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## Adolescent Borderline Personality Disorder: A Diagnosis More Hopeful Than Harmful

Senior Project Submitted to
The Division of Social Studies
of Bard College

by Brooke Taylor Tyborowski

Annandale-on-Hudson, New York

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#### Abstract

Although Borderline Personality Disorder (BPD) is a valid and treatable diagnosis, it has been one of the most stigmatized illnesses since entering the Diagnostic and Statistical Manual in 1980 (Sharp & Tackett, 2014). This disorder continues to be underdiagnosed and undisclosed in adolescent patient populations in particular (Koehne et al., 2012) despite well-founded agreement that BPD begins in adolescence (American Psychiatric Association, 2013). Because of this reluctance from clinicians to disclose a BPD diagnosis to their patients, adolescents with BPD tend to face even more stigma than adults with the same diagnosis, which then impedes their ability to seek and receive proper treatment before symptoms worsen. Considering that common symptoms of severe BPD include self-harm, multiple inpatient hospitalizations, and or suicide, early diagnosis and treatment intervention is imperative. BPD has actually been called the "good prognosis diagnosis" (Gunderson et al., 2009), but misdiagnosis and lack of education and awareness about adolescent BPD remain an issue. It is entirely possible that a BPD diagnosis in adolescence can in fact do more good than harm, and in that diagnosis itself, one can even find hope. A review of the literature includes: disclosing the diagnosis and ethical considerations, adolescent-specific challenges and perspectives on mental health in general, misdiagnosis, and the importance of psychoeducation for BPD. Finally, based on this review, a training intervention on adolescent BPD for psychiatric inpatient treatment clinicians is proposed.

#### Introduction

"Now, you would think that hearing the diagnosis of borderline personality disorder would have broken me more. After all, hearing it initially made me angry and defensive. That was a diagnosis you really didn't want to have. But once I calmed down, I was relieved in a way. I had an answer. I had something tangible that described everything I felt, everything I did, and every way I acted. I thought to myself, 'Wow, I'm not crazy - it's just this disorder.' I was actually almost proud of my diagnosis because now I had something to fight for. I knew what to attack this time and what to work on. So I went to work..." (Gunderson & Hoffman, 2016, p. 31).

Above is an excerpt from *Beyond Borderline: True Stories of Recovery from Borderline Personality Disorder*. This quotation from an actual patient speaks to the potential positive impact that can come from receiving a BPD diagnosis. Relief, explanations, a way to move forward. Something to fight for. The patient quoted above also received their diagnosis at the age of 16, still technically an adolescent. How might this person's life have taken a different course had they not been diagnosed early on?

Ultimately, the goal of the following literature review on adolescent BPD and the training intervention for inpatient care clinicians is to give these patients the hope that they too can realize "Wow, I'm not crazy." That is, not necessarily to be happy about their diagnosis, but to at least have the insight and awareness that BPD is not a death sentence. With that, they can continue living, and maybe even *want* to live. Furthermore, the hope that a BPD patient needs in order to stay alive is not fully reliant upon themselves, but also upon the various clinicians who diagnose and treat them throughout their journey. This is paramount to BPD, as this thesis will explore the ways in which people with BPD struggle to receive their diagnosis, and how they are treated not only by society but specifically by healthcare professionals. Oftentimes it is those who are supposed to help them heal the most that only perpetuate the longstanding stigma surrounding this disorder, and fail to treat these patients with the empathy they need and deserve.

An overview of the literature that has been on the rise over the past decade will provide the necessary background and reason to the need and even urgency for ongoing training for clinicians treating BPD, specifically in the adolescent inpatient setting. First, I will provide an overview of BPD as a whole, with a focus on adolescent BPD specifically, highlighting both the similarities and also differences from BPD in adulthood. After gaining context for BPD and presentation of the illness, it is important to discuss why the diagnosis so often goes undisclosed. Additionally, this section will also expand on surveys and studies of clinician perspectives on disclosing a diagnosis of BPD to patients. There is an impact that comes with this reluctance as it prevents earlier intervention and treatment, and we have to acknowledge how that reluctance to diagnose affects the course of these patients' lives from adolescence and beyond. Although it will be discussed that BPD presents similarly in adolescence as it does in adulthood, there is a need to bring further awareness to the challenges unique to children and adolescents with mental illness and how they differ from adulthood, oftentimes facing an increased amount of stigma. We cannot undermine their perspectives and rights with concern to their own treatment and insights about their illness. In the same way that clinicians are reluctant to disclose a BPD diagnosis to patients, misdiagnosis also plays a factor in prolonging the suffering of people with BPD on their journey to receiving the proper treatment, and ultimately, relief and hope. Finally, there will be a dedicated section to expanding on psychoeducation. I argue that the delivery of psychoeducation in combination with diagnostic disclosure from the clinician is absolutely necessary to the idea that a BPD diagnosis can actually be more hopeful than harmful.

Previous training interventions for clinicians, and specifically nurses, do exist; however, this proposed training will allow for a nuanced perspective by combining the need for awareness

of the clinical utility and hopefulness of the BPD diagnosis, as well as the importance of disclosing that diagnosis to patients, with the added layer of the perspective on adolescent mental health.

#### Overview of BPD & Adolescent BPD

Before exploring how the patient experience can be improved for those with BPD, let's first define BPD. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition tells us that BPD is a Cluster B personality disorder defined by "instability in interpersonal relationships, self-image, and affects, and marked impulsivity" (American Psychiatric Association [APA], 2013; DSM-5). Cluster B refers to a group of personality disorders often characterized as largely dramatic, emotional, or erratic, and it is the least prevalent category of personality disorders with an estimated 1.5% (APA, 2013). Other personality disorders in this group include antisocial, histrionic, and narcissistic. All but antisocial personality disorder may be diagnosed prior to the age of 18, but the caution against early diagnosis remains the same across all personality disorders (APA, 2013). BPD specifically in adolescence presents similarly to BPD in adults, and diagnosis at any age requires that a patient meet at least 5 of the 9 following criteria in a variety of contexts:

- 1. Frantic efforts to avoid real or imagined abandonment. (**Note**: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
- 2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
- 3. Identity disturbance: markedly and persistently unstable self-image or sense of self.
- 4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating.) (**Note**: Do not include suicidal or self-mutilating behavior covered in Criterion 5.)
- 5. Recurrent suicidal behavior, gestures, or threats, or self-mutilating behavior.
- 6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).

- 7. Chronic feelings of emptiness.
- 8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
- 9. Transient, stress-related paranoid ideation or severe dissociative symptoms (APA, 2013, p. 683).

Many of these symptoms, however, are also definitive of adolescence, and therefore often dismissed as typical. Dr. Blaise Agguire, head of the residential adolescent Dialectical Behavioral Therapy (DBT) unit at McLean Hospital asks the question: "If the DSM has no problem with diagnosing other psychiatric disorders in childhood and adolescence then why not BPD?" (Aguirre, 2011). He goes on to explain that historically, clinicians have seen BPD as an extreme form of adolescence, but the difference between BPD and typical adolescence is the function of the behavior. More specifically, say a pair of identical adolescent twins are both exhibiting impulsive behavior such as experimenting with drugs, but one twin has BPD and the other does not. The difference between the two depends upon the function of impulsive behavior. One twin may be experimenting because that is just what adolescents do, says Dr. Aguirre, whereas the other twin may be experimenting in order to actually regulate how they are feeling in the moment when they have no other coping mechanism (Aguirre, 2011). Again, because of this comparison between BPD and adolescence, it can be more difficult to diagnose BPD using the criteria listed in the DSM, but it is not impossible. For example, recall that one symptom of BPD is an unstable sense of self. It can be argued that all adolescents are unsure of who they are and to some extent trying on numerous different identities to see where they fit in. That makes this criterion for BPD not as relevant when making a diagnosis in an adolescent, therefore Dr. Aguirre pushes for a requirement of 5 out of the remaining 8 criteria (not including an unstable

sense of self) listed in the DSM (Aguirre, 2011). Even with this symptom of an unstable sense of self, however, there are patterns specific to adolescents with BPD that differentiate from typical adolescents who may be uncertain of their identity. Adolescents with BPD will try on new identities and take on the emotions of others very rapidly in comparison to typical or non-borderline adolescents (Aguirre, 2011). Dr. Aguirre sets an example in advocating for more awareness and a better understanding of BPD in adolescence and the validity of the diagnosis. The language and criteria in the DSM have proven a roadblock in helping a greater majority of people, both clinicians and the general population, to recognize the validity of BPD in adolescence and subsequently how disclosure of this diagnosis might be clinically helpful to an adolescent with BPD.

Despite these gaps in our awareness and understanding of adolescent BPD, research and theory about the disorder in this population has been on the rise over the past 10 years. This increase suggests that a diagnosis of BPD prior to the age of 18 has become more widely accepted. That said, this research is somewhat particular to a specific field, and in comparison to a depressive or anxiety disorder, for example, accurate knowledge about BPD hasn't quite reached the general public to that same extent. Even further, knowledge about BPD in adolescents is even less understood outside of this specific field of researchers and clinicians. Many continue to falsely believe that BPD cannot be diagnosed prior to age 18, but why does one's age at diagnosis matter?

At the very least, most are aware that BPD is a severe mental illness, and at its worst, many people with BPD engage in self-harm, and an estimated 10% of people with BPD die by suicide (Black et al., 2004). Specifically, those with BPD are most likely to die by suicide in

their 20's (Baskin & Paris, 2012). This is where we have to take a step back, look at the larger picture, and understand where all of this begins. BPD is typically rooted in childhood and adolescence (APA, 2013), and concurrently, that crucial developmental period is likely the onset of self-harm behavior and or suicidal ideation or attempt(s) (Hessels et al., 2018). With that suicide rate of 10%, and the frequent use of emergency medical services by people with BPD (Shaikh et al., 2017), as well as BPD being the disorder with the highest rate of people on disability, this is also a public health issue (Chanen et al., 2017). This public health issue, which again, we have to understand typically begins in childhood and adolescence, often goes undiagnosed or undisclosed, misdiagnosed, and or untreated until later into adulthood. For those with BPD, the average age of first psychiatric contact is 17 years old (Bozatello et al., 2019), but it is highly unlikely to receive a BPD diagnosis upon first psychiatric contact. It is often a long journey that could take several years to receive the proper diagnosis, but with BPD at its worst, some people do not have several years. Despite all of this, adolescence is actually the ideal period in which to intervene because of the malleability of a developing brain and BPD traits (Channen & McCutcheon, 2013). This is why earlier diagnosis is imperative, and not only earlier diagnosis, but also disclosure of that diagnosis, meaning a diagnosis of BPD clearly and thoughtfully communicated from the expertise of the clinician to the patient. Clinicians are often reluctant to disclose a diagnosis of BPD (Sisti et al., 2016), however, with an awareness of their diagnosis, people with BPD will be better able to make treatment decisions, develop trust in their therapist or psychiatrist, remain more committed to their treatment, and therefore, have a better prognosis (Sulzer et al., 2016).

#### **Importance of Diagnostic Disclosure**

Although a diagnosis of BPD in adolescence has recently become more widely accepted, and earlier diagnosis tends to improve treatment outcome, the validity of the diagnosis in adolescence is still questioned by many. The DSM-5 cautions against diagnosing BPD in children and adolescents younger than 18 years, and this has been the case since BPD first appeared in the DSM-III in 1980 (APA). Despite the nuanced perspective on adolescent BPD that has emerged from research over the past 10 years, the contents of the DSM does not necessarily reflect these new perspectives. Misconceptions about the validity of the diagnosis remain apparent. The question of the validity of a BPD diagnosis in adolescents is also often a factor in a clinician's decision whether or not to disclose the diagnosis to their patients. A study by Laurenssen and colleagues (2013) reported that 57.8% of psychologists acknowledge the existence of personality disorders (PD's) in adolescence, but only 8.7% reported that they diagnose or offer treatment aimed at PD pathology.

These misconceptions about a BPD diagnosis in adolescence can be traced back to the first presentation of BPD in the DSM-III in 1980, and this language has remained essentially the same with each new edition of the DSM. Specifically, in its introduction to personality disorders, the DSM-5 states:

"Personality disorder categories may be applied with children or adolescents in those relatively unusual instances in which the individual's particular maladaptive personality traits appear to be pervasive, persistent, and unlikely to be limited to a particular developmental stage or other mental disorder. It should be recognized that the traits of a personality disorder that appear in childhood will often not persist unchanged into adult life. For a personality disorder to be diagnosed in an individual younger than 18 years, the features must have been present for at least 1 year" (APA, 2013, p. 647).

This language has contributed to the misconception that BPD should not be diagnosed before the age of 18, which may be why much of the research on BPD is not as prevalent in adolescent populations as it is for adults (Sharp & Tackett, 2014). This false belief also contributes to misdiagnosis, or reluctance to disclose a diagnosis, and a tendency for a number of clinicians to withhold a diagnosis of BPD from patients. This in turn prevents earlier treatment intervention, and the longer it takes to receive an accurate diagnosis, a patient's suffering is prolonged from childhood and adolescence into adulthood. Although clinicians should be thoughtful in making any diagnosis no matter what the disorder, of course, some are diagnosed more carelessly than others. BPD is not one of those that is diagnosed frequently by any means, much less in adolescent populations. Despite this, lack of official diagnosis, or diagnostic disclosure to patients, and what is referred to as "borderline talk," where nurses and clinicians talk negatively about a patient who presents as borderline or has a history of suicide attempts or self-harm, is frequent (Koehne et al., 2012).

Why are we discussing BPD as if it's something to be so cautious of that it becomes shameful, and how did we get to a place where BPD has become so highly stigmatized? These are only some of the questions that will be addressed, but in doing so, consider the following theory given what we already know: a diagnosis of BPD in adolescence is actually more clinically helpful than harmful. In fact, no research has yet to indicate a negative impact of diagnostic disclosure, nor is there any research indicating that disclosure of a diagnosis puts a patient at greater risk of self-harm (Shergill et al., 1998). Nonetheless, we find that this step of disclosure of the diagnosis from clinician to patient is so often omitted. Addressing this concern needs to be a priority given the fact that a large proportion of patients with the disorder are not

even identified in practice (Biskin & Paris, 2012). Due to the severity of the disorder, we need to be doing far more to improve the quality of care for these individuals. This begins with clear communication from clinician to patient if they do wish to be informed of their diagnosis (Shergill et al., 1998). Furthermore, not only should patients be informed of their diagnosis when it is clearly recognized by a clinician, but they should also discuss treatment options and outcomes with their patients (Biskin & Paris, 2012). Despite these recommendations and what should be viewed as ethical medical practice, disclosing a diagnosis to a patient with BPD is not prioritized enough (Lequesne & Hersh, 2004; Sisti et al., 2016, Sharp, 2017; Sulzer et al., 2016). This again raises the issue of language used when discussing BPD. The hesitancy to disclose or transparently discuss BPD with patients is an example of the problematic language used in the DSM as having transferred itself into actual treatment settings.

There have been attempts to change the language around the diagnostic criteria of personality disorders in adolescents. Dr. Marsha Linehan, creator of Dialectical Behavioral Therapy (DBT), a common and effective treatment for those with BPD, feels that BPD would not only be more accurately described with the label of "emotion regulation disorder," but also that people with BPD would likely rather be referred to as having emotion regulation issues rather than being called "borderline" (Linehan, 2017). Dr. Mary Zanarini is another researcher who has contributed a great deal to the research on BPD and has even made a point to name her lab without the term "borderline" in the title. Her lab, which is focused on investigating the long-term course of BPD, is instead named the "Laboratory for the Study of Adult Development."

Continuing to challenge the language prescribed to us by the DSM, Channen & McCutcheon's "The diagnosis that dare not speak its name" in 2008 was an early example of this. Chanen & McCutcheon ask us to question the way we view the diagnosis of BPD in adolescents, and they conclude in posing the question of whether or not this section of the DSM needs to be revised. They describe a case study of a 16-year-old girl who meets the criteria for BPD. These authors also ask the question of how diagnosing this individual with BPD could add to our understanding of her, or add to the treatment planning and management of her BPD. This addresses the idea that a diagnosis can actually serve as something more than a label for the sake of labeling an individual, or a classification for insurance companies to continue paying for treatment. This case study does not ask, however, how receiving this diagnosis might be viewed as helpful or meaningful in any way from the *patient's perspective*. This is where there is a gap in the literature on *adolescent BPD* in particular: there is little research on how effective diagnoses are in aiding adolescents with BPD. That is why so much of my specific focus is on how the act of receiving a diagnosis in itself can be clinically useful to an adolescent with BPD. Addressing this gap could be crucial in understanding how best to help adolescents with BPD.

There is a question of disclosure from not only the clinician's perspective, but from the patient's perspective, as well. Thinking about how a diagnosis of BPD might inform one's course of treatment is imperative. This is a useful clinical aspect of the diagnosis for the clinician in particular. However, from a patient's perspective, a diagnosis might mean something more to them in the greater context of their life story. Receiving a BPD diagnosis could be a sort of "aha moment" from a patient's perspective, and may produce a feeling of relief (Zanarini, 2017). Dr. Zanarini explains that in her many years of experience as a clinician, a common response to

receiving a diagnosis is: "Finally someone knows what I have, and I can move forward now. I know what my problem is." There is relief not only in finally understanding what is going on, but also a relief in an explanation for behavior that could not be explained by previous diagnoses. Other diagnoses that they may have received such as major depression or an eating disorder, for example, may not have truly explained who they are, despite still being truthful for them. The diagnosis of BPD, Dr. Zanarini tells us, gets to the core of issues such as intense fear of abandonment that cannot be fully explained by these other diagnoses, which instead only explain surface-level problems. To hear "Thank god I'm sick, not evil," is an example of someone relieved to finally be able to make sense of how they got to this point (Zanarini, 2017). This is not to excuse any past behaviors, but to give them a new understanding and awareness of their behaviors and how to best move forward. There is a feeling that everything "finally makes sense" in terms of the larger clinical picture (Biskin & Paris, 2012). This feeling of understanding and relief in itself may even be more clinically significant than researchers and clinicians have yet to realize, and perhaps this is an area of interest for future studies. Regardless, it is clear that a diagnosis has more potential benefits over harmful effects on a patient's overall mental health. Retrospective studies have shown that the average age of first psychiatric contact for BPD patients was around the age of 17, but the failure of a clinician to disclose a diagnosis of BPD to the patient resulted in a missed opportunity for earlier treatment intervention before symptoms worsened (Bozzatello et al., 2019). Why then are clinicians so reluctant to disclose?

#### Reluctance to Disclose & Attitudes Towards People with BPD

More often than not, clinicians choose not to disclose a diagnosis of BPD to their patients, and also choose not to document it on medical records (Sisti et al., 2016). Research

suggests that an accurate diagnosis of BPD is less likely to be disclosed than that of other psychiatric disorders such as depression or bipolar disorder (Lequesne & Hersh, 2004). This perpetuates the stigma of disorders such as BPD even more so. The act of withholding a diagnosis only reinforces the notion that it must be "too terrible to tell the patient, and too awful to discuss" (Leguesne & Hersh, 2004). One of the reasons for withholding a diagnosis is the common misperception that people with BPD will get enraged when given their diagnosis, but in Dr. Zanarini's experience of disclosing a diagnosis of BPD to patients, people have been more likely to cry with relief rather than to become enraged (Zanarini, 2017). Many question the validity of a BPD diagnosis in general, but especially in adolescents (Sharp & Tackett, 2014). Conversely, Black and colleagues (2011) reported that most clinicians actually do consider BPD a valid diagnosis, but nearly half reported that they preferred to avoid working with these patients. One of the reasons hypothesized that clinicians may not want to work with people who have BPD is because of negative prior experience, however, this study shows that those who have more experience working with people with BPD in the past 12 months actually report a more positive view of these patients (Black et al., 2011). There are a number of studies such as this one that will help us to gain a better understanding of clinicians' reluctance to disclose, how often this occurs, and why that might be.

One of the earliest studies investigating clinicians' reluctance to disclose a BPD diagnosis to patients assessed attitudes of psychiatrists (from both the US and Japan) toward disclosing a diagnosis of BPD (McDonald-Scott et al., 1992). In this study, they provided psychiatrists with hypothetical cases in the form of vignettes about different psychiatric disorders, and then they would be asked whether or not they would disclose the diagnosis to patients and patients'

families either actively or if asked. Only 55% of US psychiatrists would inform actively, and an additional 16% would disclose if asked directly. In the Japanese sample, only 16% would actively inform people of their diagnosis, and an additional 16% would inform if asked.

Psychiatrists chose vignettes about BPD as those they were least likely to disclose, as BPD had the lowest percentage compared to all other disorders in these hypothetical vignettes, but schizophrenia also compared at similar rates.

A later study continued to look at the likelihood of disclosure and attitudes towards working with BPD patients. A survey of 134 psychiatrists revealed that 57% (n = 77) had withheld a diagnosis of BPD from their patients during some point in their career, and 37% (n =49) indicated they have previously failed to document a diagnosis of BPD on a patient's medical records (Sisti et al., 2016). 43% (n = 57) indicated that they always disclosed a diagnosis, and 63% (n = 85) always documented the diagnosis. The majority of participants in this sample were male and had been practicing for over 20 years, which leaves open the possibility and hope that opinions are shifting in younger clinicians, and also raises questions about differences in gender perceptions given that psychiatry is a male-dominated field. Contributing factors in choosing not to disclose a BPD diagnosis were an uncertainty about the diagnosis itself, and the stigma surrounding the disorder. It is perceived that with the permanency of this diagnosis on one's medical record it could make it difficult for a patient to receive further treatment because many clinicians refuse to treat patients with BPD. To test this perception, Sisti et al. (2016) also surveyed this same sample as to whether or not they would avoid taking on new patients with a previous diagnosis of BPD. Overall, 52.2% (n = 70) disagreed with this statement, 24.6% (n = 70) 33) neither agreed nor disagreed, and 23.1% (n = 31) agreed that they would avoid taking on

patients with a BPD diagnosis. This study was also limited in that it explores only one type of mental health professional, and it is important to question how therapists, clinical social workers, or counselors might respond to this survey in addition to psychiatrists. How the results of this survey translate into real-life practice is also unknown. Additionally, while this study questioned diagnosis, disclosure, and documentation of BPD in general, the patients' ages were never specified. This could be significant in that psychiatrists might be more likely to disclose a diagnosis of BPD to an adult than an adolescent. Furthermore, it is important to look at the practice and language used around adolescent BPD in particular. Although the previous study (Sisti et al., 2016) discussed reluctance to disclose, document, and even treat patients with BPD, another article by Koehne and colleagues (2012) delves into a similar subject matter, but uses a more qualitative approach, instead.

Through a series of semi-structured interviews with various mental health professionals in Child and Adolescent Mental Health Services (CAMHS) in Australia, this study sought to understand why the term "borderline" was often used as a descriptor in conversation amongst colleagues, but not used directly by clinicians in discussion with adolescent patients themselves. There was a reluctance to discuss a BPD diagnosis directly with patients for a few reasons gathered from these interviews. There was an emphasis on the feared permanency of a diagnosis, and this was rooted in the idea that adolescent psychiatry should be a practice of hope. The fact that clinicians view a BPD diagnosis as hopeless, then reinforces the idea of the diagnosis as a life-sentence for adolescents. This is stigmatizing in itself, and only supports the idea that more education on prognosis and current research is needed even for the experts whose job it is to treat those with BPD. Using language such as "emerging borderline traits" as opposed to confirming a

concrete diagnosis of BPD often helped clinicians cope to offset that permanency. Mental health professionals often speculate that adolescents may not need to be given a definitive diagnosis because it will not be as helpful to them as instead identifying their maladaptive behaviors and individual symptoms rather than contextualizing them in the framework of a BPD diagnosis (Koehne et al., 2012). This, however, is only speculation. This brings us back to the idea that we need to be more direct in our communication with adolescents as patients and people with their own autonomy who deserve a say in their treatment. That said, if a clinician is mentioning BPD in a conversation with their patient as it applies to them in some sense, and the patient meets at least five out of the nine criteria as listed in the DSM-5, then why not tell the patient definitively that they have this disorder? Many clinicians recommend against using this kind of language such as "emerging borderline" or "borderline traits" as opposed to stating a definitive diagnosis of Borderline Personality Disorder (Channen, Sharp, & Hoffman, 2017).

None of the literature quite clarifies this question of why clinicians use this kind of substitute language or seem to be more comfortable with it, as opposed to fully disclosing the disorder itself to the patient. Perhaps given the rise in the literature on patient-centered communication of the BPD diagnosis, we might soon reach a better understanding of how using this different, alternative diagnostic terminology might affect patients' perceptions of their own mental health. What does it mean to patients when a clinician tells them they have traits or symptoms of BPD, but avoid telling them that they have the diagnosis? How is it helping them to introduce the term "borderline," into their lives without actually disclosing diagnosis? For a clinician to avoid disclosing the BPD diagnosis in a straight-forward, matter of fact manner with empathy, may only leave a patient feeling more confused and therefore likely to seek out

information on their own terms (Shergill, 1998). This may end up doing more harm than good if a patient knows little to nothing about BPD.

Although a clinician's decision to withhold a diagnosis from their patient may not be ill-intentioned, we have learned that it is not ideal (Sulzer et al., 2016). Withholding this information may ultimately do more harm than good, especially if a patient later discovers that a clinician was withholding this information. In that case, patients will lose trust in their therapist or psychiatrist, and they will cease treatment with that clinician 100% of the time (Sulzer et al., 2016). There have been no accounts in the literature of patients having self-destructive or angered reactions when diagnosed with BPD. This is largely a myth that has just continued to spread among clinicians for whatever reason. Again, many actually feel relieved, and as though everything finally makes sense once they receive a diagnosis of BPD. Certainly, not everyone will feel positively towards being told they are "borderline" at first, but there is a much better chance that with time, and also sufficient psychoeducation and empathy from their therapist or psychiatrist, that the diagnosis could be helpful to them.

#### **How to Properly Disclose**

Based on what we know about the importance of a diagnosis and its implications for treatment and patient well-being, it is also important to discuss how best to disclose a diagnosis of BPD. There is no standard script on how exactly to deliver such news to a patient, so the delivery will differ depending upon the clinician, and patients' experiences will vary, but there are still recommendations on how to properly disclose. The following is a summary of those recommendations from various sources.

A reasonable set of guidelines, not specific to BPD, but certainly applicable to disclosing difficult news in medical and psychiatric settings is as follows:

"The patient has the moral and legal right to know the information."

The clinician's primary responsibility is to the patient.

The setting should be private and free from interruptions.

One practitioner should be responsible for imparting the "bad" news.

Determine what the patient knows and understands about their situation.

Respond to the reactions to the news--listen sensitively, validate, and support.

The diagnosis should be conveyed as soon as it is determined.

Provide information clearly in segments, and check for understanding.

Avoid offering prognoses with specific time projections.

Ascertain whether the patient (or family, if present) wishes to hear more details.

When there are no further questions, plan the next few practical steps." (Cleary et al., 2009, p. 317).

To expand on the above, a diagnosis should be disclosed as soon as a clinician determines that a patient meets the necessary criteria for BPD, no matter the age of the patient. This should be standard in youth mental health care practice. Furthermore, substitute diagnoses should not be used if a patient meets the criteria for BPD (Channen, Sharp, & Hoffman, 2017). In other words, if a patient meets criteria for BPD, but instead you tell them that they have Major Depressive Disorder because it is a more "socially acceptable" diagnosis, but it does not get to the core of their problems, then why not disclose the proper diagnosis as opposed to this substitute?

In a video interview with Dr. Mary Zanarini, she touches on how to helpfully rather than harmfully disclose a diagnosis of BPD to patients. In her practice, she tells us she relays to her patients that, "You have a condition called Borderline Personality Disorder, which, the good news is that it has the best prognosis symptomatically of all major psychiatric disorders" (Zanarini, 2017). This added piece of psychoeducation, in this example where Dr. Zanarini tells her patients about BPD having a good prognosis, after relaying the diagnosis to her patient, can

be key. Psychoeducation is an essential part of medical practice that is often ignored (Motlova et al., 2017). Specifically, psychoeducation is the act of providing up-to-date information and educating patients about their diagnosis and its treatment (Motlova et al., 2017), and its relevance to the BPD diagnosis will later be discussed in more depth. Psychoeducation is so crucial to maintaining hope as opposed to inflicting harm when a patient receives their diagnosis.

In comparison to other illnesses such as cancer, there is next to nothing in the public sphere of knowledge about BPD that isn't pejorative (Zanarini, 2017). This is where the importance of psychoeducation comes in, and Dr. Zanarini provides an example of how she might begin to do that by relaying some hopeful information on prognosis. Psychoeducation alone might be enough treatment in some very mild cases of BPD because it provides new insight and allows people to consider aspects of their lives in a new light. In far more severe cases, of course, psychoeducation will not be effective as a stand-alone treatment, but it can be a crucial first step after diagnosis when entering into a longer course of intensive treatment. Even a single psychoeducation session was shown to help reduce symptoms in late adolescent women diagnosed with BPD all within a week of being told their diagnosis (Zanarini, 2018).

Another component to psychoeducation could be showing patients a list of the diagnostic criteria from the DSM and going through it with them. This might also increase their understanding of BPD. Educating patients about such a highly stigmatized disorder can help to reduce anxieties about their new diagnosis. This is important with any illness, but especially those that are so highly stigmatized and misunderstood by both clinicians and the general public (Biskin & Paris, 2012).

Dr. Gunderson, another highly respected clinician and researcher in the field writes, "It is important that clinicians begin using the diagnosis openly with patients and families," and that, "It is highly useful to be explicit and unapologetic in making this diagnosis and that to do otherwise is often a product of our countertransference feelings about such patients," (Gunderson, 2001, p. 25).

Finally, it is important to touch on personal accounts from patients with BPD to best understand what is most helpful to them. Patients feel that when mental health professionals try to see past their diagnosis and see them as human, this makes for a positive experience in treatment. People with BPD crave connection and understanding from others, and there are ways for therapists and psychiatrists to establish boundaries while still showing they care and respect their patient (Veysey, 2014).

In an interview with Dr. Richard Gordon, a practicing psychologist, he agreed that there is a lack of empathy coming from professionals interacting with borderline patients, and this empathy needs to be incorporated when disclosing a diagnosis and eventually moving into treatment. Clinicians are somehow failing to understand that these BPD features are, he reflected, "something people can't really help." In order for their quality of care to improve, we need to be more empathetic towards these individuals. This is especially important when treating younger people who have less experience navigating the mental health care system. At the time of first psychiatric contact, this first experience will have a huge impact on how they view the system, and whether or not they continue seeking help in the future (Gulliver, Griffiths, & Christensen, 2010).

#### **Adolescent Perspectives on Mental Health**

Rates in adolescent mental illness have increased, yet there is not enough research about how adolescents internalize or perceive their diagnosis, how they experience mental health stigma, or how they navigate the mental health system (Moses, 2009; Gulliver et al., 2010). This type of information is critical in determining how best to help adolescents receive better treatment. Little is known about how adolescents perceive a diagnosis of BPD, but there is one study that began to investigate this.

Questioning the extent to which a BPD diagnosis is valued by adolescents has been studied using the Impact of Diagnosis Scale (IODS; Courtney et al., 2016). This is one of the only studies that seeks to fill this gap in the literature on adolescent BPD by directly asking adolescents how they feel about their diagnosis of BPD. A number of studies focus on analyzing clinician perceptions and bias toward a diagnosis of BPD in adolescents, but researchers have rarely directly asked those most affected, the patients themselves, how the diagnosis has actually impacted them. Courtney and colleagues concluded that there was no overwhelmingly negative impact from receiving a diagnosis, and the diagnosis was accurate to the experience of patients, and helped to increase an understanding of their symptoms (2016). This was a short term study with a small sample of only 25 participants, but nonetheless, experiences of these individuals should be valued.

Variables such as individual differences in age, gender, family background, and differences among their clinicians such as how the diagnosis was made and delivery of psychoeducation and therapeutic alliance were not accounted for. It might be that the older the patients are, for example, 19 versus 13, those patients might feel more relief towards this

diagnosis after living with unknown or misunderstood symptoms for even longer. Such analyses would require larger samples, but there could be a value in continuing to investigate this particular research. Studies such as this one can help clinicians to "understand their patients' perceptions as well as increase treatment engagement and rapport" (Courtney et al., 2016, p. 183). There continues to be a need for this type of work that helps adolescents feel they have a voice in their treatment, and that their opinions and experiences are valid. Validation alone has been proposed as an essential tool in BPD treatment (Linehan, 1993). Unfortunately, the literature on adolescent BPD patients' own perceptions of their diagnosis is very limited. There is, however, a more expansive literature that focuses on adolescent perceptions of mental illness in general. A study by Moses (2009), for example, reviews self-labeling and its effects among adolescents diagnosed with various mental disorders. This is less specific to BPD, but still relevant in understanding the adolescent experience of being diagnosed with a mental illness, and the extent to which a diagnosis might be helpful to them.

To examine how strongly adolescents might identify with their diagnosis is important because the fear of being stigmatized by these diagnoses as life-long labels can be a common barrier in seeking help (Moses, 2009). There is also a stronger tendency to identify with a diagnosis when it is more severe. For instance, in severe cases of BPD, one might be more likely to self-label and refer to themselves as having BPD than those with less severe illnesses who identify less with labels. Mostly, adolescents tend to view diagnoses more so in terms of problems and symptoms themselves as opposed to the actual label. For example, instead of constantly referring to themselves as "borderline," they might be more likely to refer to themselves as having a lot of difficulty regulating emotions. This actually supports the idea that

even though one might have BPD, and agree with their diagnosis, it simply provides another lens through which to view their mental health identity. This can be incredibly helpful in gaining more insight while still acknowledging that they are the same person they were before given an official diagnosis. Nothing has really changed other than now they have a label for what they are living through.

A conceptual framework on the stigma of childhood mental disorders (Mukolo et al., 2010, p. 1) highlights that "children are subject to unique stigmatizing contexts." For example, children and adolescents have less power than adults and therefore less access to resources without the help of parents or caregivers. Challenges such as this give us all the more reason to focus on adolescent BPD, specifically. Mukolo and colleagues (2010) go on to explain a hierarchy of worthiness for intervention. In other words, when struggling with an illness more attributable to personal weakness, or a symptom that might be perceived as the fault of the person, they will be less likely to seek help. This is applicable to BPD not only through possible symptoms of depression such as trouble maintaining good hygiene and other healthy life habits, but also through self-harm behaviors, which are often the reason for many of the discriminatory experiences from clinicians faced by people with BPD (Veysey, 2014). More specifically, self-harm is often seen as something that could be the fault of the person inflicting it upon themselves, and so they are shamed for it. Additionally, this behavior is even less likely to be tolerated in children as compared to adults (Mukolo et al., 2010). This only furthers a tendency towards social withdrawal, secrecy, and a reluctance to seek help, all as a consequence of stigma (Mukolo et al., 2010). Again, the longer BPD goes undiagnosed and untreated, the poorer the prognosis. This is relevant in that the earlier the age of onset, the more stigma, and thus the more reluctance to seek help. Finally, because BPD is often comorbid with other psychiatric disorders, there is an increased concern from parents about people in the community finding out about their child's struggles. The more severe their children's' problems, the more fear of stigma we see by parents (Mukolo et al., 2010). Given what we know about the nature of BPD, this could be especially difficult for adolescents with BPD.

Ultimately, based on a review of adolescent perspectives on their own mental health, we have identified some barriers to mental health help-seeking in these young people. These include stigma and embarrassment, limited social status and resources as minors, and fear of labels. Gulliver, Griffiths, & Christensen (2010), however, provide some possible facilitators to help-seeking for these adolescents. They also suggest what we might focus on in order to allow more adolescents to feel comfortable and safe seeking help. Some facilitators to help-seeking include positive past experiences, and social support and encouragement from others to get help. This can be applied to helping populations with adolescent BPD by ensuring that their experiences at the time of first psychiatric contact are positive ones. Otherwise, this will only deter them from seeking help in the future as symptoms will likely only worsen. We also need to focus on improving mental health literacy, reducing stigma, and acknowledge that young people do desire to be self-reliant. All of these are large scale, more long term goals that must be worked upon daily, but they are crucial for adolescents navigating the mental health care system in order for them to obtain the help that they need. We must also continue to uplift the voices of adolescents themselves, and hopefully, more research will be conducted in the future on adolescent perceptions of BPD in particular. These qualitative studies can help to support the idea that adolescent BPD is not only valid, but that a diagnosis of BPD in adolescence is more

helpful than harmful, and most importantly, that it is perceived as such by adolescents themselves.

#### Misdiagnosis

One of the reasons why BPD is underdiagnosed and many people are left untreated or have gone years without receiving sufficient treatment, especially in adolescent populations, is due to misdiagnosis. Because BPD is such a stigmatized disorder, it is even more likely that those with BPD will be diagnosed with a substitute diagnosis (Channen, Sharp, & Hoffman, 2017), or a comorbid diagnosis alone instead of BPD (Ha et al., 2014). Furthermore, comorbidities are more common with adolescents who have BPD as compared to adolescents without BPD, and this may contribute towards misdiagnosis, as well, seeing as many clinicians initially treat the most surface level, common conditions such as depressive disorders (Krasner, 2017). This speaks to the fact that many clinicians are often reluctant to diagnose axis-II disorders, and BPD patients are often more likely diagnosed with an axis-I disorder upon initial psychiatric contact. This, however, does not ultimately address the root cause of their suffering, which can really only be treated by addressing some of the more borderline-specific pathologies (Zanarini et al., 2018). A BPD diagnosis can help to reframe some of their suffering and life narrative up until this point, even after being previously diagnosed and treated for other conditions.

Another issue with the ongoing diagnosis of an axis-I disorder without regard or consideration for the diagnosis of a personality disorder is that, specifically when a diagnosis of BPD is not disclosed to a patient, nor is it on record for example if a patient were to switch care providers, the patient will just continue to seek help for this axis-I disorder. Without a patient's

own awareness of their diagnosis, even if a clinician thought that BPD was the appropriate diagnosis but chose not to disclose it to the patient, it could cause trouble in the future and prolong their journey towards getting proper treatment sooner rather than later because the patient would not be entirely aware of their own needs.

#### **BPD & Bipolar Disorder**

In addition to more commonly diagnosed and less stigmatized disorders such as depression and anxiety disorders, Bipolar Disorder (BD) is another commonly misdiagnosed axis-I disorder in patients with BPD (Zimmerman & Morgan, 2013). Many BPD patients will have received a BD diagnosis during previous psychiatric contact. Reasons for this common misdiagnosis include the difficulty in distinguishing between the two due to an overlap in criteria in the DSM (Zimmerman & Morgan, 2013). For this reason, researchers such as Zimmerman and Morgan suggest a reevaluation of the DSM-5 criteria for each disorder to better distinguish the two. BD has also been reported to be overdiagnosed, especially in children, over the past decade (Ruggero et al., 2009). It is puzzling as to why BD is much more commonly diagnosed in children and adolescents than BPD given that they can present so similarly. It has also been called into question as to why BD has received more funding for research, as well as why not enough people are aware of the public health significance of BPD in comparison to BD (Zimmerman, 2016). This leads me to question, again, why the stigma of the two disorders differ. Although all mental illness is stigmatized to some extent, I have to question why BPD is associated with more negativity than BD, especially given that the two are often even co-occurring disorders. Even so, as we see significant comorbidity rates with BD and BPD, they are diagnosed in the absence of one another in 80-90% of cases (Zimmerman & Morgan, 2013).

It has also been called into question which diagnostic tools are being used when screening for BD and BPD. For example, studies have shown that the clinical utility of the most commonly used screening tool for BD, the Mood Disorder Questionnaire (MDQ), is uncertain (Zimmerman et al., 2010). This was due to the fact that positive results on the MDQ when screening for BD were just as likely to indicate that the patient had BPD. This calls on clinicians to constantly consider and reevaluate which diagnostic methods for these complex and overlapping disorders are most accurate and of best service to the patient and their treatment needs. Some of the most difficult symptomatic overlap when making a diagnosis of either BPD or BD is in patients who present with both impulsivity and affective instability (Magill, 2004).

It continues to be crucial that clinicians carefully consider the patient's longitudinal history when making a diagnosis (Magill, 2004), and to focus on whether the affective instability is more transient and often a result of interpersonal stress, as is typical in BPD, or sustained as it presents in BD (Paris & Black, 2015). Again, being provided the correct diagnosis is not so important just for the sake of having a label, but of course, for the patient to receive the proper treatment, and to reframe events in their life in the context of this disorder in order to be able to make positive changes in the future. In terms of treatment, medication has sometimes been helpful but definitely not the most effective treatment for BPD as compared to the effectiveness of psychotherapy. With BD, on the other hand, medication can be a more important component of treatment (Paris & Black, 2015). BPD patients who have faced a long journey of misdiagnosis and different attempts at treatment in various settings, tend to have tried many different cocktails of mood stabilizers, antipsychotic medications, and the like, which have provided little to no relief or in some cases have even worsened their situation. This may not be the case as often in

those with BD as compared to BPD. Again, seeing as BPD often begins to emerge in adolescence and many start to seek help during this time, this is when we first see misdiagnosis, overmedication, and the beginning of a long struggle to receive a fitting diagnosis and proper treatment. Although we can see the difficulties present in differential diagnosis, what is also made clear are the troubling and sometimes incredibly damaging implications of misdiagnosis. For that reason, clinicians must remain aware of this as a common occurrence in BPD patients and the toll it can take on their overall mental health.

#### **Psychoeducation**

Perhaps one of the more important components of this training intervention for clinicians, and the disclosure of a BPD diagnosis, is psychoeducation. Psychoeducation is defined as "the provision of systematic, relevant, broad, and up-to-date information about an illness or condition, including its diagnosis and treatment" (Motlova et al., 2017, p. 447). In other words, psychoeducation is the information provided to a patient and those closest to them about their diagnosed illness, so that they can understand what they've been diagnosed with and what challenges they might face because of it or how it impacts their lives. It can also be about taking these various struggles and symptoms, or criterion for this particular disorder, and helping the patient to understand now how all of them fit together in the context of their own situation. For example, how does a tendency towards impulsivity or their instability in relationships impact their everyday lives, and what are some examples of when that happened up until this point? Putting these episodes into the context of the disorder can then be like a missing puzzle piece connecting everything together through psychoeducation, and now allowing for people to have this new awareness and insight moving forward.

Psychoeducation can take place in individual or group sessions, and it is beneficial for both patients as well as family, or those closest to them such as friends and partners. Psychoeducation can also be defined by four key components. No matter the illness for which psychoeducation is being utilized, Cummings & Cummings write that psychoeducation must include information on "treatment of the condition; management of the condition, especially those that are chronic and intractable; compliance with the medical and psychological regimen; and prevention of progression, exacerbation, or relapse" (2008). Although not all clinicians may follow these exact guidelines as to how psychoeducation should be conducted, and they may have other ideas as to what they find most helpful, these are some just some of the components that may be helpful to include for a patient. Of course, it can also depend on the particular patient and their exact situation. Psychoeducation has also been identified as useful in emergency department settings (Hong, 2016), and this is critical with BPD given that up to half of all patients with repetitive suicide attempts in emergency departments meet criteria for this diagnosis (Forman et al., 2004). Even more so, in the case of suicidal adolescents in emergency departments, up to 78% of them meet the criteria for BPD (Guile et al., 2018).

Psychoeducation is largely important to the understanding and management of one's illness, but unfortunately, it is too often overlooked. Imagine you are diagnosed with BPD, but never given a comprehensible definition of the disorder or any up-to-date information about the disorder. You would be left feeling confused, overwhelmed, and perhaps even scared. You may also take on some of the ugly stigma and misconstrued ideas about BPD if you have any previous associations with the term "borderline." Diagnosing BPD, specifically in adolescents,

does have the potential to be more helpful than harmful, but this is not the case without the added necessary component of psychoeducation.

Again, the intention with early diagnosis is for early treatment intervention and better prognosis, and this can only be the case if the adolescent patient understands their diagnosis, why it was given to them, and what it means for them. If their understanding of the meaning of the diagnosis is not accurate, or fails to provide relief in any way, then what is the point of disclosing a diagnosis?

Psychoeducation is recommended as an essential component in several schizophrenia treatment guidelines, and has even shown to reduce rehospitalization rates from 58% to 41% (Bauml et al., 2006). Given the comparison that is often made between schizophrenia and BPD in terms of stigma around diagnostic disclosure, it would make sense that psychoeducation becomes the norm with BPD similarly as it is with schizophrenia.

To restate one of the initial concerns of disclosing a BPD diagnosis to a patient, it was thought that it might damage therapeutic alliance (Sulzer et al., 2016). A pilot study conducted by Banerjee and colleagues supported the hypothesis that disclosing a patient's diagnosis does not negatively impact therapeutic alliance (2006). In this study the BPD diagnosis was disclosed within a specific psychoeducation program. This supports the idea that psychoeducation is key to the BPD diagnosis being helpful to a patient (Banerjee et al., 2006).

Psychoeducation provides the patient with a thorough understanding of their diagnosis, broken down for them to their level of understanding. This is especially important when we discuss diagnosing adolescents. It is crucial that the clinician making the diagnosis explains all of the necessary information in a way that is consistent with the patient's developmental level

(Motlova et al., 2017). Given the potential severity of BPD, Motlova and colleagues argue that if it is unethical to keep a patient's cancer diagnosis from them, then it is also unethical to do so with BPD.

Overall, psychoeducation is overlooked for mental illness in general, let alone BPD for which there is currently no standard psychoeducation treatment (Zanarini et al., 2018). There are however psychoeducation treatments that exist for most other major psychiatric disorders, so why not BPD? Furthermore, such psychoeducation interventions that exist for adults may not be useful to adolescents. Age-specific interventions are needed for BPD across the lifespan (Videler et al., 2019), particularly in adolescence given that this is when BPD first develops, yet there are fewer interventions for this age group.

However, there are a few reasons for the underutilization of psychoeducation. One of those is a lack of reimbursement, but the most prominent reason is the lack of specialized training opportunities for clinicians to learn how to deliver psychoeducation to both patients and families. Motlova and colleagues (2017) recommend that there actually be a more extensive and specific psychoeducation curriculum required in psychiatric residency programs, which would benefit those making diagnoses of BPD.

As for psychoeducation specific to BPD, there is an increased amount of attention being paid to psychoeducation for the families and friends of those with BPD rather than the patients themselves. This is not to undermine the importance of psychoeducation for those close to individuals with BPD, but instead to ask why there is more focus on psychoeducation for their loved ones as opposed to the BPD patients themselves. How are close friends and family

supposed to have an accurate and whole understanding of the person with BPD, if that person does not yet fully understand themselves?

It can be difficult when someone close to you is diagnosed with an illness, and family and friends can benefit from psychoeducation to process their own emotions, gain an accurate understanding of the diagnosis, and best support their person. Psychoeducation can help to reduce stress in the household, and help discover ways to cope with frustration. These can be especially important for adolescents since they are likely still dependent on their family and living under their household. Psychoeducation might help to provide a bit more calm in the home environment where they cannot necessarily just leave. Psychoeducation has also helped to improve both patient and family engagement in treatment.

There has been a lot of development surrounding psychoeducation programs for families of adults with psychiatric illness, but the literature is much smaller concerning children and adolescents (Fristad, Gavazzi, & Mackinaw-Koons, 2003). More specifically, there is a dearth of literature on psychoeducation interventions specific to adolescents with BPD. Even the existing literature on psychoeducation for families of those with BPD is focused on adults or is otherwise non-age-specific.

Psychoeducation has also been shown to reduce the chance of relapse (Motlova et al., 2017). According to a study about BPD in college mental health settings, disclosing a diagnosis with sufficient psychoeducation interventions has in some cases provided symptom relief, and at least paved the way for a more specific treatment plan (Brickell, 2018). In addition to the individual practice, psychoeducation in group settings has also been useful in alleviating symptoms of BPD, resulting in an easier and more cost-effective treatment to implement, which

begins to address some of the public health concerns for those with BPD (Ridolfi et al., 2019). The recent development of these treatment interventions provides a lot of promise and hope.

Finally, after receiving a diagnosis, many patients will turn to the internet to find out more or see what the rest of the world has to say. When provided more information through psychoeducation, however, it can keep both patients and family away from internet resources that may not be so reliable. For this, clinicians should have on hand additional pamphlets or information, as well as vetted online resources for patients and families to look into on their own time (Motlova et al., 2017). There is a lot of misinformation floating around the internet about BPD. Furthermore, what people learn through psychoeducation is often a lot of information to receive all at once, and it could be helpful to have hard copies to serve as reminders to look back on at a later time.

Clinicians should also be sure that psychoeducation is an interactive process. It cannot simply be a monologue delivered by the clinician, and there has to be time for questions from patients and their families. It is important to ask patients and families to recount what they've heard. That can allow for an awareness of whether or not they have an accurate understanding of the disorder and what is happening. Of course, throughout all of this, psychoeducation has to be delivered with a great deal of empathy and sensitivity to the patient and their family, and the information given should be comprehensible and reliable. Empathy continues to be a running theme with treating and working with BPD patients, and it cannot be undermined. A patient and family should feel that they are able to trust their clinician, having just received from them what might be potentially life-altering information.

As an argument for how psychoeducation can be effective, a preliminary trial of psychoeducation for young adult women with BPD (n = 50), initial results suggested that psychoeducation significantly alleviated two core symptoms of BPD, impulsivity and instability in relationships (Zanarini & Frankenberg, 2008). Given the financial tolls BPD can take, it is also important to note that psychoeducation can be a cost-effective means of treatment. Given the long wait times and high cost of psychiatric treatment, psychoeducation programs such as this one proposed by Dr. Zanarini can be useful as a preliminary form of treatment to fill the gaps while they wait, and perhaps this might even allow them to get a head start on some of the important work that lies ahead. Psychoeducation can also temporarily alleviate symptoms for mild cases of BPD for up to one year (Zanarini et al., 2018).

Although psychoeducation programs are available for most major psychiatric disorders, a standard psychoeducation program currently does not exist for BPD (Zanarini et al., 2018). Thus, it is especially important that clinicians be trained and have their own concrete understanding of BPD so that they can effectively provide a diagnosis with psychoeducation.

Because Dr. Zanarini & Frankenberg's initial study in 2008 was not adopted by treatment centers due to the cost of the program and the need for trained personnel, Dr. Zanarini and colleagues adapted their psychoeducation program to be entirely web-based to increase accessibility (Zanarini et al., 2018). This specific treatment program entailed an all-encompassing series of information about BPD including a history of the diagnosis, the stigma associated with the disorder, demographic characteristics associated with BPD, symptoms of BPD and alternative theories of how these symptoms fit together, co-occurring disorders, etiology, longitudinal course, psychosocial treatments, and psychotropic medications. This is a

lot of information that is reliable and easily accessible, and it is my hope that this model could be implemented or at least adapted loosely as a guideline for psychoeducation by more clinicians for widespread use.

I would hypothesize that if more clinicians were properly trained and understood a protocol for psychoeducation specific to BPD, there would be far less reluctance to actually diagnose the disorder. With this important piece of psychoeducation, a patient has the opportunity to understand their diagnosis and why it is being made, and to ask questions of the clinician delivering that diagnosis so that there should be less concern of a patient reacting with anger or harming themselves because of the diagnosis. This piece of education for both clinicians and patients is so crucial especially when it concerns BPD.

# The Inpatient Hospitalization Experience

While the use of psychiatric inpatient services for individuals with BPD can be necessary in a crisis, it is by no means the most beneficial treatment setting (Paris, 2004), and still, many of these patients tend to be repeat visitors. Readmission into psychiatric inpatient hospitals has also tended to indicate the bad quality of service received upon their last visit (Byrne et al., 2010).

Given what we know about BPD and hospitalization, and the idea that intensive outpatient day treatment is typically most helpful for managing chronic suicidality in those with BPD (Paris, 2004), it is important for clinicians and patients to be aware of their diagnosis if they do in fact meet the criteria for BPD. This way they will have more insight as to how they can best manage their condition and proceed in treatment, especially when it comes to health service utilization such as inpatient psychiatric treatment. Adolescent inpatient clinicians in particular

need to be aware of this, again, given the high rates of these patients who meet the criteria for BPD.

## **Training Intervention**

## Why Do We Need This?

After a review of the literature on adolescent BPD, a few glaring issues remain and should be addressed. First, although we see an increase in research focus on the topic over the past 10 years, information about adolescent BPD still remains unknown to many clinicians who specialize in other areas. We need to ensure that information and updated research about adolescent BPD be spread to a range of mental health professionals. Despite the above-discussed, contemporary understanding of BPD and its early discriminability, clinicians are still reluctant to diagnose BPD in adolescents and also to disclose that diagnosis to them directly. This delays getting appropriate treatment and undermines the potential clinical utility of a diagnosis for adolescents with BPD. Finally, we see incredibly high numbers, ranging from 33–49% of adolescents who meet the criteria for a BPD diagnosis in inpatient psychiatric units (Sharp & Fonagy, 2015; Forman et al., 2004). This calls our attention to this population in particular, and this is where early identification can be especially crucial. Previous literature has indicated a need for increased early identification of BPD, and furthermore, that it should be encouraged through workforce development strategies (Chanen, Sharp, & Hoffman, 2017). There have been educational workshops in the past which have effectively modified attitudes toward BPD (Shanks et al., 2011; Krawitz, 2001); however, there have not been any workshops to my knowledge that have focused on modifying attitudes toward BPD with a focus on

adolescents and the diagnosis itself. By narrowing this focus I believe we can get to the root of a much larger public health issue, encouraging early intervention and adequate treatment of BPD in adolescence.

For a clinician to withhold a diagnosis of BPD from the patient is discriminatory (Veysey, 2014) in that it prevents them from making informed decisions about their own mental healthcare. Adolescents are already in a vulnerable and compromised position given their age. Additionally, to be in an inpatient setting can feel as though rights and freedoms have been stripped away. To at least provide them with the insight and language to talk about their mental health and treatment is significant. Thus, it is the hope that this training can help provide clinicians with the tools to implement that as such and to improve the quality of care for adolescents who meet the criteria for BPD.

Specific to some of the training content surrounding self-harm, it is important to note that there is a need to discuss self-harm because there is an overlap between those who self harm and those with BPD. There is oftentimes the false belief that all patients who self harm also have BPD. Patients who self harm or are perceived as "manipulative" are then referred to as "borderlines," even when they may not have the diagnosis. This language has historically been commonly heard among nurses.

Gibb, Beautrais, and Surgenor (2010) surveyed a range of health professionals asking them what the most difficult thing is about working with self-harm patients, and many of the general medical staff including nurses often had a hard time communicating with self-harm patients, and this can make for overlap with BPD patients, as well. All types of medical professionals, even those specializing in psychiatric services reported a need for continued

education and training sessions in answer to what might improve their work with self-harm patients.

### **Workshop Logistics**

The ideal number of participants for this training is no more than 50 in order to allow for interesting and productive discussion but also ensure learning. This training is aimed towards a range of mental health professionals, but with two main groups in mind: psychiatric clinicians, and nurses on adolescent inpatient units. This is so that clinicians with the ability to make diagnoses will be given the tools to do so well, and to understand the importance of early diagnosis/intervention, but also so that nurses will understand their role in the treatment of adolescents with BPD on inpatient units since they tend to have some of the most frequent patient interaction on the unit.

This is a result of the various literature which has discussed the idea that staff nurses tend to display the least empathy towards BPD patients as compared to other clinicians (Black et al., 2011), and overall negative attitudes (Hauck et al., 2013; Deans & Meocevic, 2005; Markham, 2003). Many nurses perceive patients with BPD as manipulative (Deans & Meocevic, 2005), and dangerous (Markham, 2003). Furthermore, many nurses also disagree that they have adequate training to know how to care for people with BPD (Deans & Meocevic, 2005). Given the overall negativity from nurses toward BPD patients as well as the extensive hours spent with them as compared to other clinicians on the unit, this training is crucial for both groups alike. It is also a hope that by having some sections of the training where nurses and other psychiatric clinicians are in mixed groups, this will encourage more communication between the two groups and discourage previously noted hierarchy among mental health professionals (Koehne et al., 2012).

This should ultimately only help to improve the quality of care for their patients by promoting more cohesive work and treatment environments.

Continuing Education credits (CEs) will be offered for this training. It will run over the course of one day from 9 AM - 5 PM with time for a 45-minute lunch break, as well as two other smaller ten-minute breaks scattered throughout the day. The training itself will be facilitated by two clinicians who specialize in the treatment of and research on adolescent BPD. It will take place in a hospital for convenience, and will be open to staff from other hospitals and treatment facilities.

## **Workshop Content**

9 AM - 11 AM: There will be presentations about knowledge specific to youth affected by BPD, and up to date research and new findings on BPD in adolescence. Participants will be able to ask questions when they arise. Following this, there will be a discussion portion of the morning where participants can discuss clinician-centered discomfort with the label. They will be able to discuss this in smaller groups and then report back to the larger group. Following, a specialist in adolescent BPD will lead a presentation/discussion on mistaken beliefs and discriminatory attitudes toward BPD and adolescents with BPD in particular. This is all at the recommendation of Chanen, Sharp, & Hoffman (2017) on their ideas for most effectively conducting a workforce development training for clinicians on adolescent BPD. This will conclude the first portion of the training and will be followed by a ten-minute break.

11 AM - 12 PM: Next, there will be a presentation on the importance of psychoeducation in adolescent BPD and a video portion. BPD, and psychoeducation as a means of treatment itself (Motlova et al., 2017; Zanarini et al., 2018). A short clip will be shown of Dr. Mary Zanarini, a

researcher and clinician at the forefront of BPD treatment, speaking to some of the benefits of psychoeducation specifically for BPD and adolescents with BPD. Another clip will be shown of a lecture given by Dr. Blaise Aguirre, another clinician and researcher at the McLean DBT unit for adolescents, and his lecture is titled "BPD in Adolescence: Early Detection and Intervention." This lecture provides information on some of the work being done at McLean Hospital, which could be potentially beneficial for other inpatient clinicians to be aware of. Aguirre also discusses adolescent BPD in a non-judgemental de-stigmatizing manner and speaks to some of the distinctions between adolescent BPD and typical adolescence. Following this there will be time for a lunch break.

1 PM - 2 PM: At this point there will be a presentation and discussion on self-harm in adolescent BPD and self-harm stigma specifically on adolescent inpatient units. A part of this section will include ex-patient videos from those with BPD who have self-harmed. Incorporating the presence and experience of an individual with this lived experience has been beneficial in past trainings and educational workshops, and it increased empathy and understanding (Krawitz, 2001). There will also be a presentation and time for questions to address the distinction between non-suicidal self-injury and non-fatal suicide attempts. This may also be a time to open up for discussion on the hospital system in general and how useful acute hospital stays for adolescents with BPD actually are/are not. Because so many of this population are hospitalized multiple times, there is a question as to whether or not this is the most useful mode of treatment for these patients, as opposed to maybe a partial hospitalization program, for example. Some may believe that the hospital effectively encourages repeated visits and self-harm, and that

self-harm patients just clog up the system. These are all public health issues to be discussed by a range of mental health professionals as well as general medical staff.

Up until this point in the training all group discussions will have taken place in mixed groups. At this time participants will split into two larger groups between nurses and clinicians for the purposes of different training content.

2 PM - 4 PM: Among both groups, there will be roleplay exercises. Both groups will watch videos from Doctors Gunderson and Zanarini on the importance of diagnostic disclosure of BPD, which also suggests the proper language for how to disclose a diagnosis of BPD to a patient. Following that, clinicians will be able to practice actually delivering a diagnosis of BPD, and practice how they would provide psychoeducation in that moment. Nurses will also be participating in role-play exercises, practicing the language used in discussing BPD. For example, how will they talk to a patient disclosing self-harm? How might they talk to a patient who has recently received a diagnosis of BPD? Finally, in instances when they are aware that the patient has a BPD diagnosis but they have not been given it, how will they talk to a patient to talk to that patient?

There will need to be a 10-15 minute break at some point during this part of the training an hour or so in, or when it feels most needed.

<u>4 PM - 5 PM</u>: A lot of information has been covered by this point in the training. It is important now that there is an hour left for a group debrief. There will be time to break up into smaller partner discussions and also report back to the group as a whole. If there are any final questions this is the time to address them. Participants may also want to discuss any specific cases they have encountered, and ask for advice or general support from the group in navigating

these. If there is time there will also be a discussion about clinician burnout and self-care practice to ensure that these participants acknowledge the difficulty of the work they are doing, and the importance that they maintain their own health and hope as they continue their day to day lives.

## **Efficacy of the Training**

Participants in the training will be asked to complete an online survey within a week before the day of the training, and again before they leave the training at the end of the day. It will be online for convenience sake, and it will need to be taken a second time before the participant leaves the training at the end of the day to ensure completion (i.e. no one forgets to do the survey once they have left and the training is no longer on their minds). Most questions will be closed-ended questions to which participants can respond "yes," "no," or "I don't know." There will be one open-ended question asking if participants have any other information they would like us to know, or if they have suggestions for future trainings. Some of the survey questions below are modified from a study by Black and colleagues in 2011, which assessed mental health clinicians' attitudes toward BPD. Questions below specific to self-harm were selected from the Attitudes Towards Deliberate Self Harm Questionnaire (ADSHQ), originally developed by McAllister and colleagues (2002) to assess nurses' attitudes in particular toward those who self-harm (Gibb, Beautrais, & Surgenor, 2010). Questions specific to diagnosis and adolescent BPD are my own.

### Survey of Attitudes Toward BPD: Validity, Stigma, and Adolescent Diagnosis

- Is BPD a valid diagnosis in adolescence?
- Have you ever withheld a diagnosis of BPD?
- Is it ethical to withhold a BPD diagnosis?

- Would you disclose a diagnosis of BPD to an adolescent?
- Do you feel you know the proper language to use if you were to make a diagnosis of BPD?
- Do you think a diagnosis of BPD in adolescence could be clinically useful to either a clinician or an adolescent? (Guiding treatment, psychoeducation, therapeutic alliance, understanding behaviors, reducing stigma, etc.)
- Are self-harm patients difficult to work with?
- Do you feel hopeless working with self-harm patients?
- Do you believe patients with BPD to be manipulative?
- Do you believe psychoeducation to be an essential component of treatment?
- Do you feel the prognosis for BPD is hopeless?
- Do you feel professionally competent to care for BPD patients?
- Do you feel the hospital system makes it difficult to deal with self-harm patients?
- Do you feel you have the appropriate skills to help self-harm patients?
- Would ongoing education and training in treating patients with BPD be useful to you?
- Would ongoing education and training in treating self-harm patients be useful to you?

When the survey is administered again at the end of the day, there will also be a few additional questions to see whether participants liked the training and if they predict it will be useful in their everyday work with patients.

## Post Training Day Survey Questions:

- Do you feel the training will help you to be more empathetic to adolescent BPD patients?
- Do you feel better equipped to treat these patients?
- Do you feel more comfortable making a diagnosis of BPD in adolescents?
- Did you find this training to be repetitive of information you already knew?
- Do you feel more up to date on current adolescent BPD research?
- Did you enjoy the training?
- Would you recommend this training to others?
- Anything else you would like us to know, or suggestions to improve future training?

The purpose of this survey will be to compare participants' attitudes toward adolescent BPD after receiving the BPD before receiving the training. Because different questions will be applicable to each group, there will be two separate versions of the survey: one for psychiatric clinicians, and one for nurses. It will also be interesting to analyze and compare how attitudes and experiences differ based on profession/specialty. Will this sample of participants in the training reproduce similar results to those (Black et al., 2011) that cite nurses as being less empathetic, for example, and social workers being the most empathetic towards these patients?

Finally, even if the training was effective in changing attitudes of clinicians and nurses, it will be crucial to see if this attitude change was reflected in practice with actual patients.

Previous studies such as one by Hauck and colleagues (2013) expressed the need for future studies to actually examine and report the longitudinal effects of continuing education on nurses'

attitudes and outcomes for BPD patients. In other words, more research on the efficacy of these training interventions needs to be considered in addition to the content and delivery of the interventions and workshops themselves, as the outcomes have yet to be made apparent. It is my hope that this proposed intervention with the added surveys would address that concern, with the goal for this training to translate into practice and treatment with real-life patients. In hopes that we will see modified attitudes and further training put into practice, there will be a six month follow up to see how this training has impacted their day to day interactions with BPD patients. An email will be sent out with the survey questions listed below.

## 6 Month Follow-Up Survey:

- Do you feel like you treat BPD patients differently after the training?
- Do you have more empathy toward these patients in your daily interactions with them?
- Have you felt more comfortable disclosing a diagnosis of BPD over the past 6 months?
- Do you feel that you speak with more sensitivity and understanding of BPD when discussing patients with your colleagues?
- Do you have more hope working with BPD patients then you did prior to the training?
- Do you feel this training would be beneficial to others?
- Anything else you would like us to know?

### **Goals of the Training**

The goal of this training is that it will shift nurses' and psychiatric clinicians' negative attitudes of BPD patients toward a more empathetic and hopeful mindset. It is also a hope that these shifts in attitude will then be reflected in treatment. There is no way to know if the training has been effective other than based on self-report measures, hoping that participants will respond to the survey after 6 months.

Additionally, through this training, an emphasis on providing hope for clinicians is crucial, and it is a goal that this training can reassure people that working with BPD patients is not hopeless work or that their struggles are futile problems that cannot be helped (Krawitz, 2001). Again, especially in the case of adolescents, many clinicians pursue working with this population because it does feel more hopeful to work with young people who still have a lot of time left to improve their coping skills and get their lives on track, and some clinicians report feeling more likely that they will be able to make a positive impact in the lives of adolescents as opposed to adults in some cases (Koehne et al., 2012). Moreover, they worry that a BPD diagnosis will diminish this sacred sense of hope required for both themselves and their clients in doing such intensive work. This training can be one that is sensitive to that notion, and seeks to encourage clinicians to hold on to hope in the same sense that their patients need to, as well. This work is not easy for either party, and it is important to acknowledge this, especially given the fact that these clinicians can be prone to burn out. For a clinician to feel that they are competent and have the skills to treat these patients goes hand in hand with maintaining that sense of hope, as well. Additionally, given that so many refuse to work with this population, it is crucial to be sensitive to this because there need to be more empathetic clinicians willing to work with and

advocate for BPD patients, adolescents, in particular. This training also provides the opportunity for clinicians to have a designated space just to discuss specific concerns about BPD patients and early diagnosis as a whole, and find clinician solidarity in addressing difficult situations while also respecting their patients, whereas there may not always be the opportunity to draw attention towards this specific population of patients.

Of course, it is also important that clinicians attend such training sessions and workshops in order to stay up to date with the most current research and information on this patient population. It is crucial to ensure that people are staying informed, especially given the somewhat specific or niche field of adolescent BPD, especially considering that we are in a period now where more and more research is on the rise, and should continue to be in the coming years as it has only gone up in the past decade or so.

Finally, to my knowledge, this is a unique training intervention that hasn't been offered before, as it focuses specifically on the validity, clinical utility, and personal impact of disclosing a BPD diagnosis in adolescence. Trainings and workshops have existed in the past, surely, which provide up to date research on adolescent BPD, address the unique challenges of working with suicidal and or self harm-ing adolescents, and so on, as similar to some of the components in my proposed training intervention. But what I have opted to do is to take the existing literature in these subcategories to combine them with the importance of disclosing a diagnosis in adolescents with BPD in particular, and to emphasize that importance of the diagnosis in addition to these other components of the training, which is what could make it a unique and clinically useful opportunity for clinicians.

#### **Future directions**

Hopefully, this training could be improved even further based on survey responses from participants, as well, and this training could be offered a number of times to many mental health professionals and general medical staff everywhere. As previously mentioned, more data is needed on how these trainings and workshops actually translate into practice with real patients, particularly from nurses, and it is a hope that this information could be acquired through the follow-up survey six months after the training. This training in time could also be adapted for the general public. Information about diagnosis is not as relevant for everyone, but opening up a conversation about BPD stigma for the general public and providing training on how to communicate and have healthy relationships with those who have BPD can be of equal importance, whether they be a child, student, friend, or otherwise.

Even beyond this, it is a hope that this will increase screenings for BPD post suicide attempts even in emergency departments. This is especially crucial for adolescents seeing as the younger the age of the first attempt, the more likely they will be to attempt again in the future (Defayette et al., 2019; Berk et al., 2007).

#### **Concluding Thoughts**

Psychiatrist Dr. Aaron Krasner tells us that in his many years spent working in clinical psychiatric settings, rarely has he ever seen an adolescent patient with borderline pathology who did not meet criteria for a comorbid condition such as depression or anxiety. With that in mind, the way he then goes about treatment for these adolescents who he suspects may have an emerging personality disorder is to first treat these conditions such as depression or anxiety, and then see what maladaptive coping skills and borderline symptoms endure beyond that initial

treatment. While this makes sense, and still addresses the patient's need for some form of effective treatment, it then begs the question of, how long do these borderline symptoms then have to endure? When exactly can a borderline diagnosis be made? Alternative to Dr. Krasner's method, Dr. Khrista Boylan describes that in her experience of working with adolescents, it can worsen a patient's BPD symptoms when focusing on a comorbid disorder before addressing the BPD, and can cause an increase in acute mental health visits (Boylan, 2018). There are adolescents who may be in treatment for years and still never receive a borderline diagnosis only to get it when they are an adult and wonder why they hadn't been made aware of their condition sooner. There is just no real standard of treatment for adolescents with borderline pathology, and different clinicians will have different opinions about when they should make the diagnosis or if they will ever disclose it at all.

Even if certain clinicians find my intervention and push for earlier diagnosis to be bold, or maybe do not necessarily agree with the validity of the BPD diagnosis in adolescence, there still needs to be more conversation and communication surrounding adolescents who are at high risk, suicidal and or prone to self-injury, and there needs to be a consensus as to how best to treat such a vulnerable population to prevent the prolonged suffering we so often hear about in the experience of those with BPD. Even in the case with two advocates for adolescents with BPD, Dr. Krasner, and Dr. Boylan, they both seem to want the best for their patients, but they have differing opinions on how to go about the best course of treatment for these patients. There is no way of knowing which method of treatment then does more harm than good or vice versa if this topic of early diagnosis of BPD in adolescents isn't discussed more frequently in the future. Of course, while I do advocate for early diagnosis and intervention based on an extensive literature

review, there are still components of my proposed training intervention that clinicians can find helpful even if they are still reluctant towards disclosure of a diagnosis in adolescence. Clinicians can still benefit from staying as up to date as possible with the current research, treating patients who are chronically suicidal or have engaged in self-harm, and hearing personal accounts from those who actually live with BPD. It is the hope that with that information there will be less reluctance towards early diagnosis, but still, I can acknowledge that it is controversial, and progress is still in the making. Most importantly, though, it is a goal of mine that not only this training intervention but this thesis as a whole can provide a greater sense of hope about what it is to live with a BPD diagnosis. That said, one cannot have hope without something to be hopeful about and the prospect of a different future, and this is why I believe based on a combination of research and personal accounts that the disclosure of a diagnosis will ultimately do much more good than harm. Finally, hope, the importance and power of hope, and how to hold onto it when navigating BPD, whether treating it or living with it. That is the most important takeaway here.

After all, Dr. Marsha Linehan, creator of DBT, the most effective and widely used treatment for BPD, struggled with BPD herself. She suffered tremendously during her teen years, and while hospitalized, she vowed that after she got out of hell, she was going to come back and get others out, too. I'd say she was pretty successful. Dr. Linehan tells us that she succeeded not despite her diagnosis, but *because* of it (Carey, 2011). If that is not hope enough, I don't know what is.

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