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## **Parents, clinicians and the genesis of a contested diagnosis: The development of knowledge surrounding pediatric bipolar disorder in the United States**

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### **ABSTRACT**

The diagnosis of paediatric bipolar disorder (PBD) has emerged as an object of controversy in the United States over the last two decades as it continues to expand despite a lack of professional consensus surrounding diagnostic criteria. At the same time there is a push among American parents for greater acknowledgement and awareness of their position, as well as clinical alignment with what they see as indicative of the disorder. Interaction between these two groups, and their local systems of professional versus experiential knowledge, provides insight into how a contested disorder is constructed by competing knowledge systems, shedding light on psychosocial processes leading to diagnostic expansion. This paper presents findings from thematic dialogical analyses of interviews with 10 American child psychiatrists and 15 parents of children with PBD. Using a socio-psychological framework emphasizing modalities of social influence and cognitive polyphasia, the circular influence at play among and between these two key actors in the genesis and development of PBD as a diagnostic category will be explored. This paper is very

much grounded in scholarship related to the medicalization of childhood, and the construction of related diagnoses such as ADHD and Autism, however much of the literature on PBD remains in the clinical realm. As a disorder still attempting to establish itself, an exploration into the wider social and cultural factors shaping negotiated interactive processes behind how PBD emerges and takes hold is warranted.

**Keywords:** *paedriatic bipolar disorder (PBD); competing knowledge systems; social influence; cognitive polyphasia*

## INTRODUCTION

Despite over a century of agreement among psychiatrists that manic-depressive type illnesses rarely established themselves before adolescence (Healy & LeNoury, 2007) the diagnosis of bipolar disorder in children (PBD) has sharply increased in North America over the last two decades. The birth of the controversy surrounding the diagnosis came as a result of research from Harvard Medical School in the mid-1990's, which brought this broad-spectrum approach to the diagnosis of the disorder in children to a wider audience (Beiderman et al. 1996; Wozniak et al. 1995). Despite the controversy over this relabeling, the US experienced a 40-fold increase in the diagnosis from 1995-2005 (Moreno et al, 2007). This has coincided with a growing acceptance among clinicians of the expansion of diagnostic categories to include younger and younger children despite the fact that the condition itself remains unstable, with little in the way of established biomedical evidence to support it (Olfman, 2008).

Illness and disease are more than fixed realities, rather they exist as phenomena shaped by experiences, interaction, and shifting frameworks of knowledge which can only be understood and defined against the social background (Barker, 2010; Yap, 1967). The construction of illness and related issues of medicalization have been explored from multiple perspectives across the social sciences. This paper draws on scholarship surrounding the medicalization of childhood (Conrad & Bergey, 2014; Conrad & Potter, 2000), the expanding scope of diagnostic practice and the reshaping of what is considered normal vs. pathological behavior (Rose 2006; Rose 2010), and the sociology of diagnosis as both a label and a

socially elaborated process (Jutel, 2011). Central to the development of PBD are the multiple knowledges being negotiated, and the myriad social influences impacting on how these, often conflicting, knowledge systems interact. This paper seeks to illustrate the degree to which the development of this diagnosis is very much a collaboration, developed in conjunction with wider representations surrounding norms of childhood. This is of particular relevance with regards to a still ill-defined diagnostic category which counts very young children as its sufferers, and strong, often untested medications as the preferred treatment. In seeking to understand the genesis of PBD this paper explores how cognitive polyphasia and social influence processes shape the expansion of professional and parental understandings surrounding the diagnosis.

### **The development of parental knowledge**

The advancement of parental knowledge around mental health conditions has been shaped by a marked shift in cultural messages available regarding child rearing in America since the 1990's. This evolution is linked to the changing labour market in which a 'normal' brain is no longer enough for the increased competition for jobs, and children are steered towards enhancement in order to compete (Blum, 2015). Alongside this is the rise of a new knowledge economy in which parents seek to educate themselves so as to have a voice in the face of a shortage of child psychiatrists and cutbacks in services available (ibid). As families are increasingly brought into the fray of professional networks, and clinical explanations of a child's behaviour, parental knowledge development hinges on multiple competing perspectives in need of alignment. Developing the understanding of the world of diagnosis their child potentially enters in to remains an area of tension. Mothers in particular, remain a focal point of blame for their child's behaviour, thus the development of knowledge takes shape within a context, which is already positioning them as somehow responsible (Frigerio, Montali & Fine, 2013; Singh, 2004). This is especially salient in interactions with professionals, where parents of children with less visible disabilities employ multiple discourses, including that of normal development as well as medical explanations, when constructing the 'problem' of their child's diagnosis (Avdi et al., 2000; Todd & Jones, 2003). A constant subjective battle is fought in which parental understandings of more contested disorders as biological, come up against psychological and social origins of the diagnosis often perpetuated by family members or other professionals (Harborne et al., 2004). Thus,

parents find themselves having to rely on peers, online forums, or increasingly popular books such as *The Bipolar Child*, the “definitive and reassuring guide for parents childhood’s most misunderstood disorder” (Popolos & Popolos, 2006) to develop an understanding of how to best interpret their child’s behaviour.

### **Making sense of a new medical phenomenon: a psychosocial framework**

Health is one domain that can be singled out as drawing on multiple systems of knowledge to make sense of health behaviors. The acquisition and transmission of medical knowledge, through which attitudes and beliefs of professionals and the lay public are shaped and put into practice, comes as a result of the coexistence of different forms of knowing, with each fulfilling different functions and identity needs (Jovchelovitch, 1997). Moscovici (1976) introduced the idea of cognitive polyphasia, later expanded upon by Jovchelovitch (2002), to address the diversity of knowledges that can be present, “each with their own rationalities, coexisting side by side within one individual or group” (Moscovici 1976, p.122). Groups and individuals mix and match representations to act on and make sense of illness, illustrating the fragmentary nature of knowledge given its embeddedness in processes of social exchange and adaptation (Jovchelovitch & Priego-Hernandez, 2015).

Studies examining the health beliefs of Chinese communities in London for example (Jovchelovitch & Gervais, 1999), or representations of mental illness in India (Wagner et al., 2000) provide salient illustrations of how traditional and modern medical practices are understood and enacted by those equally exposed to both. The tension between biomedical and more localized explanatory models illustrates the degree to which knowledge encounters act as a mechanism through which cognitive polyphasia materializes (Arthi, 2012; de-Graft Aikins, 2005; Jovchelovitch, 2007). Knowledge encounters frequently involve a meeting between professional experts and the lay public, who contribute an expertise of their own in the form of experiential knowledge. Drawing on multiple types of knowledge becomes a useful tool to make sense of a controversial or unfamiliar health phenomenon, as evidenced in studies looking at representations of diabetes in Ghana (de-Graf Aikins, 2005), how parents made sense of the controversial MMR vaccine in the UK (Provencher, 2007), and health professionals working with the homeless and navigating multiple stakeholder positions (Renedo & Jovchelovitch, 2007).

The merging of knowledge systems is not always a straightforward, beneficial process however. Instances where one system is imposed on another, as in battles between scientific and localized understandings of illness, knowledge from the outside is positioned as somehow superior, and local systems offer up resistance (Marglin, 1990). The social group to which one belongs is central to shaping which aspects of socially embedded knowledge are drawn upon, and provide a map on which to base perceptions and comparisons. In the case of an emerging mental disorder, such knowledge shapes understandings of what constitutes normal versus pathological behavior, as a lack of standardized diagnostic criteria could lead to third parties being more influential in shaping clinical decisions. In terms of how an object such as PBD is represented, it is the level of engagement, the communicative goals and the relationship between the individual and the group to which they belong, as parents or clinicians, that contribute to how knowledge is developed, and significantly, *which* knowledge is taken on board (Jovchelovitch & Priego-Hernandez, 2015).

Diagnosing mental illness is complex, relying as it does on an interpretation of external behaviour to provide insight into internal states. When it comes to the realm of children's mental illness, such practices become even more complicated, given the clinical propensity to rely on third party verbal reports when making a diagnosis (Healy, 2008). Differing approaches over how to diagnose PBD are the clearest indication that the disorder remains unstable in its definition. Genetic and neurochemical explanations (Pavuluri et al., 2005), a lack of similarity of the episodic nature of childhood bipolar as is found in adult BPD (Faedda et al., 2004), trauma, attachment and other psychosocial factors (Parry & Levin, 2012) and PBD as an early manifestation of what is seen in adults (Post, 2009) are all in contention when it comes to how best to approach the diagnosis. Whether PBD exists as something previously overlooked, or represents a paradigm shift among mental health professionals, it remains caught in a net of contestation, debate, controversy, and vague diagnostic criteria. Clinicians are thus in a position to fend for themselves in terms of how exactly to define the disorder, leading to multiple interpretations and positioning the diagnosis as in need of continued negotiation. Shifting definitions and competing understandings contribute to a sense of a diagnosis in-flux, opening up space for clinicians and parents to rely on information that makes the most sense of their own experience in particular contexts.

## **The role of social influence**

The construction of diagnosis stems from social and psychological processes dependent on the nature of the encounter between multiple stakeholders, in which polyphasic thinking becomes a sense-making tool. Given the importance of interaction in the development of thinking around diagnosis, the role of social influence presents an interesting lens through which to examine how individuals and groups hold, and draw on, often competing forms of knowledge. The modalities outlined by Sammut and Bauer (2011) in their cycle of normativity present a useful conceptualisation on which to explore the links between the two processes. Focussing on the establishment of a frame of reference via the accommodation and assimilation of new knowledge, this cycle of normativity illustrates myriad perspectives and pertinent ideas leading to normalization (Sammut & Bauer, 2011). The link with cognitive polyphasia is brought out here in the sense that these influence processes exist in a feedback loop of sorts. Polyphasic thinking results from the accommodation of often competing forms of knowledge, but the degree to which one form is privileged over another is context dependent.

Conflict and contestation are necessary conditions of influence, creating uncertainty and ambiguity and leading to the second function of consensus, self-affirmation through making one's private reality public (Moscovici 1976, p.152). This need for what Festinger (1954) refers to as 'subjective validity', becomes a driver shaping understandings of PBD in that the need for validation that one's opinions are correct and in line with prevailing norms of the group are central for gaining the consensus needed to push wider acceptance of more controversial diagnostic categories (Roberts, 2016). Consensus is a central consideration of this paper. A lack of consensus surrounding what bipolar disorder in children should look like shapes how clinical representations and parental understandings of PBD are formed and opens up space for subjective doubt. Top-down and bottom-up pressures from peers, professional colleagues, and institutions create multiple "socially endorsed realities" (Moscovici, 1976) that clinicians and parents must then make sense of and choose from. The space for doubt and openness to the assimilation of other types of knowledge are central to debates surrounding children's mental illness, and the shifting normative frames of reference surrounding what a 'normal' child should look like.

The establishment of socially normative reference points is especially important with regards to children's mental illness, where the alignment of 'badness' with pathology has

been in place for decades (Singh, 2007; Timimi, 2005). Suggestions of norms for how children should conduct themselves have led to points of reference against which the medicalization of children takes shape, requiring medication for anything that falls outside of normative boundaries. Brown (1995) suggests medicalization is no longer a top-down phenomenon, rather it comes via active collaboration between sympathetic professionals and the patients themselves, or in the case of PBD, parent as patient-by-proxy (Roberts, 2016). It is this level of collaboration, and these different forms of knowing, that drive the development of social representations, allowing as it does the exploration of different forms of knowing which move away from more traditional notions of a linear hierarchy of knowledge (Jovchelovitch, 2002). The idea of PBD as a socially elaborated product of different spheres of expertise coming together is fundamental to exploring how unfamiliar information is made familiar, and the role uncertainty plays in opening up space for influence.

## **METHODS**

### **Context**

Mental health conditions are consistently found to be the largest expenditure for children's health in the United States (Express Scripts, 2014). Such a statistic that is fostered by a consumer-driven system in which the influence of insurance companies determines access, and a code from the Diagnostic and Statistical Manual of Mental Disorders (DSM) is required for diagnosis. Pharmaceutical options for treatment then become privileged over costlier "talk therapies". Questions surrounding broader institutional practices leading to increased medicalization provides the backdrop out of which PBD emerged and continues to be contested even as the diagnosis continues to become more common. A combination of government programs such as Medicare and Medicaid and for-profit private insurance programs provide health coverage for approximately 260 million Americans, with about 49 million remaining uninsured (Sillup & Makowska 2013, p. 6). The majority of Americans are privately insured (195 million) with the majority of that population covered through their employers (*ibid.*). The system thus provides a built in sense of expectation on behalf of consumers (in this case, parents) that they are entitled to get what they pay for. The degree to which this is accommodated by clinical professionals is one focus of this study.



## Materials and Procedure

Semi structured interviews were conducted with 8 mental health practitioners (child and adolescent psychiatrists involved in clinical practice as well as research, and one psychiatric nurse) sampled from both private and public health services. The sample comes from university clinics and community hospitals four urban areas on the East Coast (n=4) and in the Midwest (n=4). All clinicians, including those who were affiliated with research, were practitioners involved in the daily assessment and treatment of children with behavioural disorders. Parents were recruited from both rural and urban areas via an organization devoted to paediatric bipolar disorder called The Balanced Mind Foundation, based in Chicago, Illinois. 15 parents agreed to participate and telephone and Skype interviews were arranged. The sample was constructed in order to access perspectives of those working with or raising children with PBD in order to enable specific questions to be answered related to the development of knowledge around the diagnosis. It provided a set of clinical and parental voices on PBD, allowing for a comparison of how these different groups contribute to the construction of the condition, illustrating socio-psychological mechanisms at play in the construction of diagnosis. The interview protocol incorporated questions at several levels: (i) descriptions and current understandings of PBD, (ii) sources of knowledge about the disorder and (iii) personal positioning and feelings about diagnostic/parenting practice in light of the diagnosis. All interviews were conducted from 2013 to 2014 by the author, and transcribed verbatim.

## Analysis

The findings below present combined themes which came out of a first order thematic analysis (Braun & Clark, 2006) in order to see *what* was being said, followed by a second order dialogical analysis (Gillespie & Cornish, 2010) to access significant ‘others’ coming up in discussion, and what that suggested about interactive processes shaping not only conceptions of PBD, but diagnostic practice as well. By focusing on who is coming up in clinical and parental discussion, and how this ‘other’ is being referenced, one can begin to get a sense of myriad alliances and discursive positions present in what is being said, thus allowing social psychological processes to be uncovered. This also provided a means of exploring interaction in lieu of focus groups, which was not possible to geographical distance for parents and scheduling difficulties for time-poor clinicians. Codes related to ‘self’ and

‘other’ encompassed subcategories indicating who these significant others were, and what was being said about these significant others in relation to knowledge and understanding of PBD.

## AMERICAN CLINICIANS ON PBD

### Uncertainty and a realignment of thinking

A central theme in discussion with clinicians concerns the lack of consensus surrounding diagnostic criteria, in which various clinicians are looking at the same behaviour and calling it different things. Uncertainty over what behaviours *should* be seen thus leads many to realign clinical interpretation of what *is* being seen:

I will tell you that between the time I was training in 1991 and 1995 [*when early research on PBD first came to light*] there was not a dramatic increase in our clinic. It was that I saw what was in front of me in a different way. The same children were right in front of us, but when you started to say, ‘well could this be a diagnosis of mania? Why did I never call it mania before?’” Because I was told that children don’t get mania, so I’d read the same symptoms through a different lens. (USC7)

The need for validation of opinions comes as a result of ambiguity, thus clinicians refer to their social reality for orientation. This idea of choosing to see something in a different way, and the conclusions drawn as a result in this shift in thinking, is driven by the influence of professional colleagues, as well as top down institutional pressures (as from the pharmaceutical and insurance industries) and bottom up pressures from anxious parents.

Why do I put a kid in the hospital? Well, if I’m going to justify it to an insurance company, I get, it’s easy to get the insurance to cover bipolar disorder. It’s easy to get treatment authorized for BPD....sometimes it puts me in ethical dilemmas where a government agency is requiring me to do one treatment like a stimulant, which I feel is going to be worse for the patient, and I’ll lose sleep over that. Should I fight the system? Fight the bureaucracy to do what’s right, or just go along with it, and it puts me in a difficult position. (USC5)

The speaker above is confronted with pressures from superiors who maintain significant influence over diagnostic practice. Despite the fact that knowledge drawn from this professional's daily experience directly contradicts the suggestions being made, such pressures sway clinical thinking. The clinician here comes around to the institutional preference, however it is not without discomfort stemming from acting against his own subjective position.

Clinicians interviewed held representations of PBD as something more chronic and treatable than traditional notions of bipolar as manic-depressive psychosis. It is seen as a condition that has been previously overlooked, thus the increase in diagnosis comes as a result of a more fine-tuned clinical expertise, and knowledge of what behaviors to look out for:

I: How can you be certain that when you do give the diagnosis of PBD that that's what it is?

R: Oh it's a matter of going with your diagnostic skill. Years and years of experience. Scores and thousands of children over the years that have come through our threshold, and so we could tell them from a mile, which spectrum where they are, because that's something that you develop very well over time, but if you're not used to that, it's very hard. (USC4)

Here the recognition of behaviors as pathological is calibrated by the clinician's own well-developed proficiency in diagnosing. The certainty present in the speaker above indicates a sense of no question over what children with PBD look like. If that differs from what other experts see, then a lack of experience must be the culprit. Diagnoses such as schizophrenia, childhood depression, and ADHD don't always elicit the same discussion surrounding the need for a well-trained eye to make the call, however PBD is unique here as a diagnosis which clinicians continue to make sense of, with trust in their own expertise providing a grounding on which to form further opinion.

Borne out of this conviction is the perpetuation of early diagnosis and treatment as an effective way to mitigate the future social and neurological impact for children deemed 'at risk'. The notion of PBD as a potential 'future risk' was mentioned by all clinicians interviewed, perhaps as a means to justify treatment practices many found themselves

uncomfortable with. Treating the risk of a child developing PBD (and all future social and economic upheaval that would come as a result) was often discussed as beneficial even if there were no actual symptoms present, and the child in question was a very young, pre-school aged child. As one clinician explained:

Parents will sometimes say to me “isn’t it better for us to not get any treatment for as long as possible?” ...and it’s the unknown side effects which scare people, and scare me too. And I would say, I’m scared of the unknown side effects, and I’m also scared of giving medicines to someone who didn’t really need them and then gets side effects, perhaps unnecessarily. But we have to balance it out against leaving something serious untreated, which might make it worse and harder to treat later, so any disorder in medicine that you lead untreated, and unattended to tends to get worse. So, you have to say that you’re buying into that risk that the disorder might get worse, you might miss an opportunity to interrupt this difficult course earlier, and maybe save the misery later on down the road.  
(USC2)

Here there exists a perceived need to ‘catch’ something early before it does any neurobiological or social damage, emerging out of an articulation of a fear of not doing enough to help the child. PBD represents a challenge to clinical mastery, thus leading a clinician who has PBD available as an explanation to use the idea of associated risk not only as justification, but as a tool of persuasion for both parents and the wider public who may question the controversial practice of medicating such young children. Parental experience is drawn on as a way to help displace anxiety and uncertainty, as well as fear of not doing enough, or doing the wrong thing. Space is opened up for parental influence to take shape, helping to steer clinical representations.

### **A parent-driven diagnosis**

In finding themselves faced with something they are unable to understand, clinicians look to parents to shape their own clinical interpretation by defining what parents report as questionable behavior at home, and what they say they need on a clinical level.

One factor was, the factor was, parents complaining about this (USC8)

Clinicians discussed parents as being allies in the co-construction of knowledge about PBD, simultaneously representing parents as being ‘held hostage’ to their child’s diagnosis, and as an extension of this, the child themselves in which the parent was forced to “walk on eggshells”. The role of parents in the development of the diagnosis is brought to the fore in descriptions of how central their position was to the development of early clinical attention to the idea of PBD:

Now, back 12 years ago, I think a large part of the evolution of this disorder was from a clinical standpoint we were struggling with ‘what do we call it?’ but what we heard from parents was that oftentimes they were almost like the victims of an illness that didn’t have a name... If the parents are so beaten up and worn down and trounced upon and have no energy to really interface with a highly intense kid, it doesn’t matter what you do with the kid. I mean, you can help with their intensity, but their parent still needs some skills. (USC3)

It is in the discussion of the centrality of parents that the position of clinicians in a dyad with the parent becomes clearer, with the child at the center of it all rendered almost peripheral in discussion. Perhaps owing to the murkiness of PBD, the position of parents as victim takes shape, allowing their knowledge to be drawn on by professionals in a way that both advances rationale for applying the diagnosis, and removes some responsibility from the clinician through alignment with a parent’s direct experience. Collaboration and negotiation between these two groups thus prove beneficial, where parents see the legitimation of what they have been seeing in the establishment of a diagnosis that makes sense to them, while clinicians find something to grasp in parental experience, and upon which they justify the establishment of diagnostic practice, clinics and research groups. Thus, parental need and demand presents an acceptable explanation for clinicians to explain increased diagnostic rates and influence colleagues who may remain skeptical, rather than something suggesting vested interest or career advancement:

The research community was very skeptical. Some of the clinicians were too. And the parents were immediately on the bandwagon. “finally you’re describing my child. This is what I’ve been experiencing. I’ve been trying

to tell the doctor for years.”... And in fact you see these moms who either had bipolar themselves or in their families were often the best reporters, because they were knowing what to look for and were able to describe it in ways that I thought were especially articulate and insightful. So parents were immediately big fans, and believers, and relieved. And then I watched researchers get on board. (USC7)

The desire to establish a refined and discreet diagnosis and find a diagnostic home for children who no one knew how to label or what to do with is deemed necessary to create certainty in place of the discomfort that comes with ambiguity. A realm of expertise is created, so that the ability to ‘see’ PBD in a vague mass of symptoms is represented as being an acquired skill, where awareness is equated with experience. Clinicians position themselves against apprehensive and skeptical colleagues who are seen as a barrier to their own advancement and thus discredited in conversation. It is in this respect that parents become allies, albeit allies tempered by a clinicians’ sense of themselves as true experts.

Drawing on parental knowledge is an important step for clinicians seeking to gain legitimacy and face up to doubtful colleagues, however there is still a sense of wanting to maintain the distance that clinical knowledge allows here. Failure to recognize PBD is seen as risky potentially leading to a loss of esteem among colleagues, as well as a sense of one’s subjective sense of professional competence. In order to facilitate a search for what ‘should’ be seen, it becomes necessary to establish a clinical point of reference that can be drawn on as an attempted starting point. What this should look like, however, remains a source of contention among clinicians. It is from this precarious set of definitions for PBD that parents draw on to expand their own understanding of what may be going on with their child.

## **AMERICAN PARENTS ON PBD**

### **The development of experiential expertise**

The threat of blame was a central concern for parents, thus the legitimation and validation conferred by the diagnosis allowed them to find meaning in retrospective narratives of their child’s behaviour trajectory in a way that made sense. Parents aligned themselves with the experience of their child, an ‘us versus them’ positioning that provided a

new sense of purpose to confront widespread assumptions about their child and their parenting skills, as well as to educate and inform.

You get to be an expert- well, you see it in other people that may not realize that they have it, and obviously you can't go up to them and go "you know I think your kid might be bipolar" (laughs) you know, it's not really do-able. But there have been people where I have kind of shared my story a little bit and hopefully they would kind of look at it and think "huh. I wonder" (USP13)

The need to develop their own knowledge about PBD as a means to fight on behalf of their child and combat a lack of support and sense of being cast aside by clinicians, schools, and skeptical peers was a central theme to come from the data. The notion of expert knowledge is key, where parents clash with clinicians whom they feel actually negate the experiential expertise that comes from living with the child, despite findings suggesting clinicians utilize such experiences to validate their own position. Parents questioned the idea of a professional being automatically more of an expert on their child than they were, with many attitudes towards clinicians veering between disdain and disbelief over lack of awareness or professionalism. Parents mentioned desperate calls to psychiatrists going unreturned, and a tone that was often judgmental as well as dismissive:

So I went back to (psychiatrist) after he (son) had been diagnosed, and I had gone back to her because I needed to talk to somebody because I was falling apart. She actually threw her head back and laughed and said "please don't tell me that he got diagnosed Bipolar" laughing at me, and gave me a huge packet on ADHD, and I walked out the door and just fell apart. (USP2)

The move into advocacy and education was seen as a necessity stemming from an inability to acquire information from top-down sources, thus leading parents to seek other parents, online forums, and most commonly their own understanding to disseminate information on PBD and shape wider representations of what the diagnosis might look like. A lack of information and no sense of what is 'normal', combined with a sense of duty to be a good parent acknowledging the right of their child to a 'normal' childhood, ultimately leads

parents to seek control via knowledge and mastery over the diagnosis. The more they research on their own, interact with others, and challenge the judgment and opinion of professionals in the field, the more they feel that their expertise puts them in a position to educate.

### **The internalization of professional discourse and attitudes towards medicating**

For parents, developing knowledge of PBD means navigating multiple perspectives, many of which may be outwardly resisted, such as the idea of placing their child on strong antipsychotic medications. Every parent interviewed referenced the book *The Bipolar Child* as being a significant source of information in the development of their understanding of PBD. It is here that parents access a narrow scope of clinical knowledge, made all the more friendly for dissemination due to its accessibility. The knowledge about PBD perpetuated in *The Bipolar Child* suggested that the disorder is not new, nor is it uncommon. Rather, the authors suggest that PBD represents a neglected public health problem, citing research that up to one third of American children given the diagnosis of ADHD likely have PBD instead (Papolos & Papolos 2006, p. 4). The book goes on to tell parents that bipolar disorders have “probably been conserved in the human genome because it confers great energy and originality of thought” thus equating having the diagnosis with being intellectually or creatively gifted. Indeed, in speaking to American parents, each one also mentioned the gifted status of their child, suggesting that the label of the diagnosis obscured the true nature of their child, but perhaps finding comfort in the idea that the fact that the child was exhibiting certain behaviors was to be equated with heightened abilities. Thus, many children with PBD are described as:

...extremely precocious and bright-doing everything early and with gusto. They seem like they are magical children, their creativity can be astounding and the parents speak about them with real respect, sometimes even awe (Papolos & Papolos, 2006, p. 8)

The book places power in the hands of the parents, and in a sense pits them against clinicians, by presenting chapters on such topics as “How to Judge a Doctor’s Ability to Diagnose and Treat Bipolar disorder in Children”. The authors lay out a series of ten bullet points as to what parents should look for, including the need for an aggressive physician who



is not afraid to initiate treating with medications as soon as possible, as “taking too much time to give a diagnosis and initiate treatment hurts the child and the family” (Papolos & Papolos 2000, p. 60). Parents are then advised which questions to ask the physician, and which clinical responses they should take on board:

If the doctor mentions that most children who have bipolar disorder cannot be diagnosed according to current diagnostic criteria, and he or she knows that the duration of cycling is much shorter in children, and *then treats this form of the condition as bipolar anyway*, the parents should breathe a sigh of relief (Papolos & Papolos, 2006, p. 69. *Emphasis added*)

Parents are being actively encouraged to challenge clinicians who don't subscribe to the more controversial broad-spectrum approach to diagnosis advocated by the authors, instead being told to “breathe a sigh of relief” when they find someone willing to diagnose bipolar in a child despite the fact that the child may not meet traditional diagnostic criteria. It is here that the tension between the developing experiential knowledge of living with a ‘disruptive’ child and navigating the wider medical system comes up against the selective accommodation of professional knowledge.

In particular, clinical notions of PBD as a treatable risk, and the need for early intervention, resonates with parents who, like professionals, may feel that to not do anything would constitute some form of neglect, or ‘bad parenting’. For parents, the diagnosis of PBD is very much identified with the use of medication. Included in this are challenges this represents in terms of understanding their children, themselves as parents, and the wider social realities shaping how their child's behavior has come to be viewed. As one parent reflected:

The most important thing is that he gets an education, so if can't physically sit in that seat, he can't be educated, so the medicine to me, although I don't love that I have to do it either, but it's a choice you have to make...If there was no school, and he didn't need to be educated and we're just running around in the woods, you know, with animals, ok great. Be as chaotic as you want. Climb that tree. Jump off of it. Chase this, chase that, but that's not reality. Reality is, as hard as it is, they have to learn to adapt. You do have to learn how to behave in class, and if you need extra help,

and that extra help has to come from medicine, then that's what you have to do. (USP13)

The parent in the excerpt above positions themselves as at the mercy of social norms in the decision to medicate, in which the need for social adaptation is a central feature to the narrative of the child suffering from a mental illness. Societal expectation is a tool of justification: the parent would rather not medicate, but the external imposition of values is too strong. In this respect, drawing on clinical, biomedical explanations for behaviour becomes helpful. Within parental discourse there are echoes of this perspective:

Every once in a while I would think "hmmm, maybe he is over medicated, maybe he is ok" because you start to not know what's going on anymore, I mean, kids are so medicated, you start to wonder what's under there...and its kind of a reality check when you realize no, he actually can't go unmedicated. He's a sick kid. (USP12)

Again, the tension between identifying as a parent not wanting to harm the child with medication is mitigated by the adoption of the idea of the child as truly sick and unable to be without medication. A parent caught up in the anxiety over unpredictable behavior draws on, accommodates, and assimilates more widely available explanations for how to address it. Pressure to medicate comes not just from clinicians, but schools, and peers as well, leading to less of an inclination to truly believe the child is 'ok' and a sense of medication as the only option.

## **DISCUSSION AND CONCLUSIONS**

This paper has shown that when it comes to the development of knowledge around the diagnosis of PBD, psychosocial processes of social influence and the hybridization of knowledge resulting from polyphasic thinking are at play in shaping how it is understood and constructed among two key actors harboring different forms of expertise: the clinicians responsible for diagnosing and treating the children, and their parents, increasingly conversant in the realm of biomedical knowledge. As elaborated by Jovchelovitch and Priego-Hernandez (2015), new forms of knowing stem from an amalgamation of

representations generated from previously held knowledges. This can be seen in the findings presented, which suggest how the knowledge of each actor shapes the other, and interpretation of behaviors as symptoms.

Attitudes towards diagnosis and treatment are the result of the intersection of both professional and 'lay' knowledge systems. Clinical thinking, and the expertise developed around diagnostic practice, is in part influenced by parents' experiential knowledge via modalities of accommodation and assimilation, driven by the desire for validation and legitimacy. As an object, PBD is represented as something murky and unstable, clouded by uncertainty and ambiguity, yet despite this it continues to expand, encompassing an increasing number of children. The development of understanding PBD as a serious future risk in need of treatment suggests a need on the part of clinicians to justify medication practices and keep PBD firmly rooted in neurobiology. Parents are valued in helping to validate the diagnosis in the face of clinical controversy, and are seen as early shapers of knowledge in terms of identifying what they saw as a need in addressing unfamiliar behaviors they were seeing at home. It is this reconciliation of professional realities with subjective moral concerns, working in a field that counts a controversial mental illness in children as a necessary consideration, which opens up space for influence as a means to rationalize and justify current positions.

The inclusion of parental accounts and opinions surrounding a child's behavior allows a sharing of responsibility for the diagnosis. Despite collaboration among colleagues, the lack of agreement over when and how to diagnose, approaches to treatment, and what the disorder should actually even look like in children remains the reality of PBD. As long as this is the case, there is room for multiple interpretations for how the disorder should evolve. The tension present in diagnostic practice here incorporates mechanisms that allow a clinician to carry on in the face of ambiguity. Distanciation from the child is one example, in which steering discussion around the child as a cluster of symptoms, in addition to reliance on parental experience, allows for validation of what is being seen. In a sense, such modalities of social influence act as a sort of coping mechanism.

Parental knowledge of PBD, driven by a need for meaning and mastery over uncertain or questionable childhood behaviors in the face of wider social norms and expectations, is shaped by accommodation and assimilation of clinical knowledge, often filtered via less overt sources such as the *The Bipolar Child*. While discussion with American parents reveals a

conflicted view of the clinicians treating their children, their talk reflects a degree of assimilation of that thinking. This tension comes to light especially when describing attitudes towards medication, the centrality of which shapes how PBD is understood and communicated by parents. The duty and expectation of being a ‘good’ parent versus broader notions about what is best for the child reflects what is being said in wider clinical discourse, but has been shifted in such a way so as to make sense for the parent. Parents position themselves as the real experts, forging their own way when dismissed by clinicians who they feel do not truly value their knowledge. Thus, finding solidarity and purpose in advocacy groups, parents are able to take steps to end their ‘silent suffering’ through the education of peers and teachers, moving the diagnosis further towards fact.

In discussing the power of uncertainty to open up spaces for influence, Moscovici (1976) notes that the more ambiguous a “non-social stimulus situation” the more dependent one is on the social reality created through “consultation and agreement among group members on the basis of different observations they could make to support their opinions” and thus orient themselves (p. 31). Social consensus is central to the development of PBD as a diagnostic category. Consensus building in response to a new condition of childhood plays upon wider social norms of childhood; in the case of the US in the 21<sup>st</sup> century, such norms point to achievement, sociability and staying out of trouble. In establishing the idea of PBD as a new point of reference, new norms regarding what is socially (or morally) desirable are established through respectable channels: that of the expert professional.

Cognitive polyphasia is explored here with regards to understanding PBD, and can be seen as the internalized consideration of new norms still in the process of developing. Modalities of influence including the accommodation and assimilation of multiple perspectives (Sammut & Bauer, 2011) generated via knowledge encounters with the ‘other’ (Jovchelovitch, 2007) allow for PBD to be developed first as a concept, then as a category to be enacted via diagnosis. The acquisition and transmission of psychiatric knowledge then takes shape against the emerging backdrop of PBD as a previously overlooked illness, which has now been brought to light in the understanding of clinicians and parents. What has been illustrated here is the degree to which facts do not exist in any sort of established hierarchy. Instead both the clinical professional and the well-informed parent accommodate and appropriate the knowledge of the other. Which aspect of this knowledge that gets taken on board is dependent on the relevance of the object for a particular individual (Provencher, 2005; Arthi & Wagner, 2012). Thus, modalities of knowledge and influence remain fluid in

the face of constant renegotiation in which parents manage uncertainties providing a level of stability for clinicians seeking to build consensus over what PBD should look like, and clinical knowledge provides a normalizing framework within which to anchor interpretations of their child's possibly distressing behavior.

What then are the potential implications for this merging of systems when it comes to the development of knowledge around PBD? Is it always advisable to enable forms of nonmedical knowledge to shape development of medical understanding? The importance of non-professional knowledge has been advocated for decades, where the achievements linked to empowering patients via the incorporation of lay experience and understanding into policy and practice has resulted in positive steps forward, especially with regards to awareness and destigmatization campaigns around mental illness. What is needed, however, without negating the importance of user-led movements that have proved so beneficial to those living with mental illness, is space to consider any unintended consequences of these multiple pressures and anxieties coming together in a focus on the child. The confluence of these knowledge encounters enables multiple medical understandings, which may prove valuable in terms of increasing awareness of mental illness in young people, but need also be considered for their role in potentially expanding the boundaries of how pathology is attributed to a wider spectrum of childhood behaviours.

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