

Université de Montréal

**The Experience of Treatment of Persons Presenting with  
Concomitant Psychotic and Borderline Personality  
Disorders**

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Essai doctoral d'intégration présenté à la Faculté des Arts et Sciences

en vue de l'obtention du grade de D.Psy

en Doctorat en Psychologie Clinique (D.Psy)

Août 2011

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Université de Montréal  
Faculté des études supérieures et postdoctorales

Cet essai intitulé :

The Experience of Treatment of Persons Presenting with Concomitant Psychotic and  
Borderline Personality Disorders

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## Résumé

Cette étude a évalué l'expérience de traitement de 9 individus avec un trouble concomitant de personnalité limite et psychotique. Vu le peu de recherches sur l'expérience de ces personnes, l'objectif était d'explorer les *Pathways to Care*, les transitions entre les services et la perception général du traitement en utilisant une méthodologie qualitative. Une entrevue semi-structurée a été administrée à chaque participant. Les participants ont été référés par des psychiatres soit dans le programme de psychose ou la clinique des TPL. Les entrevues transcrites ont été codées en utilisant une procédure de codage ouvert et fermé avec le logiciel QDA Miner 3.2.3. Les participants ne dichotomisaient pas leur expérience en termes de tout-bon ou de tout-mauvais, mais donnaient plutôt des récits nuancés de leur traitement. Chaque participant a décrit plusieurs *Pathways to Care* qui expliquaient leur entrée dans un traitement spécifique. Seulement la coercition avait un impact négatif sur l'expérience de traitement. Plusieurs transitions ont été décrites, mais encore une fois, seules les transitions par coercition ont été vécues de manière négative. Le facteur clé dans l'expérience de traitement des participants était la relation clinicien/participant. Une relation positive permettait aux participants de faire confiance à leur clinicien et ainsi recevoir de l'aide de celui-ci. Les limites incluent un biais possible dans la procédure de recrutement et la portée réduite de l'étude. La compréhension de la perspective de ces individus peut promouvoir des meilleures expériences de traitements dans le futur.

**Mots-clés** : trouble de personnalité limite, psychose, comorbidité, expérience de traitement, qualitatif

## **Abstract**

The present study investigated the treatment experience of 9 individuals with concomitant psychotic and borderline personality disorders. Given the paucity of research on the experience of this population, the goal was to explore pathways to care, transitions between services and general perception of treatments using a qualitative methodology. A semi-structured interview schedule was administered to each participant, who was referred by participating psychiatrists in either the psychosis programme or the BPD clinic. Transcripts were coded using a mixed open and closed coding procedure and QDA Miner 3.2.3 analysis software. Results found that participants did not dichotomize their experience into all-good or all-bad categories, but gave nuanced accounts of their treatment. Each participant described several pathways to care that explained their entry into specific treatments, with only coercion negatively impacting treatment experience. Many transitions were described, though only those who were coerced experienced these negatively. The key factor that participants highlighted in their treatment experience was the clinician/participant relationship. A positive relationship permitted participants to trust and receive help from their clinician. Limits include the possible bias of the recruitment procedure and the limited scope of the study. This understanding of the perspective of these individuals can lead to promoting better treatment experiences in the future.

**Keywords** : borderline personality disorder, psychosis, comorbidity, treatment experience, qualitative

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## **Introduction**

Since its inception, the concept of borderline personality has been intricately tied with the experience of treatment of those diagnosed. In fact, one of the reasons that this diagnostic category was first developed was to better understand this type of person who did not react as expected to the classical analytic situation (Kernberg, 1985; Sakheim et al., 2010). These individuals, most of whom seemed quite high-functioning (one would have said neurotic), when faced with the classical analytic situation, were described as not able to experience a typical neurotic transference. Instead, some developed what was called a psychotic transference (splitting; projection). Hence, the term 'borderline' was used to describe these people who were thought to be on the border between psychosis and neurosis (Stern, 1938). This leads us to emphasise the conceptual rapprochement between psychosis and borderline in the context of our current discussion.

In the time since these first reflections on the link between psychosis and borderline personality disorder (as it is commonly known nowadays), concepts and empirical data have evolved greatly. The most influential authors on the subject, Stern (1938), Kernberg (1985) and Bergeret (1985), among others, thought that these two concepts were mutually exclusive diagnostic categories with only rare overlap in certain specific contexts. This idea has stayed with and influenced many currently practicing psychiatrists and psychologists. However, empirical data, based on symptoms and signs within the DSM-IV conceptualisation, have drawn a different picture to this debate. In fact, despite many varying definitions of psychosis and borderline pathology, researchers and clinicians alike have found time and time again a prevalence of 10-20% of individuals with a psychotic

disorder also having a BPD diagnosis, and a similar prevalence of individuals with BPD meeting the symptomatic criteria for an Axis I psychotic disorder, (Coid et al., 2009; Dowson, Sussams, Grounds, & Taylor, 2000; Glaser, Van Os, Thewissen, & Meyers-Germeys, 2010; Kingdon et al., 2010; Lysaker, Wickett, Lancaster, & Davis, 2004; Nishizono-Maher, Ikuta, Ogiso, Moriya, & Miyake, 1993; Pope, Jonas, Hudson, & Cohen, 1985; Wickett et al., 2006; Zanarini, Gunderson, & Frankenburg, 1990). We will elaborate on this subject in the next section.

Let us first turn to why it is important to better understand these people and their experiences in the mental health system. First, according to many clinicians' experience and some researchers (notably Lecomte, 2010; Kingdon et al., 2010; Barnow, 2010), people with both psychosis and borderline personality disorder (BPD) are considered quite disruptive in the treatment programmes they consult in. The nature of their dual diagnosis makes it quite difficult for many to integrate into group treatment settings or to follow traditional treatment guidelines. For example, a patient in a first episode psychosis programme who threatens to commit suicide every other week, and describes in great details her auto-mutilation can be quite troubling for patients and clinicians alike who are not used to such behaviours. Alternatively, a patient who regularly complains of hearing voices and of government plots to place bombs under her car can be quite disturbing to a group of patients with BPD. A better understanding of these individuals with concurrent BPD and psychotic disorder may lead to better solutions for clinicians dealing with these difficult situations. Second, the current health care system is organised into separate programmes for each mental health disorder (for example, the psychotic programme or the

borderline personality disorder clinic). This means that clinicians are faced with difficult decisions when deciding on the best treatment strategy for an individual with both disorders (Kingdon et al., 2010). It is important to note that the treatment recommendation for individuals with dual disorders involving substance abuse and a psychotic disorder is an integrated treatment approach (Drake, O'Neal, & Wallach, 2008; Mueser & Drake, 2007). It is unclear if an integrated treatment is also necessary for individuals with concomitant psychotic disorder and BPD. Third, no one has inquired into the perspective of these health care users who are faced with the clinical realities described above. This untapped source of information could lead to a more complete understanding of the situation of people presenting concomitant psychosis and BPD.

## **Literature review – BPD and psychosis**

Most of the extant literature on the link between psychosis and borderline pathologies focuses on the nature and prevalence of this concomitant disorder. Some authors have chosen to study whether psychosis is an integral part of the psychopathology of BPD (e.g. Pope, Jonas et al., 1985; Chopra & Beatson, 1988; Miller et al., 1993) while others have concentrated on the nature of psychosis in BPD both through experimental methods (e.g. Pope, Jonas et al., 1985; Nishizono-Maher et al., 1993; Links et al., 1999; Silk et al., 1989; Perry et al., 1988) and through case studies (e.g. Lotterman, 1985; Gruetter et al., 2005; Chengappa et al., 1999). Still others have investigated the presence of



borderline traits in participants with psychotic disorders (e.g. Lysaker et al., 2004; Wickett et al., 2006).

Pope, Jonas et al. (1985) found mostly broad psychotic symptoms such as depersonalization and derealisation in their sample of 33 patients with BPD (according to chart review of DSM-III criteria). Some of their participants suffered from more narrowly defined psychotic symptoms, such as hallucinations and delusions, but these symptoms were only present during affective episodes of either major depression or bipolar disorder. This led the authors to propose that most hallucinations and delusions were not part of the main BPD pathology, but were due to concurrent Axis I disorders, a hypothesis developed more thoroughly by Akiskal et al., (1985). They also found that some of their sample (37%) presented factitious psychotic symptoms, such as “fanciful and non-stereotypic symptoms described by many patients, the absence of more typical psychotic symptoms in the same individual, and other evidence of voluntary control” (p. 1289). This finding of factitious symptoms has often been cited in the subsequent literature (Chopra & Beatson, 1988; Perry, 1988; Links et al., 1989; Silk et al., 1989; Nishizono-Maher, 1993; Dowson et al., 2000). This definition, although concordant with some criteria for factitious disorder (Pope, Jonas et al., 1985; p. 1287), leaves the possibility that psychotic symptoms in BPD are simply non-stereotypic representations of psychotic symptoms in other disorders with psychosis (i.e. schizophrenia, bipolar disorder). Other studies support the finding that psychotic symptoms in BPD are different qualitatively from psychotic symptoms in other disorders (Dowson et al., 2000; Zanarini, Gunderson et al., 1990). Likewise, Pope, Jonas et al. (1985) themselves questioned whether the term ‘factitious’ is appropriate in all cases. In

fact, they reported that their participants experienced their symptoms as very real. If factitious psychotic symptoms are less common in BPD than originally thought, BPD clients may not be as liable to fake psychotic symptoms and are therefore more reliable informants of their condition than previously considered. This has important implications for researchers and clinicians examining the perspective of these clients.

Further, Links et al. (1989) conducted a study with similar hypotheses to Pope, Jonas et al. (1985). In their sample of 88 in-patients with BPD (according to preliminary criteria for the DIB in Gunderson & Kolb, 1978: low achievement, impulsivity, manipulative suicide, heightened affectivity, mild psychotic experiences, high socialization, and disturbed close relationships), they found that: “The present results suggest that when confronted with a borderline inpatient with psychotic symptoms, clear-cut delusions and hallucinations will usually be attributable to a concomitant disorder. Broadly defined psychotic symptoms will be in support of the BPD diagnosis. Psychotic symptoms are not likely to be factitious, and such a diagnosis may not be any more likely in BPD patients than in patients with related personality features.” (p. 193). The results of Benvenuti et al.’s (2005) study of 39 mood-disordered and 21 non-mood-disordered patients with BPD (according to DSM-IV criteria) are concordant with those of Pope, Jonas et al. (1985) and of Links et al. (1989) in the sense that most psychotic features found were not hallucinations or delusions. In Nishizono-Maher et al.’s (1993) study, the authors found that clear-cut delusions and hallucinations were also rare among 31 participants suffering from BPD (according to the Diagnostic Interview for Borderlines – 2, Zanarini & Gunderson, 1989, a well-recognized measure of BPD according to Paris, 2008). Over 50%

of their sample experienced derealisation and depersonalization symptoms. In parallel, according to these authors, there appears to be wide agreement in the literature that ‘true psychotic symptoms’ or ‘narrowly defined symptoms’ are not characteristic of BPD itself but of concurrent axis I diagnoses. Dowson et al. (2000) evaluated 57 patients in their study. Thirty-five had a diagnosis of BPD according to the SCID-II (DSM-III criteria). The article does not report the frequency of hallucinations or delusions, but rather the correlation between a positive, self-report rating of past hallucinations and delusions and the number of positive criteria for each DSM-III personality disorder ( $.25. \leq r \leq .48$ ).

Thus, this line of inquiry supports the idea that broad psychotic symptoms (depersonalisation and derealisation) are a common occurrence in BPD whereas narrow psychotic symptoms (hallucinations and delusions) may be attributable to concomitant Axis I disorders. This is concordant with the DSM-IV conceptualisation of the possible concomitance of BPD and psychosis.

Contrary to the results of the previous studies, Miller et al. (1993) found that the most common type of symptom in their sample of clients with BPD (according to DSM-III criteria) corresponded to Pope, Jonas et al.’s (1985) definition of narrowly defined psychotic symptoms, i.e. visual and auditory hallucinations as well as delusions. Their study was based on an examination of 92 patients’ charts, like Pope, Jonas et al. (1985). They did not evaluate depersonalisation or derealisation in their study. More recently, Glaser et al., (2009), found that in their sample of 224 individuals with BPD, psychotic disorder, cluster C personality disorder or healthy controls, BPD participants reported as much daily psychosis (hallucinations, paranoid ideation, dissociative symptoms) as those

with psychotic disorder. Psychosis in BPD was more reactive to daily stressors than any other group. Thirty-four (34%) of their sample with BPD also took anti-psychotic medication. These studies suggest the existence of a sample of patients with both BPD and frank psychotic disorder.

In comparison to the majority of large-scale empirical studies, the case studies reviewed that examined psychosis in BPD profile a different type of participant. These two small studies (Chengappa et al., 1999; Gruetter et al., 2005) investigated the efficacy of medications in the treatment of specific patients with psychosis and BPD. The individuals who are described present with much self-injuring behaviour and suicidal thoughts, mostly ineffective psychotropic medication use as well as severe psychosis (persistent delusions and hallucinations). In one study (Gruetter et al., 2005), exclusion criteria were bipolar I or II, schizophrenia or prominent suicidal ideation. The sample retained was of patients who met criteria for BPD according to the DSM-IV, the ICD-10 and the Diagnostic Interview for Borderlines – Revised criteria. Oddly, participants also had to present with persistent psychotic symptoms. Despite these stringent criteria, all patients presented with at least 2 clinically relevant comorbid disorders; substance abuse and previous hospitalisations were common; all patients showed self-injuring behaviour and only 2 of 12 had not attempted suicide. In Chengappa et al.'s (1999) study, Axis I diagnoses included psychosis not otherwise specified, bipolar I disorder, chronic paranoid schizophrenia and impulse-control disorder, all in addition to BPD.

On the other side of the fence, researchers working with people with psychosis have also studied the link between borderline personality traits and psychosis (Snyder et al.,

1986; Hogg et al., 1990; Lysaker et al., 2004; Wickett et al., 2006). Snyder et al. (1986) gathered an impressive sample of 4 800 psychiatric in-patients with a variety of diagnoses (i.e. major affective disorder, dementia, schizophrenia, personality disorder, etc.) in order to study the relationship between schizophrenia, depression and borderline traits (using DSM-I criteria). The study added a borderline subscale to the BPRS (Brief Psychiatric Rating Scale; no author indicated for the version included in the study). This subscale was developed by consensus of five clinicians familiar with the DSM-III; BPD criteria and was not tested empirically before use. Few of the items in this subscale correspond to the current DSM-IV criteria for BPD. The findings indicate that the group of participants with personality disorders and the group with schizophrenia had the highest scores on the borderline subscale of the BPRS. Despite a different conceptual framework, this study still suggests a link between psychosis and borderline pathology. Hogg et al. (1990) examined the prevalence of personality disorders and personality disorder traits in recent-onset schizophrenia (according to DSM-III) using the MCMI-I and the SIDP (DSM-III criteria). In the sample of 40 clients with schizophrenia, the SIDP revealed 7 clients with BPD and the MCMI-I found zero. Lysaker et al. (2004) are one of the few to examine borderline traits in psychotic clients according to DSM-IV criteria. Their findings indicate that in a sample of 26 people with a diagnosis of schizophrenia and 12 people with a diagnosis of schizoaffective disorder, 40% had a likely presence of borderline traits, equivalent to a base rate score above 75% on the borderline scale of the MCMI-III. In a study by Wickett et al., (2006) the researchers evaluated the presence of Cluster B (histrionic, antisocial, borderline and narcissistic personality disorders) and Cluster C (avoidant, dependent and obsessive-

compulsive personality disorders) traits in a sample of 46 participants with schizophrenia or schizoaffective disorder using the MCMI-III. No results were reported for specific personality disorders, but 59% of participants endorsed Cluster B items at the trait level (base rate score of 75% or greater) and 24% endorsed Cluster B items at the personality disorder level (base rate score not reported). The authors found that borderline traits were associated with emotional discomfort symptoms, outpatient medical visits and in-patient psychiatric visits.

It is evident that borderline traits are present in certain people with a diagnosis of psychotic disorder. However, the methodology in the previous studies makes it difficult to understand the characteristics of a sub-population of people with DSM-IV criteria for both psychotic disorder and BPD.

However, a recent study sheds interesting light on the nature of concurrent psychotic disorder and BPD. Kingdon et al. (2010) recruited a sample of 111 participants with schizophrenia or BPD and found that 19 had both diagnoses. This group had significantly more paranoid delusions than the group with BPD but not the group with schizophrenia only. Ninety percent (90%) of people with both diagnoses experienced auditory hallucinations, compared with 50% and 66% of the BPD and schizophrenia groups respectively. The comorbid group presented 82% moderate-to-severe emotional abuse, 44% severe sexual abuse and 67% moderate-to-severe physical abuse. The authors therefore propose the term 'traumatic psychosis' to describe individuals with both psychosis and BPD, emphasising the high rate of trauma among this population. This finding resonates with others who have equally identified trauma to be a significant risk factor for this

population (e.g. Lysaker et al., 2004; Glaser et al., 2009). In regards to the subject of our study, the authors highlight the rigidity of clinical practice when faced with individuals with concomitant psychosis and BPD, naming the often ‘procrustean’ attempts of clinicians to fit these people into either one or the other category.

## **Experience of treatment**

Despite frequent diagnostic debates in clinical practice between schizophrenia and BPD (Skodol & Oldham, 1991), few studies have examined the experience of treatment of people having a diagnosis of both psychotic disorder and of BPD (Lecomte, 2010; Barnow et al., 2010; Gruettert & Fringe, 2005; Chengappa, Ebeling, Kang, Levine, & Parepally, 1999). These few studies have focussed mainly on medication. For example, in their review, Barnow et al. (2010), provide evidence for the efficacy of certain antipsychotics in the reduction of cognitive-perceptual distortions in BPD. Gruettert et al. (2005) found that in their sample of 12 women diagnosed with BPD and persistent psychotic symptoms, Quetiapine significantly improved psychotic symptoms, impulsivity, depressed mood, and global functioning in all participants. However, Chengappa et al. (1999) painted a different picture. In their study, they briefly describe the treatments that 7 participants with BPD and persistent psychosis had received prior to entering their study: most had received numerous pharmacological molecules, including antipsychotics, with little to no effect on their self-mutilation or hetero-aggression. They had also seen various modifications in their treatment plan, often without significant improvements, whereas community treatment was excluded

given the potential of self-harm, aggression and unstable psychotic symptoms. Lecomte (2010), in a literature review, describes that people with concomitant psychosis and BPD often have to overcome various obstacles in order to receive effective treatment, namely the belief among clinicians that psychotic symptoms are factitious in individuals with BPD and the lack of knowledge of clinicians regarding this concomitant disorder. This leads to a lack of coherent treatment plans for the individuals concerned. Thus, few studies have looked directly at the clinical treatment of individuals with a psychotic disorder and a BPD.

Nonetheless, the literature provides us with useful concepts in the experiences of individuals with either psychosis or BPD when navigating the mental health system. These concepts refer to three levels of experience: (1) experience of a specific treatment; (2) experience regarding treatments in general; (3) experience in entering treatment (pathways to care).

Researchers examining the experience of specific treatments (Abba, Chadwick & Stevenson, 2007; Hummelen Wilberg & Karterud, 2007; Perseius, Ojehagen, Ekdahl, Asperg et al., 2003) all emphasise the deep suffering of their participants, regardless of their diagnosis. In the case of Abba et al. (2007), mindfulness helped their participants develop a new relationship with their psychosis, thus reducing their participants' suffering. In Perseius et al. (2003), their participants with BPD thank their experience in DBT for saving their lives (p. 222). However, Hummelen et al. (2007) describe a somewhat different picture. Their participants with BPD, who had just dropped out of outpatient group therapy following a transition from day therapy, represent a different subgroup than that of most qualitative studies on the experience of treatment. The vivid emotional reactions of these



participants suggest that transitions are difficult for these participants and may cause many of them to drop out of therapy. Their accounts of their experience in therapy are therefore more negative than those presented by the two authors previously mentioned and are evidence of the importance of continuity of care.

This leads us to discuss two other important themes represented in the literature on the experience of treatment in general for people with BPD (Fallon, 2003; Langley & Klopper, 2005; Perseius, Ojehagen, Ekdahl, Asperg et al., 2003; Perseius, Ekdahl, Asperg, Samuelsson, 2005) and with psychotic disorders and severe mental illness (Buck & Alexander, 2005; Geanellos, 2001; MacDonald & Sheldon, 1997; Tunner & Salzer, 2006): trust and understanding. These two themes take best into account the narratives of the participants with BPD or psychotic disorders.

According to the literature, trust and understanding form the foundation of any intervention described by participants as positive and helpful (Fallon, 2003; Langley & Klopper, 2005; Perseius, Ojehagen, Ekdahl, Asperg et al., 2003; Perseius, Ekdahl, Asperg, Samuelsson, 2005; Buck & Alexander, 2005; Geanellos, 2001; MacDonald & Sheldon, 1997; Tunner & Salzer, 2006;). The lack of understanding and trust experienced by some participants (Perseius et al., 2003; Persieus et al., 2005) leads them to experience suffering regarding their care (Eriksson, 1994, cited in Perseius et al., 2005), in addition to the personal suffering already well documented by authors exploring specific treatments. In Geanellos' (2001) study, case managers for people with severe mental illness in Australia speak about the importance of forging a therapeutic relationship characterized by trust and understanding. Client participants further emphasize the importance of these aspects in their

positive experience of the therapeutic relationship, and therefore of the treatment in which they participated (outpatient case management).

The next level of treatment experience studies is focused on how individuals enter into formal treatment. In their study on individuals with severe mental illness, Pescosolido, Brooks Gardner & Lubell (1998) describe three ways in which individuals can enter treatment: choice, coercion and ‘muddling through’. Choice is based on a view of the individual as a rational decision-maker. The individual rationally decides that entering into treatment is the best way to solve his or her problems; at minimum, they actively agree to enter into treatment, at most, they experience proactive participation in the choice treatment programmes. Some individuals in their study experienced what the authors describe as ‘supported choice’, i.e. choice encouraged by others, in contrast to ‘individual choice’. Other individuals in their study described accounts of coercion when entering treatment. The authors differentiate between ‘hard’ coercion, i.e. legal coercion, or ‘soft’ coercion, i.e. extra-legal or informal social support coercion. These individuals felt in some way obliged to enter into a treatment which they would not have chosen for themselves. The third experience of entering treatment was described as ‘muddling through’. Muddling through accounts were characterized by one of two major aspects: lack of a clear sense of agency or a high degree of ambivalence regarding entering into treatment. The authors suggest that although their analyses lead them to differentiate these distinct ways of entering treatment, most accounts were characterized by more than one of the categories described above. This data from individuals with psychosis is concordant with a more recent study by Strike et al.

(2008) on pathways to care in individuals with BPD. This consistency suggests that the individuals in our study population are likely to experience similar pathways.

In addition to the categories described by Pescosolido et al. in 1998, it is possible to find another type of account of entering treatment described in the literature. In fact, in Spence et al. (2008), participants describe a reason for entering treatment which does not fit neatly into any of the categories described by Pescosolido et al. (1998). Although the authors do not use this model to describe the experience of suicidal, substance-using males presenting frequently to the emergency department (most of whom equally had BPD), their study portrays well another reason for entering treatment of their participants. The reason most referred to can be described as a ‘last resort’. Avoidance of care due to past negative experiences (passive choice) leads to waiting until a crisis necessitates care (self-imposed coercion); the participants stay ambivalent towards entering treatment (muddling through). Despite acknowledging the need for care and experiencing distress and desperation, as well as a certain feeling of coercion, all participants came to the emergency department only when they perceived no other option; they had negative expectations about their visit. Thus, we believe that it is useful to consider ‘last resort’ as a distinct category. This concept, as well as those previously mentioned, has yet to be investigated in the accounts of people with both BPD and psychotic disorders.

In conclusion, through the descriptions of their participants, Perseus et al. (2003) eloquently linked together many important concepts of the literature in their study on the perception of DBT in participants with BPD. Based in a respectful attitude towards the client, DBT was experienced as fostering a sense of respect and confirmation towards the

participants. Although the participants reflected upon many difficult emotional aspects of the therapy, the understanding they were able to experience from the therapists, as well as the trust they were able to put in them, permitted them to benefit from this therapy. These participants with BPD (as well as the ones interviewed in Perseius et al., 2005) had experienced discontinuity and betrayal, not being understood and disrespectful attitudes in their previous treatment experiences. In the DBT experienced by the participants, the therapists fostered a sense of responsibility or choice (c.f. Pescosolido et al., 1998) towards participation in therapy. Although the participants found this aspect difficult, they ascribed a great importance to this sense of responsibility in their pathway to recovery.

# The experience of treatment of persons with concomitant psychotic and borderline personality disorders<sup>1</sup>

The present study investigated the treatment experience of 9 individuals with concomitant psychotic and borderline personality disorders. Given the paucity of research on the experience of this population, the goal was to explore pathways to care, transitions between services and general perception of treatments using a qualitative methodology. A semi-structured interview schedule was administered to each participant, who was referred by participating psychiatrists in each program. Transcripts were coded using a mixed open and closed coding procedure and QDA Miner 3.2.3 analysis software. Results found that participants did not dichotomize their experience into all-good or all-bad categories, but gave nuanced accounts of their treatment. Each participant described several pathways to care that explained their entry into specific treatments, with only coercion negatively impacting treatment experience. Many transitions were described, though only those who were coerced experienced these negatively. The key factor that participants highlighted in their treatment experience was the clinician/participant relationship. A positive relationship permitted participants to trust and receive help from their clinician. Limits include the possible bias of the recruitment procedure and the limited scope of the study. This understanding of the perspective of these individuals can lead to promoting better treatment experiences in the future.

Keywords: borderline personality disorder; psychosis; comorbidity; treatment experience; qualitative

## Introduction

There is a paucity of research on the co-occurrence of psychosis and borderline personality disorder (BPD) (Kingdon et al., 2010). Despite the controversy surrounding the existence of individuals with both a psychotic disorder and BPD, the literature consistently finds a prevalence of 10-20% of individuals with a psychotic disorder also having a BPD diagnosis, and a similar prevalence of individuals with BPD meeting the symptomatic

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<sup>1</sup> Cet article a été accepté pour publication dans un numéro spécial sur la personnalité dans la revue *Psychosis*.

criteria for an Axis I psychotic disorder, (Coid et al., 2009; Dowson, Sussams, Grounds, & Taylor, 2000; Glaser, Van Os, Thewissen, & Meyers-Germeys, 2010; Kingdon et al., 2010; Lysaker, Wickett, Lancaster, & Davis, 2004; Nishizono-Maher, Ikuta, Ogiso, Moriya, & Miyake, 1993; Pope, Jonas, Hudson, & Cohen, 1985; Wickett et al., 2006; Zanarini, Gunderson, & Frankenburg, 1990).

Various hypotheses have been put forward to explain this concomitant disorder. A complete review exceeds the scope of the present article, and has to some degree been published elsewhere (Lecomte, 2010, Barnow et al., 2010). While most of the extant literature debates the conceptual nature of concomitant psychosis and BPD, only a few studies mention issues related to treatment (Lecomte, 2010; Barnow et al., 2010; Gruettert & Fringe, 2005; Chengappa, Ebeling, Kang, Levine, & Parepally, 1999). These few studies have focussed mainly on medication. For example, in their review, Barnow et al. (2010), provide evidence for the efficacy of certain antipsychotics in the reduction of cognitive-perceptual distortions in BPD. Gruettert et al. (2005) found that in their sample of 12 women diagnosed with BPD and persistent psychotic symptoms, Quetiapine significantly improved psychotic symptoms, impulsivity, depressed mood, and global functioning in all participants. However, Chengappa et al. (1999) painted a different picture. In their study, they briefly describe the treatments that 7 participants with BPD and persistent psychosis had received prior to entering their study: most had received numerous pharmacological molecules, including antipsychotics, with little to no effect on their self-mutilation or hetero-aggression. They had also seen various modifications in their treatment plan, often without significant improvements, whereas community treatment was excluded given the

potential of self-harm, aggression and unstable psychotic symptoms. Lecomte (2010), in a literature review, describes that persons with concomitant psychosis and BPD often have to overcome various obstacles in order to receive effective treatment, namely the belief among clinicians that psychotic symptoms are factitious in individuals with BPD and the lack of knowledge of clinicians regarding this concomitant disorder. This leads to a lack of coherent treatment plans for the individuals concerned. Thus, few studies have looked directly at the clinical treatment of individuals with a psychotic disorder and a BPD.

The treatment recommendation for individuals with dual disorders involving substance abuse and a psychotic disorder is an integrated treatment approach (Drake, O'Neal, & Wallach, 2008; Mueser & Drake, 2007). It is unclear if an integrated treatment is also necessary for individuals with concomitant psychotic disorder and BPD. Prior to suggesting changes in existing practices or to presuppose that the current separation of services for the treatment of BPD and of psychotic disorders is detrimental for this population, an initial qualitative study is needed. Such a study investigating subjective descriptions of pathways to care and of satisfaction with services can shed some light on potential treatment or services issues that might need to be further addressed.

The literature investigating the experience of treatment of individuals with either a serious mental illness or BPD provides useful concepts to investigate in the current study, such as trust in and feeling understood by treating clinicians (Fallon, 2003; Langley & Klopper, 2005; Perseius, Ojehagen, Ekdahl, Asperg, & Samuelsson, 2003; Perseius, Ekdahl, Asperg, Samuelsson, 2005; Buck & Alexander, 2005; Geanellos, 2001; MacDonald & Sheldon, 1997; Tunner & Salzer, 2006). Regarding pathways to care,

Pescosolido, Brooks Gardner, & Lubell (1998) and Strike, Rhodes, Bergmans, & Links (2006) have documented with individuals with a psychotic disorder or BPD the following relevant processes: individual or supported choice; hard or soft coercion; and muddling through – concept referring to either a lack of a clear sense of agency or a high degree of ambivalence regarding treatment. Spence et al. (2008) add a new concept where patients consult services only because they perceive no other choice but have negative expectations in regards to treatment; we refer to this as “last resort” in the current study. The presence of and the impact of transitions between treatment settings or services were another issue to be explored in the present study

## **Methodology**

### **Aims**

A qualitative methodology was undertaken in the present investigation to better understand the factors impacting upon the experience of treatment of individuals with concomitant psychotic disorder and BPD. Specific aims were to explore transitions between different treatment programs, determine the pathways to care of individuals with both psychosis and BPD and to explore the general perception of treatment of participants.

### **Participants**

Following approval by the hospital research ethics board, participants were recruited through participating psychiatrists working in the Psychosis clinic and the



Personality Disorder (PD) clinic at Louis-H Lafontaine Hospital, a major French-language psychiatric hospital in Montréal, Canada.

The participants were 9 French- and/or English-speaking individuals currently receiving treatment with one of the four participating psychiatrists. Psychiatrists used the following inclusion criteria to refer potential participants: 1) the presence of concomitant psychotic and borderline personality disorder diagnoses or having received treatment in both the Psychosis clinic and the PD clinic for BPD at some point; 2) the ability to communicate their experience to the interviewer in French or English; 3) the capacity to give informed consent. Of the psychiatrists' referrals, most participants were recruited from the PD clinic (N=6). Two were referred from the Psychosis clinic. Other referrals from the Psychosis clinic (N=4) refused participation. In order to reduce the possible bias due to selective recall of the participating psychiatrists, we tried another recruitment method, with little success. A list of potential participants was generated from the hospital archives. This list provided us with service users with concomitant diagnoses of BPD and psychotic disorders at inpatient admission who were still actively being followed at the hospital (N=130). Most of the potential participants on this list were not contacted because they were not followed by the participating psychiatrists. Of those who were (N=26), only five were available for interview during the recruitment period. Two of these refused participation and two were excluded when they mentioned never having heard of the diagnosis of BPD. Therefore, this list only provided one participant (who was followed in the BPD clinic) for the current study. This was a convenience sample; due to the difficulty in recruitment, other methods of sampling (i.e. theoretical sampling of participants, Corbin

& Strauss, 2008) were not possible in choosing participants. Participants' ages ranged from 24 to 53 years (Mean = 37 years). Average time since first consultation was 8.25 years, and all had received antipsychotic medication at some point. All nine were currently outpatients. Eight participants were women. All were of Caucasian descent. Education and marital status were not available.

### **Data Collection**

Data was generated through in-person, semi-structured interviews. Participants were met once for 20 to 50 minutes. The interview schedule was developed by the authors (P.T., C.T., T.L) based on the literature and on clinical experience. After taking down personal narratives of their treatment history, the interviewer (P.T) first inquired about the experience of each treatment, then asked more specific questions regarding the perception of particular treatments. After this section was completed, the interviewer asked for the participants' view of the diagnoses they had received, with a specific question regarding the impact of transitions between services when it applied. All interviews were transcribed into text verbatim and coded by the principal investigator (P.T) using Q.D.A Miner 3.2.3 software. Coding was discussed with the second author (C.T.), using both audio and transcribed material. A mixed approach was used to code meaning segments in the interviews. First, coding was completed using codes developed according to the literature (pathways to care). Then, once the verbatim interviews had been read over several times and discussed, others codes were determined through open coding of meaning segments emerging from the participants' accounts (transitions and perceptions of treatment).

Outputs including the segments from each of the codes were produced and these were analysed in detail. Themes and processes from this analysis were grouped according to the three overarching themes of the study: transitions, pathways to care and perceptions of treatment. Results are shown below.

## **Results**

Participants gave nuanced descriptions of their treatment experience. Transitions between programs, pathways to care and perceptions of treatment are discussed in the following sections.

### **Transitions between programs**

The participants each had very different treatment trajectories in the mental health system. A vast array of combinations of settings was found, either concomitantly or at different times, each describing numerous hospitalisations. For example, P4 went from being treated in the PD clinic for a short period, then several years of numerous hospitalisations for psychosis and suicide attempts in general and psychiatric hospitals, to eventually receiving services in a dual diagnosis (substance abuse and psychosis) clinic. P1 recalls often being transferred from one clinician to the next, having to repeat her story countless times, and the relief she felt once she was finally referred to the PD clinic:

“It's really, really tough, you know, switching social workers a lot, foster homes and psychiatrists. They were always sending me to hospitals (...) But now it's a lot easier I find, because they know what's wrong with me (...)” (P1)<sup>2</sup>.

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<sup>2</sup> Most citations are translated from French by the authors.

Most participants felt that the transfer was not of their making (N=5), with some among these emphasising the forced or coercive factor behind the change (N=2). Only these few participants described the transitions between different settings as actually difficult or unpleasant. P1 felt rejected and abandoned through her numerous transitions. However, many of the participants did not emphasise the importance of transitions between treatments in different settings, either at different times or concomitantly. In fact, one participant (P7) even took pride in her great adaptability each time she was transferred, though she suggested that it might be hard for other people.

### **Pathways to care**

Pathways were considered to be the explanation the participant gave for entering a particular treatment (Pescosolido et al., 1998). In line with the literature, we found four types of pathways to care in our interviews: choice, coercion, muddling through and last resort. Choice was divided into two categories: individual and supported. Each participant spoke of several types of pathways, some even citing more than one for a specific treatment. Muddling through was used more often (N=8) as an explanation than coercion (N=6), choice (N=4) and last resort (N=3). Muddling through, choice and last resort were not associated with any particular perception of treatment (either positive or negative). Coercion, however, was related to negative perceptions of clinicians, treatment settings and medication.

### *Muddling through*

The most salient characteristic of muddling through accounts was the passivity the participants experienced when entering treatment. For example, when asked how she came to consult at the PD clinic, P9 explained that it was the verdict of the hospital's evaluation module, rather than her own choice. These passages suggest an absence of a sense of agency on the part of the participant, with the decision-making done by someone else, most often a clinician. Participants at times found themselves in treatments or services based on decisions made by clinicians, without necessarily understanding the rationale behind this decision. When asked why they accepted to enter the new treatment or service, some participants explained: "why not? (...) I figured I might as well try it" (as P6 said). It is important to mention that some participants expressed their utmost confidence in their clinician and did not express their opinion about their preferred treatment to their clinician. In fact, it seems that when participants had complete confidence in their psychiatrist for instance, they relinquished their decision-making power. For example, when we discussed the fact that P3 had not received treatment in the psychosis clinic, despite persistently complaining of hallucinations and having delusional ideas, he said:

"For sure [I would like to go to the psychosis clinic], if it can help me. (...) But it's not me who's going to decide. It's going to be [psychiatrist]. If he says it'll do you good, yes, if he says it won't do you any good, no."

### *Choice*

For other participants, clinicians helped them make decisions that they actively agreed on. We differentiated supported choice and muddling through by identifying the locus of agency (participant as main agent: supported choice; other person as main agent: muddling through). People who used supported choice were less emphatic about the

confidence they put in their clinician. They described their pathway in terms of recommendations which were perceived as helpful and that they chose to follow. For example: “[My psychiatrist] recommended that I come back to the hospital’s emergency because it was all too much for me” (P7). As opposed to supported choice, individual choice does not implicate anyone else than the participant in the decision-making process. Participants who described individual choice chose to enter a treatment because they felt like they needed treatment, and they recognized that they had a problem. For example, P7 starts off her narrative by saying “I presented myself [to the hospital] because I was suffering from certain borderline personality disorder traits”. However, when we analysed the discourse of one participant, P6, we found that individual choice also lead to her choosing to leave treatment when it no longer suited her needs.

### *Coercion*

Participants who described coercion to explain their entry into a treatment typically mentioned an extremely negative experience. Some were legally forced into a treatment they did not agree with. Others felt forced, even without court involvement, and mentioned feeling obliged by clinicians to take medication or remain at the hospital. Participants emphasised the fact that it was not their decision to enter this treatment and felt forced into passivity. For example P8 relates her experience regarding her prescriptions:

“P8: Like now, I’m not sleeping and I’m not taking any pills for sleeping either and I’m not sleeping at all.

Interviewer: Ok. Did you talk to [psychiatrist] about that?

P8: Well, not really. I take what they force me to take and that’s it. The extra, I put it aside, like pills for sleeping, I just don’t take any, it’s not mandatory.”

As in muddling through, participants who described being coerced into treatment did not understand the reasons why they were referred to this treatment. During the interview, participants elaborated less on the reasons behind the treatment referral and focused more on the negative consequences of being forced into treatment. For example, when P8's treatment team insisted she take medication when she didn't want to, she focussed on the negative side effects and stopped taking them.

#### *Last resort*

The concept of last resort did not frequently appear (N=3), and participants did not give rich descriptions of the processes involved. Nevertheless, we found that some Participants who actively sought treatment did not feel they had any other choice but to do so, even though no one was forcing them to consult. They consulted a service as a last resort to ease unbearable suffering. For example, when P6 went to the emergency room to get medication, she explains: "It was either that, or I take my life".

#### **Perceptions of treatments**

In most cases, participants did not evaluate a treatment as all-good or all-bad but named positive and negative aspects for each. Although a few participants gave vague positive answers ("good", "ok", etc.) it was evident in the way that participants formulated their responses that they aimed at giving us an accurate picture of their experience.

#### *Relationship with clinicians*

Relationships with their principal clinicians were what stood out the most in the participants' accounts of their perceptions of treatment. When asked who their principal

clinician was, most participants described their psychiatrist. Therefore, most, but not all, of the information retained in this section is based on relationships with psychiatrists. Other important clinicians mentioned were: occupational therapists, group therapists, psychologists, group home workers and social workers. More detailed analyses revealed that in regards to these clinicians, participants described the positive clinicians they encountered as: caring, diplomatic and good listeners (P5 explains: “I like Dr B. (...) He is very diplomatic. He is kind. I can really tell him a lot.”). Negatively perceived clinicians, for their part, were essentially described as the opposite (not caring, don’t listen, and unprofessional). Participants felt they had a good relationship with their clinician when they felt listened to, given this was perceived as helpful to them. For example, P3 felt understood by his psychiatrist because he was “super attentive” and this led him to feel comfortable asking for help. Inversely, clinicians negatively perceived are described as non-listeners, as in P1’s account:

“They're supposed to be there to help you, to listen when you have no one else you can take your whole feelings on. But they're just sitting there, writing, bowing their head, and not really listening and I feel like: what's the point?”

Psychiatrists perceived as caring were those who took more time for meetings and changed medications when the participants felt it necessary. Uncaring psychiatrists did not change prescriptions when asked. For example, P4 described not sleeping for 2 months at the hospital, and wanted medication to help her sleep, which her psychiatrist refused because he apparently didn’t believe her.

Some participants (N=3) emphasised the importance of being believed by their clinician when they spoke about their symptoms. In all three cases where this was present,



the participant felt that their clinician did not believe them when they spoke of a particular symptom. We have already cited P4's example where her psychiatrist did not believe that she was not sleeping. To elaborate further, she had decided to stop talking about it, and let it run its course out without medical help. P1 also speaks of feeling that her psychiatrist did not believe her when she spoke of psychotic symptoms. When asked to elaborate, she said that her psychiatrist explained that these symptoms were "just acting-out" or the result of a recent loss of a loved one. This made her feel judged and she was hesitant to speak of these symptoms to her current psychiatrist. Thus, we have found that when participants felt that their clinician did not believe them, the participant felt judged and opted to no longer mention the subject.

#### *Safe treatment setting*

A sense of security in the hospital was discussed by several participants (N=3). This was different than the trust they put in their clinicians; it was the physical space and the experience associated with it that affected their sense of security. Feeling safe in the treatment setting enabled some participants to fully engage in their treatment. For example, P3 explained that the hospital was like a second home to him, meaning that he automatically felt safe going there. When the participants did not feel safe or comfortable at the hospital, they were reticent to receive services there. For example, P6: "I don't like to present myself there, either. I don't like having my follow-up in a psychiatric hospital. It's not necessarily very comfortable to go there."

## Discussion

Participants did not dichotomize their treatment experience into all-good or all-bad terms. They gave nuanced accounts of their treatments, often even being able to offer details regarding positive aspects and negative aspects for the same treatment. This is a particularly interesting finding considering the well-documented tendency for service users with BPD to use splitting (c.f. Kernberg, 1985), especially in treatment settings (Linehan, 1993).

Regarding transitions, we were interested in exploring whether participants with concomitant psychosis and BPD, not fitting neatly into the admission criteria of most specific-disorder clinics, were often transferred from one clinic to the next, and whether this had a negative impact on their treatment experience (i.e. increasing dropout rates as is the case for dual diagnoses involving substance abuse; Drake et al., 2008). Although there were many transitions, most participants (N= 7) did not experience these as particularly negative, and none expressed the impression of “falling through the cracks”. Instead, subjects stressed the clinician/participant relationship as the key determinant of the treatment experience. This is consistent with the literature on treatment experience in BPD and in psychosis, which emphasises trust and understanding (Fallon, 2003; Langley & Klopper, 2005; Perseius, Ojehagen, Ekdahl, Asperg et al., 2003; Perseius, Ekdahl, Asperg, Samuelsson, 2005; Buck & Alexander, 2005; Geanellos, 2001; MacDonald & Sheldon, 1997; Tunner & Salzer, 2006). Yet, it contrasts with the extant literature and clinical experience on patients with borderline personality disorder and psychosis, which cites problems with medication (Barnow et al., 2010; Gruettert & Fringe, 2005; Chengappa,

Ebeling, Kang, Levine, & Parepally, 1999) and transitions between programmes (Lecomte, 2010) as having a great impact on treatment experience. We propose that this difference may be due to different methodologies (qualitative vs. quantitative) as well as a different focus of the investigation (perspective of the service user vs. symptom evaluation).

Although our participants equally spoke of medication and transitions, this study suggests that it may be useful for clinicians working with this population and researchers developing new treatments to focus on relationship issues.

In fact, developing genuine alliances built on feelings of trust and of being understood is not always an easy enterprise. Difficulties in developing such an alliance with service users presenting with severe symptoms and often troublesome behaviours (such as those seen in individuals with concomitant psychotic and BPD disorders) can lead to a Compassion Deficit Disorder. This concept, developed by Sakheim et al. (2010), attempts to explain the high incidence of abuse by clinicians towards service users with BPD. It is often difficult not to attribute psychotic symptoms to “acting-out” and thus disqualify the distress associated with these experiences, leading service users to feel invalidated. The authors suggest that understanding troublesome behaviours in the context of past traumatic events can help clinicians become more compassionate towards patients with BPD. As trauma is also a documented risk factor for concomitant psychosis and BPD (Lysaker et al., 2004; Kingdon et al., 2008), this empathy-increasing strategy might be not only clinically useful, but also scientifically based.

Alternatively, service users might have difficulty accepting a caring relationship with their clinicians. The difficulty might thus not lie in a deficit in compassion on the part

of the clinician, but in the service user's tendency to develop ego-syntonic turbulent relationships, therefore having difficulty establishing the compassionate, stable and positive relationship described above. Sakheim et al. (2010) describe that patients with BPD having experienced sexual trauma at a young age are especially vulnerable to difficult interpersonal relationships and that this expresses itself in the treatment setting. This has not been evaluated in a population of service users with BPD and psychosis and warrants further study.

### **Limits of the study**

This is an exploratory study on the experience of treatment and the pathways to care of individuals with concomitant psychotic and borderline personality disorders. A study including individuals seeking services in the community (rather than hospital-attached clinics) or having severed their treatment links might have brought different results. Future research might use different recruitment methods in order to reduce the possibility of psychiatrists recruiting a select cohort of patients with whom they have a good enough relationship that they would accept participating in a research project.

Given clinicians' difficulty in giving these concomitant diagnoses (Kingdon et al., 2010), it is possible that our sample is biased and not truly representative. Relevant diagnostic interviewing (i.e. SCID I & II) might have been helpful in determining with greater reliability the diagnoses of the sample.

The fact that this was a convenience sample, and we were not able to use theoretical sampling (Corbin & Strauss, 2008) to choose our sample may have affected the saturation

and breadth of certain themes. For example, it seems that the concept of last resort, although mentioned, was not elaborated completely enough to understand the process by which this decision was made.

Future research should take into account the clinicians' perspective on treating people with concomitant psychosis and BPD, especially considering the possibility of a Compassion Deficit Disorder (Sakheim et al., 2010), which we were not able to evaluate in the context of this research design.

Due to the qualitative nature of the interview, structured information on specific treatments (for example: DBT, CBT, psychotropic medication) was not specifically recorded. It is telling that subjects focussed spontaneously on relationships with clinicians rather than specific treatments, showing a clear difference of perspectives on what really matters in clinical encounters. This difference in perspective was found in other studies (e.g. in low income subjects with severe mental illness (Ware, 1994) and is of utmost importance for clinicians and administrators designing treatment interventions.

This first study of treatment experience of participants with concomitant BPD and psychosis has shed light on the variety of pathways to care and the paramount importance of the therapeutic relationship from the subjective perspective of the patient.

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## **Conclusion**

This study draws from both the literature on the experience of treatment and the literature on people presenting with concomitant psychosis and BPD. It is the first, to our knowledge, that has applied the concepts and methods present in the literature on the experience of treatment to a population of service users presenting with concomitant psychosis and BPD. Thus, this study introduces novel concepts to both fields and may open the way for researchers interested in the development of treatments for people presenting concomitant psychosis and BPD.

This investigation permitted us to apply validated concepts drawn from the literature on the experience of treatment of service users with BPD and those with psychosis. We focussed on Pathways to Care, a concept developed and tested by Pescosolido, Brooks Gardner, & Lubell (1998) and Strike, Rhodes, Bergmans, & Links (2006) in samples of people with severe mental illness. Concepts related to pathways to care can also be found in the literature on the experience of treatment of individuals with BPD (Spence et al., 2008). These ideas had never been tested in people with BPD and psychosis. In our sample, we found that these concepts of choice, coercion, muddling through and last resort illustrated well the accounts of our participants' entry into treatments.

The literature regarding service users with both BPD and psychosis has focussed mainly on symptoms and diagnostic issues. Few studies have focussed on treatment experience (Lecomte, 2010) and none have explicitly inquired into the perspective of the service user on their treatment. Our study has focussed on both these areas. In our sample, we found that service users gave nuanced accounts of their treatment. Their experience was

most greatly influenced by the relationship with the principal clinician. This information contrasts with the extant literature and clinical experience which cite problems with medication (Barnow et al., 2010; Gruettert & Fringe, 2005; Chengappa, Ebeling, Kang, Levine, & Parepally, 1999) and transitions between programmes (Lecomte, 2010) as having a greater impact on treatment experience. We propose that this difference may be due to different methodologies (qualitative vs. quantitative) as well as a different focus of the investigation (perspective of the service user vs. symptom evaluation). Yet, the data collected in our study does not contradict the literature, as our participants equally spoke of medication and transitions. It does however suggest that it may be useful for clinicians working with this population and researchers developing new treatments to focus on relationship issues. This is especially pertinent following the work of Sakheim et al. (2010) on Compassion Deficit Disorder in clinicians working with people with BPD. The literature on BPD and psychosis points towards the importance of complex trauma (Lysaker et al., 2004; Kingdon et al., 2008) in the lives of these service users. As such, more compassion and empathy towards the often complex traumas experienced in childhood can help clinicians develop better alliances and help individuals with concomitant psychosis and BPD develop trust and feel understood, thereby ensuring a more positive treatment experience.

The development of a tailored treatment for these individuals is still at a nascent phase. Lecomte (2010) proposes that the integration of CBT for psychosis and DBT for BPD may constitute an interesting avenue of future research for the development of such a treatment. This study has added an important dimension to our understanding of how these

individuals experience treatment. This information, based in the literature on BPD and psychosis and on the experience of treatment, can be useful in determining a more effective treatment for individuals with concomitant psychosis and borderline personality disorder.

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