population under investigation. It is possible, for example, that only patients with a relatively good mental condition and euthymic mood state were approached by the psychiatrist or CPN to participate in the present study. Patients with a high illness burden may decide against participation due to the fear that an interview could destabilize their mood. Relatives can also discourage patients from participation for largely similar reasons. Our study sample was further drawn from a population of outpatients in particular, which means that the present results do not apply to all patients or individuals with a bipolar disorder. It is well-documented, for example, that many patients with a bipolar disorder withdraw from treatment or do not pursue further treatment following acute episodes of depression or (hypo)mania (Ten Have et al. 2002). Only those patients who are truly motivated for treatment maintenance and with a significant degree of disease insight are likely to continue with outpatient treatment and to have participated in the present studies. The same limitations hold for the population of family caregivers investigated in Chapter 7. They are the relatives of the outpatients investigated in Chapters 4, 5 and 6 which means that they also may not constitute a representative population.

#### *The use of self-report data*

Although we used questionnaires with known validity and good psychometric properties, all of the data collected in this research were self-reported which raises the risk of socially desirable responding and thus a bias. In Chapter 3, the CPNs were asked to compose a hierarchical list of problems encountered by their patients, as well as desired nursing outcomes and interventions used. In the focus group interviews, these findings were expanded to include specific signs and symptoms, specific indicators and specific nursing activities. However, we could not corroborate these findings with information from the patient records as the CPNs did not record specific nursing plans.

It should be noted within this context that the few patients who encountered writing troubles, which were often a side effect of medication (i.e., due to a tremor), were helped to complete the patient questionnaire by the researcher or a research assistant.

#### *Study design*

All of the studies in the second part of this thesis were descriptive, exploratory and involved a cross-sectional design. This means that all of the data were collected at a single point in time. Because of this, we could not do more than describe the

relationships between the variables without comprehending the causalities that could exist.

### *Confounding factors*

It is possible that patient mood state during questionnaire administration may have confounded the results of the coping style study reported upon in Chapter 5. Although the patients were explicitly instructed to report upon how they would react *in general*, the participants in a (hypo)manic mood state at the time of data collection may nevertheless have overestimated their coping abilities while the participants in a depressed mood state at the time of data collection may have underestimated their coping abilities.

Patient mood state may have similarly confounded the results of the care needs study reported upon in Chapter 4. Patients in a (hypo)manic mood state may not experience or report significant care needs despite the burden which they often constitute for themselves and their families.

In addition, the results of the different studies described in the second part of this thesis might have been confounded — or even caused — by comorbid mental illnesses, comorbid somatic illnesses, mental or somatic illness on the part of the patient's caregiver or other unmeasured variables.

### *Use of norm groups for purposes of comparison*

In Chapter 5 (i.e., the study of patient coping styles), Chapter 6 (i.e., the study of reported psychopathological symptoms and patient QOL) and Chapter 7 (i.e., the study of caregiver consequences, caregiver coping style and caregiver distress), the results for our study sample were compared to the results for already existing norm groups. The norm groups involved large samples drawn from the general Dutch population and were used with the permission of the copyright owners. Unfortunately, we simply do not know if the demographic characteristics of the norm group were comparable to the demographic characteristics of our sample because this information was not available for the norm group.

### *Generalizability*

The studies reported on here were all performed in the Netherlands which is a country with relatively easy access to treatment for all of its inhabitants. A certain degree of social distance (i.e., stigma, reserve) exists with regard to mental health patients (Van 't Veer et al. 2005). An active knowledge centre for bipolar disorders exists in addition to a regularly updated, national guideline for the treatment of bipolar disorders (Nolen et al., 2001, 2007). A well-organized patient association is

also active and regularly organizes meetings for patients and caregivers, distributes information via a magazine and the internet and participates in a psycho-education training programme organized by the local mental health institutions throughout the Netherlands. We can therefore only assume that our results are generalizable to countries which resemble the Netherlands with respect to the aforementioned characteristics.

### **Implications for daily nursing practice**

On the basis of the studies in this thesis, it can be concluded that patients with a bipolar disorder and their relatives can certainly benefit from a more structured and systematic approach to the organization of the nursing process as indicated in Chapters 2 and 3.

In Chapter 4, the specific care needs of outpatients with a bipolar disorder and the fulfilment of these needs were examined. Many of the care needs mentioned by the outpatients remained unmet. Nurses appeared to be particularly involved in the treatment of outpatients with care needs in the domains of psychiatric and psychological help. Although many of the other items responded to by the patients are within the scope of community psychiatric nursing, no particular involvement of the CPNs was found. Is the focus of the CPNs on the psychological and psychiatric needs of the outpatients with a bipolar disorder possibly caused by a lack of such help (i.e., an actual shift of task from the psychiatric or psychological professional to the nursing professional) or have the CPNs perhaps left their domain of expertise and crossed over into the therapist's domain of expertise? Only structured needs assessment using such clearly validated instruments as the Needs of Care Questionnaire (NCQ) (Kroon, 2003) or the Camberwell Assessment of Needs (CAN) (Phelan et al., 1995) by the CPNs during initial nursing assessment and periodically thereafter during treatment, will reveal the patients' real nursing care needs. In addition, accurate intervention planning to meet the needs of the outpatient with a bipolar disorder can presumably enhance the patients QOL (Wiersma, 2006).

In addition to routine needs assessment, the use of a retrospective life chart (Denicoff et al., 1999), a specific mood disorder nursing assessment tool (Goossens & Houtjes, 2006) and a hetero anamnesis with a relative of the patient can give the CPN greater insight into the patient's situation, mental condition, illness history and care needs.

On a different front, the use of an active coping style was found to increase the self-efficacy and positive affect on the part of patients (Schaufeli & Van

Dierendonk, 1992). This means that CPNs should encourage and support their patients in the development and use of action plans. There is also evidence that the use of action plans actually increases the time to next manic relapse and can improve the social functioning and performance of patients with a bipolar disorder (Perry et al. 1999). And the patient problems referred to were all among the top five patient problems identified in Chapter 3 of this thesis.

Complete remission of subsyndromal and other symptoms of psychopathology will positively affect the perceived quality of life for patients with a bipolar disorder. We should therefore not settle for a treatment response in the form of reduction or relapse of manic and depressive episodes alone but strive for full symptom remission. This obviously requires a clearly structured treatment process with a multidisciplinary approach to diagnosis, determination of treatment objectives and choice of intervention. Regular evaluation of treatment process and patient progress are a critical part of this treatment process and, in order to monitor the effects of treatment on various subsyndromal and residual symptoms, the Symptom Check-List-90 (SCL-90) (Arrindell & Ettema, 2005) could be regularly administered. Outpatients with a euthymic mood state further are at risk for “invisibility” at a thriving general psychiatric outpatient clinic. Compared to other patients, these patients will report fewer psychopathological complaints but, when such complaints are not articulated, the risk of not receiving help for clear functional impairments and a concomitant reduced QOL will only increase. Structured and regular assessment of patient care needs is thus again a necessity.

CPNs and other members of the multidisciplinary treatment team should also be alert to signs of caregiver distress and particularly distress on the part of the patient’s children. When caregiver distress is noticed, efforts should be undertaken to support the caregiver and, if present, the children of the patients. Specific skills for coping with the consequences of a bipolar disorder should be taught. Examples of relevant interventions are caregiver support groups for patients with a bipolar disorder held throughout the Netherlands. Psycho-education groups using the “Maastricht protocol” with patients and their relatives have also been shown to reduce the level of caregiver expressed emotion (EE) (Hofman et al. 1992). In turn, patients with low EE caregivers have been found to have a significantly lower number of hospital admissions when compared to patients with high EE caregivers (Honig et al. 1997). The children of patients with a bipolar disorder are at risk for the development of mood disorders (Reichart et al. 2007). Bipolar disorder is further known to be a disease which runs in families, which makes the routine

monitoring of children a task of considerable concern. The General Behavior Inventory (GBI) can be used for this purpose (Reichart et al., 2005). In the Netherlands, several interventions have already been initiated by mental health organizations to provide support for the children of parents with psychological problems. The most recent interventions are group prevention courses which involve the exchange of experiences, the provision of illness information and advising children with respect to how to deal with the behaviour of an impaired parent (Trimbos Institute, 2002).

### **The developing roles in mental health nursing**

National and international developments in the provision of mental health care will have their effects on the development of the nurse's role. In this paragraph we discuss the potential implications of these developments.

Psychiatric and mental health nursing has changed significantly during the past years, nationally as well as internationally. The movement from large inpatient mental health institutions towards the provision of mental health care in the community in many 'western' countries, changed the role of the psychiatric and mental health nurse. Nursing education and training in the Netherlands have undergone a fundamental shift from in-service training towards bachelors' and masters' levels of nursing education. New roles emerged since the mid ninety's such as the Clinical Nurse Specialist (CNS) and the Advanced Nurse Practitioners (ANP), a development that is seen in other countries as well (Wheeler & Haber, 2004; Williams et al., 1998; Delaney, 2005; Kudless & White, 2007). According to the WHO publication 'Atlas: nurses in mental health 2007' the number of CPNs per inhabitant is especially high in high income countries such as the USA, Australia, Japan and some European countries including Great Britain, The Netherlands, Spain, Sweden and Finland (WHO, 2007). The consumer satisfaction of patients who had received care and treatment provided by ANPs in Australia (Wortans, Happell, & Johnstone, 2006) and private CNSs in the United States of America (Baradell & Bordeaux, 2001) is high. The ANP in psychiatry is not a common professional employed in Dutch mental health care today and the debate about his role and position is still ongoing. (Koekkoek, 2004). However, the CNS in psychiatry is well accepted in Dutch mental health care.

Although the role of the CPNs in multidisciplinary teams is not always clear (Haque et al. 2002; Cunningham & Slevin, 2005), CPNs generally focus on people with severe and enduring mental illnesses and take case management roles in community teams (Gournay, 2005). In a recent systematic review of interventions

delivered by UK mental health nurses 52 RCTs were included. The results show that UK nurses are involved in the delivery of a wide range of interventions including psycho education, CBT, outpatient care programs, case management programs and Assertive Community Treatment (ACT) (Curran & Brooker, 2007).

One example of current variation in the role of CPNs, is the application of nurse-delivered Cognitive Behavioural Therapy (CBT). In his 1996 article, Gournay argued for the further development of training programmes for nurses in the area of CBT (Gournay, 1996). In a more recent (2005) article, the same author states that this has not been realised and that it is unlikely that this situation will change (Gournay, 2005). In Ireland, a national survey of CPNs and their client care activities revealed that no evidence exists on the effects of CPNs practising CBT (McCardle et al. 2007). In the Netherlands, CBT is mainly provided by psychologists although some mental health nurses are trained to perform CBT. The publications demonstrate that the nurse's role varies across countries and can include interventions such as CBT that are performed by psychologists in other countries.

In countries such as Australia, Canada, New Zealand, Great Britain and the United States of America, prescriptive practice for nurses is legal and common practice by ANPs (Kaas & Markley, 1998b; Dresser et al. 2001; Latter et al. 2007; Gournay, 2005). In the before mentioned WHO report, information is provided on prescriptive roles of mental health nurses world wide. Nurse are more likely to be allowed to prescribe in low income and African countries than in high income and European countries. In many low income countries nurses are often the only caregivers for patients with mental illness (WHO, 2007). In the UK, mental health nurse prescribers saw their prescribing task as a means to improving services to clients, engagement with clients, access to care, information about treatments, quality of care, and to increase their own job satisfaction and careers (Nolan & Bradley, 2007). In the Netherlands, only medical professionals, dentists and midwives were allowed to prescribe medication. In March 2007 however, Dutch laws were adapted and ANPs and CNS can be granted prescriptive authority within the area of their specialisation after the legislation process is finished. Before prescriptive authority can be granted, nurses need to be competent and qualified to do this task. There are yet many barriers to conquer in the organisation of this new practice. These barriers probably include the acceptance and support of the prescriber role, equitable reimbursement and organizing the process of obtaining prescriptive authority (Kaas et al. 1998a).

What will be the impact of nurses with prescriptive authority in the organisation of care for outpatients with a bipolar disorder? Will the organisation of the outpatient clinics become nurse driven and will the psychiatrist become an expert consultant? It can be asked if, in times of increasing demands on mental health care and limited resources, the role of the CPN can expand by shifting tasks from other professionals to the CPN. Also, it can be asked to what the effects of such a shift in tasks would be. Will there be an increase in therapeutic tasks and a decrease in nursing tasks? Will the patient benefit from it? Will the nurse provide a better quality of care? All these questions will remain unanswered until studies that examine the implementation and effects of this kind of organisation of mental health care delivery are performed.

### **Implications for the nurse's role in the provision of mental health care to outpatients with a bipolar disorder**

Basic treatment for outpatients with a bipolar disorder will commonly consist of pharmacotherapy, psycho education and self-management interventions. Psychotherapies such as cognitive behavioural therapy, interpersonal and social rhythm therapy, and family focussed therapy and supportive- and rehabilitation interventions will be provided when needed. The psychiatrist will be responsible for the treatment process for the patient, but other professionals such as the CPN can play a mayor role in the provision of treatment and care and in the coordination or management of care (Nolen et al., 2007).

When our implications for daily nurses' practice are implemented, this will stress the role of the CPN as a case manager for the patient in the multidisciplinary treatment process of the outpatient with a bipolar disorder. Also, using a nursing care plan will make his actions and goals transparent and testable. Choosing his interventions based on results of proper assessments will help both nurse and patient focussing on those problems with the largest impact on patients' daily lives. The CPN will make decisions based on results of indicators such as life chart results, (un)fulfilled needs for care, and number of psychopathological symptoms the patient is bothered by.

Some interventions are strictly in the domain of one profession. Pharmacotherapy for instance is still very much within the domain of the medical professional by law (although nurses will have some authority in future years; see above). Psychotherapies are mostly within the domain of psychiatrists and psychotherapists. Other interventions however such as psychoeducation, self

management interventions, and supportive and rehabilitation interventions are within the scope of several professionals.

Nurses provide various interventions in the treatment process of the patient. The question could be raised if these interventions are nursing interventions or just interventions carried out by nurses. Does the fact that nurses carry out activities justify the qualification of these activities as nursing interventions? Is psycho education carried out by a medical professional a medical intervention? What if this psycho education was carried out by nurses?

We have described earlier that the kind of interventions performed by nurses can differ between countries and cultures. Tasks are regularly shifted from other mental health professionals to the nursing profession, and tasks can be carried out by several professionals. There will always be a diffuse area between professionals regarding to the tasks and interventions they perform.

McCloskey and Bulechek (2002) define a nursing intervention as *"...any treatment, based on clinical judgement and knowledge, that a nurse performs to enhance patient/client outcomes. Nursing interventions include both direct and indirect care; those aimed at individuals, families, and the community; and those for nurse-initiated, physician initiated, and other provider-initiated treatments"*. McCloskey and Bulechek's definition is rather liberal and could potentially include anything from pharmacotherapy and psychotherapy to assistance with activities of daily living. A definition that is probably closer to current practice is given by Orem (1995). She defines nursing as *"...a human service related to the client's need and ability to perform self-care, and to help them sustain health, recover from disease or injury or cope with their effects"*. Although Orem's definition does not strictly exclude treatment of disease, it presents a clear and dominant focus on health promotion and disease prevention, assisting with self-care and supporting patients faced with the consequences of disease or injury.

Current developments in the roles and tasks of CPNs and mental health nurses in general can be seen in the light of the liberal Bulechek and McCloskey definition as nurses are increasingly involved in tasks that previously belonged to professionals within other disciplines. Results from this thesis however point out the need to revisit the core nursing tasks described by Orem, as our data showed the almost complete lack of evidence and the absence of systematic nursing activities in relation to these core tasks.

### **Implications for future research**

In Chapter 3, 5 of 22 patient problems, 5 out of 10 desired outcomes and 5 of the 18 current interventions were studied in depth. In order to enlarge the body of knowledge the remaining patient problems, outcomes and current interventions should also be studied in a similar way.

Twelve of the 157 patients we studied reported care needs related to sexuality but no fulfilment of the care needs (see Chapter 4). Sexual problems and interventions to address these problems were not mentioned by the CPNs in the initial study of actual nursing practices (Chapter 3). Future research should certainly examine the occurrence and nature of the problems with sexuality or sexual functioning in order to develop the necessary nursing interventions or adjust existing nursing interventions to include sexual counselling (McCloskey & Bulechek, 2002).

Future research on the care needs of patients with a bipolar disorder should also address the risk factors related to the occurrence of particular care needs. CPNs should be informed about such risk factors in order to help prevent their occurrence and should intervene when they do arise. Studies using mixed methods with patients who have recently been diagnosed as having a bipolar disorder can also provide insight into the emergence of particular care needs and those factors which appear to play a role in the emergence of such care needs during the illness process.

In order to gain greater insight into the consequences of a bipolar disorder for caregivers and the incidence of caregiver distress, future research should be undertaken with the aid of the Involvement Evaluation Questionnaire (IEQ) (Schene & van Wijngaarden, 1992) and focus on the caregivers of patients during an acute episode of bipolar depression or (hypo)mania. Many of the participants in the present study assured us that the results would have been totally different if they had completed the relevant questionnaire while their relative was suffering from an acute episode of bipolar depression or (hypo)mania. And although the majority of the caregivers reported feeling reasonably happy, a topic which remains to be explored is the impact of the consequences of a bipolar disorder for the caregiver and the degree of caregiver distress on the daily functioning and quality of life for the caregiver him/herself.

An intervention currently in practice in the Netherlands is to help patients develop and utilize personal action plans. Although the use of action plans is perceived to be highly promising (Sierra et al. 2007; Morriss, 2004; Scott, 2001), only a single randomized clinical trial with a rather small sample (n=69) has been

conducted to examine the efficacy of personal actions plans (Perry et al., 1999). Replication of this randomized control trial but then in a larger, multi-centre study is clearly necessary to confirm the promise of actions plans and strengthen the evidence in their favour.

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## **Summary**

Ambulatory treatment of patients with bipolar disorder is a long-term process in which community psychiatric nurses (CPNs) are increasingly being involved. Examination of Dutch mental health care programs and existing guidelines for mental health care has shown that the professional contributions of nurses are not at all, or only very briefly described. The available guidelines for the treatment of bipolar disorders provide good quality information on pharmacotherapy, psycho-education, and psychotherapeutic interventions but do not reflect the role of the mental health nurse in the care and treatment process, nor the nurses' contribution to it. The establishment of a body of knowledge pertaining to the nursing of patients with a bipolar disorder is therefore vital for the development of integrated evidence-based treatment.

### **Chapter 1**

Chapter 1 contains a general introduction. In chapter 1 background information is given on diagnosis and epidemiology, treatment, consequences of the disease and the rationale for this thesis. This thesis focuses on opening up nursing knowledge for the nursing of outpatients with a bipolar disorder. This general aim is specified in two sub-aims:

1. To describe what is known in literature about nursing patients with a bipolar disorder and what nurses actually do in daily practice while nursing outpatients with a bipolar disorder.
2. To provide information on care needs, coping styles, psychopathological symptoms, quality of life, and caregiver consequences in outpatients with a bipolar disorder to nurses, that can support them in their critical decision making process while planning, conducting and evaluating the nursing care.

### **Chapter 2**

Chapter 2 presents the results of a literature review carried out to identify the nursing processes described in the international literature and to investigate whether these nursing processes are supported by evidence. A sensitive literature search was conducted in which Medline, EMBASE, Psychlit, CINAHL, and INVERT and Cochrane databases were searched for papers regarding bipolar disorder and nursing published in the period January 1980 to January 2006. Not only scientific papers were included in the review, descriptive reports by practising nurses were included as well. The results show that formal research on the

nursing of patients with a bipolar disorder is remarkably limited. Three quantitative studies and six qualitative studies addressing a broad range of topics were identified. The remaining articles meeting the inclusion criteria contained mostly descriptive reports.

An overview of the nursing processes used during the euthymic stage of a bipolar disorder and during an acute episode of (hypo)mania is presented. No specific nursing processes for acute episodes of bipolar depression are described in the literature. The most promising nursing processes for the care of patients with a bipolar disorder appear to be: a specific bipolar disorder nursing assessment; concrete formulation of both care and crisis plans; protection; psycho-education measures, and other measures aimed to enhance self-management and treatment compliance; support for the patient, caregivers, family, and friends; observation of treatment effectiveness and any side-effects of medication; and easy access to the nurse as a case manager. The results show hardly any evidence for the described nursing processes.

### **Chapter 3**

Chapter 3 describes the results of a qualitative study that was undertaken to gain insight into the daily practice activities of CPNs involved in the nursing of outpatients with bipolar disorders in the Netherlands.

Semi-structured interviews were undertaken with 23 CPNs and additional focus group interviews were conducted. Information was gained on the problems encountered by the patients, desired outcomes, interventions used, and the role of the CPNs in the treatment of these outpatients.

Non-acceptance of the disease appeared to be the most common problem which nurses see. Maintenance of an euthymic mood state was the most desired outcome, and nurse accessibility constituted the most common nursing intervention. In total 22 nursing problems, 10 desired outcomes, and 18 nursing interventions were identified. The nursing process as it is conducted by the nurses lacked a systematic approach. It can nevertheless be concluded that CPNs in the Netherlands use all but two of the most promising nursing processes mentioned in Chapter 2. Dutch CPNs do not undertake a specific bipolar disorder nursing assessment and do not formulate a nursing care plan, which shows the decisions made during the nursing process to be largely ad hoc and based upon the experiences of the particular CPN. Thus, a generally sufficient level of quality cannot be guaranteed. The nurses whom we interviewed stated that the care for outpatients with a bipolar disorder is definitely within the scope of their tasks. In

fact, the nurse is often a continuous factor in the extended treatment of a patient, knows the patient inside and out, and is very capable of predicting instabilities that can lead to episodes of (hypo)mania or depression.

In the second part of this thesis we describe the results of cross sectional, explorative, studies on care needs, coping styles, psychopathological symptoms and quality of life of 157 outpatients with a bipolar disorder, and caregiver consequences, coping styles and distress of 115 informal caregivers of these outpatients. The sample was taken from the population of 5 outpatient clinics in the Netherlands. Data were collected through questionnaires.

#### **Chapter 4**

A strong predictor of a lower quality of life among people with a severe mental illness is the presence of unmet care needs. Chapter 4 describes the results of a study that was conducted to investigate the care needs, care received and unmet care needs for a population of outpatients with a bipolar disorder in the Netherlands. The participants completed the Need for Care Questionnaire and a questionnaire addressing various demographic and clinical characteristics. The results show the care needs to mainly involve the domains of psychological help, psychiatric help and social functioning. Unmet needs are frequently reported for all of the scales and almost all of the items. Some significant associations between source of income, number of hospitalizations and involvement of CPNs, on the one hand, and reported care needs on the other hand, are identified. Closer inspection of the items showed the majority of the items on which care is needed to address coping with the consequences of the disease or the skills needed for self-management of the disease. A very important skill for patients with a bipolar disorder is to recognize early warning signs and undertake measures to prevent mood destabilization and relapse. While life charts and action plans are among the most important relapse prevention techniques available to outpatients with a bipolar disorder, only 28.7% and 37.6% report using the respective techniques. It is possible that the care needs go largely unmet because little attention is paid to the structured assessment of their needs during treatment. That is, many of the needs of the patient with a bipolar disorder go largely unnoticed. An important point for improvement is thus incorporation of assessment procedures to evaluate the care needs of patients during the treatment process.

## **Chapter 5**

In Chapter 5, the results of a study of the coping styles of outpatients with a bipolar disorder are reported. The study was undertaken to gain greater insight into the coping styles of outpatients with a bipolar disorder when confronted with problems and unpleasant events. The participants completed the Utrecht Coping List and a questionnaire addressing various demographic and clinical characteristics. The results showed outpatients with a bipolar disorder generally reported using a less active, more passive and more avoidant style of coping when confronted with problems or unpleasant events than people in the general population. Although causality cannot be assumed, more active coping styles in which the patients disentangle the problematic situation and intentionally work to solve the problems appear to occur relatively more often among patients with higher educational levels and among patients who already have or are currently developing an action plan to cope with the prodromal phase of disease relapse. A passive coping style in which the patient is overwhelmed by the problem and unable to solve the relevant problems appears to be associated with the frequent occurrence of acute episodes of depression and/or (hypo)mania. Again, causality cannot be assumed given our cross sectional study design.

## **Chapter 6**

Growing evidence exists that patients with a bipolar disorder in a euthymic mood state can suffer from subsyndromal or residual symptoms of depression or hypomania causing considerable burden and functional impairment. In chapter 6 the results of a study that was undertaken to gain insight into the broader spectrum of psychopathological symptoms and quality of life (QOL) associated with it are presented. The participants completed the Symptom Check-List-90 (SCL-90), the World Health Organisation Quality Of Life–Bref (WHOQOL-Bref) and a questionnaire addressing demographic and clinical characteristics. Outpatients with a bipolar disorder reported more symptoms of psychopathology than the general population but a number of symptoms comparable to patients visiting their general practitioner. Compared to psychiatric outpatients in general, the population of outpatients with a bipolar disorder in the present study reported fewer psychopathological symptoms. As might be expected, the overall QOL scores were significantly lower for the outpatients with a bipolar disorder than for the general population. The more psychopathological symptoms reported, the lower the QOL score. Patients with a depressive mood state during the interview reported significantly more psychopathological symptoms and lower QOL than

patients with a euthymic or (hypo)manic mood state during the interview. It can thus be hypothesized that symptoms of depression are the most important cause of a reduced quality of life for individuals living with a bipolar disorder. However, those patients who reported euthymia also reported psychopathological symptoms, and not only depressive subsyndromal symptoms, which all contributed to reports of a reduced QOL.

## **Chapter 7**

In Chapter 7, the consequences of bipolar disorder for the caregivers of outpatients with a bipolar disorder, the coping styles of these caregivers and the distress experienced by the caregivers of outpatients with a bipolar disorder are examined. The family caregivers of the patients from the previous studies were asked to complete the Involvement Evaluation Questionnaire (IEQ) to measure caregiver consequences, the Utrecht Coping List (UCL) to measure caregiver's coping styles, and the 12-item General Health Questionnaire (GHQ-12) to measure caregiver distress. The results show relatively few consequences for the caregivers of outpatients with a bipolar disorder during a period of 4 weeks prior to the time of assessment although more than 30% of the caregivers reported being psychological distress. The consequences for the children under the age of 16 of outpatients with a bipolar disorder appear to be much more eminent. With respect to the coping styles of the caregivers, male caregivers are generally found to report using a more avoidant coping style and undertaking more activities to provide distraction than males in the general population. Female caregivers, in contrast, generally report the use of a less active coping style and the pursuit of less social support than females in the general population. Finally, feelings of distress were reported more often by caregivers who reported relatively greater consequences of the disease for themselves, a relatively more avoidant coping style and a relatively passive pattern of reacting to problems.

## **Chapter 8**

In Chapter 8 the main findings and conclusions of our studies, the strengths and limitations, the implications for daily nursing practice, and the implications for future research are presented and discussed.

The nursing care for outpatients with a bipolar disorder is not evidence-based and not conducted in a systematic manner by Dutch CPNs. Nursing care plans are not utilized. Many of the care needs of outpatients with a bipolar disorder go largely unnoticed and thus unmet.

Our study sample was drawn from a population of outpatients, which means that the present results do apply to all individuals with a bipolar disorder. It can further be asked if our sample of outpatients with a bipolar disorder is representative of the population under investigation. It is possible, for example, that only patients with a relatively good mental condition and euthymic mood state were approached by the psychiatrist or CPN to participate in the present study. This may have caused selection bias in all the studies in the second part of this thesis.

A promising intervention for the nursing of outpatients with a bipolar disorder is certainly the use of an action plan to prevent relapse and thus the occurrence of acute episodes. Patients who are using or have used an action plan tend to adopt more active coping styles which can foster increased self-efficacy and levels of positive affect. The provision of support for the development and maintenance of an action plan is therefore one of the key interventions for CPNs caring for outpatients with a bipolar disorder. Although there is some evidence that supports the use of action plans, we recommend to perform a more in depth study to strengthen the level of evidence of this intervention.

Outpatients with a bipolar disorder typically suffer from a broad range of psychopathological symptoms and experience a decreased quality of life relative to the general population. The greater the number of symptoms and particularly symptoms of depression, the lower the QOL score. CPNs can play a major role in helping outpatients with a bipolar disorder maintain a euthymic mood state. However, even when the patient is in a stable mood state, attention must be paid to the remainder of the patient's care needs, existing symptoms, and to efforts to improve the patient's quality of life as well. Conducting this nursing care in a systematic way might improve quality of care and patient outcomes.

## **Samenvatting**

De poliklinische behandeling van patiënten met een bipolaire stoornis is een langdurig proces waar de ambulant werkende verpleegkundige meer en meer een rol in heeft gekregen. Binnen de Nederlandse zorgprogramma's en de (inter)nationale richtlijnen zien we dat de inhoudelijke bijdrage van verpleegkundigen zeer beperkt of in het geheel niet is terug te vinden. De beschikbare richtlijnen voor de behandeling van patiënten met een bipolaire stoornis geven kwalitatief goede informatie over medicatie, psycho-educatie en psychotherapeutische interventies maar voorzien niet in een beschrijving van de rol van de GGZ verpleegkundige in het zorg- en behandeltraject, noch van diens bijdrage daarin. De ontwikkeling van een kennisstock over het verplegen van patiënten met een bipolaire stoornis is van essentieel belang voor de ontwikkeling van een geïntegreerde evidence based behandeling.

### **Hoofdstuk 1**

In hoofdstuk 1 is een algemene inleiding beschreven met daarin informatie over de diagnose, de epidemiologie, de behandeling, en de consequenties van de ziekte. Tevens zijn de achtergronden van dit proefschrift beschreven. Dit proefschrift heeft tot doel om kennis te ontsluiten voor en over het verplegen van patiënten met een bipolaire stoornis. Deze algemene doelstelling is uitgewerkt in 2 subdoelstellingen:

1. Beschrijven wat er in de bestaande literatuur bekend is over het verplegen van patiënten met een bipolaire stoornis en beschrijven wat verpleegkundigen momenteel doen als ze poliklinische patiënten met een bipolaire stoornis verplegen.
2. Informatie verstrekken aan verpleegkundigen over zorgbehoeften, coping stijlen, psychopathologische symptomen, kwaliteit van leven en over de gevolgen voor de naastbetrokken van poliklinische patiënten met een bipolaire stoornis. Deze informatie kan verpleegkundigen ondersteunen in hun kritische besluitvormingsprocessen tijdens het plannen, uitvoeren en evalueren van de verpleegkundige zorg.

### **Hoofdstuk 2**

In hoofdstuk twee worden de resultaten gepresenteerd van een literatuuronderzoek dat werd uitgevoerd om de verpleegkundige hulpverleningsprocessen en hun wetenschappelijke evidentie te identificeren in de internationale literatuur.

Een sensitieve zoekstrategie werd gebruikt In Medline, EMBASE, Psychlit, CINAHL, INVERT en de Cochrane databases werd gezocht naar artikelen over het verplegen van patiënten met een bipolaire stoornis die gepubliceerd waren in de periode van januari 1980 tot en met januari 2006. Niet alleen wetenschappelijk artikelen werden opgenomen in dit literatuuronderzoek, maar ook niet wetenschappelijke artikelen, geschreven door verpleegkundigen werden meegenomen. Uit de resultaten van het literatuuronderzoek bleek dat er nauwelijks wetenschappelijk onderzoek gedaan was. Drie kwantitatieve studies en 6 kwalitatieve studies beschrijven een brede range aan onderwerpen. De resterende artikelen die binnen de inclusiecriteria vielen bestonden voornamelijk uit niet wetenschappelijke artikelen.

In hoofdstuk 2 wordt een overzicht gepresenteerd van de verpleegkundige processen tijdens de euthyme fase en tijdens de (hypo)manische episode van de bipolaire stoornis. De meest veelbelovende verpleegkundige processen die zijn beschreven zijn: een specifieke verpleegkundige anamnese afgestemd op de bipolaire stoornis; het opstellen van een verpleegplan en een noodplan; het bieden van bescherming; het geven van psycho-educatie en voorlichting; het aanleren en ondersteunen van zelf-management activiteiten en activiteiten gericht op het bevorderen van therapietrouw; ondersteuning bieden aan patiënten, naast betrokken en andere hulpverleners; het observeren van de effectiviteit van de behandeling en de (bij)werkingen van medicatie; en de gemakkelijke toegankelijkheid en bereikbaarheid van de verpleegkundige als case-manager. Uit de resultaten van dit literatuuronderzoek blijkt dat er voor de beschreven verpleegkundige processen nauwelijks wetenschappelijke evidentie is.

### **Hoofdstuk 3**

Hoofdstuk drie beschrijft de resultaten van een kwalitatief onderzoek dat tot doel had om inzicht te krijgen in de dagelijkse activiteiten van ambulant werkende verpleegkundigen tijdens het verplegen van poliklinische patiënten met een bipolaire stoornis in Nederland.

23 ambulant werkende verpleegkundigen werden individueel door middel van semi-gestructureerde interviews en later in focus groepen geïnterviewd. Informatie werd verzameld over de problemen die ze zagen bij hun patiënten, de verpleegkundige zorgresultaten en de interventies die ze gebruiken en over de rol die de verpleegkundigen voor zichzelf zagen in de behandeling van deze groep poliklinische patiënten.

Het niet accepteren van de ziekte bleek het meest voorkomende probleem te zijn. Het behouden van een euthieme stemming het meest nagestreefde zorgresultaat en de gemakkelijke bereikbaarheid en toegankelijkheid van de verpleegkundige de belangrijkste interventie. In totaal werden 22 problemen, 10 zorgresultaten en 18 interventies geïdentificeerd.

Het verpleegkundig proces, zoals uitgevoerd door de geïnterviewde verpleegkundigen verloopt niet op een systematische wijze. Desalniettemin kunnen we concluderen dat ambulant werkende verpleegkundigen op 2 na alle veelbelovende verpleegkundige processen gebruiken die zijn beschreven in hoofdstuk 2. Nederlandse ambulant werkende verpleegkundigen maken geen gebruik een specifieke verpleegkundige anamnese en ook niet van een verpleegplan. Dit betekent dat de besluiten die worden genomen tijdens het verpleegkundig proces grotendeels ad hoc plaatsvinden en gebaseerd zijn op de ervaringen van een individuele verpleegkundige. Een gemiddelde kwaliteit van zorg kan dan ook niet worden gegarandeerd. De verpleegkundigen die we interviewden gaven aan dat de zorg voor patiënten met een bipolaire stoornis zeker binnen de reikwijdte van hun taken behoort. De verpleegkundige is vaak de continue factor binnen een behandeling, kent de patiënt door en door en is goed in staat om kwetsbaarheden te identificeren die zouden kunnen leiden tot episoden van depressie of (hypo)manie.

In het tweede deel van dit proefschrift beschrijven we de resultaten van beschrijvende studies met een dwarsdoorsnede design naar zorgbehoeften, coping stijlen, psychopathologische symptomen en kwaliteit van leven binnen een steekproef van 157 poliklinische patiënten en naar de consequenties voor 115 naastbetrokkenen, hun coping stijlen en klachten. De steekproef was getrokken uit een populatie patiënten met een bipolaire stoornis van 5 psychiatrische poliklinieken in Nederland. Data werden verzameld door middel van vragenlijsten.

#### **Hoofdstuk 4**

Een sterke voorspeller van een lagere kwaliteit van leven bij mensen die lijden aan een ernstige psychische stoornis is de aanwezigheid van onvervulde zorgbehoeften. Hoofdstuk 4 beschrijft de resultaten van een onderzoek dat tot doel had om te inventariseren welke zorgbehoeften, ontvangen zorg en onvervulde zorgbehoeften poliklinische patiënten met een bipolaire stoornis in Nederland hebben. De deelnemers aan het onderzoek vulden de zorgbehoeftenlijst en een vragenlijst om de demografische en klinische kenmerken

in kaart te brengen in. De resultaten laten ons zien dat de behoeften aan zorg zich vooral bevinden in het domein van psychologische hulp, psychiatrische hulp en sociaal functioneren. Onvervulde zorgbehoeften worden frequent gerapporteerd voor alle schalen en bijna alle items. Een aantal significante verbanden tussen de bron van inkomsten, het aantal klinische opnamen en de betrokkenheid van ambulant werkende verpleegkundigen aan de ene kant en de gerapporteerde zorgbehoeften aan de andere kant konden worden geïdentificeerd. Een nadere bestudering van de items leerde ons dat de meerderheid van de items waarop zorg nodig wordt geacht gerelateerd zijn aan het leren omgaan met de consequenties van de ziekte en de vaardigheden die nodig zijn voor het zelfmanagement van de ziekte. Zeer belangrijke vaardigheden voor patiënten met een bipolaire stoornis zijn het tijdig herkennen van de vroege voortekenen van een episode en het ondernemen van acties om destabilisatie en terugval te voorkomen. Life charts en nood- signaleringsplannen zijn hierbij belangrijke hulpmiddelen. Toch zien we dat respectievelijk slechts 28,7% en 37,6% van de respondenten gebruik maakt van deze hulpmiddelen. Het is mogelijk dat veel zorgbehoeften onvervuld blijven omdat er weinig aandacht wordt besteed aan een gestructureerde anamnese van de zorgbehoefte van de patiënt gedurende diens behandeling. Een belangrijk aandachtspunt voor verbetering is dan ook het implementeren van een procedure om de zorgbehoeften van de patiënt te meten gedurende diens behandeltraject.

## Hoofdstuk 5

In hoofdstuk 5 worden de resultaten van een studie naar de copingstijlen van poliklinische patiënten met een bipolaire stoornis beschreven. De studie had tot doel om inzicht te verkrijgen in de copingstijlen die de patiënten gebruiken wanneer ze zich geconfronteerd zien met problemen en onplezierige situaties. De deelnemers aan het onderzoek vulden de Utrechtse Coping Lijst en een vragenlijst om de demografische en klinische kenmerken in kaart te brengen in. De resultaten laten ons zien dat poliklinische patiënten met een bipolaire stoornis over het algemeen een minder actieve, meer passieve en vermijdende copingstijl gebruiken dan de gemiddelde Nederlander wanneer ze geconfronteerd worden met problemen en onplezierige situaties. Hoewel causaliteit niet kan worden verondersteld blijkt dat een actieve copingstijl waarbij de patiënt de problematische situatie analyseert en vervolgens werkt aan het oplossen van de problemen meer voorkomt bij patiënten met een hoger opleidingsniveau en bij patiënten die een nood- of signaleringsplan gebruiken of er ooit één gemaakt

hebben. Een passieve copingstijl, waarbij de patiënt zich laat overweldigen door de problemen en geen mogelijkheden ziet om ze op te lossen lijkt gerelateerd te zijn aan het frequenter voorkomen van acute episoden van depressie en/of (hypo)manie. Wederom kan geen causaliteit worden verondersteld als gevolg van het dwarsdoorsnede design van dit onderzoek.

## **Hoofdstuk 6**

Het is bekend dat patiënten met een bipolaire stoornis met een euthieme stemming kunnen lijden aan subsyndromale of restsymptomen van depressie of hypomanie die een aanzienlijke lijdensdruk en functionele beperkingen tot gevolg hebben. In hoofdstuk 6 worden de resultaten gepresenteerd van een onderzoek dat tot doel had om inzicht te geven in het voorkomen van psychopathologische symptomen en de samenhang met de ervaren kwaliteit van leven. De deelnemers aan het onderzoek vulden de Symptoms Checklist 90, de World Health Organisation Quality of Life-Bref en een vragenlijst om de demografische en klinische kenmerken in kaart te brengen in. Ambulante patiënten met een bipolaire stoornis rapporteerden meer symptomen dan de algemene bevolking maar ongeveer evenveel als de gemiddelde bezoeker aan een huisartsenpraktijk. Vergeleken met patiënten die een psychiatrische polikliniek bezoeken rapporteerden de deelnemers aan ons onderzoek gemiddeld minder psychopathologische symptomen. Zoals verwacht rapporteerden de deelnemers aan ons onderzoek een significant lagere kwaliteit van leven dan de gemiddelde Nederlander. Verder zagen we dat hoe meer psychopathologische symptomen werden gerapporteerd hoe lager de kwaliteit van leven werd ervaren. Patiënten in een meer depressieve stemming tijdens het interview rapporteerden significant meer psychopathologische symptomen en een lagere kwaliteit van leven dan patiënten die ten tijde van het onderzoek een euthieme of hypomane stemming rapporteerden. Het kan dus verondersteld worden dat symptomen van depressie de meest belangrijke oorzaak zijn van een verminderde kwaliteit van leven bij patiënten met een bipolaire stoornis. Patiënten in een euthieme stemming rapporteerden echter ook psychopathologische symptomen, en niet alleen symptomen van depressie. Deze symptomen droegen allen bij aan een verminderde kwaliteit van leven.

## **Hoofdstuk 7**

In hoofdstuk 7 worden de gevolgen voor de naastbetrokkenen van de ambulante patiënten met een bipolaire stoornis beschreven. Tevens worden de copingstijlen

en de lijdensdruk van deze naastbetrokkenen onderzocht. De naastbetrokkenen van de patiënten die deelnamen aan de vorige studies werden gevraagd de Betrokkenen Evaluatie Schaal in te vullen waarmee de consequenties in kaart werden gebracht. Tevens vulden ze de Utrechtse Copinglijst en de 12 item General Health Questionnaire om de psychologische lijdensdruk te meten in. De resultaten toonden aan dat de naastbetrokkenen betrekkelijk weinig gevolgen voor zichzelf rapporteerden in de periode van 4 weken die voorafging aan het interview. Meer dan 30% gaf echter aan een grote psychologische lijdensdruk te ervaren. De gevolgen die gerapporteerd werden voor kinderen onder de 16 jaar bleken echter aanzienlijk. Ten aanzien van copingstijlen blijkt dat mannelijke naastbetrokkenen in het algemeen een meer vermijdende en afleiding zoekende copingstijl hanteerden dan mannen in de algemene bevolking. Vrouwelijke naastbetrokkenen bleken een minder actieve copingstijl te gebruiken dan vrouwen in de algemene bevolking. Daarnaast zochten ze minder sociale steun. Psychologische lijdensdruk werd meer gerapporteerd door deelnemers die meer gevolgen voor zichzelf rapporteerden, een meer vermijdende copingstijl hanteerden en passief reageerden op de voorkomende problemen.

## Hoofdstuk 8

In hoofdstuk 8 worden de algemene bevindingen en conclusies uit onze studies, de sterke punten en beperkingen van de kozen onderzoeksmethoden, de implicaties voor de verpleegkundige praktijk, de gevolgen voor de rol van de verpleegkundige in het behandelproces en de implicaties voor vervolgonderzoek beschreven en bediscussieerd.

De verpleegkundige zorg voor ambulante patiënten met een bipolaire stoornis is niet evidence based en wordt niet op een systematische wijze uitgevoerd door ambulante werkende psychiatrisch verpleegkundigen in Nederland. Verpleegplannen worden niet gebruikt en de zorgbehoeften van deze groep patiënten blijven grotendeels onopgemerkt en er wordt zodoende niet in voorzien. De steekproef werd getrokken uit een populatie van ambulante patiënten. Dit betekent dat de gevonden resultaten niet toepasbaar zijn op alle personen die lijden aan een bipolaire stoornis. Verder kunnen we ons afvragen of onze steekproef representatief is voor de onderzochte populatie. Het is mogelijk dat slechts patiënten in een relatief goede mentale conditie en een euthieme stemming werden gevraagd door hun psychiater of verpleegkundige om aan dit onderzoek deel te nemen. Dit kan selectie bias veroorzaakt hebben in alle studies in het tweede deel van dit proefschrift.

Een veelbelovende verpleegkundige interventie voor ambulante patiënten met een bipolaire stoornis is het gebruik van het nood- of signaleringsplan om acute episodes te voorkomen. Patiënten die een nood- signaleringsplan hebben of hebben gehad blijken een meer actieve copingstijl te hanteren waardoor meer vertrouwen in de eigen mogelijkheden en een positiever zelfbeeld ontstaan. Het ondersteunen van de patiënt bij het opstellen en onderhouden van dit nood-signaleringsplan is daarom één van de sleutelinterventies van de ambulante werkende verpleegkundige bij patiënten met een bipolaire stoornis. Hoewel er enige evidentie is voor het gebruik van deze plannen bevelen wij vervolgonderzoek aan om de bewijskracht van deze interventie te versterken.

Ambulante patiënten met een bipolaire stoornis lijden, vergeleken met de algemene bevolking, aan een brede range van psychopathologische symptomen en een verminderde kwaliteit van leven. Hoe meer symptomen, depressieve symptomen in het bijzonder, hoe lager de kwaliteit van leven. Ambulant werkende verpleegkundigen spelen een belangrijke rol in het helpen van patiënten om een euthieme stemming te behouden. Echter, zelfs als deze euthieme stemming is bereikt dient blijvend aandacht te worden geschonken aan nog bestaande zorgbehoeften en de nog voorkomende psychopathologische symptomen. Verder dienen interventies te worden ingezet om de kwaliteit van leven verder te verbeteren. Het op een systematische manier uitvoeren van deze verpleegkundige zorg zou de kwaliteit van de geboden zorg en de resultaten voor de patiënt verder kunnen verbeteren.



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