QUALITY OF LIFE

AND

EXPLANATORY MODELS IN PATIENTS

WITH SCHIZOPHRENIA

Dissertation submitted to

The Tamil Nadu Dr M.G.R. Medical University

In part fulfilment of the requirement for

M.D. Psychiatry final examination

March 2016

CERTIFICATE

This is to certify that the dissertation titled "Quality of life and Explanatory models in patients with schizophrenia" is the bonafide work of Dr. Jibi Achamma Jacob towards MD Psychiatry Degree Examination of Tamil Nadu, Dr M.G.R Medical University to be conducted in March 2016. This work has not been submitted to any university in part or full.

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CERTIFICATE

This is to certify that the dissertation titled “Quality of life and Explanatory models in patients with schizophrenia” is the bonafide work of Dr Jibi Achamma Jacob towards MD Psychiatry Degree Examination of Tamil Nadu, Dr M.G.R Medical University to be conducted in March 2016 and that this study has been done under my guidance. This work has not been submitted to any university in part or full.

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DECLARATION

I hereby declare that this dissertation titled **"**Quality of life and explanatory models in patients with schizophrenia**"** is a bonafide work done by me under the guidance of Dr.Anju Kuruvilla, Professor of Psychiatry, Christian Medical College, and Vellore. This work has not been submitted to any university in part or full.

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October 21, 2014

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Sub: **Fluid Research Grant:**
Quality of life and explanatory models in patients with schizophrenia.
Dr. Jibi Achamma Jacob, Psychiatry, Dr. Anju Kuruvilla, Psychiatry, CMC, Vellore.

Ref: IRB Min. No. 9036 [OBSERVE] dated 04.09.2014

Dear Dr. Jibi Achamma Jacob,

I enclose the following documents:-

1. Institutional Review Board approval
2. Agreement

Could you please sign the agreement and send it to Dr. Nihal Thomas, Addl. Vice Principal (Research), so that the grant money can be released.

With best wishes,

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Dear Dr. Jibi Achamma Jacob,

The Institutional Review Board (Blue, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project entitled "Quality of life and explanatory models in patients with schizophrenia" on September 4th 2014.

The Committees reviewed the following documents:

1. IRB Application format
2. Curriculum Vitae of Dr. Jibi Achamma Jacob, Dr. Anju Kuruvilla
3. Informed Consent form (English & Tamil)
4. Information Sheet (English & Tamil)
5. Data & Scoring Sheet
6. No of documents 1-5

The following Institutional Review Board (Blue, Research & Ethics Committee) members were present at the meeting held on September 4th 2014 in the CREST/SACN Conference Room, Christian Medical College, Bagayam, Vellore 632002.

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We approve the project to be conducted as presented.

The Institutional Ethics Committee expects to be informed about the progress of the project, any **adverse events** occurring in the course of the project, any **amendments in the protocol and the patient information / informed consent**. On completion of the study you are expected to submit a copy of the **final report**. Respective forms can be downloaded from the following link: http://172.16.11.136/Research/IRB_Polices.html in the CMC Intranet and in the CMC website link address: http://www.cmch-vellore.edu/static/research/Index.html.

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Until Grant Allocation:

A sum of 6,000/- INR (Six Thousand only) will be granted for 1 year.

Yours sincerely,

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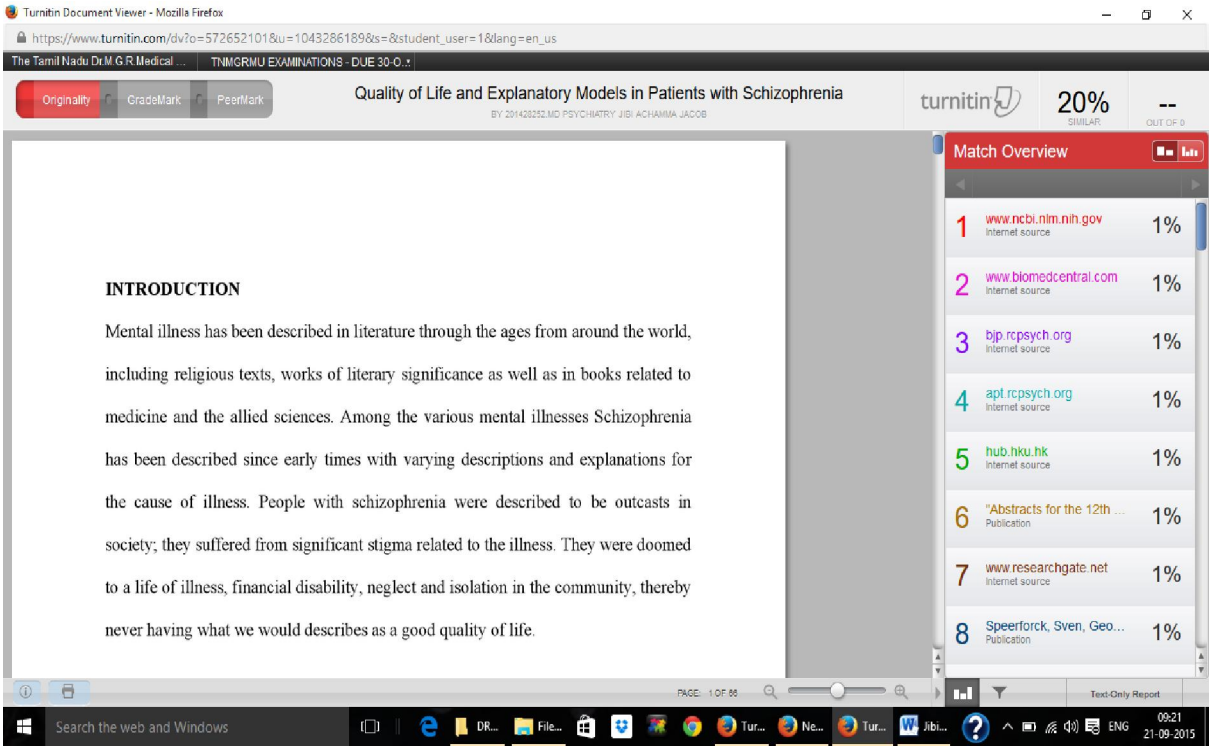

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Submission ID:	572652101

ACKNOWLEDGEMENTS

I would like to extend my sincere gratitude to Dr.Anju Kuruvilla without whom, this study would not have been possible. She has been a constant source of knowledge, practical help, encouragement, support and an excellent guide.

I am indebted to all the study participants who patiently and willingly consented to share their personal experiences.

I extend my sincere gratitude to Dr.K.S.Jacob who awakened my interest in my chosen topic.

I also thank Dr. Rajesh Gopalakrishnan and Dr.Subhalakshmi T.P for their valuable suggestions.

I extend my heartfelt gratitude to Dr. Thangadurai, for his help with the Tamil questionnaires and translations.

I especially thank all the MRD staff and doctors who helped me immensely with the recruitment of the patients.

I also thank Mr.Suresh and Mr.Palani for their invaluable help in the preparation of the forms and the final manuscript.

I would like to express my genuine gratitude to my parents for their unconditional love and encouragement and consistent motivation.

I would also like to express my gratitude to my son for his unconditional love, and to my spouse and my in-laws for their valuable support.

I thank God for His grace, strength and continued presence in my life and endeavours. I am extremely blessed to have been a part of this study.

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INTRODUCTION

Mental illness has been described in literature through the ages from around the world, including religious texts, works of literary significance as well as in books related to medicine and the allied sciences. Among the various mental illnesses Schizophrenia has been described since early times with varying descriptions and explanations for the cause of illness. People with schizophrenia were described to be outcasts in society; they suffered from significant stigma related to the illness. They were doomed to a life of illness, financial disability, neglect and isolation in the community, thereby never having what we would describes as a good quality of life.

While the treatment of such patients in mental asylums of yore was described as inhumane and cruel, the era of deinstitutionalization did not change the situation very much. Once back in the community, people with major mental illness continued to suffer at the hands of their fellow beings secondary to stigma and the fear that mental illness evoked in the lay public.

This scenario was in prevalence till the past few decades when the concept of schizophrenia evolved from Kraeplins' *Dementia praecox* to its current status in the DSM –5 and ICD – 10 and the future ICD -11.Schizophrenia, however emerged as a medical condition worthy of research and management only in the 18^{th} century.

However with the advent of antipsychotic medication symptoms of illness were beginning to get under control and the focus shifted to the reintegration of such

individuals into society. Along with this, interest grew in other aspects of the individual's life such as the patient's own perceptions of the illness and the quality of their life in the background of a disabling, stigmatizing and chronic illness. Since then much research has been carried out on the themes of quality of life and explanatory models of illness in schizophrenia.

1. LITERATURE REVIEW

1.1 SCHIZOPHRENIA

1.1.1 DEFINITION

Schizophrenia is a group of disorders that is significantly disabling and chronic in nature. It is characterised by positive psychotic symptoms such as delusion, hallucinations, and thought abnormalities, conceptual disorganisation along with disorganized communication and behaviour, poor planning, decline in motivation, and disturbance in affective domains. The level of disability arising secondary to this illness affects the socio-occupational and interpersonal domains of the individual to a significant level such that the impact of the illness per say and the side effects of medication along with stigma from the society can be significantly detrimental to the well-being of the affected individual.

The disease concept of schizophrenia is relatively new, even though conditions simulating the above said symptoms and dysfunction have been described under different names since many years. The current understanding about schizophrenia is that it is a disorder which is yet not fully understood, with a complex aetiology, with variable phenotypic expression involving interactions between genetic factors, and the surrounding environment(1).

Schizophrenia is one of the major contributors to the global burden of disease. Among the diseases which add on to the global burden of disease, schizophrenia is one of the major contributors. The substantial burden of disease is a reflection of two features of schizophrenia: (a) its onset in early adulthood, and (b)

approximately two-thirds of affected individuals have persisting or fluctuating symptoms despite optimal treatment (2).

1.1.2 EPIDEMIOLOGY

Even though the incidence of schizophrenia is relatively low (median value 15.2 per 100,000 persons per year), it is one of the major contributors to the global burden of disease(3).

A large number of studies have estimated the prevalence of schizophrenia. In spite of differences in methodology, most studies have found a point prevalence of between one and half and seven per thousand populations at risk (4).

The conclusion from epidemiological studies the world over suggests that incidence and prevalence of schizophrenia across populations are similar. A minority of epidemiological studies have shown that some populations deviate significantly from this central tendency, however the significance of these deviations is modest compared with the differences observed across populations in relation to other non-communicable, multifactorial diseases such as diabetes mellitus , coronary artery disease or malignancies(5).

The World Health Organization (WHO) 10 Nation study is one of the most important studies on the incidence of schizophrenia. This landmark study, employing uniform methodology across various research sites, provided incidence data from eight sites in seven nations. The incidence ranged from 7 to 14 per 100,000 when narrow criteria for schizophrenia were used ;the range was 16 to 42 per 100,000 with criteria from ICD9 (6).

The prevalence of schizophrenia in developing countries was found to be significantly lower than in the “emerging” and “developed” countries. Epidemiological studies done in Indian have shown that the prevalence of schizophrenia is lower in India than in the West ,but the data is inconclusive(2).

The incidence of schizophrenia is comparable across cultures. Using broth the ICD-10 and diagnostic and statistical manual of mental disorders (DSM -III) have found that the incidence rates for “restrictive” diagnostic group was 0.07-0.14 per 1000 and the difference across areas was not significant(2).

In a study done in an urban community in Chennai, India, the incidence rate for schizophrenia was found to be near 0.35/1,000 using the community field survey, which also accounted for the cases from the leakage study done to assess for cases that might have been missed secondary to social stigma(7).

1.1.3 CLINICAL FEATURES

Schizophrenia is characterized by fundamental distortions of thinking and perception, along with changes in affect which is either inappropriate or blunted. This disturbance involves the most basic functions that give person individuality, self-direction and a sense of being unique.

The onset may be acute with behaviour that is seriously disturbed, or insidious, with a gradual development of changed thinking, affect and conduct. The course of schizophrenia also shows great variation and is by no means inevitably chronic or deteriorating, with the outcome being, in some cases, complete, or near complete recovery.

The 10th Revision of the International Classification of Diseases and Related Health Problems – Mental and Behavioural Disorders (ICD 10, WHO 1992)
(a) Thought echo, thought insertion or withdrawal, and thought broadcasting; (b) Delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception; (c) Hallucinatory voices giving a running commentary on the patient's behavior, or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body; (d) Persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities; (e) Persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content, or by persistent over-valued ideas, or when occurring every day for weeks or months on end; (f) Breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms; (g) Catatonic behavior, such as excitement, posturing, or waxy flexibility, negativism, mutism and stupor; (h) "Negative" symptoms such as marked apathy, paucity of speech, blunting or incongruity of emotional responses, usually resulting in social

withdrawal and lowering of social performance; with these not being due to depression or neuroleptic medication;

(i) A significant and consistent change in the overall quality of some aspects of personal behavior, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.

The requirement for a diagnosis of schizophrenia is that a minimum of one very clear symptom belonging to groups (a) to (d), or at least two of the groups from (e) to (h) should have been present for a minimum period of one month. Group (i) applies only to a diagnosis of simple schizophrenia, with duration of at least one year being required.

According to the ICD 10, the diagnosis of schizophrenia should not be made in the presence of excessive depressive or manic symptoms unless it is clear that the schizophrenic symptoms preceded the affective disturbance. It should not be diagnosed in the presence of overt brain disease or states of substance intoxication or withdrawal.

The subtypes of schizophrenia described are – paranoid, hebephrenic, catatonic, undifferentiated, post-schizophrenic depression, residual, simple, other and unspecified schizophrenia.

The classification of the course is divided into the following – continuous, episodic with progressive deficit, episodic with stable deficit, episodic remittent, incomplete remission, complete remission, other and course uncertain, period of observation too short.

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM 5, 2013)
A. Two or more of the following, each present for a significant portion of time during a one-month period, with at least one of these being from (1), (2) or (3) 1. Delusions 2. Hallucinations 3. Disorganized speech 4. Grossly disorganized or catatonic behaviour 5. Negative symptoms B. For a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations or self-care is markedly below the level achieved prior to the onset. C. Continuous signs of the disturbance persist for at least 6 months. This must include at least 1 month of symptoms that meet criterion A and may include prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or by two or more symptoms listed in criterion A in an attenuated form. D. Schizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out because either 1) no major depressive or manic episodes have occurred concurrently with the active-phase symptoms, or 2) if

mood episodes have occurred during active-phase symptoms, they have been present for a minority of the total duration of the active and residual periods of the illness.

E. The disturbance is not attributable to the physiological effects of a substance or other medical condition.

F. If there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia are also present for at least one month.

G Course specifiers are as follows:

A. First episode, currently in acute episode, partial remission or full remission

Multiple episodes, currently in acute episode, partial remission or full remission

Continuous

Unspecified

B. With catatonia

Severity is rated by a quantitative assessment of the primary symptoms of psychosis, including delusions, hallucinations, disorganized speech, abnormal psychomotor behaviour, and negative symptoms. Each of these symptoms may be rated for its current severity on a 5-point scale ranging from 0 (not present) to 4 (present and severe)

1.2 QUALITY OF LIFE

The term Quality of Life was coined by Dr.Lyndon Johnson in 1964 and since then has been widely used in health care as a measure of quality of services. Quality of life' (QoL) is a phrase that became popular after the World War II in 1945. An individuals' appreciation of their Quality of Life is personal and can be influenced by several factors, including the stage of life one is in and the illness trajectory.

According to the World Health Organisation, quality of life can be defined as the individual's perception about his or her own position in life within the context of the culture and system of values in which the individual lives, as well as their own aims, expectations, standards and interests. Quality of life has been described by Norman Sartorius as the "individual's perception of their position in life in relation to their goals and within the value system which they have accepted and incorporated into their decision making". It is thus a holistic concept which takes into consideration the environmental health, development in economy and vitality of the society. The core domains on which subjective and objective quality of life depend upon are the physical, psychological and social function highlighting the need for medical care to be provided in a holistic and comprehensive manner to be truly addressing the quality of the patient's life(8).

Research related to quality of life includes the study of the social characteristics, mental and physical health, living environment political stability and economic

factors of the population being assessed. Such research has two basic principles: multi-dimensionality and subjectivity(9).

A review of literature on the quality of life in relation to health and illness have distinguished four models of quality of life; (a) subjective satisfaction model, (b) combined subjective satisfaction/importance model ,(c) role functioning model and (d) dynamic process model of quality of life (10).

Over the years many instruments have been developed to assess the quality of life in individuals with physical as well as mental illness. Attempts have also been made to develop rating scales which assess the subjective and objective quality of life (11).

The General Health Questionnaire which was developed by Goldberg was found to be useful in population health surveys as well as clinical settings. Its criterion related validity helps to distinguish persons at risk for acute psychological distress from "normal".

Comprehensive Quality of Life Scale by Cummins was developed as an attempt to assess the quality of life among the mentally challenged population.

Lehman's Quality of Life Interview is a semi-structured interview which is designed in such a way so as to assess the life circumstances of individuals with severe mental illness on both objective and evaluative domains. Quality of Life of chronic mentally ill populations in a wide range of settings can be assessed using this scale.

Lancashire Quality of Life Profile which was introduced by Oliver was based on a shorter form of Lehman's QoL Interview. It was aimed at assessment of individuals with chronic mental illness.

Quality of Life Inventory by Frisch is a scale that is adequately sensitive to clinical improvement. It can be used clinically as a treatment planning tool within inpatient and outpatient mental health settings.

Various rating scales have been developed for assessing the health related aspects of quality of life in individuals with schizophrenia. Among these are Schizophrenia Quality of Life Scale by Wilkinson et al, Heinrichs-Carpenter Quality of Life Scale, the Subjective Well-being under Neuroleptics and the Drug Attitude Inventory .The last two have been used to assess the effectiveness of anti-psychotic medications on Health Related Quality Of life(12).

In the 1990s, the World Health Organization undertook a project to develop an instrument called the WHO-QOL to measure the quality of life. This instrument was developed as a collaborative project involving numerous centres in different cultural settings, with New Delhi and Chennai being the Indian centres. One thousand and eighty-two patients with physical health conditions, persons without any health related issues, individual with schizophrenia, and primary caregivers from the family of patients with schizophrenia participated on the WHOQOL-100 and WHOQOL-BREF (a shorter version) field trials.

These scales were analysed using traditional standard psychometric methods and it was found that both versions of the WHOQOL showed satisfactory psychometric properties such as acceptability, evidence of convergent and

discriminant validity and internal consistency. (Lloyd et al., 1998) These are suitable for use in patients with different health related issues, including mental illnesses like schizophrenia, and in various populations, including caregivers(13).

1.2.1 QUALITY OF LIFE IN CHRONIC DISEASES AND SCHIZOPHRENIA

A study comparing two groups of 50 patients each, one group with schizophrenia and the second with systemic lupus erythymatosis, using the WHO-QOL BREF, concluded that the scores on the three domains of physical wellbeing, psychological health and environment were comparable in both groups; patients with schizophrenia differed significantly from the other group only in the social domain. There was a significant correlation between general psychopathology scores in the Positive and Negative Symptom Scale (PANSS, Kay et al.), and the scores on in the physical health domain and environmental domains. While patients with insight had lower scores on QOL-indicating a lower quality of life - in the domains of physical health, psychological well-being and environment, higher scores were found in the social domain. These associations were however not statistically significant. Among the clinical and demographic factors ,duration of illness was significantly associated with psychological well-being while age significantly correlated with the environmental domain of QOL(14).

In another study comparing 20 patients each of schizophrenia and multiple sclerosis it was found that that the total scores of WHODAS II and WHOQOL-

BREF were higher in patients with multiple sclerosis because of the higher scores in the physical domain. Both groups of patients expressed difficulties in the social domain(15).

In another study comparing the quality of life in 100 psychiatric service receivers and normal population and with individuals with diabetes mellitus among Turkish citizens, using the WHOQOL – BREF it was found that individuals with schizophrenia alcohol dependence and bipolar disorder scored lower than normal subjects on the physical domains of quality of life. Patients with alcohol dependence, bipolar disorder, and schizophrenia scored lower than healthy subjects on the physical aspects of quality of life. Schizophrenics had reduced scores in the psychological domain compared to individuals with affective disorder and diabetes, and healthy subjects. Also in the social relationship aspect, individuals with schizophrenia and substance dependence scored lesser when compared to healthy counterparts. Schizophrenia patients fared worst in relation to bipolar patients and diabetics in domains of social relationship(16).

1.2.2 QUALITY OF LIFE IN SCHIZOPHRENIA

An individual's well-being, both at the objective and subjective level is reflected in the quality and the general satisfaction with life. It is known that patients with schizophrenia have a poorer quality of life in comparison with healthy people in the community(17).

In a longitudinal study conducted in 64 patients at 1 year, and a mean of 8 years after their first hospitalization, it was found that the score in most domains of

WHO - QOL was significantly higher in patients with remission in the first as well as the second examination and did not differ significantly from a normal population of healthy subjects. At both points in time, significant correlations were found between Positive and Negative Symptom scale scores and WHO - QOL scores, especially in patients who were still significantly symptomatic(18). In a comparative study of 86 subjects with schizophrenia who were followed up after 1 month and 1 year after discharge ,it was found that both day to day functioning and subjective quality of life scores were low and significantly lower that of a matched control group. It was also found that both objective and subjective quality of life are significantly reduced immediately after hospitalization, and they remained relatively stable during the next 12 month period(19).

1.2.3 CORRELATES OF QUALITY OF LIFE IN SCHIZOPHRENIA

Quality of life in schizophrenia has been studied extensively in the last few decades'. Its correlation with various neuropsychiatric and psychosocial factors have been explored in many studies.

Quality of life and Neurological correlates

In a French study comparing 31 patients with schizophrenia of whom 19 had a high quality of life, Tc-labeled Ethylcysteinate dimer uptake study of the brain showed significant bilateral temporal hypo perfusion, primarily in the superior temporal sulcus (STS) in individuals with a high quality of life as compared with those who had a lower quality of life. This part of the brain has been reported to

be associated with self/other awareness and metacognition, which are associated with the functional substrate underlying QOL(20).

Quality of life and Psychological correlates

281 patients with schizophrenia were evaluated to study if Theory of Mind deficits are related to reduction in quality of life .It was found that only one item – difficulty in expressing feelings- in the subjective QOL scale had a significant negative correlation with ecological validity where real life and interpersonal situations were described. Otherwise the score of subjective quality of life did not correlate significantly with the Theory of Mind performance(21).

Quality of life and socio – demographic correlates

Socio - demographic factors have been found to influence the quality of life in patients with schizophrenia. In a study from Brazil it has been found that males and single status were a predictor of poorer quality of life(22). However another study from China showed that women scored less on quality of life. The difference in the quality of life as experienced by the two genders might be attributed to the socio cultural variation in role expectation (Amira Alshowkan et al 2012). Another study from Taiwan however, reported young age and single status to be associated with poorer QOL(23).Marital issues were reported to have the highest impact on quality of life, with individuals who chose non-disclosure reporting a better quality of life(24). A cross sectional study from France showed higher quality of life in those who were married and employed(25).

The patient's economic status has also been shown to influence the perception of quality of life (26). Assessment of 1208 participants of the European

Schizophrenia Cohort revealed that, accommodation, nation of residence and employment status were the most important predictors of subjective quality of life. The participants from Germany reported better QOL, possibly secondary to the mental health benefits available(27).

Quality of life and clinical correlates

Prospective Studies done on 1208 patients from a cohort of 3 European countries using the brief version of Lehman's Quality of Life Interview showed that Objective QoL scores were mostly related to the equivalent subjective Quality of Life scores. Mood symptoms suggestive of depressive and positive symptoms had a significant effect on almost all subjective domains of quality of life assessment scale(26).

In a study conducted on 165 in- patients with schizophrenia it was found that illness span, severe negative symptoms and processing speed in cognitive domain correlated with the QOL which was measured with Heinrichs-Hanlon-Carpenter Quality of Life Scale(28).

In a study on 80 patients with schizophrenia, quality of life studies done using the Lancashire Quality of Life Profile showed that more than 50 per cent of patients were satisfied with their life in general. The maximum subjective dissatisfaction was noted in the domains of partnership and mental health. The components of anxiety and depression in the PANSS, drug induced parkinsonian symptoms, and a negative attitude toward antipsychotic medication were shown to negatively influence the quality of life , while cognitive symptoms and employment status correlated with higher QOL scores(29).

120 schizophrenic patients from Taiwan were assessed for the subjective quality of life; self-efficacy, self-esteem, social impact of illness, depressive symptoms and number of hospitalisations had significant correlation with the quality of life(30).

The European Schizophrenia Cohort found that depressive symptoms were an important predictor of subjective quality of life (27).

While quality of life among patients with schizophrenia have clearly been shown to correlate with multiple factors like illness severity, medication and stress ,many protective factors have also been delineated including premorbid personality, the level of psycho social support and modalities of treatment used(31).

83 Asian patients with schizophrenia were compared with 47 matched controls it was found that high scores of negative symptoms on PANNS and general psychopathology, cognitive deficits which included working and verbal memories and poor functioning scores were associated with poor quality of life. A low level of psychosocial functioning were associated with poorer QOL, however the level of psychosocial functioning was not found to mediate the effects of symptoms and neurocognitive deficits on quality of life(23).

In a study done among 66 middle aged women with schizophrenia it was found that there was no significant correlation between the objective and subjective QOL measures. Among the various items, PANSS items for lack of energy and Rehabilitation Evaluation Hall and Baker (REHAB) item for community skills

were found to affect the objective QOL ,whereas the PANSS depression and paranoia items had impact on the subjective QOL(32).

117 patients with schizophrenia were evaluated under the Early Assessment Services for Young People with Psychosis (EASY) and compared with normal population; persons with schizophrenia were found to have low scores in all domains of quality of life. Scores of various domains of the QOL had significant inverse correlations with the total score of depression. Young patients with an index episode of schizophrenia had poorer QOL during the period of untreated psychosis than the normal population in the community(33).

A German study on 84 patients revealed that among the PANNS sub scores the scores of anxiety as symptoms and depression at syndrome level were associated with various domains of quality of life, during and post hospitalization. However while positive symptoms did not have any significant association , negative symptom profile and cognitive symptoms were associated with various domains of QOL(34).

In a study conducted on 60 patients with schizophrenia it was found that PANSS score for general psychopathology had the most predictive value for subjective and combined Quality of Life scores, while the PANSS score for positive symptom domains had the most predictive value for objective QOL ,depression score on CDSS was not a determining factor for QOL. A negative correlation was found with treatment side effects and disability with the domain of subjective and combined QOL(35).

Studies conducted in 64 patients on the subjective and objective quality of life showed that only the motivation/energy scale, but not the other scales of the Schizophrenia Quality of Life Scale, correlated with the objective Quality of Life scale and the negative symptoms score on Brief Psychiatric Rating scale predicted the Quality of Life Scale score. It was also noted that the Calgary Depression Scale for Schizophrenia score predicted each scale of the Schizophrenia Quality of Life Scale(36).

Studies done on 36 patient on psychotropic medication for schizophrenia revealed that the scores for delusions a positive symptom, anxiety and depression which are components of general psychopathology on the Positive and Negative Symptom scale correlated prominently with Quality of Life and subjective well-being scores(37).

In a study conducted among 53 patients with adolescent psychotic illness it was found that ,a diagnosis of schizophrenia was associated with overall low QOL compared to a mood illness with psychotic symptoms .It was found that depression was one the most strongly associated factor with QOL in the same subjects(38).

Study done on the Data of Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) trial on 1477 patient with schizophrenia were analysed on other domains of Health Related QoL , symptomatology and resource use. The group was divided into 4 (a) neither prominent positive nor prominent negative symptoms (n=575) (b) only prominent negative symptoms (n=274) (c) only prominent positive symptoms (n=295) or (d) with both prominent positive

and negative symptoms (n=303). It was found that there was a significant linear decline in the outcome measures with each subsequent symptom group, with both prominent positive and negative symptoms being combined together incrementing the decline further on quality-adjusted life-years .Patients with both prominent positive and negative symptoms of schizophrenia are independently associated with significant decline in functionality, HR QoL, and lost workdays for the primary caregiver. An elevated burden is observed in patients with highest symptomatology(39).

In a group of patients with schizophrenia, presence of symptoms which are obsessive and compulsive in nature were assessed and it was found that here was no difference in the Quality of Life among patients without obsessive compulsive symptoms, with obsessive compulsive symptoms and those with comorbid obsessive compulsive symptoms. However the quality of life subscale score on interpersonal relationship were lower in patients with obsessive compulsive symptoms that win those without. Also it was recognized that individuals with cleaning and repeating compulsions had lower Quality of Life (40).

Quality of life and Duration of Untreated Psychosis

In 84 Polish patients with schizophrenia a follow up study showed that both the subjective and objective quality of life was low one month after hospitalisation .On follow up it was found that subjective Quality of life did not change but the objective quality of life improved on 43 domains, decreased in one and remained

unchanged in another. The duration of untreated psychosis and psychopathology were the major predictors of both subjective and objective QOL(41).

In 53 patients who presented with schizophrenia for the first time in Dublin it was found that the quality of life was determined by the duration of untreated psychotic symptoms along with premorbid adjustment and the symptoms , irrespective of age of onset of symptoms and gender(42).

Quality of life and Insight

A study conducted in Japan on 47 patients with chronic schizophrenia who were hospitalized showed no correlation between insight and quality of life. The only predictor for poor quality of life was poor attention span(43).

In a cohort study on 139 Chinese patients with schizophrenia it was found that lack of adequate insight was associated with higher scores on the mental and physical components of QOL and all three domains of PANNS, that is positive, negative and general psychopathology(44).

In a cross sectional study done in France it was found that, those with good insight into illness had a poorer quality of life while patients who were aware of their positive and negative symptoms had a better QOL. No statistically significant basic neuropsychological measure deficits were present(25).

Quality of life and stigma

In 199 Taiwanese patients who were under treatment for schizophrenia ,it was found that the direct predictors for all 4 domains of quality of life were symptom profile , stigma, mastery, and social support .Among them mastery was found to

have the greatest direct effect on Quality of Life, whereas stigma had the highest indirect effect which was mediated by mastery and social support(45).

Quality of life and Suicide

A study conducted in the United States reported that quality of life; especially the social relationship domain and self-esteem combined together could collectively predict suicidal ideation based on the escape theory of suicide. In this study self-esteem was found to mediate the correlation between intentional self-harm ideation and quality of life(46).

Quality of life, Family and Expressed Emotions

Improved perception of family function is seen in clients with schizophrenia with good quality of life, confirming the importance of families as support networks both socially and emotionally and also as agents in meeting the individuals' needs(47).

31 adolescents with early onset schizophrenia and their family members were evaluated and it was found that perceived criticism was associated with very poor quality of life in the patients' relationship with parents and peers(48).

A follow up study of 128 schizophrenia patients found that the levels of distressing emotions, coping with tasks, levels of activation symptoms, self-esteem and support from peers affected the quality of life at the time of index admission. The changes in quality of life over time showed correlation with social support, expressed emotions, avoidance and emotion based coping skills, side effects to drugs, self-esteem emotional distress paranoid symptoms and lack

of energy. The determinants of the change quality of life was found to vary in a hospital setting when compared to a non-hospital setting(49).

Quality of life and functioning

Clients diagnosed with schizophrenia often present with problems in diverse areas of daily life: they are mostly unemployed, single, and have a low educational level with difficulty in obtaining residential facilities. A significant proportion of individuals with schizophrenia have poor social contacts or friendship, are isolated and have difficulties in engaging in leisure activities(50).

A community study of 201 participants from Hong Kong revealed that community and social functioning were the strongest predictors of quality of life(51).

In China a study among 119 individuals with schizophrenia showed that the individuals had a moderate quality of life, lower QOL being correlated to long work hours, working in rehabilitation associated careers and deriving welfare from social support schemes. The above along with stigma related issues and job related satisfaction accounted for approximately more than 48% of total QOL variance (24).

In 295 patients from 11 centres with chronic schizophrenia, those who were working or studying had better functionality and quality of life. Better QOL was observed in those who were engaged in academics or fulltime employment than those who were part time students or workers(52).

Quality of life and Needs

The European Psychiatric Services: Inputs Linked to Outcomes and Needs (EPSILON) study compared clients' needs in five cities in the European continent and found that needs diverge in various contexts; most of the unmet needs were found in large urban areas, where poverty, unemployment, and other psychosocial problems are more severe. Psychosocial needs are the most common unmet needs and they included activities of daily living, company, and intimate relationships. Among the unmet needs poor social contact was one of the domains of maximum dissatisfaction leading to poor quality of life(53).

In a cross sectional study of 255 patients with schizophrenia, family and oral needs (food, smoking, drinking-related statements) were found to be positive predictors of QOL irrespective of gender and age. The inverse predictors of the subjective score of QOL were various aspects of the illness and also negative wellbeing(54).

In a 5 nation study on 404 patients with schizophrenia it was found that increased quality of life and decreased unmet needs were seen in low and high functioning level score subgroups respectively. An increased variability in Quality of life scores was seen in low functioning patients when compared to those who were either medium or high functioning. In the low functioning subgroup, both illness-related and other needs had an impact on Quality of Life, whereas non-illness needs influenced QOL in medium and high functioning patients(55).

In a study done on 95 patients the scores of Quality of life score in the domain of general activity along with scores of other factors such as support from friends , life satisfaction and satisfaction with medicine were found to be the negative predictor of Camberwell Assessment of Need–Patient Version subscale scores(56).

In a study of 130 patients with schizophrenia from Kuwait, it was found that the major correlates of physical QOL were unmet social needs, care giver burden, medical professionals' awareness and perception of unmet needs, self-esteem, and positive psychotic symptoms on the BPRS scale(57).

Quality of life and cognitive symptoms

Studies done in schizophrenia have shown that resolution of cognitive symptoms and positive symptoms lead to a better quality of life, secondary to being engaged in fruitful labour. Among the cognitive symptoms, valid predictors of employment success which are in independent of the intensity of positive symptoms are verbal learning and executive function which could directly affect employment possibilities and thereby the quality of life of the individual(58).

Among the aspects of cognitive inhibition, in a study conducted among 10 healthy controls and 10 stable patients with schizophrenia it was found that individuals with schizophrenia had major impairments only in the suppression function, while the access and restrain function were intact. No correlation could be elicited with the QOL and functions of cognitive inhibition(59).

A study which compared 53 patients with 31 controls found that the performance of the former was lower in the domains of memory, executive functioning,

learning and social knowledge. It was found that the deficits in memory and social knowledge were associated with poor QOL especially the capability for empathy and social initiative(60).

In an assessment done on 44 individuals comparing changes in various aspects of cognition and QOL and subjective satisfaction with life, it was found that verbal memory (a cognitive measure) and facial recognition (a social cognitive measure) were associated with betterment of objective QOL, while improvements in subjective satisfaction with life were associated with verbal skill and verbal memory(61).

In a study from Austria on 60 patients with a diagnosis of schizophrenia for more than 2 years on Clozapine or Olanzapine, it was found that the subjective quality of life and needs for care scores did not show any significant correlation with cognitive functioning(62).

Quality of life and physical health

In 225 Japanese patients, aspects related to quality of life such as mental health, functioning in physical and emotional domains and general health role were negatively associated with increased body mass and obesity(63).

In a cross sectional study done in a Canadian population with 36 participants with early schizophrenia, it was found that total body fat had a positive correlation with sedentary behaviour which in turn was associated with negative health-related QOL(64).

A German study compared 31 patients with schizophrenia and a normal population with respect to their physical capacity and quality of life. Physical

Capacity was assessed by peak oxygen uptake and power output. Patients with schizophrenia showed reduced VO2peak and power output and had lower QOL. While correlations were found between physical capacity and several subscales of quality of life in the control group, the restricted physical capacity seen in the patient group showed no relation to their subjectively assessed worsened quality of life. This suggests that patients with schizophrenia evaluate limitations arising from physical capacity differently than healthy controls(65).

A study on the quality of sleep in patients with schizophrenia reported that patients who sleep poorly were more depressed, distressed and scored low on all domains of quality of life. These patients also reported increased side effects to medications. The correlation between the poor quality of life and poor sleep quality was found to be appears to be both independent and synergistic with depression, level of distress and drug related side effects(66).

Quality of life in the Geriatric population

There have been only a few studies of quality of life (QOL) among older persons with schizophrenia. A study on a community-dwelling multi-racial geriatric population compared 198 patients with schizophrenia and 113 controls; a low Quality of Life Index score was obtained in patients as compared to the control group. Variables that were significantly associated with Quality of life Index included fewer depressive symptoms, more cognitive deficits, fewer acute life stressors, fewer medication side effects, absence or reduced financial strain, and better subjectively rated health (67).

In another study that included geriatric patients with schizophrenia, it was found that severity of negative symptoms and insight directly affected the functional capacity and quality of life(68).

Quality of life and Treatment Options

In a study conducted among 4239 patients in China, it was found that patients on antipsychotic poly pharmacy obtained higher scores on QOL on the mental domain as compared to those on antipsychotic monotherapy(69).

In a study conducted among Japanese patients a positive correlation was seen between the chlorpromazine equivalent doses of typical antipsychotics were correlated with the QOL subscale score for dysfunction of psycho-social activity Increased duration of exposure to antipsychotics was found to have a dose dependent correlation with dysfunction in the psychosocial domain. A significant correlation was also found between the extrapyramidal symptom score and dysfunction in the psychosocial domain and between the negative symptom score in BPRS and all the subscales on the quality of life assessment scale(70). Hayhurst et al studied the predictors of change in observer-rated QOL in 363 patients with schizophrenia during the CUtLASS clinical trial. It was found that improvement in QoL was predicted by reduction in negative and depressive symptoms and improvement in adherence rating. They also reported that that greater social activity, reflected in better QoL scores, improves negative symptoms (71).

An Austrian study on 60 patients with schizophrenia, who were on Clozapine or Olanzapine reported that drug side effects and psychopathology, along with

weight gain and female sex were associated with a lower quality of life while cognitive symptoms correlated with better quality of life(72).

An Iranian study on 60 patients with schizophrenia found that needs-assessment-based psycho-education resulted in a statistically significant improvement in quality of life in the psychosocial, symptoms and side effect subscale, but not on the energy subscale, as compared to the control group. The quality of life among the caregivers of both group however, remained the same(73).

A randomized control trial involving 64 patients with schizophrenia had four arms with different interventions: no intervention, education, progressive muscle relaxation alone and education combined with progressive muscle relaxation It was found that the last intervention reduced functional disability and positive symptoms significantly and this change was sustained at follow up ,with a significant improvement in QOL from baseline(74).

A randomized control trial of 67 patients with schizophrenia studied the differences between a control arm and those that received computer assisted cognitive remediation. In the intervention arm improvement was seen in domains of processing speed, working memory and reasoning and problem solving, leading on to an improvement in the overall quality of life(75).

Quality of life - Indian Studies

As in other countries, in India in the past treatment for schizophrenia was primarily limited to institutional settings. Since the advent of psychotropic drugs the process of deinstitutionalization has resulted in a shift of patient care from

hospital to home and community based setting, subsequently resulting in a greater focus on QOL and strategies to improve it(76).

60 patients with schizophrenia in remission were assessed at a hospital in Ranchi and it was found that there was significant difference between the genders with respect to quality of life and disability. While males had a better quality of life, females had more disability(77).

Religious affiliation was assessed among 103 patients with residual schizophrenia and it was found that all domains of religiosity have an impact on QOL. The domain of inner peace had the maximum variance with all aspects QOL except on the domain of independence, which showed variance with spirituality of the individual(78).

In a study from eastern India among patients with schizophrenia, it was found that the scores of quality of life varied in the various sub domains. Single status, male gender and higher educational level predicted a not so good quality of life. The domains of the WHO–QOL which assessed the physical and psychological domains showed correlation with the PANSS general psychopathology and total scores while the domains of social well-being and environmental health had no significant correlation with scores on the PANSS score. Of 34 patients with schizophrenia in the acute phase, it was found that positive symptoms showed significant negative correlation with the psychological domains of QOL The PANNS total and general scores were significantly and negatively correlated with physical and psychological health and significantly correlated with the social domain in the maintenance phase(79).

Another Indian study utilized the WHO-QOL BREF and the PANSS .Scores on the positive subscale and the total PANSS scores showed a negative correlation with the physical, psychological and social relationship domains and the total QOL scores. General psychopathology had a negative correlation with all subscales of WHOQOL –BREF(80).

A high level of negative expressed emotions in the family secondary to negative symptoms, formal thought disorders and bizarre behaviour were found to be associated with a poor quality of life(81).

Studies on Assessment of Quality of life

In a stratified sample of patients with schizophrenia it was found that the patient group which was similar in clinician rated and self-reported QOL, it showed low to moderate correlation between symptom domains and side effects(82).

A 6 month prospective randomized controlled open label study on 124 schizophrenia patients it was found that among the 3 arms of assessment a higher global satisfaction was present in the Quality of Life feedback group compared to the standard psychiatric assessment and Quality of Life assessment with standard psychiatric assessment. Even though this was not statistically significant during the follow up period, it shows that measuring quality of life in clinical practice is relevant(83).

However a systematic review of the results of studies on quality of life of patients with schizophrenia did not show consistent relationships between objective living conditions and the patients' subjective evaluation of quality of

life. The subjective quality of life was often influenced by the level of depressive symptoms, personality related issues and coping skills and methods(84).

1.3 EXPLANATORY MODELS OF ILLNESS

Explanatory models (EMs) of illness as defined by Young, are a set of generalisations which enable the thinker to produce information about particular sickness episodes or events(85). Klienman, one of the pioneers in this field, defined it as the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process(86).

Some research and medical practice have been influenced by the Germ Theory of illness, by which individuals are conceptualized as chemico–physical entities. Explanatory models of illness help to understand how illness is subjectively experienced in people who do not always agree with the biomedical model(87).

During the early phase explanatory models were presented as conceptual tools to appreciate how different socio-cultural contexts affect the ways that individuals negotiate their experiences with an illness. Explanatory models are created and recreated by individuals living within a cultural matrix of relationships, expectations, social values and beliefs, and these matrices were what were defined as social or cultural reality, which should be and can be differentiated from the physical reality of the environment and the biological reality of the body. In any particular episode of an illness, an individual tends to attach meaning to the experience of illness by creating narratives describing its aetiology, symptoms, pathophysiology, course, and treatment. Individuals apply content from their cultural reality to define each of these five categories in a

creative process that is motivated by the need to make sense of dysfunction. A semantic network is formed by the connections among these five concepts, guided by symbolic reality. Explanatory models, as originally conceptualised, are basically schematics of these above said semantic networks(88).

It has been noted that three domains are present within most pluralist systems: the professional, popular, and folk sectors. Each of these sectors within the pluralistic system consists of its own social reality through which each individual can formulate and modify explanatory models pertaining to particular illness episodes(89).

The fund of esoteric knowledge held by a professional in the system of traditional healing differentiates it from the western system of medicine. This esoteric background can be utilized in assessing the explanatory model held by the individual(90).

In a study conducted among clients during their index visit to mental health services, it was found that explanatory models were not a set of coherent beliefs, instead a collection of various explanations that are either simultaneously held or that are accepted or given up rapidly. Hence it was countered that the "explanatory model" concept is too firm and fixed to imply the fluidity of beliefs among clients who receive mental health services. Therefore the conceptualization of "explanatory map" was introduced briefly as a replacement with implications in both the clinical and theoretical domains(91).

Since recent years there has been an emphasis in medical anthropology on eliciting explanatory models of illness. Research into health and illness

behaviour requires both the elicitation of patients' explanations of illness and examination of what they really do in practice. It has been found that language may not directly reflect concepts about diseases and that explanation do not directly predict health-related actions. Health-seeking behaviour and attitudes may be determined more by socio-political factors than by underlying models of illness(92).

Explanatory models should help medical professionals better communicate with their patients and are as important as their biomedical viewpoints. This helps them to identify what is at stake for the clients, their families, and the community at large as well what is at stake for them. It helps physicians perform a mini ethnographical assessment which provides crucial information that can be used to negotiate the various treatment options available with the client. Exploring the explanatory model is an elective affinity to the patient and this orientation to explore the explanatory model finally becomes a part of the clinicians' sense of self and this interpersonal skill forms a part of his clinical resources(93).

The explanatory model of illness can be considered as a tool which helps to conceptualise the operational definition of representation of mental disorder in the social context. They are mostly applicable to both consequences (impact or outcome) and causes of the illness.

Explanatory model of illness refers to the manner in which patients explain their health conditions and consequences. It is an important part of illness appraisal and in making sense of it from the patient's, clinician's and caregivers'

perspective. Patients often search for causes to which they attribute the onset of an illness and hence it has been considered as a predictor of patient coping, adherence with treatments and as predictor of disease and treatment outcome. Contrasting explanatory models exist that attribute diseases to physical cause as well as to psychosocial aetiologies. The former category may include examples such as one's genetic profile, an underlying pathophysiological process (e.g. inflammation), injury, infectious agent etc. The second includes "stress," often a generic term referring to life events, inter personnel issues and spiritual causes, to name a few(94).

It has been known that etiological or causal factors have an impact on psychiatric illness at the micro and macro levels, both internal and external to the individual, and involves processes that are best understood from biological, sociocultural and psychological perspectives. Hence traditional models of scientific explanations that strive for single broadly applicable explanatory laws are poorly compatible to psychiatry. According to the levels of explanation, rather than adopting a single explanatory approach, as is often advocated in conventional theories of science, etiological models for mental illnesses need to be pluralistic or multilevel in nature and concept(95).

An explanatory model reveals how people make sense of their illness and their experiences of it. Explanatory models are often used to explain how people view their illness in terms of what causes it, how it happens, what will make them feel better and how it affects them. This is a method which can be used in both clinical settings and qualitative research and it is considered as a method to

obtain an individual' explanations for a particular phenomenon. In research setting, these explanatory models allow researchers to collect textual data. The 'explanatory model' concept was intended to draw on social-anthropological approaches to understanding subjective experiences of distress and to apply them to psychiatric practice. Cultural variations in appreciation of mental distress are important issues for implementing healthcare measure. They can affect the pattern of communication between clients and professionals and may be a precipitating factor for patient disengagement, misdiagnosis and disparities in outcomes, access, and overall experiences of treatment by clients. Taking into account patients' explanatory models (EMs) of mental distress along with an ethnographic assessment is fundamental to client-centred care, and improved treatment outcome and experiences of treatment(96).

Asian American patients may not often express their emotional pain, instead Somatic complaints may be expressed. This somatization may be interpreted as a defence mechanism for the guilt and shame associated with seeking treatment for mental illness(97).

According to the American Psychiatric Association (2002), DSM –IV recommends five elements in the cultural formulation. The second of these relates to the client's explanatory model of the illness, and explores cultural factors beyond race and ethnicity. Physicians often feel that the patient's view is exotic, unscientific and, more specifically, embedded in a cultural world view that is beyond their comprehension. In a clinical setting the psychiatrist does not have to be from the same cultural background to achieve a therapeutic alliance

with adequate empathy .Instead exploring the explanatory models held by service users may allow a broader exploration of the affects and emotions associated with their own understanding of their problems and it will lead on to a better empathetic therapeutic alliance. It has also been shown that evidence-based interventions can be delivered despite differing explanatory models(98).

It is known that local culture and beliefs influence many aspects of human behaviour such as idioms of help-seeking, distress, treatment adherence, patient satisfaction and coping. Perspectives of psychiatric illness, or explanatory models, play an important role in health-related behaviours and in patient–health worker interaction. It has been found that Asian Americans and Pacific Islanders have the lowest rates of utilization of mental health services of any ethnic population. This may be explained to be secondary to cultural stigmas and financial shortcoming(99).

Queries have existed regarding the relationship between explanatory models of illness, patient satisfaction with psychiatric care provided and the ethnicity of the patient. In a study which included 21 white British nationals and 63 ethnic minority patients who were in-patients, either voluntary or involuntary, it was found that patient satisfaction was dependent on the explanatory model of the illness. If there was concordance between the patient's and psychiatrist's explanatory model, the chance of achieving patient satisfaction was maximum(100).

There are conceptually 5 major questions in explanatory models regarding an illness episode, which covers the domains of aetiology, symptom onset mode

and time frame, underlying pathophysiology, course of illness, including both severity degree and the sick role which can be described as acute and chronic etc. and the treatment required for the illness.

It has been noted that individuals with psychotic symptoms, who are able to re label their experiences with psychosis are later able to give a non-psychotic explanation for the alterations in themselves. These explanations often match the illness beliefs held by their culture and community. Based on this explanation the individual is said to possess insight if he is able to agree to the need for restitution and is able to seek indigenous help(101).

Explanatory models are elicited through a series of specific open-ended questions. Arthur Kleinman is famed for devising the first explanatory model questionnaire, which contained eight questions. Explanatory models make an attempt to distinguish between illness and disease, and attempts to connect the gap between constructions of reality and knowledge in the clinical framework(102).

Later researchers have refined Kleinman's model of explanatory model of illness into a mixture of open-ended and direct questions that lets them quantify results and a number have been devised with this purpose in mind.

BEMI: The Bart Explanatory Model Inventory was developed by a researcher who identified a gap in culturally varied beliefs assessed by other instruments. It is a mixed methods instrument aimed at helping clinicians understand and assess patients' explanatory models.

EMIC: The Explanatory Model Interview Catalogue is a semi - structured interview was an attempt to integrate frameworks from clinical, epidemiological and social science work. It is based on the framework presented by Kleinman. The EMIC, similar to the SEMI, is developed for use with a clinical population.

CMQS: The Causal Models Questionnaire for Schizophrenia was developed in China and was aimed at exploring patients' and their family members' causal explanations for their illness. The instrument is has four parts.

MDEMQ: From his experience with Cambodian patients, Eisenbruch developed the Cambodian Explanatory Model Schedule (CEMS), specifically aimed to explore the illness beliefs among South East Asians. An expanded from of CEMS gave rise to MDEMQ which made it possible for implementation among people from various cultures and background. Eisenbruch and Handelman developed the CEMS on the basis of Murdock et al's framework, the World Ethnographic Atlas. This framework consists of a classification of theories of the causes of illness, divided into natural and supernatural categories. The natural category consists of infection, stress, organic deterioration, accident and overt aggression. The supernatural category, on the other hand, consists of mystical, animistic and magical causes of illness. The researchers added some aspects of illness causations derived from Cambodian participants, including humoral problems and vital organ disruption. From this background, a 26 - item questionnaire was developed and pre-tested. Findings suggested that the categories put forward by Murdock et al. could not cover every aspect of illness causation presented by the Cambodian sample. Thus, Eisenbruch developed a

questionnaire to cover several more aspects of the theories about causations of mental illness, drawing on skeletal a framework which was presented by Murdock et al.

Qualitative methods: Different qualitative methods are useful in obtaining in - depth knowledge and to elaborate upon the realities of the participants, and the meanings given to these realities, both in clinical and non - clinical populations. Open questions can more easily elicit thoughts about EMs not targeted by questionnaires(103).

1.3.1 SHORT EXPLANTORY MODEL OF ILLNESS

The SEMI interview explores '*emic'* perspectives of illness. It employs questions which are open-ended and semi-structured. The clients are encouraged to speak openly about their attitudes and experience with the aim of eliciting concepts held, and relationship to current situation and culture. Probes are also employed to confirm the concepts which are mentioned by the client and to explore domains, which the clients did not volunteer. The interview is divided into domains to cover the nature of presenting problem, subject's background, help seeking behaviour, beliefs related to mental illness and interaction with physician/healer(104).

The role and impact of individual explanatory models on client satisfaction with consultations by physicians, joint working towards health, treatment adherence and outcomes in clinical domains could not be assessed systematically. This was due to the lack of equipoise between quantitative and qualitative research

methodology. It was found that using Short Explanatory Model Interview (SEMI) bridge the gap in a flexible manner between quantitative and qualitative methodology in the gathering of health belief data(105).

1.3.2 EXPLANTORY MODEL OF ILLNESS IN MEDICAL ILLNESS

Explanatory models of illness have been explored in both medical and surgical conditions which are chronic in nature. In a study conducted among the traditional health practioners from Sub Saharan Africa regarding their explanatory model of illness of HIV and Sexually transmitted illness, it was found that even though they acknowledged the allopathic risk factors and modes of disease transmission, their beliefs around aetiology were generally located in the religious domains with infection often being attributed to lack of respect for/non-adherence to traditional rituals and rites resulting in ‘a polluted or dirty haematological status’(106).

In a study conducted in Chicago among 75 South Asian respondents it was found that, people conceptualised health and disease in e four domains- the physical, religious, behavioural and psychosocial domains. Among individuals of Islamic faith more spiritual factors were evoked while females considered domestic skill and needs along with positive mood as essential in their concept of health. Males were found to attribute behavioural issues such as substance use as an aetiology for disease(107).

1.3.3 EXPLANATORY MODEL OF ILLNESS IN MENTAL DISORDERS

In Germany a study was conducted among 3642 individuals from a normal population using case vignettes of patients with schizophrenia, depression and alcohol dependence to assess whether the lay person was in agreement with the three biogenetic explanations of the illness; 'Chemical imbalance of the brain', 'brain disease' and 'heredity'. It was found that Chemical imbalance of the brain' and 'brain disease' were associated with a stronger desire for social distance in schizophrenia and depressive disorders, and with increased acceptance in society in alcohol dependence, whereas 'heredity' was not significantly associated with social distance in any of the investigated mental disorders. All the three bio-genetic causal and etiological beliefs were associated with more fear in all three illnesses. Explanations from the genetic point of view were found to have different effects in different disease conditions, and it was found to be detrimental in depressive disorders and schizophrenia. No de-stigmatizing potential of the explanatory model of 'chemical imbalance' could be found in any of the three illnesses(108).

In London, a study conducted in community psychiatric patients who were referred for cultural consultation were assessed using narrative-based ethnographic method of assessment. They were interviewed using Barts Explanatory Model Inventory and Checklist (BEMI) to assess the EMs of their mental distress. It was found that patients mainly attributed the causes and consequences of their mental distress to emotional and psychological factors,

which were invariably linked to existing social issues and interpersonal events. Also the solutions desired by the patients mainly focused on treatment, social and systemic interventions. It was concluded from this study that eliciting the Explanatory Model of Illness could contribute to a comprehensive psychiatric assessment in routine care and can be used by professionals within a short timeframe and with minimal training(96).

In a study conducted among South African traditional healers it was found that they held various explanatory models for psychotic and non-psychotic mental disorders. Eighteen in-depth interviews were conducted among traditional healers and four case vignettes were presented which included schizophrenia, depression, panic and somatization. Following this the traditional healers' views on the nature of the problem, aetiology, sequlae and outcome, treatment and expectations of patients were elicited. It was found that psychotic diseases appear to be the main example of mental disorders and were offered treatment with traditional systems of medicine, while non-psychotic presentations were not viewed as a mental illness at all(109).

In a paper which analyzed various studies from sub-Saharan Africa, which examines beliefs relating to mental disorders, it was found that there was a rich diversity of beliefs. However a number of common and shared concepts were found within this diversity. It was found that African cultures do distinguish between the mind and body. According to them mind is cited as residing in the head as well as the heart or abdominal region. Also religious or spiritual causes were frequent explanations for mental disorders. It was found that there were

some similarities with biomedical concepts of mental disorders, but there are also significant differences. Psychotic disorders were often identified as 'madness' though importance was placed on behavioural symptoms rather than delusions .Among neurotic presentations explanations for their symptoms were much more varied and often somatically defined and may often not be considered to be mental disorders at all(110).

A study which explored causal attributions of mental disorders was conducted among 159 participants from 16 community samples, 2 patient samples and 2 caregiver samples in Jamaica. It was found that the most common causal attributions of mental disorders were substance – related causes (including cannabis), biological causes (including chemical imbalance, familial transmission, and bad blood), psychological causes (including stress and increased thinking), social causes (including inter personnel problems and loss of job), and spiritual or religious causes (including Obeah)(111).

In a study conducted in United States using the Explanatory Model Interview Catalogue in 190 depressed Chinese immigrants, it was found that clients were more likely to report chief complaints and illness labels related to depressed mood than physical symptoms as was thought earlier. Approximately fifty percentages stated that they would conceal the name of their problem from others and mean stigma levels were found to be significantly higher. A majority of the clients identified psychological stress as the most likely cause of their problem even though there has been an increase in the acceptance of biomedical model of the illness(112).

A study using the Revised Clinical Interview Schedule and Short Explanatory Model Interview was conducted in 100 patients with medically unexplained somatic symptoms attending a primary care facility and it was found that a good proportion of patients held a combined medical and non-medical view about their condition. A substantial proportion considered themselves to be having specific physical diseases and attributed their problems to variety of causes, considered their condition as serious and feared death or major disability as a sequlae. Only a minority attributed the conditions to psychological causes even though many acknowledged emotional dysfunction secondary to their conditions(113).

In a study conducted in South Africa using semi-structured qualitative interviews on women from a lower socio-economic background who had a diagnosis of depressive disorders, to understand the explanatory models of depression, it was found that domains of poverty (food and financial insecurity and insecure residential facility), unwanted pregnancy, and interpersonal problems especially rejection by partner, infidelity and general lack of support were reported as the causes of depression. Factors which were found to be exacerbating the depression included negative thoughts and social isolation(114).

In a study addressing 24 clients of mental health services as a part consumer-operated service centre it was found that participants of the study held explanatory models which included developmental stressors and biomedical aetiology, which was in consistence with the stress-diathesis model of mental illness. It was found that incorporating the stress-diathesis constructs into the

functioning programme at this centre helped to increase potential of service meaning and relevance(115).

1.3.4 EXPLANATORY MODEL OF ILLNESS IN SCHIZOPHRENIA

In a study conducted in the United Kingdom among 8 participants from 4 ethnic groups, twice over the span of one year, using the Short Explanatory Model of Illness, it was found that the explanatory model regarding the illness was not consistent. It was found to vary between the index assessments and follow up interview. However the prognosis of the illness and perceived illness severity remained more or less constant over time(116).

In a comparative study between 23 German and 24 Jordanian patients, it was found that nationals from Jordan who were of Islamic origin had the tendency to give an esoteric explanation for the causality of their illness , found the illness more fear evoking and had increased trust in the clinician treating them. They also gave explanations in favour of religion as an underlying factor of their illness and also reported that the farther away they were from the family the better they felt. However both groups responded similarly regarding the biological model of illness ,that psychosocial stress was a factor for their illness and regarding their belief in drugs(117).

In Britain a study conducted among 3 groups of second generation immigrants of different ethno-cultural backgrounds and a 4^{th} group of patients of British origin, it was found that the explanatory models varied among the ethnic groups. The clients with British origin preferred to cite the biological model of illness while the other three non-British groups gave supernatural causes for the same illness.

While the explanatory model did not affect the compliance of treatment, it was found that the biological model was associated with better therapeutic alliance and satisfaction with treatment(118).

In a German study which compared the relatives of patients with schizophrenia and the lay public, it was seen that the primary caregivers held on to a biological model of illness while the lay public held on to psychosocial factors like stress as the reason for schizophrenia. This difference could have been secondary to the caregiver exposure to psycho education and might also stem from their need to deal with their guilt of possibly having precipitated the mental illness in their loved one(119).

In an another study conducted among German citizens in two time periods with a time span of 2 decades separating the assessments, it was found that the publics' concept about the causality of schizophrenia had changed considerably from a non-medical model of sociocultural, behavioral and psychological stressor to that of a biomedical model. In spite of the change in the model of illness the fear with which the public held people with mental illness seemed to have increased, thereby increasing the social distance with patients .This was because a biological model seem to have the rendered to the public the feeling that the patients did not have control over their symptoms and were hence more dangerous(120).

In a systematic review of 105 literatures which yielded 45.2% of schizophrenia like spectrum disorder, it was found that many of them had attributed the psychotic symptoms to Jinn, based on Islamic beliefs. This non-medical model

of illness was seen to have a major impact on the evaluation, management, course and outcome of the psychotic symptoms(121).

In Hong Kong a study done on 162 patients with schizophrenia in a rehabilitation setting which was community based, it was found that intellectual insight and a non-medical causal explanation of personal responsibility for the aetiology of the illness was found to have significant correlation with increased levels of stigma related to self(122).

In a pluralistic community like India multiple contradictory explanatory models which are the least stigmatizing will be attributed to schizophrenia. These complex explanatory models help the individual to cope with challenges of mental illness like disabilities as symptoms and as sequlae and psycho social dysfunction. Insight acts in a similar way, such that it helps with the overcoming of stigma and disabilities associated with mental illness(123).

In a study conducted among 80 community health workers in rural Tamil Nadu, India, it was found that even they held a multitude of native and sociocultural explanations for the aetiology of psychosis, with poverty being described as a major aetiology for the same. It was also seen that the inclination of having a non-medical model on schizophrenia can be detrimental to the treatment because of late detection ,lack of early institution of treatment ,impact on treatment adherence and follow up leading on to an overall negative outcome of the illness(124).

In another study done in Tamil Nadu among patients with schizophrenia and their relatives it was found that many of the patients and caregivers were holding

on to models of illness and management which was multiple and contradictory. Also it was found that specific illness related beliefs regarding causation of mental illness were associated with stigma among the patients and their caregivers(125).

In a five year prospective study among 131 patients with schizophrenia, it was found that female gender, rural background and the number of non-medical explanatory models correlated significantly with the BPRS score in the initial part of study. Insight and the number of non-medical explanatory models and the individuals' explanatory model had a significant relation with long term outcome to illness. Also a positive correlation between insight and non-medical explanatory models exist, with both showing a relationship with improvement in psychosis. Overall it was found that insight and explanatory model share a complex interaction with intermingling of socio cultural, psycho social and disease variable(126).

Diverse explanations are offered to explain mental illness including societal issues, interpersonal problems, witchcraft or sorcery, or a taboo which is broken. Eliciting the local explanatory models in routine clinical psychiatric practice gives a better understanding of the attitude towards and compliance with treatment and subjective experience of illness, and thus helps to promote therapeutic adherence and thereby improve clinical outcome and there by the quality of life of patients(127).

Patients with schizophrenia were assessed for their explanatory model of illness and a significant proportion of them were found to have a magico – religious

explanation, while many held onto a multi-factorial explanation. Patients who had a non- medical approach to the explanation for their illness were found to score less on their insight scales(128).

In a tertiary centre in North India a study done on 73 schizophrenia patients it was found that 84% agreed to the fact their community members had faith in magico religious and super natural phenomenon. 25-50% of the patients themselves believed in spiritual and magical and supernatural explanations. 66% of the clients believed in non-medical–magico religious supernatural causative model of mental illness. More than 50% believed in multiple non-medical causative explanations of mental illness. Also it was found that 50% believed that magico religious interventions are sufficient for the betterment of their mental health status. In spite of the high prevalence non-medical model of mental illness only 25% had admitted to non-medical magico religious management of symptoms in the last episode of illness(129).

Review of literature shows that approximately 66 -70% of Indian patients have a supernatural or magico religious explanation for illness, though the entity on whom the belief rests varies based on socio cultural and religious background. Among other nationals 10% have a spiritual or supernatural explanatory model of illness. It has been shown that the non–medical explanatory models often have an impact on the insight and the help seeking attitude of the patients and have an overall poor outcome in the illness(130).

A North Indian study on 122 patients showed that more than half the caregivers of patients had a supernatural or magico-religious explanation for illness, with

many of them having more than one supernatural belief. Also more than one fifth the caregivers took the patients to a faith healer or for supernatural intervention as the index treatment, and this was seen more in individuals whose caregiver expressed non-medical explanatory models of illness. Non-medical explanatory model also showed a relationship with the duration of untreated psychosis and hence a poor outcome of illness(131).

In a study conducted among first degree relatives of 100 patients with schizophrenia, it was found that the relatives held multiple explanatory models of psychosis that were diverse and often contrary to each other. Most of the beliefs were naturalistic (disease) or personalistic (magico religious and supernatural) and were simultaneously held. The care givers also believed that help for the patients can be obtained from multiple sources including medical treatment, indigenous treatment and magico-religious treatment. Following psycho education regarding the biomedical model of illness without negating the indigenous model it was found that the explanatory models could be altered for some time immediately after the psycho education, but reverted back to the original ones after some time, especially the ones related to treatment aspects(132).

1.4 RATIONALE FOR THE STUDY

Quality of life is significantly affected in patients with schizophrenia. While studies have assessed the relationship between symptoms of illness and quality of life, none have looked at possible associations between the patient's explanatory model of illness and the quality of life in schizophrenia. An exploration of the relationships between these factors and relevant demographic and clinical characteristics can provide clinicians with a better understanding of the experiences of those patients whom we seek to help. It can also help us provide care that is more relevant and nuanced and plan for strategies that can improve the individual's quality of life.

2. AIMS AND OBJECTIVES

2.1 AIM

To assess the relationship between the quality of life and the explanatory models of illness among schizophrenia patients.

2.2 OBJECTIVES

i. To assess the quality of life and explanatory models of psychosis held by patients with schizophrenia.

ii. To assess the relationship between quality of life and the explanatory models of psychosis held by patients with schizophrenia and selected relevant demographic characteristics.

iii. To assess the relationship between quality of life, explanatory models of psychosis held by patients with schizophrenia and disease and treatment characteristics

3. METHODOLOGY

3.1 STUDY DESIGN

This was an observational study.

3.2 SETTING

This study was carried out in patients who attend the outpatient clinic at the Department of Psychiatry, Christian Medical College. This 122-bed hospital provides short-term care for patients with all types of psychiatric diagnoses from the town of Vellore and a wider rural area beyond. It also functions as a tertiary referral centre for management of patients with mental and behavioural disorders from different parts of India. The emphasis is on a multidisciplinary approach and eclectic care using a wide variety of pharmacological and psychological therapies. The hospital has a daily outpatient clinic in which 400-450 patients are seen. Patients were recruited over a period of 12 months .Following recruitment participants were interviewed at a single point in time. All patients received treatment as usual.

3.3 PARTICIPANTS

Consecutive patients who present to the outpatient clinic at the Department of Psychiatry who satisfied *International Classification of Diseases - 10* (ICD-10) diagnostic criteria for research diagnosis of schizophrenia (WHO, 1992) were contacted for possible recruitment to the study. Informed consent was obtained. Subjects in remission (defined as defined as PANSS items P1, P2, P3, N1, N4, N6, G5, and G9 $\leq$ 3), above the age of 18 years, who speak Tamil, were eligible

to take part. Subjects with severe language, hearing or cognitive impairment were excluded. Patients with a primary mood disorder, substance use disorder or organic disorder were also excluded.

3.4 VARIABLES

Patients who consented to take part in the study were assessed for sociodemographic and clinical variables (duration and severity of illness, treatment variables etc.); Positive and Negative Symptom Scale was used to rate symptom severity in patients.

Sources of data included patients, carers and case records.

3.5 DATA MEASUREMENT

3.5.1 POSITIVE AND NEGATIVE SYNDROME SCALE (PANSS) (Kay et al, 1986) to assess symptom profile. The PANSS is used to evaluate persons with schizophrenia and other psychotic disorders in clinical and research settings. It is an operationalized, standardized, drug-sensitive instrument that provides a balanced representation of positive and negative symptoms and gauges their relationship to one another and to global psychopathology.

The PANNS was published in 1986 by Kay and colleagues (133) consisting of 3 subscales measuring seven positive, seven negative and sixteen general psychopathology symptoms. Based on the PANNS scale many researchers have proposed the five factor model of schizophrenia consisting of a positive factor, a negative factor an excitement factor, a cognitive factor and a depressive/anxiety factor. This model has proved to consistent across the different phases of illness,

subtypes of the illness, cross culturally, and longitudinally and to be stable after treatment with anti-psychotic agents(134).

In April 2003, The Remission in Schizophrenia Working Group was convened to come up with a definition of remission in schizophrenia as in non-psychiatric and other non-psychotic psychiatric illness. They chose to define remission as a state in which patients have experienced an improvement in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behaviour and are below the threshold typically utilized in justifying an initial diagnosis of schizophrenia(135).

Specific items of the PANNS are selected for consideration as criteria for remission in schizophrenia and were chosen to map the three dimensions of psychopathology identified by factor analyses and the five criteria for schizophrenia specified in DSM-IV. With regard to severity, the working group consensus defined a score of mild or less for scores of ≤3 over a period of six months as remission in schizophrenia(136).

3.5.2 TAMIL VERSION OF THE MODIFIED SHORT EXPLANATORY MODEL INTERVIEW (SEMI) to assess beliefs about the illness(137),(124) . This interview explores *emic* perspectives of illness. The language is simple and does not include any medical or technical words or phrases. It is used to elicit patients', attributions of their presenting complaints; their previous help-seeking behaviour (including visiting a temple, a shamam / mantrawadi, a traditional

healer, or a doctor); their causal models (e.g. previous deeds/karma, evil spirits, punishment by god, black magic, or disease); perceived consequences (change in the body or mind); and their expectations regarding the index consultation. The SEMI, which combines open-ended questions and a case vignette with a structured coding frame, has been used successfully in a variety of countries and cultures(138), including India and is regularly used in the department to study EMs.

3.5.3 WORLD HEALTH ORGANIZATION QUALITY OF LIFE-BRIEF (WHO QOL-BREF) This questionnaire, available in 19 languages, is the short version of the WHOQOL 100. It includes 26 items measuring the following four domains: physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). Two further items evaluate the individual's overall perception of quality of life and their health. Domain scores are scaled in a positive direction with higher scores corresponding to better quality of life and rated on a 5-point Likert scale (low score of 1 to high score of 5). The average score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 into a scaled score in order to make domain scores comparable with the scores in the WHOQOL -100.

Where more than 20% of data is missing from an assessment, the assessment should be discarded. Where an item is missing, the average of the other items in the domain is substituted. Where more than two items are missing from the

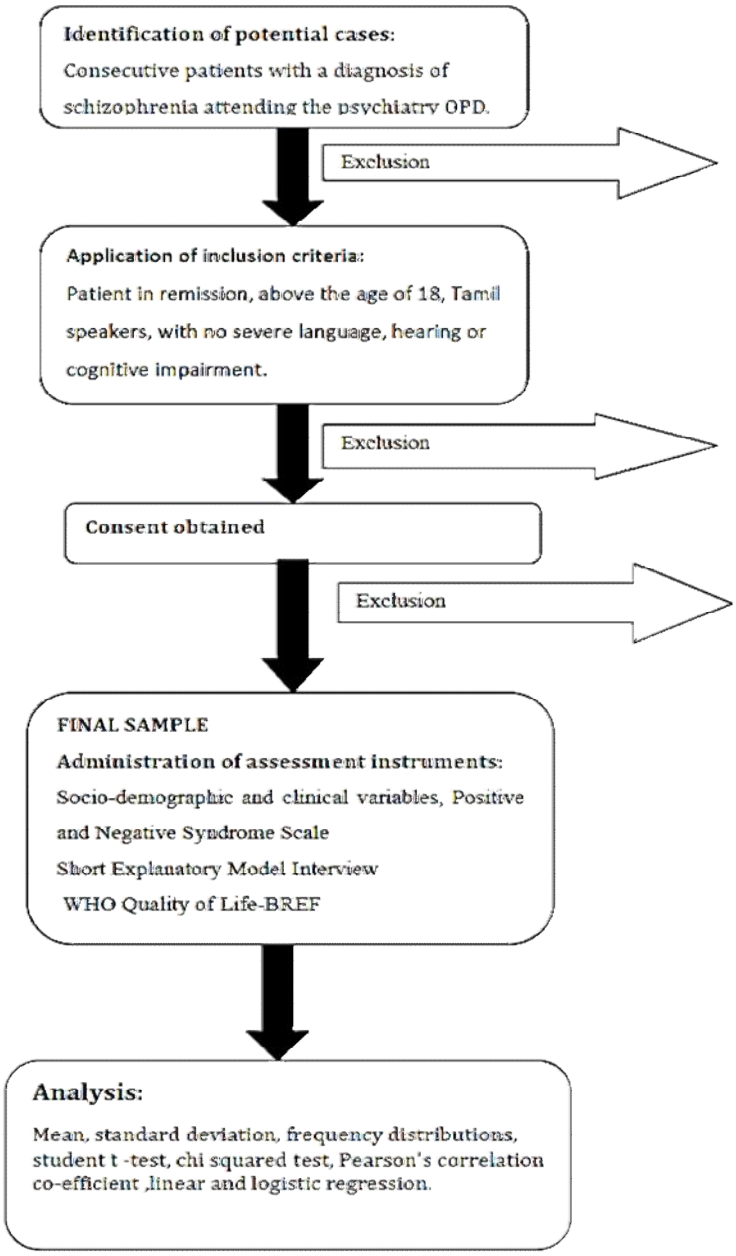
domain, the domain should not be calculated (with the exception of domain 3, where the domain should only be calculated if <1 item is missing(139).

Self-administration is recommended if the respondent has sufficient ability; if not, interviewer assisted or interview-administered forms should be used.

3.5.4 PROFORMA FOR SOCIO-DEMOGRAPHIC AND CLINICAL VARIABLES

Details regarding socio-demographic variables and clinical details were recorded in this proforma.

FLOWCHART FOR RECRUITMENT OF SUBJECTS



3.6 STATISTICAL METHODS

3.6.1 DETERMINATION OF SAMPLE SIZE

The sample size was estimated using the formula $4pq/d^2$, where p denotes the prevalence of nonmedical explanatory models in schizophrenia, estimated to be 80% (126), q = (100-p) and d, the expected difference between the two arms under study, taken as 7. The required sample size was 130.

3.6.2 DATA ANALYSIS

The statistical software SPSS for Windows (version 16) was employed for the analysis of data. The following data were analysed: (i) baseline socio-demographic details (ii) clinical details (iii) explanatory models and the (iv)quality of life. Mean and standard deviation were employed to describe continuous variables, while frequency distributions were obtained for categorical data. The chi square test and the Student's t-test were used to assess the significance of associations for categorical and continuous variables respectively. The Pearson's correlation coefficient was employed to assess the statistical significance of the association between two continuous variables. Linear and logistic regressions were employed as multivariate statistics to adjust for common confounders.

4. RESULTS

4. 1 SUBJECTS

4.1.1 THE STUDY SAMPLE

A total of 157 subjects who fulfilled eligibility criteria were contacted for the study; 27 did not consent to participate. Therefore a total of 130 individuals were recruited into the study. The age and gender of those who consented (henceforth known as the sample) and those who did not participate in the study were compared. These factors were not significantly different between the 2 groups.

4.2 SOCIODEMOGRAPHIC PROFILE OF SAMPLE

Table 4.1 documents the sociodemographic profile of the sample. The mean age of the participants was 35.2 years with a range between 19 and 62 years. Many were employed (43.8%). Many patients were from a low socio-economic background. The mean monthly family income was rupees 20,357. 56 (43.1%) of the respondents said that the family had financial debts. The majority (92.3%) of the participants was able to read and write. 20% of the respondents had co-morbid medical illnesses: 6 (4.6%) had diabetes, 5(3.8.3%) had hypertension and 5 (3.8%) had thyroid disease.

Table 4.1 Sociodemographic profile of sample

Characteristic	Score	Range
Age, years: mean (s.d.)	35.2 (9.5)	19-62
Gender, *n* (%) Male Female	 69 (53.1) 61 (46.9)	
Religion, *n* (%) Hindu Christian Muslim	 106 (81.5) 12 (9.2) 12(9.2)	
Literacy, *n* (%) Read and write Read only Illiterate	 120 (92.3) 7 (5.4) 3(2.3)	
Schooling, years: mean (s.d.)	12.4 (3.9)	0-21
Marital status, *n* (%) Married Single Widow/widower Separated Divorced	 66 (50.8) 47 (36.2) 6 (4.6) 7(5.4) 4 (3.1)	
Housing, *n* (%) Own Rented Squatting	 93 (71.5) 36 (27.7) 1(0.8)	
Residence, *n* (%) Rural Urban	 63(48.5) 67(51.5)	
Meals per day, *n* (%) 3	 130 (100)	
Number of people living in the house: mean (s.d)	4.2 (1.5)	2-10

Contd. Sociodemographic profile of sample		
Monthly family income, rupees: mean (s.d.)	20,357.6 (33863.8)	500-3,00,000
Debt, *n* (%) No Yes	 74 (56.9) 56 (43.1)	
Amount of debt, rupees: mean (s.d.)	147,476.9 (355318)	0-30,00,000
Occupation, *n* (%) Housewife Unemployed Student Employed	 31 (23.8) 38(29.2) 4(3.1) 57(43.8)	
Physical illness, *n* (%) No Yes	 104 (80) 26 (20)	
Substance use, *n* (%) No Yes	 113 (86.9) 17 (13.1)	

4.3 CLINICAL PROFILE OF PATIENTS

The mean age of onset of illness was 30 years and the mean duration of illness was 82 months. Mean PANSS scores were 7.0 on the positive subscale, 7.5 on the negative subscale, 17.9 on the general psychopathology subscale and 32.5 on the total score. The majority reported that they were compliant with treatment (73.8%) and had side-effects (78.5%). The common side effects experienced were extrapyramidal symptoms (27.7), weight gain (9.2), sedation and tardive dyskinesia (8.5 % each), sexual dysfunction (6.9%) and irregular menstrual cycles (6.2%). There was no history of substance use or medical comorbidity in

most patients (86.9% and 80% respectively).Details of the clinical profile is in Table 4.2.

Table 4.2 Clinical profile of sample

Characteristic	Score	Range
PANSS positive score: mean (s.d.)	7.00(0.2)	7-8
PANSS negative score: mean (s.d.)	7.5 (0.7)	7-10
PANSS general psychopathology score: mean (s.d.)	17.9 (1.4)	16-21
Total PANSS score: mean (s.d.)	32.5 (1.7)	30-37
Age of onset of illness, years: mean (s.d.)	30.0 (19.5)	15-230
Duration of illness, months: mean (s.d)	82.0 (73.0)	7-396
Number of hospitalizations: mean(s.d)	0.3(0.85)	0-7
Duration of treatment, months: mean (s.d)	53.8(55.6)	6-384
Duration of remission, months: mean (s.d)	20.3(25.5)	4-192
Subtype of schizophrenia, *n* (%)		
Paranoid	86 (66.2)	
Undifferentiated	18 (13.8)	
Hebephrenic	1 (0.8)	
Episodic	13 (10)	
Treatment resistant	12 (9.2)	
Side effects, *n* (%)		
No	28 (21.5)	
Yes	102 (78.5)	
Compliance, *n* (%)		
Poor	5 (3.8)	
Occasional miss	29 (22.3)	
Good	96 (73.8)	
Substance use, *n* (%)		
No	113(86.9)	
Yes	17(13.1)	

4.4 QUALITY OF LIFE IN PATIENTS WITH SCHIZOPHRENIA

The WHOQOL-BREF was used to assess the four domains of physical and psychological health, social relationships and environmental issues. The domain of 'Physical health' included activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity.

The 'Psychological' domain included bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality, religion, personal beliefs, thinking, learning, memory and concentration.

The domain on `Social relationships' assessed personal relationships, social support and sexual activity.

The domain of `Environment' reviewed financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation, leisure activities, physical environment (pollution / noise / traffic / climate) and transport.

The scores in the individual domains as well as the total scores are shown in Table 4.3

Table 4.3: Domain scores on WHOQOL-BREF

Domain	Physical Health	Psychological	Social relationships	Environment	Mean Total
Mean	64.1	59.3	64.0	63.1	62.6
Median	63.0	56.0	69.0	63.0	61.8
Std deviation	16.2	16.0	22.2	16.5	14.7
Range	25-100	19-100	0-100	19-100	15.75-92.5

The most affected was the psychological domain where the mean score was 59.3.The median of the total WHOQOL-BREF score for the population was 61.87.

4.5 FACTORS ASSOCIATED WITH QUALITY OF LIFE

The total WHOQOL -BREF score was considered as a continuous variable; using the Pearsons correlation coefficient and the t-test for continuous and categorical variables respectively, the data was tested for associations.

Of the sociodemographic factors, (Table 4.4.1.1 and 4.4.1.2) a higher quality of life score was found in single persons as compared to currently married individuals. The score was higher in those living in their own homes as compared to those squatting and in those whose homes were made of concrete as compared to others, suggesting that a better socioeconomic status correlated to a better quality of life. No other demographic factors were significantly associated with quality of life though the monthly income should a trend towards a positively significant correlation with the score.

Of the clinical factors (Tables 4.4.2.1 and 4.4.2.2), those who did not abuse substances had a higher quality of life score. The negative, general psychopathology and total PANSS scores were negatively correlated with the WHOQOL-BREF scores, though the positive subscale score did not show any correlation.

On linear regression analysis (Table 4.4.3) the negative, general psychopathology and total PANSS scores remained significant after adjusting for age, gender and literacy.

Table 4.4.1.1 Sociodemographic factors and Quality of Life

Variable	Quality of Life score		t value	Degrees of freedom	*p* value
	Number	Mean			
Gender Male	69	61.8	-0.663	128	0.508
Female	61	63.5			
Debt Present	74	63.9	1.184	128	0.239
Absent	56	60.9			
Religion Other	24	58.7	-1.462	128	0.146
Hindu	106	63.5			
Literacy Illiterate	3	74	1.353	128	0.178
Literate	127	62.4			
Employment					
Unemployed	38	62.9	0.144	128	0.885
Employed	92	62.5			
Marital status Single	47	66.1	2.027	128	0.045*
Married	83	60.7			
House Squatting	1	17.25	-3.207	128	0.002*
Own, rented	129	63.0			
Type of house Other	15	53.6	-2.572	128	0.011*
	115	63.8			
Concrete					

Table 4.4.1.2 Sociodemographic factors and Quality of Life

Variable	Mean	SD	r	*p* value
Age	35.2	9.5	-0.095	0.284
Years of education	12.4	3.9	-0.022	0.807
Income per month	20357.6	33863.8	0.171	0.051
Number of people at home	4.2	147476.9	-0.039	0.656
Debt	1.5	355318.0	-0.062	0.482

Table 4.4.2.1 Clinical factors and Quality of Life

Variable	Mean	SD	r	*p* value
Age onset illness	30.0	19.5	0.067	0.448
Number of hospitalizations	0.36	0.85	0.054	0.538
Duration of illness	82.0	73.0	-0.087	0.323
Duration of treatment	53.8	55.6	-0.031	0.728
Duration of remission	20.3	25.5	0.112	0.204
PANSS positive score	7.0	0.24	-0.076	0.390
PANSS negative score	7.5	0.7	-0.282	0.001*
PANSS general psychopathology score	17.9	1.4	-0.210	0.017*
PANSS total score	32.5	1.7	-0.287	0.001*

Table 4.4.2.2.Clinical factors and Quality of Life

Variable	Quality of life score		t	Degrees of freedom	P
	Number	Mean			
Side effects to medication			1.541	128	0.126
no	28	66.4			
yes	102	61.6			
Substance use			2.264	128	0.025*
no	113	63.7			
yes	17	55.2			
Compliance			-0.125	128	0.901
no	34	62.3			
yes	96	62.7			
Comorbidity			-0.629	128	0.530
no	104	62.2			
yes	26	64.2			
Paranoid schizophrenia			0.607	128	0.545
no	44	63.7			
yes	86	62.1			
Treatment resistant			0.236	128	0.813
no	118	62.7			
yes	12	61.7			

Table 4.4.3 Linear Regression: Sociodemographic factors and Quality of Life (Adjusted for age, gender and literacy)

Characteristic	r/t	p	Linear regression Beta SE	95% CI p
Marital status			-.229 3.44	-13.81 to -.163 0 .045
House			.305 14.41	22.66 to 79.71 0.001
Type of house			.258 4.109	3.69 to19.9 0.005
Substance use			-.188 4.023	-16.12 to -.205 0.044
PANSS negative score	-0.282	0.001*	-.297 1.849	-9.85 to -2.53 0 .001
PANSS-general psychopathology score	-0.210	0.017*	-.209 0 .913	-3.99 to -.376 0.018
PANSS total score	-0.287	0.001*	-.292 0 .711	-3.802 to -.988 0 .001

4.6 EXPLANATORY MODELS ASSOCIATED WITH SCHIZOPHRENIA

All the respondents completed the Short Explanatory Model Interview. The responses to the SEMI are given below in Table 4.4.3.1 to 4.4.3.

Table 4.5.1 Response to the question: "What is the reason for your visit?"

Characteristic	Frequency	Percentage
Specific physical complaints	29	22.3
Nonspecific physical or other complaints	56	43.1
Psychological complaints	45	34.6

Many patients reported non-specific reasons for their visit including:for a check-up, to get well etc. while several stated that they had come for treatment of fear, suspicions ,auditory hallucinations and other emotional problems.

Table 4.5.2 Response to the question: "Have you had any illness or health problems?"

Characteristics	Frequency	Percentage
No	45	34.6
Yes	85	65.4

Almost 35% of respondents said that they had no illness or health problems.

Table 4.5.3 Responses to the question: "What do you call these problems? Probe: If you had to give them names what would they be? "

Characteristic	Frequency	Percentage
no name	4	3.1
physical illness	7	5.4
psychological problem	119	91.5

Several descriptions from the local language were used to describe the psychological problem including `mana kashtam', 'mana thalarcha',' manasorvu' etc. Some also used the terms depression and schizophrenia.

Table 4.5.4 Responses to the question: "Is there anything you have or haven't done that has caused this?"

Characteristic	Frequency	Percentage
no	91	70.0
substance use	2	1.5
too much study	6	4.6
too much faith/ meditation	4	3.1
job stress	4	3.1
excessive interest in sex	2	1.5
interpersonal problems	8	6.2
bad influences	2	1.5
superstitions	2	1.5
anxiety and worry	3	2.3
failure in love	2	1.5
financial problems	2	1.5
poor life skills	1	.8

Many patients felt they had contributed to their problems by their own actions including excessive focus on study, religion and interpersonal problems.

Table 4.5.5 Responses to the question: "Who or what is the cause of you getting this?"

Characteristic	Frequency	Percentage
None	79	60.8
black magic	22	16.9
interpersonal	27	20.8
academic/job stress	1	0.8
spirits	1	0.8

The majority of the patients did not feel that the illness was because of anything others had done/not done.

Table 4.5.6 Responses to the questions on causal models

Question	Number	Percentage
Do you believe that your problem is due to black magic?Yes	44	33.8
Do you believe that your problem is due to karma? Yes	29	22.3
Do you believe that your problem is due to punishment from God?Yes	40	30.8
Do you believe that your problem is due to evil spirits?Yes	29	22.3
Do you believe that your problem is due to disease? Yes	73	56.2

The majority of the respondents attributed their problems to a disease though many also explained their problems as secondary to black magic and punishment from God.

Table 4.5.7 Responses to the question: "How serious are your problems?"

Response	Frequency	Percentage
Not serious	16	12.3
mild	45	34.6
moderate	24	18.5
severe	45	34.6

An equal percentage of patients believed their problems were mild or severe.

Table 4.5.8 Responses to the question: "What do you fear most about these problems?"

Response	Frequency	Percentage
not fearful	17	13.1
affecting future	21	16.2
affect family	11	8.5
affect job study	10	7.7
financial consequences	2	1.5
social consequences	9	6.9
effects on health	11	8.5
effects on fertility	1	.8
reduce abilities	1	.8
Symptoms of illness	36	27.7
adverse effects of treatment	8	6.2
effects on offspring	1	.8
Did not answer	2	1.5

A significant percentage of patients were afraid of the symptoms of the illness including aggression and suicidal thoughts, in addition to concerns about their health, future and family.

Table 4.5.9 Responses to the question: "Where did you go first to get help for your problem?"

Response	Frequency	Percentage
hospital	94	72.3
religious place	24	18.5
magical treatment	11	8.5
indigenous treatment	1	.8

The hospital was the first port of call for the majority of participants.

Table 4.5.10 Responses to the questions on expectations of medical care

Question	Number	Percentage
Will it help you, if you visit a doctor or a nurse for treatment for your problem ? Yes	127	97.7
Will it help you, if you visit a traditional healer for treatment for your problem ?Yes	21	16.2
Will it help you, if you visit a mantrivadi for treatment for your problem?Yes	12	9.2
Will it help you, if you visit a temple or a church or a mosque for your problem ?Yes	87	66.9
Will it help you, if you observe any diet restrictions or special diet for your problem ?Yes	48	36.9
Do you know if there is anything else which may help your problem ? Yes	32	24.6

While the majority of patients reported that they believed they would get help from medical personnel, a large group also believed that religious and spiritual factors would also help.

Table 4.5.11 Responses to the questions on other things that would help the problem

Response	Frequency	Percentage
Prayer	5	15.6
Yoga, meditation	11	34.4
physical exercise	3	9.4
counselling	2	6.3
marriage	2	6.3
social interaction	6	18.8
relaxation strategies	2	6.3
sort stressors	1	3.1

32 patients mentioned other strategies that would help manage their problems. These included yoga and meditation as well as increased social interaction.

Table 4.5.12 Responses to the question: "What do you hope to gain from seeing the doctor"?

Response	Frequency	Percentage
Get well	105	80.8
advice	8	6.2
medication	15	11.5
give mental peace	1	.8
Did not respond	1	.8

Most of the patients expected to 'get well 'while some also expected concomitantly to get medication, advice and peace.

Table 4.5.13 Responses to the question: "What are the main difficulties your problem has caused you"?

Response	Frequency	Percentage
None	10	7.7
Job/ academics	28	21.5
family	9	6.9
finances	2	1.5
physical problems	34	26.2
social	7	5.4
ability to think	9	6.9
positive symptoms	8	6.2
stress	12	9.2
effect on offspring	1	.8
long duration of treatment	2	1.5
infertility	2	1.5
Did not respond	6	4.6

Physical problems and dysfunction in the area of job and academics were the commonest concerns

Table 4.5.14 Responses to the question: "How have you been affected emotionally by what you've described"?

Emotions	Frequency	Percentage
nil	32	24.6
sadness	67	51.5
anxiety	10	7.7
hopelessness	3	2.3
fear	14	10.8
anger	4	3.1

Most patients expressed feeling sad because of their problems and experiences.

Table 4.5.15 Responses to the question: "What are the main effects of your problem"?

Effects of illness	Number	Percentage
Mobility-yes	56	43.1
Social life-yes	51	39.2
Home life-yes	67	51.5
Relating to others-yes	67	51.5
Work-yes	79	60.8

The area most reported to be affected was work, followed by home life and relationships with others.

Table 4.5.16 Responses to the case vignette of a woman with psychosis

Question		Number	Percentage
What is her problem?	none	4	3.1
	environmental	42	32.3
	emotional /psychological	69	53.1
	physical problem/ loss of function	13	10.0
	spiritual	2	1.5
What is her illness?	none	32	24.6
	psychological	96	73.8
	spiritual	1	0.8
	fits	1	0.8
What is the cause of her problem?	nil	20	15.4
	interpersonal difficulties	31	23.8
	environmental problems	27	20.8
	physical factors	5	3.8
	religious/ supernatural	4	3.1
	emotional/psychological	30	23.1
	no issues	10	7.7
	don't know	1	.8
	not taking treatment	1	.8
	hereditary	1	.8
	spontaneous		
What should she do about it?	nil	5	3.8
	do good	22	16.9
	solve problems in environment	9	6.9
	visit doctor	65	50.0
	religious/magical intervention	20	15.4
	lifestyle modification	6	4.6
	Did not answer	3	2.3

4.7 RESPONSES TO SHORT EXPLANATORY MODEL INTERVIEW AND ASSOCIATION WITH QUALITY OF LIFE SCORE.

The QoL score as a continuous variable was compared with the various explanatory models elicited on the SEMI to check for statistical associations using the t-test, shown in Table 4.6.1

Table 4.6.1 : Responses to SEMI and associations with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
Reason for visit: Non-psychological Psychological	 85(64.14) 45(59.8)	1.582	128	0.116
Presence of illness: No Yes	45(67.3) 85(60.1)	2.722	128	0.007*
Name of illness: Non-psychological Psychological	11(64.2) 119(62.5)	.371	128	0.711
Self-treatment: No Yes	128(62.8) 2(50.8)	1.143	128	0.255
Medication details: No Yes	84(61.7) 45(64.6)	-1.053	127	0.294

Patients who did not think they had an illness had a significantly higher quality of life score as compared to those who felt they had an illness.

Table: 4.6.2 Explanatory models for cause of illness and associations with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
Evil spirit Other	29(59.6) 101(63.5)	1.27	128	0.206
Punishment Other	40(58.9) 90 (64.3)	1.96	128	0.051
Black magic Others	44(59.1) 86(64.4)	1.94	128	0.54
Karma Others	29(58.9) 101(63.7)	1.55	128	0.122
Physical illness Others	73(61.1) 57(64.5)	1.30	128	0.193

Those who believed that their problems were a result of punishment form God had lower quality of life scores as compared to those who did not hold such an explanatory model.

Table 4.6.3 Responses to consequence of illness and associations with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
No fear Other	17(69.3) 113(61.6)	-2.046	128	0.043*
Fear of future Other	21(55.1) 109 (64.1)	2.60	128	0.010*
Family Others	11(61.6) 119(62.7)	0.24	128	0.805
Job Others	10(61.7) 120(62.7)	0.205	128	0.838
Finances Others	2(54) 128(62.8)	0.838	128	0.403
Social Others	9(63.3) 121(62.6)	-.134	128	0.894
Health Others	11(59.4) 119(62.9)	.750	128	0.454
Treatment Others	8(67.3) 122(62.3)	-0.93	128	.353

Those who reported a lack of anxiety had a higher quality of life score than those who had concerns. Those who had a fear of the future had a significantly lower quality of life score than other participants.

Table 4.6.4 Responses to difficulties caused by problem and associations with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
No difficulty Other	10(72.8) 120(61.8)	-2.314	128	0.022*
Family Others	9(56.1) 121(63.1)	10.372	128	0.172
Job Others	28(62.6) 102(62.6)	0.000	128	1.000
Finances Others	2(67.3) 128(62.5)	-0.454	128	0.650
Health Others	34(61.8) 96(62.9)	.382	128	0.703
Social Others	7(62.9) 123(62.6)	-.054	128	0.957
Positive symptoms Others	8(68) 122(62.3)	-1.076	128	0.284

Those who perceived that their problems had not caused them any difficulty in life had a significantly higher quality of life score than the others.

Table 4.6.5 Responses to part of body affected and association with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
None Other	7(70.6) 123(62.2)	-1.487	128	0.140
Brain Others	85(62.4) 45(63.0)	0.186	128	0.853
Other parts of body Others	31(62.9) 99(62.5)	-0.132	128	0.895

There were no significant associations between the quality of life score and the part of the body considered affected.

Table 4.6.6 Responses to area of life affected and association with quality of life score

Variable		QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
Emotions	No	32(68.6)	2.718	128	0.007*
	Yes	98(60.7)			
Mobility	No	74(65.9)	2.967	128	0.004*
	Yes	56(58.3)			
Social	No	79(65.1)	2.412	128	0.017*
	Yes	51(58.8)			
Family	No	63(65.6)	2.247	128	0.026*
	Yes	67(59.8)			
Relationships	No	63(65.6)	2.247	128	0.026*
	Yes	67(59.8)			
Work	No	51(66.0)	2.122	128	0.036*
	Yes	79)60.4)			

In every domain assessed, it was found that those who felt that the area was affected by their illness had a significantly lower quality of life score.

Table 4.6.7 Responses to case vignette and association with quality of life score

Variable	QoL score *n* (mean)	t/r	Degrees of freedom	*p* value
What is her problem?				
Other None	126(62.3) 4(73.5)	-1.511	128	0.133
Others Environmental	88(63.9.1) 42(60.0)	1.418	128	0.159
Others Emotional	61(61.3) 69(63.8)	-0.965	128	0.337
Others Physical problems	117(62.5) 13(63.6)	-0.258	128	0.797
What is the reason?				
Black magic No Yes	97(63.9) 33(59.8)	1.277	128	0.204
Karma No Yes	98(64) 32(58.4)	1.873	128	0.063
Punishment from God No Yes	98 (64) 31(58)	2.093	128	0.038

The majority of respondents believed that the person's problems were due to psychological factors and felt that the doctor would be the best one to help.

4.8 SUMMARY

157 patients were contacted to participate in the study and 130 consented to the interview. The mean age of the participants was 35.2 years. The majority were married (63.8 %), men (53.1%), and literate (97.7), belonged to the Hindu religion (81.5%), and were unemployed or housewives (53.1%). The mean age of onset of illness was 30.0 years and the mean duration of illness was 82.0 months. Mean total PANSS score was 32.5.

Quality of life was affected in every domain .The mean score on the WHOQOL –BREF for the psychological domain was the least (59.3). Of the sociodemographic factors, a higher quality of life score was found in single persons as compared to currently married individuals, those with better living conditions. Of the clinical features, those who did not abuse substances had a higher score. The negative, general psychopathology and total PANSS scores were negatively correlated with the WHOQOL- BREF scores.

Common explanatory models for the cause of illness included disease, black magic and punishment from God. Patients were afraid of the symptoms of the illness in addition to concerns about their health, future and family. While the majority of patients reported that they would get help from medical personnel, a large group also believed that religious and spiritual factors would also help. Quality of life scores for those who did not perceive themselves to have a problem was significantly higher than for other respondents.

5. DISCUSSION

5.1 INTRODUCTION

Quality of life is often compromised in people with schizophrenia across the world and across cultures. There are several factors that can influence quality of life. This study attempted to study the relationship between explanatory models in schizophrenia and quality of life, in an out-patient hospital setting in Tamil Nadu, as well as the sociodemographic factors that may influence quality of life in this population. This section discusses the methodological issues and the results.

5.2 METHODOLOGICAL CONSIDERATIONS

1) Translation -The instruments used in this study were translated into Tamil, as spoken by the local people, to ensure that it would be appropriate to the study population.

2) The sample size was sufficiently large to draw valid conclusions from the study.

3) Subjects 130 of the subjects contacted participated in the study, resulting in an 82.8 % second stage response rate.

4) Setting -The interview procedures were carried out in the privacy of a consultation room in the hospital. Despite the attempt to ensure privacy, in some cases the lack of it and the socially and culturally sensitive nature of the issues discussed could have influenced the results of the administered instruments.

5) Procedure - Though the majority of the subjects were literate, to ensure uniformity, the instruments were not self-administered but were instead read out to them using the recommended procedure.

6) Instruments - Subjects were initially interviewed for their sociodemographic and clinical details. The patients were rated on the PANSS for severity of psychopathology .The SEMI and the WHOQOL-BREF were then administered to assess explanatory models of illness and quality of life. These instruments were chosen as they have been translated into Tamil and used extensively in the local population.

5. 3 QUALITY OF LIFE IN SCHIZOPHRENIA

Quality of life is known to be affected in patients with schizophrenia (140). Our study found that quality of life in patients with schizophrenia is affected in all areas assessed by the WHOQOL-BREF, particularly in the psychological domain. This is similar to previous reports (16),(41)suggesting similarities across cultures.

5.4 FACTORS ASSOCIATED WITH QUALITY OF LIFE IN SCHIZOPHRENIA

A higher quality of life score was found in single persons as compared to currently married individuals. This is unlike reports from previous literature(22) (25). It could be postulated that those who were not currently married did not have the burdens associated with family life and therefore had a higher quality of life score. A better socioeconomic status was found to be associated with higher quality of life scores ,similar to findings of other studies (26).

In this study the negative, general psychopathology and total PANSS scores were negatively correlated with the WHOQOL-BREF scores indicating that those with more of these symptoms had a poorer quality of life. This finding has been reported earlier in literature (28);(23). In the present study positive symptom score was not correlated with the quality of life scores ; this was similar to findings of (34) but unlike that reported by (37).

Other factors that have previously been reported to be associated with quality of life such as age, gender, duration of illness and side -effects were not found to be significant in this study.

5. 5 EXPLANATORY MODELS FOR SCHIZOPHRENIA

34.6% of patients responded initially by saying that they did not have a problem. This possibly reflects the nature of the sample which was a group of patients with schizophrenia who were in remission without active positive psychotic symptoms. A majority of the respondents considered an emotional or psychiatric label for their problems. Many of the patients were unable to say why their problems had started at the time they did but others explained it as secondary to interpersonal problems or excessive preoccupation with different things such as academics and religion. While a large group believed their problems to be due to a disease, other common explanatory models included punishment from God and black magic. The presence of a disease model in the majority could suggest that interventions in the hospital had led to this, however as this was a cross-sectional, single assessment it is not possible to draw definite conclusions as the explanatory models prior to intervention have not been documented. Many

respondents did consider their problems severe. Most individuals considered going to the doctor as the best source of help; mantravadis and religious places were also considered useful. Considering the fact that these patients were regularly following up in the hospital for predominantly medical management, it highlights the fact that patients often simultaneously accept multiple and contradictory explanatory models of illness and diverse sources of help seeking (126). Yoga, meditation and prayer were also considered useful strategies, reflecting their popularity within our culture. Most people felt that the illness had affected different aspects of their lives; only a very few did not acknowledge any problems. Problems included mobility, social life, family life, work, relating to others and emotions; the area most reported to be affected was work, followed by home life and relationships with others.

In the case vignette, similar responses were elicited .The majority of respondents believed that the person's problems were due to psychological factors and felt that the doctor would be the best one to help.

This study has brought out some of the common beliefs of people in this region regarding schizophrenia. The current psychological methods of treatment of these conditions are derived from the West .Incorporating locally accepted beliefs and appropriate culturally acceptable protocols will help in cost-effectiveness and patient compliance with intervention strategies.

5.6 RELATIONSHIP BETWEEN QUALITY OF LIFE AND EXPLANATORY MODELS VARIABLES

Patients who did not think they had an illness had a significantly higher quality of life score as compared to those who felt they had an illness. As this study was cross-sectional the direction of association between these two factors cannot be definitely commented on-it could be postulated that those who had a better quality of life were able to cope well therefore did not consider themselves to be having an illness; it could also be that those who had decided that they do not have a problem had a better quality of life secondary to their decision to focus away from the problem and on other aspects of life. Similarly, those who reported a lack of anxiety related to their problems had a higher quality of life score than those who had concerns. Those who acknowledged that different domains of their life were affected by the problem had a significantly lower quality of life score than other participants.

Those who believed that their problems were a result of punishment from God had lower quality of life scores as compared to those who held other models; this may suggest that personalistic models associated with a sense of guilt cause more distress than other beliefs that attributed the problems to outside forces. There was no difference in the quality of life among those who held a disease model of illness as compared to other models suggesting that acceptance of the medical model alone was not necessary for a better quality of life.

5. 7 IMPORTANCE OF QUALITY OF LIFE AND EXPLANATORY MODELS IN HEALTH CARE

Quality of life in schizophrenia is a complex and multidimensional area influenced by other multiple variables. The relationships among quality of life, explanatory models and psychopathology in psychosis are complex. The relationship between these factors is mediated by the interaction of additional variables such as illness factors and sociodemographic factors.

From a clinical point of view, it is every clinician's duty to make an attempt to understand the patient's problems, to discuss and negotiate every aspect of treatment with patients and to incorporate their views in service development which are all of great value in improving the patients' quality of life. Explanatory models are an important aspect of treatment acceptance and adherence. Understanding the relationship between the patients' perceptions about the quality of life and prevailing belief systems will help in designing interventions that will be acceptable to the population and improve engagement of patients with mental health services.

5. 8 STRENGTHS AND LIMITATION

Limitations of the study

1. Given its cross-sectional design, data collection was carried out during a single interview. Longitudinal studies are needed to examine the possible fluctuations and changes in the nature of quality of life and explanatory models in patients with schizophrenia.

2. Given the sensitive nature of the topic under study, some respondents may have been reluctant to discuss their true beliefs, attitudes and concerns.
3. A single interviewer carried out all the assessments and no attempt was made at blinding.
4. The study has a cross-sectional design and does not allow one to make inferences on the direction of causality and the precise nature of association between the variables.

Strengths of the study

1. The study included a heterogeneous population in terms of age, socioeconomic status, education etc.
2. The participants were selected in a consecutive manner to avoid selection bias during recruitment.
3. A single interviewer who was aware of the social and cultural backgrounds of the participants and was well versed in the local language conducted the interview. This ensured that there was no significant reporting bias.

5. 9 RECOMMENDATIONS AND FUTURE DIRECTIONS FOR RESEARCH

Quality of life in patients with schizophrenia is an area that requires further study so that clinicians can make efforts to address the felt needs of patients and provide holistic care. Future research goals should focus on:

- Refining understanding of the relationship between quality of life, explanatory models and long-term outcome in schizophrenia.
- Developing cost-effective strategies to improve quality of life which can be applied in primary care practice
- Qualitative research to focus on attitudes and beliefs of people about schizophrenia which could help identify areas that require attention

6. CONCLUSIONS

1. Quality of life is affected in multiple domains of life in patients with schizophrenia.
2. Socioeconomic factors and clinical symptoms influence quality of life.
3. Most patients held a disease model of illness.
4. Those who held personalistic explanations tend to have a lower quality of life score.
5. Multiple, simultaneous and contradictory explanatory models are often held by individuals with illness.

This study has examined a little-studied topic, has provided information on quality of life and explanatory models, and raises issues to be addressed in future studies

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ANNEXURES

1. CONSENT FORM

1.1 CONSENT FORM – ENGLISH

INFORMED CONSENT

Informed Consent form to Participate in a research study

Study Title: Quality of life and explanatory models in patients with Schizophrenia

Study Number: _____

Subject's Initials: _____

Subject's Name: _____

_____

Date of Birth/Age: _____

(Subject)

(I) I confirm that I have read and understood the information sheet dated _____ for the above study and have had the opportunity to ask Questions.

(ii) I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my

medical care or legal rights being affected.

(iii) I agree not to restrict the use of any date or results that arise from this study provided such a use is only for scientific purpose(s).

(iv) I agree to take part in the above study.

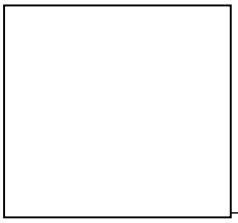
Signature (or Thumb impression) of the Subject/Legally Acceptable

Date: _____/ _____/ _____

Signatory's Name: _____

Signature:

Or



_____

Date: _____/ _____/ _____

Signatory' Name: _____

Signature of the Investigator:_____

Date: _____/ _____/ _____

Study Investigator' Name: _____

Signature of the Witness: _____

Date: _____/ _____/ _____

Name & Address of the Witness: _____

INFORMATION SHEET

Title of study:

Quality of life and explanatory models in patients with schizophrenia

Institution:

Christian Medical College, Vellore

Nature and purpose of the study:

You are invited to take part in a study that attempts to determine your ideas, Views and perspectives on your illness and how these may affect the day to day Quality of your life.

Procedure to be followed:

A doctor from the Department of Psychiatry will conduct this study. She will Collect information regarding your views on your illness and quality of life by Administering some standard instruments. Related information will also be Collected from your medical records.

Expected duration of involvement:

The assessment will be done in one session that will last about half an hour.

Possible benefits of the study:

The information we obtain will help us better understand how you understand your illness and cope with the challenges you face. This can in turn benefit others in a similar situation.

Confidentiality:

The records and details obtained in this study will remain confidential at all

Times. Your personal data will be collected and processed only for research purposes. Your will not be referred to by name or identified in any report or Publication.

Right to withdraw from the study:

You are free to leave the study at any time. Your decision to/not to participate In this study will not affect your or your relative's future medical or psychiatric Care in our hospital. For further queries you may contact:

Dr .Jibi Achamma Jacob

Department of Psychiatry,

Christian Medical College, Vellore 632002.

Phone: 0416 2284516, email: psych1@cmcvellore.ac.in

1.2 CONSENT FORM –TAMIL

xgg[j y; got k;

Ma;tpy; g'nfwgjw;fhd bjhptpf;fggl;l xgg[jy; gotk;

Ma;tpd; jiyggq

kdr;rpij t[nehapw;wth;fspd; thH;f;ij j; juk; kwWk; tps f;f khjphpfs; Ma;t[vz; ____________

fye;J bfhsgthpd; Kjwpbgah ____________

fye;J bfhsgthpd; bgah; ____________

gpwe;j ehs; - taJ: ____________

fye;J bfhsgth;

1) ehd; cWjp bra;tJ vd;dbtdwhy; ____________ njjpapy; nkw;fz;l Ma;t[Fwpj;j jfty; jhis KGikahf goj;J gpe;J bfhz;nld/ nkYk; ,ijggwpw nfs;tp nfl;f thagg[fpilj;jJ/

2) ehd; gpe;J bfhz;lJ vd;dbtdwhy; ehdhf Kd;te;J ,e;j Ma;tpy; fye;J bfhs;fpnwd; vdWk; ehd; vgbghGJ nt z;LkhdhYk; Ve;j fhuzKk; ,y;yhky; ehd; Rje;jpukhf nkYk; ve;j rpfpr;irnah rl;l chpiknah ghjpf;fgglhky; ,e;j Ma;tpy; ,Ue;J tpy fpf bfhs;syhk; vdgij jak; mwpnt d/

3) ehd; gpe;J bfhz;lJ vd;dbtdwhy; ?? kUj;J t ghpnrhjidf;F gz cjtp bragth;fs; mt;thW gz cjtp bragth;fSf;fhf nt iy bragth;fs; edbdwp FG. kwWk; Kiwgglj;Jk; mjpfhhpfs; Mfpnahh Uf;F. ehd; ,e;j Ma;tpy; ,Ue;J tpy fpf bfhz;lhYk; vd;Dila cly? kd eyk; gwwpa Fwpgg[fis. jwnghija Ma;tpwpfh my;yJ ,J rkge;jggl;l ntW Ma;tpw;fhfnth ghhggjw;F vd;Dila mDkjp nji tapy;iy/ ehd; ,e;j thaggpw;F xj;J fbfhs;fpnwd;/ ,UggpDk; vdJ milahsk; K:dwhk; egh;fSf;F my;yJ bts paPlfSfnfh juggLk; ve;j jfty;fspYk; bjhpaggLj;jgglkhl;lhJ vdgij mwpnt d/

4) mwpt[ay; nehf;f j;jpw;fhf kl;Lnk gadgL j;jggLk; vdpy; ,e;j Ma;tpy; ,Ue;J fpilf;Fk; ve;j jfty; myyJ Kot[fis gadgL j;j fl;Lgghl fpilahJ vdgij xj;Jf;bfhs;fpnwd/
5) ehd; nkw;Twpa Ma;tpy; g'nfw;f rkkhj;f;fpnwd/

g';Fbfhsgthpd;rl;lhPjpahf Vw;Wf;bfhs;sgl;lthpd;
ifbahggk(myyJ ifehl;L :

njjp :
ifbahggk; ,l;llthpd; bgah; _____
ifbahggk _____
gpujpepjp _____
njjp _____
bgah; _____
Ma;thshpd; ifbahggk _____
njjp _____
Ma;thshpd; bgah; _____
rhl;rpapd; ifbahggk; _____
njjp _____
rhl;rpapd; bgah; kw;Wk; Kfthp _____

j f t y; jhs;

Ma;tpd; j i ygg[

k d rp i j t[neha[w;w th;f spd; thH;f ;i f j ;juk; kw;Wk; tps f ;f kh j phpf s;

ep i yak; :

fpU j ;J t kU j ;J t f ; f y;Yhhp. n t Yhh;

Ma;tpd; , aygpk; neh f ;f k;

c ';f s; neha; kPj h d c ';f s; v z ;z ';f s; neh f ;f k; kw;Wk; ghh;i t m i t c ';f spd; m dw;wh l thH;f ;i f juj ;i j v t ;thWghj pf ;F k; vdg i j Fwpj ;J jPh;khdpf ;F k; Kaw;rpahd , e;j Ma;tpy; g 'nf w;f c ';f i s tun t w;fpnwhk;

gpdgw;w , U f ;F k; b r a y;K i w:

k dneha; kU j ;J tg; ghpt pypUe;J xUkU j ;J th; , e;j Ma;tp i dnkwbfhs;thh; m th; c ';f spd; neha; kw;Wk; thH;f ;i f juk; gw;wpa c ';f s; v z ;z ';f i sgw;wpa tptu ';f s; rpynf s;tpr;rhj d ';f s; K:yk; nr fhpggh;

c ';f s; cwtpdhpd; kU j ;J tgjpt[f spypUe;J k; , i j rhhe;j j f t y;f Sk; nr fhpf ;fggL k;

v j phghh;f ;f ggL k; g ';fnwg[fhy k; :

Rkhh; m i uk z pneuk; t i ueP f ;f f ; Toa xUmkh;tpy; , e;j k jpggP b r a;agg L k;

, e;j Ma;tpd; K:yk; VwgL k; e d;i k f s; :

v ';f S f ;F , e;j Ma;tpd; K:yk; fp i l f ;F k; j f t y;f spdhy; eP;f s; c ';f s; neh i av t ;thW gpe;J b f h z pU f ;f pwPh;f s; kw;Wk; re;j p f ;f neUk; r thy;f i s v t ;thWrkhspf ;f pwPh;f s; vdg i j v ';f f shy; gpe;J b f hs;s c j tpk; , J , e;j R{Hpep i yapy; cs;s kw;w th;f S f ;F e d;i kahf , U f ;F k;

,ufrpafhgg[

,e;jMa;tpd; Kyk; bgwggLk; Mtd';fs; kwWk; jftyfs; vyyhneuj;jpYk; ,ufrpakhfitf;fggLk/ c';fspd; jdpggl;l jftyfs; nrfhpf;fggl;L ,e;jMa;tpw;fhfkl;Lnkgadg Lj;jggLk/ j';fspd; bgah; kwWk; milahsk;

ve;jxUmwpf;ifapnyhmyyJbtspaPpYnyhbjhpagLj;jkhl;lhJ/

Ma;tpypUe;Jtpyfpfbfhs;tjw;fhd chpik:

Ma;tpypUe;Jtpyfpfbfhs;tjw;Fve;jneuKk; j';fSf;F KGRje;jpuk; cz;L/ jh';fs; ,e;jMa;tpy; g'nfwgjw;Fk; myyJkWgg[bjhptpwgjw;Fk; vLf;Fk; Kot[c';fSilamyyJ c';fsJcwtpdUilavjph;fhykUj;Jtkw;Wk; kdneha; rpfpr;iriaghjpf;fhJnkYk; Vnj Dk; renjf';fSf;F fPH;fz;lKfthpapidbjhlhgb[bfhs;S';fs;

lhf;lh; $pgpmr;rk;khn$f;fg;

kdeykUj;Jtggphpt[

fpUj;Jtkuj;Jtf; fy;Yhhp

ntYhh; ? 632 002/

bjhiyngrpvz; 0416 ? 22845216

kpd;d";ry; psych1@cmcvellore.ac.in

2. CLINICAL RESEARCH FORM

2.1 SOCIODEMOGRAPHIC AND CLINICAL DATA SHEET

1. Serial No.
2. Patient Hospital No.
3. Gender(1) Male (2) Female
4. Age (in years)
5. Religion (1) Hindu(2) Muslim (3)Christian (4)Others (details)
6. Number of years of education
7. Literacy (1) Illiterate (2) Read only (3) Read and write
8. Occupation (1) Unemployed (2) Employed (3) Housewife
9. Marital Status (1) Single (2) Married (3) Widow/Widower (4) Separated/Divorced
10. Residence (1) Rural (2) Urban
11. Family Income per month (Rupees per month)
12. No of people staying in the same house
13. Debts (1) Absent (2) Present
14. Total amount of debt (if present)
15. No of square meals per day (0)(1)(2)(3)
16. House (1) Own (2) Rented (3) Squatting
17. Type of house (1) Concrete (2) Mud wall (3) Thatched hut (4) Other (Specify)
18. Duration of illness (in months)
19. Age of onset of illness

20. Number of hospitalizations
21. Duration of treatment in months
22. Duration in remission months
23. Antipsychotic induced side effects (1) No (1) Yes
24. Compliance with medication (1) Poor (2) Occasionally misses medication (3) Good
25. Substance use (1) Absent (2) Present (Details)
26. Medical co-morbidities (1) No (2) Yes (Details)

Current PANSS Score

Positive

Negative

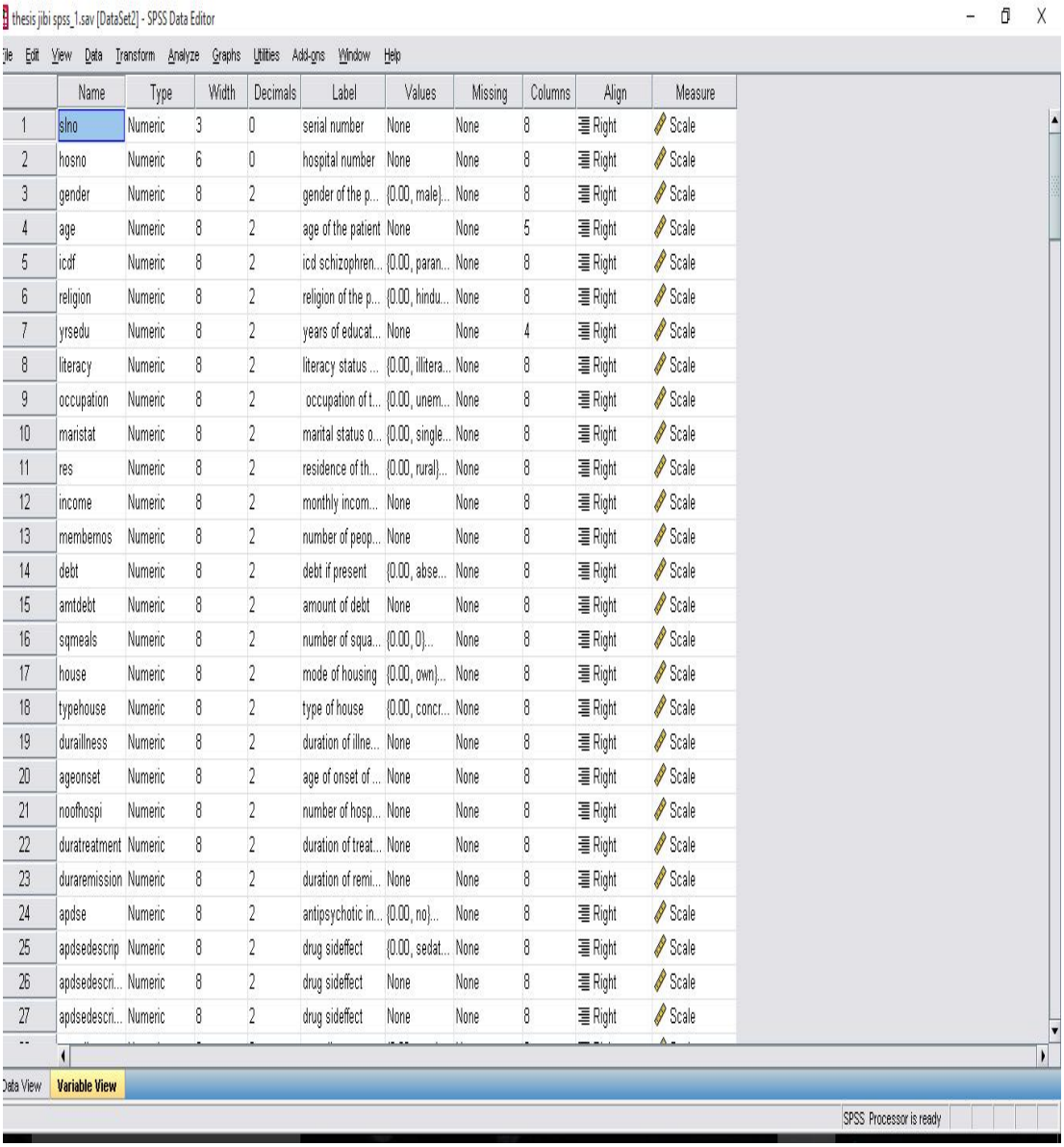
General psychopathology

Total

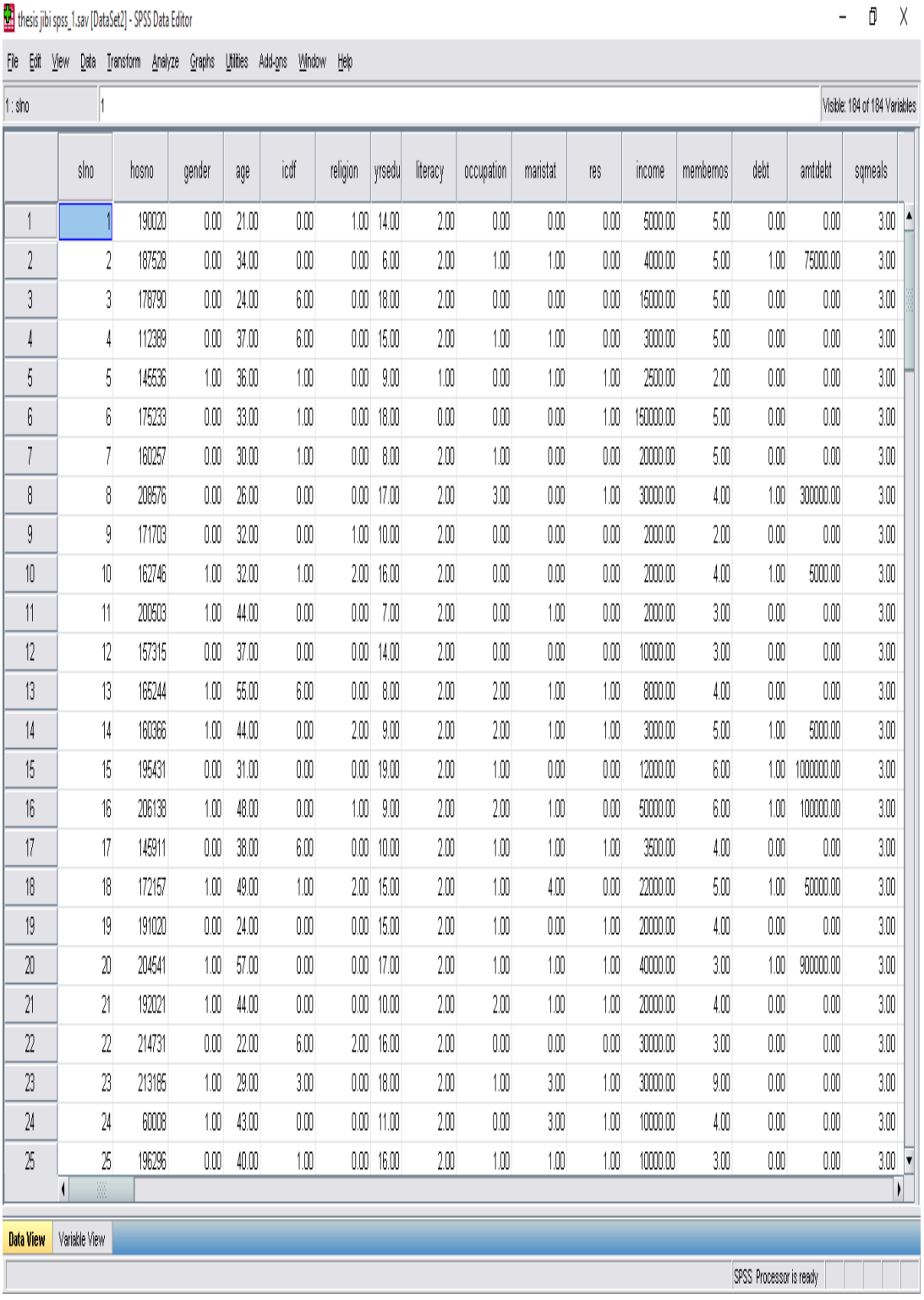
SEMI:

Quality of life:

3. DATABASE



	Name	Type	Width	Decimals	Label	Values	Missing	Columns	Align	Measure
1	slno	Numeric	3	0	serial number	None	None	8	Right	Scale
2	hosno	Numeric	6	0	hospital number	None	None	8	Right	Scale
3	gender	Numeric	8	2	gender of the p...	{0.00, male}...	None	8	Right	Scale
4	age	Numeric	8	2	age of the patient	None	None	5	Right	Scale
5	icdf	Numeric	8	2	icd schizophren...	{0.00, paran...	None	8	Right	Scale
6	religion	Numeric	8	2	religion of the p...	{0.00, hindu...	None	8	Right	Scale
7	yrsedu	Numeric	8	2	years of educat...	None	None	4	Right	Scale
8	literacy	Numeric	8	2	literacy status ...	{0.00, illitera...	None	8	Right	Scale
9	occupation	Numeric	8	2	occupation of t...	{0.00, unem...	None	8	Right	Scale
10	maristat	Numeric	8	2	marital status o...	{0.00, single...	None	8	Right	Scale
11	res	Numeric	8	2	residence of th...	{0.00, rural}...	None	8	Right	Scale
12	income	Numeric	8	2	monthly incom...	None	None	8	Right	Scale
13	membemos	Numeric	8	2	number of peop...	None	None	8	Right	Scale
14	debt	Numeric	8	2	debt if present	{0.00, abse...	None	8	Right	Scale
15	amtdebt	Numeric	8	2	amount of debt	None	None	8	Right	Scale
16	sqmeals	Numeric	8	2	number of squa...	{0.00, 0}...	None	8	Right	Scale
17	house	Numeric	8	2	mode of housing	{0.00, own}...	None	8	Right	Scale
18	typehouse	Numeric	8	2	type of house	{0.00, concr...	None	8	Right	Scale
19	duraillness	Numeric	8	2	duration of illne...	None	None	8	Right	Scale
20	ageonset	Numeric	8	2	age of onset of ...	None	None	8	Right	Scale
21	noofhospi	Numeric	8	2	number of hosp...	None	None	8	Right	Scale
22	duratreatment	Numeric	8	2	duration of treat...	None	None	8	Right	Scale
23	duraremission	Numeric	8	2	duration of remi...	None	None	8	Right	Scale
24	apdse	Numeric	8	2	antipsychotic in...	{0.00, no}...	None	8	Right	Scale
25	apdsedescrip	Numeric	8	2	drug sideffect	{0.00, sedat...	None	8	Right	Scale
26	apdsedescri...	Numeric	8	2	drug sideffect	None	None	8	Right	Scale
27	apdsedescri...	Numeric	8	2	drug sideffect	None	None	8	Right	Scale


thesis jibi spss_1.sav [DataSet2] - SPSS Data Editor

File Edit View Data Transform Analyze Graphs Utilities Add-ons Window Help

1 : slno 1 Visible: 184 of 184 Variables

	slno	hosno	gender	age	icdf	religion	yrsedu	literacy	occupation	maristat	res	income	membernos	debt	amtdebt	sqmeals
1	1	190020	0.00	21.00	0.00	1.00	14.00	2.00	0.00	0.00	0.00	5000.00	5.00	0.00	0.00	3.00
2	2	187528	0.00	34.00	0.00	0.00	6.00	2.00	1.00	1.00	0.00	4000.00	5.00	1.00	75000.00	3.00
3	3	178790	0.00	24.00	6.00	0.00	18.00	2.00	0.00	0.00	0.00	15000.00	5.00	0.00	0.00	3.00
4	4	112389	0.00	37.00	6.00	0.00	15.00	2.00	1.00	1.00	0.00	3000.00	5.00	0.00	0.00	3.00
5	5	145536	1.00	36.00	1.00	0.00	9.00	1.00	0.00	1.00	1.00	2500.00	2.00	0.00	0.00	3.00
6	6	175233	0.00	33.00	1.00	0.00	18.00	0.00	0.00	0.00	1.00	150000.00	5.00	0.00	0.00	3.00
7	7	160257	0.00	30.00	1.00	0.00	8.00	2.00	1.00	0.00	0.00	20000.00	5.00	0.00	0.00	3.00
8	8	208576	0.00	26.00	0.00	0.00	17.00	2.00	3.00	0.00	1.00	30000.00	4.00	1.00	300000.00	3.00
9	9	171703	0.00	32.00	0.00	1.00	10.00	2.00	0.00	0.00	0.00	2000.00	2.00	0.00	0.00	3.00
10	10	162746	1.00	32.00	1.00	2.00	16.00	2.00	0.00	0.00	0.00	2000.00	4.00	1.00	5000.00	3.00
11	11	200503	1.00	44.00	0.00	0.00	7.00	2.00	0.00	1.00	0.00	2000.00	3.00	0.00	0.00	3.00
12	12	157315	0.00	37.00	0.00	0.00	14.00	2.00	0.00	0.00	0.00	10000.00	3.00	0.00	0.00	3.00
13	13	165244	1.00	55.00	6.00	0.00	8.00	2.00	2.00	1.00	1.00	8000.00	4.00	0.00	0.00	3.00
14	14	160366	1.00	44.00	0.00	2.00	9.00	2.00	2.00	1.00	1.00	3000.00	5.00	1.00	5000.00	3.00
15	15	195431	0.00	31.00	0.00	0.00	19.00	2.00	1.00	0.00	0.00	12000.00	6.00	1.00	1000000.00	3.00
16	16	206138	1.00	48.00	0.00	1.00	9.00	2.00	2.00	1.00	0.00	50000.00	6.00	1.00	100000.00	3.00
17	17	145911	0.00	38.00	6.00	0.00	10.00	2.00	1.00	1.00	1.00	3500.00	4.00	0.00	0.00	3.00
18	18	172157	1.00	49.00	1.00	2.00	15.00	2.00	1.00	4.00	0.00	22000.00	5.00	1.00	50000.00	3.00
19	19	191020	0.00	24.00	0.00	0.00	15.00	2.00	1.00	0.00	1.00	20000.00	4.00	0.00	0.00	3.00
20	20	204541	1.00	57.00	0.00	0.00	17.00	2.00	1.00	1.00	1.00	40000.00	3.00	1.00	900000.00	3.00
21	21	192021	1.00	44.00	0.00	0.00	10.00	2.00	2.00	1.00	1.00	20000.00	4.00	0.00	0.00	3.00
22	22	214731	0.00	22.00	6.00	2.00	16.00	2.00	0.00	0.00	0.00	30000.00	3.00	0.00	0.00	3.00
23	23	213185	1.00	29.00	3.00	0.00	18.00	2.00	1.00	3.00	1.00	30000.00	9.00	0.00	0.00	3.00
24	24	60008	1.00	43.00	0.00	0.00	11.00	2.00	0.00	3.00	1.00	10000.00	4.00	0.00	0.00	3.00
25	25	196296	0.00	40.00	1.00	0.00	16.00	2.00	1.00	1.00	1.00	10000.00	3.00	0.00	0.00	3.00

Data View Variable View

SPSS Processor is ready

4. ADDITIONAL TABLES
4.1 APPENDIX A -POSITIVE AND NEGATIVE SYMPTOMS SCALE (PANSS)

	KEY	Absent (1)	Minima (2)	Mild (3)	Moderate (4)	Moderate Severe(5)	Severe	Extreme (7)
P1	Delusions	1st WK	2nd WK	3rd WK	4th WK	5th WK	6th WK	7th WK
P2	Conceptual Disorganization							
P3	Hallucinatory behaviour							
P4	Excitement							
P5	Grandiosity							
P6	Suspiciousness/ Persecution							
P7	Hostility							
N1	Blunted affect							
N2	Emotional withdrawal							
N3	Poor rapport							
N4	Passive/apathetic social withdrawal							
N5	Difficulty in abstract thinking							
N6	Lack of spontaneity & flow of conversation							
N7	Stereotyped thinking							
G1	Somatic concern							
G2	Anxiety							
G3	Guilt feelings							
G4	Tension							
G5	Mannerisms & posturing							
G6	Depression							
G7	Motor retardation							
G8	Uncooperativeness							
G9	Unusual thought content							
G10	Disorientation							
G11	Poor attention							
G12	Lack of judgment & insight							
G13	Disturbance of volition							
G14	Poor impulse control							
G15	Preoccupation							
G16	Active social avoidance							

5.2 APPENDIX B - WHO QUALITY OF LIFE BREF SCALE (WHOQOL-BREF) – ENGLISH

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate**. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither Poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5

24	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Do you have any comments about the assessment?

……..

5.3 APPENDIX C - WHO QUALITY OF LIFE BREF SCALE (WHOQOL-BREF) – TAMIL

thH;f;i f j; juk; gwwpa nfs;tpfs;

vy;yh nfs;tpf isaKk; goj;J. c';fs; c zh;r;rpf is kjpggpl;L .x tpb thU

nfs;tpf;F k; Vwwp v z;i z r; Rwwp xU tl;lk; nghl tk;/

t/ vz;	nfs;tp	kpf tk; nkhrk;	nkhrk;	edwhf tk; , y;iy nkhrkhf t[k; , y;iy	edwhf cs;sJ	kpf tk; edwhf cs;sJ
1/	c';f Si la thH;f;i f juj;i j vggo kjpggpL fpwPh;fs;?	1	2	3	4	5

t/ vz;	nfs;tp	kpf tk; mjpUg;jp	mjpUg;jp	jpUg;jpaK; , y;iy mjpUg;jpaK; , y;iy	jpUg;jp	kpf tk; jpUg;jp
2/	c';fs; cly; eyj;i j gwwp ve;j ms t[f;F jpUg;jpahf , Uf;fpwPh;fs;?	1	2	3	4	5

fPH cs;s nfs;tpfs; eP;fs; fle;j ,uz;L thu';fspy; ve;j ms t[rpy tw;iw mDgtpj;jpU f;fpwPh;fs; vdgi j gwwp cs;sd/

t/ vz;	nfs;tp	, y;yt , y;iy	rpwpjs t[	Xhs t[	mjpfkhf	kpf tk; mjpfkhf
3/	eP;fs; braa nt zpai j bra;t jw;F typ ve;j ms tpw;F j il ahf cs;sJ?	1	2	3	4	5
4/	jpdrhp thH;f;i f aply; braygl c';fSf;F kUj;Jt rpfpr;i r ve;j ms t[f;F nji tggL fpwJ	1	2	3	4	5

5/	eP;fs; thH;fi fia ve;j mstpw;F renjhckhf mDgtpf;fpwP,fs;	1	2	3	4	5
6/	c';fs; thH;if ve;j mstpw;F mh;j;jk; cilj hf csJ vdW njhdWfpwJ/	1	2	3	4	5

t/vz;	nfs;tpfs;	,yynt ,y;iy	rpwpjst[	Xhmst[	mjpfkhf	kpftk; mjpfkhf
7/	c';fshy; ve;j mstpw;F edWwhf ftdk; brYj;j Kofpwj	1	2	3	4	5
8/	c';fs; jpdrhp thH;fi fpy; ve;j mst[ghJ fhg;ig czh;fpwP,fs?	1	2	3	4	5
9/	c';fs; RwWrR{Hy; vt;tst[Mnuhf;fpakhf csJ/	1	2	3	4	5

fPH csJ nfs;tpfs; fle;j ,uz;L thu';fspy; c';fshy; vt;tst[KGikahf rpytw;iw mDgtpf;f myyJ braa Kofpwj vdgi jg; gwwp csJ/

t/vz;	nfs;tpfs;	,yynt ,y;iy	rpwpjst[	Xhmst[	mjpfkhf	kpftk; mjpfkhf
10/	jpdrhp thHf;i ff;F nghJkhd rf;jp ,Uf;fpwjh>	1	2	3	4	5
11/	c';fs; cly; njhwpwj;ij c';fshy; VwWfbfhs;s Kofpwjh>	1	2	3	4	5
12/	c';fs; nji tfis g{h;j;jp bra;tjw;F nghJkhd gzk; ,Uf;fpwjh>	1	2	3	4	5
13/	jpdrhp thH;fi fapy; c';fSf;F nji tahd jfty;fs; ve;j mst[f;F fpilf;ff; Toajhf csJ>	1	2	3	4	5
14/	bghGJnghf;F bray;fspy; <LgL tjw;F ve;j mst[re;jhgg';fs; csJ>	1	2	3	4	5

t/vz;	nfs;tp	kpftk; nkhrk;	nkhrk;	edwhftk; ,y;iy nkhrkhftk; ,y;iy	edwhf Css;sJ	kpftk; edwhf css;sJ
15/	c';fshy; vt;tst[edwhf elkhl Kofpwj>	1	2	3	4	5

fPH css;s nfs;tpfs; c';fs; thH;f;if apy; bttntW mk;rk; Fwpj;J ePf;fs; fle;j ,uz;L thu';fspy; jpUg;jp mile;jPf;fs; vdgijg; gwwp cs;sd/

t/vz;	nfs;tpfs;	kpftk; mjpUg;jp	mjpUg;jp	jpUg;jpak; ,y;iy mjpUg;jpak; ,y;iy	jpUg;jp	kpftk; jpUg;jp
16/	c';fs; Jhf;fk; Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
17/	jpdrhp thHf;if apy; eltof;iffis braypak; c';fs; jpwik Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
18/	c';fs; ntiyf;Fhpa Fwpj;J ve;j mst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
19/	c';fis Fwpj;j vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
20/	c';fs; jdpggl;l cwt[fs; Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
21/	c';fs; clypdg thHf;if Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	
22/	c';fs; ezgh;fsplk; ,Ue;J fpilf;Fk; Mjut[Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5
23/	ePf;fs; thGk; ,lj;jpd; epiy Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPf;fs;	1	2	3	4	5

24/	kUj;Jt trjp fpilf;Fk; tpjk; Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwPfs;	1	2	3	4	5
25/	c';fSila nghf;Ftuj;J Fwpj;J vt;tst[jpUg;jpahf ,Uf;fpwh;fs;	1	2	3	4	5

fPH css;s nfs;tpfs; ePq;fs; fle;j ,uz;L thu';fspy; vj;jid Kiw rpytw;iw mDgtpj;jpUf;fpwPfs; vdgij gwwp css;sd/

t/vz;	nfs;tp	,yynt ,y;iy vgpghGjht J	r py rkak;	gy rkak;	VgpghGJk;
26/	Jdgkhd czh;r;rpfs; mof;fo VwgLfpwjh> (cjhuzk; nrhfk; ,ayhik. gjl;lk; kdjsh;r;rp)	5	4	3	2	1

,e;j kjpggPL fUtpapy; css;s nfs;tpfSf;F gjpy; mspggjw;F ahuht J cjtp brajhh;fsh> 1/ Mkhk; 2/ ,y;iy

,e;j kjpggPq;L fUtpia Koggjw;F vt;tst[neuk; vLj;Jf; bfhz;bdfs>

,e;j kjpggPq;L f; fUtpia gwwp ePq;fs; vd;d epidf;fpwPfs;

---

c';fs; cjtpf;F edwp

5.4 APPENDIX D - SHORT EXPLANTORY MODEL OF ILLNESS – ENGLISH VERSION

SEMI

Record number Date of interview

Gender Age

1. INTRODUCTION

"Thank you for agreeing to talk about your health. I would like to ask you Some questions about your health and how it affects you. The questions have

Already been written out so it will not sound like a normal interview and some

Things may not have much to do with your situation. I would like to stress that

All you answer will be strictly confidential."

1. HEALTH & ILLNESS:

CURRENT HEALTH:

a. I would like to ask you about your visit to the doctor

Problem1

Problem2

Problem3

HEALTH OVER LAST YEAR

b. Over the past year have you had any illness or health problems?

Year1

Year2

Year3

c. What do you call these problems? Probe: If you had to give them names What would they be?

Name1

Name2

Name3

d. When did you first notice<specify identified problem>Probe: how long ago Was it, when did it start?

Onselt1

Onset2

Onset3

e. Why do you think these problems started when they did?

Why1

Why2

Why3

f) Is there anything you have or haven't done that has caused this? Probe for example.

Internal

g) Is there anything anyone else has done or not done that has caused this? Probe

External

h) So who or what is the cause of you getting this?

In text

i)) Do you believe that your problem is due to black magic?

1) Yes 2)No

j) Do you believe that your problem is due to karma?

1) Yes 2) No

k) Do you believe that your problem is due to punishment from God?

1) Yes 2) No

l. Do you believe that your problem is due to evil spirit?

1) Yes 2) No

m) Do you believe that your problem is due to any disease?

1) Yes 2) No

3. PERCEIVED SEVERITY

a. How serious are your problems?

Serious1

Serious2

Serious3

b. What do you most fear about these problems?

Fear1

Fear2

Fear3

c. Why did you go to the doctor? Probe: Had it got worse? How? Were You afraid what it might be, did other people advise you to go?

4. EXPECTATIONS OF/SATISFACTION WITH MEDICAL CARE

1. Will it help you, if you visit a doctor or a nurse for treatment for your problem?

1) Yes 2) No

2. Will it help you, if you visit a traditional healer for treatment for your problem?

1) Yes 2) No

3. Will it help you, if you visit a mantrivadi for treatment for your problem?

1) Yes 2) No

4. Will it help you, if you visit a temple or a church or a mosque for your problem?

1) Yes 2) No

5. Will it help you, if you observe any diet restrictions or special diet for your problem?

1) Yes 2) No

6. Do you know if there is anything else which may help your problem

1) Yes (list)

2) No

7. What do/did you hope to gain from seeing your doctor? What do/did you want the doctor to do?

Expect1

Expect2

Expect3

8 Have you asked the doctor about these problems?

9. What did the doctor do0 about these problems?

Gpact1

Gpact2

Gpact3

10. Was it useful talking to the doctor about your problems? Can you say why?

11. Was there anything about your treatment you are unhappy about?

5. ACTIVITIES AND FUNCTIONING

a. What are the main difficulties your problems have caused you (list up to3)?

Difs1

Difs2

Difs3

b. Which parts of your body are most affected by your problems (list up to 3)?

Body1

Body2

Body3

c. How have you been affected emotionally by what you've described (give e.g)

Emotion

d. Have these problems stopped you getting about as well as you used to? (e.g.)

Mobile

e. Have these problems affected your social life? (Give example)

Social

f. Have these problems affected your home life (give example)

Family

g. Have these problems affected how you get on with people in general (give e.g)

Relate

h. Has your work been affected (how?)

Work

6. OTHER HEALTH BEHAVIOUR

a. Have you asked for advice from anyone else about these problems? Probe:

Hospital, pharmacist, friends, family, Church, healers, osteopaths etc.

Advice

b. Has anyone else apart from your doctor given you any Rx or advice about this?

Non gp

c. Are you treating yourself for the problem? Self

d. If so how?

How

e. Are you taking any medication? (What is it?)

Meds1

Meds2

Meds3

f. Are you taking any other cures or remedies?

Cures

g. Do you smoke (how much?)

Cigs

h .Do you drink alcohol (how much)

Alcohol

i. What about any<street/recreational>drugs (What? Give examples)

Drugs

VIGNETTES:

Read out “You’ve been kind enough to tell me about yourself and your visit to the doctor. Finally - I’d like to ask your opinion about another person’s visit to

the doctor. I'd like to read a short account of the problem and then ask you a few questions about them."

7. VIGNETTE I

Mrs. A is a 30 year old housewife with three small children. Her husband works as a manual laborer. For the past 6 months she has stopped doing household work. She has been socially withdrawn and prefers to be alone. Her family has noticed that she smiles to herself and admits to hearing voices of strange people specking to her. She is convinced that other will harm her. Her sleep is disturbed and appetite is poor. Her in-laws live next door but are not supportive.

a. What if anything is her problem?
b. Does she have an illness? If yes, what is it?
c. What are the causes of her problems?
d. What should she do about It.?
e. What should the doctor do about it?

8. Finally is there anything else about your recent trip to the doctor or health we Haven't talked about you would lie say?

5.5 APPENDIX E- SHORT EXPLANTORY MODEL OF ILLNESS – TAMIL VERSION

thp i r v z ; :
kU j;J t k i d v z ; :
neh;fh z y; n j j p :
Mukgp f;Fk; neuk; :
Kof;Fk; neuk; :
neh;fh z y; :
kdey f;fy;tp f;F
Kd;gpd; :

xU tps f;fkhd neh;fh z y;

A/jwnghi jha cly;epiyapd; Mnuhf;fpak; rhhpe;j neh;fh z y;

1/eP;fs; fle;j Kiw ve;j fhuz j;jpw;fhf kU j;J t iu fh z te;jP,fs;

a.

b.

c.

B. fle;j tUl';fspy; ,Ue;j Mnuhf;fpaj;jpid epiyik

1/ fle;j rpy tUl';fspy; c';fs; cly; epiyapy; Vnj Dk; khwpw';fs;
gpur;ridfs; ,Ue;j jh>

a.

b.

c.

2/ ,e;j gpur;ridfis eP;fs; vd;dbtd W brhy;tP,fs;
(tpsf;fkhf nfl;L vGjtJk)

a.

b.

c.

3/ c';fsplk; Vwgl;l ,e;j gpur;ridfis Kjd; Kjypy; eP;fs; vgpbghGJ czhpe;jP,fs; mit vd;d gpur;ridfs;
(vj;jid fhyj;jpw;F Kd; Vwgl;l J> vgpbghGJ bjhl';fpa J>

a.

b.

c.

4/ c';fS f;F ,e;j gpur;r id fs; Mukgpj;j J ve;j fhuz j;jpdhy; vd;W epid f;fwPf;fs;

a.

b.

c.

5/ eP;fs; Vnjh xU fhhpaj;j ij bra;j jhnyh myyJ braahj jhnyh ,e;j gpur;r id te;j J vd;W eP;fs; fUJ f;fwPf;fsh> (tpsf;fk)

a.

b.

c.

6/ kwwth;fs; Vnjh xU fhhpaj;j ij c';fS f;F bra;j jhnyh-braahj jhnyh ,e;j gpur;r id fs; te;j J vd;W fUJ f;fwPf;fs; (tpsf;fk)

a.

b.

c.

7/ c';fS f;F ,e;jkhjph gpur;r id fs; te;j jw;F vd;d fhuzk; vd epid f;fwPf;fs;

a.

b.

c.

8/ahnuh xUth; bra;j ke;jpuj;jpdhy; c';fS f;F ,e;j gpur;r id fs; te;j J vd;W eP;fs; epid f;fwPf;fs;

a.

b.

c.

C. c z uggl;l nehad; eP uk/

1/ c ';f sd; , e;j ggur;r i dahd J v t;t s t[tghP khd J v dW f U J f wP,f s?

a.

b.

c.

2/ c ';f sd; ve;j gur;r i dahd J c ';f S f;F m j f khd ga j ;i j j U f w J >

a.

b.

c.

3/K j d;K j yy; , e;j gur;r i d f S f;f h f eP ;f s; v ';F b r dwP,f s;

a.

b.

c.

4/k U j ;J t k i d f ;F ve;j f hu z j ;j dhy; t e;j P,f s?

a.

b.

c.

6/ ahU i l a mwt[i uadhy; eP ;f s; k U j ;J t k i d f ;F t e;j P,f s?

a.

b.

c.

D.k U j ;J t c j t i aggwyw c ';f sl k; v j hghhgg[f s;- j Ug;j f s;

1/ k U j ;J thl k; eP ;f s; v d;d f i l f ;F k; v dw ekg f ;i f a[l d; t e;j P,f s? (c j t i a v j hghh;j ;J) c ';f S f ;F k U j ;J t nuh- b r t yanuh v d;d b r a;a n t z ;L k; v dW t U kg[f wP,f s?

a.

b.

c.

2/ kUj;J thplnkh-brtypahplnkh c';fSf;F cs;s gpur;rid iag; gwwp

tprhhpj;jPf sh>

a.

b.

c.

3/ c';fSf;F cs;s gpur;rid fs; gwwp mth;fs; vd;d bra;jhh;fs;

a.

b.

c.

4/ c';fSf;F cs;s gpur;rid fs; gwwp kUj;J th;brtypah; ,lk; ngRtJ cgnahfkhdJ vdW fUJfwPf sh> Vd; vdW TwKoa[kh>

a.

b.

c.

5/ c';fSf;F mspf;fggLk; rpfpr;ira py; Vjht J c';fSf;F gpof;f tpy;iyah>

a.

b.

c

E.eltof;iffs; kwWk; eilKiwfs; gwwpa nfs;tpfs;

1/ c';fSila ,e;j gpur;rida dhy; c';fSf;F Vwgl;l Kf;fpakhd

ghjpgg[fs; vd;d>

a.

b.

c.

2/ c';fs; cly;y; ve;jggF j;ahd J c';fS ila g;ur;rid a;dhy; k;ftk; ghj;f;fggl;Lss;s J>

a.

b.

c.

3/ c';fs;d; kd czh;r;r;fs;y; vt;tst[ghj;f;fggl;Lss;s J>

a.

b.

c.

4/ eP;fs; vg;bghGJk; nghy; ,Ugg ij ,e;j g;ur;rid fs; jLj;J t;l;ld vd;W eP;fs; e;idf;fwP;fsh>

a.

b.

c.

5/ c';fs;d; g;ur;rid fs;dhy; c';fS ila FLkg thH;f;if ghj;f;fggl;l jh> (ve;j t;jj;j;y; cjhuz';fs; brhy;ytk;)

a.

b.

c.

6/ c';fs; g;ur;rid fshy; c';fs;d; rK:f thH;f;if ghj;f;fggl;l jh>

a.

b.

c.

7/ c';fs; g;ur;rid fs; eP;fs; g;wh;lk; rf$khf gHFtij ghj;f;f;d;wjh>

a.

b.

c.

8/ c';fS ila ,e;j Rftpdj;jpdhy; cfSila ntiy ghjpf;fggl;l jh>

a.

b.

c.

F. Muhf;fpakhd gHf;f tHf;f ';f isg; gwwpa nfs;tpfs;

1/ c';fspd; ,e;jg; gpur;ridfs; gwpw ntW ahhplkht J Mnyhrid bgwwPfsh>kUj;J tkid-brtpyahe;ezgh;fs;FLkgj;jpdh; jpUr;rigapdh;kUe;J jUgth;

2/ kUj;J tiu jtpu ntW ahuht J c';fis gwwpa gpur;rida;y; rpfpr;if- mwpt[iu mspj;jjhh;fsh>

3/ ePP;fs; jhkhfnt c';fSila gpur;ridfSf;F VJk; kUe;J rhggpLfpwPfsh>

4/ mggobadwhy; vggoggl;l rpfpr;ir>

5/ ePP;fs; c';fs; gpur;ridfSf;F kUe;J rhggpLfpwPfsh>

6/ c';fSila gpur;ridfis jPf;f ntW VJk; kUe;J rhggpLfpwPh>

7/ c';fSf;F g[ifgpof;Fk; gHf;fk; czl;h (vt;tstp)

8/ c';fSf;F FoggHf;fk; czl;h> (vt;tstp)

9 ePP;fs; kUe;Jfs; rhggpLfpwPh> (cjhuzk)

G nehapd; fhuzj;ijg; gwwpa nfs;tpfs;

1/ c';fs; gpur;ridfshdJ

a. ePP;fs; Kwgpwtpay; bra;j rpy fhupa';fshy; Vwgl;ljh>

b. jPa Mtpfspdhy; czlhdjh>

c. jPa ke;jpu';fspdhy; Vwgl;ljh>

d. fltpsplkpUe;J te;j jzlidapdhy; czlhdjh>

e. ,J xU neha; vdwW fUJfpwPfsh>

cjtpfs; bgWtijg; gwwpa nfs;tpfs;

1/ nfhapYf;F miHj;J brdwhy; c';fS ila gurridfs; jPUk; vdW fUJfwP,fsh>

2/ cs;Shy; ,Uf;Fk; ke;jputhjpadhy; c';fs; gurridfis jP,f;f Koak; vdW epidf;fwP,fsh>

3/ ghukghpa kUj;Jtuhy; c';fs; gurridsis FzggLj;j Koak; vdW epidf;fwP,fsh>

4/ xU kUj;Jth; c';fis Fzkhf;f ,aYk; vdW fUJfwP,fsh>

I. xU nehahspiaggwwpa Fwpgg[

Rpy kf;fs; kUj;Jtiu mQqFtijg; gwwpa c';fspd; fUj;J vd;dbtdgij mwpa tpUkg[fpnwd/

fP,H cs;s gFjpapYs;s mtuJ gurridfs; gwwpa c';fs; fUj;ij ja[k; rpy nfs;tpfisa[k; nfl;f tpUkg[fpnwd/

jpUkjp X vdgth; Kggj;jpuz;L taJ epukgpa xU FLkgj iytp mtUf;F 3 FHe;ij fs; cs;sd/ mtUila fzth; Typ ntiy bragth/ fle;j vl;L khj';fshf jpUkjp X mth;fs; tP,L ntiy bra;tJ ,y;iy/ FHe;ij fis ftdpggnjh. mth;fnshL ngRtnjh fpilahJ/ jd;id Rj;jpfhpj;Jf; bfhs;tJ fpilahJ/ gpwhpk; rf$khf ngrhky; jdpikahf ,Uggijna tpUkg[fpwhh/ mth; jdf;Fsnsna rpwpj;J bfhs;tija[k; ahnuh bjhpahj Fuy;fSf;F mth; fP,gotija[k; mtUila FLkgj;jpdh; fz;Ls;sdh/ kwwth;fs; mtUf;F jP,k tpistpf;f nghtjhf jpUkjp X TWfpwhh/ mth; xG';fhf cW';Ftnjh my;yJ rhggpLtnjh fpilahJ/ mtUila khkdhh;khkpahh; gf;fj;J tP,oy; ,Ue;jhYk; mtUf;F Mjut[mspggJ ,y;iy/

nfs;tpfs;

1/ mtUf;F Vwgl;Lss;s gurridvd;d>

2/ jpUkjp X nehapdhy; ghjpf;fggl;Ls;shuh> Mk; vdwhy; vd;d nehap?

3/ mtUila gurridfSf;F fhuz';fs; ahit>

4/ mtUila gur;ridahdJ jR MtadhnyhmyyJ ke;juj;jdhnyh VwgI;I jh>

5/ mtUila gur;ridahdJ Kwgwtay; bra;j ght j;jdhy; VwgI;I jh>

6/ fIt[sIkUe;J te;j jz;I idadhy; VwgI;II jh>

7/ mtUila gur;ridfsyUe;J tLgLtjw;F mth; vd;d braa ntz;Lk;?

8/ mth; nfhaY f;F bryy ntz;Lkh>

9/ ahnuh xU rj;j itj;jaiu ghh;f;f ntz;Lkh>

10/ mth; ke;juthjaIk; bryy ntz;Lkh>

11/mth; xU kUj;J thIn kh myyJ bryyahInkh rfr;i ff;fhf bryynt z;Lkh>

12/ kUj;J tnuh myyJ brtyanuh mtuJ gur;ridfis jP;f;f vd;d cjt braa ntz;Lk; vdW eid f;fwP;fs?