

## Introduction

Schizophrenia impacts approximately 20.9 million people globally of which more than 70% or 14.8 million are between the ages of 25 and 53. It is one of the top 25 leading causes of disability worldwide.<sup>1,2</sup>

Schizophrenia is a continuous, lifetime disorder most prevalent in young adults leaving family members with the responsibility of caring for the person living with schizophrenia (PLS). Symptoms of schizophrenia can be viewed as awkward and strange leading to stigmatizing stereotypes. This stigma impacts the PLS but can also extend to family, commonly known as courtesy stigma.<sup>3,4</sup>

## Background and Significance

- The prevalence of courtesy stigma is high with a range of findings from 43% to 89.3%.<sup>5,6</sup>
- Measuring the concept of stigma is difficult but what is consistent in it spans across all cultures
- Negative impact includes
  - Shame
  - Isolation
  - Alienation from the community
  - Personal Physical Health Issues
  - Personal Emotional Health Issues
  - Altered personal relationships
- These experiences have a profound effect on the family members quality of life impacting their ability to support the PLS.

## Methods

**Design:** Qualitative Systematic Review Approach

**Search Strategy:** Both Published and unpublished studies were included in the search. 1503 article abstracts were screened for relevance on the topic of stigma experiences of family members of PLS. 93 full text articles were further assessed for eligibility. 57 of those articles were further excluded due to non relevance of the phenomena being addressed.

**Sample:** Articles were assessed using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist and included for quantitative synthesis. 36 articles were included for meta-synthesis.

**Analysis:** Data was extracted using the Joanna Briggs Institute Qualitative Data Extraction Tool

## Results

36 Studies

114 Findings

17 Categories

4 Synthesized Statements

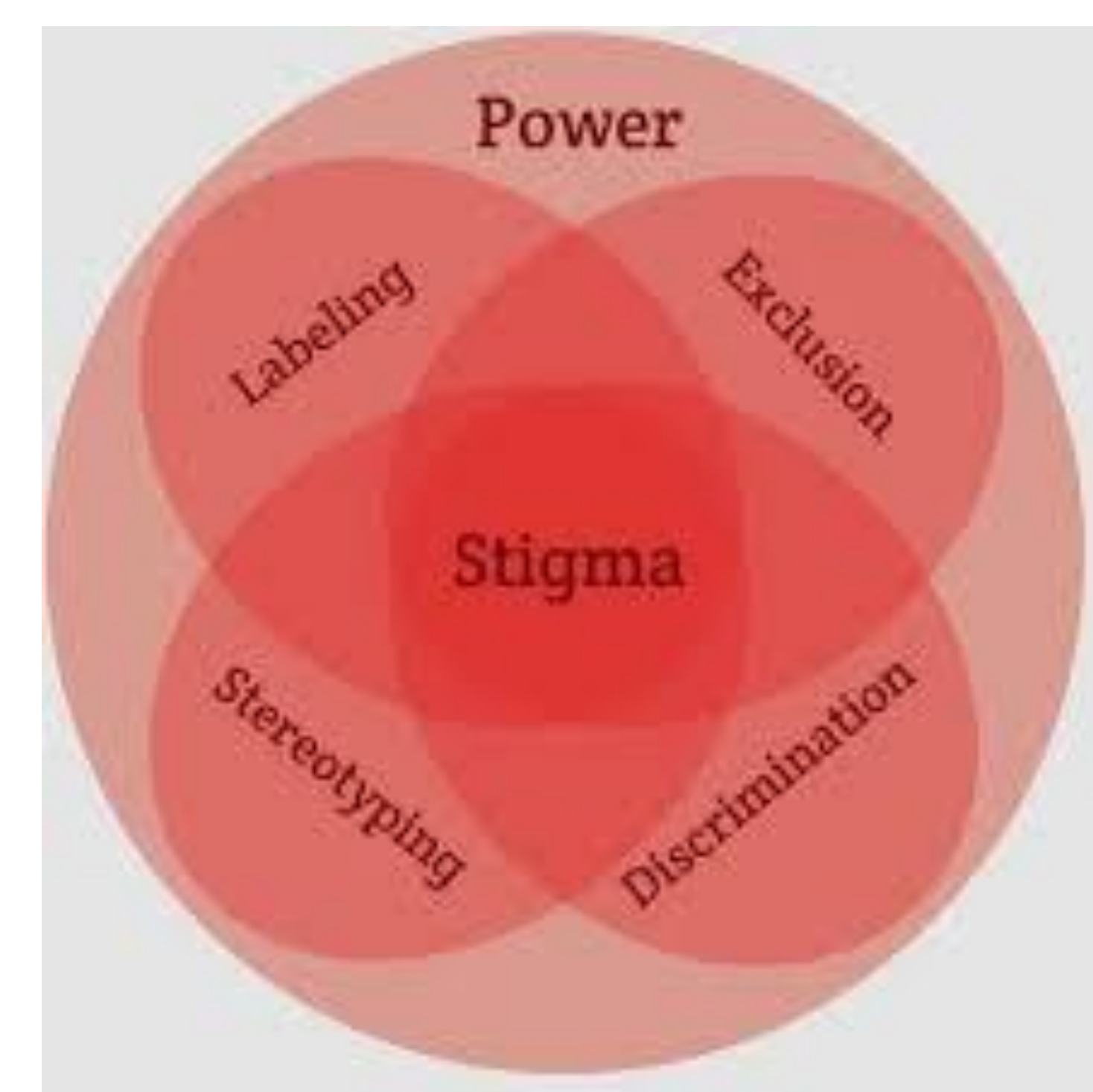
1. *Held Hostage by Stigma: Hiding the Secret*
2. *Isolated and Constrained by Stigma Imposed by Others*
3. *Family Carries the Burden with Little Support*
4. *What do I need?*

*Held hostage by stigma: Hiding the Secret reflected several stigma components: 1) Anticipated Stigma, 2) Label Avoidance 3) Self-Stigma.*

*Isolated and Constrained by Stigma Imposed by Others described the actual and perceived experience of public stigma imposed by the outside world.*

*Family Carries the Burden with Little Support addresses structural discrimination from government and healthcare.*

*What do I need provides insight into family members suggestions on what facilitated personal coping and what would be helpful in reducing stigma.*



## Illustrations

“For I haven’t told anyone (the schizophrenia) ... They’ll definitely feel sorry and they’ll definitely keep their children away. We didn’t tell my sister’s family for a while in case they might hurt us or treat us differently.”<sup>7(p.500)</sup>

“There were no cases where someone would devalue us face to face, but I know they must be talking about us behind our backs.”<sup>8(p.206)</sup>

“The first few years I was ashamed of having a son who was mentally ill”<sup>62(p.20)</sup> “It is a bad mark for the whole family...So, I do not tell anyone.”<sup>9(p.759)</sup>

A mother of a young woman with schizophrenia avoided seeking treatment for her daughter stating: “In the back of my mind I was worrying that if I took her in [for care], that whoever I took her to would think I was crazy, so I took her home and we tried to watch her.”<sup>10(p.79)</sup>

One relative noted, “most of my relatives withdrew, one after the other stayed away. Only a few ask about my son’s condition.”<sup>71</sup> No one wants to be our friend...I have no friends to talk to. I have to do everything by myself...no one cares about your pain.”<sup>11(p.283)</sup>

“The first doctor who saw my son really was judgmental...“she even went so far as to say that he was jail-bait... and that my son’s illness is my own fault”<sup>12(p.20)</sup>

Relatives complain that professionals exclude them from the treatment process and reject co-operation from the family—they are “pushed to the back seat and are not considered part of the team”<sup>13(p.10)</sup>

I ask God, how long can I handle all of this? The only thing I can say keeps me sane is my faith in God”.<sup>14(p.456)</sup>

## Discussion

The review examined the experience of associative or courtesy stigma. Although intertwined, the first three metasynthesis statements predominantly capture the different stigma experiences family faced and the last synthesis describes approaches the family used to cope with this stigma.

The major implications of this review are that the experiences of courtesy stigma are universal. The pain felt is real and can leave family members feeling isolated, helpless, and alone. Even in the absence of direct stigmatizing experiences, family members internalized feelings of blame, guilt, and shame due to the societal view and beliefs about schizophrenia. Not only were the societal views a factor but many family members felt devalued and unsupported by the healthcare system and other governmental agencies such as law enforcement; the very people who are tasked with providing support. Strategies used by family members included self-isolating, relying on prayer and faith, and talking to those who they felt were supportive. Stigma prevention education must be brought to the healthcare systems and the public in order to fully support the family member in caring for themselves their loved one.

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