

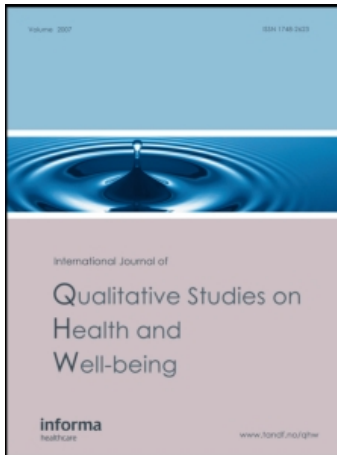
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### Extra dimensions in all aspects of life—the meaning of life with bipolar disorder

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ORIGINAL ARTICLE

## Extra dimensions in all aspects of life—the meaning of life with bipolar disorder

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### Abstract

Living with Bipolar Disorder (BD) greatly affects the whole life; still the meaning of it is poorly explored from the perspective of the individuals actually living with it. The aim of this study is thus to explore the existential meaning of life with BD. Ten persons, six women and four men, (aged 30–61), diagnosed with BD were interviewed. A reflective lifeworld perspective based on phenomenological philosophy was used. The findings show that living with BD entails experiencing extra dimensions in all aspects of life, expressed in terms of a magnitude and complexity beyond that which is perceived as pertaining to normal life. The essential meaning of the phenomenon is further described by its constituents: “a specific intensity”, “a struggle to understand”, “an illness that is intertwined with one’s whole being”. Living with BD means more for the individual than having episodes of depression and mania and must therefore be understood from a holistic perspective. Adequate care for persons with BD, therefore, includes places for safe and profound reflecting about existential issues, such as identity, trust and self-confidence. The present study recommends the caring services to change their ways to explain and talk about the BD illness.

**Key words:** *Bipolar disorder, caring science, extra dimensions, holistic understanding, lifeworld research, phenomenology*

### Introduction

Living with Bipolar Disorder (BD) greatly affects the whole life of individuals affected by the illness as well as their families and close friends. Issues such as care, health, need for support and social interaction together with ethical questions are important parts of life with BD (Baker, 2001; Elgie & Morselli, 2007).

BD is a diagnostical classification term for a large variety of lifelong mood swings characterized by depressive, hypomanic, manic or mixed episodes as described in the DSM-IV (APA, 1994) and the ICD-10 (WHO, 2007). There are a number of different diagnoses in the BD spectrum, each of which focus on different aspects or combination of aspects of BD. Pharmacological treatment is recommended for most of them. There has been a consensus of opinion regarding the incidence and prevalence for BD at 1–2% of the population (Sheppard & Hill,

1996; Hilty, Brady & Hales, 1999). Recent studies show, however, that the incidence and prevalence has been seriously underestimated and suggest that it could be as high as 3–6% (Tugrul, 2003; Leboyer, Henry, Paillere-Martinot & Bellivier, 2005; Elgie & Morselli, 2007). Ninety per cent of patients with BD have recurrent episodes of the illness and the suicide risk is estimated to 6–15% during depressive as well as manic episodes (Inskip, Harris & Barraclough, 1998; Elgie & Morselli, 2007).

Many studies show that psycho-education and recognition of early signs is needed and has a good impact on life with BD (see, for example, Perry, Tarrier, Morriss, McCarthy & Limb, 1999; Cutler, 2001; Dogan & Sabanciogullari, 2003; Jose, Bladdery & Mathew, 2003; Bauer, Grof, Rasgon, Bschor, Glenn & Whybrow, 2006; Reinares et al., 2008). Pollack has carried out substantial research on the treatment of inpatients with BD, where the main

focus has been on group therapies (Pollack, 1993a; Pollack & Cramer, 2000; Pollack, Harvin, & Cramer, 2001). These studies also show that patients with BD experience problems in many different aspects of life, for example, understanding the disorder, relating with others, managing daily life, relating with self and living in society, and also point to the need for patient education.

Another research field focuses on care needs of outpatients with BD (Goossens, Knoppert-Van der Klein, Kroon & Van Achterberg, 2007), showing that the needs were mainly to be found in the areas of psychological help, psychiatric help and social functioning. The data in the study by Goossens et al. (2007) was collected by using a survey technique with fixed questions. Existential issues were not in focus. They seem to have been reduced to psychological and/or social issues. A literature review by Elgie and Morselli (2007) shows, however, that BD has a negative impact on existential issues such as interpersonal relations and companionship and that the patients' lack of understanding about BD is a major problem. More education, information and greater awareness are thus needed for patients, relatives as well as advocacy organizations. The same review also states that previously undervalued subjective experiences, i.e. lived experiences, do determine well-being and Quality of Life (QOL). A study by Michalak, Yatham, Maxwell, Hale and Lam (2007) shows that BD has an extensive impact upon work functioning. Based on a literature review (Baker, 2001) a questionnaire was developed to explore users' experiences of BD (Baker, 2002) in terms of hospital services, community care, pharmacological treatments, coping strategies as well as life changes and experiences of having bipolar disorder illness. In the last category, which was considered relevant for the present study, a sense of loss was highlighted. The loss concerned an effect on the individual's personality, a loss that family and friends experience, a loss of normal social activities and a loss of the future.

Two studies show that the sexual life of women living with BD was negatively affected by the illness (Pollack, 1993b; McCandless & Sladen, 2003). This area of life is neglected and there is a need for sexual health promotion strategies for women with BD. No studies were found concerning sexual health of men with BD.

Patients hospitalized for treatment of BD and attending inpatient bipolar therapy groups participated in a grounded theory study (Pollack, 1996). Semi-structured interviews with a focus on the participant's informational needs and activities in six areas, described in an earlier study of Pollack (1993a), were conducted. The results of this study

emphasize the importance of finding information-seeking actions in order to help the patients to be able to understand their life and illness better. Lim, Nathan, O'Brien-Malone and Williams, (2004) used a client-focused approach with the aim of identifying the psychosocial issues and difficulties faced by bipolar patients. Three focus group discussions and two additional individual interviews were conducted. The study shows that persons with BD appear to experience low self-efficacy with regard to managing their illness and life circumstances. That may affect the way they view themselves, their role in the community and their future. Karlsson (2004), utilizing an interpretative approach, studied one aspect of bipolar disorder with the aim of describing and understanding the phenomena of mania and suffering in order to contribute to knowledge development in psychiatric nursing. Patient's experiences of mania are characterized by strong emotions, involvement and vitality. The experiences fluctuate between elated mastery and paralyzed, anxious isolation.

BD is well explored from a biological, psychopharmacological and psychological perspective but poorly explored from the perspective of the individuals actually living with it (Sheppard & Hill, 1996; Goodwin, 2000; Olofsson, 2000; Baker, 2001; Lim et al., 2004; Elgie & Morselli, 2007; Ghaemi, 2007; Inder et al., 2008). Patients also often experience a gap between their lived experiences and the biological explanation of them (Toombs, 1993). Furthermore the studies that focus on experiences of BD partly use predetermined questions. Lived experiences of life with BD are more frequently described in biographies, for example, by Redfield Jamison (1995). Despite the paucity of studies focusing on subjective experiences of BD there is a growing awareness of the importance of knowledge of the lived experiences of life with BD. The aim of this study is therefore to explore the existential meaning of life with BD. The specific research questions are: What is bipolar disorder from a lived perspective? How is life with bipolar disorder experienced? With a caring science perspective the present study focuses on the largely unexplored areas of the lived experience of BD in order to contribute to the knowledge base about BD. Thereby we hope to reduce the gap between biological, psychopharmacological, psychological knowledge and the lived experience of BD.

### **Approach and Method**

In order to understand the meaning of the lived experience of BD a reflective lifeworld perspective based on phenomenological philosophy was chosen (Dahlberg, Dahlberg & Nyström, 2008). By that approach we aimed to come as close as possible to

the essential meaning and its variations and thereby further develop the understanding of individuals living with BD. The leading principles for the chosen approach are an understanding of the world and body as lived and experienced *as* something, a focus on meaning as well as reversibility. Such research demands a phenomenological attitude, which is characterized by openness for the lifeworld phenomenon, ongoing reflection upon the meanings, bridling of the understanding as well as a movement between distance and closeness (Dahlberg et al., 2008).

The present study is part of a major project aiming to gain a greater understanding of different aspects of the lived experience of BD. Lived experiences of BD and support in life with BD were explored in connection to each other in open interviews. In this paper the analysis of the phenomenon “lived experience of BD” is presented. The analysis of statements concerning the phenomenon “lived experience of support in life with BD” will be analysed separately and presented in another paper.

#### *Informants and data collection*

The directors for two Swedish psychiatric clinics and a contact person for a patient advocacy group for people living with BD were contacted and informed about the study. After permission was granted to conduct the study, the nurses at two community psychiatric clinics and the contact person for the patient advocacy group were informed and asked to make the initial contact with persons meeting the inclusion criteria and to inform them of the study. Those persons who declared an interest in participating then received verbal and written information from the first author about the study and what it would mean to participate. Written consent was given from the informant before the interview, made by the first author (MR). In accordance with the leading principle of openness access to the informants’ medical records was not sought for and furthermore it was not considered important to know what type of BD the informants had been diagnosed with.

In reflective lifeworld research variation should be considered when choosing informants. The number of informants depends on the need to attain as great a variation of data as possible. The nurses making initial contact with presumptive informants were thus after some time asked to address male and young persons about participation in the study. Ten persons, six women and four men, 30 – 61 years old, diagnosed with BD, having experienced institutional psychiatric care, living in their own homes, and at the time of the interview not suffering from severe

depression or mania were interviewed and asked to describe their experience of living with BD. The interviews were tape-recorded and lasted between 50 and 80 min. Apart from the initial question “Would you like to tell me about your experience of living with Bipolar Disorder?” no pre-determined questions were asked. In order to gain richer illustrations of the experiences of the phenomenon questions like “Would you like to tell me more about that?” and “What does that mean to you?” were asked during the interview. The setting for the interview was chosen by the informant. Five interviews took place in their homes, one at a community psychiatric clinic and the other four at neutral settings. Some of the informants in the present study were patients at the chosen psychiatric clinics at the time of being contacted but the informants from the patient advocacy group were not. The authors have, therefore, chosen not to use the word “patient” but “person” or “individual” when talking about the informants in the findings.

#### *Data analysis*

The interviews were transcribed verbatim by the first author and the text was analyzed for meaning in relation to the research questions for this initial study. The data analysis was conducted following the structure of whole-parts-whole described by Dahlberg et al. (2008). To get a sense of the whole the text was initially read twice, trying to retain an open mind without starting the analysis process. With this sense of a whole as a background the focus of the analysis process changed to the parts. Meaning units were marked and described with a few words and in order to structure the meanings, clusters of these were formed and after having formed a number of clusters in several different ways a pattern of meanings emerged. A new whole, a structure of the essential meanings of the phenomenon “the lived experience of Bipolar Disorder” was formulated and further described by its constituents, which are the variations of the essence.

#### *Ethical considerations*

The study was approved by the directors of the psychiatric clinics. In accordance with the then existing Swedish legislation, no formal ethical permission was needed for research studies that have no intention of affecting the informants physically or mentally (SFS, 2003, p. 460). The specific legislation on ethical aspects of research had only recently been introduced and thus the regional board for ethical approval was consulted about the present study and a written verification that no

formal permission was needed was received. Information to the presumptive informants as well as the informed consent agreement was designed in accordance with the basic principles as stated by the regional board for ethical approval.

Participation through one's own choice, an option to terminate participation without an explanation, confidentiality for the participant and written consent was emphasized. The present study elucidates the life situation and needs of individuals with severe psychiatric illness and can contribute to the rights of this group of patients to receive even better psychiatric healthcare services. The process of reflection that could start through participation could be positive and profitable for the informant. In order to minimize the risk of discomfort the informants were also informed of the possibility of having an extra appointment with a professional caregiver at the psychiatric clinic if needed. The value of the study was assessed to weigh up eventual discomfort for the informant.

## Findings

The meaning of the lived experience of Bipolar Disorder, the essence and the variations, is presented below. Presentations of essential meanings are written in present tense while they describe how the phenomenon is, i.e. the meaning and not what the informants said about it.

### *The essential meaning of the lived experience of bipolar disorder*

Living with bipolar disorder (BD) entails experiencing extra dimensions in all aspects of life, expressed in terms of a magnitude and complexity beyond that which is perceived as pertaining to normal life.

Magnitude entails a specific intensity and tension in the individuals' feelings and experiences and these are of all different kinds existing side by side and creating chaos in life. Life is simultaneously predictable and unpredictable. Despair exists alongside hope with room for experiences of both reality and unreality. Life is characterized by containing "both" rather than discerning between "one or the other"; the differing experiences do not exclude each other but are a part of the magnitude of experiences. There is more of this tension and simultaneousness when living with BD than that which is understood as pertaining to normal life. The magnitude also entails a life in which past experiences together with future expectations of experiences are more evident.

Complexity entails an existence in which the illness is intertwined with life and, therefore, always present. It means trying to understand and respond

to experiences that are so complicated, to the extent of being almost intangible and diverse, that they are thus difficult to comprehend in relation to that which is perceived as being normal life. It means being involved in an ongoing struggle to keep contact with oneself and to be able to have a life that corresponds to how one perceives oneself to be.

The magnitude and complexity of life is explicitly experienced but words are felt to be inadequate for describing what is actually experienced. This leads to feelings of having difficulties in comprehending what it means to live with BD and thus difficulties in communicating it to other people. Different illustrations and comparative words are used in order to attempt to communicate what it is like to live this life with a magnitude of experiences. Such words that are used are: out of the ordinary and the comparative forms of adjectives such as larger, deeper, stronger, faster, slower, brighter, more than usual, less than, beyond, lower, easier, more difficult, higher, lighter, weaker and darker. However, the adjectives are not used in a comparable sense or as opposites but as an attempt to describe experiences of something *more*.

The meaning of the lived experience of BD is further described by its constituents, which represent the variations of the meaning: *a specific intensity, a struggle to understand, an illness that is intertwined with one's whole being*.

### *A specific intensity*

Individuals with BD have the same kind of experiences in life as other persons but there is a significant difference. Their experiences are characterized by more dimensions and a specific intensity. The feeling that "something is wrong" has been experienced since childhood or youth and thus it is a relief to receive a biological explanation of BD. However, the meaning of living with BD goes beyond these explanations. The specific intensity in life with BD manifests itself in many different ways and is experienced as being difficult to understand and to describe for others, thus the need to use illustrations and metaphors. The intensity in life is, for example, illustrated as ocean waves that are sometimes threatening while at other times just a ripple on the surface of the water.

The specific intensity affects levels of activity, time needed to do things, reflection and time itself. In periods of rapidity it is possible to do many things at the same time. "The brain starts spinning". Experiences of increased capacity to think and act are very strong and life is infinite, without limits or boundaries.

Yes, I can experience a hundred things in one second. They just flash past. And when I regain consciousness I'm still sitting there smoking, I haven't even taken a puff of my cigarette [laughs].

There are also periods when the capacity to think and act decreases; it takes an eternity for the evening to come. Thus the meaning of time changes and the connection to time as measured in hours, minutes and seconds is lost.

The specific intensity also concerns sensitivity, which is illustrated as an "emotional opening upwards". Feelings that are impossible to express in words can be expressed, understood and felt in paintings, poems and music. Intense perception increase the individual's sensibility regarding himself/herself, other people and surrounding conditions, making it possible to instantly feel warmth or the cold.

I've been able to both think and feel at different levels at the same time. . . . I could register feelings about people whilst at the same time standing to one side. . . . But if I count them then I could perhaps be on five to six levels at the same time feeling, being in myself and changing back and forth.

Having close relationships with truthful, honest and faithful others becomes a necessity. The specific intensity is also valid for the ability to think and reflect. Intense sensitivity added to intense reflection makes it difficult to understand oneself and life. Furthermore, a feeling of not being understood by others emerges. Lack of concentration and focus makes it hard, for example, to carry on a conversation, to read a book and to watch TV, together with experiences that such things are very simple. This intensity is experienced both as a gift and as a weakness. It is, however, extremely difficult to live with such intensity for a long period of time. It seems, for example, as if the body is aware of the need for limitations and thus blocks up the connection to some of the intensity without consciously thinking of it. Another solution can be medication and limitations of that kind are experienced as both a relief and a loss.

Other areas of life where the specific intensity is experienced are: well-being, suffering, tiredness and weariness. Sometimes daily living, thinking, understanding and doing things becomes difficult and everything is experienced as being onerous. At other times one has no worries and sufficient energy to achieve whatever is needed. Life with BD also entails intensely dark periods. One's mind is as though it is out of order and a breakdown can be close at hand.

Dark thoughts and images of negative experiences increase to a great degree and are repeatedly shown on an inner movie screen. At these times it becomes difficult to live and hope for a change.

It's as though the doors to everything that's been negative in my life open up and all those previous depressions have been stored in that room. And when the doors open so all this negativity and darkness just pours right into me so that I [sighs] feel really bad.

Fluctuating between the extremes of self-confidence is also characterized by intensity. Life on "high mountains" exists together with great trust in one's own ability. Life "in the valleys" is the reverse. Great self-confidence often turns into an experience of sadness, of low self-esteem and of being worthless. Then need for sleep and time spent sleeping can vary, for example, in difficult times sleeping brings protection and rest, while in times of great energy levels and intense clarity in thought and emotion the need of sleep is less. One may only sleep a few hours a day without a sense of being tired, however, even without being tired the need for sleep is there. One informant talks about a situation when trying to convince himself/herself of that need and when not feeling it, by writing the words "be silent" on the wall.

The capacity of being "enormously strong" on some occasions and "shivering and weak as a kitten" on others together with the awareness of having a potentially violent streak is dangerous for the individual experiencing it. Sensory experiences are also characterized by intensity, for example, colours (including black) sometimes have more nuances and auditory sensations are sometimes stronger and more intense. Such intense sensory experiences also include experiences of seeing and hearing things that have actually not occurred.

. . . and I was going to buy nappies, I recall, and I was standing there with my hands on a packet of nappies and then they called out on the loudspeaker 'Domus customer radio, Mrs [interviewees surname] to the information desk' and so I went there but there was no one there.

Life with BD has a specific recurring rhythm, both general and individual, consisting both of bottom and top levels as well as different phases. The highs and lows are the same as for all persons but they differ in intensity. Experiences in one phase affects life in other phases and are, therefore, intertwined with life as a whole. The general and the individual side of the rhythm are illustrated as being a roller

coaster with a small roller coaster inside, a life with big threatening waves together with a ripple on the surface of the water and also as high mountains on the sunny side of life together with deep valleys on the dark side of life.

### *A struggle to understand*

Living with BD means an ongoing struggle trying to understand a life in which there is always more to consider. There is an additional principal activity that, over and above all the common everyday activities, occupies the individual's attention, and that is thinking. It entails trying to understand oneself, other people and situations, what is helpful in life, what is to be avoided and also what is real and is not real. This struggle to understand is so complicated and difficult that it is described as a daily battle. Meeting others who are able to understand what it is like to be in this struggle, even just to some extent, is experienced as being "wonderful". One aspect of this struggle is a vague awareness of "not being normal" and of being "stupid" and "wacky". It means in one sense not knowing that one lives with what is labelled as BD though in another sense knowing it, which can create chaos and confusion. The struggle to understand also concerns to what extent one can trust oneself and be confident in one's own judgement and abilities to discern. Living with BD means lacking harmony in terms of self-confidence.

One of the major difficulties in having bipolar disorder is that one can't really trust oneself. Philosophically it is not possible for anyone to do it but you can still know who you are and what you are, etc. It becomes so damn obvious, I feel good now but can't be sure if I will in a year's time and most other people can do this in some way.

The individual is in contact with himself/herself and is deeply rooted when experiencing what is perceived as normal life. It is possible to know oneself and to live a life that corresponds to one's own perception of oneself, however, this is not true for experiences, thoughts, feelings and wishes in times of extremes of self-confidence. The senses are out of order and it is difficult to control and cope with life as well as to make good judgements and decisions. That entails a feeling of being in total darkness, but still connected to oneself "by a thin and fragile thread". The struggle is about maintaining and strengthening this contact with oneself, to hold oneself together and not to lose one's foothold. It is a terrifying experience to lose hold of oneself.

One informant uses a part of a well-known cartoon film to describe how it is like.

Yes it feels like, like one's body's going to pieces. It's like, it's like an egg, you're like an eggshell that starting to crack, you know like Piff and Puff, when they're in that cartoon film, that's what it's like, you really feel like an eggshell that's going to crack. ... And it's, it's really terrible, it is.

Another example of the struggle to not lose contact with oneself is a transition of mind from a familiar everyday fog to a terrifying clarity, where the unreal appears. On Christmas Eve morning the informant wakes much earlier than usual with a feeling of having a completely clear mind. Life is usually lived with a feeling of being in a fog, almost as if being intoxicated. The expectation and wish for a life without BD arises together with that extreme clarity of mind. However, for this informant the clarity of mind involves strong feelings of fear and means contrarily that life will become worse and that hospital care will be needed in approximately four weeks. Thus having a clear mind, which would normally be experienced as being positive, turns out to be the first step towards losing the contact with oneself. In order to avoid that the informant desperately tries to find a way back to the foggy and secure state of mind by increasing the medicine dosage and by limiting contact with others and the world around him/her. The large number of varying descriptions, provided in the interviews, illustrates the difficulties in understanding and communicating the meaning of living with BD.

Yes, I felt sort of, not elated but, some, something happened inside me sort of. It was something that, well it's a bit difficult to ... [Int: Difficult to describe?] Yes, it's very difficult to describe ... Yes and now I can say that it didn't happen like that [laughter]. I see things very clearly today. It was just fantasy. But then in that particular situation I was in it felt incredibly strong and real.

Another important example for understanding life with BD is given and in this case the struggle to be in contact with and to be deeply rooted in oneself is taking place in a kind of non-visible inner nervous system. This system contains channels for streams of energy and if too much waste is left in these channels then an emotional vulnerability is created that ends with an inner explosion. This kind of explosion breaks down the normal ways of controlling oneself and navigating in life and leads to emotional chaos and thus control and contact with reality and oneself is lost. In order to avoid that it is important to listen

to one's feelings and try to live one's life without letting feelings be put aside.

The struggle to understand and to be in contact with oneself means a life in chaos, experiencing shame, confusion, anguish, horror, anger, wrath, self-contempt, powerlessness and violence. There is also much happiness, joy, gratefulness and satisfaction in life with BD but even then the struggle is more or less present. The struggle can appear through worry whether the peace and happiness will last or if a new period of unreality lurks round the corner.

*An illness that is intertwined with one's whole being*

BD pervades the individual's whole life. The illness is intertwined with one's whole being and indivisible from one's identity. It is always present but manifests itself in different ways in different times in life. Some aspects of the magnitude, for example, creativity and spirituality, are present since childhood. A common experience is that caregivers offer simplified explanations of BD as something lying outside oneself. Using his big hand he says this is the illness or this is you and this is the illness that we'll fight against.

Such an explanation most often at first brings a feeling of relief but that can change into doubt. To fight against the illness is impossible because that means fighting *against oneself*. The struggle is the reverse; it is all about fighting *for oneself*, for being in contact with oneself. In this intertwined life another complex aspect emerges. Sometimes the illness is "skin-tight" and "close", one "is bipolar and ill", while at other times one "is in contact with oneself", one "has bipolar disorder" and "is healthy". It is very important to have others to talk to about the tension and complexity. Reflections on one's being in relation to the illness are necessary and important as a part of the journey towards accepting having BD. Being able to accept that one has this illness is a turning point in life, and acceptance is essential for a higher degree of self-control.

Even when the individual has strong contact with himself/herself the illness simultaneously expresses itself through feelings of guilt and shame for what has occurred when having weak contact with oneself as well as through concern and anxiety for what may happen in the future.

It can be unbearable to think about how one has hurt those who are most important in one's life. The shame and guilt of driving without self-control is so terrible that it is impossible to verbalize. One such experience forces one informant into a feeling of being in darkness almost unable to maintain contact with his/her inner self for two days. The individual is thus left to deal with both the practical consequences

of what has happened on such occasions as well as a bad conscience. Relations to others are also affected and the individuals can suffer greatly, sometimes evoking thoughts of suicide in the realization that one has been uncontrollably angry with a friend or employer or has hurt loved ones. Life with BD also contains strong experiences of self-contempt and disappointment.

Sometimes I can feel very bitter about not having got help before, because I've lost contact with so many people on the way, or neglected them or how should I describe it . . . I haven't had the life that I thought I would have when I was younger is one way of saying it. Had or perhaps not been able to get that life because of how I've felt. I've been on the way to reaching some of my goals but then there's come nothing of it and it's not good for your self-esteem, you hate yourself also.

Such feelings increase when understanding that others feel let down and judge the tiredness as unwillingness or laziness. BD is also present when grief is experienced for having lost important time in life by not having been able to understand life with BD as well as for not having energy to live more than half the life one wishes to live. Tiredness makes it hard to keep promises such as meeting friends or going to a party as planned. The suffering due to not having energy to support one's children as desired is immense, sometimes helping with homework is impossible or an apparently short parent-teacher meeting can be more than one can bear. It is difficult to meet the expectations of being involved in school matters, it can for example, be overwhelming to prepare for a picnic at short notice, and the feeling of letting the children down while they are taking a great deal of responsibility is difficult to bear.

All these experiences of shame and guilt are experienced as a background for the always present anxiety and concern for the future.

I now have a relationship with a girl and I'm worried if I'll start doing too much or be depressed and that it will ruin things in my life again as it has done several times before.

Anxiety also concerns matters of economy and education. Life with BD may make it difficult to pursue an education programme, and it may be necessary to take a break and wait until one has more energy or an ability to concentrate. Experiences of this kind influence self-confidence. Life with BD also means to struggle with financial matters, being as receiving care and being unable to work reduces one's income. In order to think and to try to

understand oneself and one's life entails a great effort and thus it is difficult to respond to society's expectations concerning a capacity to work.

[Sighs] I don't know what it will be like in the future as I'm supposed to be well enough to work part-time, as I've been work training since May at a day nursery. The doctor at the Social Welfare Office says that I'm well enough to work 50%. 'You can start working now, we'll send you to the Employment Office'. [Int.: And what did you think about that?] Forget it, I'm not well enough, I have been work training on my conditions, and I've felt well because of that, I've not had any responsibility, they've not given me any groups of children to take care of. If I don't come to work one day then there's no disaster, I don't cause anyone else any trouble. To start work with all that it entails, I can't manage that, I can't go out and sell myself. I haven't the self-confidence or the energy to do that.

It is a common experience among the informants that they are treated for recurrent depressions and not BD until some caregiver begins to ask questions about their whole life situation and especially what has happened prior to feeling depressed. Such questions and interest open up for an understanding of life with BD, for an illness intertwined with life.

## Discussion

The findings of the present study show that living with BD entails experiencing extra dimensions in all aspects of life, expressed in terms of a magnitude and complexity beyond that which is perceived as pertaining to normal life. A specific intensity characterizes all experiences in life with BD. There is an ongoing struggle to understand this intensive life in which there is always more to consider. Questions of trust and self-confidence are of great importance. As the illness is intertwined with one's whole being it is even more complex to understand existential issues such as: who was I before, who am I now and what will I become. Experiencing extra dimensions are also evident in more of shame and guilt for past experiences together with an always present anxiety and concern for the future.

Previous research does not, as far as we have found, discuss and critically reflect on labelling the illness as BD and thus, BD has predominantly been understood from a perspective of polarity, i.e. episodes of mood changes alternating between the two extremes of depression and mania, which has contributed to a disjointed understanding of BD. The present study challenges that concept of polarity

and suggests that BD must be understood from a holistic perspective, considering experiences of more inner tension, which is created by the extra dimensions of magnitude and complexity *in all aspects of life* with BD. Living with BD thus means much more for the individual than having episodes of depression and mania. BD is a label that only reflects the more obvious and visible dimensions of the illness excluding the more invisible dimension that causes a large amount of confusion and tension. When living with BD the illness is always present in life whether depression or mania is present or not. As the present study shows, the illness is intertwined with one's whole being. It pervades the individual's whole life and is indivisible from one's identity. It seems fair, therefore, to conclude that it is insufficient to divide life with BD into different episodes without considering the holistic dimension of BD.

The present study thus supports the research that states that BD is often underestimated and wrongly being understood as just depression (Tugrul, 2003; Leboyer et al., 2005; Elgie & Morselli, 2007). Most of the informants in the present study were treated for recurrent depression but they knew that there was "something more" with them. That "more" was the meaning of life with BD as described in this study. The present study shows that, when caregivers ask patients treated for recurrent depression questions about the whole life situation and what has happened before having a depression, difficulties related to BD will more certainly be revealed.

Hence this study emphasizes the importance of a holistic understanding of life with BD, which in turn corresponds with the studies emphasising the significance of psycho-education (see, for example, Perry et al., 1999; Cutler, 2001; Dogan & Sabanciogullari, 2003; Jose et al., 2003; Bauer et al., 2006; Reinares et al., 2008). However, the present study shows that questions of trust, self-confidence and comprehension of identity are essential for individuals with BD, strongly influencing the sense of having control in life. As found in the present study these issues should be given a leading position in patient education in order to enhance understanding of other issues dealt with in the patient education. For example, recognition of early signs of BD grounded in an understanding of life with BD can affect the ability to live a meaningful and good life.

While using five different research methods, four qualitative and one quantitative, similar research findings on significant issues concerning life with BD have been found (Baker, 2002; Pollack, 1996; Lim et al., 2004; Inder et al., 2008, Jönsson, Wijk, Skärsäter & Danielsson, 2008). The issues mentioned are about the sense of self, identity, the view of self, illness and future, trust in self and self-acceptance.

The present study describes those issues as well but goes one step further while describing the meaning of life with BD. It goes without saying that depression and mania are the more obvious and visible expressions of BD and has therefore been explored with many types of research methods. A lifeworld perspective can thus contribute to the study of the meaning of life with BD in its entirety.

Nurses play an important role in that entirety, as they often are responsible for the patient education and for motivation for treatment (Morrissey, 1998; Tugrul, 2003). Therefore, it is important that nurses are able to create a caring relationship with the patient so that the patient can experience understanding and good care over time (Morrissey, 1998; Johansson & Eklund, 2003). Such a caring relationship is where dialogues can take place, about what it means to have the diagnosis of BD and to live with the illness.

Michalak et al. (2007) studied the impact of BD upon work functioning. Five main themes of problems were presented: lack of continuity in work history, loss, illness management strategies in the workplace, stigma and disclosure in the workplace and interpersonal problems at work. The present study emphasizes a further issue related to difficulties in work, namely the difficulty to respond to society's expectations concerning an ability to work. As the BD illness is intertwined with life it does not correspond to the generally accepted approach in Sweden when assessing a person's ability to work and his/her illness in terms of percentages. The ability to work could change in many ways and the support from the Employment Office should also be of variety, considering the holistic perspective of BD. Tse and Walsh (2001) states that clinical recovery does not necessarily mean functional recovery for individuals with BD and that this may reduce preparedness for employment. The present study shows that the specific intensity in life with BD might be useful in occupational situations of a creative nature.

Another issue that needs to be discussed is the use of the word "normal". Does anyone live a normal life? In this study the word "normal" is used in accordance to how the informants use it. All the informants mean that their lives are not normal; they know that there is something more in their lives than in the lives of persons without BD. The use of the word does not express a value, it is just a statement that it differs from what they find to be a normal life. They may use different words as "ordinary", "commonly understood" for that but the meaning is clear, it means that life with BD entails experiencing extra dimensions in all aspects of life, dimensions not deemed to pertain to normal life.

### *Methodological reflections*

In this study a descriptive phenomenological method (Dahlberg et al., 2008) has been a guide for the work with data collection and analysis. Is it possible to describe a phenomenon without interpreting? As humans we are always living with influence from our historical context (Gadamer, 2004) and cannot be completely free from preconception but with a phenomenological reflective attitude it is possible to set aside more of one's preconceptions than without, in order to maximize possibilities for an open attitude. During the interviews a balance between immediacy and reflection was strived for. As the findings show, words were often felt to be inadequate for the informants when describing experiences of BD. This was also a challenge for the interviewer. It required great concentration to follow the narratives closely whilst constantly reflecting. On some occasions during the interviews the interviewer was not certain if the informants really talked about the phenomenon in question, and therefore asked if what they talked about did concern living with BD. In all of these cases they confirmed that it concerned life with BD. The informants also were sensitive about the ability of the interviewer to follow the descriptions of experiences that went beyond what is commonly shared and accepted. In the analysis process following question was constantly asked and reflected upon: "Does the text really say and mean this?"

The question of generalization also needs to be addressed. Phenomenological findings do have an essential part of the meaning as well as parts showing the variations of the meaning. If the collected data is of great variation, the essential meaning can be widely applicable in similar contexts. This means that experiencing extra dimensions in all aspects of life, expressed in terms of a magnitude and complexity beyond that which is perceived as pertaining to normal life, most probably is general for all individuals living with BD. The variations of that essential meaning are closely and reversibly connected to the essence but show the different expressions of the meaning of life with BD.

### **Conclusions**

- Living with BD means more for the individual than just having episodes of depression and mania and must, therefore, be understood from a holistic perspective.
- An understanding of the meaning of life with BD may strengthen the sense of control and involvement in life and care for individuals

living with BD and also improve the quality of psychiatric health care.

- Individuals with BD need to be offered a work situation that corresponds to the illness being intertwined with life.

### Clinical implications and future research

- Adequate care for persons with BD includes places where safe and profound reflection on existential issues, such as identity, trust and self-confidence, can be carried out. Such a place could, for example, be a caring relationship, a group setting created for that purpose, perhaps in connection with a patient education group.
- In the process of detecting BD it is important to ask patients treated for recurrent depression questions about the whole life situation and especially what has happened prior to feeling depressed.
- The caring services are recommended to change their ways of explaining and talking about the BD illness. It is better to support individuals with BD in the fight *for* being in contact with themselves than in a fight against the illness, while that would mean that they are fighting against themselves.

The present study shows that persons living with BD are involved in a struggle trying to understand a life in which there is always more to consider. Therefore, future research will focus on the meaning of support in life with BD.

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