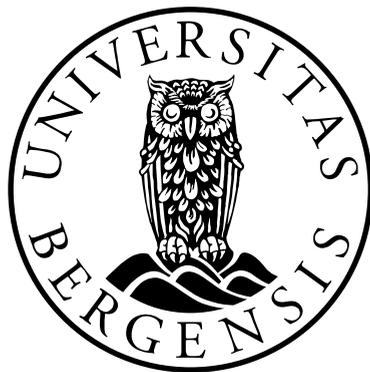


# Recovery in bipolar disorder

*A reflexive-collaborative exploration of the lived experiences of healing and growth when battling a severe mental illness*

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## **Scientific environment**

This research project is a shared enterprise between the Group for Qualitative Research on Mental Health at the Department of Clinical Psychology, University of Bergen, and the Regional Research Network on Mood Disorders (MoodNet) at Haukeland University Hospital. It has been financially supported by the Norwegian Extra Foundation for Health and Rehabilitation through EXTRA funds. The project has received additional funding from MoodNet as well as the Meltzer Fund at the University of Bergen.

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I also thank student Caroline Petersen for help with transcriptions of the interviews in the second study of this project and for assistance in recording the process of data analysis of this material in field notes.

I am very grateful for the opportunity to learn from the participants in both of the studies that comprise this thesis, and hope their stories as told in various publications and presentations will be understood and appreciated as much by others as by me.

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## **Abstract**

The aim of this thesis is to explore processes of recovery in bipolar disorder. What do people with bipolar disorders do to promote healing and growth in their lives, and what challenges do they meet over the course of their recovery? How do professionals view their patients' struggles and efforts when facing a bipolar disorder, and what role do they see the individuals themselves as having in processes of improvement and positive change?

We conducted two qualitative studies to approach this aim. In the first study we performed semi-structured individual interviews with people who have battled a bipolar disorder and in the second study with experienced therapists who have engaged with people in this struggle. These investigations were developed and conducted within a reflexive-collaborative framework where a group of people with first-hand knowledge of the phenomena of focus participated as coresearchers. We cooperated in the process of designing the present research project, making preparations for the data collection and analyzing the transcribed interviews. A hermeneutical-phenomenological approach was utilized in our efforts to understand the participants' experiences of healing and growth when facing a bipolar disorder. From this perspective, the phenomenological goal of exploring participants' lived experiences is seen as requiring a hermeneutical process of interpretation and reconstruction of meaning. The understandings generated in the present research project will therefore require the fusion of the experiential horizons of researchers, coresearchers and participants.

The findings of this thesis are presented in three articles. The first paper explores how participants in the first study experience their own efforts toward improvement and positive change in an everyday life confronted with a bipolar disorder: what do individuals with bipolar disorders do to promote their personal recovery, and what challenges do they meet? The second paper examines these participants' accounts of what it is like discovering that one is struggling with a bipolar disorder: what does it

mean for a person to find out that their symptoms and distress match the description of what is commonly seen as a severe mental illness? The third paper presents results from the second study focusing on how these participants view processes of recovery in bipolar disorder as well as the person's own initiatives to heal and grow: how do psychiatrists and clinical psychologists view their patients' struggles and efforts when facing a bipolar disorder?

In the articles we present our findings as themes that summarize important aspects of the participants' descriptions. In the first paper, four themes are drawn from our analysis of the participants' efforts to improve and recover: (1) handling ambivalence about letting go of manic states; (2) finding something to hang on to when the world is spinning round; (3) becoming aware of signals from self and others; and (4) finding ways of caring for oneself. In the second paper, we describe first-person perspectives on the process of finding out that one is struggling with a bipolar disorder through three phases: (1) uncertainty and confusion; (2) grasping the novel and unusual experiential states; and (3) giving meaning to the lived experiences of intense ups and downs. In the third paper, three themes summarize the participants' narratives of their patients' struggles and efforts when facing a bipolar disorder: (1) a puzzling given; (2) the protagonist of the recovery process; and (3) the heroic fighter does not always win.

The findings in each of the articles are discussed in relation to established theory, research and practice. The limitations and strengths of the studies are explored, as well as our experiences of conducting the research. As the present research project is based on a novel and innovative approach to generating knowledge in the field of mental health, this thesis not only aims to explore recovery processes, but also to discuss and make the reflexive-collaborative methodology that we have utilized available to the scientific community.

## List of publications

- Paper 1: Veseth, M., Binder, P. E., Borg, M., & Davidson, L. (2012). Toward caring for oneself in a life of intense ups and downs: A reflexive-collaborative exploration of recovery in bipolar disorder. *Qualitative Health Research*, 22, 119-133. doi: 10.1177/1049732311411487 (originally published online 8 June 2011)
- Paper 2: Veseth, M., Binder, P. E., Borg, M., & Davidson, L. (in press). How I found out I had a bipolar disorder: A reflexive-collaborative exploration of the process of identifying that one is struggling with a severe mental health problem. *Qualitative Studies*.
- Paper 3: Veseth, M., Binder, P. E., Borg, M., & Davidson, L. (submitted). Experienced therapists' view of their patients' struggles and efforts when facing a bipolar disorder.

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## Table of contents

<b>Scientific environment</b> .....	2
<b>Acknowledgments</b> .....	3
<b>Abstract</b> .....	5
<b>List of publications</b> .....	7
<b>Table of contents</b> .....	8
<b>Introduction</b> .....	10
Qualitative inquiry.....	12
Bipolar disorders.....	15
Recovery.....	18
Aims.....	24
<b>Methods</b> .....	25
Researchers and coresearchers.....	25
Collaboration in the process of developing the study, preparing the data collection, and performing the analysis.....	26
Study 1.....	30
Study 2.....	31
Ethical considerations.....	32
<b>Findings</b> .....	34
Summary of paper 1.....	34
Summary of paper 2.....	35
Summary of paper 3.....	36
<b>Discussion</b> .....	37

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The principal role of the person.....	38
Much more simply human than otherwise.....	41
The importance of the first-person perspective.....	42
Collaboration and reflexivity.....	44
Evaluating qualitative inquiry.....	48
Strengths and limitations.....	51
Implications for research and practice.....	52
Concluding comments.....	53
<b>References.....</b>	<b>54</b>
<b>Paper 1.....</b>	
<b>Paper 2.....</b>	
<b>Paper 3.....</b>	

## Introduction

This is the story of a collaborative research project – a joint enterprise of knowledge creation carried out in partnership between a group of researchers with competence in therapy in the field of mental health and qualitative research within this area and a group of coresearchers with lived experiences of mood disorders and recovery processes. Over a four-year period we worked together in developing and designing the project, collecting the data, performing the analysis, and disseminating the project in publications and presentations (see Borg & Hauge, 2009; Borg, Veseth, Binder, & Topor, 2011; Moltu, Stefansen, Svisdahl, & Veseth, 2012, in press; Sundfør, 2011; Svisdahl, Moltu, & Sletvold, 2010; Veseth, 2012; Veseth, Binder, Borg, & Davidson, 2012, in press, submitted). In cooperation with Marit Borg, I have acted as the principal investigator in the process of facilitating the collaborative efforts that constitute this research project.

The project is comprised of two qualitative studies in which we explored processes of recovery in bipolar disorder through individual in-depth interviews with people who have battled these conditions and with therapists who have engaged with people in this struggle. That being so, our collaborative efforts have been directed at examining the experiences of improvement and growth both from the perspective of the individuals affected with a bipolar disorder and from the perspective of psychiatrists and clinical psychologists who work with these people. The research project therefore contains a multitude of layers or views on processes of recovery: (1) the experiences of those who are struggling with a bipolar disorder, and (2) the experiences of therapists who engage with these people in their efforts to manage distress and promote positive change; as well as (a) the understanding of these experiences from the point of view of researchers who have a background as professionals within this field, and (b) the understanding of these experiences from the perspectives of coresearchers who themselves have experienced processes of recovery in mood disorders.

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Collaborative research is one of many routes to scientific knowledge. In the present project, reflexivity has been the guiding methodological principle paving the way. To examine our participants' first-person perspectives on healing and growth in bipolar disorder, we utilized what we have termed a hermeneutical-phenomenological approach developed within a reflexive-collaborative framework (Veseth et al., 2012, in press, submitted). The phenomenological element in this approach lies in our aim and commitment to explore everyday experiences through dialogical engagement with our participants in the interview situation as well as through the transcribed text. The hermeneutical element lies in our acknowledgment of interpretation as a necessary and unavoidable part of this exploration (Binder, Holgersen, & Nielsen, 2010; Smith, 2007; van Manen, 1990). From this perspective, then, we can only approach and understand our participants' lived experiences through an active, co-constructive process of interpretation of meaning.

To improve the quality of research, being aware of one's own presence in the research process is seen as critical (Kvale & Brinkmann, 2008; Malterud, 2001a, 2001b). In this project, we made use of our collaborative framework of service user-involved research (Faulkner & Thomas, 2002; Rose, 2009; Telford & Faulkner, 2004; Trivedi & Wykes, 2002) as an important means for considering the possible effects of this presence. Two different positions can lead to the development of different, although equally meaningful, understandings of the phenomena of study (Malterud, 2001b). The coresearcher group, however, did not just supplement and challenge the understandings generated from a researcher perspective in the present project; they also provided a continuous reminder of the value of a reflexive attitude (Alvesson & Sköldbberg, 2000; Finlay, 2002, 2003). This is because being aware of how different positions can provide different understandings holds the potential for eliciting a dual focus in studies. Not only are the phenomena of investigation – processes of recovery in bipolar disorder as described by the participants – at the center of attention, but also the very process of conducting research – the co-construction of meaning and knowledge from the dialogue between researchers and coresearchers. Hence, the different positions that we as researchers and coresearchers represented may have

helped to create a metaperspective on the research process, which can be seen as an important strategy for enhancing quality of the studies (Malterud, 2001b).

### **Qualitative inquiry**

Qualitative research is a broad umbrella term describing a constellation of approaches that are directed at helping us understand the world from people's own perspectives. At the center of these approaches are the systematical mapping and exploration of the meaning of an area of human experience. The aim here is to provide the researchers and audience with rich descriptions and possible explanations of how people make sense of their world and how they experience particular events (Coyle, 2007; McLeod, 2011). That being the case, qualitative inquiry, on its most basic level, is concerned with people's grasp of their world.

Malterud (2001b) defines qualitative research as the collection, organization, and interpretation of textual material derived from talk or observation. It is a process of gathering and analyzing non-numerical data. The aim of this process is to unfold the meaning of people's experiences (Kvale & Brinkmann, 2008) – that is, to understand and answer questions of “how,” “what,” and “why”: how do people experience living with individuals who struggle with severe mental distress? what is it like being admitted to an acute psychiatric ward? why do some people stop taking their medication?

In recent years, such research questions have been posed more and more often within the field of mental health as qualitative inquiry has become increasingly influential: “We are witnessing an explosion of interest in qualitative psychology” (Smith, 2008, p. 1). Many practitioners in mental health services find that results from conventional quantitative research may be statistically significant but at the same time hold little clinical value, and feel that the knowledge generated by qualitative research by being nuanced, personal and contextual is a knowing that is familiar to them (McLeod, 2011). Furthermore, mental health professionals are interested in and trained to help

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others express information about their experiences (Kvale & Brinkmann, 2008). Therefore, qualitative inquiry may be particularly appropriate for therapists' training and practice. Whereas quantitative and qualitative research previously tended to be described and characterized as being in opposition to each other, pluralism and integrative views are increasingly becoming more apparent in the scientific community (McLeod, 2011; Moltu, 2011). There is now a growing concern to make connections between the knowledge one generates oneself and that produced by researchers using other approaches.

A main advantage of qualitative research is that it offers a set of flexible and sensitive methods for engaging with the meaning of areas of life that have generally been little understood (McLeod, 2011). These methods are, however, not homogeneous (Smith, 2008). Different approaches to qualitative inquiry are based on different assumptions on how we should produce knowledge and what we can know. Furthermore, they also hold divergent scientific goals and various criteria for evaluation (Lyons, 2007). That being the case, there are both differences in methods and more basic differences in world views and theories of knowledge within this field (Stige, Malterud, & Midtgarden, 2009).

In utilizing a hermeneutical-phenomenological approach, the present project leans on an epistemology which recognizes that "there is a phenomenon ready to shine forth, but detective work is required by the researcher to facilitate the coming forth, and then to make sense of it once it has happened" (Smith, Flowers, & Larkin, 2009, p. 35). Therefore the approach will differ, for example, from the descriptive phenomenological method of Giorgi and Giorgi (2003, 2008) as an interpretative stance will dispute the epistemology that there are universal and essential structures in phenomena which can become known to researchers in their pure form. It is important to bear in mind such differences in the theories of knowledge as they hold consequences for the process of evaluating quality in an investigation (Stige et al., 2009). When a hermeneutical-phenomenological approach questions the idea that scientific knowledge starts with an unbiased description of its subject matter and

challenges the principle of querying the very nature of a phenomenon, the practice of bracketing out one's preconceptions as described by Giorgi and Giorgi (2003, 2008) will not be seen as desirable or even possible (Moltu, 2011; Råbu, 2011). Instead, new understandings are viewed by this approach as a fusion of the experiential horizons of researchers and participants (Binder et al., 2010; Binder, Moltu, Hummelsund, Sagen, & Holgersen, 2011). The researchers' experiences and subjectivities are recognized as necessary and unavoidable in every study – both for good and for bad. They are not only sources of potential errors but also the means by which researchers understand their participants' experiences (Kvale & Brinkmann, 2008; Malterud, 2001a, 2001b; van Manen, 1990). A consequence of this line of thinking is the importance of making one's pre-understandings explicit and transparent in order for the wider audience and oneself to be able to evaluate the quality of the study.

Based on this view of how knowledge is produced and what we can know, the present research project builds on a reflexive-collaborative framework in the design and conduct of the two qualitative studies on recovery in bipolar disorder. We have actively used reflexive practice (Alvesson & Sköldbberg, 2000; Finlay, 2002, 2003) through dialogue and collaboration with our coresearcher group in order to increase our understanding of the participants' experiences of what promotes healing and growth in severe mental illnesses as well as to become aware of our own presence in the process of investigation. As argued, these efforts aimed at facilitating the development of a metaperspective on the research process, which is seen as an important strategy for improving the quality of studies (Malterud, 2001a, 2001b).

Through involving service users in every aspect of the research process, the project is embedded within a cooperative tradition (Faulkner & Thomas, 2002; Rose, 2009; Telford & Faulkner, 2004; Trivedi & Wykes, 2002). This is a philosophy of engagement in research where people with experience of the phenomena of focus participate as partners throughout all stages in order to make the research better (Davidson, Ridgway, Schmutte, & O'Connell, 2009; Davidson et al., 2010; Schneider, 2010). Although there are different ways of collaborating in research

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(Faulkner & Thomas, 2002; Trivedy & Wykes, 2002), the basic theory of knowledge that underpins this tradition is in line with the hermeneutic-phenomenological approach utilized in the present research project. This is because both perspectives underscore the co-creation of knowledge and the value of exploring different perspectives on the phenomena of study. Whereas, for example, participatory action research is more explicitly directed at transforming the lives of the people who take part (Schneider, 2010), we adopted an explorative aim in our project: to describe and give accounts of processes of healing and growth in bipolar disorder. We share, however, the intention to produce practical knowledge that is potentially useful for people in their everyday lives – both for those battling a bipolar disorder and the professionals who engage with these individuals in their struggles to achieve healing and growth.

## **Bipolar disorders**

Bipolar disorders are heterogeneous affective disorders characterized by periods of extreme mood, including depression, mania or hypomania, as well as mixed episodes (American Psychiatric Association, 2000). Within this diagnostic category, there is a continuum or spectrum of severity from the milder subsyndromal cyclothymia to bipolar II disorder to full-blown bipolar I disorder (Cassano et al., 1999). The illnesses have a lifetime prevalence in about 3.9 % of the adult population (Kessler et al., 2005), and account for the highest suicide rate of all mental health conditions (Proudfoot, Doran, Manicavasagar, & Parker, 2010). Moreover, bipolar disorders have frequent co-morbidity, and marked levels of distress are also often reported by partners and caregivers (Perlick, Hohenstein, Clarkin, Kaczynski, & Rosenheck, 2005). The World Health Organization has furthermore identified bipolar disorder as one of the six most debilitating conditions (Murray & Lopez, 1997). That being so, the disorders are a considerable source of distress and suffering to the people affected as well as to their family and friends, and are often understood as representing a major mental health problem for the wider community.

At the same time studies indicate a broad diversity in the outcome of bipolar disorder, and demonstrate that people can experience long periods of stability (Michalak, Yatham, Kolesar, & Lam, 2006). Many individuals who themselves suffer from these severe mental health problems report that they are able to handle their symptoms and distress as well as regain control over their everyday lives (Russell & Browne, 2005; Suto, Murray, Hale, Amari, & Michalak, 2010). Moreover, investigations also highlight that people are able to take ownership of their well-being and overcome stigma and other principal barriers to improvement and growth (Todd, Jones, & Lobban, 2012). Many people battling a bipolar disorder are therefore capable of living a rich and meaningful life despite the distress and suffering that may follow such a severe mental health issue.

Historically, bipolar disorders have been approached and understood from a biomedical perspective (Bentall, 2004; Healy, 2008; Jones & Bentall, 2006). Genetic and biological elements are seen as the most important etiological factors, and the mainstay of intervention has been pharmacotherapy (Scott, 2006). In many cases the treatment of choice for a bipolar disorder is in fact a pure and simple element – lithium. Finding one of the most common therapies for these illnesses in the periodic table substantiates the importance of biology. From this dominant perspective, a bipolar disorder is accordingly often described as a brain disease; some kind of neurobiological pathology that can only be effectively met with the assistance of drugs. Studies now demonstrate, however, that psychological processes play an important role in terms of both symptoms and the processes of recovery (Bentall, Tai, & Knowles, 2006), and research shows that most people struggling with a bipolar disorder do not derive maximum benefit from medications alone (Miklowitz & Scott, 2009; Scott, 2006). Different psychotherapeutic approaches, including group psychoeducation (Colom et al., 2009), interpersonal and social rhythm therapy (Frank et al., 2008), family-focused treatment (Miklowitz, George, Richards, Simoneau, & Suddath, 2003) and cognitive-behavioral therapy (Lam, Hayward, Watkins, Wright, & Sham, 2005), for example, are increasingly found to be helpful for individuals in the process of managing their symptoms and signs.

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From the biomedical perspective, a bipolar disorder is described as an entity in and of itself that has entered the life of a previously healthy individual (Bentall, 2004; Davidson & Strauss, 1995; Slade, 2009). The main focus here is on the disorder and its amelioration, which makes it difficult to see the person battling the illness as of equal importance as the bipolar disorder. From a clinical point of view this is particularly problematic because it is not possible to do therapy with an illness, and each person with a severe mental health condition is different from the next:

Just as the generic, anatomical heart does not exist, neither does the schizophrenic or the multiple or the bipolar exist outside of a generic textbook. What exists, in the truly existential sense, is not an illness or disease. What exists is a human being (Deegan, 1996, p. 97).

The only real option for therapy is therefore to work with the particular person who is suffering a bipolar disorder; to collaborate with him or her in their individual process of battling mental health issues and promoting well-being.

In the biomedical approach lies also an understanding of mental health as a pre-existing state and illnesses as deficits in this, which may pose challenges to both the person suffering from a mental health problem and professional therapists: “If it is assumed that health is something that is passively given at the outset, or taken away by illness, then it follows that the process of restoring health be viewed as a similarly passive affair” (Davidson & Strauss, 1995, p. 47). Consequently, the biomedical view is in danger of conceptualizing the person as a spectator in his or her treatment rather than as an active participant working toward healing and growth.

Bipolar disorders tend from this perspective to be characterized as lifelong illnesses that require lifelong treatment. Although the symptoms may come and go, these severe mental disorders are understood and described as more or less permanent conditions (Healy, 2008). This is because the illnesses are seen as a manifestation of an underlying biological pathology (Slade, 2009). As shown, this view of bipolar disorders as chronic illnesses is not consistent with research that indicates that people

are both able to handle their symptoms and capable of acquiring meaning and purpose in their lives (Murray et al., 2011; Russell & Browne, 2005; Suto et al., 2010; Todd et al., 2012). For many people battling a severe mental illness it can also be unhelpfully simplistic to be informed that their symptoms and distress are chronic. This is because it sounds like a sentence of treatment for life rather than providing faith and hope in overcoming problems and distress (Bentall, 2004; Davidson, 2003; Slade, 2009). Consequently, there is clearly a need to explore views and approaches that have a broader focus than the dominant biomedical perspective.

In the last few decades, researchers have begun to shift this center of attention. They are now not only examining the genetic and biological underpinnings of bipolar disorders and the effects of different pharmacological therapies, but also focus on other factors that influence the disorders and various areas that contribute to healing and growth (Jones & Bentall, 2006; Veseth, 2012). Knowledge about the experiential dimension of recovery in bipolar disorder is, however, still scarce and limited.

Qualitative research methods are applicable when we aim to generate new knowledge on areas we know little about. They are also suitable for exploring and examining first-person perspectives (Kvale & Brinkmann, 2008; Malterud, 2001b). The present research project aims to contribute to the development of new understanding of what people experience as meaningful and helpful when facing a bipolar disorder – both the individuals battling these conditions and the therapists who work with people in this struggle. Our two qualitative studies, the interviews with those who struggle with a bipolar disorder and the interviews with professionals, therefore investigate healing and growth in severe mental distress; what we call processes of recovery.

## **Recovery**

Recovery is a dynamic and multifaceted concept. Although central to the debates on which purposes and goals mental health services should embrace, the term has been used in different ways to mean different things (Borg & Davidson, 2008; Davidson et

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al., 2005; Slade, Adams, & O'Hagan, 2012). Traditionally, recovery has been narrowly defined as a clinical outcome – an effect or ending that is objectively rated by the expert researcher or clinician. From this perspective, recovery is invariant across individuals, and such definitions are often dichotomous as people are described as either having recovered or not (Slade, 2009). Albeit professional training and practice in the field of mental health have generally been oriented toward this understanding, those who have struggled with severe mental illness and distress have tended to conceptualize recovery as more like a process. From their point of view, recovery is a way of working through and finding ways of living with problems, as having an attitude in which occasional distress is acceptable (Davidson, 2003). Individuals may thus consider themselves to be in recovery while continuing to be affected by a mental illness (Davidson & Roe, 2007). This understanding of the concept reflects its individually defined and experienced nature, and aims at providing us with a snapshot of what it looks and feels like from the inside (Slade & Davidson, 2011).

Given these different meanings of the term, Slade (2009) has distinguished between *clinical recovery*, recovery in the sense of an outcome and a cure, and *personal recovery*, recovery in the individual and experiential sense. Similarly, Davidson and Roe (2007) have differentiated between recovery *from* a serious mental illness and being *in* recovery *with* a serious mental illness. The following descriptions point up these different understandings and the values that underpin them. In the largest prospective examination of bipolar disorder outcomes conducted to date, recovery is on the one hand defined as “two or fewer syndromal features of mania, hypomania, or depression for at least 8 weeks” (Perlis et al., 2006, p. 219). This is consistent with DSM-IV criteria (American Psychiatric Association, 2000) for partial or full remission of bipolar disorder, and exemplifies the first meaning of the concept. The definition is relatively clear and reliable, which makes it possible for a researcher or clinician to define, measure, and link recovery to dysfunctions or well-being in different areas of life (Davidson & Roe, 2007; Slade & Davidson, 2011). Anthony

(1993) has on the other hand given the following definition that captures the second meaning of the concept:

Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (p. 15).

The advantage of this definition is that it gives a broad perspective on healing and growth as it includes both the process of minimizing the impact of the illness and a simultaneous focus on the person's strength and competences so he or she can build a meaningful life beyond that of a psychiatric patient (Davidson & Roe, 2007).

It is this second meaning of the concept that is the foundation of what is termed a recovery perspective. The knowledge that constitutes the basis for this approach to mental health has been derived from two principal sources: stories as written and told by people who have themselves lived experiences of improvement in the face of severe mental distress (see, for example, Deegan, 1988) as well as qualitative studies of first-person accounts (see, for example, Davidson, 2003). In recent years we have also seen important contributions to this perspective from systematic reviews (see, for example, Leamy, Bird, Le Boutillier, Williams, & Slade, 2011), scholarly overviews (see, for example, Slade, 2009) as well as randomized controlled trials (see, for example, Barbic, Krupa, & Armstrong, 2009). Consequently, researchers are now starting to validate knowledge generated from the lived experiences of mental distress and recovery processes (Slade et al., 2012). But what do we know about processes of healing and growth in serious mental illnesses? What characterizes first-person perspectives on improvement and positive changes?

At the heart of the recovery perspective lies the individual and his or her point of view: "Recovery refers to the lived or real life experiences of people as they accept and overcome the challenge of the disability" (Deegan, 1988, p. 15). As argued,

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improvement and growth in severe mental illness is here understood to be not so much about clinical outcome or being a mental patient but rather about recapturing roles as a contributing citizen and a healthy person: “[Recovery is] a process of restoring a meaningful sense of belonging to one’s community and positive sense of identity apart from one’s condition while rebuilding a life despite or within the limitations imposed by that condition” (Davidson et al., 2007, p. 25). Following this understanding, we may say that mental health is not an end-product but something that is continually negotiated – it is gained and lost, something we all have to struggle for every day. And because human beings are developing forward, we cannot return to a premorbid state, a former condition where we had fewer or different symptoms or signs. In this sense, recovery is also about progression – it is an active and forward-looking movement in which something more than one’s previous way of being is recreated (Veseth, 2012).

This does not mean that symptom abatement is unimportant from a recovery perspective. Many people who have battled serious mental illness describe managing their symptoms as essential in their efforts to take an active role in their own process of healing and growth (Davidson, 2003). Furthermore, research evidence also suggests that people struggling with severe mental illnesses do recover in line with the clinical meaning of the concept. People are capable of finding pathways to handle life and its inevitable challenges, and they have the capacity to move forward even when faced with serious mental illness (Davidson & Roe, 2007; Slade, 2009; Todd et al., 2012). Many of them experience amelioration of symptoms and other deficits associated with the disorder to the degree that they no longer interfere with their daily functioning. Most people who have struggled with a severe mental health problem, however, describe that from time to time they still have to battle against their symptoms and distress. In such accounts, people often see recovery as constituting considerably more than the remission of symptoms (Davidson, 2003; Slade, 2009).

Because the process of healing and growth may vary widely from individual to individual, it is difficult to summarize elements that have a place in every journey of

recovery. There are, however, areas that tend to be highlighted and emphasized in many first-person accounts of improvement in severe mental illness (Davidson, 2003). In addition to management of symptoms and distress, these include: redefining oneself as a person of whom mental illness is just one aspect; accepting that one is ill so that one can begin to discover who one can be and what one can do; overcoming the social consequences and devastation of the stigma of mental illness; renewing hope and the commitment to move ahead in life; resuming control of and responsibility for one's life; participating as a contributing and responsible member of society; getting and being able to receive support from others; as well as being involved in meaningful activities and expanded social roles (Davidson, 2003). Similarly, Slade (2009) highlights four main tasks in recovery processes: developing a positive identity apart from that of a person with a mental illness; finding a personally satisfactory meaning to frame the experience which professionals describe as a mental illness; establishing ways of self-managing the mental illness; and acquiring valued social roles.

Although recovery from this perspective is something that is worked toward and experienced by each individual, it is not seen as a process that arises in a social vacuum. In the first-person accounts of individuals who have experienced healing and growth in severe mental illness, relationships are often highlighted as having played an important part (Davidson, 2003; Topor, Borg, Di Girolamo & Davidson, 2009). Even though the majority of these relationships are with friends, family members, peers and, in the case of believers, higher beings (i.e. God), and commonly not with mental health practitioners, there may of course still be a role for treatment and therapy in the personal journey of recovery (Davidson, 2003; Slade, 2009). Many individuals who struggle with a severe mental health problem may, for example, experience dread and fear when searching for their own path toward healing and growth. To explore new territory may be scary and challenging, especially when the uncharted land is as unknown and dark as a depression or as strange and intense as a hypomanic or manic state. Just like the great explorers leaned on porters and carriers, people with bipolar disorders and other severe mental illnesses may too be in need of

assistance and support to travel safely. From a recovery perspective, this will be a principal challenge to the roles of therapists and helpers: individuals battling a severe mental illness will have to make the journey by themselves, but professionals may be there to help and guide. This help can, for example, involve supporting people in each of the areas described above by Davidson (2003) as well as collaborating with individuals to find ways of meeting the tasks emphasized by Slade (2009).

Whereas some people are only able to recover with the proper support and facilitation from a variety of services, other people are able to overcome their mental health challenges and fully enjoy their lives without any kind of therapy. Others again may experience healing and growth despite rather than because of treatment (Slade, 2009). Unfortunately, many people battling a severe mental illness describe experiences of mental health services impeding their efforts to make positive changes and improve their life situation. Coleman (2011) underscores, for example, how it was not until he left the psychiatric system that the recovery process really got under way in his life. He felt the system emphasized maintenance of his condition rather than believing in his potential for recovery and positive change. This obstructed the hope he needed to initiate his process of healing and growth. Such first-person descriptions can provide information and insight on how professionals and services could change to offer better mental health care for the people affected:

What they did not do was to consider the possibility that I could return to being a person. Not as I once was, but the person that I could become; perhaps even more than I once was. Indeed, I could become Ron Coleman (Coleman, 2011, p. ix).

Does this mean that everyone who suffers from a bipolar disorder will improve? Following this perspective, we may say that all people have the capacity for personal recovery – they are potentially able to recover in mental illness. This is because healing and growth can co-exist with mental distress and suffering. Recovery can thus be a real option, not just for the lucky few, but for each and every person battling a severe mental health issue (Davidson, 2003; Coleman, 2011). From this perspective it

will therefore be important for mental health professionals to keep in mind that improvement and positive changes partly depend upon the beholder – recovery is about whatever works for each individual. Following Deegan (1996), we may also say that this question is perhaps not foremost for the professionals and others who work with people who struggle with severe mental illnesses: “Our role is not to judge who will and will not recover. Our job is to create environments in which opportunities for recovery and empowerment exist” (p. 97).

## **Aims**

The main aim of this thesis is to explore the lived experiences of recovery in bipolar disorder: what do people with bipolar disorders do to promote healing and growth in their lives, and what challenges do they meet over the course of their recovery? how do professionals view their patients’ struggles and efforts when facing a bipolar disorder, and what role do they see the individuals themselves as having in processes of improvement and positive change? To this end, we conducted two qualitative studies based on individual in-depth interviews with people who have first-hand knowledge of recovery in bipolar disorder, and with professional therapists who have experiences of working with patients fighting a bipolar disorder. We utilized a hermeneutical-phenomenological approach developed within a reflexive-collaborative framework to analyze and interpret these data. A secondary aim of this project has been to develop collaborative research methods suitable for examining processes of recovery in severe mental illness. The thesis is also directed at investigating the benefits and challenges that we experienced with this methodology in the process of carrying out the present research project.

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## Methods

We chose a hermeneutical-phenomenological approach developed within a reflexive-collaborative framework to stay close to our participants' descriptions while remaining aware of our own presence in conducting the studies. As argued, our commitment to exploration of the participants' experiences on a concrete level is the basis of the phenomenological element in this approach. The hermeneutical element lies in our recognition of interpretation as necessary and unavoidable when we try to understand the meaning of the participants' descriptions (Kvale & Brinkmann, 2008; Malterud, 2001a, 2001b; Smith, 2007; van Manen, 1990). In order to meet the challenges that accompany this approach, in which researcher influence is seen as inevitable, we conducted the research project within a reflexive-collaborative framework in order to make researcher perspectives and interpretations explicit and transparent. This framework emphasizes the exploration of our own positions and reflection on how these may have influenced the studies (Alvesson & Sköldberg, 2000; Finlay, 2002, 2003). In collaborating with the group of service user coresearchers (Faulkner & Thomas, 2002; Rose, 2009; Telford & Faulkner, 2004; Trivedi & Wykes, 2002) we aimed to work with this reflexive attitude throughout the process of the two qualitative investigations that the present research project comprises. This methodology is also presented and discussed in further detail in Borg and Hauge (2009), Moltu et al. (2012, in press), Sundfør (2011), Svisdahl et al. (2010) and Veseth et al. (2012, in press, submitted).

### Researchers and coresearchers

The project is a collaborative effort by MoodNet, the Regional Research Network on Mood Disorders in the Western Norway Health Authorities, and the Group for Qualitative Research on Mental Health at the University of Bergen. It originated when MoodNet, in the fall of 2007, recruited people with lived experiences of mood disorders and recovery processes in order to establish a coresearcher group. The aim

was to encourage collaboration between researchers affiliated with the network and people with valuable first-hand knowledge on phenomena of focus to the network and its members.

This coresearcher group was comprised of 12 people selected from the largest service user organization in the field of mental health care in Norway and from the local health trusts in the western part of the country. In addition to their experiences with and knowledge of recovery processes, all of them were interested in contributing to research on mental health. Moreover, many of the coresearchers described having experiences as service user representatives in the mental health system, and most of them were active within service user organizations. A core of six coresearchers was involved throughout the project period, whereas others only participated in specific parts of the investigations.

The researchers in the present project have experiences with therapy in the field of mental health care and qualitative research on topics within this area. Per-Einar Binder, Larry Davidson and I have practiced as clinical psychologists, Marit Borg as an occupational therapist within the mental health services. I have professional experience of qualitative studies as a research fellow in clinical psychology, Binder and Davidson as professors in clinical psychology, and Borg as a professor in mental health care.

### **Collaboration in the process of developing the study, preparing the data collection, and performing the analysis**

The researchers and coresearchers met regularly throughout the research process – from identifying the focus of the study to analysis of the results. A total of 18 collaborative meetings were arranged over the four-year project period from 2007 through 2011, each lasting about four to five hours. I participated at all meetings, Borg at most, and Binder only at the meetings focusing on analysis of the data. Davidson held a workshop for researchers from MoodNet on service user

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involvement and collaboration in mental health research that initiated the implementation of the research project in 2007, but did not take part in the meetings with the coresearchers. The size of the coresearcher group varied across these collaborative meetings from six to 12 participants. Even though some of the coresearchers left and others were introduced during the project period, the group was comfortable together and relatively coherent (see also Moltu et al., 2012, in press and SundfØr, 2011, for descriptions of the coresearchers' experiences of participating in this group).

The project originated from three initial meetings in which we aimed to develop a research project based on the coresearchers' lived experiences of mood disorders and processes of recovery. These collaborative meetings were facilitated by a moderator who actively encouraged the focused discussions. The coresearchers were asked two key questions by this moderator at the first of these meetings: what are your research priorities as mental health care service users? what kind of research on mood disorders would be important and useful from your perspective? The following two collaborative meetings focused on narrowing down the immense number of questions and themes that was generated in this process. Through negotiations the group thereafter arrived at a shared consensus on the aim of the project. The group's resulting top research priority was to investigate service user perspectives on processes of recovery in bipolar disorder. In these meetings, the coresearcher group also articulated clear expectations that they would be given the opportunity to participate throughout the project period. They also gave a direction for the research methodology through emphasizing the importance of exploring the experiential dimension in research related to mood disorders (see also Borg and Hauge, 2009, and Veseth et al., 2012, for further information on the process of co-constructing the research project).

The meetings that followed this initial phase of developing the research project focused on making extensive preparations for data collection in the first study of the project. We developed a semi-structured interview guide, a brief demographic

questionnaire, a newspaper ad and an information letter for interviewing people who had lived experiences of recovery in bipolar disorder. I conducted the individual in-depth interviews with the participants of this study.

Over the course of carrying out this research project, many of the coresearchers pointed to challenges in their role as coresearchers, and called for knowledge and information about the process of doing research. To meet this need and to empower them to participate in analysis of data from the interviews, a five-day academic program in qualitative methodology and theories of science was offered. Borg and Binder developed the curriculum for this training course especially for the coresearcher group, and presentations were provided by experienced researchers. The program focused on hermeneutics and phenomenology as presented by Kvale and Brinkmann (2008), and weight was given to the concept of reflexivity (Alvesson & Sköldbberg, 2000; Finlay, 2002, 2003). Other central themes included research ethics, the different stages of research projects, and service user involvement in mental health research. The coresearchers participated in lectures and group-based activities, which gave them concrete and practical training in the different stages of qualitative research (see also Moltu et al., 2012, in press; Sundfør, 2011; and Svisdahl et al., 2010 for a presentation of this academic program and descriptions of the coresearchers' reflections on the training).

After this five-day training we analyzed data from the first study. The first article of this thesis (Veseth et al., 2012), gives thorough details of this process. The basic steps were inspired by Malterud (1993), and comprise the following broad stages that we modified and adapted for use in the present research project:

1. Reading all the material to obtain a basic sense of the participants' experiences.
2. Identifying units of meaning that represent different aspects of the participants' experiences.
3. Developing codes for those units.

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4. Condensing and abstracting the meaning within each of the coded groups of text fragments.
  5. Summarizing the contents of each code group to overall descriptions of patterns and concepts reflecting the most important aspects of the participants' experiences.

I took the lead role in performing the analytical steps, and cooperated with Binder in this process which resulted in the formulation of tentative themes. At a collaborative meeting with the coresearchers' group I presented a brief summary of these overall descriptions. The coresearchers and Borg were thereafter given extracts of the transcribed interviews that were of relevance to the research questions. This text was anonymized, but apart from removing identifiers and selecting the parts that I considered relevant to our aim, I did not edit the transcripts. The group thereafter spent four to five hours reading and discussing the interviews, and through a process where Binder acted as a facilitator and moderator we aimed to develop a shared group consensus on what stood out as the most important aspects of the participants' experiences. Through this process the tentative themes were transformed and reformulated. I recorded the discussions in field notes in which I tried to pay attention to both the homogeneity and the heterogeneity of the group's interpretations. After this collaborative meeting I reorganized the themes and discussed the research process and resulting findings with Davidson.

The same collaborative process was utilized in analyzing the parts of the interviews that were of relevance to the research questions in the second article (Veseth et al., in press) of this thesis. A two-day collaborative meeting was arranged to discuss and analyze these parts of the interviews with individuals who reported having experienced healing and growth when battling a bipolar disorder. The procedure for analysis is described in detail in the paper. The two first articles are thus based on the first study of the present research project.

After this process we initiated the second study. We organized another two-day meeting in order to prepare interviews with professionals who had experiences of working with people with a bipolar disorder. In these collaborative meetings we developed a semi-structured interview guide and a brief demographic questionnaire. Thereafter I gathered the data through individual in-depth interviews with psychiatrists and clinical psychologists, and we arranged a final two-day collaborative meeting to analyze and interpret transcripts from these interviews. This process followed the basic steps for analysis as presented here, and is elaborated further in the third article (Veseth et al., submitted) of this thesis.

## **Study 1**

The first study is based on individual in-depth interviews with thirteen informants, seven women and six men, who self-identified as having lived experiences of recovery in bipolar disorder. They contacted me after reading a newspaper ad or receiving initial information about the study from their therapists. Ten of them were recruited through their local outpatient clinic and three through the advertisement. The participants' ages ranged from 27 to 65 years, with a mean age of 47 years. All of them were ethnic Norwegians residing in the western parts of the country. They reported both bipolar I and bipolar II diagnoses; and many described co-morbid clinical problems such as anxiety, post-traumatic stress disorder, psychosis and attention-deficit/hyperactivity disorder. The participants recounted how they had struggled with symptoms of bipolar disorder over the past two to 30 years, with a mean period of 18 years. Exclusion criteria for participation were alcohol or substance abuse as a primary diagnosis and inpatient and/or electroconvulsive treatment within the past six months, so that none of the participants were in a severe episode of illness at the time of interview.

All participants contacted me by telephone or e-mail. Thereafter I conducted the interviews at a location of each participant's choice, preferably at their local

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outpatient clinic, at the university or in their home. The interviews were semi-structured and addressed how the participants discovered that they struggled with their mental health; how they experienced the signs of mental distress and what they did to cope with their complaints; how they lived with their mental health problems; how they described recovery; what they had done themselves and what others had done to promote their personal recovery; what they had experienced as hindering their recovery; and what they saw as having contributed most to positive changes and improvement in their lives. The duration of the in-depth interviews ranged from 45 to 110 minutes with most lasting about 80 minutes. They were audio-taped and transcribed verbatim by me.

## **Study 2**

In the second study we used a technique of snowball sampling to recruit our participants. Through MoodNet we identified a few therapists who had extensive experience working with people with bipolar disorder. These participants were used to identify others, and they in turn others. Twelve experienced therapists, seven men and five women, were included in the study. Their ages ranged from 46 to 68 years, with a mean age of 55 years. All participants were working in the western parts of Norway, both in private practice and in the public mental healthcare system. Ten of them were medical doctors specialized in adult psychiatry and two were psychologists with a specialist license in clinical psychology. The participants reported additional education that included research (PhDs), child and adolescent psychiatry, general practice, cognitive behavioral therapy, and psychodynamic therapy. Their overall experience as therapists ranged from 16 to 41 years, with a mean period of clinical practice of 27 years.

I conducted semi-structured interviews with the participants. In the initial contact they were invited to select two concrete experiences they had had working with people with bipolar disorders – one in which they felt they succeeded and one in which they

felt they did not. In the interviews, the participants' descriptions related to these narratives constituted a framework for discussing healing and growth in bipolar disorder. The interviews addressed what the individual did him/herself to recover (or tried to do to recover); what the participants did to help the person as well as what other healthcare professionals did (or tried to do to help the person); what other people did to enable the person to recover (or tried to do); what the participants felt had contributed the most to the individual's improvement (or what had hindered the individual's improvement the most); how they described recovery in bipolar disorder; what they saw healing and growth as being about (and not about); and how much improvement they saw as possible for people struggling with a bipolar disorder. The mean duration of the individual interviews was 68 minutes, with a range from 62 to 82 minutes. All of them were audio-taped and transcribed verbatim. I transcribed one of the interviews, a graduate student in psychology the remaining eleven.

### **Ethical considerations**

The first study was approved by the Regional Committee for Medical and Health Research Ethics (Western Region) and the Norwegian Social Sciences Data Services were informed. Because of the exclusion criteria for participation, none of the participants were in a period of severe distress at the time of interview. All were, however, offered the opportunity of a follow-up contact after the interview, and informed consent was a requirement for participation. Before the coresearcher group was presented with extracts of the transcript material, all identifiers were removed. The coresearchers also signed a declaration of confidentiality before they took part in the data analysis.

Because the second study was an investigation of professional therapists' experiences of working toward recovery together with people who had a bipolar disorder, no patients were included in this study. The Regional Committee for Medical and Health Research Ethics (Western Region) considered that formal approval of this study

should be given by the Norwegian Social Science Data Services. The protocol was presented and approved by this entity. Before extracts of the transcribed data material were offered to the coresearcher group all identifiers were removed, and the members of the group also signed a confidentiality statement. The psychiatrists and clinical psychologists who took part were informed about the methods and purposes of the study prior to their participation.

## Findings

The results are presented in three articles. As indicated, the first two papers present findings from the first study, the third paper those from the second study. All of them utilize the hermeneutical-phenomenological approach developed within a reflexive-collaborative framework as described in this thesis, and aim to examine the lived experiences of healing and growth in bipolar disorder. These phenomena are explored through first-person accounts given by both individuals fighting these conditions and by professional therapists engaged with people in their struggle. Our understandings of the participants' descriptions are co-constructed and shaped by the reflexive-collaborative dialogue that we as researchers and coresearchers carried out. The articles are therefore also directed at discussing and reflecting on our experiences of conducting the present research project. As the project is based on a novel and innovative approach to knowledge generation in the field of mental health, making the methodology available to the scientific community and the wider audience is considered an important task.

### Summary of paper 1

The first article is called "Toward caring for oneself in a life of intense ups and downs: A reflexive-collaborative exploration of recovery in bipolar disorder" and presents findings from the first study. The aim of this article is to examine the participants' experiences of their own efforts toward improvement and positive change in an everyday life confronted with a severe mental illness: what do individuals with a bipolar disorder do to promote their own recovery, and what challenges do they meet? The following themes are drawn from our analysis: (1) handling ambivalence about letting go of manic states; (2) finding something to hang on to when the world is spinning round; (3) becoming aware of signals from self and others; and (4) finding ways of caring for oneself. The meaning content of each of these four categories is explored, as well as the interrelationships between the themes.

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The findings are discussed in relation to a recovery perspective on processes of healing and growth in severe mental illnesses, as well as to the existing empirical context on what trials and tribulations individuals may face when battling a bipolar disorder and what strategies they may utilize in order to meet these challenges in their everyday lives. The paper is moreover directed at addressing the methodology that we made use of in the present research project. The design and conduct of the study are examined in relation to the field of qualitative inquiry as well as to central aspects of service user involvement in mental health research. The paper has been published in *Qualitative Health Research*.

### **Summary of paper 2**

The second article is called “How I found out I had a bipolar disorder: A reflexive-collaborative exploration of the process of identifying that one is struggling with a severe mental health problem.” The paper explores first-person accounts of what it is like discovering that one is battling a serious mental illness, and reports findings from the first study of the present research project. The results are organized and presented as three phases in our participants’ process of finding out what their symptoms and distress were about. We describe here how they maneuvered from (1) uncertainty and confusion through (2) grasping the novel and unusual experiential states to (3) giving meaning to the lived experiences of intense ups and downs. This third phase of meaning-making was built up of a multitude of views and reactions, and we identified two sub-phases in our analysis of the participants' descriptions: (1) challenges in defining one’s symptoms; and (2) recognition as a step toward recovery. The themes are explored and discussed in the light of established theory, research and practice. We draw on Heidegger’s concept of *Unheimlichkeit*, knowledge generated from first-person accounts of the recovery perspective, as well as empirical studies in order to approach and understand what the process of finding out that one has a bipolar disorder may be like. The paper has been accepted for publication in *Qualitative Studies*.

### **Summary of paper 3**

The third article is called “Experienced therapists’ view of their patients’ struggles and efforts when facing a bipolar disorder” and reports findings from the second study. On the basis of the individual in-depth interviews that we conducted with professional therapists, we examine how psychiatrists and clinical psychologists view processes of recovery in bipolar disorder as well as their patients' own initiatives and activities to encourage healing and growth. We present three categories that were common across the participants. These themes summarize important aspects of their experiences of their patients’ struggles and efforts with regard to bipolar disorder: (1) a puzzling given; (2) the protagonist of the recovery process; and (3) the heroic fighter does not always win. The themes' relation to existing theory, research and practice is examined in the paper. We utilize a recovery perspective as well as a humanistic line of thinking to discuss our findings. We also explore possible implications of the investigation along with limitations and strengths. The article has been submitted for publication in an international, peer-reviewed journal.

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## Discussion

This thesis is directed at exploring processes of recovery in bipolar disorder and examining the experiences we had in approaching these phenomena within the context of our reflexive-collaborative framework. My purpose for this discussion is therefore twofold. First, I aim to analyze and interpret our findings on the lived experiences of healing and growth in bipolar disorder in relation to a recovery perspective as well as to relevant research on bipolar disorders. What do our findings tell us about processes of recovery? How can the results expand and nuance the established understanding of what contributes to improvement and positive change for people with severe mental illnesses? Second, I reflect upon the process of conducting this research project and consider the production of meaning that we performed in partnership with our coresearcher group of people with lived experience of the phenomena of focus. What were our respective roles and contributions in the process of constructing knowledge based on the participants' accounts? How can collaborative research improve the quality of investigations within the field of mental health?

As I described initially, the present research project is comprised of a multitude of layers or views that may contribute to enriching our knowledge on processes of recovery: (1) the descriptions of people who are struggling with a bipolar disorder, and (2) the descriptions of therapists who engage with these people in their efforts to manage distress and promote positive change; as well as (a) the understanding of these accounts from the point of view of researchers who have a background as professionals within this field, and (b) the understanding of these accounts from the perspectives of coresearchers who themselves have experienced processes of recovery in mood disorders. What do our studies indicate are the central aspects of the lived experiences of healing and growth in bipolar disorder? And what is the value of this reflexive-collaborative approach to research on issues in the field of mental health?

## **The principal role of the person**

A central aim of this thesis has been to develop concrete and experience-near knowledge that can be relevant for people with a bipolar disorder as well as for professional therapists and helpers who engage with people in their struggle. We have aimed to illustrate our findings in each of the articles with rich descriptions so that every reader can independently arrive at an understanding of them, and evaluate if the results hold value when working toward healing and growth in bipolar disorder from his or her particular position. The purpose of the project is to establish practical understanding useful for both the individuals battling these conditions as well as for people who aspire to support people in their journey of recovery.

A general finding in both of the studies that comprise this thesis is the importance of the person for processes of recovery. In the interviews in the first study, we found that each participant had developed his or her own way of making use of their capacities and competences in order to improve their lives (Veseth et al., 2012). We interpreted this to mean that finding ways of caring for oneself is a central aspect of recovery in bipolar disorder. One of the accounts from the participants that we present in this paper sheds light on the person's own active role in processes of healing and growth:

If I hadn't listened to my body, right, and thought, "Let's act on all these ideas, let's initiate this and that, let's do this," then I would. . . . It wouldn't have lasted. I would have been exhausted. Or hyperactive at the same time. . . . I'm trying to take control of my thoughts, thinking, "We shouldn't do this because that's not good." And I think that's important, because if I don't, if I just keep going . . . I don't think that's any good, because . . . so I have to be kind of considerate and listen to my body (Veseth et al., 2012, p. 126).

The participant underscores in this quote her own strivings as an essential part of her recovery. Through making the necessary efforts to listen to signals from her body, she started to find new ways of caring for herself and to move forward in her life.

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The interviews that I conducted with the experienced therapists in the second study of the present research project also gave examples of this understanding as the principal agent in processes of recovery. Said one of the professionals when reflecting on one of her patients' struggles to heal and grow:

She stops, that is, she takes hold of herself. She sits down when she's having an intense emotional reaction, and exerts herself. That is, she sits down: What happened? What did I think? What did I do? What would have happened if I had thought about it like this? Could I have thought about it like that? Would this be valid for me? Would it make me react differently? Would it make me less vulnerable? Would it contribute to my well-being? (Veseth et al., submitted, p. 16).

The fundamental role of the person in recovery in bipolar disorder was a finding that was consistent across our participants in this second study. This was somewhat surprising because I initially expected the participants to emphasize therapy and care to a greater extent, perhaps also when discussing their patients' personal efforts. As described in the article, the psychiatrists and clinical psychologists weighted treatment as important for recovery in bipolar disorder, but their descriptions of their patients' own efforts to heal and grow were more vivid and richer in information (Veseth et al., submitted). Therefore, we found in both studies that the person battling a bipolar disorder is an active and goal-directed agent who is on center stage in terms of making positive changes in his or her life.

This importance of the person for processes of improvement in severe mental illness is also a central lesson learned from the first-person accounts that form the foundation of the recovery perspective. Deegan (1996) relates this for example to her own journey of healing and growth: "Now I do not just take medication or go to the hospital. I have learned to use medications and to use the hospital. This is the active stance that is the hallmark of the recovery process" (p. 96). Similarly, Coleman (2011) claims that when all comes to all healing and growth are ultimately in each individual's own hands:

Yes, supports can be identified and put in place; yes, we can go to therapists or take medication; yes, we can attend self-help groups and be part of campaigns against abuses in psychiatry. But unless we are prepared to do the hard, grueling work to achieve our personal recovery, then recovery will always remain a word instead of a fact (pp. 153-154).

As I have argued in this thesis, the dominating biomedical approach tends to assign a peripheral role to the individual with regard to mental health. Recovery therefore risks being viewed as a passive process of restoring a previous condition characterized by no or fewer symptoms and signs (Bentall, 2004; Davidson & Strauss, 1995; Healy, 2008; Veseth, 2012). When we apply the understanding generated from the recovery perspective, however, healing and growth are understood more broadly and the individual is positioned at the very heart of the recovery process. This line of thinking provides each individual with a variety of options as a bipolar disorder is understood as something that one can make go away over time (in the meaning of clinical recovery or recovery from a severe mental illness), but also something that one can learn to handle (in the meaning of personal recovery or being in recovery from a severe mental illness). The individual can recover in the traditional understanding of the concept or find ways of attaining a rich and meaningful life despite their symptoms (Davidson, 2003; Davidson & Roe, 2007; Slade, 2009; Slade & Davidson, 2011).

Bipolar disorders are often described and experienced as conditions that run their own race (Lam & Wong, 2006). In the papers in this thesis (Veseth et al., 2012, in press, submitted) we have highlighted how this underscores the need for the person battling these illnesses to reclaim a position as an active agent and resume control and responsibility for his or her life. The recovery perspective offers understanding that puts this knowledge at the fore, and may therefore be a valuable line of thinking when we aim to approach the meaning of mental distress and processes of improvement in these severe mental illnesses.

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## **Much more simply human than otherwise**

Another overall finding in the present research project is the general and common qualities of the individuals' attempts to heal and grow when facing a bipolar disorder. The strategies described by the participants' in the first article of this thesis, for example, include activities such as gardening, food preparation and fly-tying, which they experience as important for balancing their intense and vivid inner life. We termed this theme "finding something to hang on to when the world is spinning around," in order to summarize the participants' efforts to remain centered on something meaningful despite mood changes (Veseth et al., 2012). The process we describe in the second paper of this thesis is also something many people may recognize and be familiar with. When experiencing something new and frightening happening to themselves, many people may identify with the participants' process of taking steps to grasp and understand these experiences as well as their efforts to develop ways of giving meaning to the things they suddenly find going on in their lives (Veseth et al., in press). The professional therapists in the third article of this thesis also described phenomena that may be known to many of us. In their narratives they highlighted for example their patients' numerous efforts to become an agent in their own lives as well as experiences of illness as an opponent that sometimes is so strong that it is overpowering (Veseth et al., submitted). Consequently, we can say that a person's activities and efforts to heal and grow when battling a bipolar disorder are relatively similar to the struggles we all may face when trying to handle our everyday distress in order to live full and meaningful lives.

Referring to Harry Stack Sullivan's one-genus postulate, Davidson (2005) argues that people with severe mental illnesses are "much more simply human than otherwise." This is because they utilize the same actions that people who do not suffer a severe mental illness use under similar circumstances – "they" are in fact just like "us." This insight relates well to the results of the present research project as people's strategies and efforts when battling a bipolar disorder are not dissimilar but very much akin to the "normal" activities and struggles of people who do not have a bipolar disorder.

We may therefore say that there is something common to all humanity with regard to these struggles and efforts. Individuals who themselves have lived experiences of severe mental distress and processes of healing and growth also underline this point. Deegan (1992) claims for example that this is a fundamental idea in the recovery perspective: “The concept of recovery is rooted in the simple yet profound realization that people who have been diagnosed with a mental illness are human beings” (p. 12).

### **The importance of the first-person perspective**

A third point I will highlight in this thesis is the value of the lived experiences to issues in the field of mental health. In the recovery perspective, the person reemerges from his or her position behind the severe mental illness and takes the center stage (Davidson, 2003). When the aim is to describe the role of the individual in processes of healing and growth in severe mental illnesses, the first-person perspective will necessarily be an essential and invaluable element. This is because it is the person who is the expert on his or her own needs and experiences. Each individual holds a particular competence in terms of identifying what will be helpful in promoting his or her personal recovery. Thus, although the person has traditionally tended to be viewed as lost to the illness and others have spoken for him or her, the recovery perspective’s focus on the person requires that his or her voice is listened to and heard (Davidson, 2003; Slade, 2009).

These voices that speak from the first-person perspective can differ from the voices of professionals in research and services. In an essay called “Two accounts of mental distress,” O’Hagan (1996), for example, presents excerpts from her diary and the hospital files written during one of her stays at an inpatient unit. She describes the process of putting the chaotic events of this period down on paper as a profound experience for her; “but down the other end of the long polished corridor,” she comments, “others recorded their own version of my distress in the course of a very ordinary day’s work” (p. 44). The incongruence between her journal entries and the

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staff's descriptions is highlighted in this essay. They are often striking and also somewhat disquieting:

*Today I wanted to die. Everything was hurting. My body was screaming. I saw the doctor. I said nothing. Now I feel terrible. Nothing seems good and nothing good seems possible.*

*I am stuck in this twilight mood where I go down into a lonely black hole. Where there is room for only one.*

Flat. Lacking in motivation, sleep and appetite good. Discussed aetiology. Cont. LiCarb 250mg qid. Levels next time (O'Hagan, 1996, p. 46, italics in the original).

Reading this essay it is not difficult to identify which are O'Hagan's descriptions and which are notes made by the hospital's healthcare workers. From a recovery perspective such first-person accounts are important as they document and detail the lived experiences of mental distress and processes of healing and growth (Borg & Davidson, 2008; Ridgway, 2001). They communicate both what life is like with a mental illness and what helps in moving beyond the role of a psychiatric patient. The first-person perspective may also hold the potential for overturning stereotypic understandings, such as the idea that bipolar disorders are chronic illnesses that can only be contained with the long-term assistance of drugs. The lived experiences as written and told by people who themselves have battled such conditions and moved forward in their lives may thus contest and challenge the dominating understanding from the biomedical perspective. In doing so these accounts may contribute to shifting the focus from treatment designed to prevent deterioration to growth-promoting interventions as they demonstrate that recovery is a real option for the person struggling with a severe mental illness.

## **Collaboration and reflexivity**

Understanding the person as playing an active role in his or her own process of healing and growth is connected to understanding the person as playing an active role in the research process. As argued, this has been a central principle in the present research project. We have viewed the participants in our studies as actively contributing to the construction of knowledge, and have collaborated with a coresearcher group in order to attain different perspectives on the phenomena of study and to attend to our joint production of meaning when preparing and performing the studies. What is the value of this reflexive-collaborative approach to research? And how does this line of thinking relate to the field of qualitative inquiry?

Morse (2010) makes a distinction between insider and outsider researchers in qualitative health studies. This may serve as a starting-point for discussing the value of cooperating with people with lived experience of the phenomena of focus in conducting research on mental health. Traditionally, the disadvantages of involving service users in research has been emphasized – they are regarded as having an insider perspective on topics in mental health and therefore as not being able to hold a naïve perspective on the phenomena under study, and as having an outsider perspective on issues in research and therefore being in danger of violating protocol (Faulkner & Thomas, 2002; Telford & Faulkner, 2004). From a hermeneutical-phenomenological perspective, however, the researchers' experiences and subjectivities are unavoidable parts of every study (Alvesson & Sköldberg, 2000; Finlay, 2002, 2003; Kvale & Brinkmann, 2008; Malterud, 2001a, 2001b; Smith, 2007; van Manen, 1990). This means that there is no research free of value or bias (Underwood, Satterthwait, & Bartlett, 2010). As argued, the researchers' preconceptions and intentions are, however, not only sources of errors, but will also provide the researchers with means to understand the participants' lived experiences. We therefore need to consider the flip-side of this insider/outsider coin, as there will necessarily be advantages and disadvantages to both perspectives in qualitative health research (Morse, 2010). For example, many service user coresearchers by virtue of

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their inside position are able to direct research toward understudied areas that are of importance to the people most interested in such research, as well as to understand phenomena described by participants more directly because of commonalities in their experiences (Faulkner & Thomas, 2002; Rose, 2009; Telford & Faulkner, 2004; Trivedi & Wykes, 2002). Furthermore, researchers can be astute at recognizing novel phenomena but, like fish who are the last to discover the water, scientists, too, may from time to time be in need of a fresh pair of eyes when conducting research. Service user involvement may here represent a valuable outsider perspective that can help researchers recognize what may be right in front of them as well as contribute in terms of monitoring the researchers' positions and presence in the investigation.

One example of useful products generated from collaboration with the coresearcher group in the present research project can be drawn from the process of constructing the interview guide in the first study. At that point the members of the group emphasized the importance of centering the questions on the participants' own initiatives and activities to promote healing and growth. I was initially somewhat ambivalent about this focus as I was afraid it would lead to cursory answers about how the participants followed their therapists' advice or complied with their pharmacotherapy. Through discussions with the coresearchers, however, I increasingly became aware of the various ways in which they themselves handled symptoms and distress in different mood disorders. Through this process I also became aware of how my own background and experiences of this subject might influence my approach: could it be, for example, that my practice as a clinical psychologist within a healthcare system where bipolar disorders are described and understood from a biomedical perspective played a part in my entering this research field? could it be that my position as a research fellow with relatively limited experience of qualitative research had an impact on my thoughts about what might be suitable questions and good probes for such a study? or could it be that my experiences of a somewhat silent and reserved grandmother who struggled with a bipolar disorder when I was a child affected my thoughts about how to ask questions that could elicit interesting answers? My point here is that collaboration with the

coresearcher group made such reflections possible and allowed a dual focus in the present research project: both the phenomena of investigation and our presence in conduct of the studies were at the center of our attention. The focus on the participants' own efforts and initiatives retrospectively provided some of the richest descriptions in the interviews that I conducted in this first study (Veseth et al., 2012). Consequently we may say that our collaborative efforts and reflexive attitude not only helped us monitor the study process, but also helped us stay close to our phenomenological aim of exploring the complexity and richness of recovery in bipolar disorder as described by the participants.

Another illustration of the value of this cooperation can be drawn from the collaborative meetings which focused on analysis of the anonymized transcripts from the individual interviews. One of the participants in the first study described, for example, how he had learned to become attentive to early signs that he was entering an episode of elevated mood:

Gradually I've gotten to know myself quite well, and I know that the mania is . . . It hurts physically being in that condition. I feel a distaste in my body. For example, my oral cavity: I feel a stress arising there. It's not easy to explain, but it's like I detect this myself (Veseth et al., 2012, p. 126).

In the article we have presented this as “becoming aware of signals from self and others,” a process that we highlight as important for recovery in bipolar disorder. In analyzing the transcript where this description was included, the coresearchers made me aware of how this was not only about developing an ability to be aware of signs of hypomania or mania but also about utilizing one's own experiences and knowledge. A stress arising in the oral cavity is probably not a valid signal for everyone who suffers from a bipolar disorder, but for this participant it was. Over the course of his recovery he had learned to recognize this sign, and he was now able to put this knowledge to use. Consequently, the coresearchers both validated the initial understanding of this phenomenon and expanded on it by emphasizing that this process of becoming aware of signals from self and others is not something one can learn from books or

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therapists, but something each person has to discover for themselves through a process of utilizing his or her knowledge and lived experiences (Veseth et al., 2012).

A final example of this process of co-creating knowledge in partnership with people who have lived experience of the phenomena of focus can be drawn from the second article (Veseth et al., in press) in this thesis. As presented earlier, we describe and discuss in this paper first-person perspectives on the process of realizing that one's symptoms and distress may be because of what is commonly termed a bipolar disorder. Our findings are organized as three phases: (1) "uncertainty and confusion"; (2) "grasping the novel and unusual experiential states"; and (3) "giving meaning to the lived experiences of intense ups and downs." In the individual interviews, the participants described powerful experiences of something going on in their lives that they had not experienced before. At this point in the process of finding out they were battling a severe mental illness they asked themselves: why does everything suddenly seem so gray and dull? and why are my thoughts and feelings racing away? In my initial interpretations of this data material I emphasized the anxiety in this process. Many of the participants observed that it was very frightening not being able to recognize themselves when new and unusual experiential states started to impact their everyday lives (Veseth et al., in press). When we analyzed this material in collaboration with the coresearcher group, other aspects of the data also emerged. In discussing this process of discovering they had a bipolar disorder, the group described how they had experienced being alone at this point. They did not know what was going on in their lives and were not able to communicate their problems well to their friends, family or professional healthcare workers. This created increasing experiences of loneliness and alienation. In the collaborative meeting focusing on data analysis of this material, the coresearchers nuanced my initial understandings by pointing out an important dimension I had omitted from my preliminary analysis: it was not only illness and anxiety that characterized the initial phases of the process of finding out what one's symptoms and distress might be about, but also existential dimensions of loneliness and alienation (Veseth et al., in press).

As argued, the hermeneutical-phenomenological approach we have utilized in our investigations is in line with the reflexive-collaborative framework that we applied. Interviews from these perspectives are described and understood as dynamic and interactional events, and the resulting findings are seen as products of the interplay between researchers and participants (Underwood et al., 2010). This means that there are no passive objects in studies, containers of answers or information; and there are no detached scientists, neutral researchers who observe the world as it is. A participant in an interview study may on the one hand respond differently to the same question posed by, for example, a medical doctor, psychologist or priest, and medical doctors, psychologists or priests may on the other understand the meaning of the answer in different ways. Researchers and participants therefore exert mutual influence on each other as knowledge is developed and constructed between them throughout the research process. As I have underscored in this thesis, an important consequence of considering the quality of an investigation from this perspective is that these influences are rendered explicit and transparent: “The illusion of denying the human touch is countered by establishing an agenda for assessment of subjectivity” (Malterud, 2001b, p. 484). How does this relate to established understandings within the field of qualitative inquiry? How can we assess the quality and value of qualitative research?

### **Evaluating qualitative inquiry and the present research project**

Evaluations of research can be performed in many ways. Malterud (2001a) proposes, for example, that relevance, validity, and reflexivity can be formalized as criteria for assessing qualitative investigations. Smith et al. (2009) describe sensitivity to context; commitment and rigor, transparency and coherence, and impact and importance as principles central to the evaluation of quality. Finlay and Evans (2009) claim that research can be assessed in terms of rigor, relevance, resonance, and reflexivity.

As shown earlier, the different theories of knowledge that underpin various approaches to research will prioritize different aspects in the evaluation of studies (Stige et al., 2009). This means that when the quality of investigations is assessed, it needs to be done within the frame of the studies' own terms and values. A consistent and reliable use of measures that allows for studies to be replicated will, for example, be of importance in the assessment of a quantitative study. Qualitative researchers tend, however, to reject the idea that situations can be identically reproduced (Finlay, 2011). As qualitative investigations are often conceptualized as products of a specific context, replicability will not be a very helpful criterion for evaluating the value of such studies.

Within the field of qualitative inquiry too, different approaches propose and emphasize different criteria for evaluation. Giorgi and Giorgi (2003, 2008) put relatively more weight on systematic credentials in underscoring the importance of studies being thoroughly and coherently conducted, whereas Finlay (2011) emphasizes the extent to which the research is able to move the audience:

I personally believe that the best articles are resonant, textured and wield emotional power. . . I believe that the special contribution and strength of phenomenological research is precisely the way it can capture the ambiguity, ambivalence and richness of lived experience while touching the diversity and complexity of the social world (p. 270).

Both the head, the scientific credentials, and the heart, the artistic flair and resonance, will therefore be of relevance when the quality of a qualitative investigation is assessed (Finlay, 2011). Reflecting on the present research project, we can apply the criteria proposed by Finlay and Evans (2009) as there is a reasonable match between our two qualitative studies and these criteria. The project is based on a reflexive-collaborative framework, and the extent to which reflexivity is demonstrated in studies is one of the criteria for assessment underlined by Finlay and Evans (2009). Reflexivity is described as concerning awareness and openness about the research process: have the researchers taken into account their own positions and presence?

and are these communicated clearly and openly? The other three of their four R's for evaluating quality and value are rigor, relevance and resonance (Finlay & Evans, 2009). Rigor refers here to the extent that the investigation has been systematically worked through and competently managed. Relevance asks for the value of the research in terms of applicability and contribution. Resonance concerns the study's ability to touch the reader by, for example, being vivid or powerful (Finlay & Evans, 2009).

I have argued that the present research project demonstrates reflexivity, the first of Finlay and Evans's (2009) four broad principles. We have aimed to utilize self-inquiry and examination of the assumptions that guided the research process, and we have as far as possible documented our positions both in the articles and in this thesis. The second criterion, rigor, can be linked to the quality of the data as well as the thoroughness of the analysis. As all papers in this thesis offer a number of quotes from the individual interviews, the readers are to some extent given the opportunity to evaluate for themselves the interviews that I conducted as well as the understandings that we developed through our analysis. As demonstrated in this thesis, the knowledge generated in the two studies has been tested, validated and expanded in dialogue with the coresearcher group; this can also be seen as a way of ensuring rigor in the present project. This collaboration with the coresearchers helped us to consider Finlay and Evans's (2009) principle of relevance as well. The research questions and themes of the project were considered to hold actuality and importance both from the perspectives of coresearchers with lived experience of the phenomena of focus and from the perspectives of the researchers with professional experience as therapists and scientists. The extent to which the research says something useful or interesting is, however, in the end a judgment each reader has to make for him- or herself. The final criterion proposed by Finlay and Evans (2009) will also lie in the eye of the beholder. What is regarded as emotionally moving and communicatively powerful through having resonance with the audience is a subjective question. When disseminating their research, however, scientists often receive comments and feedback that enable them to some degree to evaluate whether or not the study resonates with the audience.

## **Strengths and limitations**

The present research project has several strengths and limitations. As argued, a major strength is its ability to approach processes of recovery within a framework that builds on a multitude of layers or views: (1) the experiences of people who are struggling with a bipolar disorder, and (2) the experiences of therapists who engage with these people in their efforts to manage distress and promote positive change; as well as (A) the understanding of these experiences from the point of view of researchers who have a background as professionals within this field, and (B) the understanding of these experiences from the perspectives of coresearchers who themselves have experienced processes of recovery in mood disorders. This multiplicity of views allows the phenomena of focus to be seen in new ways and allows us to move beyond possible impasses in the research process where an individual researcher may become stuck. The studies' aim to encompass and describe themes that stay close to the lived experiences of healing and growth in bipolar disorder was approached through our close collaboration with the coresearcher group. As presented in the thesis, this collaboration was also directed at enhancing the quality of the research project by providing us with a continuous reminder of the importance of a reflexive attitude. I consider this a major strength of the research project.

A methodological limitation of the project is the small and relatively homogeneous groups of participants that were included. In both studies they were all resident within the western parts of Norway. The participants in the first study had struggled with mental illnesses at approximately the same time, and had received help and support from the same mental health services. The participants in the second study were working as professional therapists within this system and had done so for a long time. Consequently, the mental health system may have had an impact on the present research project. The second study also included more psychiatrists than clinical psychologists. This may, however, also illustrate how people with bipolar disorders tend more often to be in treatment with medical doctors than psychologists.

## **Implications for research and practice**

As argued in this thesis, the dominant understanding of bipolar disorder and recovery as put forward by the biomedical perspective may lead to a focus on maintenance and stabilization rather than on promoting development and growth. Therapy tends to be based on treatment goals set by the clinician rather than on recovery goals informed by the person's own dreams and aspirations (Slade & Davidson, 2011). Treatment goals will in many cases focus on avoiding negative outcomes such as hospitalization or relapse. They may typically be relatively general and are often formulated in order to prevent harm or limit damage; for example, to "reduce periods of elevated mood" or "prevent aggression on the ward". Recovery goals will on the other hand be unique and idiosyncratic as they center on the person's hopes and ambitions (Slade & Davidson, 2011). They focus on what the individual actually wants and will therefore also focus on the person as an active agent in his or her life. This means that for professionals, recovery-oriented therapy is not about leading the person to recovery or fixing his or her problems, but rather about supporting the individual in his or her personal journey to build a meaningful and rich life. The recovery perspective's positioning of the person at the center stage therefore holds implications for how we approach and reflect upon treatment and care.

The present research project has aimed at developing new understanding of processes of recovery in bipolar disorder based on the individual interviews that we conducted with people who have battled a bipolar disorder and with professional therapists who have engaged with people in this struggle. The importance and value of the themes generated by these interviews may additionally be explored by various methods and approaches. For example, can different strategies for handling ambivalence about letting go of manic or hypomanic states as described in the first paper of this thesis be examined further? What can the community and mental health system do to alleviate the challenges described in the second paper in relation to the process of identifying that one is struggling with a severe mental illness? And how should therapists set

about supporting their patients' agency as discussed in the third paper? The findings of this thesis suggest that these may be interesting areas for scientific investigation. As described, there is also a need to investigate other aspects of recovery in bipolar disorder. Research in this field has traditionally been limited to the biomedical paradigm, and the experiential dimension has tended to be overlooked or neglected. Qualitative studies may therefore be particularly called for when we aim to approach and understand processes of healing and growth in bipolar disorder.

### **Concluding comments**

The overall topic of this project was recovery in bipolar disorder. As shown, this focus was developed through back-and-forth discussions with the coresearcher group in which the individual with a bipolar disorder and his or her efforts to heal and grow were underscored as an important center of attention. In the process of developing the project, the service user coresearchers also emphasized early detection and timely treatment as central to improvement in bipolar disorder. That being so, the research questions of all three articles that comprise this thesis were a focal point for the coresearcher group from the very beginning.

This narrative has now come to an end, and the collaborative research project as carried out by researchers and coresearchers is in its concluding phases. For people struggling with a bipolar disorder and the professionals supporting them, healing and growth are still an everyday challenge as they continue to fight these mental health issues. I have underscored in this thesis that, albeit demanding and difficult, recovery is a real option for each and every individual. It is his or hers for the taking. What this implies will, however, vary from person to person: “The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human” (Deegan, 1996, p. 92).

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