

## Commentary: Is Coping with Stigma by Association Role-Specific for Different Family Members? A Qualitative Study with Bipolar Disorder Patients' Relatives

Sophie Favre<sup>1\*</sup>, H  l  ne Richard-Lepouriel<sup>1,2</sup>

<sup>1</sup>Mood disorder unit, Psychiatric Specialties Service, Geneva University Hospital, Geneva, Switzerland

<sup>2</sup>Department of Psychiatry, University of Geneva, Geneva, Switzerland

\*Correspondence should be addressed to Sophie Favre, sophie.favrel@hcuge.ch

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### Abstract

Mental stigma literature identifies different dimensions of stigma, including public stigma, perceived public stigma, self-stigma also referred to as internalized stigma, and stigma by association also referred to as courtesy stigma or affiliate stigma. Family members, friends, or professionals related or associated with persons living with a mental illness report experiences of stigma. Experiencing stigma by association has many consequences, such as poorer psychological well-being, distancing oneself from a stigmatized relative, poor quality of life. Our team conducted a qualitative study with family members of persons living with bipolar disorder to understand the experiences of stigma by association as described by family members themselves. Our results emphasized not only the destigmatization process but also the importance of considering the specific role of the family member. This commentary focuses on the importance of role-related experiences and stereotypes. Stigma by association addresses a complex and multi-level area in the more general stigma research field. More research is needed in this emergent field to identify specific mechanisms and impacts of family role-related stigma.

### Stigma by Association

Stigmatization refers to discrediting, devaluing, and shaming a person because of a characteristic. The main elements of stigma are labeling, stereotyping, social isolation, prejudice, rejection, ignorance, status loss, low self-esteem, low self-efficacy, marginalization, and discrimination [1]. These components as part of an explanation of why the stigma of mental illness has been described as potentially more harmful than the illness itself [2,3]. Mental stigma literature identifies different dimensions of stigma, including public stigma, perceived public stigma, self-stigma also referred to as internalized stigma, and stigma by association also referred to as courtesy stigma or affiliate stigma. Corrigan and colleagues described a progressive model of self-stigma in mental illness [4,5]. It is differentiated into four different stages that are awareness of public stigma, endorsement of public stigma, internalizing the stereotypes, and harm to self (i.e., self-esteem decrement). Stigma affects persons living

with a mental illness (PWMI) and people who are related or associated with them as well, such as family members, friends, or professionals. They can be stigmatized as well because they are, in some way, connected to someone with a stigmatized identity [6- 8]. This emergent field is guided by models of stigma similar to those including PWMI. "Associate stigma" is defined as the awareness of public stigma, while "stigma by association" is defined as the internalization of public stigma by the caregivers or family members of PWMI [9,10]. Family members reported experiences of stigma by association in different contexts, such as community gatherings, mental-health professionals, or co-workers [11,12]. Experiencing stigma by association is associated with poorer psychological well-being, distancing oneself from a stigmatized relative, poor quality of life, withdrawal from social relations [13,14], as well as burden, stress, depression, distress, and face concern [15]. Different studies also reported how disease-related characteristics, such as disease attribution or behavioral manifestations of mental illness, were shaping relatives'

experience of stigma and affiliate stigma [11,14,15]. Stigma by association can also affect the usage of health facilities by delaying or diminishing their use [16]. Stigma by association is different in families living with a person with schizophrenia, bipolar disorder, or depression. Family members of persons with schizophrenia reported a higher stigma when living with a relative with schizophrenia than when living with persons with bipolar disorder (PWBD). Family members of PWBD reported a higher stigma than relatives of persons living with depression [17]. The stigma of relatives of PWBD evolved around negative judgment, shame, and social isolation [18]. In a recent meta-analysis, Perich et al. [19] reported that family members of PWBD reported many experiences of stigma due to living with someone and/or caring for someone with bipolar disorder (BD). Moreover, the family members who reported high stigma by association also reported poorer coping.

Managing stigma does not always lead to self-stigma or stigma by association. Research with PWMI also described how some persons may be energized by the injustice of public stigma, and forcefully react to it. This paradox in self-stigma was labeled as "righteous anger" [20]. Stigma resistance was also described in PWMI and initially understood as the process of not internalizing stigma [21]. It was assessed by 5/29 items of the Stigma Resistance subscale of the Internalized Stigma of Mental Illness Scale (ISMI) [22]. Firmin et al. [23] developed a 20 items stigma resistance scale that demonstrated a 5-factor structure, namely: (1) self-other differentiation, (2) personal identity, (3) personal cognitions, (4) peer stigma resistance, and (5) public stigma resistance. Different studies indicated the importance of addressing stigma resistance in patients with mental illness [24,25]. To our knowledge, there is no data to this date with family members of PWMI or PWBD.

Our team conducted a qualitative study with family members of PWBD aiming at understanding the experiences of stigma by association as described by family members themselves [26]. The interviews were semi-structured, and the thematic analysis showed that the relatives were aware of different characteristics of the public stigma of BD, and that these were role related. Coping was therefore linked to specific components of public stigma and was described as a distinct response to the specific stigma. Our results emphasized not only the destigmatization process but also the importance of considering the specific role of the family member. This commentary will focus on the latter to enhance the importance of these results in current research on families with PWBD.

### **Public Stigma, Public Stigma Awareness, Family Roles, and Coping Responses**

The family members in our sample were either parents, spouses, or siblings. They reported different public stigma related to their role in the family. These perceived stigmas may be associated with stigma by association [27]. In our study

[26], perceived public stigma was related to responsibility for parents, the choice for partners, and duty for siblings. Corrigan and colleagues [6] summarized research that showed that the public stigma holds family members, especially parents, as responsible for the mental illness of their child. Mainly mothers were the target of the stigma and worried that people may blame them for the mental illness. The attribution of parental responsibility moved from incompetence to procreation with time. A review [28] showed that parents perceived mental illness stigma related to violations of social and cultural norms related to parenting, while children reported experiences of stigma such as bullying, embarrassment, guilt, social isolation, and efforts to conceal their parent's mental illness. These occurrences prevented both children and parents from seeking much-needed support [28]. Serchuk and colleagues [29] investigated "self-stigma" when parents internalize stereotypes about themselves as bad; and a relatively newer concept of "vicarious stigma", when parents react with sadness or anger when they observe their child living with mental health or neurodevelopmental disorders being discriminated against, and secrecy coping. They showed that higher scores on both types of stigmas were associated with more depression and lower quality of life. Coping through disclosure rather than secret was correlated with better quality of life. They invited research to better understand what it means to disclose someone else's stigmatizing experiences. In our study [26], mainly the spouses discussed not disclosing their partner's illness without his or her approval. Spouses and siblings were viewed as having greater responsibility for the status and were often blamed for not helping the relative to avoid unnecessary relapses [6]. Van der Sanden and colleagues (2015) [11] reported different manifestations of stigma by association related to being a parent or a spouse versus being a sibling or a child of a person living with mental illness. There were also other factors, such as gender and living together or not that influenced these experiences [11], or in family caregivers of PWBD, affiliate stigma correlated with lower income and lesser time spent in caregiving [30]. Children were perceived as more likely to be contaminated by their parent's illness [6]. No children were included in our sample, due to lack of availability. Theoretically, we could hypothesize that children of PWBD would have perceived the public stigma of the heredity of the illness. The coping response attached to this specific stigma may have been to prove it wrong. These stereotypes related to heredity should theoretically also be attributed to parents and siblings of PWMI as they are also first-degree relatives, meaning they also share half of their genetic information with the person living with mental illness. However, this public stigma seems to be more endorsed by children. Epigenetic studies may inform the public and contribute to diminishing the misconceptions about the role of genetic factors in the disorder, although the impact of educational anti-stigma interventions in changing public stigma in a significant and lasting way has given mixed results [31]. Public awareness of the genetic and neurobiological

origins of mental illness can produce a backlash effect generating higher levels of stigma after the educational intervention [32]. A more recent study [33] extended on how bias shapes the reproduction of stereotypes. Connecting social psychological work with medical sociological literature on mental illness stigmas, they showed how retelling stories about a person with schizophrenia alter the narrative making it more consistent with stereotypes about individuals with schizophrenia. They also found that stereotype-inconsistent information was more likely to be transformed to align with public stigma, thus pertaining to the stereotypes. In our study [26] the specific perceived public stigmas were perceived and described with a certain type of distance with the stereotypes that could be partly disputed. The stigma awareness produced different coping strategies or specific answers that were related to the family role. Parents were drawn towards acceptance, while partners felt they had to position themselves as partners of PWBD, and siblings reported functioning as mediators between PWBD and other family members, friends, or persons on the street. Another qualitative study [34] with "immediate family members" who kept regular contact with the family member who had a mental illness, presented more global results. They showed that siblings, parents, spouses, and children used either separately or simultaneously problem-focused (e.g., selective disclosure) and emotion-focused coping strategies (e.g., seeking emotional support) to cope with the negative impact of stigma by association. These strategies were also mentioned by the participants of our study and did not seem to be related to a role. A quantitative study [35] with family members of people with mental illness used a 28-item coping scale to assess 14 coping strategies. Adaptive coping was assessed by active coping, seeking emotional support, seeking instrumental support, planning, positive reframing, acceptance, and humor. Maladaptive coping was assessed by self-distraction, denial, substance use, behavioral disengagement, turning to religion, venting, and self-blame. Participants applied more frequently adaptive coping than maladaptive coping. In our study, acceptance was mentioned by different parents as a coping response to the stigma of responsibility for the child's bipolar disorder. Acceptance was also mentioned as one of the strategies adopted by family caregivers as well as mental health professionals when coping with discrimination related to their proximity with a person living with mental illness, along with rationalization, tactical ignoring, self-motivation, and religious coping [36]. In that study, acceptance by family caregivers was related to two attributions to the condition of the person living with a mental illness a natural occurrence, the condition having a natural occurrence and being long-lasting and manageable although not eliminable [36].

### Implications for Intervention and Research

Different levels of anti-stigma interventions have been described. Approaches target individual, interpersonal,

community, and structural levels [37]. From the perspective of PWMI and their caregivers, stigma reduction strategies should encompass (1) raising mental health awareness, (2) social contact, (3) advocacy by influential figures or groups, and (4) the legislation of anti-discriminatory laws [38]. In a meta-analysis, Shi and colleagues [15] argued that the relatives of PWMI could not only benefit from support groups and educational interventions but also psychotherapies.

In our study [26], the specificity of stigma to the role of the family member was described in terms of specific family roles, specific perceived stigma, specific coping strategies, and specific needs. Future interventions should consider these particularities as part of the multilevel process, by integrating these specificities as one of the focuses of their interventions. Deconstructing stigma by association should be addressed on different levels and considered in therapy.

Currently, there are much more studies focusing on self-stigma and PWMI versus stigma by association in family members, as shown in the reviews for both fields [24,58]. Moreover, there is a place for standardization. Not only is stigma by association designated by different names, but it is also measured by different scales (e.g., affiliate stigma scale (ASS) [14], Family Interview Schedule (FIS) [39]; self-stigma in relatives of people with mental health (SSRMI) [40]). Rigorous research methods are essential to validate the link between discriminatory attitudes, perceived stigma, coping and stigma reduction programs for family members. Additional studies and longitudinal designs are also recommended [15].

Other areas of research in this field could also be developed. For example, in a current review of the literature on stigma in bipolar disorder, Perich and colleagues [19] reported on how self-stigma in younger persons with BD was associated with worse medication adherence. It would be also important to understand the impact of stigma by association with different family members on medication adherence in PWBD or PWMI. The prevalence of stigma resistance in family members and its impact on the outcome of the PWMI could also be investigated. Dubreucq and colleagues [24] showed that stigma resistance was associated with better functioning in patients with serious mental illness. The potential role of stigma resistance in family members on treatment outcomes in their relatives with mental illness should be investigated. Stigma research will benefit from understanding more stigma by association in families with PWMI, as family members can both suffer and be perpetrators of stigmatizing behavior [41-43].

In short, stigma by association addresses a complex and multi-level area in the more general stigma research field. Research on stigma by association in family members of PWBD or PWMI is a relatively emergent field that yields new concepts and results. More research is needed in this field to identify specific mechanisms and impacts of family role-related stigma.

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## Conflict of Interest

The authors declare that they have no conflict of interest.

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