

RESEARCH ARTICLE

Impact of Diagnosis Disclosure on Adolescents with Borderline Personality Disorder

Darren B. Courtney MD, FRCPC¹; Judy Makinen PhD, C.Psych²

Abstract

Objective: Establishing a diagnosis of Borderline Personality Disorder (BPD) in adolescents is often met with controversy, in part, due to potential stigmatizing effects. We wished to explore the adolescent patient experience of being diagnosed with BPD. **Method:** The Impact of Diagnosis Scale (IODS) is a self-report measure we developed with questions targeting patients' subjective experience of receiving a diagnosis of BPD. The IODS was administered to 23 adolescents approximately one month after a diagnosis of BPD had been disclosed to them. **Results:** Twenty-one participants had analyzable data. The internal consistency of the measure demonstrated Cronbach's alpha of 0.66. We found wide variability in responses. Patients tended to view the diagnosis as an accurate representation of their symptoms. **Conclusion:** The IODS represents a novel means by which clinicians might better appreciate how disclosing the diagnosis of BPD may impact a patient's understanding of one's difficulties.

Key Words: *borderline personality disorder, adolescent, disclosure, stigma, diagnosis*

Résumé

Objectif: Établir un diagnostic de trouble de la personnalité limite (TPL) chez les adolescents soulève souvent la controverse, en partie à cause des effets de la stigmatisation potentielle. Nous avons voulu explorer l'expérience d'un patient adolescent qui reçoit un diagnostic de TPL. **Méthode:** L'échelle d'impact du diagnostic (EID) est une mesure d'autoévaluation que nous avons élaborée avec des questions ciblant l'expérience subjective des patients qui reçoivent un diagnostic de TPL. L'EID a été administrée à 23 adolescents environ un mois après qu'on leur a divulgué un diagnostic de TPL. **Résultats:** Vingt-et-un participants avaient des données analysables. La cohérence interne de la mesure démontrait un alpha de Cronbach de 0,66. Nous avons constaté une grande variabilité des réponses. Les patients avaient tendance à voir le diagnostic comme étant une représentation exacte de leurs symptômes. **Conclusion:** L'EID représente un nouveau moyen grâce auquel les cliniciens pourraient mieux apprécier comment la divulgation d'un diagnostic de TPL peut influencer sur l'aptitude du patient à comprendre ses difficultés.

Mots clés: *trouble de la personnalité limite, adolescent, divulgation, stigmates, diagnostic*

Borderline personality disorder (BPD) is a persistent and disabling condition characterized by impulsivity, emotion dysregulation, an unstable sense of self and others, and recurrent self-injurious thoughts and behaviours (American Psychiatric Association, 2013). The DSM-5 allows for such a diagnosis to be made in adolescents when “traits appear to be pervasive, persistent, and unlikely to be limited to a

particular developmental stage or another mental disorder (pg. 647)”. Epidemiological studies have found variable rates of BPD in adolescent community samples, ranging from 0.9% (Mohammadi, Shamohammadi, & Salmanian, 2014) to 14% (Chabrol, Montovany, Chouicha, Callahan, & Mullet, 2001). This variability may be attributable to

¹Staff psychiatrist at the Youth Addictions and Concurrent Disorders Service, Centre for Addiction and Mental Health, Toronto; Assistant Professor in the Department of Psychiatry at the University of Toronto

²Psychologist at the Youth Program at The Royal Ottawa Mental Health Centre, Ottawa, Ontario

Corresponding E-mail: dr.courtney.research@gmail.com

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research methods and distinct cultures in which studies took place.

Making a diagnosis in adolescents is controversial (Chanen & McCutcheon, 2008). For example, in a survey of 52 child and adolescent psychiatrists, only 37% indicated that a diagnosis of BPD in adolescents was valid (Griffiths, 2011). Bondurant et al. examined prior studies and concluded that there is substantial support for construct validity of the BPD diagnosis in adolescents; however, it is not as coherent as adult populations in that it did not strongly predict stability of the specific diagnosis and there was significant overlap with other personality disorder diagnoses at follow-up (Bondurant, Greenfield, & Tse, 2004). Miller, Muehlenkamp, and Jacobson (2008) reviewed the literature and suggest that diagnosing adolescents with BPD is a scientifically valid model; also noting that there is a severely ill subgroup of adolescents for whom symptoms of BPD are stable and less severely ill subgroup of teens where symptoms appear to fluctuate with time.

The difference between a diagnosis of BPD versus a classical mood disorder (e.g., Major Depressive Disorder or Bipolar Affective Disorder) has important treatment implications. In a clinical sample, BPD in adolescence was found to be associated with greater deficits in adaptive functioning and greater severity of psychiatric symptoms relative to adolescents with other personality disorders or no personality disorder (Chanen, Jovev, & Jackson, 2007). A diagnosis of BPD may lead to having limited expectations from medications (Paris, 2008) and a greater emphasis on structured psychotherapies, like Dialectical Behaviour Therapy (Mehlum et al., 2014) or Mentalization-Based Therapy (Rossouw & Fonagy, 2012). Prolonged hospitalization is relatively contraindicated in patients with BPD as it may reinforce maladaptive coping strategies (Paris, 2008).

Assuming the diagnosis is scientifically valid, making a diagnosis of BPD in an adolescent and disclosing the diagnosis to the affected individual has the potential to be very helpful to such patients. Linehan (1993) proposed that psychological validation of one's experience is a key therapeutic tool in the treatment of people with BPD. Discussing a diagnosis of BPD may orient the adolescent to their experience, help them "make sense of" the experience and make them aware that many other people have similar struggles; all of which has the potential to be quite psychologically validating. In addition, it can be argued that informing the patient of the diagnosis does promote autonomy and empowers the patient to engage in informed discussions around treatment options. Lastly, establishing a diagnosis and disclosing it to the patient could lead to earlier intervention, and thus, has the potential to lead to better outcomes. Indeed, Zanarini et al. found preliminary evidence that educating young people diagnosed with BPD about their symptoms seemed to improve outcomes (Zanarini & Frankenburg, 2008).

Conversely, the experience of being diagnosed with BPD may be counter-therapeutic. Patients may experience a sense of shame regarding their illness. This shame, in turn, can promote further pathology (Rusch et al., 2006). Moreover, the diagnosis may promote discriminatory behaviours among clinicians working with the individual in the future. This could lead to a "self-fulfilling prophecy" phenomenon where negative interactions with providers may promote further distress and dysfunction (Aviram, Brodsky, & Stanley, 2006). Indeed, research has supported the idea that even reading the term "borderline personality disorder" in a patient's record negatively affects impressions of clinicians (Lewis & Appleby, 1988). Moreover, one study demonstrated that family member distress was positively correlated to knowledge about the BPD concept (Hoffman, Buteau, Hooley, Fruzzetti, & Bruce, 2003), indicating a potentially unfavourable outcome of psychoeducation.

While there is some literature describing adult patient experiences with being diagnosed with BPD (Bilderbeck, Saunders, Price, & Goodwin, 2014; Rusch et al., 2006; Sansone & Sansone, 2013), we did not find any such studies as the experience pertains to adolescents. Within our clinical work, we had found variable responses from adolescents with regards to receiving the diagnosis of BPD. Many expressed relief, while others expressed further distress. The question arises then; in general, do adolescent patients experience a diagnosis of BPD helpful or unhelpful?

The lead author of the current study developed a clinical tool named the "Impact of Diagnosis Scale" (IODS) to measure adolescent patient perceptions of receiving such a diagnosis. We hypothesized that:

1. The IODS would demonstrate preliminary support of internal consistency.
2. The majority of adolescents receiving a diagnosis of BPD would experience the process of hearing about the diagnosis as it applies to them to be helpful.

Methods

This study was intended to be a pilot and naturalistic. Participants were recruited from the Youth Department at the Royal Ottawa Mental Health Centre, a tertiary care psychiatric hospital in Ottawa, Canada during the time interval of 2012 to 2014. Many patients were initially admitted from the emergency room to the acute care adolescent unit at the local children's hospital and subsequently transferred to the Royal's Youth Inpatient Unit (YIPU) for diagnostic clarification and further treatment. In general, the YIPU has a medium length-of-stay and has eight beds; corresponding to an approximately 35-40 individuals being admitted each year. Upon admission to the YIPU, the patient had a comprehensive psychiatric admission assessment where early formation of a differential diagnosis was established. Consent to participate in program evaluation, including the IODS, was requested by the Youth Department's Program

Evaluation Co-ordinator (PEC) soon after admission. Over the subsequent weeks, diagnostic impressions were fine-tuned as observations on the ward were taken into account. As the study was naturalistic, there was variability in how a diagnosis was made. Some patients had a comprehensive psychodiagnostic assessment by the unit psychologist (JM) which often included the Millon Adolescent Clinical Inventory (MACI) (Millon, 2004) and the Personality Assessment Inventory-Adolescent (PAI-A) (Lorey, 2007). In more recent years, the treating psychiatrist had been utilizing a newly available and newly validated tool: the Childhood Interview for Borderline Personality Disorder (Sharp, Ha, Michonski, Venta, & Carbone, 2012). Collateral history from parents and other care providers was obtained. Ultimately, the final diagnosis of BPD was determined by clinical impression of the patient's psychiatrist after consideration all of the information gathered; with DSM-IV criteria being the reference standard. "Features of BPD" was diagnosed if patients did not meet threshold criteria; however have representative symptoms that lead to distress and dysfunction based on the psychiatrist's opinion. This process is representative of what would happen in natural clinical practice on the unit.

Upon establishing a diagnosis, the psychiatrist and/or psychologist would provide feedback around the impression to the patient and families.

Affected patients were provided with a handout explaining the construct of Borderline Personality Disorder as it pertains to adolescents. Parents were provided a very similar handout. The handout outlined the nine criteria of BPD in the DSM-IV-TR (unchanged in the DSM-5). It also outlined associated concepts such as "splitting" and "lack of object constancy" (Gabbard, 2005) in accessible language. For example, "splitting" was described as the tendency for people with BPD to view others as "all good" or "all bad"; in keeping with DSM criterion of relationships characterized by idealization and devaluation. Risk factors for developing BPD were also outlined in the handout; namely, genetic and neurobiological factors (Goodman, Mascitelli, & Triebwasser, 2013), and early life adversity or trauma (Ball & Links, 2009; Infurna et al., 2016; Liotti & Pasquini, 2000). The handout also promoted a focus on outpatient, structured psychotherapy as being the treatment of choice (Mehlum et al., 2014; Rossouw & Fonagy, 2012) and a limited role for medication management (Paris, 2008). It also discussed the lack of long-term stability of diagnosis in adolescents who meet criteria for BPD (Biskin, Paris, Renaud, Raz, & Zelkowitz, 2011; Garnet, Levy, Mattanah, Edell, & McGlashan, 1994; Meijer, Goedhart, & Treffers, 1998). The parent handout provided a brief description of the importance of psychological validation when communicating with their adolescent.

Approximately four weeks after the diagnosis was provided, the PEC would provide the IODS to the patient to complete

in the outpatient waiting area (most patients would have been discharged by this point). The four-week interval was intended to allow for time for the patient to process the information and discuss it further with the clinical team. The IODS took 5-10 minutes to complete and many patients appeared to be engaged and willing in the process. The PEC collected the completed measures and research assistants entered results into the database.

The Impact of Diagnosis Scale is a ten-item scale developed by the lead author based with the intent of preliminary exploration of patient's experiences with receiving a diagnosis of BPD. It is intentionally brief so as to optimize the chances of participation. Each item consists of a statement that the patient indicates a score on a 7-point Likert-type scale ranging from "strongly disagree" (coded as a 1) to "strongly agree" (coded as a 7). A score of 4 indicates a "neutral" stance towards the statement. Had the patient not remembered having been diagnosed with BPD (or features) or the patient had not taken time to learn about the diagnosis, the remainder of the questions would not have face validity. As such the first two items were as follows:

1. I clearly remember a clinician using the term "borderline personality disorder" to describe some of my symptoms.
2. I have learned about "borderline personality disorder" and the symptoms of the disorder.

If the participant indicates a score of 3 ("slightly disagree") or less, the remainder of the scale is deemed invalid and excluded from analysis.

The analysis was conducted on the remaining items, which were as follows:

- Item 3: Hearing the term "borderline personality disorder" to describe my symptoms has made me very confused.
- Item 4: Using the term "borderline personality disorder" to describe my symptoms seems to be an accurate way to describe a lot of my difficulties.
- Item 5: I have had a hard time getting access to outpatient treatment (where I sleep at home and get treatment at the hospital during the day) since my symptoms were described as being part of "borderline personality disorder".
- Item 6: Learning about "borderline personality disorder" has helped me understand my difficulties.
- Item 7: Hearing my symptoms being described as part of "borderline personality disorder" has made me feel better about myself.
- Item 8: My main symptoms are better described **without** using the term "borderline personality disorder".

Table 1. Internal Consistency of the Impact of Diagnosis Scale

Item	Cases	Item-Test Correlation	Item-Rest Correlation	Average Interitem Correlation	Alpha
«Diagnosis has made me confused» (reversed)	21	0.27	0.04	0.25	0.7
«BPD is accurate»	21	0.73	0.59	0.16	0.58
«Cannot access treatment» (reversed)	20	0.05	-0.19	0.3	0.75
«Diagnosis helped me understand my symptoms»	21	0.7	0.55	0.17	0.59
«Diagnosis made me feel better»	21	0.5	0.31	0.2	0.64
«Symptoms better described without BPD» (reversed)	21	0.56	0.38	0.19	0.62
«Clinicians treat me better»	21	0.88	0.81	0.13	0.5
«Parents treat me better»	21	0.67	0.5	0.17	0.58
Test scale				0.2	0.66

- Item 9: Clinicians seem to treat me with more understanding since the term “borderline personality disorder” was used to describe my symptoms.
- Item 10: My parent/parents seem to treat me with more understanding since the term “borderline personality disorder” was used to describe my symptoms.

Cronbach’s alpha and inter-item co-relations were calculated with items 3, 5 and 8 intentionally reversed, as high scores would indicate that the diagnosis was not helpful to the patient. Histograms of response patterns were created for items 3 through 10. One-sample t-tests were used on each item response set to test against null hypothesis that the mean response was equal to 4, which represents a “neutral” stance on the item. As this is project is exploratory, t-tests were two-tailed and the threshold *p*-value for each item (<0.05) was not adjusted for multiple comparisons.

The Research Ethics Board at the Institute of Mental Health Research associated with the Royal Ottawa Mental Health Centre approved the study as part of a larger Program Evaluation project within the Youth Psychiatry Program.

Results

Twenty-five patients were asked to complete the IODS. Two had refused. Of the remaining twenty-three, one indicated that she did not recall being diagnosed with BPD (or features thereof) on item 1. Another reported that she did not learn about BPD on item 2. These two participants were excluded from the remainder of the analysis.

The mean age of the remaining sample analyzed (n=21) was 16.1 (SD:0.8, range 15-17). Eighteen (85.7%) were female. Ten patients were assessed using the CI-BPD, nine of whom were scored in the “definitely meets criteria” category and the remaining one was scored in the “probably meets criteria” category. One patient did not respond to item 5 and so this one data-point is missing.

The internal consistency calculation led to a Chronbach’s alpha of 0.66 (see Table 1). The inter-item correlations are described in Table 2.

In examining the distribution of responses (see Table 3 and Figure 1), statistically significant findings were noted for item #4 (indicating that patients found the diagnosis to be accurate), item #5 (indicating that patients do *not* feel they have a hard time getting treatment), item #7 (indicating that hearing about their difficulties described as part of BPD did *not* make them feel better about themselves) and item #8 (indicating that they did *not* think that there would be a better way to explain their symptoms; consistent with item #4).

Discussion

Our study addresses a wide gap in the literature as it represents a preliminary exploration into adolescent patient experience of being diagnosed with borderline personality disorder. Our analysis of this newly developed scale revealed a low level of internal consistency, though this is could be attributable given the limited number of items, small sample size and that the item topics are quite disparate from each other.

As was experienced clinically, the response to items was quite variable. In general, patients seemed to understand the construct, did feel that the diagnosis was an accurate reflection of their difficulties and did seem to help them understand their symptoms.

Item 7 (“the diagnosis made me feel better”) was of key interest as it was an attempt to see if patients found the diagnosis psychologically validating or not. The statement yielded unfavourable results; however, in retrospect, the item could have been interpreted two ways: (1) that the symptoms of the illness itself are making the patient feel bad; or (2) the process of being labeled with a diagnosis is

Table 2. Inter-item Co-relations of the Impact of Diagnosis Scale

	Item 3 (reversed)	Item 4	Item 5 (reversed)	Item 6	Item 7	Item 8 (reversed)	Item 9	Item 10
3. «Diagnosis has made me confused» (reversed)	1							
4. «BPD is accurate»	-0.19	1						
5. «Cannot access treatment» (reversed)	0.36	-0.49*	1					
6. «Diagnosis helped me understand my symptoms»	-0.32	0.86*	-0.43*	1				
7. «Diagnosis made me feel better»	0.14	0.29	-0.32	0.32	1			
8. «Symptoms better described without BPD» (reversed)	0	0.58*	-0.35	0.44*	0.17	1		
9. «Clinicians treat me better»	-0.09	0.75*	0	0.73	0.47*	0.46*	1	
10. «Parents treat me better»	0.36	0.24	0.3	0.33	0.13	0.16	0.47*	1

* < p .05, two-tailed

Table 3. Distribution of item responses on the Impact of Diagnosis Scale

Item #	n	M (SD)	t	p
1	23	6.4(1.0)	11.3	<0.001*
2	23	5.9(1.2)	7.6	<0.001*
3	21	3.4 (1.7)	-1.5	0.15
4	21	5.2 (1.7)	3.3	<0.01*
5	21	3.0 (1.8)	-2.4	0.03*
6	21	4.8 (1.8)	2.0	0.06
7	21	3 (1.7)	-2.7	0.01*
8	21	3.2 (1.4)	-2.4	0.03*
9	21	4 (1.6)	0	1.00
10	21	3.9 (2.1)	-0.3	0.75

* Indicates two-tailed p-values <0.05 with regards to probability that the mean is significantly different from 4 ("neutral").

adding to distress already experienced. Future iterations of this scale may attempt to clarify this distinction.

Item 5 ("I am finding it hard to access outpatient treatment") may be less relevant to the current research situation, as patients were provided the survey in the waiting room prior to an outpatient appointment; moreover, the Royal's Youth Psychiatry Program does offer outpatient DBT and other programs implementing DBT for youth in the Ottawa area have been surfacing in recent years. Results may be quite different should the survey be re-administered after patients have turned 18 and are looking for treatment options in the adult system.

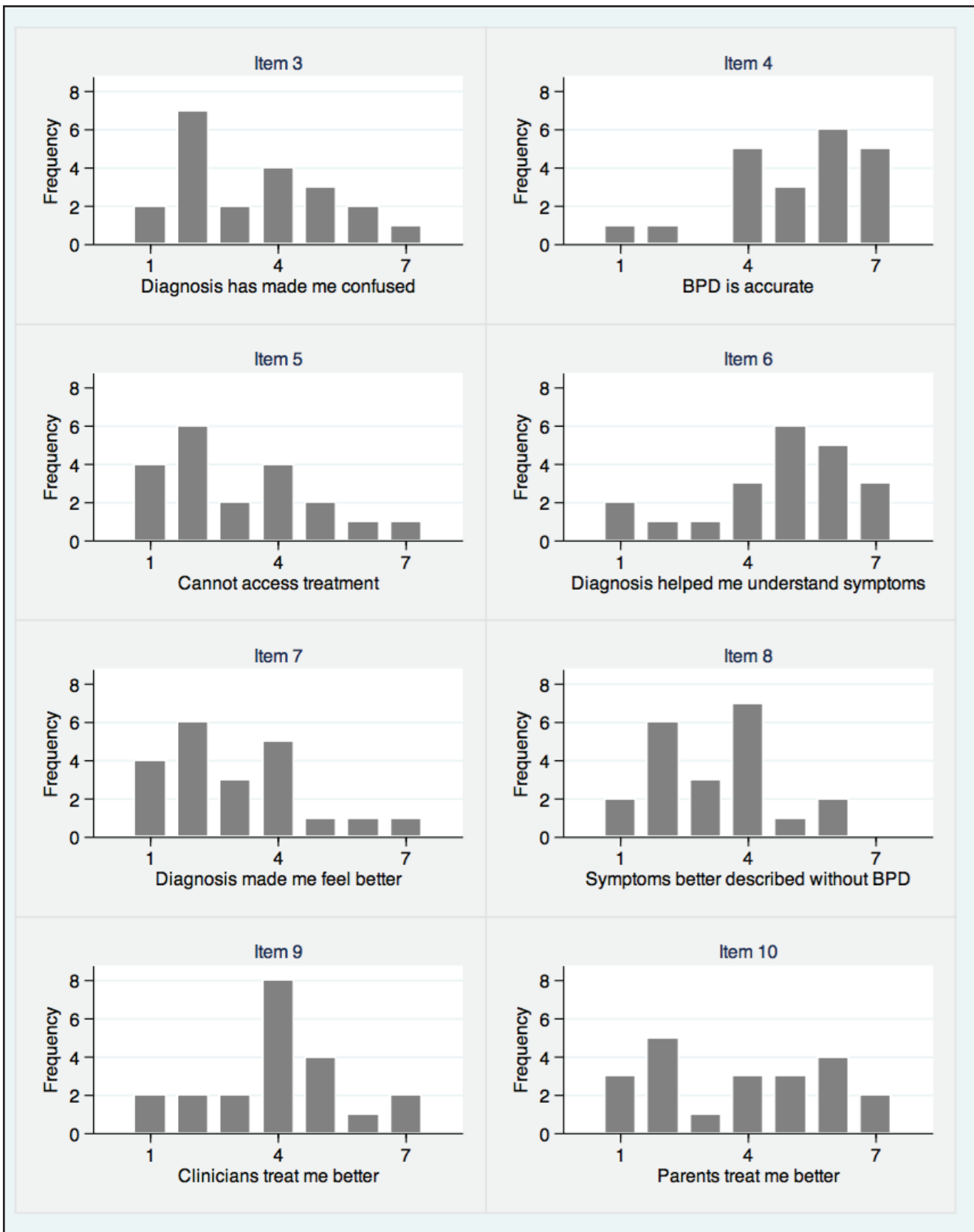
Patients generally did not notice a change in how clinicians treated them after the diagnosis was made; however, these patients had contact with many clinicians and "averaging affects" of various experiences could have led to the relatively neutral results observed. Patients had noticed that parents treated them differently after the diagnosis was

made; however, this change seemed to occur in both positive and negative directions.

Implications for practice

We did not find overwhelming evidence that patients have a negative experience with being diagnosed with BPD, at least in the short-term and in the context of offering disorder-specific treatment. Based on our clinical experience and these pilot results, we provide a few recommendations: (1) if a thorough assessment reveals that an adolescent meets criteria for BPD (or has prominent features thereof), we currently recommend establishing the diagnosis and discussing the diagnosis with adolescents and their families; and, (2) we also recommend follow-up up this discussion with comprehensive psychoeducation. This approach has the potential for patients and families to be engaged in informed decision-making around their treatment. We acknowledge that these recommendations have a weak evidence-base and

Figure 1



could shift with further research. Moreover, long-term effects of the diagnostic label have yet to be explored.

Implications for future research

Revised versions of the IODS may benefit from addition of other items exploring feelings of “hope” or “shame” upon learning about the diagnosis. More specific statements around whether or not the patient experiences psychological validation with the diagnosis would be important. Expanding investigations to other clinical situations, such as adolescent crisis units (that is, secondary care) and adult clinics may yield different results. Clarifying which patients benefit from discussing the diagnosis may also be helpful. For example, low levels of perceived discrimination predicted higher rates of self-esteem in adults diagnosed with BPD (Rüsch et al., 2006). Further iterations of the IODS may assist in determining whether changes in the way information is presented could be more helpful for such patients. It would also be interesting to compare reactions of adolescent patients receiving diagnoses of BPD relative to other psychiatric diagnoses. Administration of the survey at one-year follow-up would also be an interesting area to explore. A similar process could occur exploring parental experiences of having their child diagnosed with BPD. Correlating the IODS with previously validated measures would also be important. Experts in health care ethics may also want to explore the moral implications of disclosing or withholding a psychiatric diagnosis.

Strengths

Keass et al. argue that the concept of adolescent BPD is valid, distinct from normal adolescence and represents sufficient stability. They also note a hesitancy for clinicians to make the diagnosis due to stigmatizing effects. As such, they call for more information on the potential stigmatizing effects of the diagnosis on adolescents (Kaess, Brunner, & Chanen, 2014). This study offers an avenue to explore such effects. On the surface, patients did seem to appreciate that their opinions on the matter were being sought. This approach has the potential to find ways for clinicians to better engage their clients, and ideally, improve patient outcomes.

Limitations

Sample size limits the findings. The internal consistency of the IODS was modest. Future iterations of the scale may include more items to clarify the nature of the responses. Moreover, this study took place in a tertiary care setting, where many patients had already experienced multiple assessments and were resistant to standard first-line treatments for depression and anxiety. Some patients in secondary care with cross-sectional BPD features may respond to supportive counseling, cognitive behavioral therapy or family therapy without the need to go into discussions around the BPD construct at the risk of the potential impact of the

diagnostic label. Our results may not be generalizable to primary or secondary care. A recent study calls into question previous findings that BPD in adolescence tends to remit (Greenfield et al., 2015). This information may also affect patient experiences of the diagnosis.

Conclusions

The Impact of Diagnosis Scale represents an avenue to investigate the adolescent patient experience of being diagnosed with Borderline Personality Disorder. Our current study presents some preliminary data suggesting modest reliability of the scale and variable qualities of experiences with having been diagnosed. While revisions to the scale are indicated, new iterations have great potential for clinicians to better understand their patients’ perceptions as well as increase treatment engagement and rapport.

Acknowledgements / Conflicts of Interest

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