Experiences of stigma and psychological well being among adult children of parents with schizophrenia

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ABSTRACT

Background: Children of parents with schizophrenia are reported to be vulnerable to various kinds of psychological and psychosocial problems. Stigma is one of the significant psychosocial impacts often studied in patients with schizophrenia. However the experiences of stigma and psychological well being of the healthy adult children of the parents with schizophrenia is less explored.

Aims: To study the perceived stigma and psychological well being of the adult children of parents having schizophrenia and to assess the relationship between perceived stigma and psychological well being.

Methods: The study adopted a two group comparison cross sectional methodology. The study group comprised of 30 adult children of parents with schizophrenia and control group consisted of 30 individuals without the history of any mental illness in the parents. The tools used were Sociodemographic Data Sheet (SDS), the stigma items of Explanatory Model Interview Catalogue (EMIC) and Psychological Well Being scale (PWB).

Results: More than 50% of the participants in study group experienced stigma. Perceived stigma was positively correlated with current psychopathology of the parents. Active psychopathology in parents turned out to be a significant predictor of the stigma. The control group had better psychological well being compared to the study group.

Conclusion: Even in the absence of any diagnosable psychological problems, children of patients with schizophrenia experience stigma and they have poor psychological well being compared to children of parents without psychiatric illness.

Key words: Stigma, psychological well being, adult children of parents with schizophrenia

INTRODUCTION

Adverse psychosocial outcomes for children of parents with mental illness are well established in the literature. [1-3] Some of the stressful experiences specific to children of parents with mental illness recorded across the studies include intermittent or permanent separation (resulting from parental hospital admissions or the child’s receipt into care); [4] frequent changes in residence/school, interrupted or unsatisfactory education and occupational planning, poverty, having to take care giving role early on, and reduction of social and leisure activities. [5] With respect to family organization, there is disruption and disorganization in the family unit, marital conflict, lack of communication with parents, lack of emotional support from parents as well as significant others. [6-8] As care givers, most of the children had to take on increased responsibilities (parenting the parent or younger children in the family), seek out help for the parent, resulting in mixed feelings of love and anger. [9,10] They also had to face losses by means of suicide or early death of a parent; experience of social stigma, and consequent to these experiences, developed low self esteem, health problems, fear, anxiety, guilt and depression; social alienation and isolation and difficulty in intimate relationships as adults. [11-13] In a few of the quantitative studies, investigators have reported that compared with controls, adult offsprings had elevated work and marriage problems, lower overall functioning; more social avoidance and lower self-esteem, [14,15] poor social adjustment, and increased levels of drinking alcohol. [16] However, the relationship between the age of the children and the adverse/harmful impact of parental illness is unclear. [3]

The literature is largely skewed towards children and adolescents in comparison to adult children. In one of the important qualitative studies conducted with adolescent children of parents with schizophrenia, Chan and Heidi [9] found four common themes 1) stigma and discrimination 2) mixed feelings of love and anger 3) the role of being a carer and 4) positive gains. In a similar vein interviews regarding everyday situation in adolescents has revealed themes of need for conversation, love for their family, maturity, experience of fear and blame, feelings of loneliness, responsibility and associated stigma. [17] Similar study conducted on adult children, resulted in 4 themes: (1) Being uncertain about the future hardships (2) Struggling to connect with the parent (3) Being responsible and (4) Seeking balance of the situation.
Being an adult child of a parent with serious mental illness can involve a chaotic family life where adult children assume substantial care giving roles. In the process of care giving, many of the adult children could not establish their own vocational or educational goals or get into committed relationships. The findings are supported in a more recent study where in 157 women with serious mental illness reported that 80% their adult children (18-30) were working or in training, and about one-third had not completed their high school.

Link and Phelan define stigma as the resultant of co-occurrence of several components including labelling, stereotyping, separation, status loss, and discrimination. Experience of stigma reported by children or significant others in the family of a person with mental illness is termed as “associative stigma”, as they are considered contaminated by association with the person. While there is some research looking into the stigma experiences of the parents with mental illness and its impact on help seeking and parenting, not much information is available on the experiences of stigma in adult children. There is severe lack of information on the number of children with parents having severe mental illnesses, as well as the kinds of problems they face, across the countries, not limited to developing countries like India.

Studies on factors affecting stigma experiences and responses to handle stigma reveal the following: psychiatric labels like psychiatric hospitalization and psychiatric diagnosis and family factors such as relationship with the patient and gender elicit stigmatizing responses. The pattern of reactions and coping among the relatives of the patients with stigma is that of aggressive concealment, avoidance of relatives, and moving away to different part of the town. Concealment was more if the relative was a female, symptomatic and if the relative did not live with them. In support of the above a study from India found that socially unacceptable behaviour produced by hallucinations and delusions during the acute phase of schizophrenia was most responsible for the experience of stigma.

Stigma is not found to be affected by the social class. The most cited impact of stigma was damage to self esteem, difficulty in maintaining relationships, finding a job, increased risk of emotional disturbances, poor well being and poor quality of life in significant others. These adult children had little informal support and professionals did not address their needs. Ng and Wolf et al. opine that the Indian findings are similar to West; however, there is a great deal of misconception, superstition and ignorance among people. In agreement with this, a recent study concludes that often stigmatization was a direct resultant of lack of knowledge about the causation, transmission and remedies available for mental illness. A qualitative study by Herbert et al. exploring the experiences growing up with parent with schizophrenia in adult offspring’s reported that about 9% of the sample reported stigma as one of the vividly remembered experience. The stigmatizing experiences reported were experience of embarrassment in the public places, others making fun of them, and fear that others would think of them as having mental illness.

In the background of limited information on the stigma experiences of the adult children of parents with schizophrenia, the current study aims to elaborate on the stigma experiences and psychological well being of the adult children living with a parent having mental illness.

Aims and Objectives:
The objectives of the study are to study the perceived stigma and psychological well being among adult children of parents with schizophrenia and also to examine the relationship between psychological well being and perceived stigma.

MATERIALS AND METHODS
Sample: The sample consisted of 30 individuals in the study group selected from inpatient and outpatient departments of NIMHANS, Bangalore, India and 30 in the control group selected using snow ball technique from the community. Inclusion criteria for the study group included having one parent diagnosed with schizophrenia (ICD-10, F 20.0-20.9) with the duration of at least 2 years; children above 18 years, unmarried, currently living with the parent and with minimum education of VII standard. Children with history of psychiatric consultation and parents having other chronic medical conditions were excluded. The inclusion and exclusion criteria for control group were same as the study group, except for the criteria that parents should not have history of mental illness.

Measures:

Socio-demographic data sheet: The data sheet was developed for the present study to collect demographic details of the adult children as well as illness details of the parents.

Psychological Well Being scale (PWB): The scale developed by Bhogle and Jaiprakash has 28 items representing 13 factors. First 12 factors have two items each and last factor has four items. The questions are answered in yes or no format. The scores range from 0-28, higher scores indicating better psychological well being. The psychometric properties are established for the scale. Test-retest reliability is 0.71, split half co-efficient is 0.91, and alpha co-efficient is 0.84 (internal consistency).

The stigma scale: The scale developed by Raguram, Weiss and Channabasavanna consists of stigma related queries from the explanatory model interview catalogue (EMIC). A section of the EMIC examines issues directly related to stigma. The questions cover concerns about disclosure, diminished self esteem, concerns about social rejection, etc. There are 13 items which obtain perceptions of stigma. The items are scored on 0-3 scale. Maximum possible score is 39, higher scores indicate greater stigma. Inter rater reliability
has been established with a kappa co-efficient of 0.748 indicating high reliability and Cronbach’s alpha value is 0.71 indicating internal consistency of the items.

Procedure
Participants fulfilling inclusion and exclusion criteria and consenting for study were interviewed for collecting demographic details, the stigma experiences and psychological well being. First born children were preferred when there was more than one adult child. The control group was matched for age, gender and ordinal position with the study group, they were interviewed for demographic details and psychological well being scale was administered. The protocol was reviewed by the review committee of the department of clinical psychology, NIMHANS, Bangalore, India and suggestions were incorporated. The data was analysed using descriptive statistics such as mean, standard deviation, and percentages. Inferential statistics such as ‘t’ test and chi-square test were used to compare the groups on psychological well being and demographic data and Cronbach’s alpha was determined to establish the internal consistency of the items of the EMIC.

RESULTS:
Majority were male children in both the groups (70%). The groups were comparable with respect to age (mean age of group 1 = 20.53; group 2 = 20.70 yrs; t=1.12, p<0.027) and gender distribution (21 males and 9 females each in both the groups), type of family (nuclear family) and ordinal position (46% of study group and 36% of the control group were first born). The control group was better educated (t=3.85, p<0.001), however more number of study group participants were employed (group 1 = 16 and group 2 = 3; ÷2=13.01; p<0.001), however more number of study group participants were employed (group 1 = 16 and group 2 = 3; ÷2=13.01; p<0.001). About 76% of the parents of the study group were females with history of chronic mental illness (average duration is 11.67 years), among them 60% were symptomatic at the time of study. Mean age of the children at the onset of illness was 10.60 years with 46.6% participants below 10 years of age and 53% above 10 years of age.

Table 1 shows that the mostly endorsed items on the interview were concealment (63%), loss of face (73%), people thinking less of them (60%), others refusing to visit them, fear of disclosure, difficulty for themselves to get married (56.6%) and other relatives to get married (56.6%). The value of Cronbach’s alpha was 0.74 indicating that the items are internally consistent.

Table 2 gives the stigma and psychological well being in relation to the demographic characteristics of the adult children and illness variables of parents. Children of symptomatic parents experienced significantly more stigma than children of symptom free parents (t=2.79, p<0.001). However there was no difference in well being in relation to symptoms of the parents. The control group had significantly better psychological well-being (mean=21.53±4.27) than study group (mean = 16.50±5.97; t=3.75, p<0.001).

Duration of illness of the parent was not related to either psychological well being (r=0.02) or stigma (r=0.07). Similarly, psychological well being and stigma were not related (r=-0.19).

Current status of the parental psychopathology predicted stigma perceived and accounted for 22% of variance (R²= 0.217).

Table 1: Distribution of scores on the stigma scale (EMIC)*

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Items on EMIC</th>
<th>No Number (%)</th>
<th>Uncertain Number (%)</th>
<th>Possibly Number (%)</th>
<th>Yes Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Concealment</td>
<td>6 (20)</td>
<td>1 (3.3)</td>
<td>4 (13.3)</td>
<td>19 (63)</td>
</tr>
<tr>
<td>2.</td>
<td>Low self esteem</td>
<td>17 (56.6)</td>
<td>0 (0)</td>
<td>2 (6.6)</td>
<td>11 (37)</td>
</tr>
<tr>
<td>3.</td>
<td>Loss of face</td>
<td>8 (26.6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>22 (73)</td>
</tr>
<tr>
<td>4.</td>
<td>Disrespect</td>
<td>10 (33)</td>
<td>2 (6.6)</td>
<td>6 (20)</td>
<td>12 (40)</td>
</tr>
<tr>
<td>5.</td>
<td>Adverse effect on others</td>
<td>25 (83)</td>
<td>1 (3.3)</td>
<td>1 (3.3)</td>
<td>3 (10)</td>
</tr>
<tr>
<td>6.</td>
<td>Avoidance by others</td>
<td>17 (56.6)</td>
<td>0 (0)</td>
<td>1 (3.3)</td>
<td>12 (40)</td>
</tr>
<tr>
<td>7.</td>
<td>Others might refuse to visit</td>
<td>10 (33)</td>
<td>0 (0)</td>
<td>3 (10)</td>
<td>17 (56.6)</td>
</tr>
<tr>
<td>8.</td>
<td>People thought less of them</td>
<td>7 (23)</td>
<td>4 (13)</td>
<td>1 (3.3)</td>
<td>18 (60)</td>
</tr>
<tr>
<td>9.</td>
<td>Problem for the family</td>
<td>10 (33)</td>
<td>2 (6.6)</td>
<td>4 (13)</td>
<td>14 (46.6)</td>
</tr>
<tr>
<td>10.</td>
<td>Fear of disclosure</td>
<td>8 (26.6)</td>
<td>4 (13)</td>
<td>2 (6.6)</td>
<td>16 (53)</td>
</tr>
<tr>
<td>11.</td>
<td>Difficulty in getting married</td>
<td>10 (33)</td>
<td>0 (0)</td>
<td>3 (10)</td>
<td>17 (56.6)</td>
</tr>
<tr>
<td>12.</td>
<td>Problem for the family</td>
<td>16 (53)</td>
<td>5 (16.6)</td>
<td>4 (13)</td>
<td>5 (16.6)</td>
</tr>
<tr>
<td>13.</td>
<td>Problems for relatives to marry</td>
<td>7 (23)</td>
<td>0 (0)</td>
<td>5 (16.6)</td>
<td>17 (56.6)</td>
</tr>
</tbody>
</table>

*Explanatory model interview catalogue (EMIC)

DISCUSSION:
The sample consisted of more male children, the reason being that most often they accompanied their sick mothers to the hospital or came as proxy to collect medicines for their mothers and thus got into the study. The findings reflect on the prevailing socio cultural practices with respect to visiting hospital: often men accompany the female patients. [37] Adult children in the study group were less educated but more number of them were employed. The findings imply that perhaps many children with parents having mental illness have had to give up their education and get into employment to support the family. [5,10, 20] One of the reasons for this as reported by the adult children was that, since there was marital discord and substance abuse in the family, these children had to discontinue education at young age and had to take up low profile jobs. The findings seem to indicate that mental illness in the family may contribute to the family pathology and unhelpful coping patterns in the family. [37] The fact that most of the parents had chronic illness indicates that the children were witnessing and experiencing the similar environment for most of their growing up years.

The stigma experiences as presented in table 1 shows that concealment was used by more than half of the sample; the account of reasons given by them included fear of being called as a son of mad person, fear of losing friends as they would think that it is heritable and consider him/her different, fear of as a son of mad person, fear of losing friends as they would think that it is heritable and consider him/her different, fear of others making fun of the parent as well as the family, and
fact that both positive and negative symptoms were
experience of shame and loss of face. The studies support the
behaviour towards friends and relatives. The findings indicate
noticing the parent's abnormal behaviour and aggressive
inappropriate behaviour in the functions; people on the roads
with the neighbour, shouting and creating a scene,
was because of the reasons such as the parent quarrelling
reported loss of face and sense of shame (3/4ths, item 3) which
findings are consistently supported by several studies
with doctors and a close friend who can understand. The
and misguiding them. However, they were willing to share
reasons admitted were: trouble created by the parent,
agreement (83%) agreed that it did not have adverse impact on others
(item 5) as they felt that it is not contagious. They also agreed
stigma experiences were more. In addition the unpredictable
environment at home contributed to apprehension of others
getting to know, thus children avoided bringing the friends home. [12]
Nearly half of the sample reported that others would
think less of them (item 4), the reasons given were similar to the
reasons for concealment. The children believed that others
looked down upon them because they suspected that it is a
heritable illness. The finding can be understood as a direct
result of lack of knowledge and beliefs about causation,
transmission and treatment. [16] However, most of the sample
(83%) agreed that it did not have adverse impact on others
(item 5) as they felt that it is not contagious. They also agreed
that relatives and others avoided them (40%; item 6), the
reasons admitted were: trouble created by the parent,
apprehension that they may have to help, and belief that they
were less in some ways. However, it is possible that the
avoidance by others is reduced because of the concealment
and not revealing the problem.

About half the sample reported that people refused to visit
their family (item 7) mainly because of the trouble created as a
result of the positive symptoms of the parent. Other studies
support the fact that the initial symptomatic phase leads to
weeding out of friends resulting in a small circle of social
network that is stable. [20] The children also reported that the
family had to go through a number of problems (46%; item
9) because of the illness in the parent which majorly included,
not able to continue education, inability of the parent to take
care of the younger siblings and as a result they have to stay
in others house, not having friends and relatives, and others
not wanting to make any relationship. In a similar study
Williams (1998) [8] reported that the daughters of the mothers
with mental illness reported lack of extended family support,
ongoing stigma and isolation and also having had to assume
responsibilities and give up on their educational, vocational
goals. [18, 19] Similarly about half of them expressed concern
about disclosure (item 10) as they felt that they would treat
the parent differently and think less of the family.

About the concern on getting married (item 11) more than
half of the sample felt that marriage will be difficult because
people will be scared of getting mental illness both in the
adult child and their future children and also the fact that
nobody would take the responsibility of arranging their
marriage. The problem seems to be unique to the country as
most of the marriages are arranged by the families and that
parents play a very important role in that. More than half of the
sample was willing to reveal the information to their
prospective partners so that there will not be conflicts on the
issue later. It is interesting to note that more than half of the
sample felt that their relatives also may face problems in
getting married (item 13). Another interesting finding is that
most of the male children (which constituted majority in the
current study) felt that their sisters will have more difficulty
in getting married (item 13). Another interesting finding is that
most of the male children (which constituted majority in the
current study) felt that their sisters will have more difficulty
in getting married as heritability will be more from mother to
daughter and since they have to go in the other family they
will not take the daughter of a mentally ill person. Thus it is
evident from the findings that the stigma experiences of the
adult children were significant and some of the experiences
were culture specific as well.

The relationship between the illness related variables and
demographic details of the children (table 2) shows that stigma
was perceived more when the parents were symptomatic since
it was difficult to conceal. It is clearly established in the
literature that the symptomatic behaviour, the severity and
number of symptoms would clearly increase the fear of stigma
in family members. [23] This may be because as the severity
increases it makes it more difficult for the relatives to conceal,
thus increasing the chances of being stigmatized. There was
no significant relationship between stigma and psychological
well being although they had low well being and experienced
stigma, indicating that low well being may be related to other
stressors.
The duration of illness was not related to psychological well being which is contrary to the findings of other studies which report a negative impact of longer duration of illness in the family member on the subjective health of significant others. [43] Similarly duration was not related to stigma perceived; the findings are in commensurate with study by Phelan et al (1998). [23] The findings may be explained in the background that once others know about the illness and impressions are formed the longer duration actually does not make any difference.

The finding of insignificant relationship between birth order and psychological well being as well as stigma indicates that irrespective of the birth order, the experience of stigma will be similar as both undergo similar situations. Hence mere birth order does not change either perception of stigma or the feelings of well being. Similar explanation holds well with respect to the age of the child at the onset of illness in the parent.

There was no relationship between the psychological well being and stigma which is contrary to the other studies examining the stigma experiences and psychological well being of patients themselves.[33, 42] The finding that stigma perceived was predicted by symptom severity is been very well documented in the literature as well. [23, 31]

The study has certain limitations such as the sample primarily comprised of male children, thus the experiences of stigma may be different for the female children. The groups were not matched for socioeconomic status which would have influenced the well being as well as the perception of stigma. The adult children of both the groups were not assessed using standardized tools for any psychopathology and only history of consultations was considered, thus missing out on the presence of psychopathology. However the study has strengths such as having a comparison group matched for age and gender, using a standardized tool for conducting the interview of stigma, selection of the unmarried children to eliminate the effects of the relationships in the context of marriage on well being. Future studies should consider taking larger sample sizes since there are limited studies on stigma and well being in adult children without any diagnosable mental illness. The studies should also consider including both the genders and comprehensive assessments to evaluate psychopathology as well as psychosocial functioning. Interventions to alleviate the impact of parental illness on psychosocial functioning are very essential.

CONCLUSION:

The adult children of parents with schizophrenia undergo significant stigma experiences. These experiences largely reflect on the understanding about the mental illness in the general population as well as the social cultural stand on people with mental illness. They also have low psychological well being as compared to control group. The findings have implications since it brings attention to the psychosocial impact such as stigma experiences of the otherwise neglected group. The findings have implications in planning intervention programs to address stigma and improving support networks for children of parents with mental illness in the Indian context.

Acknowledgements: Nil


References


10. Grant G, Repper J, Nolan M. Young people supporting parents with mental health problems: experiences of
11. Cowling V. Meeting the support needs of families with dependent children where the parent has a mental illness. Family Matters 1996;45:26-30.


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### Table 2: socio-demographic and clinical variables, stigma and psychological well being of the study group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Stigma</th>
<th>Psychological well being</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>‘t’</td>
</tr>
<tr>
<td>Illness status of the parent</td>
<td></td>
<td>score</td>
</tr>
<tr>
<td>Symptomatic (n=11)</td>
<td>16.27 (9.20)</td>
<td>-2.79**</td>
</tr>
<tr>
<td>Non symptomatic (n=19)</td>
<td>24.36 (6.66)</td>
<td></td>
</tr>
<tr>
<td>Order of birth of the offspring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First born (n=14)</td>
<td>19.71 (8.69)</td>
<td>-1.04NS</td>
</tr>
<tr>
<td>Other positions (n=16)</td>
<td>22.87 (8.35)</td>
<td></td>
</tr>
<tr>
<td>Age of the offspring at the onset of parental illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 year and below (n=14)</td>
<td>23.35 (8.23)</td>
<td>0.569 NS</td>
</tr>
<tr>
<td>Above 10 year (n=16)</td>
<td>20.56 (8.94)</td>
<td></td>
</tr>
</tbody>
</table>

* p<0.05, **p<0.01, NS=Not significant