Comparing Case Studies: Examining Stigma Within the Family of a Child with Mental Illness

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Abstract: *We will discuss how we found evidence of courtesy stigma in a early case study and through those parental interviews, determined that siblings have an important story of their own to share. The issues surrounding courtesy stigma are that the family members of the child with an E/BD feel diminished and de-valued by the very professionals that should be providing services and support to them.*

Many people believed that with the passing of the Patient Protection and Affordable Care Act (PPACA) in 2010 that mental illnesses would be treated on parity with physical illness (Quass, 2012). However, loopholes exist due the court interpretations of a federal employment law from the 1970s (ERISA), meaning denial of services, exorbitant co-pays, limits on treatments (Boison, 2005). Even after the stronger regulations were written within the PPACA, families have had to file lawsuits against the nation's largest insurers, with the American Psychiatric Association joining in a complaint against Anthem Health Plans (Moran, 2014). Families are left confused, stressed, and searching for services that should be readily available at a time they are often most desperate.

Allowing families to have a voice and speak of their experiences is critical. Research has shown that a diagnosis of mental illness carries a stigma on the person diagnosed; their family members or close friends may carry what is termed *courtesy stigma* (Karnieli-Miller et al., 2013). In some cases, they feel this directed at them from education professionals. One mother stated, "What really made me mad were these teachers.... They were merciless, awful people, I wish that someday I could pull back and just tell them...they were horrible, so unprofessional...pointing fingers that you were the bad parent, when they said nothing about diagnosis, nothing about treatment, nothing about referrals, it was just awful, I am horrified, the way I was treated, how dare they?" (Karnieli-Miller et al., 2013, p. 257). Others share a lack of support or concern from professionals when seeking help for their child, "It was only at this crisis point that night that he came home all wet and solemn and crying that we thought, 'Who do we ask for? [help]' We phoned all different people and no one could help," (Olasoji, Maude, & McCauley, 2016, p. 223). We conducted two case studies to examine the phenomenon of courtesy stigma within the family of a child with a mental illness.

LITERATURE REVIEW

Families of children with mental health diagnoses (or as they are typically referred to in education, emotional/behavioral disorders [E/BD]) face a multitude of problems from the time the child first begins showing symptoms of a mental illness. One issue many families discover is a problem termed mental health parity. The concept behind mental health parity is to ensure equitable insurance coverage of mental illness and physical illness. The concept can also be extended to examine issues related to disparities in access to treatment and the costs associated with the care of mental illness as compared to physical illness.

Historically, insurers have limited coverage for mental health due to the perceived high costs associated with long-term psychotherapy and inpatient and/or residential treatment stays (Barry & Busch, 2007). Additionally, insurers have included higher cost sharing, deductibles, and/or had more restrictive limitations on the amount of inpatient and/or outpatient doctor visits for mental health conditions, sometimes with even greater restrictions for substance abuse treatment (Barry & Busch, 2007; Greenfield, 2005). These inequities were examined in a report by the news program *60 Minutes* in which reporter Scott Pelley stated, "When insurance companies deny the mentally ill the treatment their doctors prescribe, seriously ill people are often discharged, and can be a danger to themselves or others," (2014).

CHILDREN AND ADOLESCENTS WITH E/BD

Some data indicate that almost half of all adolescents (ages 13-18) experience a lifetime prevalence of a diagnosable mental illness, including substance abuse, with a quarter of youth exhibiting illnesses considered severe (Merikangas et al., 2010). Anywhere from half to two-thirds of these youth do not receive treatment, with treatment delays lasting into adulthood (Bailey & Davis, 2012). Reasons why children and adolescents are not receiving treatment are unclear, but may be related in part to mental health parity. Estimates vary, but children primarily receive health care funding (approximately 60%) through private health care insurance (2009 U.S. Census, in Bailey & Davis, 2012).

MENTAL HEALTH AND COURTESY STIGMA

While a diagnosis of mental illness often feels like it carries a stigma for the person diagnosed, family members or those close to them may also feel stigmatized (Goffman, 1963). These feelings of stigma experienced by those close to the individual with a mental illness were first identified by Goffman (1963) as courtesy stigma. While much of the previous research on experiences of living with mental health disorders have focused on the individuals with the diagnosed disorder or overall family functioning, the experiences of siblings and their relationships with the sibling with a mental health diagnosis has mostly been overlooked in research (Barnett & Hunter, 2011). Sin, Murrells, Spain, Norman, & Henderson (2016) examined the experiences of siblings of individuals with psychosis, and found they carried concerns unique from parents, including genetic and hereditary risk factors, as well as what they termed as "survival guilt" (p. 1248).

STUDY DESIGN/METHODS

While past studies have examined different components of the family experience when caring for a child with an emotional/behavioral disorder (E/BD), we designed our study to examine

the experience as a whole and look for the shared phenomena that families of children with E/BD experience. We also would like to determine how educators and mental health providers could better work together to serve families in a more seamless fashion.

This study is based on our findings from a case study completed with one family. The family at the time of the first interview consisted of a married mother and father, a 19-year old daughter, diagnosed with bipolar disorder, comorbid with multiple substance abuse, and a 17-year old son. The daughter was a high school graduate and the son was still in high school. The researchers analyzed the data from the first study (the mother) before determining the second study was needed. At the time of the second study, the parents were still married, the daughter was 20 years old and recently moved out of the home, and the son was 18-years old, recently graduated from high school, and still living in the home. IRB approval was gained separately for each study. Initially the second author read and coded the mother's interviews independently, searching for any ideas or issues they might suggest, no matter how varied and disparate (Ryan & Bernard, 2003). Next, a constant comparison approach was used (Denzin & Lincoln, 2003; Glesne, 2005) to determine initial themes that emerged from the first coding. She then compared and contrasted themes and decisions were made to collapse or add new themes. Findings from this analysis were shared with the first author who read through the raw data to determine whether all data was being represented through analysis. Frequently returning to the data to constantly compare and reflect allowed the authors to ensure each issue and both participants were heard and respected as we examined this phenomenon. This detailed analysis established the notion of courtesy stigma as the basis of our theoretical perspective from the perspective of the mother's interviews. The third author reviewed both interview sets to independently identify instances of courtesy stigma in both interview sets.

However, while the foreshadowed question of this study relative to a common experience of courtesy stigma was confirmed as a similar analysis of the sibling's interviews proceeded; it became increasingly clear that the actual experiences of courtesy stigma differed across family members. Comparing the results from the two studies led us to recognize that while both family members described feelings and situations that could be seen as courtesy stigma, the mother was more likely to have feelings of responsibility/blame, the sibling was more likely to have feelings of guilt and conflicts and/or secrets. For example, when discussing conflicts with school personnel, the mother stated:

> … when you've got a child who you know has a history of mental health problems and now you go into substance abuse and you try to work with schools, especially kids with substance abuse, I think the prevalent view in schools is … it's the parents fault. … 'You guys should have done a better job parenting your kid. Why didn't you teach them drugs were bad?'

Our interview with the mother yielded a conversation she shared that she had with the younger sibling, which caused us to realize that we needed to examine the sibling relationship:

> I said, look, I know how it is in Band. I said, especially around a bunch of drummers. I said, has anybody ever tried to get you to smoke pot? And he goes, all the time. He goes, and I just tell them, 'Haven't you seen my sister?' He goes I'm not about to do that. He goes, and that's all I have to tell them. 'No haven't you seen my sister?'

In analyzing our interview with the mother, when reading that comment, we decided we needed to examine the sibling relationship further, and look at courtesy stigma in that relationship. As mentioned, the evidence for courtesy stigma from the sibling appeared to manifest more as guilt and conflict, and/or secrets. For example, when recounting an explosive incident from his sister, the younger sibling said:

> So she goes storming to her room, slams her door because she's pissed at me … She's angry at me now … I'm in the living room, trying to watch tv so I just drown the tv and just get under the blanket. I'm just like why is this happening? Did I cause this?

The conflict between the close sibling relationship and the pain caused by the behaviors manifested in the E/BD and the substance abuse were clear in the interview. Our participant verbalized this emotional conflict:

> It felt like why should I care about a person that's gonna drag my life down? I mean, she's actively choosing to do these things and she just doesn't care. She doesn't care that she's ruining, she's ruining other people's lives. So like why should I care about her if she doesn't care about me? But then those thoughts are quickly shooed away. This is my sister I'm talking about. She would never try to hurt me on purpose.

That close sibling bond was further revealed as our interview closed, and we believe, demonstrates the importance of continued research into the experiences of siblings of individuals with E/BD:

> When she stopped using, she started … I was just, I was so happy. It was probably the happiest I ever was, point in my life, to see her like that. To see a person go from the horrible circumstances that she, I don't wanta say that she put herself in and just come back and to be a successful adult. It just, it really did make me happy.

DISCUSSION

While families of children with other disabilities, such as autism, often speak out and lobby for legislation and support, families of children with E/BD feel stigmatized (Corrigan & Miller, 2004; Perlick et al., 2011). As one sibling in a previous study stated, as recounted by her mother "'If David's body were hurting, people would send gifts, but because it is his mind that is hurting, they throw bricks.' And so we were thrust into the stigma/blame loop," (Ben-Dor, 2001, p. 330). This type of study is critical to allow families to recount their experiences with mental health care providers, insurance companies, and the education system. As educators, we must hear their voices to determine how we can better help families during these very difficult times in their lives and not add more stress.

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