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“What makes you well?” Supports of well-being in bipolar disorder. A qualitative study

Julien Jupille^a, Yves-Antoine Harscoet^b, Mélanie Duval^b, Marie Grall-Bronnec^{b,c}, Leila Moret^{c,d}
and Marion Chirio-Espitalier^{b,c}

^aCREhab'S, Support Center for Psychosocial Rehabilitation in the Loire Region, Nantes University Hospital and Angevin Mental Health Center, Sainte Gemmes sur Loire, France; ^bNantes Université, CHU Nantes, UIC Psychiatrie Et Santé Mentale, Nantes, France; ^cNantes Université, Univ Tours, CHU Nantes, INSERM, MethodS in Patients Centered Outcomes and HEalth ResEarch, SPHERE, Nantes, France; ^dUniversity Hospital Centre Nantes Department of Medical Information Evaluation and Public Health, Nantes, Pays de la Loire, France

ABSTRACT

Objective: Subjective experience of people living with bipolar disorder is gaining attention in the field of research. Improving well-being could be as important as symptom remission, but this constitutes a vague concept. This study aimed at exploring the boundaries and the determinants of the well-being of people living with bipolar disorder in a French context.

Methods: Individual semi-structured interviews were conducted with 16 patients by three professionals. Interviews were transcribed and analysed using the thematic analysis method.

Results: Various dimensions emerged as contributing to well-being: daily routines, connectedness, regaining a positive identity, and self-awareness for self-management.

Conclusions: In addition to those common to the general population, this study highlighted specific determinants of well-being: the construction of a positive identity through acceptance of the diagnosis, the importance of self-awareness and self-management. They are highly intertwined with those of personal recovery and could help caregivers design interventions that directly target these goals. This study aimed to identify specific components of well-being for people living with bipolar disorder. Understanding the determinants of well-being enable caregivers to design tailored interventions that directly target quality of life and help improve bipolar disorder outcomes.

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Bipolar disorder; well-being; quality of life; personal recovery; qualitative research; patient experiences





Background

The Cambridge dictionary definition of well-being is “the state of feeling healthy and happy”(WELL-BEING | *English meaning—Cambridge Dictionary*, s. d.). In the general population, well-being is a subjective perception whose evaluation requires the individual to determine his or her own standards, which is larger than health. In medicine, pathogenic factors and deficits are often studied, and the focus is more on pathologies than on health. These traditional conceptions are countered by salutogenic approaches, which focus on resources and positive factors that reinforce health and well-being. In this framework, the concept of health itself has been defined by the World Health Organization (WHO) with reference to well-being as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (« The World Health Organization Quality of Life Assessment (WHOQOL) », 1995). Well-being has been recently defined as “a state of positive feelings and meeting full potential in the world. It can be measured

subjectively and objectively, using a salutogenic approach” (Simons & Baldwin, 2021, p. 984).

Bipolar disorder (BD) is a mental disorder affecting up to 2,6% of the population (Merikangas et al., 2011). The difficulties faced by people living with BD have been well described: cognitive impairment, alteration in social and professional functioning which persists outside thymic decompensation episode (Gitlin & Miklowitz, 2017a), reduction in QoL and well-being (C. del M. Bonnín et al., 2019, Michalak et al., 2005, Vieta & Torrent, 2016). This reduced QoL situation has an important impact: BD has the highest rate of suicide of all psychiatric conditions (de Abreu et al., 2012). Lithium is the reference thymoregulatory treatment, and it is recommended to combine pharmacological treatments with psychosocial therapies. Some of these recommended treatments are offered by outpatient psychosocial rehabilitation services currently being developed in France.

As many other people living with specific condition, people with BD are no longer satisfied with the mere remission of their clinical symptoms, but also want to

CONTACT Julien Jupille  julien.jupille@gmail.com  CREhab'S, support center for psychosocial rehabilitation in the Loire region, Nantes University Hospital and Angevin mental health center, CREHPSy, 27 route de Bouchemaine, 49130 Sainte Gemmes sur Loire, France; Marion Chirio-Espitalier  marion.chirioespitalier@chu-nantes.fr  Nantes Université, CHU Nantes, UIC Psychiatrie et Santé Mentale, CREHPSy, 27 route de Bouchemaine, 49130 Sainte Gemmes sur Loire, Nantes F-44000, France

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“do well” and “be well” (Vieta & Torrent, 2016). For example, they aspire to return to a “normal functioning” (Michalak et al., 2005) and to achieve “meaningful living” (C. del M. Bonnín et al., 2019). In the same way, improvement of QoL is rated by patients themselves as “the most treatment outcome” (Gitlin & Miklowitz, 2017b). Quality of life (QoL) is a subjective sense of well-being in large and various areas of life, including school or work, family relationships, peer/romantic relationships, physical health and self-esteem (O'Donnell et al., 2017). This concept is more commonly used in the health field than in the social sciences.

Considering mental health as a complete state supports the idea of promoting protective factors such as well-being which may provide protective effects against recurrence (Keyes et al., 2010). This is the background to the development of psychosocial rehabilitation care in psychiatry and, more broadly, care supporting the personal recovery (PR) of people affected by severe psychiatric disorders. PR is defined as a personal process in the particular context of living with a mental illness, towards a fulfilled and self-determined life despite the limitations associated with the disorder (van Weeghel et al., 2019). These include first-line psychoeducation, second-line cognitive-behavioural therapy and family-focused care. Interpersonal and social rhythm therapy and peer support may also be offered, depending on the individual's needs (Verdolini et al., 2021, Yatham et al., 2013).

These psychosocial rehabilitation care are promoted by public authorities, expected by users, and aim to improve people's day-to-day functioning, the quality of their social integration and to promote conditions favourable to their recovery. The research team behind this study is in charge of a regional support centre for psychosocial rehabilitation care in France. Thus, taking into account the subjective experience of people living with BD to achieve better outcomes has become a vast field of research, including well-being and QoL (Russell & Browne, 2005).

However, QoL, well-being, health, life satisfaction or PR have broad definitions and overlapping conceptual fields. Moreover, these concepts are highly subjective, culturally and historically variable (C. M. Bonnín et al., 2018).

Despite the complexity, some studies tried to reach a better conceptualization and particularly to identify the components and domains of these variables. Leamy et al. (2011) proposed a framework including five domains that would constitute PR: Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment (CHIME) (Leamy et al., 2011).

Michalak et al. defined QoL as “the sum of a person's physical, emotional, social, occupational and spiritual well-being”, and as an important indicator of well-being (Michalak et al., 2005, p. 2). More recently, studies on QoL in BD tend to identify specific components. As stated, QoL in BD refers to “Physical, Sleep, Mood, Cognition, Leisure, Social, Spirituality, Finances, Household, Self-esteem, Independence, Identity, Work, and Education” (CREST.BD, Michalak and Murray, 2010, p. 737). If some dimensions are common to the general population (Physical, Social, Leisure, Mood, Work and Education), others are shared with other mental disorders (cognition). The authors highlight that identity, self-esteem and spirituality are major areas in this population that deserve to be assessed (CREST.BD, Michalak and Murray, 2010).

The scientific understanding of well-being is considered to be multidimensional. It includes different elements: Positive emotion, Engagement, Relationships, Meaning and Accomplishment (Seligman, 2018). Well-being, however, suffers from a lack of clarity and consensus, despite some attempts to better define its boundaries (C. del M. Bonnín et al., 2019). For instance, Keyes and colleagues identified three dimensions of well-being: (a) emotional (e.g., presence of positive emotions), (b) psychological (e.g., autonomy and environmental mastery), and (c) social well-being (e.g., social acceptance or social coherence) (Keyes et al., 2010).

As mentioned, while some work has explored QoL and well-being tools in schizophrenic disorders (Valiente et al., 2019), qualitative studies in which people with BD could give their own definition of QoL and its components are required (Morton et al., 2017). Beyond the constituents, the subjective perception of QoL and well-being levers are relevant research questions in which data are lacking.

By collecting the views of the people concerned, this study aims to explore the boundaries and determinants of well-being from the perspective of people living with BD in a French context. Thus, by enriching this knowledge, the authors hope to be able to develop more specific tools for measuring well-being in these populations, in order to refine outcomes in the field of mental health research and care.

Method

Design & recruitment

This is a monocentric (i.e patients were recruited from a single centre) qualitative (i.e no quantitative data were collected) study exploring patients' perspectives about their well-being. The study consisted of qualitative in-depth individual interviews with 16 people diagnosed with bipolar disorder.

Participants

Participants were recruited from an outpatient psychosocial rehabilitation centre in France, through participation in a therapeutic education programme for BD from December 2019 to February 2020. Participation in the individual interviews was open to all patients taking part in the therapeutic education programme at the psychosocial rehabilitation centre from December 2019 who met the inclusion criteria, which was the case for all patients who agreed to take part: none were therefore excluded.

Participation in the study was subject to certain inclusion criteria: diagnosis of BD type 1 or 2 by a psychiatrist. According to the DSM V classification, BD type 1 is characterized by at least one episode of mania, and BD type 2 by at least one episode of depression and at least one episode of hypomania (Fredskild et al., 2021). Participants in this study should be aged between 18 and 70 years, should have a medical follow-up and be receiving mood-regulating treatment. The choice of an age below 70 years was made because of an increased risk of cognitive impairment in elderly people living with BD (Shobassy, 2021). Minors, people with poor French language skills, people with obvious cognitive disorders and people under guardianship should be excluded.

Data collection

The semi-structured interviews were conducted by three investigators with different perspectives, who had no previous connection with the participants: an advanced practice nurse in psychosocial rehabilitation with experience of caring for people with BD, a medical intern and a sociologist who were not professionally involved with people with BD.

The investigators followed interview guides containing four open-ended questions: Q1) Can you tell me about what helps you to do well, generally speaking, in your life? Q2) What has helped you so far, since the first symptoms appeared? What has been your main supports? Q3) Can you tell me how your support has helped you? How has your support been a resource? Q4) What needs have your support met?

The order of the questions foreshadows a possible course of the interview (Combessie, 2007). In a concrete situation, the interview has its own dynamics that can change its course. The order of the questions has therefore been adapted to the answers and themes raised by the participants.

Given the health restrictions in place during the COVID-19 pandemic, interviews were conducted by phone or video call. Interviews lasted between 30 minutes and 1.5 hour. All interviews were audio-

recorded with the patient's consent and were destroyed after transcription.

Recruitment only stops when interviews or observations of new participants no longer reveal new trends or themes. This saturation was reached after 16 participants had been recruited, and hence study recruitment was ceased.

Data analysis

All interviews were transcribed manually by each interviewer without the use of specific software. The interviews were analysed by the first author using an inductive and semantic approach (Frith & Gleeson, 2004), that is to say without a pre-existing coding frame. The participants' responses were analysed using thematic analysis (Braun & Clarke, 2006) which consisted of identifying, analysing and reporting patterns from the participants' discourse and organizing them into categories in the following steps: i) a "floating" reading, in order to have an overview of the content without coding; ii) the production of initial codes from data; iii) searching for potential themes using a visual representation (mind maps); iv) verifying the consistency of the themes; v) organizing and refining the themes; and vi) producing the report. The themes that emerged were not necessarily directly related to the questions initially posed, since the interview modalities were sufficiently flexible to allow other themes to emerge spontaneously. Their construction could be modified throughout the analysis of the discourse content.

Results

Description of the sample

Among participants in the therapeutic education programme, sixteen people were included in the present study. The average age was 37 years and the average duration of the disease was 5 years. Women constituted 75% of the sample. In addition, a set of socio-demographic data was collected at the time of inclusion: age, employment, family status, year of diagnosis of bipolar disorder, year of last hospitalization and type of BD. Characteristics of the participants are described in Table I.

Elements of well-being

Four categories emerged from the qualitative analysis of the interviews content: 1) Regular rhythm of life and meaningful activities; 2) Overcoming stigma through connectedness; 3) Regaining a positive identity in all spheres of life namely through work; 4) Achieving a better understanding of the disease in order to improve self-management.

Table I. Socio-demographic characteristics of participants.

Patients' characteristics (N=16)	
Gender	
Male	4
Female	12
Age	
Range	20–51
Mean	37
Family status	
Single without children	5
Single with children	2
In couple without children	4
In couple with children	5
Employment status	
Student	2
With employment	6
Unemployed	8
Time since onset of symptoms in years	
Range	5–27
Mean	16
Time since diagnosis in years	
Range	1–16
Mean	5
Type of bipolar disorder	
Type 1	5
Type 2	8
Not determined	3

Within these categories, 9 themes emerged. The categories and themes identified in each category are listed in Figure 1 and are developed in more details below.

Category 1. Regular rhythm of life and meaningful activities

Daily routines and fulfilling activities were the first theme raised by participants as essential contributors to their well-being.

By daily routines, we essentially mean a regular rhythm of life such as fixed schedules including physical activities, regular working hours, or everything that structures the day.

• Theme 1: Balanced lifestyle

As several participants pointed out, getting enough sleep and falling asleep at regular times is an important part of their well-being, as it contributes to a balanced lifestyle and serves as a routine for preventing relapses.: *"I know that if I don't get a good night's sleep, I'm starting to fall apart"* (Woman, 42). Daily routines also mean keeping busy. For many of the participants, structuring their daily lives meant identifying activities, whether professional or leisure. As one interviewee explained: *"If you don't keep yourself busy, you think, and if you think, you brood, and if you brood, it's less and less okay..."* (Man, 40).

Indeed, often associated with unemployment, boredom is seen as something that can worsen the health status of the interviewees. Maintaining a structured rhythm of life, whether through physical activity or by setting goals, seems important to them as in the case of this woman who lunches every day in a social restaurant: *"It makes me get up in the morning because I wouldn't get up, take a bath, make myself look pretty, go out, have contacts within the association, eat well, leave again [...]"* (Woman, 54).

According to the participants, employment plays a dual role in well-being: it is both a vector of social identity (see the "Identity" section below) and a structuring activity that contributes to life balance and improved quality of life. As a participant puts it: *"Getting up in the morning and having something to do, getting up and having somewhere to go, to work, to have a salary contributes to my well-being[...]. To have my place, to take my place and to be autonomous"*

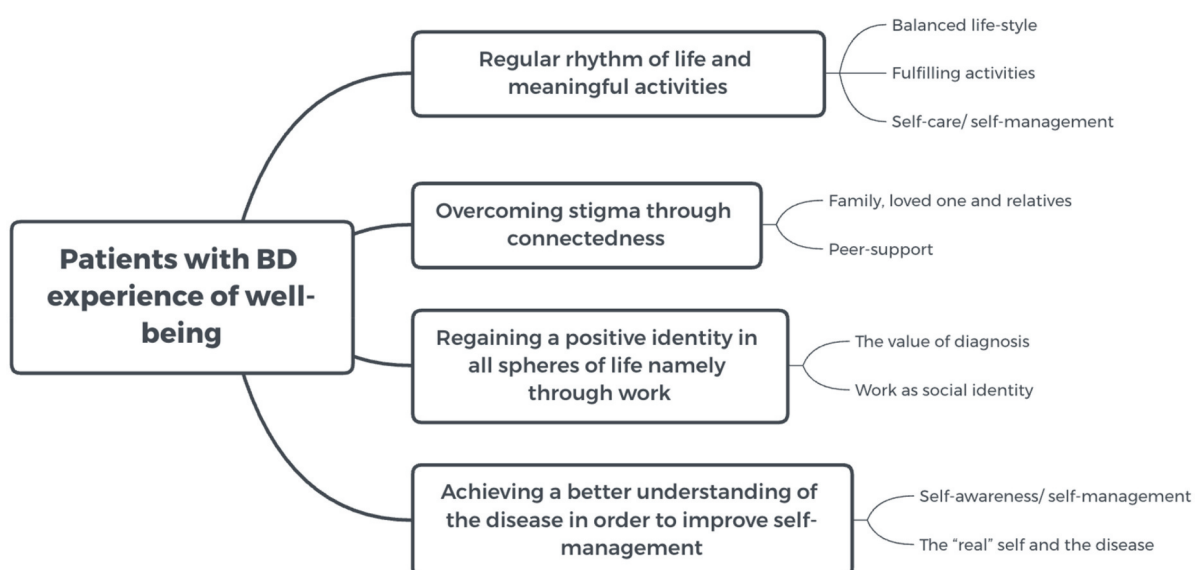


Figure 1. Categories and themes.

(Woman, 42). Another participant adds that work gave him an “aim” and is a “landmark”.

Conversely, not working even affects mental health for this participant: “when you don’t work the days are long and when the days are long there is boredom and at the end of the boredom there is discomfort” (Man, 49) whereas another one says: “What is particularly important to me is self-realization in work. If I do well at work, my health is fine” (Man, 40).

- **Theme 2: Fulfilling activities**

The second theme mentioned by the participants was fulfilling activities including both physical and artistic activities like reading, walks, dancing, yoga, cooking, etc. People living with BD we interviewed regularly seek the same soothing and relaxing effects summarized by the need to “clear one’s head” (Woman, 40). As she says about cooking: “I find myself by doing the things I have to do and it is quite pleasant ». Another explains: “I practice yoga and meditation every day. It is vital for me. Yoga relaxes the body. Meditation is essential for my mind. It’s something that clears my head and settles me down for the whole day” (Woman, 42). Physical activities “make me forget my illness” (Woman 42) or “allow me to be able to refocus on myself, to stop having my ideas go all over the place” (Woman, 30) for two other participants.

The interviewees expressed that these activities were part of a more balanced lifestyle despite mental health symptoms and allowed them to distance themselves from the illness.

All participants attach great importance to and developed such strategies into their daily lives to stay well. These activities can be mobilized for recreational purposes enhancing global health or self-esteem (staying fit for example). But, at another level, they can be part of symptom self-management strategies to prevent or manage episode of relapse.

Maintaining or achieving a structured life with a regular schedule and timetable provides a sense of security for interviewees. Work is an important part of this need. Whether they are employed or not, paid work is permanently associated with positive effects. Firstly, by providing a salary, it enables the realization of projects (holidays, lifestyle, and leisure) and promotes autonomy and independence. Second, it is correlated with the fulfilment of a rewarding social role and meaningful activity that makes people feel part of the social organization that nurtures a sense of belonging and a sense of usefulness.

- **Theme 3: Self-care/self-management**

In addition, people expressed that these activities allowed them to regulate their emotions and better manage their symptoms. While they contribute to

everyone’s well-being, participants see them as a means of self-managing their disorders. For example, this woman said that cycling “clear my head” (Woman, 40) when she feels unstable. Taking walks by the countryside had “a self-relaxing side” for this man who explained: “Often if I’m in a bad mood, unwell, or tense, I’ll go for a walk. On the way back, I realize that something has given way” (Man, 50). For another one physical activity provided the same relief as meditation which “helps me manage my emotions” (Woman, 45). Thus, for the majority of participants, attention to ways of calming variations in their mood or emotional experiences is at the heart of their contribution to their own well-being.

Category 2. Overcoming stigma through connectedness

According to the participants, mood swings are sometimes difficult to understand and tolerate by parents, friends and those around them. As a result, they may feel misunderstood, sidelined or even rejected, which can exacerbate their distress or unease. That’s why they often mentioned connectedness and supportive relationships as being very important, as they play an important role in their well-being. Social support from family and peers were particularly mentioned in the participant’s speech.

- **Theme 1: Family, loved one and relatives**

The people interviewed often related that they had spent years hiding their mental health problem and felt unable to talk about it freely, particularly to their family and friends. This characteristic is common to those who experience stigma. They often feel judged and tend to keep their disorder a secret, which can reinforce their exclusion and may delay access to care. But since this woman revealed her illness to her family, she has noticed: “My family has changed their outlook. At first they said to me: ‘You let yourself go, you are lazy’ whereas now they have understood that it is a disease.” (Woman, 54).

Indeed, interviews showed that people with BD hope and need to be understood, not to be judged and not to feel guilty about what their experience. This acceptance from family members or friends seemed very important for them: “I’m lucky enough to have friends that I can do activities with or call regularly. So, I think that the entourage is important. I don’t feel like I’m alone” (Woman, 43). Concerning a depressive episode, another speaks about the supportive role of her family: “When it happens to you, life doesn’t make sense: getting dressed, washing, breathing, brushing your teeth, eating. It’s all meaningless. You have to find the desire to do all that again. So that’s what my relatives helped me to do. Go for a walk, go outside, go shopping, buy clothes, etc.” (Woman, 36). The notion of destigmatization is reported in the

participants' discourse, with a significant expectation on the part of relatives in this respect.

From participant's point of view, relatives are a source of well-being because they make them feel supported, as this woman described: *"When I'm in low periods, I know he [her husband] will do more things around the house, take care of the kids, give me time to myself and in high periods, he'll say "listen, you need to calm down" even if it means calling my doctor"* (Woman, 40). Another one even recognizes: *"My husband is a solid person which makes me feel safe and secure"* (Woman, 40). In addition, being able to share one's experience of BD tends to *"makes my illness less of a burden for me"* states this woman (Woman, 43).

Alongside the supporting role they may have, relatives can play the role of alerters. With regards to her family, a woman noted: *"They are able to see beforehand if something is going to happen... so they play a bit of an early warning role"* (Woman, 42). In the same way: *"Friends or my husband are there to warn me when things are not going well: 'You're going a little bit crazy'; 'I think you're a little bit depressed'... These are my little warning signs. I know he's looking for signs of relapse and I know he usually sees them first"* (Woman, 40).

Relatives and friends can have several roles: discussion, going-out and have fun, or they can have a function in the symptoms management. In all cases, they help to reduce stigma, increase the feeling of being understood and supported, which is another decisive dimension of well-being. Being able to share one's experience without judgements seems to be a key component.

This support function can also be provided by peers.

• Theme 2: Peer-support

For those who have experienced it, peer-support appears as a key component of well-being and another connectedness tool. By peer-support we mean relationship with people living with the same condition and engaged in a relation of trust and help. People with BD often *"fell alone with the disease"* (Woman, 25). Meeting other people with BD not only makes them feel less lonely as she puts it: *"We understand each other directly because we have experienced the same things; it was quite... well I don't know, I felt supported in fact. The fact of being able to explain something without having to go into details and that the person opposite just says "I understand indeed, I did this, that and that too..."*

Peer support provides a space for non-judgemental discussion and mutual understanding, which contributes to their well-being:

Investigator: *"So the fact of having exchanged with other people who live the same situation as you is something that makes you feel good?"*

Participant: *"Oh yeah. It's essential. It reinforces to me that I'm not crazy in the sense that there is something wrong with me. To confront myself with reality and people who live like that. Because in my circle of friends, I've had so many judgments, criticisms, certainly also because I didn't accept it, but I don't want to hear all that anymore. So I prefer to see people who really understand and who have the same background."* (Woman, 45)

In addition being able to table with peers, tends to make it easier to accept the illness or even allowed them to feel "normal" in their experience of the disease: *"What I feel happens to others in fact. It's true that when we talk to friends about this without having experienced it on their side, without being a doctor, nurse, psychiatrist or others, they often look at me and say 'eh?' And to be understood at last..."* It can even be a relief to realize that you have a "real" problem: *"Talking with other people who have the same problems and saying "yeah, I'm not alone". Perhaps to have confirmations about your diagnosis and also to say to myself "oh yes, so that's part of the disease. So in fact I do have a problem"* (Woman, 45). This normalization can play a role in better acceptance of the reality of disorders, making them more acceptable because they are shared by others. Identification with peers is a source of hope for many of those interviewed. Some even made a link between peer-support and the construction of a new identity.

Category 3. Regaining a positive identity in all spheres of life namely through work

• Theme 1. The value of diagnosis

Identity is a theme that stands out in a first dimension. After a long or short period of time, people reported that the diagnosis ended a period of medical uncertainty and had social and subjective repercussions that improved their well-being. From the first difficulties (behaviour, moods) to a "satisfying" life, they go through a quiet long process along which they face a range of uncertainties (medical, social, personal). Several participants mentioned these difficulties as being related to the search for diagnosis and effective and comfortable treatment. In addition to medical issues, personal and social difficulties constitute a burden. Indeed, they often deal with a phase of social withdrawal (some tell how they lost some friends or their job) marked by the experience of stigmatization and self-blaming that negatively affect their self-perception and their identity. The diagnosis seems to be a turning point. *"The fact that we have*

put a word on the disease" (Woman, 51), to identify it, made it easier to talk about. Participants described their journey through the diagnosis and acceptance of bipolar disorder, and the initiation and acceptance of appropriate treatment. They linked these developments to feeling better. *"We found the right dosage and the right molecules in terms of treatment. It took a long time to find it, the diagnosis took a long time too, and it was also difficult to accept it."* (Woman, 42).

In addition to the medical expertise it brings, diagnosis, it contains a social value. It allows both to decide what to do medically and to assign a social place to the person, even an identity. This change in the way of looking at someone's behaviour and moods positively alters the person's perception of themselves. This shift is linked to self-acceptance of their mental disorder as this woman says: *"Until I came to terms with the disease, it was hard to talk about it"* (Woman, 45). Over time, another acknowledged that she was now able to talk about it more freely and that she now presented herself as a person living with an illness. *"I say I have an illness. Now, I don't hide from it anymore, it's... Yes, it's a disease and that's it, yeah, it doesn't stop me from living. I can live with it"* (Woman, 54). In the same way, a better understanding of the disease can alleviate the shame of being sick, stigma and self-stigmatization: *"Now I know that I have a peculiarity. I take care of it, I treat myself and I am no longer ashamed to say that I am bipolar"* (Woman, 54). In this sense, many people left the role of victims and exchanged it for the role of actors in their lives. This shift participated in the process of normalization of the disease, i.e., its deep integration into one's identity while not being defined solely by it as a respondent puts it: *"Because I am more accepting of the fact that I am ill, I also find it less difficult to set limits, even when I know that others may not like them."* (Woman, 25). Diagnosis is the result of a process leading to greater self-acceptance and a tool for building a positive identity for people living with BD.

- **Theme 2. Work as social identity**

In addition to contributing to daily routines and self-realization, work was described as a vehicle for social identity. When unemployed, participants felt a sense of shame and exclusion: *"Getting a job would be a victory for me. For me, it's really about reintegrating into society, feeling useful, because I'm ashamed of not working [...]. Some people don't mind, but I'm actually ashamed."* (Woman, 30). Reintegrating into society and feeling useful through work is what enables the people interviewed to regain a valued social identity.

Many participants agreed that work plays a role in providing a positive social identity as this woman

stated: *"Not working for 3 and half years is complicated for me. My identity also goes through my professional identity. And now I don't really have any."* (Woman, 43); *"Work is recognition, and fulfilment in my work is feeling that I am doing something useful for others"* (Man, 40). Work was clearly associated with well-being and considered as a tool for self-realization. It was also associated with a meaningful life and social roles because it was considered as providing a feeling of usefulness for others.

Category 4. Achieving a better understanding of the disease in order to improve self-management.

- **Theme 1. Self-awareness and self-management.**

Throughout the interviews, participants unanimously acknowledged the benefits of getting a better understanding of themselves in order to identify their mood. A better understanding of oneself and the BD can therefore encourage the self-management mentioned above: *"It's very important to know oneself in order to uh... identify as quickly as possible when the phases change, whether it's in the high phase or in the low phase, to identify quickly in order to temporize on one side or the other"* (Woman, 51) This self-awareness leads to a feeling of empowerment that has a significant impact on participants' well-being. This can be achieved by keeping a sleep diary: *"I'm going to write down every morning when I get up what time I slept, did I drink and did I talk with friends, did I do sports? So I have a list of things and that helps me a lot, because it allows me to really spot when things change."* (Woman, 25)

- **Theme 2. The "real" self and the disease.**

Their well-being is brought about by a better knowledge of oneself and of the disease but self-awareness is a theme closely linked to identity. The gradual acceptance of the disease and a better knowledge of its manifestations correspond to a quest for meaning and identity in order to distinguish what is part of the illness and what is the "real" self as this woman stated: *"In fact, that's what's so constraining about this illness. By dint of going through manic phases, depressive phases, in the end we don't even know what our abilities, qualities and faults are anymore; we don't know what is part of the illness or what is part of our character..."* (Woman, 30)

A better understanding of the illness allowed them to distinguish what in their behaviour or in their mood is part of the illness and what is the "real" self. This mother expresses it when she talks about her children who progressively understand her mood swing or loss of power come from:

Sometimes I tell them when I'm very irritable, when I don't feel well and they want a cuddle; I tell them that maybe it's because the illness is coming back and I don't want to because I don't feel well because of the illness. It's the difference between their mum who loves them and the illness that can be invasive in everyday life.

Finding out what can be attributed to illness and what is the real self as if the disease was something added to the self.

Discussion

The aim of this study was to explore the boundaries and determinants of well-being from the perspective of people living with BD in a French context. Interviews highlighted four determinants: 1) Regular rhythm of life and meaningful activities; 2) Overcoming stigma through connectedness; 3) Regaining a positive identity in all spheres of life namely through work; 4) Achieving a better understanding of the disease in order to improve self-management. As stated, a lot of these determinants are non-specific to the population of bipolar people living in France that we studied (CREST.BD, Michalak and Murray, 2010). Indeed, the satisfaction of basic psychological needs, such as food and housing, self-esteem and respect by others, financial comfort, independence, social and family environment, socio-professional integration, contribute to the subjective well-being of each person (Diener et al., 2018). However, it's important to emphasize that people living with bipolar disorder have many of the same needs as the general population, and that it's up to caregivers, supporters and society as a whole to meet these needs as effectively as possible.

For people living with Severe Mental Illness (SMIs), a qualitative study highlighted central elements contributing to their well-being: the role of quality social relationships, connection with others and support from health professionals. The sense of personal control over symptoms and stressors, and self-care, giving a feeling of control and accomplishment also contributes to that (Morse et al., 2022).

However, our study suggest that some levers of well-being seem to be more specific to people with BD.

The construct of a positive identity

Our results suggest that diagnosis is an integral part of the process of building a positive identity. The diagnosis has a great value and seems to be a turning point in their trajectory. Beyond medical expertise, it provides a social identification, gives a better understanding of themselves and meaning of past and actual experiences (failures, mistakes,

overflowing periods of energy, romantic instability etc.). From a sociological point of view, participants endorse a new identity, the identity a sick person which gives them a social status, historically called the "sick role" (Parsons, 1975). Since, their behaviour, considered as "deviant" by many, can be now attributed to the disease, i.e., an entity out of themselves, this external attribution contributes to alleviate blaming and self-blaming.

In addition, diagnosis allows them to rationalize, explain and justify their own trajectories, negotiate accommodations with their employer, or find a more suitable job. Diagnosis can also change the nature of one's relationships with family, friends or work colleagues and, beyond, to renegotiate a form of order in all domains of life (Baszanger, 1986). This highlights the role of diagnostic disclosure as a tool for empowerment and the conquest of a positive identity. As stated by P. Deegan (1988), the quest for a positive identity (Deegan, 1988), is part a the recovery process through which someone tends to incorporate the diseases, herself as a sick person, and then managed to differentiating themselves from the illness (Inder et al., 2008a). Some participants with long experience of BD even tend to see themselves as people living with a "particularity" i.e., without reference to any psychiatric category. It would be interesting to examine whether concept of "neurodiversity" which is gaining attention in the fields of autism and ADHD (Sonuga-Barke & Thapar, 2021) could reflect future transformations in the field of BD.

As argued by participants, the construct of a positive identity can be achieved by having meaningful roles (as spouse or husband, co-worker, mother or father, friend, etc.). Quality of relationships and maintaining employment appears particularly important but depends on social acceptance and understanding of the illness. Our results are in line with those of previous studies which highlight the fact that paid employment is associated with positive benefits for people living with SMIs, such as self-esteem and pride, financial benefits and the deployment of symptom coping strategies. This marker of status and social inclusion is a source of PR (Dunne et al., 2019, Marwaha et al., 2013). Being able to fulfill role expectations at work, home or school, and the quality of interpersonal relationships are often cited as the most important outcomes to patients with BD and their family members (Michalak et al., 2005).

Acceptance of the diagnosis

In our study, sense of self and identity are closely linked to the acceptance of the diagnosis and the disease which can be a long process (Inder et al., 2008b). However, Proudfoot et al. have shown that the announcement of the diagnosis can lead to

various reactions such as shock, denial or anger (Proudfoot et al., 2009) which often delays compliance (poor treatment adherence and hindering self-management) (Clatworthy et al., 2007) while others may experience “relief” since they get words to talk about what they go through (Proudfoot et al., 2009). Thus, the announcement of a diagnosis, as well as psycho-educational actions, must always be accompanied by action aimed at sustaining the person’s hope: hope for a better future despite the diagnosis, which can be embodied by peer helpers, for example. Peer helpers are people affected by psychological disorders and in recovery, whose mission is to support their peers in accepting the disorders and to embody the bearer of hope.

Self-management

According to the review by Barlow and colleagues, self-management refers to the “*individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition*” (Barlow et al., 2002). Daily management of symptoms was considered as important for our participants. As Proudfoot notes, the ability to identify trigger and early signs of relapse are central in the management of illness (Proudfoot et al., 2009). This ability involves sufficient knowledge of the disease, condition which can be achieved by different means: information, reading, daily self-monitoring (mood, sleep, energy, etc.), advice from health professionals, sharing experiences with other patients. We noticed that a balanced lifestyle and fulfilling activities (including work) were part of the goals and routines of all our participants.

Levers of well-being and personal recovery

Our findings are also in large agreement with the CHIME framework (Leamy et al., 2011) who identified five main components in the recovery process: Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment.

We can therefore assume that the concepts of well-being and recovery are largely overlapping and intertwined. However, “Hope” doesn’t seem to be a part of our findings while it is a central element of the personal recovery concept. Rather than a simple element of well-being, hope would be the driving force behind recovery.

Two recent systematic reviews have helped to specify the characteristics of personal recovery (PR) in BD (Chirio-Espitalier et al., 2022, Jagfeld et al., 2021). The review of Chirio-Espitalier and colleagues showed that PR is intimately linked with metacognitive relationships maintained with mood fluctuations including resilience and decreasing of hypervigilance. We can

make the link with the reshaping of self-knowledge and maintenance of the self through the mood fluctuations described by our participants. The same author founded the particular importance of connectivity in bipolar people, in agreement with our results. Jagfeld’s review added a “tensions” dimension to the CHIME model: in particular, the tensions between the need to be open to others and the risk of stigmatization. In our study, the subjects largely considered self-disclosure and diagnosis as a lever for well-being with their relatives and in the professional field. The latter, having been accompanied by a rehabilitation centre and recruited during a therapeutic education programme, had possibly already been on the road to recovery.

Strength, limitations and future directions (words 177)

While a few qualitative studies have looked at the elements that enable us to assess the well-being, QoL or recovery of people with BD, our study is, to our knowledge, the first that has looked at the concrete levers of well-being in their daily lives. By clarifying these patient-centred outcomes, it provides some perspectives for improving the goals of care. The panel of 16 people allowed us to reach data saturation that is to say that the latest interviews did not provide new elements or other dimensions.

All interviewees had been followed in the same psychosocial rehabilitation centre, and had participated in a therapeutic education programme. They were therefore not naive in their knowledge of wellness and self-care, which may be considered a selection bias in this work. It would be relevant to conduct further interviews with people who have not participated in this kind of programme and outside of any care setting. Indeed, people who are further away from care may have a slightly different view of the levers of their well-being, drawing on other resources.

Implications for practice (words: 259)

We tried to better understand the boundaries determinants of well-being for people living with BD. It gives guidance to caregivers in their efforts to support well-being, but if we are to support recovery, hope seems to be a key, alongside destigmatization and self-management.

Some concrete implications for clinical practice can be drawn from these results.

Firstly, we found that disclosure of the diagnosis is important, provided it is accompanied by messages of hope and destigmatization. Supporting a positive identity also requires caregivers to consider the person before the sick person, by focusing on the person’s own resources rather than their deficits. The

importance of supporting professional projects was also highlighted as central to the reconstruction of a positive identity.

We also noted the particular importance of self-management for the well-being of people with BD. To foster these approaches, caregivers need to share knowledge and skills, and help empower bipolar people. This presupposes that their “experiential” knowledge is taken into consideration, with the individual considered an actor, capable of deciding for himself or herself outside of acute situations of endangerment. Caregivers move from a position of expert legitimizing power, to one of collaborative partnership, making their professional skills, tools and networks available to the individual. Placed at the heart of their care and the decisions that concern them, patients can gain a sense of control and responsibility.

The question arises as to the place of well-being in the recovery process. Are the two concepts directly related or equivalent? Further research should determine more precisely its place in the recovery process.

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Notes on contributors

Julien Jupille is a sociologist at the regional support center for psychosocial rehabilitation care in Pays de la Loire (CréHab’s) and at the Centre Ressources Handicap Psychique (CRéHPsy). Since 2006, he has been interested in the social and cultural dimensions of mental health in contemporary societies. His ethnographic research focuses on the involvement of patients, families and users’ associations in the recomposition of public health policies in psychiatry in France. He is now interested in the processes of recovery and, more broadly, in the theme of mental disability.

Yves-Antoine Harscoët is an advanced practice nurse in psychiatry and mental health. He works at the regional support center for psychosocial rehabilitation care in Pays de la Loire (CRéhab’S) and at the psychosocial rehabilitation outreach center of the Nantes University Hospital (CRéSERC). He is involved in research on the following themes of recovery in mental health.

Mélanie Duval is a public health physician. She works at the center for evaluation and information on

pharmacodependence-addictovigilance (CEIP-A) of Nantes, within the pharmacology department of the Nantes University Hospital. She carries out pharmaco-epidemiology studies. She also participates in researches on the following topics: characterization of addicted individuals, epidemiology of emerging addictions, recovery in mental health.

Marie Grall-Bronnec is a psychiatrist-addictologist. She is a hospital practitioner in the University Department of Addictology and Liaison Psychiatry at the Nantes University Hospital and Professor of Addictology at the Nantes Faculty of Medicine. Her research focuses on the assessment of addicted individuals and addictive risk; therapeutic innovation for addicted patients; prevention of risks associated with addictions. She is also interested in mental health recovery. She joined a WHO working group on Gaming Disorder and conducted for it a field testing in France concerning the category of “Disorders due to substance use and addictive behaviours” of the next version of the International Classification of Diseases.

Leila Moret is a full-time professor and hospital practitioner. Her research focuses on public health and more specifically on patient experience and participation.

Marion Chirio-Espitalier is a psychiatrist and hospital practitioner at the University Hospital of Nantes and at the Centre Ressources Handicap Psychique (CRéHPsy) in the Pays de la Loire region of France. She is involved in psychosocial rehabilitation care. She leads a research team interested in the stigmatization of mental disorders, and in care and devices supporting the personal recovery of the persons concerned.

Ethical Statement

This research did not fall within the scope of the “Jardé” law, in force in France for research involving human beings. However, approval from a local ethics committee was obtained on 4 January 2021. An information note concerning the study protocol, including oral data collection and recording procedures, was provided to participants prior to their participation, who gave their oral consent. Participants were also informed that they could freely withdraw from the study at any time. All data were anonymized and recordings were destroyed after use.

ORCID

Julien Jupille  <http://orcid.org/0000-0003-1128-9623>

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