

## The study of General Well-being of Caregivers of Schizophrenic Patients

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### ABSTRACT

The study was conducted on 25 Caregivers of diagnosed Schizophrenic patients, all subjects randomly selected from various rehabilitation centres. The caregiver's age ranges between 20s-80s years. All Subject subjected to PGI General Wellbeing Measure, it was hypothesized that physical and mental health of caregivers and also negative emotional experiences. The result indicated that there was significant correlation between physical and mental health of caregivers of schizophrenic patients ( $r = 0.503 > 0.05$ ). Caregivers who devote their time and energy in taking care of their family member with schizophrenia, their own General Well Being get impacted in the process.

**Key words:** Schizophrenia, Caregiver, Mental Health, Mental Illness.

### INTRODUCTION

Schizophrenia is a [mental disorder](#) characterized by a breakdown of thought processes and by poor emotional responsiveness. Common symptoms include [auditory hallucinations](#), [paranoid](#) or bizarre [delusions](#), or [disorganized speech and thinking](#), and it is accompanied by significant social or occupational dysfunction. The onset of symptoms typically occurs in young adulthood, with a global lifetime [prevalence](#) of about 0.3–0.7%. Diagnosis is based on observed behavior and the patient's reported experiences.

A person diagnosed with schizophrenia may experience [hallucinations](#) (most reported are [hearing voices](#)), [delusions](#) (often bizarre or [persecutory](#) in nature), and [disorganized thinking and speech](#). The latter may range from loss of train of thought, to sentences only loosely connected in meaning, to incoherence known as [word salad](#) in severe cases. Social withdrawal, sloppiness of dress and hygiene, and loss of motivation and judgment are all common in schizophrenia. There is often an observable pattern of [emotional](#) difficulty, for example lack of responsiveness. Impairment in [social cognition](#) is associated with schizophrenia, as are symptoms of [paranoia](#); [social isolation](#) commonly occurs. Difficulties in [working](#) and [long-term memory](#), [attention](#), [executive functioning](#), and speed of [processing](#) also commonly occur. In one uncommon subtype, the person may be largely mute, remain motionless in bizarre postures, or exhibit purposeless agitation, all signs of [catatonia](#).

According to DSM IV, schizophrenia is a disorder that lasts for at least six months and includes at least one month of active phase symptoms (i.e. two or more of the following: delusions, Hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, negative symptoms). The characteristic symptoms of schizophrenia may be conceptualized as falling into two broad categories: positive and negative.

The positive symptoms appear to reflect an excess or distortion of normal functions, whereas the negative symptoms appear to reflect a dimension or loss of normal functions. The positive symptoms include distortions in thought content (delusions), perceptions (hallucinations), language and thought process (disorganized

speech), and self monitoring of behaviour (grossly disorganized or catatonic behaviour). The negative symptoms are affective flattening, alogia (poverty of thoughts/ speech), anhedonia (inability to experience pleasure), associability (lack of desire to form relationships) and volition (lack of motivation) (Kaplan and Sadock, 2003).

There are sub types of schizophrenia: Paranoid, Hebephrenic (also called disorganized), Catatonic, Undifferentiated, Simple and Residual schizophrenia (WHO, 1992). Paranoid schizophrenia is dominated by relatively stable, often paranoid delusions, usually accompanied by hallucinations, particularly of the auditory variety, and perpetual disturbance. Catatonic schizophrenia is dominated by prominent psychomotor disturbance that may alternate between extremes such as hyperkinesias and stupor, or automatic obedience and negativism (WHO, 1992). Hebephrenic schizophrenia is a form of schizophrenia which is dominated by prominent affective changes, fleeting and fragmentary delusions and hallucinations, irresponsible and unpredictable behaviour (WHO, 1992). Undifferentiated schizophrenia is psychotic conditions meeting the general diagnostic criteria for schizophrenia but not conforming to any of the subtypes, or exhibiting the features of more than one of them without a clear predominance of a particular set of diagnostic characteristics (WHO, 1992). Residual schizophrenia is a chronic stage in the development of a schizophrenia illness in which there has been clear progression from an early stage to the later stage characterized by long-term, though not necessarily irreversible, “negative” symptoms, e.g., psychomotor slowing (motor retardation); under-activity; blunting of affect; passivity and lack of initiative (a volition); poverty of quality or content of speech (alogia); poor nonverbal communication by facial expression, eye contact, voice modulation and posture; poor self-care and social performance (WHO, 1992). In Simple schizophrenia there is an insidious but progressive development of oddities of conduct, inability to meet the demands of society, and decline in total performance (WHO, 1992). The characteristic negative features of residual schizophrenia (e.g. blunting of affect and loss of volition) develop without being preceded by any overt psychotic symptoms (WHO, 1992).

Genetics, early environment, neurobiology, psychological and social processes appear to be important contributory factors; some recreational and prescription drugs appear to cause or worsen symptoms. Current researches are focused on the role of neurobiology, although no single isolated organic cause has been found. The many possible combinations of symptoms have triggered debate about whether the diagnosis represents a single disorder or a number of discrete syndromes.

According to the WHO 2009, Schizophrenia is a severe form of mental illness affecting about 7 per thousand people, mostly in the age group 15-35 years. Schizophrenia affects about 24 million people worldwide and 90% of the untreated cases of schizophrenia are in the developing world (WHO, 2009).

Schizophrenia, from the public health perspective, is a major concern as the onset of the illness occurs early (15-35 years of age). According to WHO (2009) reports it may affect about 1.0% of the general population in any given country.

It is a major public concern because the problems caused by it are large in number. It causes chronic disability due to which the education opportunities and proper cognitive and social growth of the patient get hampered. To the family members apart from stress, burden and emotional trauma, it causes financial disadvantages as well. Stigma is another important thing to consider as both patient and his/her family faces tremendous social stigma in all aspects of their lives.

Schizophrenia is a chronic condition and affects patient's thinking and behaviour and hence they require help from outside (mostly provided by Caregiver).

A caregiver is someone who is responsible for the care of someone who has poor mental health, physically disabled or whose health is impaired by sickness or old age (WikipediaThe Free Encyclopedia, 2014).

Tasks of a caregiver may range from: Taking care of someone who has a chronic illness or disease, to manage medications or talk to doctors and nurses on someone's behalf, to help them bathe or dress someone who is frail

or disabled, to take care of household chores, meals, or bills for someone who cannot do these things alone (Wikipedia The Free Encyclopedia, 2014).

A study done on 'Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships' by Mitnick, S.; Leffler, C.; Hood, V in 2010 emphasis the role of family caregivers. It says "Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals" (Mitnick, S.; Leffler, C.; Hood, V. 2010).

The importance of the role of family caregivers in the treatment of a person with mental illness is emphasized in another research 'A Qualitative Study On The Needs Of Caregivers Of Inpatients With Schizophrenia In India' by Jagannathan et al. Family caregivers provide considerable support to their ill relatives even while they experience significant burden (Leff, 1994 cited in 'A Qualitative Study On The Needs Of Caregivers Of Inpatients With Schizophrenia In India' by Jagannathan et al). In a survey conducted by Consumer Health Sciences (CHS) and the National Mental Health Association (NMHA), one third of the 1,328 family caregivers surveyed said that the emotional and behavioural symptoms of the illness caused them extreme hardship and was a constant source of anxiety (Consumer Health Sciences, 2008 cited in 'A Qualitative Study On The Needs Of Caregivers Of Inpatients With Schizophrenia In India' by Jagannathan et al).

In India, the majority of the people with schizophrenia stay with their families (Tharaet al., 1998; Murthy, 2006. Cited in 'A Qualitative Study, on the Needs of Caregivers Of Inpatients With Schizophrenia In India' by Jagannathan et al). Some Indian researches have been focussed on the impact of illness on caregivers of people with Schizophrenia. One by Shrivastava (2005) studied the perception of burden experienced by caregivers of patients with Schizophrenia and found that they feel the burden. In some researches the relations between attitude towards the illness and the burden experienced by caregivers has been explored. Urizar et al. (2011) found that caregivers who have negative attitude towards the illness and towards person suffering from it experience more burden. A study done by Grandon, Jenaro and Lemos (2008) got the same results and highlighted the relevance of psycho educational interventions for the families. Another study in Indian setting by Nirmala, Vranda and Reddy (2011) explored the relationship between caregiver's burden and level of expressed emotion by patients with schizophrenia and got high correlation between the two and also highlighted the need for addressing expressed emotion in psychosocial intervention plan. These all studies addresses concept of Mental Health of Caregivers as well.

According to WHO, 2007 Mental Health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community and is not just the absence of mental illness.

The positive dimension of mental health is stressed in WHO's definition of health as contained in its constitution: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

There is history attached to the term of mental health. In the mid-15th century, William Sweetzer was the first to clearly define the term "mental hygiene" which can be seen as the precursor to contemporary approaches to work on promoting positive mental health. [Isaac Ray](#), one of the thirteen founders of the [American Psychiatric Association](#), further defined mental hygiene as an art to preserve the mind against incidents and influences which would inhibit or destroy its energy, quality or development (Wikipedia the Free Encyclopaedia, 2014).

[Dorothea Dix](#) (1802–1887) was an important figure in the development of "mental hygiene" movement. At the beginning of the 20th century, [Clifford Beers](#) founded the [National Committee for Mental Hygiene](#) and opened the first outpatient mental health [clinic](#) in the [United States of America](#).

After year 1945, references to mental hygiene were gradually replaced by the term 'mental health' (Wikipedia, The Free Encyclopaedia, 2014).

Mental ill health is often confused with mental illness. Mental ill health refers to the kind of general mental health problems we can all experience in certain stressful circumstances; for example, work pressures can cause us to experience: poor concentration mood swings and sleep disturbance

Such problems are usually temporary and generally get better support and reassurance. All of us suffer from mental problems at times, and such temporary problems do not necessarily lead to mental illness. However, being mentally unhealthy limits our potential and may lead to more serious problems.

Where Mental illness is can be defined as the experiencing of severe and distressing psychological symptoms to the extent that normal functioning is seriously impaired. Examples of such symptoms include: anxiety, depressed mood, obsessional thinking, delusions and hallucinations.

Some form of professional medical help is usually needed for recovery or management, this help may be in the form of counselling or psychotherapy, and drug treatment and/or lifestyle change (Mental Health Ireland-Supporting Positive Mental Health, last updated on September 01, 2014).

Objective: What is the effect of well-being of caregivers of Schizophrenic patients?

**Hypotheses**

- Significant correlation between physical and mental health of Schizophrenic patients’ caregivers.
- Significant negative emotional experiences in caregivers of Schizophrenic patients.

**Sample**

In this pilot study 25 Caregivers of diagnosed Schizophrenic patients randomly selected from rehabilitation centres are studied. The age ranges from 20s-80s.

Test Administered

The test administered on Caregivers of Schizophrenic patients is PGI General Wellbeing Measure by S.K Verma& Amita Verma, 1988.

**Reliability** of PGI General Wellbeing Measure- it was measured by K.R.20- formula and was found to be .98 (p<.01) (S.K.Verma, Dube and Gupta 1983), while test-retest reliability was .91 (p<.01) (Moudgil et al. 1986) for the English version and .86 (p<.01) for the Hindi version (Moudgil et al. 1986).The scale showed good inter-rater (.86, p<.01) and inter-scorer (1.0, p<.01) reliabilities (Moudgil et al., 1986).

**Validity** – the test was correlated with a number of tests in different studies. The scale showed significant relations with other scales like another Wellbeing Scale, with Quality of Life Scale, and to some extent with Learned Helplessness Scale.

Result:

<b>Mean, SD and Correlation of PGI General Well Being Test</b>			
N-25	MEAN	S.D	r
MENTAL HEALTH	2.08	0.65	r=0.503 P>0.05
PHYSICAL HEALTH	4.56	0.80	

The result indicates that there is significant correlation between physical and mental health of caregivers of schizophrenic patients. It means if mental health of caregivers is affected the physical health of them also gets affected and vice versa.

The Mean value which has come out to be 6.48 states the General Well Being of caregivers of schizophrenic patients is below average level. The sample of 25 caregivers who are devoting their time and energy in taking care of their family member with schizophrenia, their own general well being gets impacted in the process.

## **CONCLUSION AND DISCUSSION**

Schizophrenia is a severe mental disorder affecting 1% of the general population is characterized by positive symptoms of Hallucinations (mostly hearing voices and seeing things without any stimuli), Delusions (fixed firm false beliefs), Disorganized thoughts, Disorganized behaviour; and negative symptoms of A volition (lack of motivation), Anhedonia (inability to experience pleasure), Blunt Affect (mask like face), Associability (lack of desire to form relationships) and Alogia (poverty of thoughts and speech). This mental disorder is major concerns in public as it causes chronic disability in the patient due to which not only the patient's life the people around him (family and friends) their lives also get impacted. A caregiver's role becomes important as his tasks may range from – taking care of the patient with chronic illness by managing medications, talking and taking patient to doctors, to help the patient in their basic functions like bathing, to care of household chores simultaneously. A study done by Mitnick et al. 2010 on 'Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships emphasizes the role of family caregivers as patient depends on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals.

The task of providing care to a person with chronic disorder must be difficult and taxing for their caregivers. Another research 'A Qualitative Study on the Needs of Caregivers of Inpatients with Schizophrenia in India' by Jagannathan et al. focusing on importance of the role of family caregivers in the treatment of a person with mental illness; also emphasizes the experience of significant burden in them. In a survey by Consumer Health Sciences (CHS) and the National Mental Health Association (NMHA) it came out the emotional and behavioural symptoms of the illness caused caregivers extreme hardship and was a constant source of anxiety (Consumer Health Sciences, 2008).

Another research from India which focuses on the impact of illness on caregivers is by Shrivastava (2005) who studied the perception of burden experienced by caregivers of patients with Schizophrenia and found similar results that they feel the burden. These all researches strengthens the results of the present study in which a significant correlation has been found between physical and mental health of caregivers and also resulted in below average General Well Being of caregivers of Schizophrenic patients.

The results of present study with other researches which focus on negative emotional experiences in caregivers with constant feeling of stress, burden and anxiety; it also highlights the need to address these feelings of caregivers. A study done by Nirmala et al. 2011 in Indian setting with addressing the relationship between caregiver's burden and level of expressed emotion by patients also highlights the need for addressing expressed emotion in psychosocial rehabilitation plan and the concept of Mental Health of Caregivers as well. Two other studies one by Urizar et al (2011) and Grandson et al (2008) also highlighted the relevance of psycho educational interventions for the caregivers. The same issue was addressed in another study 'A Study of Sociocultural Perspectives of Caregivers in Burden Coping Behaviour in Bipolar Disorder and Schizophrenia Cases' in 2009 by Ganguly et al. where Qualitative dimension of care giving and burden coping strategy was assessed by doing Focus Group Discussion and appropriate educational intervention were designed thereafter to help improve quality of coping strategy and reduce the burden of the care givers. It was evident from the results of this study that the sessions had positive impact for coping behaviour and increased confidence and also states that caregivers' health status and moral are required to be kept in good state so that the patents are taken care of appropriately.

**REFERENCES**

1. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR).
2. Ganguly KK, Chadda RK, & Singh TB. (2009). A Study of Socio Cultural Perspectives of Care Givers in Burden Coping Behaviour in Bipolar Disorder and Schizophrenia Cases. *International Journal of Psychosocial Rehabilitation*. Vol 13(2). 93-10. Available at [http://www.psychosocial.com/IJPR\\_13/Socio\\_Cultural\\_Perspectives\\_Ganguly.html](http://www.psychosocial.com/IJPR_13/Socio_Cultural_Perspectives_Ganguly.html). Accessed on: 19<sup>th</sup> September, 2014.
3. Grandon, P., Jenaro, C., Lemos, S.; (2008). Primary Caregivers of Schizophrenia Outpatients; *Psychiatry Research* 158, 335-343.
4. Jagannathan. A, Thirhalli, J, Hamza. A, Hariprasad V.R., Nagendra. H.R., Gangadhar. B.N. A Qualitative Study on the Needs of Caregivers of Inpatients with Schizophrenia. *International Journal of Social Psychiatry*. © The Author(s), 2011. Reprints and permissions: <http://www.sagepub.co.uk/journalsPermissions.nav> Vol 57(2): 180–194 DOI: 10.1177/0020764009347334. Available at <http://isp.sagepub.com/content/57/2/180.abstract> Accessed on: 1<sup>st</sup> October, 2014.
5. Kaplan, Sadock, B.J., Sadock, A.J.; (2003) *Synopsis of Psychiatry Behavioral Sciences/ Clinical Psychiatry*; Lippincott Williams and Wilkins.
6. Mental Health Ireland- Supporting Positive Mental Health (Monday, September 01, 2014). Available at <http://www.mentalhealthireland.ie/information/what-is-mental-health.html>. Accessed on: 1<sup>st</sup> September, 2014.
7. Mitnick, S.; Leffler, C.; Hood, V.; American College of Physicians Ethics, P. A. H. R. C. (2010). "Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships". *Journal of general internal medicine* 25 (3): 255–260. doi:10.1007/s11606-009-1206-3. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2839338/>. Accessed on: 19<sup>th</sup> September, 2014.
8. Nirmala, B.P., Vranda, M.N., Reddy, S., (2011). Expressed Emotion and Caregiver Burden in Patients with Schizophrenia; *Indian Journal Psycho Med*. Jul-Dec; 33(2):119-122.
9. Shrivastava, S.; (2005). The perception of burden by caregivers. *India Journal Psychiatry*. Jul-Sep; 47(3): 148-152.
10. Urizar, A.C, Maldonado, J.G., Garcia, M.F., Salazar, C.P., Araya, D.R., Peralta, A.C.; (2011). Attitudes and Burden in Relatives of Patients with Schizophrenia in a Middle Income Country; *BMC Family Practice*, 12:101.
11. Wikipedia The Free Encyclopaedia 30<sup>th</sup> August, 2014 15:28. Mental health. Available at [http://en.wikipedia.org/wiki/Mental\\_health](http://en.wikipedia.org/wiki/Mental_health). Accessed on: 1<sup>st</sup> September, 2014.
12. Wikipedia The Free Encyclopedia. 19<sup>th</sup> September, 2014 at 04:29. Caregiver. Available at <http://en.wikipedia.org/wiki/Caregiver>. Accessed on: 19<sup>th</sup> September 2014.
13. World Health Organization. (1992). *International Statistical Classification of Diseases and Related Health Problems-10th Revision (Vol. 1)*. Geneva: World Health Organization
14. World Health Organization. Mental health: a state of well-being updated August 2014. Available at [http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/). Accessed on: 1<sup>st</sup> September, 2014.