

QUALITY OF LIFE
AND
EXPLANATORY MODELS IN PATIENTS
WITH BIPOLAR AFFECTIVE DISORDER



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 Bipolar Affective Disorder” is the bonafide work of Dr. Sweta Sheth 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 Bipolar Affective Disorder is the bonafide work of Dr Sweta Sheth 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 Bipolar Affective Disorder” is a bonafide work done by me under the guidance of Dr.K.S Jacob, 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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Explanatory models and quality of life in patients with affective disorders.
Dr. Sweta Sheth, PG Registrar, Dr. K. S. Jacob, Psychiatry Unit 1, CMC, Vellore.

Ref: IRB Min No: 9296 [OBSERVE] dated 05.02.2015

Dear Dr. Sweta Sheth,

The Institutional Review Board (Blue, Research and Ethics Committee) of the Christian Medical College, Vellore, reviewed and discussed your project entitled "Explanatory models and quality of life in patients with affective disorders." on February 5th 2015.

The Committees reviewed the following documents:

1. IRB Application format
2. Short explanatory model of illness – English and Tamil versions
3. WHO QoL BREF – English and Tamil versions
4. PANSS Rating scale
5. Informed Consent Form (English)
6. Information Sheet (English and Tamil)
7. HAMILTON RATING SCALE
8. SEMI Tamil version
9. A CD containing documents 1 – 8

The following Institutional Review Board (Blue, Research & Ethics Committee) members were present at the meeting held on February 5th 2015 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_Policies.html in the CMC Intranet and in the CMC website link address: <http://www.cmch-vellore.edu/static/research/Index.html>.

Fluid Grant Allocation:

A sum of 6,100/- INR (Rupees Six Thousand One Hundred only) will be granted for 1 year.

Yours sincerely

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9	arul	112849m	35	0	1	1	2	3	1	0	1	1	0	0
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12	rani	083451m	55	1	0	0	1	0	1	0	0	1	1	1
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INTRODUCTION

Psychiatry is a relatively young science; even so, it can trace its roots back to the origin of civilization itself. It has long flourished as a rather loosely defined discipline, one that dealt with unraveling the secrets of the mind. People have always been fascinated with why we think, act, speak the way we do; and have always sought answers to these questions. Much of our present understanding of psychiatric illness rests on those foundations; what has changed is probably our understanding of biological underpinnings of disease. Our relentless search for meaning and explanation for the illnesses that plague us have led to various formulations of disease. Beginning with supernatural, to demonological, to astrological explanations, man has always tried to make sense of the understandable, and to convey this meaning to his fellow humans. Even as we have dawned into the era of scientific discovery, we have not yet fully unraveled the mysteries of the human body, and wherever science has failed, there has been a rich proliferation of non-scientific explanations and rationale that is used to explain both ordinary and out of the way phenomena.

The study of these explanatory models has today become a vast field, with scope for still further research. The study of patient explanations for their disease has been studied in diverse medical specialties. But nowhere is this more relevant than in the field of psychiatry, where biology is still seemingly at a loss to explain why people think and feel the way they do; and why the human mind sometimes seems to go haywire.

The study of explanatory models is a vital but oft neglected area of interest, both for clinicians and researchers. An explanatory model provides the sum total of the patients' understanding and perspectives on disease, in terms of aetiology, onset of symptoms, pathophysiology, course of illness and treatment. Clinical decisions are often taken without involving patients and their families in the decision making process. This may lead to poor cooperation from the patients and their families. Also, disregard of patients' models of illness leads to poor compliance with therapy. Assessing their explanatory model will go a long way in allowing clinicians to take more balanced decisions regarding patient care. Knowing explanatory models also helps us to propose alternate models of disease, which helps in psycho education of the patients and families.

Research in explanatory models in psychiatry has mainly focused on conditions like schizophrenia or depression. It has been well established that patients suffering from these conditions tend to hold both medical and non-medical explanatory models. In contrast, there is very little literature on patients' perspectives or explanatory models in mania, which would seem to be the hallmark of Bipolar Disorder. This is a glaring lacuna which needs to be addressed.

Bipolar disorder is a chronic debilitating condition with a worldwide prevalence of 0.3-1.5%. Patients often require long term medication, which itself can pose a significant burden. Their Quality of Life (QOL) is often quite severely impaired. While there are several studies looking at QOL in Major Depressive Disorder (MDD), similar literature

in BPAD is relatively lacking, however this is a trend that seems to be slowly changing. Quality of life in mental illness is known to be determined by several factors. Studies of QOL in BPAD consistently show poorer QOL in BPAD. One study has shown that the impact of BPAD on quality of life can be similar to schizophrenia. Several factors affecting QOL have also been identified. No studies so far have looked at the relation between explanatory models and QOL. We would specifically seek to address this issue with this study.

REVIEW OF LITERATURE

BIPOLAR AFFECTIVE DISORDER

Bipolar Affective Disorder (BPAD) is a chronic and debilitating psychiatric illness that is characterized by episodes of mania and depression. The disease characteristically has a relapsing and remitting course with full recovery in between episodes. Manic episodes are characterized by elated or irritable mood; increased goal directed activity and decreased need for sleep, whereas depressive episodes are characterized by a core triad of low mood, anhedonia and anergia. Both phases of the illness are associated with significant disturbance of biological functions as well as socio-occupational dysfunction. Diagnostic criteria for BPAD have been developed by several major international bodies and are included in most major classificatory systems for mental illness, including the International Classification of Diseases-10 (ICD-10) and the Diagnostic and Statistical Manual (DSM 5).

The understanding of the term Bipolar Affective Disorder has also undergone tremendous change. Historically, BPAD or Manic Depressive Psychosis was seen as being distinct from schizophrenia, a dichotomy that was made by Kraepelin. This distinction was made based on the course and clinical outcome of BPAD, without further sub typing of the disorder(1). BPAD did not again receive much attention till the mid-60s, when the concept was revived by the work of Angst and Perris(2). The DSM III officially added the category of Mood Disorders to its' classificatory system, and the DSM IV further expanded on the classification of mood disorders. With the advent of newer

pharmacotherapeutic options, research in to BPAD intensified, leading to our current understanding of the disorder.

The traditional understanding of Bipolar disorder was that it is a distinct entity with alternating phases of mania and depression with full inter-episode remission. However, it was soon realised that Bipolar Disorder was being underdiagnosed with the application of such a narrow definition. Today however, research has highlighted on the heterogeneous nature of the disorder. The DSM has included two distinct subtypes of BPAD- BPAD I and BPAD II based on severity of the manic episodes in its classification. A bipolar spectrum has been postulated, with disorders ranging from full blown BPAD I to cyclothymia. Researchers have argued for splitting this spectrum into several subgroups and forming distinct subtypes of the disorder, thus widening the diagnostic category. With the use of these subgroups in making a diagnosis of BPAD, the burden of BPAD has been found to be significantly higher than what previous research had estimated.

CLASSIFICATION OF BPAD

ICD-10 CRITERIA FOR BPAD

The International Classification of Diseases, 10th edition (1994) classifies Bipolar Affective Disorder as follows:

F31 BIPOLAR AFFECTIVE DISORDERS

F31.0 Bipolar Affective Disorder, current episode hypomanic

F31.1 Bipolar Affective Disorder, current episode manic without psychotic symptoms

F31.2 Bipolar Affective Disorder, current episode manic with psychotic symptoms

F31.3 Bipolar Affective Disorder, current episode mild or moderate depression

.30 Without somatic syndrome

.31 With somatic syndrome

F31.4 Bipolar Affective Disorder, current episode severe depression without psychotic symptoms

F31.5 Bipolar Affective Disorder, current episode severe depression with psychotic symptoms

F31.6 Bipolar Affective Disorder, current episode mixed

F31.7 Bipolar Affective Disorder, currently in remission

F31.8 Other Bipolar Affective Disorders

F31.9 Bipolar Affective Disorder unspecified

It employs an alpha-numeric classificatory system, with the F category being assigned to mental illness. Each disorder is described by two numbers followed by decimals to signify subdivisions. A fourth character can be added as a specifier. The disorders are arranged hierarchically, with organic disorders at the top of the hierarchy.

A diagnosis of BPAD can be made if the patient has had at least two episodes of altered activity and energy levels, which can either be an elevation of and increased energy and activity (mania or hypomania); or conversely, a lowering of mood and decreased energy and activity (depression). There is usually complete recovery in between episodes.

EPIDEMIOLOGY AND BURDEN OF DISEASE

GLOBAL PREVALENCE

Bipolar disorder is one of the most common mental health disorders worldwide. The global lifetime prevalence of Bipolar Affective Disorder I is 0.6% and Bipolar Affective Disorder II is 0.4%. The lifetime prevalence of the so called Bipolar Spectrum is at 2.4%(3). The worldwide incidence is estimated to be 22 per 100,000(4)

A majority of 12-month Bipolar Spectrum cases reported severe or moderate manic/hypomanic or major depressive episodes in the past year. Combined manic/hypomanic and depressive episodes in the past 12 months were more severe among BP-I and II

INDIAN PREVALENCE

Data on Bipolar Affective Disorder in India are lacking as compared to western data. Data extrapolated from the World Mental Health Survey (Merikangas et al) show the prevalence of Bipolar Spectrum in India to be 0.1%, with about 20% of these cases being Bipolar Disorder(5).

LOCAL PREVALENCE

An extensive Pubmed search did not reveal any data on the prevalence of Bipolar Affective Disorder in Tamil Nadu.

BURDEN OF ILLNESS

According to the Global Burden of Bipolar Disorder survey by the World Health Organisation (WHO), BPAD contributes to 2.5% of the global Years Lived with Disability (YLDs), and is the sixth leading cause of the same globally. The average duration of BPAD is about 23 years, with low rates of remission. The Disability Adjusted Life Years (DALYs) due to BPAD is 13,645.

74% of patients with depression and 50.9% of patients with mania reported severe and very severe role impairments. 25% of patients with BPAD a history of suicide attempts(3)

Indian data can be found under the regional breakup of the WHO, with YLDs estimated to be 3164, and DALYs of 3191(4)

BPAD is also associated with a high rate of medical and psychiatric comorbidity. At least 75% of those with BPAD also meet criteria for another lifetime disorder. The most common comorbid psychiatric conditions are Anxiety Disorders (76.5%), Behaviour Disorders (54.1%) and Substance Use Disorders (52.3%). Lifetime comorbidity of Bipolar Disorder with any psychiatric disorder is 88.2%; and with 3 or more disorders is 16.6%. (3).

In a study conducted in Assam, India to assess the disability associated with different mental disorders, it was found that the severity of BPAD correlated positively with the total scores on the Indian Disability Evaluation and Assessment Scale (IDEAS). At the

domain on the IDEAS- self-care, interpersonal relationships, communication and work were affected, with self-care being affected the last.

COURSE AND OUTCOME OF BIPOLAR AFFECTIVE DISORDER

Bipolar Disorder has a chronic course and is classified as a severe mental illness. The average age of onset is 23 years, with no preponderance for either sex. The average duration of illness is 23 years, with low remission rates(4)

Indian research shows similar statistics. In one study from Pondicherry, the authors found the mean age of onset to be 24.8 years, with 11.1% of illness duration spent in a mood episode and the median duration of mood episodes being 2 months (5). Another study from Bangalore showed mean age of onset as being 27.7 years, and mean duration of illness to be 20.2 years(6). This is similar to global data on course and outcome of BPAD.

RATING SCALES FOR BIPOLAR AFFECTIVE DISORDER

There are several validated scales use to rate BPAD. The scales used to rate BPAD include:

1. Young Mania Rating Scale: (Young, Biggs, Ziegler, & Meyer, 1978) is a 15 to 30 minute interview designed to be conducted by a trained clinician. It combines the physicians' own assessment as well as the patients' report of their symptoms over the previous two days. Scores on the YMRS also statistically differentiate patients

before and after two weeks of treatment. It has high inter rater reliability as well as high correlations with other mania rating scales.

2. The Bech-Rafaelen Mania Assessment Scale (MAS)(Bech et al., 1979) is a clinician-rated instrument. It has 11 items, rated on a scale of 0-4.It has cut offs indicating the severity of mania It has good internal consistency and inter-rater reliability. The MAS scores can reliably detect improvement in symptoms with treatment

EXPLANATORY MODELS OF ILLNESS

DEFINITION AND EVOLUTION OF THE CONCEPT

Explanatory models of illness can be defined as “the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process”

(Kleinman 1988). The study of interest in explanatory models is widely believed to have begun in the 70s, with the work of Arthur Kleinman. Explanatory models were expected to provide a framework to direct ethnomedical studies of societies and health systems.

Explanatory models acknowledge the patients’ views as complementary to the physicians’, even though the two may be starkly different. They cannot be seen as rigid or predictive or being formally structured, but rather as just the way people think and feel about their illness(7)

When a person is sick, they attach meanings to the experience of illness by creating narratives that describe its causes, manifestations or symptoms, its effects on the body, how it progresses and what should be done about it. People look to their cultural reality to define each of the above categories in a creative process that is motivated by the need to make sense of dysfunction. Connections among the five concepts form a semantic network is created by connections among the five concepts, which is guided by symbolic realities.

The work on explanatory models and culture and the way it influences both patients and healers had its underpinnings in prior work. One of these was the distinction between disease and illness which highlighted the shortcoming of an exclusively technical or medical approach to medicine. Another was the propagation of the biopsychosocial concept of disease, with the argument that each perspective alone was inadequate.

The study of explanatory models is a vital but oft neglected area of interest, both for clinicians and researchers. An explanatory model provides the sum total of the patients' understanding and perspectives on disease, in terms of aetiology, onset of symptoms, pathophysiology, course of illness and treatment. Clinical decisions are often taken without involving patients and their families in the decision making process. This may lead to poor cooperation from the patients and their families. Also, disregard of patients' models of illness leads to poor compliance with therapy.(8) Assessing their explanatory model will go a long way in allowing clinicians to take more balanced decisions

regarding patient care. Knowing explanatory models also helps us to propose alternate models of disease, which helps in psycho education of the patients and families

KLEINMANS' CONTRIBUTIONS

Kleinman pioneered research in the field of explanatory models. His background in anthropology and his extensive work in East Asian societies led to novel perspectives on mental health. He has done much to demonstrate that depression and distress are likely to be expressed as somatised distress than as psychological distress in non-western cultures. He devised 8 simple questions to elicit patients' perspectives on their illness. These questions are meant to be open ended and encourage the patient to express their feelings in their own words.

1. What do you think has caused your problems?
2. Why do you think it started when it did?
3. What do you think your sickness does to you?
4. How severe is your sickness? Will it have a long or short course?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to receive from this treatment?
7. What are the chief problems your sickness has caused for you?

8. What do you fear most about your sickness?

These questions were devised to improve doctor-patient exchanges by helping doctors understand their patient's experience of illness through narratives.

THE NEED FOR EXPLANATORY MODELS IN CLINICAL CARE

The value of explanatory models in clinical practice is based on two considerations. The first is that they provide a means of bridging cultural differences between patients and doctors from differing cultural backgrounds. Secondly, they also bridge conceptual differences between patient and physician and promote empathy and a better therapeutic alliance, even when the patient and doctor are from similar backgrounds. Explanatory models have become fundamental both to the study of general psychiatry and cultural psychiatry.

Assessing explanatory models is appealing because it is important to examine relationships and consequences of interactions between patients' ideas about their health problems and those of the medical professionals who are responsible for their care.

Patients are most satisfied when their notions of illness are espoused by their doctors as well(9). This is likely to be due to the easier sharing of information which facilitates the healing process. Careful attention and a sympathetic understanding of the patients' EM can be seen as a mark of empathy and ethical practice, whereas a failure to do so could be construed as disrespect. Discordance in beliefs between the patient and doctor usually

leads to the doctors' explanatory model being rejected by the patient for being implausible, and being felt as less satisfying.(10)

An explanatory model may be looked at from different perspectives(7). In its' narrowest sense, an EM may be seen as simply an account of causation and attributions for an illness, devoid of social or cultural influences. Such models are easier to relate to and may be beneficial for clinicians who are engaged in purely clinical work. Another formulation looks at explanatory models as semantic networks that link together concepts and experiences, and are not concerned with perceived causation alone. The third formulation is concerned with looking at interactions between Ems of the patients, their families, and those held by the doctor. Kleinman argued that congruent models would result in better outcome, whereas incongruent ones would require further discussion between the patient and therapist.

Explanatory model studies have been conducted in almost all medical specialties. Beginning from the 70s, there has been a steady output of research that has looked in to explanatory models. One of the first studies was from India, which looked at EMs in leprosy patients, and found that a significant number (nearly 70%) held non-medical explanatory models(11). EM studies have also been conducted for hypertension, diabetes mellitus, heart disease and tuberculosis. Apart from providing data on patients' explanatory models, they have also yielded insights in to patient preferences for medication and reasons for non-compliance to therapy.

While patient beliefs about health are important in determining their health seeking and health utilization behavior, they are also important in their own right. There is a growing movement to see patients as individuals whose own unique ideas and experiences should be obtained and addressed(12).

TYPES OF EXPLANATORY MODELS- THE EMIC-ETIC PARADIGM

The Emic-Etic paradigm was first provided by Pike for providing insiders' and outsiders' perspectives for cultural studies and social analysis. When proposed several decades ago, this concept was highly controversial but today has become fundamental to social research. This concept was borrowed and brought in to medical research by Kleinman and Eisenberg(7)

Etic models provide perspectives usually based outside the patient's culture and seek patterns of behaviour as defined by an observer. Emic models elicit patient perspectives by the manner in which they conceptualize their sickness episode including beliefs and behaviours concerning aetiology, course and timing of symptoms, meaning of sickness, diagnosis, methods of treatment, roles and expectation of sick individuals(13). An Etic model is one based on professional ideology, and more of an outsiders' perspective, whereas an Emic model is derived from beliefs rooted in culture and is an insiders' perspective into illness.

CULTURE AND EXPLANATORY MODELS

Explanatory models tend to differ among cultures. Both psychological and physical symptoms are interpreted differently across different cultures. While Kleinman was among the first to point this out, several subsequent studies among non-western as well as western societies have looked at the impact of culture on explanatory models.

Culture impacts every aspect of the doctor-patient interaction. Most significantly, it affects patient interpretation of their symptoms and their illness behaviour. A distinction needs to be made between disease and illness here. "Disease" refers to abnormalities of the structure and function of bodily systems, whereas "illness" refers to the subjective response of the patient to being unwell (Eisenberg, 1977)(14). Patients perceive and cope with illness based on their explanations of sickness, which in turn are derived from the social positions and worldviews they employ. Illness behaviour is also governed by cultural rules, in the sense that patients learn to appropriate ways of behaving when they are sick. The variations can be quite marked, not only between societies, but between ethnic, class and family boundaries within a society as well. Disease and illness cannot be viewed as distinct entities, but as explanatory models which mirror separate aspects of the complex phenomenon of illness.

Patients see illness problems as constituting the entire disorder, whereas health professionals look upon the disease as the disorder and often neglect the illness problems. Both these views are contradictory and often not enough to solve the problem at hand. Anthropological studies have shown that traditional healers in developing countries are

mainly concerned with treating illness rather than disease, that is, to address the larger and more complex persona, family and community issues surrounding a sickness episode. On the other hand, illness as perceived by patients is being increasingly dismissed by modern health care professionals as an object of clinical concern. This inattention might possibly lead to non-adherence to therapy, patient dissatisfaction with healthcare and also inadequate clinical care. It may also lead to patients taking legal action against their doctors and pushing them to resort to alternative forms of healing and treatment(15)

In one study comparing the explanatory models for schizophrenia of four ethnic groups in an East London suburb, it was found that Whites tended to hold biological models, whereas the non-white racial groups (Bangladeshis, African-Caribbean, and West Africans) held supernatural explanatory models.(6). An early study in Sri Lanka (Waxler, 1997) showed that symptoms of low mood, anergia, and social withdrawal, which would be treated as depression in the West, would not receive much attention in Sri Lankan society. Another study from Jamaica showed that Jamaican patients also supernatural explanatory models for mental illness and hence visited spiritual healers for their problems(16). It also highlighted the rift between doctors who practice western biomedicine and their patients. A common observation is that Western societies view mental illness as biological in origin, and describe the manifestations of their illness in terms of stress, depression, or nervous breakdowns, whereas non-western societies tend to report their symptoms in terms of somatosocial terms(17). A westerner may describe schizophrenia or psychosis as having delusions and hallucinations, whereas in African

societies, violence, disrobing and talking illogically are seen as symptoms of “madness”. Kleinman’s work in Chinese societies revealed that patients express minor physical symptoms in the form of somatic complaints. This is due to the extreme stigma associated with mental illness. This influences expectations from treatment as well, with patients expecting to receive medications for their perceived illness, and refusing to accept psychological interventions(15)

No culture allows for bizarre or deviant behaviour in any context. Most societies have set frameworks for expressing certain symptoms and physical illnesses, and patients tend to use these to communicate their problems. One argument for this is that all cultures have their own “language of distress” which helps them to bridge the gap between their subjective wellbeing and gaining social acceptance for their symptoms

Patients rarely hold a single explanatory model; most often they have multiple explanations for their symptoms. These multiple models are usually non-medical in nature. It has also been shown that holding multiple and contradictory explanatory models does not necessarily hamper treatment.

One of the problems of current trend in research is the danger of stereotyping, of viewing all societies as homogenous and making preconceived assumptions about explanatory models and preferred treatment based on a persons’ ethnicity or culture. This is especially true of western perspectives about nonwestern societies. In a recent study done to assess explanatory models of traditional healers in South Africa(18), the authors talk about these stereotypes and argue that one reason why patients resort to traditional healers is that they

may lack access to more modern methods of treatment(18). This study also showed that non-psychotic disorders were not perceived to be mental illnesses, but were seen to be stress related. This highlights more complex social and economic factors that influence today's health care practices.

ASSESSMENT OF EXPLANATORY MODELS

There have been several scales that have been devised to measure explanatory models. Most have derived from Kleinman's work. Table 1 shows a comparison of the EMIC, IPQ and the SEMI

1. The Explanatory Model Interview Catalogue (EMIC; Weiss, 1992) : This is a flexible semi structured interview guide that researchers can adapt to different cultural contexts to elicit information about local categories of illness. Both qualitative and quantitative data are collected using open ended questions. Three components of an explanatory model are assessed- experience, meaning and behaviour. However it is long and time consuming and therefore impractical to use in clinical settings(19)
2. The Short Explanatory Model Interview (SEMI, Lloyd et al, 1998): This is a semi-structured interview. It employs open ended questions that assess
 - (i) the patient's personal and sociocultural background,
 - (ii) the nature of the presenting problem

- (iii) help-seeking behaviour;
- (iv) interaction with the clinician; and
- (v) Attitudes toward mental health and illness elicited by brief vignettes.

The SEMI has been used to study explanatory models among patients and community health workers in a variety of settings. It has also been translated into several Indian languages, including Tamil and Urdu.

3. The McGill's Illness Narrative Interview (MINI): It is a qualitative semi-structured interview designed to elicit narratives in health research. It is divided into five sections exploring different domains- initial narrative, prototypes, explanatory models, health seeking and service utilization; and impact of illness. It is time consuming, requiring over 2 hours to administer(20)
4. Illness Perception Questionnaire (IPQ, Weinman et al, 1996): The IPQ was mainly used for the assessment of physical illness, but has recently found use in psychiatry as well. It is different from the other scales in that it asks patients to respond from a fixed set of predetermined causal explanations. It assesses five dimensions of the illness model- identity, cause, duration, consequences and cure. It has a poor cross cultural validation(21)
5. The Barts' Explanatory Model Inventory (BEMI): The BEMI explore how people express their distress by asking questions on five domains based on the explanatory model framework- identity, cause, consequence, course, or

control/treatment. Each domain is further sub-categorised in to distinct groupings.

It is an easy to use questionnaire and can be therefore applied to both research and clinical settings(19)

Table 1: EXPLANATORY MODELS AND ILLNESS PERCEPTION QUESTIONNAIRE(9)

IPQ (Weinman et al, 1996)	SEMI (Lloyd et al, 1998)	EMIC (Weiss, 1997)
Identity	Naming the condition	Patterns of distress
Causes	What causes it? Is it an illness?	Perceived causes
Consequences		Disease-specific queries
Controllability	Who do you see about it? What you can do about it? What your doctor can do about it?	Seeking help and treatment
Time line		General illness beliefs

THE APPLICATION OF PREVAILING EXPLANATORY MODELS TO PSYCHIATRY

Traditionally, medicine has looked to science for explanations about causation and cure. The scientific paradigm is to ignore complexity and try to explain several differing phenomena by the means of a few underlying tenets and principles. While this approach may be more suited to the study of natural phenomena, it has also been influential in the other clinical branches of medicine, and has largely shaped the practice of modern medicine as we know it today. Modern biomedicine tries to explain phenomena based only on causality. Causal determinism is the theory that phenomena we observe have antecedent causes that can be explained through scientific law. The best example for this is probably the germ theory, which when it was propounded, was revolutionary. Each disease that plagued mankind could be explained by a single underlying cause. Treatment was similarly simple, and antibiotics were hailed as the new panaceas. However, if one looks back and examines closely the fight against infectious diseases, it can be seen that the attack was on several fronts. While there was single aetiological agent, the actual factors leading to illness were diverse. It was a combination of improved sanitation, nutrition, vaccination as well as the advent of antibiotics that ultimately led to the control and elimination of several communicable diseases. The germ theory exemplifies the biomedical model of illness, undermining all other factors that come in to play in disease causation. Similarly, the western world has tried to explain all illnesses with this rather inadequate one-dimensional concept, failing to account for complex other factors that

contribute to illness. Biomedicine sees ill health as “disease”, which is equated to an abnormality in the functioning of some body part or process.

In contrast to biomedicine, the term illness denotes the patients’ subjective experience of ill health their account of it. This is explored by patient narratives, which are often part of their explanatory models. Allowing the patient to narrate their stories and suffering helps them to express their feelings and experiences and provide meaning and perspective for their predicament, and thus insight in to their perception of illness(22)

Special attention needs to be paid to psychiatric illnesses. Psychiatry is a field where the understanding of biomedical concepts and aetiology seems limited, and therefore pluralistic explanatory models that look at a holistic biological, social and psychological perspective are needed. The application of rigid tenets of science to explain psychiatric illness has been less than satisfactory, and has given rise to opposing perspectives which are mutually exclusive and wholly counterproductive. One is reductionism, which argues that all mental illnesses arise solely from underlying biological dysfunction. This is in contrast to emergentism, which holds that psychiatric illness can only be explained by social mechanisms and cannot be explained by biology. However, both these models are based on rather rigid underlying principles and tend to overlook processes and mechanisms that underlie mental illness.

In order to have a better and more coherent framework for understanding illness, it is necessary to have an approach that looks at processes and mechanisms rather than at rigid immutable laws. This is the so called “mechanistic” approach, which looks at illness as a

complex multi-level problem and seeks to understand it based on its many component parts and their interactions(23). This provides for better integration of biological, psychological and social perspectives which cannot be done by the former two approaches. A mechanistic approach to any psychiatric illness “decompose” the illness or break the illness in to its known underlying etiologies and vulnerabilities- biological or genetic, psychological, social, and cultural or economic. These constituent parts are aggregative, i.e. they correlate with each other in a simple additive manner.

EXPLANATORY MODELS IN BIPOLAR AFFECTIVE DISORDER

There is a relative paucity of literature that looks at explanatory models for bipolar disorder. There are several studies which have documented explanatory models in depression, both from India and globally. (17)(24)(25)(26)(27)(28). There is similarly a wealth of research into explanatory models in psychosis. Explanatory models may be different in BPAD as the disease has 2 distinct phases.

In several cultures where diagnostic labels of mental illness are unacceptable, depression may masquerade as somatic symptoms or may be attributed to various psychological problems. There are no studies that look at patient explanations for manic or hypomanic episodes. Patients may have varying explanations for the different phases of the disease. One study looked at patients' perspectives of mood episodes in self and others, and reported that patients were able to see the relationship between their own illness and that described in others(29)

Studies have shown that insight in BPAD can vary with the course of a manic episode(30,31). Patients who initially lack insight and judgment at the onset of the illness may later develop insight in to their illness. While there is scanty literature on insight in mania, there is very little literature on explanatory models about mania.

EXPLANATORY MODELS AND INSIGHT

Insight in mental illness has traditionally been seen as a predictor of outcome and is negatively correlated with psychopathology. Several studies have shown that a disease model of illness is associated with good insight which correlates with improvement in psychopathology. Western literature assumes that good insight means acceptance of a biomedical disease model as explanation of disease. The same does not however hold true for non- western societies. One study from India which looked at schizophrenic patients found that the presence and number of non-medical explanatory models was correlated with good insight, and that explanatory models tended to change with time. It can therefore be argued that explanatory models also serve as a coping mechanism, helping the patient to adjust with whatever stage of the illness he or she is in(32)

QUALITY OF LIFE

DEFINITIONS AND CONCEPTS

The World Health Organization has described QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". Good quality of life includes more than just good health, and represents the sum of a person's physical, emotional, social, occupational and spiritual well-being.

There are several reasons why the measurement of Quality of Life is an attractive measure of outcome in psychiatry(33). Since severe mental illnesses are not curable, it is important to measure comfort. Mental illnesses are inherently complex, and therefore need complex tools for measurement. Quality of Life measures are more consumer focused, and more holistic than traditional methods. They can also detect minor changes in response to treatment which may not be picked up by routine outcome measures.(34)

In a study conducted in Madras, India among schizophrenia patients, the patients were asked to give their perspectives on recovery. The majority of the patients (88%) reported that recovery absence of symptoms. 73% also said not having any more relapses equaled recovery. A significant number also included other parameters, like getting back to their regular lives in terms of their previous functioning (70%). 62% of patients said they would consider themselves recovered if they were able to fulfill their previously held responsibilities(35)

QUALITY OF LIFE IN BPAD

Although there is a relative scarcity of literature, of late there has been a growing interest in QOL measures in Bipolar Disorder. This initial scarcity may have been due to either lack of disease specific reliable instruments to measure QOL in BPAD. Another reason may be that patients may lack the ability to reliably and accurately complete self-report measures, especially in the manic phase.

Several studies have shown that there is impairment in functioning and QOL similar to that seen in schizophrenia. This impairment is present even during periods of sustained remission of the disease, and is shown to be a predictor of relapse(36). Table 1 shows a selected list of studies looking at QOL in BPAD.

What is the need to measure QOL in patients with BPAD? The assessment of QOL in BPAD patients can provide additional information over and above that provided by other symptom measures. The adoption of more holistic, recovery-oriented assessment may improve treatment adherence and patient outcomes. There may be discordance between symptom change and QOL change in response to treatment, i.e. QOL may not always change proportionately with symptom change. Some patients' functioning remains poor in spite of relatively few symptoms, while others function well in spite of having more severe symptoms.(37)

Traditional outcome measures in Bipolar Disorder have included parameters like rates of remission and relapse, rates of hospitalisation, or degree of symptom reduction; measured by clinician administered scales. These measures, while providing adequate information

about the current disease activity, fail to provide a wholesome picture of the patient's current level of functioning. Evidence shows that quality of life measures are not simply the opposite of measures used in assessment of symptom severity. An improvement in disease activity does not always imply a change in QOL, often QOL is found to be lagging behind. Using symptoms of disease as outcome measures is a relic of the organic disease mindset, which assumes that symptoms have a unidirectional relationship with an underlying pathology. Measures of QOL on the other hand are more in keeping in line with the biopsychosocial approach, as they stress on patient participation, provide context and focus on lived experience.

As research has started to focus on QOL, the definitions of recovery in BPAD have also changed and now include QOL. One definition of recovery is that it is “a broad-spectrum goal with multiple features, each of which is required to consider the patient recovered. This includes achieving remission of symptomatology, functional recovery, prevention of relapse or recurrence and finally, improved subjective quality of life” (Harvey, 2006)(38). In addition to this health care consumers are increasingly focusing on personal meanings of recovery and wellness, which is not always related to symptom reduction interventions. Health care providers therefore have been forced to shift away from symptom-reduction interventions and focus on subjective meanings of recovery for individual patients.

TABLE 1: Selected list of studies looking at quality of life in BPAD

AUTHORS	YEAR	LOCATION	SAMPLE SIZE
Abraham et al	2014	Michigan, USA	141
Brissos et al	2007	Portugal	76
Chand et al	2004	India	50
Syl de la Cruz at al	2013	USA	384
Kim et al	2013	Republic of Korea	56
Mackala et al	2014	Canada	54
Miller at al	2013	USA	384
Subero et al	2013	Australia	240
Sylvia et al	2013	USA	452
Sylvia et al	2014	USA	283
Xiang et al	2014	China	47
Talwar et al	2010	New Delhi, India	15
Costa et al	2012	Brazil	41
Amini et al	2012	Iran	102

CORRELATES OF QOL IN BPAD

Most studies that have assessed QOL in BPAD have looked at BPAD in remission, or euthymic BPAD. There is an almost universal impairment of quality of life as measured by standardized instruments(39)(40)(41)(42)(43)(44). Factors associated with poor QOL include

- Poor premorbid functioning,
- Lower socioeconomic status,
- Longer duration of illness,

- Multiple episodes,
- Presence of depressive symptoms in between episodes,
- Presence of cognitive deficits,
- Use and side effects of psychotropic medication,
- Presence of stigma and discrimination owing to illness,
- Presence of medical comorbidities and comorbid substance use.

Of these, persistence of depressive symptoms in between episodes has been found to be one of the strongest predictors of poorer QOL and functioning. Sociodemographic factors including age and sex have not been consistently associated with impaired QOL, with different studies showing varying results.

Factors that have been shown to improve the QOL in BPAD include

- Good premorbid functioning,
- Use of Lithium as prophylaxis,
- Engaging in regular physical exercise
- Presence of religious beliefs.
- Self-efficacy

Interventions such as Optimal Personal Therapy (OPT) and group psychotherapy have been tried, with good results(36)(45) One study found that engaging regularly in Yoga led to better functioning in periods of remission(46)

One study by Chand et al looked at QOL in BPAD patients who were stabilized on Lithium compared to healthy controls and schizophrenia patients(44). They found that BPAD patients had QOL scores comparable to healthy patients, and higher QOL scores than schizophrenia patients. They did not find any correlation between socio-demographic variables and QOL. A significant positive finding was better QOL in those who stayed in treatment for longer periods, emphasizing the need for regular compliance to drugs.

An extensive Pubmed and Indmed search revealed very scarce Indian literature on correlates of QOL. One study was done by Chand et al(44) is mentioned above. Several other studies (1,5,46,47) have looked at the course and outcome of BPAD, however, have not looked at QOL as an outcome measure

The major limitations of the studies that have looked at QOL in BPAD include small sample sizes, lack of adequate comparison groups, use of diverse instruments to measure QOL, and inclusion of only patients and remission(34)

INSTRUMENTS USED TO MEASURE QOL

There are currently several standardized instruments that can be used to measure QOL. Research has shown that ethnic and racial minorities tend to have lower QOL as compared to their White counterparts. This can be explained by the fact that psychiatric research assumes that certain concepts, such as mental illness, treatment and QOL are equal. This cultural bias is readily reflected in certain instruments which are used to calculate QOL and in their conceptual origins as well.(48)

One of the most convenient to use instruments is the WHO Quality of Life Scale (WHOQOL-100, World Health Organisation). This is a 100 item scale developed by the WHO for cross cultural application. In the recent years, there has been an expansion in focus of measurement of health beyond traditional health indicators such as mortality and morbidity to include measures of the impact of disease and impairment on daily activities and behaviour, These measures, whilst beginning to provide a measure of the impact of disease, do not assess quality of life *per se*. most measures of health status have been developed in white, western societies, and are meant for use only in English, and the translation of these measures for use in other settings is time-consuming, and quite unsatisfactory. Medicine has become increasingly mechanistic and concerned only with the eradication of disease and symptoms. This reinforces the need for the introduction of a humanistic element into health care. By assessing QOL in health care, attention is focused on this aspect of health, this led to the development of WHOQOL instruments. The WHOQOL-BREF is a 26 item abbreviated version of the WHOQOL-100 and was

developed using data from the field trials of the WHOQOL-100. The scores from the WHOQOL-BREF can be transformed to give equivalent WHOQOL-100 scores. The scores on WHOQOL100 and WHOQOL-BREF show excellent correlation for all domains with a correlation 0.89. The WHOQOL-BREF has good reliability and validity, and has been translated into over 20 different languages. The WHOQOL instruments provide a patients' own perspective on their disease, instead of measuring it using reports of health workers or laboratory assessments. It can assess QOL in a variety of situations and populations.

Other instruments such as the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) and the 36 item Short Form Health Survey (SF-36) have been used in mental health settings, but they are better suited to monitoring health in entire communities; and may lack the sensitivity to detect intra- and inter person differences in QOL in psychiatric populations(49). The Q-LES-Q is a self-report measure designed to enable investigators to easily obtain sensitive measures of the degree of enjoyment and satisfaction experienced by subjects in various areas of daily functioning. It also has an abridged version, the Q-LES-Q SF.

The Quality of Life in Bipolar Disorder Scale (QoL.BD, Michalak et al, 2010) is a specific scale to measure QOL in BPAD patients. It has two versions, a longer 56 item version and a shorter 12 item version, the Brief QoL.BD. The scale is meant to be employed across all the mood states as well as diagnostic categories seen in BPAD. It has

good internal consistency and reliability, and is a sensitive measure of change in clinical state(37)

METHODOLOGY

STUDY SETTING

The study was conducted in the outpatient department of the Christian Medical College, a tertiary care centre in Vellore, Tamil Nadu. Consecutive outpatients who fulfilled the ICD 10 diagnostic criteria for BPAD were recruited. Christian Medical College is a 122 bedded tertiary care hospital which caters not only to the local population and surrounding districts, but also attracts a sizeable number of patients from all over the country.

AIMS AND OBJECTIVES

- To assess Quality of life (QOL) & Explanatory Models (EM) of illness in Bipolar Affective Disorder patients (BPAD)
- To assess relationship between QOL, EM and selected patient variables: age, gender, marital status, education, religion
- To assess relationship between QOL, EM and selected disease variables: nature of first episode, presence of psychotic symptoms, duration of illness, number of episodes, rapid cycling, presence of comorbidities, family history of mental illness, medication cost and side effects, suicide attempts.

INCLUSION CRITERIA

The eligibility criteria are as follows:

- Subjects aged 18 and above
- Tamil speaking
- Subjects meeting the International Classification of Diseases-10 (ICD-10) criteria for Bipolar Affective Disorder, currently in remission

EXCLUSION CRITERIA

The following patients were excluded from the study:

- Patients who were still symptomatic
- Patients with severe sensory or cognitive impairment
- Patients with a primary diagnosis of schizophrenia or schizoaffective disorder.

METHODS

SAMPLING

Consecutive outpatients who met eligibility criteria for the study were recruited. Informed consent was taken from the subjects to be part of the study.

INSTRUMENTS USED

Consenting patients were screened and administered the following scales

- i. HAM-D: Hamilton Depression Rating Scale: The Hamilton Depression Rating Scale (HAMD) is to be a valid measure of illness severity and outcome in major depression. It has several versions in clinical use. The original was a 17 item scale, today there are 21 item and 24 item version scales as well. It measures several domains of depressive symptoms, including anxiety-related, physical distress symptoms and purely psychiatric symptoms of depression. It is conducted as a semi structured clinician rated interview. A cut off of less than 6 indicates an absence of depression(50). The 21 item version was used in this study
- ii. PANSS: Positive and Negative Symptom Scale: The Positive and Negative Symptom Scale is an operationalized rating scale originally developed for schizophrenia. However, later research has also established it as a valid tool for measuring negative and psychotic symptoms in mood disorders. It has 30 items which are measured on a 7 point Likert scale. There are no specific cut off scores defined(50). The use of the PANSS in BPAD is justified by the fact that many clinical scales used in BPAD assess only negative symptoms, and not psychotic symptoms(51)

- iii. WHOQOL-BREF: WHO Quality of Life Scale: The WHOQOL BREF contains 26 items that assess functioning in 4 domains: physical health, psychological health, social relationships and environment. The domain scores are then transformed into final scores in order to make them correlate with the scores on the WHOQOL-100. The scale has been validated by several studies and is considered to be a sound, cross culturally valid assessment of quality of life(52).
- iv. SEMI: Short Explanatory Model Interview: The Short Explanatory Model Interview was born out a need to develop a brief, simple interview schedule to elicit patients' models of illness. It is unique in that it is culturally sensitive. It explores areas which the patient does not volunteer to mention, by means of an open-ended semi-structured questionnaire. It explores emic perspectives of illness. Its non-technical nature allows for easy translation into different languages. It has been validated for use in Tamil(13,53) It takes 20-30 minutes to administer.

DETERMINATION OF SAMPLE SIZE

Sample size was calculated by using the formula $4pq/d^2$, where p is the prevalence of non-medical explanatory models in common mental disorders, which is about 83% (Nambi et al 2002); $q=100-p$; and d is the precision taken as 10. With this a sample size of 56 was obtained. This is a pilot study as it uses an in depth qualitative interview SEMI in bipolar patients who are in remission and attending hospital.

STATISTICAL ANALYSIS:

Mean and standard deviations were used to describe continuous variables, while frequency distributions were used for dichotomous variables. The student t-test was used to test the statistical significant of association for continuous variables between two groups. Chi-squared test was used to assess the statistical significance of categorical variables between two groups. Pearson's correlation coefficient was used to assess the statistical significance of the relationship between continuous variables. SPSS version 16 for windows was used for statistical analysis.

RESULTS

The results are described under the following headings

1. Sociodemographic profile of the sample
2. Explanatory Models
3. Quality of life

SOCIO-DEMOGRAPHIC PROFILE OF THE SAMPLE

The socio-demographic details of the sample are given below in Table 1. The mean age of the sample was 43 years (SD 12.59), with a majority of the patients being married (76.5%), and belonging to the Hindu religion (85.3%). Only a small minority of the sample was illiterate (26.5%), with 23.5% having a primary school education, 17.6% having attended secondary school, 23.5% having studied up to higher secondary and 8.8% having graduated college. 38.2% of the patients were unemployed. 9% of patients had a family monthly income of less than Rs. 2000 per month, and 5.9% had a family income of more than Rs. 15000 per month. 50% of patients were from lower and middle socioeconomic status backgrounds each. 44.1% of patients were from a rural background, and 55.9% were from an urban background. 11.8% of patients had a family history of schizophrenia, 14.7% each had a family history of mood disorder and substance use (alcohol use in close male relatives) and 26.5% of patients reported history of other mental illness, most commonly suicide and acute psychosis. 11.8% of patients had

history of alcohol use and smoking, whereas one patient had history of long standing benzodiazepine use.

Table 1: SOCIO DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

CHARACTERISTIC	MEAN (SD)	NUMBER (PERCENTAGE)
Age	43 (12.59)	-
Sex		
• Male		18 (52.94)
• Female		16 (47.05)
Marital status		
• Married		26 (76.5)
• Single		5 (14.7)
• Widowed		3 (8.8)
Religion		
• Hindu		29 (85.3)
• Christian		4 (11.8)
• Muslim		2 (2.9)
Education:		
• Illiterate		9 (26.5)
• Primary school		8 (23.5)
• Secondary school		6 (17.6)
• Higher secondary school		8 (23.5)
• Graduate		3 (8.8)
Employment status		
• Unemployed		13 (38.2)
• Unskilled labour		10 (29.4)
• Semi-skilled labour		5 (14.7)
• Professional work		6 (17.6)
Family Monthly Income		
• Less than Rs. 2000		9 (26.5)
• Rs. 2001-5000		12 (35.3)
• Rs. 5001-1500		11 (32.4)
• Rs. 15001-30000		2 (5.9)
Socioeconomic Status		
• Lower		17 (50)
• Middle		17 (50)

Residence		
<ul style="list-style-type: none"> • Rural • Urban 		15 (44.1) 19 (55.9)
Family history of Mental Illness		
<ul style="list-style-type: none"> • Schizophrenia • Mood disorder • Substance use • Other mental illness • Unknown mental illness 		4 (11.8) 5 (14.7) 5 (14.7) 9 (26.5) 5 (14.7)
Personal history of substance use		
<ul style="list-style-type: none"> • Alcohol • Cigarettes/beedis • Other 		4 (11.8) 4 (11.8) 1 (2.9)

ILLNESS CHARACTERISTICS

Select illness variables are given below.

AGE AT ONSET OF ILLNESS:

The mean age at onset of illness was 30.8 years. Of the 34 patients, 28 had contact with health services at the immediate onset of the illness, whereas 6 patients had delayed contact with health services. The reasons cited for delay were unawareness that it was an illness or lack of information on where to get care from. They had history of prior episodes of mood disorder that were untreated. The results are in table 2

Table 2: AGE AT ONSET OF ILLNESS

Mean age (in years)	30.8
Standard deviation	9.56
Range	16-53

TOTAL NUMBER OF EPISODES

The number of episodes was calculated based on patient interview as well as chart review. The results are shown in Table 3.

Table 3: TOTAL NUMBER OF EPISODES

Mean	4.03
Standard deviation	2.25
Range	2-9

MARKERS OF ILLNESS SEVERITY

The following characteristics were taken as markers of illness severity. No patients reported rapid cycling. A majority (85.3%) of patients had psychotic symptoms in episodes. One patient had attempted suicide, and 5.9% and 26.5% of patients required electro-convulsive therapy (ECT) and inpatient admission respectively. The results are shown in Table 4

Table 4: MARKERS OF ILLNESS SEVERITY

ILLNESS CHARACTERISTICS	NUMBER (PERCENTAGE)
Rapid cycling	0
Psychotic symptoms in episodes	29 (85.3)
Suicide attempts	1 (2.9)
Electroconvulsive therapy ever given	2 (5.9)
In patient admission	9 (26.5)

MEDICATION RELATED FACTORS

NUMBER OF MEDICATIONS

The number of medications that patients are taking is as follows. 85.3% of patients were taking a mood stabilising drug- either lithium, valproate carbamazepine.61.8% of patients were also receiving an anti-psychotic drug. Only 8.8% of patients were receiving an anti-depressant. 20.6% of patients were receiving other drugs, including Benzodiazepines and Trihexyphenidyl. The results are shown in Table 5.

Table 5: MEDICATIONS RECEIVED

MEDICATION	NUMBER (PERCENTAGE)
Mood stabilizer	29 (85.3)
Anti-psychotic drug	21 (61.8)
Anti-depressant drug	3 (8.8)
Other medicines	7 (20.6)

MEDICATION SIDE EFFECTS

The medication related side effects seen in the patients is as follows. The most common neurological side effects reported were extra pyramidal symptoms like tremor and rigidity. 5.9% of patients reported development of Diabetes mellitus secondary to drug use. 8.8% of patients had endocrine side effects in the form of hypothyroidism secondary to medications. 8.8% of patients developed sexual dysfunction. Of the patients that complained of other side effects (5.9%), one patient each complained of Lithium toxicity and an allergic reaction to Carbamazepine. The results are shown in Table 6.

Table 6: MEDICATION SIDE EFFECTS

SIDE EFFECT	NUMBER (PERCENTAGE)
Neurological	18 (52.9)
Metabolic	2 (5.9)
Endocrine	3 (8.8)
Sexual	3 (8.8)
Other side effects	2 (5.9)

COMPLIANCE TO MEDICATION

Compliance to medication was assessed both by patient interview and by review of records. 52.9% of patients were non-compliant to medications, having missed medications for long periods and experiencing subsequent relapses. The reason for

noncompliance varied from poor finances to absence of disease activity. The results are shown in Table 7.

Table 7: COMPLIANCE TO MEDICATIONS

COMPLIANCE	NUMBER (PERCENTAGE)
Compliant with medications	16 (47.1)
Non-compliant	18 (52.9)

COST OF MEDICINES PER MONTH

Patients were asked about the expenditure they incurred every month for medications. Several patients were also receiving medications at a concessional rate. Majority of the patients (61.8%) were paying less than Rs. 500 per month for medications. The results are shown in Table 8.

Table 8: MONTHLY COST OF MEDICATIONS

COST PER MONTH	NUMBER (FREQUENCY)
Less than Rs. 500	21 (61.8)
Rs. 501-1500	12 (35.3)
More than Rs. 1500	1 (2.9)

EXPLANATORY MODELS OF ILLNESS

HEALTH AND ILLNES

REASONS FOR VISIT

Most of the patients gave diverse reasons for their visit. Patients were asked to list up to 3 problems for their visit. Many patients did not list 3 problems (89.6%), instead answering with “no problem” (5.9%) or “I don’t know” (32.1%). Psychological causes such as anger, poor sleep, acting abnormal, feeling sad, being unable to eat were reported more frequently than physical causes such as body aches, headache, nerve problem or health problem. Only six patients (14.7%) labeled their current problem as a mental illness. The results are shown in Table 9.

Table 9: REASONS FOR VISIT TO THE DOCTOR

REASON FOR VISIT	NUMBER (PERCENTAGE)
Altered/increased speech	4 (5.9)
Anger	11 (32.1)
Acting abnormal	3 (8.8)
Body aches	4 (11.8)
Feeling sad	2 (5.9)
Poor sleep	13 (38.3)
Headache	1 (2.9)
Can't eat	3 (8.8)
Nerve problem	4 (11.8)
Health problem	3 (8.8)
Mental illness	6 (17.6)
To get medicines	5 (14.7)
I don't know	11 (32.1)
No answer	28 (89.6)
Other	2 (5.9)
No problem	2 (5.9)

NAME OF THE CURRENT PROBLEM

Patients were asked to give up to three names for their current problem, as per their understanding of illness. Most patients did not give three answers. Most patients were able to describe their problem in terms of a physical or bodily illness; i.e. as a mental illness (26.5%), nerve problem (20.6%) and health problem (11.8%). Only one patient was able to name his problem as Bipolar Disorder, and recognized it as a mental illness. The “other” names included “sudden shock”, “mind change” and “possession”. A significant number of patients also called their problem as “madness” (*paityam*). Interestingly, some patients describe their problem as both physical and as “madness”. The results are shown in Table 10.

Table 10: NAME OF THE PROBLEM

NAME OF THE PROBLEM	NUMBER (PERCENTAGE)
Mental illness	9 (26.5)
Mental problem/madness	14 (41.2)
Nerve problem	7 (20.6)
Health problem	4 (11.8)
Other	3 (8.8)
I don't know	7 (20.6)

REASONS FOR ONSET OF PROBLEM

Patients were asked to list why their problems started when they did. Most patients listed psychological causes as being responsible for the onset of their problem. The most common causes as listed by patients are shown in Table 11.

Table 11: REASONS FOR ONSET OF PROBLEM

PERCEIVED CAUSE	NUMBER (PERCENTAGE)
Problem with the nerves	3 (8.8)
Poor sleep	5 (14.7)
Fever	2 (5.8)
Problems at home	8 (23.5)
Marital problems	7 (20.6)
Tension/too much thinking	6 (17.6)
Gods' will	2 (5.8)
I don't know	6 (35.3)

CAUSE OF PROBLEM

Patients were asked to list what could be the underlying cause for their problem. Most patients replied that they did not know any particular aetiology for their problem. Again, most patients listed psychological reasons as the cause of their problems; with 11.8% each listing family problems and tension; and 2.9% listing fear as the cause. Only 11.8%

quoted an underlying organic basis for their problem, saying it could be due to a problem in the nerves. The perceived causes for the problem are listed in Table 12.

Table 12: PERCEIVED CAUSE OF PROBLEM

CAUSE	NUMBER (PERCENTAGE)
Fear	1 (2.9)
Problem in the nerves	4 (11.8)
Family problem	4 (11.8)
Tension	4 (11.8)
I don't know	21 (61.8)

ATTRIBUTION OF PROBLEM

Patients were given a list of possible causes and asked if their problems could be attributed to those causes. A list is given below. 8 patients (23.5%) attributed their illness to both disease and black magic. A list of all attributions is given in Table 13.

Table 13: ATTRIBUTION OF ILLNESS

ATTRIBUTION	NUMBER (PERCENTAGE)
Black magic	14 (41.2)
Karma	0
Punishment from God	8 (23.5)
Evil spirit	1 (2.9)
Disease	27 (79.4)

PERCEIVED SEVERITY

SERIOUSNESS OF PROBLEM

Patients were asked to rate how severe they thought their problems were. 14% replied that their problem were not very serious, 35.3% felt that their problem were moderately serious, while 8% responded that their problems were very serious. The results are shown in Table 14.

Table 14: SERIOUSNESS OF PROBLEM

PERCEIVED SEVERITY	NUMBER (PERCENTAGE)
Not serious	14 (41.2)
Moderately serious	12 (35.3)
Very serious	8 (23.5)

FEARS:

Patients were asked to list what they problems or consequences might arise due to their disease. Patients were asked to list up to three fears that they had. 8.8% feared their disease may hamper their future wedding prospects, 5.9% each expressed concern over their future and financial security, 5.9% were worried about their children getting the same illness as them. 17.6% expressed fear about never getting better and having to continue medications lifelong. The common fears listed by patients are given in Table 15.

Table 15: FEARS

FEARS	NUMBER (PERCENTAGE)
No fear	23 (67.6)
Marriageability	3 (8.8)
Future/old age concerns	2 (5.9)
Financial concerns	2 (5.9)
Heritability of illness	2 (5.9)
Never getting better	6 (17.6)

EXPECTATIONS FROM CARE

EXPECTATIONS FROM THE DOCTOR

Patients were asked to list their expectations of the doctor. They were asked to list up to three things each that they expected the doctor to do for them. Most patients (67.6%) expected a cure or to get better. 53.2% expected the doctor to change medications or stop medications based on patient complaints and preferences. 5.8% had sleep disturbance and wanted help with the same. the most common expectations from the doctor are listed in Table 16.

Table 16: EXPECTATIONS FROM THE DOCTOR

EXPECTATIONS	NUMBER (PERCENTAGE)
Cure me/make me better	23 (67.6)
Change or stop medications	18 (53.2)
Help with sleep	2 (5.8)
No other expectations	3 (8.8)
I don't know	4 (11.8)

PREFERRED TREATMENT OPTIONS

Patients were also asked what forms of treatment they thought would help with their problems. A majority of the patients confirmed that they would it would be helpful to visit a doctor. Only 5 patients said that they would not benefit from seeing a doctor. The rest of the patients who said that non-medical forms of treatment would be beneficial also preferred medical treatment for their problem. The preferred treatment options are given in Table 17.

76.5% of patients found it useful to talk to the doctor about their problems, whereas 17.6% said it did not help. The reason for the dissatisfaction was mainly the refusal on the part of the doctor to discontinue medications.

Table 17: PREFERRED TREATMENT OPTIONS

PREFERRED TREATMENT	NUMBER (PERCENTAGE)
Doctor	29 (85.3)
Traditional healer	3 (8.8)
Mantravadi	2 (5.9)
Religious place	1 (2.9)
Dietary restrictions/special diet	2 (5.9)
Anything else	1 (2.9)

ACTIVITIES AND FUNCTIONING:

Patients were asked to list the difficulties they faced due to their problems, and the different domains of their life and functioning that were affected due to their current problem. They were asked to list up to 3 difficulties they faced. The difficulties most often reported by the patients included financial problems, and difficulty in travelling to the hospital frequently. The reasons for this were distance, lack of finances and lack of social support. The main difficulties are listed in table 18.

Table 18: DIFFICULTIES

DIFFICULTIES	NUMBER (PERCENTAGE)
Financial	11 (32.3)
Frequent visits	6 (17.6)

Patients were also asked if they faced problems in other domain of life such as emotional problems, family problems etc. 8.8% of patients responded that they were sad because of their disease. 20.6% of the respondents faced social problems, mainly in the form of stigma due to being known as mentally ill patients, and also the prospect of not getting good marriage alliances. The results are given below in Table 19

Table 19: PROBLEMS FACED BY PATIENTS

PROBLEMS	NUMBER (PERCENTAGE)
Emotional problems	3 (8.8)
Mobility problems	6 (17.6)
Social problems	7 (20.6)
Family problems	7 (20.6)
Relational problems	0
Work problems	7 (20.6)

QUALITY OF LIFE

The quality of life as per the WHOQOL-BREF can be calculated in 4 domains- Physical health, psychological health, Social relations and Environment. The means scores for the four domains are shown below in table 20.

Table 20: DOMAIN WISE MEAN WHOQOL SCORES

DOMAIN	MEAN SCORE	STANDARD DEVIATION
Physical health	55.53	10.47
Psychological health	57.09	9.71
Social relations	56.06	17.66
Environment	57.56	13.36
Total	56.5	41.57

While there are no established cut-offs for QOL on the WHOQOL-BREF, the scores are scaled in a positive direction, with higher scores denoting higher QOL. The scores seen above correlate with several studies in BPAD which have shown low scores on the WHOQOL-BREF (37)(54)(40).

FACTORS ASSOCIATED WITH QOL

One of the objectives of the study was to assess correlations between quality of life and patient characteristics. An independent samples T test was done to assess significance of association between QOL and Sociodemographic variables and illness variables. QOL was not significantly associated with age, gender, religion, marital status or employment.

It was significantly associated with educational qualification and socioeconomic status.

The results are as follows

GENDER:

There was no significant difference in QOL for male gender and female gender. The results are shown in Table 21.

Table 21: COMPARISON OF QOL BY GENDER

GENDE R	N	MEAN	SD	t SCORE	df	p value	95% CI
Female	16	55.90	12.77	–	–	–	–
Male	18	57.13	8.06	–	–	–	–
Total	34	–	–	-0.332	24.772	0.743	-8.88 to 6.42

MARITAL STATUS

There was no significant difference in QOL for married and unmarried patients. The results are shown in Table 22

Table 22: COMPARISON OF QOL BY MARITAL STATUS

MARITAL STATUS	N	MEAN	SD	t SCORE	df	p value	95% CI
Married	26	56.61	11.01	-	-	-	-
Single/widowed	8	56.37	8.72	-	-	-	-
TOTAL	34	-	-	-0.56	32	0.995	-8.28 to 7.80

EMPLOYMENT STATUS

There was no significant difference in QOL for employed and unemployed patients. The results are shown in Table 23.

Table 23: COMPARISON OF QOL BY EMPLOYMENT STATUS

EMPLOYMENT STATUS	N	MEAN	SD	t SCORE	df	p value	95% CI
Unemployed	13	58.03	9.53	-	-	-	
Employed	21	55.64	11.01	-	-	-	
Total	34	-	-	-0.647	28.40	0.522	-9.93 to 5.14

EDUCATION

There was no significant difference in QOL for educated and illiterate patients. The results are shown in Table 24

Table 24: COMPARISON OF QOL BY EDUCATION

EDUCATION	N	MEAN	SD	t SCORE	df	p value	95% CI
Educated	25	60.42	7.78	-	-	-	-
Illiterate	9	45.83	9.37	-	-	-	-
Total	34	-	-	4.571	12.21	0.000	8.08 to 21.08

SOCIOECONOMIC STATUS (SES)

There was a significant difference in QOL for patients from lower and middle socioeconomic statuses (p 0.015). The results are shown in Table 24.

Table 25: COMPARISON OF QOL BY SOCIOECONOMIC STATUS

SES	N	MEAN	SD	t SCORE	df	p value	95% CI
Lower	17	60.83	6.95	-	-	-	-
Middle	17	52.27	11.64	-	-	-	-
Total	-	-	-	2.602	26.11	0.015	1.80 to 15.31

RESIDENCE

There was no significant difference in QOL for patients from urban or rural backgrounds.

The results are shown in Table 26.

Table 26: COMPARISON OF QOL BY RESIDENCE

RESIDENCE	N	MEAN	SD	t SCORE	df	p value	95% CI
Rural	15	54.93	8.37	-	-	-	-
Urban	19	57.84	11.81	-	-	-	-
Total	34	-	-	0.806	32	0.426	

FAMILY MONTHLY INCOME (FMI)

There was a significant difference in QOL for patients with monthly family income less than Rs. 2000 and above Rs. 2000 (p 0.000). The results are shown in Table 27.

Table 27: COMPARISON OF QOL BY FAMILY MONTHLY INCOME

FMI	N	MEAN	SD	t SCORE	df	p value	95% CI
<2000	9	46.02	10.22	-	-	-	-
>2000	25	60.35	-	-	-	-	-
Total	34	-	-	4.436	32	0.000	7.74 to 20.89

FAMILY HISTORY OF MENTAL ILLNESS

There was a significant difference in QOL for patients who had positive family history of mental illness. The results are shown in Table 28.

Table 28: COMPARISON OF QOL BY FAMILY HISTORY OF MENTAL ILLNESS

DISORDER	N	MEAN	SD	t SCORE	df	p value	95% CI
Schizophrenia	4	61.81	2.67	-2.49	20.47	0.021	-10.93 to -0.97
Mood disorder	5	62.35	2.80	-2.84	26.38	0.008	-11.68 to -1.89
Substance use	5	63.30	3.97	-2.95	16.66	0.009	-13.55 to -2.25
Other mental illness	9	58.91	9.66	-0.789	32	0.436	-11.48 to 5.07

PRESENCE OF PSYCHOTIC SYMPTOMS IN EPISODES

There was no significant difference in QOL for patients with and without psychotic symptoms in episodes. The results are shown in Table 29.

Table 29: COMPARISON OF QOL BY PRESENCE OF PSYCHOTIC SYMPTOMS

PSYCHOSIS	N	MEAN	SD	t SCORE	df	p value	95% CI
Present	29	56.38	12.53	-	-	-	-
Absent	5	57.55	12.53	-	-	-	-
Total	-	-	-	0.228	32	0.821	-9.23 to 11.56

SUICIDE ATTEMPTS

There was a significant difference in QOL for patients with and without suicide attempts (p0.086). The results are shown in Table 30.

Table 30: COMPARISON OF QOL BY SUICIDE ATTEMPTS

SUICIDE ATTEMPTS	N	MEAN	SD	t SCORE	df	p value	95% CI
Present	1	39.00	-	-	-	-	-
Absent	33	57.09	10.07	-	-	-	-
Total	34	-	-	1.769	32	0.086	-2.73 to 39.91

IN PATIENT ADMISSION

There was no significant difference in QOL for patients who required inpatient admission and those who did not. The results are shown in Table 31.

Table 31: COMPARISON OF QOL BY IN PATIENT ADMISIION

IP ADMISSION	N	MEAN	SD	t SCORE	df	p value	95% CI
Required	9	55.89	11.29	-	-	-	-
Not required	25	58.41	7.60	-	-	-	-
Total	34	-	-	-0.620	32	0.540	-10.83 to 5.78

USE OF ELECTROCONVULSIVE THERAPY (ECT)

There was no significant difference in QOL for patients who required ECT and those who did not. The results are shown in Table 32.

Table 32: COMPARISON OF QOL BY USE OF ECT

USE OF ECT	N	MEAN	SD	t SCORE	df	p value	95% CI
Required	2	61.12	4.41	-	-	-	-
Not required	32	56.12	7.60	-	-	-	-
Total	34	-	-	-0.635	32	0.530	-20.42 to 10.72

INTER EPISODE REMISSION

There was no significant difference in QOL for patients who achieved full inter-episode remission and those who did not. The results are shown in Table 33.

Table 33: COMPARIOSN OF QOL BY INTER-EPISODE REMISSION

INTEREPISODE REMISSION	N	MEAN	SD	t SCORE	df	p value	95% CI
Full	22	57.64	10.89	-	-	-	-
Partial	12	54,56	9.51	-	-	-	-
Total	34	-	-	-0.823	32	0.530	-10.72 to 4.54

SUBSTANCE USE

There was no significant difference in QOL for patients who had history of substance use and those who did not. The results are shown in Table 34.

Table 34: COMPARSION OF QOL BY SUBSTANCE USE

SUBSTANCE	N	MEAN	SD	t SCORE	df	p value	95% CI
Alcohol	4	61.43	9.42	-0.999	32	0.325	-16.79 to 5.73
Smoking	4	50.93	10.32	1.158	32	0.256	-12.24 to 19.01

MEDICATION SIDE EFFECTS

There was no significant difference in QOL for patients who had medication related side effects and those who did not. The results are shown in Table 35.

Table 35: COMPARSION OF QOL BY MEDICATION SIDE EFFECTS

SIDE EFFECT	N	MEAN	SD	t SCORE	df	p value	95% CI
Neurological	18	54.66	8.49	1.131	32	0.267	-3.22 to 11.26
Metabolic	2	62.62	2.2	-0.847	32	0.403	-21.94 to 9.05
Endocrine	3	47.50	3.92	1.619	32	0.115	-2.56 to 22.43
Sexual	3	50.08	6.12	1.135	32	0.265	-5.64 to 19.24
Other	2	61.00	0.00	-0.617	32	0.542	-20.29 to 10.85

COMPLIANCE TO MEDICATION

There was no significant difference in QOL for patients who were compliant with medication and those who were not. The results are shown in Table 36.

Table 36: COMPARISON OF QOL BY COMPLIANCE

COMPLIANCE	N	MEAN	SD	t SCORE	df	p value	95% CI
Yes	16	59.02	10.63	-	-	-	-
NO	18	59.40	9.65	-	-	-	-
Total	34	-	-	1.53	32	0.134	-12.50 to 1.70

MONTHLY COST OF MEDICATIONS

There was a significant difference in QOL for patients with monthly cost of medications less than Rs. 2000 and above Rs. 2000 (p 0.071). The results are shown in Table 37.

Table 37: COMPARISON OF QOL BY MONTHLY MEDICATION COST

COST PER MONTH	N	MEAN	SD	t SCORE	df	P value	95% CI
<2000/month	21	54.33	11.89	-	-	-	-
>2000/month	13	60.15	6.22	-	-	-	-
Total	34	-	-	1.626	31.37	0.071	-0.53 to 12.17

EXPLANATORY MODELS

There was a significant difference in QOL for those who held black magic and disease explanatory models, and those who held other disease models. Several patients held more than one explanatory model, simultaneously believing in both black magic and disease.

The results are given in Table 38.

Table 38: COMPARISON OF QOL BY EXPLANATORY MODELS

EXPLANATORY MODEL	N	MEAN	SD	t SCORE	df	p value	95% CI
Black magic	14	50.48	11.06	3.23	32	0.003	3.82 to 16.83
Punishment from God	8	55.06	16.00	0.460	32	0.748	-11.56 to 15.48
Disease	27	59.48	7.58	-3.82	32	0.001	-21.74 to -6.64

HEALTH SEEKING BEHAVIOUR

There was a significant difference in QOL for those who sought treatment from medical or nonmedical sources. Several patients had resorted to both medical and non medical forms of treatment. The results are given in Table 39.

Table 39: COMPARISON OF QOL BY HEALTH SEEKING BEHAVIOUR

HEALTH SEEKING BEHAVIOUR	N	MEAN	SD	t SCORE	df	P value	95% CI
Visit doctor	29	58.40	8.54	-2.727	32	0.010	-21.93 to -3.17
Visit traditional healer	3	46.41	8.87	1.83	32	0.076	-1.2 to 23.49
Visit mantravadis	2	42.25	4.59	2.10	32	0.043	0.52 to 34.46
Visit religious place	1	39.00	-	1.769	32	0.086	-2.73 to 38.91

DISCUSSION

LIMITATIONS OF THE STUDY:

There were certain limitations to the study

1. Due to lack of time, an adequate sample size could not be collected. This will be addressed in a follow up study.
2. The study was conducted in a busy outpatient setting. Patients who visit are usually pressed for time, and it may be possible that this may have influenced their answers- ex: answering “I don’t know” to questions instead of pondering on the question and giving a meaningful answer
3. Many patients in our setting are usually wary of giving critical answers to questions asked. This was addressed by the information provided on the Participant Information Sheet
4. Information on medical comorbidities could not be included because several patients were not aware if they had any.
5. This was a study done on stable Bipolar disorder patients in remission. Patients might have had different QOL if interviewed during disease phase

DISCUSSION OF RESULTS

SOCIO-DEMOGRAPHIC PROFILE

There were nearly equal number of males and females. There was a wide age distribution. Most of the patients were Hindu. There was nearly equal number of patients from rural and urban backgrounds, with all the patients belonging to lower and middle socio-economic backgrounds. A small number of the sample was illiterate and unemployed. 13 of the patients did not have a diagnosis of a mood disorder at the time of presentation, instead were diagnosed as acute psychosis, adjustment disorder, or grief.

All 34 patients had a current diagnosis of BPAD, in remission, as evidenced by scores of <6 on the Hamilton Depression Rating Scale. All patients had scores of 7 on the positive and negative symptom subscales of the PANSS, and some of the patient scored on the general psychopathology items on the scale.

QUALITY OF LIFE

The patients' quality of life scores as assessed by the WHOQOL-BREF have been mentioned above. While there is no accepted cut off for the scores on the WHOQOL instruments, one study has proposed a cut off of less than 60 for overall quality of life. This showed good sensitivity and negative predictive value for patients with worse QOL and dissatisfaction with health.(55). The mean scores obtained in this study then fall well below this cut off, indicating poorer quality of life in this population.

The study aimed to look at the relationship between QOL, EM and selected patient variables and selected disease variables

The study established factors associated with QOL as follows

1. Education
2. Socioeconomic status
3. Family monthly income
4. Lower monthly cost of medicines

Lower QOL was also found to be associated with family history of mental illness, including schizophrenia, mood disorder and substance use. This could be due to loss of productivity due to chronic mental illness, expenditure of additional income on medicines, and loss of income on alcohol.

These factors highlight the socio-economic burden of disease, especially in a country like India, which is characterized as a Low and Middle Income Country. In a country where poverty is rampant and is a major determinant of accessibility and affordability of health care, factors like education and socioeconomic status become important in determining quality of life, especially in relation to health. As shown in other studies, variables like age, gender, marital status were not associated with QOL.

QOL was also found to be associated with beliefs in black magic and disease model of illness. In keeping with this, there was also an association of QOL with all forms of

health seeking behaviour, including visiting doctors, traditional healers, mantravadis, and temples or other religious places.

QOL was found to be significantly inversely correlated with scores on the Hamilton Depression Rating Scale (Pearson's $r=0.629$, p value 0.000) and with the scores on general psychopathology on the Positive and Negative symptom Scale (Pearson's $r=0.616$, p value 0.000). While most of the patients might seem to be clinically in remission based on their HAM-D or PANSS scores, the QOL was poor as compared to data from general population studies. This goes on to highlight the disjunction between symptom based measures of remission and actual functional recovery.

EXPLANATORY MODELS

The study sought to look at explanatory models in BPAD. Bipolar disorder is included in the category of severe mental illness. Explanatory model studies in India in BPAD have been scarce, and most studies which have studies mood disorders have looked at depressed patients(17,56,57). These studies have found that most patients attribute depressive symptoms to psychological causes. This study on BPAD patients revealed similar results. A majority of the patients attributed their illness to psychological causes such as “worry”, “tension”, “thinking too much”, or to interpersonal and marital conflicts. Since the sample in this study had more manic episodes their explanation for these episodes was also quite different from that for depressive episodes. Most patients, when asked to describe their current problem, spoke of their illness in terms of “madness”, “increased anger”, “and decreased sleep”.

A significant number also held believed black magic to be responsible for their problems. An interesting facet is the use of multiple explanatory models by patients- both medical and non-medical. This was evidenced both by their beliefs as well as health seeking behaviour, as several patients who held beliefs about black magic initially visited traditional healers before coming into contact with health care systems, and held on to the belief that both systems of treatment might be beneficial. While patients might believe they had a “disease” as defined by medicine, they also attributed the disease to non-medical causes, thus sometimes defying traditionally held notions of illness causation. This goes on to show that patients can hold multiple and contradictory explanatory models of illness. This leads them to seek diverse forms of healing and treatment from varied settings. It would be unwise to disregard culturally sanctioned explanatory models as they also serve as a coping mechanism.

This inherently conflicting attitude is further reflected in the expectations from care. Most patients simply expected a “cure” for their illness, and were dissatisfied about continued use of medication. Expectation of a cure amounts to conceptualizing an organic basis for the disease. Most patients revealed that they continued to take medicine only because they had spoken to the doctors about their illness, and had been explained that stopping medications might result in relapse. In fact, several patients had suffered multiple relapses of disease due to noncompliance before they finally became regular on medication.

Several patients also had difficulties arising from the illness. Most patients reported general and non-specific complaints in the form of aches and pains or pulling sensations in the nerves. Some patients were able to be more specific and reported developing side effects such as hypothyroidism or dyslipidaemia due to medication. Several patients also reported interpersonal and psychological problems. Most reported having to face stigma due to their mental illness, others reported discrimination by family members; usually in-laws; as a consequence of being seen as a person with mental illness. Several others reported not being able to get married, or concerns about future marriage prospects due to the illness, highlighting another aspect of the stigma faced by people with mental illness.

When asked about the severity of illness, most patients' response was that the illness was initially serious, but was now under control. Most patients feared for their future and financial security. A few patients also expressed concern about the heritability of the illness, having heard from other sources about the possibility of certain diseases being hereditary.

CONCLUSIONS

Bipolar disorder is a chronic and debilitating illness. It leads to significant morbidity and is responsible for a large proportion of the global burden of mental illness. Traditionally, studies have attempted to evaluate different outcome measures in BPAD, but these have been based on symptomatic recovery and not on overall functioning, which can be quite different. In order to overcome this discrepancy and to provide a better assessment of functioning, quality of life measures are being used to study outcomes. Quality of life is found to be significantly impaired in all domains in BPAD patients. Some studies have shown QOL in BPAD to be comparable with schizophrenia, while many others have not shown such bleak outcomes. QOL has been found to be associated with several patient and disease related factors, the most significant among them being presence of inter-episode depressive symptoms. In our study, we found QOL to be associated with factors like socio-economic status, education, cost of medication, family monthly income, and monthly cost of medications, along with family history of mental illness.

Explanatory models are the notions about sickness held by a patient. They help us understand a patients' perspective on illness and help bridge the cultural gap that might exist between patient and physician. One might argue that when the patients and doctors are part of the same social fabric, the need to elicit explanatory modles might be redundant; however, a closer look at the doctors and patient would reveal stark differences in socio-cultural backgrounds. Patients are more satisfied with their doctors if the doctors' explanatory models match their own. There has been extensive research in

explanatory models in mental illness, most of it in schizophrenia and depression. In our study, patients with BPAD held multiple models of illness, both medical and non-medical. Patients attributed their illness to both physical and supernatural causes, with belief in black magic being widely prevalent and socio-culturally acceptable.

DIRECTIONS FOR FUTURE RESEARCH

The field of explanatory models in psychiatry had garnered much interest over the years, but only certain disorders have been studied in depth, whereas for other disorders, literature has been found to be lacking. In a busy general hospital setting, where majority of the patients are poorly educated and from lower and middle socioeconomic backgrounds, further knowledge of their explanatory models would help the treating doctors engage more fully with the patient, and also make the patient a more active participant in decisions about health care. Future studies on explanatory models need to be carried out for various disorders, and with larger sample sizes. Another avenue for research would be assessing explanatory models of traditional healers, who absorb a large burden of illness and are often the point of first contact for patients.

Similarly, QOL has emerged to be a better indicator of functioning than most traditional outcome measures. In a society like India, where poverty is a way of life, QOL becomes all the more important as mere symptom recovery might not actually be a realistic reflection of current status. Along with fostering more research, a realistic understanding of QOL and explanatory models should motivate doctors to adopt a more empathic and socio-culturally sensitive approach with their patients.

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APPENDIX

The following is a list of rating scales and instrument used in the study. The participant information sheets and consent forms are also enclosed.

1. English consent form
2. Tamil consent form
3. English participant information sheet
4. Tamil participant information sheet
5. English version of Short Explanatory Model Interview
6. Tamil version of Short Explanatory Model Interview
7. English version of WHOQOL-BREF
8. Tamil version of WHOQOL-BREF
9. Hamilton Depression Rating Scale
10. Positive and Negative Symptom Scale

ENGLISH CONSENT FORM

INFORMED CONSENT FORM

I am giving my consent to be interviewed by Dr. Sweta Sheth (Post Graduate Student, CMC Vellore) by signing on this document. I understand that I will be part of the research study called “Explanatory Models of Illness and Quality of life in Patients with Affective Disorders”.

I further understand that I will be asked some questions regarding my illness and current health status; and that my responses will not affect my ongoing treatment. My participation in this study is free and voluntary; and I may revoke my permission at any point without this decision affecting my treatment in any way.

I am convinced that this information will be kept confidential; will only be used for this study and for no other purposes; and that I can access the results if I ask for them.

DATE:

NAME OF THE PARTICIPANT

SIGNATURE

TAMIL CONSENT FORM

Tamil Consent Form

ஒப்புதல் படிவம்

மருத்துவர். சுவேதா சேத் (முதுநிலை மருத்துவ மாணவி, CMC, வேலூர்) அவர்கள் என்னை நேர்காணல் செய்வதற்க்கு ஒப்புதல் அளித்து கையொப்பம் அளிக்கிறேன். நான் உணர்ச்சி சீர்குலைவு நோயாளிகளின் தெளிவுபடுத்தும் மாதிரிகள் மற்றும் வாழ்க்கை தரம் என்ற ஆராய்ச்சியின் பங்கேற்பாளர் என்பதை புரிந்து கொண்டேன்.

மேலும் என்னுடைய நோயை குறித்தும் தற்போதைய நிலைமையை குறித்தும் கேள்விகள் கேட்கப்படும் என்பதை அறிந்துள்ளேன். என் விளக்கங்கள் என்னுடைய சிகிச்சையில் எவ்வித மாற்றத்தையும் ஏற்படுத்தாது என்பதையும் புரிந்துகொண்டேன். என் சுய விருப்பத்துடன் இந்த ஆராய்ச்சியில் பங்குகொள்கிறேன் இதில் எவ்வித நேரத்திலும் மாற்றிக்கொள்ள முழு உரிமையுண்டு இதனால் என் சிகிச்சையில் எவ்வித பாதிப்பில்லை.

என்னுடைய விவரங்கள் மிகவும் இரகசியமாக வைக்கப்படும். அவைகளை இந்த ஆராய்ச்சிக்காக மட்டுமே பயன்படுத்த முடியும். இந்த ஆராய்ச்சியின் முடிவை எனக்கு வேண்டுமானால் நான் கேட்டு தெரிந்து கொள்ளலாம்.

பங்கேற்பவரின் பெயர்

கையொப்பம்.

ENGLISH PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

“EXPLANATORY MODELS AND QUALITY OF LIFE IN PATIENTS WITH AFFECTIVE DISORDERS”

My name is Dr. Sweta Sheth and I am a post graduate student in the department of Psychiatry at Christian Medical College, Vellore. I am currently undertaking research on Explanatory Models and Quality of Life in Patients with Affective Disorders.

Previous research in this domain is very limited, however some preliminary work already done in this field reveals that the explanatory models that patients hold for their illness may affect their quality of life. I would like to study this relationship further, for which I will require your cooperation.

If you choose to be part of my research, you will be asked some questions about your illness and what you believe caused your illness. You may have to provide verbal as well as written answers. I may also access your hospital file for old data. You may have to stay back for 30-45 minutes after OPD to finish the interview.

Whatever information you provide will be kept confidential, and will not be shared with anybody. You have the right to refuse to participate in this study if you wish so. This will not affect your treatment in any way.

If you have any doubts, please feel to contact me. My contact details are as follows:

Dr. Sweta Sheth

Dept. of Psychiatry, CMC Vellore

Ph. No 0416-2284520

Email: sweta_s14@yahoo.co.in

TAMIL PARTICIPANT INFORMATION SHEET

Participant Information Sheet பங்கேற்பவரின் தகவல் படிவம்

உணர்ச்சி சீர்குலைவு நோயாளிகளின் தெளிவுபடுத்தும்
மாதிரிகள் மற்றும் வாழ்க்கை தரம்.

எனது பெயர் **Dr.சுவேதா சேத்** நான் மனநல மருத்துவ
துறையில் முதுநிலை மாணவி (**CMC, வேலூர்**) நான் இப்பொது
உணர்ச்சி சீர்குலைவு நோயாளிகளின் தெளிவுபடுத்தும்
மாதிரிகள் மற்றும் வாழ்க்கை தரம் பற்றிய ஆராய்ச்சி
செய்கிறேன்.

இதைப்பற்றிய ஆராய்ச்சிகள் மிகவும் குறைவு இருந்தாலும்
முதற்கட்ட ஆராய்ச்சிகள் நோயாளிகளின் வாழ்க்கை தரத்தை
அவர்களின் தெளிவுபடுத்தும் மாதிரிகள் பாதிக்கலாம் என்பதை
தெரிவிக்கின்றன. நான் இதைப்பற்றி மேலும் ஆராய்ச்சி செய்ய
விரும்புகிறேன் அதற்க்கு உங்கள் ஒத்துழைப்பு தேவை.

நீங்கள் இந்த ஆராய்ச்சியின் பங்கேற்பாளராக இருந்தால்
உங்களிடம் சில கேள்விகள் எழுத்துப்பூர்வமாகவோ அல்லது
நேர்காணல் முறையிலேயோ கேட்கப்படும் இதற்காக உங்கள்
மருத்துவ பதிவேடுகளிலிருந்து விவரங்கள் எடுக்கப்படும்

நீங்கள் அளிக்கும் அனைத்து விவரங்களும் இரகசியமாக
பாதுகாக்கப்படும். இந்த ஆராய்ச்சியிலிருந்து விலகிக்கொள்ள
முழு உரிமை உண்டு. இது எந்த விதத்திலும் உங்கள்
சிகிச்சையில் பாதிப்பு ஏற்படுத்தாது.

இதில் ஏதாவது சந்தேகமிருப்பின் கீழ்க்கண்ட முகவரியில்
தொடர்பு கொள்ளவும்.

Dr. சுவேதா சேத்

SHORT EXPLANATORY MODEL INTERVIEW- ENGLISH VERSION

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 your answers will be strictly confidential.”

2. HEALTH & ILLNESS:

CURRENT HEALTH:

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

What have you come about ? .

problem1

problem2

problem3

HEALTH OVER LAST YEAR :

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

Year1

Year2

Year3

a. 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?

Onset1

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? In what way? 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 do 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 to 3)?

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 examples)?

Social

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

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 labourer. For the past 6 months she has stopped doing household work. She does not interact with the children or look after their needs. Her personal care is poor. 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 speaking to her. She is convinced that others will harm her. Her sleep is disturbed and her 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 he 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 like say?

SEMI TAMIL VERSION

வினாக்களின் தேர்வுகாணல்

அ. தரீயோதைய உடல் ஆரோக்கியம் சார்ந்த தேர்வுகாணல்:

1) நீங்கள் கடந்த மூன்று வந்த காரணத்திற்காக உங்கள் குழந்தையுடன் மருத்துவரை காணவந்தீர்கள்? (3 காரணங்கள் மட்டும்)

- a)
- b)
- c)

ஆ. கடந்த வருடங்களில் இருந்த ஆரோக்கியத்தில் நிலைமை?

1) கடந்த சில வருடங்களில் உங்கள் குழந்தையில் உடல் நிலையில் ஏதேனும் தோய் / பிரச்சனைகள் இருந்ததா?

- a)
- b)
- c)

2) உங்கள் குழந்தையில் இந்த பிரச்சனைகளை நீங்கள் என்னவென்று சொல்வீர்கள்?

- a)
- b)
- c)

3) உங்கள் குழந்தையிடம் ஏற்பட்ட இந்த பிரச்சனைகளை முதல் முதலில் நீங்கள் எப்பொழுது கண்டுபிடித்தீர்கள்? (எப்பொழுது ஆரம்பித்தது?, எவ்வளவு நாளாக இருந்தது?)

- a)
- b)
- c)

4) எந்த காரணத்தினால் உங்கள் குழந்தைக்கு இந்த பிரச்சனைகள் ஆரம்பித்தது என்று நினைக்கிறீர்கள்?

- a)
- b)
- c)

5) உங்கள் குழந்தை (நீங்கள்) ஏதோ ஒரு காரியத்தை செய்யாதபோது (அ) செய்யாதபோது இந்தப் பிரச்சனை வந்தது என்று கருதுகிறீர்களா? (வினாக்கம்)

- a)
- b)
- c)

6) மற்றவர் ஏதோ ஒரு காரியத்தை உங்கள் குழந்தைக்கு செய்தாலோ (அ) செய்யாதாலோ இந்தப் பிரச்சனை வந்தது என்று கருதுகிறீர்களா? (வினாக்கம்)

- a)
- b)

- c)
- 7) உங்கள் குழந்தைக்கு இந்தமாதிரி பிரச்சனைகள் வந்ததற்கு என்ன காரணம் என்று நினைக்கிறீர்கள்?
- a)
- b)
- c)
- 8) யாரோ ஒருவர் செய்த மந்திரத்தினால் உங்கள் குழந்தைக்கு இந்த பிரச்சனைகள் வந்தது என்று நினைக்கிறீர்களா?
- a)
- b)
- c)

C. உணரப்பட்ட தேயின் தீவிரம்:

- 1) உங்கள் குழந்தையின் இந்த பிரச்சனையானது அவ்வளவு தீவிரமானது என்று கருதுகிறீர்கள்?
- a)
- b)
- c)
- 2) உங்கள் குழந்தையின் எந்த பிரச்சனையானது உங்களுக்கு அதிகமாக பயத்தை தருகிறது?
- a)
- b)
- c)
- 3) முதல்முதலில் இந்த பிரச்சனைகளுக்காக உங்கள் குழந்தையை எங்க அழைத்துச் சென்றீர்கள்?
- a)
- b)
- c)
- 4) மருத்துவமனைக்கு உங்கள் குழந்தையுடன் எந்த காரணத்தினால் வந்தீர்கள்?
- a)
- b)
- c)
- 5) யாருடைய அறிவுரையினால் நீங்கள் மருத்துவமனைக்கு வந்தீர்கள்?
- a)
- b)
- c)

D. மருத்துவ உதவியைப்பற்றிய உங்களின் எதிர்பார்ப்புகள் / திருப்திகள்:

1) மருத்துவரிடம் நீங்கள் என்ன கிடைக்கும் என்ற நம்பிக்கையை உங்களின் வந்திரிகள்? (உதவியை எதிர் பார்த்து) உங்கள் குழந்தைக்கு மருத்துவரோ/ செவிலியரோ என்ன செய்ய வேண்டும் என்று விரும்புகிறீர்கள்?

- a)
- b)
- c)

2) மருத்துவரிடமோ/ செவிலியரிடமோ உங்கள் குழந்தைக்கு உள்ள பிரச்சனையைப் பற்றி விசாரித்தீர்களா?

- a)
- b)
- c)

3) உங்கள் குழந்தைக்கு உள்ள பிரச்சனைகள் பற்றி அளர்கள் என்ன செய்தார்கள்?

- a)
- b)
- c)

4) உங்களின் குழந்தைக்கு உள்ள பிரச்சனைகள் பற்றி மருத்துவரிடம் செவிலியர் இடம் பேசுவது உடையோகையானது என்று கருதுகிறீர்களா? ஏன் என்று கூறமுடியுமா?

- a)
- b)
- c)

5) உங்கள் குழந்தைக்கு அளிக்கப்படும் சிகிச்சையில் ஏதாவது உங்களுக்கு திருப்திகரமாக இல்வையா?

- a)
- b)
- c)

E. நடவடிக்கைகள் மற்றும் நடைமுறைகள் பற்றிய கேள்விகள்:

1. உங்களுடைய குழந்தையின் இந்த பிரச்சனையினால் உங்களுக்கு ஏற்பட்ட முக்கியமான கஷ்டங்கள் பிரச்சனைகள் என்ன?

- a)
- b)
- c)

2. உங்களுக்கு உடலின் எந்தப்பகுதியானது அவருடைய பிரச்சனையினால் மிகவும் பாதிக்கப்பட்டுள்ளது?

- a)
- b)
- c)

3. மனஉணர்ச்சிகளினால் நீங்கள் எவ்வாறு பாதிக்கப்பட்டுள்ளீர்?

- a)
- b)
- c)

4. நீங்கள் எப்பொழுதும் போல் இருப்பதை இந்தப்பிரச்சனைகள் தடுத்ததுவிட்டன என்று நீங்கள் நினைக்கிறீர்களா?

- a)
- b)
- c)

5. உங்கள் குழந்தையின் பிரச்சனைகளினால் உங்கள் இயல்புவாழ்க்கை பாதிக்கப்பட்டதா (சந்த விதத்தில், உதாரணங்கள் சொல்லவும்)

- a)
- b)
- c)

6. உங்கள் குழந்தையின் பிரச்சனைகளால் உங்கள் வீட்டு வாழ்க்கை பாதிக்கப்பட்டதா?

- a)
- b)
- c)

7. உங்கள் குழந்தையின் பிரச்சனைகளால் உங்கள் சமூக வாழ்க்கை பாதிக்கப்பட்டதா?

- a)
- b)
- c)

8. உங்கள் குழந்தையின் பிரச்சனைகள் நீங்கள் பிரிடம் சுகஜமாக பழகுவதை பாதிக்கின்றதா?

- a)
- b)
- c)

F. ஆரோக்கியமான பழக்கவழக்கங்களைப் பற்றி கேள்விகள்.

1. உங்கள் குழந்தையின் இந்தப் பிரச்சனைகள் பற்றி வேறு யாருடனாவது

ஆலோசனை பெற்றீர்களா ? மருத்துவமனை / செவிலியர் / நண்பர்கள் / குடும்பத்தினர் / திருச்சபையின் / மருத்து நடுவன்

2. மருத்துவரை தவிர வேறு யாராவது உங்கள் குழந்தையைப் பற்றிய பிரச்சனையில் சிகிச்சை / அறிவுரை அளித்தார்களா ?

3. உங்கள் குழந்தை நாமாகவே நன் பிரச்சனைகளுக்கு ஏதேனும் சிகிச்சை செய்கின்றாரா ?

4. அடையென்றால் எப்படி உட்க சிவிரசை ?

5. தீங்கி உங்கள் குழந்தைக்கு அவரது பிரச்சனைகளுக்கு மருத்து தருகிறீர்கள் ?

6. உங்கள் குழந்தை தன் பிரச்சனைகளை தரிக்க வேறு ஏதும் சிகிச்சை எடுக்கவில்லார்களா?

7. உங்கள் குழந்தைக்கு புறக்கீட்கும் பழக்கம் உண்டா? (எவ்வளவு)?

8. உங்கள் குழந்தைக்கு குடிப்பழக்கம் உண்டா? (எவ்வளவு)?

9. உங்கள் குழந்தைக்கு ஏதாவது மருத்துகள் எப்பிடுகிறாரா? (உதாரணம்)

தோயின் காரணத்தைப்பற்றிய கேள்விகள்:

1. உங்கள் குழந்தையின் இந்த பிரச்சனைகளானது-

a) தீங்கி முற்பிறவியில் செய்த சில காரியங்களால் ஏற்பட்டதா?

b) தீய ஆவிகளினால் உண்டானதா?

c) தீய மந்திரங்களினால் ஏற்பட்டதா?

d) கடவுள்பிரிந்து வந்த தண்டனைவினால் உண்டானதா?

e) இது ஒரு தோய் என்று கருதுகிறீர்கள்?

உதவிகள் பெறுவதைப் பற்றிய கேள்விகள்:

1. கோபிலுக்கு அவைத்து சென்றால் உங்கள் குழந்தையின் பிரச்சனைகள் நீரும் என்று கருதுகிறீர்கள்?

2. உள்ளூரில் இருக்கும் மந்திரவாதியினால் உங்கள் குழந்தையின் பிரச்சனைகளை தரிக்க முடியும் என்று நினைக்கிறீர்கள்?

3. பாரம்பரிய மருத்துவரால் உங்கள் குழந்தையின் பிரச்சனையை குணப்படுத்த முடியும் என்று நினைக்கிறீர்கள்?

4. ஒரு மருத்துவரால் உங்கள் குழந்தையை குணமாக்க இயலும் என்று கருதுகிறீர்கள்?

WHOQOL-BREF ENGLISH VERSION

WHOQOL-BREF

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 doing what you need to do?	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?	5	4	3	2	1

Do you have any comments about the assessment?

[The following table should be completed after the interview is finished]

	Equations for computing domain scores	Raw score	Transformed scores*	
			4-20	0-100
27. Domain 1	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:
28. Domain 2	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$	a. =	b:	c:
29. Domain 3	$Q20 + Q21 + Q22$ $\square + \square + \square$	a. =	b:	c:
30. Domain 4	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:

* See Procedures Manual, pages 13-15

APPENDIX E (II)

வாழ்க்கைத் தரம் பற்றிய கேள்விகள்

எல்லா கேள்விகளையும் படித்து, உங்கள் உணர்ச்சிகளை மதிப்பிட்டு, ஒவ்வொரு கேள்விக்கும் ஏற்ற எண்ணைக் கற்றி ஒரு வட்டம் போடவும்.

வ. எண்	கேள்வி	மிகவும் மோசம்	மோசம்	நன்றாகவும் இல்லை மோசமாகவும் இல்லை	நன்றாக உள்ளது மிகவும்	நன்றாக உள்ளது
1.	உங்களுடைய வாழ்க்கைத் தரத்தை எப்படி மதிப்பிடுகிறீர்கள்?	1	2	3	4	5

வ. எண்	கேள்வி	மிகவும் அநிநுப்தி	அநிநுப்தி	திருப்தியும் இல்லை அநிநுப்தியும் இல்லை	திருப்தி	மிகவும் திருப்தி
2.	உங்கள் உடல் நலத்தை பற்றி எந்த அளவுக்கு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5

கீழே உள்ள கேள்விகள், நீங்கள் கடத்த இரண்டு வாரங்களில் எந்த அளவு சிலவற்றை அனுபவத்தில்க்கிறீர்கள் என்பதை பற்றி உள்ளன.

வ. எண்	கேள்விகள்	இல்லையே இல்லை	சிறிதளவு	ஒரே அளவு	அடுவதாக	மிகவும் அதிகமாக
3.	நீங்கள் செய்ய வேண்டியதை செய்வதற்கு, வலி எந்த அளவிற்கு தடையாக உள்ளது?	1	2	3	4	5
4.	நினைச்சி வாழ்க்கையில் செயல்பட உங்களுக்கு மருந்துவ சிவீக்கை எந்த அளவுக்கு தேவைப்படுகிறது?	1	2	3	4	5
5.	நீங்கள் வாழ்க்கையை எந்த அளவிற்கு சந்தேகமாக அனுபவிக்கிறீர்கள்?	1	2	3	4	5

6.	உங்கள் வாழ்க்கை எந்த அளவு அபந்தம் உருவாக உள்வாழ்வு என்று தோன்றுகிறது?	1	2	3	4	5
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வ. எண்	கேள்விகள்	இல்லவே இல்லை	சிந்தனையுடன் அளவு	அதிகமாக	மிகவும் அதிகமாக	
7.	உங்களை எந்த அளவிற்கு தந்தை கவனம் செலுத்த முடிகிறது?	1	2	3	4	5
8.	உங்கள் தினாதி வாழ்க்கையில் எந்த அளவு பாதுகாப்பை உணர்ச்சிகரமாக உணர்வீர்கள்?	1	2	3	4	5
9.	உங்கள் கற்றுக்கொள்ள எவ்வளவு ஆர்வம் உண்டாக உள்ளது?	1	2	3	4	5

கீழே உள்ள கேள்விகள், கடந்த இரண்டு வாரங்களில் உங்களை எவ்வளவு முழுமையாக நிலவற்ற அனுபவிக அல்லது செயல் முடிகிறது என்பதைப் பற்றி உள்ளது.

வ. எண்	கேள்விகள்	இல்லவே இல்லை	சிந்தனையுடன் அளவு	அதிகமாக	முழுமையாக	
10.	தினாதி வாழ்க்கைக்கு போதுமான சக்தி இருக்கிறதா?	1	2	3	4	5
11.	உங்கள் உடல் நோற்றத்தை உங்களை எற்றுக்கொள்ள முடிகிறதா?	1	2	3	4	5
12.	உங்கள் தேவைகளை பூர்த்தி செய்வதற்கு போதுமான பணம் இருக்கிறதா?	1	2	3	4	5
13.	தினாதி வாழ்க்கையில் உங்களுக்கு தேவையான தகவல்கள் எந்த அளவிற்கு கிடைக்கக் கூடியதாக உள்ளது?	1	2	3	4	5
14.	பொழுதுபோக்கு செயல்களில் ஈடுபடுவதற்கு எந்த அளவு சந்தர்ப்பங்கள் உள்ளது?	1	2	3	4	5

வ. எண்	கேள்வி	மிகவும் மோசம்	மோசம்	நன்றாகவும் இல்லை மோசமாகவும் இல்லை	நன்றாக உள்ளது மிகவும்	நன்றாக உள்ளது
15.	உங்களை எவ்வளவு நன்றாக நடமாட முடிவிறது?	1	2	3	4	5

கீழே உள்ள கேள்விகள், உங்கள் வாழ்க்கையில் வெவ்வேறு அம்சம் குறித்து நீங்கள் கடந்த இரண்டு வாரங்களில் திருப்தி அடைந்தீர்கள் என்பதைப் பற்றி உள்ளன.

வ. எண்	கேள்விகள்	மிகவும் அதிருப்தி	அதிருப்தி	திருப்தியும் இல்லை அதிருப்தியும் இல்லை	திருப்தி	மிகவும் திருப்தி
16.	உங்கள் ஈடுகம் குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
17.	தினாதி வாழ்க்கையில் நடவடிக்கைகளை செய்யும் உங்கள் திறமை குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
18.	உங்கள் வேலைக்குரிய தகுதி குறித்து எந்த அளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
19.	உங்களை குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
20.	உங்கள் தனிப்பட்ட உறவுகள் குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
21.	உங்கள் உடலியை வாழ்க்கை குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
22.	உங்கள் நண்பர்களிடம் இருந்து கிடைக்கும் ஆதரவு குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
23.	நீங்கள் வாலும் இடத்தில் திணை குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5

24.	மருத்துவ வசதி கிடைக்கும் விதம் குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5
25.	உங்களுடைய போக்குவரத்து குறித்து எவ்வளவு திருப்தியாக இருக்கிறீர்கள்?	1	2	3	4	5

கீழே உள்ள கேள்விகள், தீர்வுகள் கட்டித் தர இரண்டு வாரங்களில் எந்தனை முறை சிலவற்றை அனுபவித்திருக்கிறீர்கள் என்பதை பற்றி உள்ளன.

வ. எண்	கேள்விகள்	இல்லவே இல்லை	சம்பொழுது	சில சமயம்	பல சமயம்	எப்பொழுதும்
26.	இப்பொழுது உணர்ச்சிகள் அடிக்கடி ஏற்படுகிறதா? (உதாரணம்: கோபம், இயலாமை, பதட்டம், மனதளர்ச்சி)	5	4	3	2	1

இந்த மதிப்பீடு கருவியில் உள்ள கேள்விகளுக்கு பதில் அளிப்பதற்கு பயனாவது உதவி செய்தார்களா? 1. ஆமாம் 2. இல்லை

இந்த மதிப்பீட்டு கருவியை முடிப்பதற்கு எவ்வளவு நேரம் எடுத்துக்கொண்டீர்கள்?

இந்த மதிப்பீட்டு கருவியை பற்றி தீர்வுகள் என்ன திணைக்கிரிங்க?

உங்கள் உதவிக்கு நன்றி!

HAMILTON RATING SCALE

1. Depression (0 – 4)

(Gloomy attitude, pessimism about future, feeling of hopelessness, tendency to weep)

- 0 Not depressed
- 1 Doubtful, trivial
- 2 Mild (e.g. occasional weeping)
- 3 Moderate (e.g. frequent weeping)
- 4 Severely depressed

2. Guilt (0 – 4)

(Pathological guilt)

- 0 Absent
- 1 Feelings of self reproach
- 2 Ideas of guilt
- 3 Belief that illness might be punishment
- 4 Delusions of guilt

3. Suicide (0 – 4)

- 0 Absent
- 1 Life not worth living
- 2 Wishing he were dead
- 3 Suicidal ideas, half hearted attempts
- 4 Serious suicidal attempts

4. Initial Insomnia (0 – 2) (Difficulty in getting to sleep)

- 0 Not present
- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

5. Middle Insomnia (0 – 2)

(Disturbed sleep during the night)

- 0 Not present
- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

6. Delayed Insomnia (0 – 2)

(Early morning awakening)

- 0 Not present

- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

7. Work and interests (0 – 4)

(Loss of interest in and decreased performance at work or in home duties)

- 0 No disturbance
- 1 Doubtful, trivial
- 2 Mild
- 3 Moderate
- 4 Severe – Unable to carry on

8. Retardation

- 0 Absent
- 1 Slight flattening of affect, fixity of expression
- 2 Monotonous voice, delay in answering questions, tendency to sit motionless
- 3 Retardation prolongs interview to an extreme degree
- 4 To a degree which makes interview impossible

9. Agitation (0 – 4)

(This may co-exist with retardation)

- 0 Not present
- 1 Fidgetiness at interview
- 2 Obviously restlessness, picking at hands and clothes
- 3 Has to get up during interview
- 4 Cannot stay still, tearing clothes

10. Anxiety (Psychic) (0 – 4)

(Tension, difficulty in relaxing, irritability, worrying over trivial matters, apprehension, feelings of panic, fears, difficulty in concentration etc. Rate these as symptoms of present illness and not as features or previous disposition)

- 0 Absent
- 1 Doubtful, trivial
- 2 Mild
- 3 Moderate
- 4 Severe

11. Anxiety (Somatic) (0 – 4)

(Effects of autonomic over activity, attacks of giddiness, blurring of vision and tinnitus)

3

- 0 Absent
- 1 Doubtful, trivial

- 2 Mild
- 3 Moderate
- 4 Severe

12. Gastro-Intensional Symptoms (0 – 2)

(Loss of appetite, co-operation, 'heavy feelings in abdomen', differentiate from symptoms which could be rated under Anxiety above)

- 0 Not present
- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

13. General somatic symptoms (0 – 2)

(Fatigability, loss of energy, diffuse and ill-defined muscle ache, heaviness of limbs)

- 0 Not present
- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

14. Loss of libido (0 – 2)

(Assess deterioration obviously related to present illness)

- 0 No less, inadequate or no information
- 1 Mild, trivial, infrequent
- 2 Obvious and severe symptoms

15. Hypochondriasis (0 – 4)

- 0 Absent
- 1 Trivial, doubtful, some preoccupation with bodily functions
- 2 Much preoccupation with physical symptoms and with thoughts of organic disease
- 3 Strong convictions of presence of organic disease to account for symptoms
- 4 Delusions, hallucinations of rotting, blockage, etc.

16. Loss of insight (0 – 2)

- 0 Has full insight
- 1 Doubtful, mild, some denial
- 2 Lacks insight

17. Loss of weight (0 – 2)

- 0 No change or increase in weight
- 1 Doubtful, slight loss
- 2 Obvious, severe loss

18. Diurnal Variation (0 – 2)

- 0 Not present
 - a. Symptoms worse in morning
 - b. Symptoms worse in evening
- 1 Doubtful, present to a mild degree
- 2 Clear presence

19. Derealization and Depersonalization (0 – 4)

(Difference from lack of concentration or interest)

- 0 Not present. Patient does not understand feelings from the question asked
- 1 Recognizes feelings when asked but only experiences
- 2 Recognizes feelings when asked and experiences them frequently
- 3 Asserts that these feelings are present as part of his illness
- 4 Claims that these feelings are an important symptoms of his illness

20. Paranoid symptoms (0 – 4)

(Check affirmative answers carefully, Differentiate from guilt feelings. Include attitude of suspicion and malevolence imported to others)

- 0 Not present. Not elicited
- 1 Doubtful, trivial suspicion
- 2 Thinks others may wish him harm
- 3 Delusions that others may wish him harm
- 4 Paranoid hallucinations

21. Obsessional symptoms (0 – 2)

(Differentiate from preoccupations with depressive thoughts, ideas of guilt, hypochondriasis, paranoid thinking. Patient recognizes thoughts as being alien to normal thoughts and feelings, as producing distress and always struggles against them)

- 0 No evidence
- 1 Doubtful or to a mild degree
- 2 Definitely present to a severe degree

PANSS RATING SCALE

PANSS RATING FORM

		<u>absent</u>	<u>minimal</u>	<u>mild</u>	<u>moderate</u>	<u>moderate severe</u>	<u>severe</u>	<u>extreme</u>
P1	Delusions	1	2	3	4	5	6	7
P2	Conceptual disorganisation	1	2	3	4	5	6	7
P3	Hallucinatory behaviour	1	2	3	4	5	6	7
P4	Excitement	1	2	3	4	5	6	7
P5	Grandiosity	1	2	3	4	5	6	7
P6	Suspiciousness/persecution	1	2	3	4	5	6	7
P7	Hostility	1	2	3	4	5	6	7
N1	Blunted affect	1	2	3	4	5	6	7
N2	Emotional withdrawal	1	2	3	4	5	6	7
N3	Poor rapport	1	2	3	4	5	6	7
N4	Passive/apathetic social withdrawal	1	2	3	4	5	6	7
N5	Difficulty in abstract thinking	1	2	3	4	5	6	7
N6	Lack of spontaneity & flow of conversation	1	2	3	4	5	6	7
N7	Stereotyped thinking	1	2	3	4	5	6	7
G1	Somatic concern	1	2	3	4	5	6	7
G2	Anxiety	1	2	3	4	5	6	7
G3	Guilt feelings	1	2	3	4	5	6	7
G4	Tension	1	2	3	4	5	6	7
G5	Mannerisms & posturing	1	2	3	4	5	6	7
G6	Depression	1	2	3	4	5	6	7
G7	Motor retardation	1	2	3	4	5	6	7
G8	Uncooperativeness	1	2	3	4	5	6	7
G9	Unusual thought content	1	2	3	4	5	6	7
G10	Disorientation	1	2	3	4	5	6	7
G11	Poor attention	1	2	3	4	5	6	7
G12	Lack of judgement & insight	1	2	3	4	5	6	7
G13	Disturbance of volition	1	2	3	4	5	6	7
G14	Poor impulse control	1	2	3	4	5	6	7
G15	Preoccupation	1	2	3	4	5	6	7
G16	Active social avoidance	1	2	3	4	5	6	7