



# Life Experiences of Spouses of Persons Living with Schizophrenia

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**ABSTRACT:** Schizophrenia is a brain disorder, which affects the way a person acts, thinks, and sees the world. Understanding the life experiences of spouses of persons living with schizophrenia will help the professionals understand the challenges they face while taking care their loved ones. It will be useful in developing special programmes in order to enable them to provide better care to their loved one and also face the challenges that they may come across. This study is in focus of this aim and for a better understanding, researcher adopted qualitative approach to conduct the study.

As a result of the study researcher found out that spouses are the real sufferers of mental illness as it affects not only the patient's life but also the people living around them. Therefore, through this article, researcher is trying to suggest measures in order to reduce the problems faced by the spouses and to enable them to cope with the various situations they have to go through.

**Keywords:** Schizophrenia, Spouse, Caregivers, Life Experiences, Sufferings



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## 1. INTRODUCTION

Altered perception of reality is a common thing among the people living with schizophrenia. It results in a significant loss of contact with reality (Willis and Dalrymple 2015). They may see or hear things that don't exist, speak in strange or confusing ways, believe that others are trying to harm them, or feel like they're being constantly watched. With such a blurred line between the real and the imaginary, schizophrenia makes it difficult—even frightening—to negotiate the activities of daily life. In response, people with schizophrenia may withdraw from the outside world or act out in confusion and fear.

Most cases of schizophrenia appear in the late teens or early adulthood. However, it may start to come out for the first time in middle age or even later. In rare cases, schizophrenia can even affect young children and adolescents, although the symptoms are slightly different. In general, the earlier schizophrenia develops, the more severe it is (Mann 2016).

## 2. LITERATURE REVIEW

The research study is about the life experiences of spouses of persons with OCD and Schizophrenia. For conducting the study, the researcher reviewed the literatures about mental health and related topics. The review of literatures thus helped the researcher to get knowledge about the study.

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In the study of Gurese, Adewunmu A. (1988) "Link between social network and quality of life of schizophrenia", it reveals that the context of better outcome of schizophrenia among India and other developing countries, consideration of social support as an influential variable assumes importance. It is thought that social support available to the patients and the caregivers because of joint and extended family systems minimizes the damaging effects of the illness and thus improves outcome. There is some support for this supposition however, despite the interactive appeal of social support as a significant variable in the outcome of schizophrenia; research data pertaining to it is rather thin. Hence, more rigorous and quality research needs to be carried out to establish the credibility of this variable in research.

According to Sethi and Chaturvedi (1993) "Social support and mental health" the ingredients of family and social support system varies in different mentally ill patients. He has identified the important ingredients of family and social support systems in the care of schizophrenia, namely education about the nature of illness, improvements of problems, solving techniques, improvements of communication patterns, lowering of expectations and improvement of social network. Primary social support has a remarkable effect on the prevention of psychiatric morbidity. At the level primary social support system encouragement of family wontedness has been recommended by for primary prevention of psychiatric morbidity.

Brichwood M Meaden (1999) in his book "Impact of schizophrenia upon the family" explains several negative impacts of having schizophrenia family members in one's family. The extreme stress and chaotic life style that families of schizophrenia individual experience because of the patients often irrational and bizarre behavior is not accurately perceived by many people, including mental health professionals. Also the extend of stress that a person with psychosis causes for the close family members has not been documented until recently. Schizophrenia causes such a tremendous change in all family members live that the resulting psychological misery and depression can be prolonged grief that is never resolved. Family life was reported to be so painful that families consider schizophrenia patients as a worse burden than other serious illnesses.

Mary Janevic, (2001) research Associate of University of Michigan in her book "What is caregiver stress?" explains, caregiver stress is the emotional strain of care giving. Studies show that care giving takes a toll on physical and emotional health. Caregivers are more likely to suffer from depression than their peers. Caring for another person takes a lot of time, effort and work. In the process caregivers put their own needs aside. Caregivers often report that it is difficult to look after their own health in terms of exercise, nutrition and doctor's visits. So, caregivers often end up feeling angry, anxious, isolated and sad.

### **3. METHOD**

For understanding the lives of spouses of persons living with Schizophrenia, case study method has been adopted and it was done through interview, which reviled the life situations of spouses.

#### 4. CASE PRESENTATIONS

##### *Case 1*

Mrs. D belonged to a very poor family of 10 members, who depend only on the earnings of a single person. As poverty was severe, and she had 3 more sisters younger than her, she was compelled to marry Mr. A. Without knowing anything about Mr. A, she agreed for the marriage.

As the patient was irregular and was often admitted in the hospital they have no other source of income. It is the patient's sister and her husband who is now helping them financially. The spouse lead a poor social life and receives no social support. Avoidance and laughter is what she received from everywhere. She now avoids all kinds of functions and celebrations and spent time with her ill husband and daughter. She was ignored by both the families and so she developed hatred towards both the families. She believes that treatment and medication can cure or control his weird behavior and it is the discontinuity of medication that worsen his condition. Earlier, she used to express negative emotions, but now she is more hopeful about the treatment and is much supportive.

##### *Case 2*

Mrs. D belonged to a very poor family of 10 members, who depend only on the earnings of a single person. As poverty was severe, and she had 3 more sisters younger than her, she was compelled to marry Mr. A. Without knowing anything about Mr. A, she agreed for the marriage. She said, "I didn't have many concepts about my life partner because my family situation was like that. So when a proposal came, my family accepts it and I also had no disagreements.

Mr. A belongs to a small family with father, mother and a sister. He was suffering from mental disorder from his school days itself. But he married Mrs. D without revealing anything about the disorder. it was only after 3 months of their marriage she identified that he had some problems with his behavior. He had his own tailoring shop, but he used to go there rarely. Mostly he spends his time in home itself. She noticed this behavior after 1 month, but didn't take it seriously. But soon she found some other changes too. He often seemed to be murmuring to himself and shows some kind of gestures with his hands. she used to ask him, but he never listened to me. Then she decided to ask about this to his parents.

It was reported that, his parents behave as if this was happening for the first time and they asked her to take him to a physician. Mrs. D realized that her husband is suffering from mental disorder, only when the physician referred him to a psychiatrist. She also came to know that he was under treatment 6 months before, but for 6 months he was not taking any medicine and so was relapsed.

The Mr. A was under treatment for the last 15 years and six months before he was discharged. Only with the support of medicines he stayed normal. When he was discharged, he stopped taking medicine and so the symptoms began to appear again. These details were told to her by his parents only when they found that she was informed about his disorder.

After 6 months of treatment Mr. A was discharged and the only thing they asked him was to take medicines regularly. Though Mrs. D has hatred towards him, she took proper care of her husband. His father worked in the shop during this time and managed the expenses of households. Slowly

he came back to his normal life. Still, medicines were continued and they consulted the psychiatrists occasionally.

Though once she had hatred towards her partner, treatment and medications gave her back her life. She said that their life was not as pleasing as normal couples. She had to face many problems from the society and the family because that her husband is suffering from mental disorder. Neighbors made fun of them when they go outside and so they rarely went somewhere. Functions and celebrations were totally avoided with the fear of society's negative attitude. Still she was happy with what she had. She felt happy that her husband is taking care of her and they had a daughter too.

This sudden change had affected the balance of their life. But she is hopeful about the treatment. She believes that treatment can cure him and continuous intake of medicine will help him in maintaining a normal life.

### *Case 3*

Mr. B and Mrs. XX married 11 years before with the blessings of both the families. It was a late marriage. They both belonged to a middle class family. Mr. B has two elder sisters and one younger brother and Mrs. XX have one elder brother. After three months days, his mother who found the abnormality in her daughter in law. He too began to notice these changes in her.

Mr. B had no idea about the medicine, so he decided to ask his wife about it. Once he asked directly while she was medicating at night. But she said its to reduce tension. As he is not convinced by her reply he visited her parents. Then their parents revealed about her illness. Her parents said that their daughter was a very bright student and she wished to go for higher studies too. She scored good marks in 10th Std. But when she was in 11th Std., she began to show fear towards some subjects especially English. She didn't attend the English exams twice and felt much tensed. Therefore her parents took her to hospital. She said to the doctor that she often hears some voices telling about her death and so she is afraid that someone will kill her. This was the initial occurrence of disease. She was taken to hospital and on continuous treatment and medication healed her but after one and half years she again showed fear about death and some voices too. Again treatment was given and for a long time she found to be normal.

It was reported that as the family members felt that she is getting normal and it would be better if she gets a better partner. But he felt that he was cheated by her family. He was shocked to hear that his wife is a mental patient and was decided to leave her legally. But seeing the helplessness of her family he accepts her. But her parents asked him to consult her psychiatrist once. He did not show any kind of negative emotion towards her. She was free to live as she likes. But her strange behavior towards the child often makes him sad and confused. He led a good social life and received good social support from friends and neighbors. This reduces his burden. He always faces questions regarding his wife's illness but he always avoids such talks.

### *Case 4*

Mr. K and Mrs. M belonged to a well-settled family. Mr.'s father expired when he was only 10 years old and it is his mother who looked after him. He has a younger sister too. They had their own farm and it was their main source of income. Mrs. M is the eldest daughter of her family. She has a younger sister. Both her parents are working. Five years back Mr. K and Mrs. M got married. After

few days of marriage, he recognized his wife's disorder. She was always felt that she was very possessive. Because she doesn't like others spending time with me. He began to notice that she hardly asked me to take her outside or even if we go somewhere we will come back with quarrel. It was because, she began to doubt him if I talk to others. Therefore he began to realize that it was not just possessiveness but she was suffering from something else. So he decided to take her to the hospital. She was completely withdrawn from her social and family life. She gradually stopped communicating with me too. She behaved as if we were her enemies. Then She was admitted there for two years.. After that he was totally depressed. It took long time for him to accept her illness. But he never accused her though her mother dislikes her. He convinces his mother about his helplessness in taking her care alone and so she too helps him. The spouse stayed jobless for 3 months due to her illness as he was in the hospital with her. Now he has a job in a private firm but they won't pay him when he is in leave. Therefore now he depends on his farm and it is with the income from the farm he meets their daily needs. He fails to lead a proper social life. He avoids taking her to functions and other public get together. He is ashamed of introducing her before others. He also rarely go outside as everyone knows about her disorder. He is deeply stressed with his family life.

## **5. ANALYSIS AND INTERPRETATIONS**

The data analysis was done in two stages. In the first stage, the cases are narrated in detail and discussed the major points relevant to the phenomenon. After that, comprehensive narration of each case was done. In the second stage, researcher analyzed the case history and interpreted with relevant studies.

- *SOCIO DEMOGRAPHY*

Among the four spouses of Schizophrenia, 3 of them were not highly educated while one of them is a degree holder. Three of them belonged to poor socio-economic backgrounds who suffer to meet the daily expenses of their family and only one among the four spouses comes from a financially well-settled family. The female spouses are not working and they completely depend on their diseased husband for their living while both the male spouses work and one of them earn 9,000/- and the other earn 20,000/- if they work regularly. Three of the families completely depend on the income of a single earning person of their family while for one respondent father also contributes to the family needs. In that family father decides every matter related with the patient and the spouse and it is the spouses who are the decision makers in other 3 families.

It is evident from the study conducted by Davis and Drummond, (1991) on "Long Term Course and Outcome of Schizophrenia".

He has reported that although the costs of drug therapy for people with schizophrenia are relatively low, the total costs of treatment and care are high. It is probably the most costly illness that psychiatrists treat.

Therefore, it is important to have a job for the spouses of such patients. In the data analyzed it can be seen that the female spouses of schizophrenia patients are not working and it increases the financial burden of the spouses.

- *PSYCHO SOCIAL AND FAMILY AREAS*

Three of the respondents belong to joint family and one come from nuclear family. Spouses of all the four patients took care of them. But the spouses are not always the key providers of basic needs like food, clothing etc. to the patients. Except one spouse all the three are dependent on someone else for providing food and clothing for the patients. Church and prayer groups provide these facilities for one patient while for the other it is the patient's sister who is the key provider and in the case of third spouse the father and sibling help the spouse in meeting patient's basic needs.

Two of the respondents are couples with preschool children while the other two couples do not have children. The spouses with children could not take care of their children properly and both the respondents depend on family members for child rearing. It is the patient's sister who takes care of the child of one respondent while it is with the grandmother the other child lives. The children receive guidance and supervision from these family members. It is these family members who provide the basic needs for the children.

Mutual communication is comparatively poor in all the four families. Even if they communicate it may be either verbal communication or disguised communication. The couples keep a poor interaction with the family. In the case of two respondents having children, the children communicate to the parents not directly but through the family members.

Family support from both the patient and the spouse's family were comparatively poor. It was the same for all the four respondents. One of the families helped the respondent at first as they feel guilty, but they ignored them soon. The family of female patients were much helpful than that of male patients. The male spouses thus receive support only from the in-laws and not from their family. The male spouse's family wanted their son's to leave the ill daughter-in-laws. But the male spouses have convinced their family and seek their help in taking care of the patient. One male spouse is getting help from his own family at present also while the other family provided help till the last treatment and now they withdrew from it. Among the female spouses one of the families neglected her while the other family helped occasionally.

Social support each respondent receives differs. Still the support they receive from the society is poor and pathetic. The neighbors of one of the respondent help her in taking the patient to the hospital but they spread gossips behind regarding his illness and the couple having no children. Two of the respondents didn't get any kind of support and the neighbors made fun of the patient's illness. The friends and neighbors of the other respondent express sympathy towards the spouse which was unbearable at the same time their company reduce the pain of the spouse. Three of the respondents maintain a poor social life. They lead a life completely isolated from the society. They always remain in the home itself. One of the spouse spent time with the friends and this was a relief for him. Functions and celebrations were completely avoided by all the four. They neither went for these with the partner nor alone. Three of them used to go for functions and outing before diagnosing the disease and they later avoid it as they feel ashamed. The other respondent avoid it earlier itself as she knew about the illness.

A study on "Mental Health: Society and Stigma" supports this. It says that stigma is a social devaluation of person because of personal attribute leading to an experience of sense of shame, disgrace and social isolation. Marriage, fear of rejection by neighbors and the need to hide the fact

from others were some of the major stigmatizing aspects. Many spouses reported feelings of depression and sorrow

- *IMPACT OF ILLNESS ON THE SPOUSE*

Except one spouse, all the other three spouses got married without knowing the illness of their partner. The one, who married knowingly, was compelled to do so. Poverty was the factor that leads female spouses to marry mentally ill patients while increasing age compelled the male spouses to marry their partners without having enough knowledge about their past. The three respondents develop hatred towards the patient's family for cheating them by hiding the patient's illness. The other spouse though knew about the illness also express hatred as she was compelled to marry the person.

Among the four respondents one who married knowingly, is not satisfied with the married life. The spouse has only hatred towards the partner and had not enjoyed any moments happily. The other three respondents enjoyed the life till they realize about the illness, but later developed hatred. Though hatred is there in all the four respondents, the male spouses do not accuse their partners, but their families for the marriage. Both the male spouses give freedom for their partners to live as they will and they do not interfere in their activities. But both the female spouses consider both the patient and the family guilty.

One of the female spouses is depressed of not having a child. The male spouse without children is not much bothered about it. The birth of a child had changed the life style of the patient and spouse of both the families. It brought happiness and relief in them but at the same time increased their financial burden and responsibility. They couldn't take proper care of the children while they are in the hospital. All the four respondents show various levels of depression due to various reasons.

Three of the respondents have younger siblings. Sibling's marriages are postponed or cancelled due to the illness of the patient. The family of all the spouses accused the patient for this. They quarrel with the spouse for supporting the patient.

Both the female spouse's are not working. Their main source of income was their ill husbands. During treatment, one of them depend on the church and prayer group to meet the expenses of treatment as well as daily living while it is the patient's sister who help the other financially. Two of the male spouses are working. Though they are not dependent on the patient they couldn't go for work when the patient is admitted. One of the male spouse lost job once and the new firm pay him only for the days he work. So he depends on his farm for an alternative income. The other female spouse did not suffer much as he is a merchant and his father helps him in his work. Both the male spouses face direct and indirect emotional torturing from their customers and colleagues.

- *SPOUSES UNDERSTANDING, INTERPRETATION OF ILLNESS*

All the four respondents are fed up with the life but each approach the patient and treatment differently. One of them is completely fed up and had no hope of her husband's recovery. She is the only respondent who feels happy while the patient is in the hospital that she could meet and interact with other patients and their families. She curses her destiny for her present situation and her husband's illness. The other three also had hatred at the beginning but now they get adjusted

with the life. One believes that treatment can cure her husband's condition and is still hopeful about his recovery. One of the male spouses is not expecting a complete recovery but wishes for it so that they both could live happily. The other male spouse believes in the medicine and treatment and is very hopeful about the patient's recovery. Three of the respondents believe that it is the discontinuity of medicines that worsened the situation and continuing the medicines can change the severity of the illness. But the other spouse curses her destiny and believes that it is hereditary.

- *INFLUENCE OF GENDER ON THE LIFE EXPERIENCE OF THE SPOUSE*

Male spouses found receiving more support from their own family and their partner's family. Male spouses were able to convince their family members about the disorder than the female spouses. Female spouses are often married because of poverty and it also contributes to the neglect they receive from their family. Female spouses exhibit more stress and depression than males. Males consider having children as an extra burden and thus overcome from this depression. Still, both the male and female spouses suffer as they are married to a mentally ill person.

## 6. FINDINGS

- Socio – economic condition greatly influence the quality of life of the spouse. Those coming from poor socio economic condition fail to lead a satisfying life than those come from an economically well settled family.
- Spouses having job have less financial burden than that of spouses without job.
- Spouses having more than one source of income have less financial burden.
- Occupational status has an important role in the social life of the spouses. Spouses having a job are forced to interact with the society as it is a part of their work.
- The spouses prefer isolated social life due to the social stigma they experiences.
- The social support influences the social life of the spouses.
- Spouses having occupation face difficulty in hiding the fact from others.
- Social supports received by the spouses are comparatively poor.
- Fear of rejection by neighbours and the need to hide the fact from others were some of the major stigmatizing aspects.
- Majority of them have gone through some psychological problems in some stages of life.
- Infertility, unsatisfied married life, ignorance from the partner, family and society, burden of care giving and treatment lead them to psychological problems mainly depression.
- Female spouses exhibit more stress and depression than males.
- Female spouses without children are more depressed than those having children.
- Child rearing is a challenge for the spouses.
- The spouses belonging to joint family suffers less challenge than those in nuclear family regarding child rearing.
- Male spouses consider having children as an extra burden.
- Female spouses express negative emotion than male spouses.
- Male spouses show more ignorance towards the patients than the female spouses.
- Male spouses receive more support from their own family and their partner's family.
- Spouses are accused for the siblings staying unmarried.



## 7. CONCLUSION

It is pathetic to say that in this 21st century, where humans consider themselves as extremely intelligent, fails to realize that mental illness is not the result of fate or destiny and that it can happen to anyone.

It was found from the study that caregivers especially spouses are the real sufferers of mental illness as it affects not only the patient's life but also the people living around them. The spouses suffer socially, economically, occupationally, emotionally and so on. They are forced to suffer the whole life in serving a person from whom they cannot expect anything or they couldn't hope for something better.

Along with their personal problems, they are ignored by the society and family only because that they are married to a mentally ill person knowingly or unknowingly. They are avoided from enjoying the basic rights they have in the society. They are avoided from public programmes, functions, and other celebrations. They are treated as something funny. By this we, the human beings are contributing more psychologically ill people to the society. If we can't help them, then we don't have the right to treat them so.

The attitude of the society and family should be changed. Majority of the spouses lead a life completely withdrawn from the society. Ignorance and rejection along with ill treatment increases the stress and burden of the spouses.

Therefore it is important that the society should widen their perspectives and attitudes in treating such people. Shock news, or any undesirable event in life can lead us also into such illness. Therefore it is important to ensure that the mental ill people and their spouses are not victims of our neglect but they are treated as one among us.

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