

**Psycho-educational training for schizophrenic
patients at Mankweng Hospital in the Limpopo
Province**

by:

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Declaration

“I declare that the Dissertation hereby submitted to the University of the North for the degree of masters has not previously been submitted by me for a degree at this or any other university, that it is my own work in design and execution and that all the material contained therein has been duly acknowledged.”

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Date 2/8/2002

Dedication

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I dedicate this dissertation to my parents, especially “my mother” who gave me support throughout the sufferings that I come across on my work, my two kids and my siblings who missed me physically during the preparation of this document.

*I would like to thank “God, the Almighty”, who strengthened me to work on my dissertation and showed me His power on each and every step I passed.

*I pass the great respect to my parents, especially “my mom”, who gave me great support throughout the difficulties that I experienced in my work.

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*Dr M. M. Mabeba, the co-supervisor, who was involved in correction of this dissertation. The above supervisors did a great deal for my work.

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*To all those who took part in this project, I say “Peace unto you”.

The aim of the study was to assess as to whether psycho education can lead to compliance, and to strengthen the families to be long-term caregivers in Mankweng hospital (psychiatric clinic) of the Limpopo Province. It is included two phases(1) baseline and (2) follow-up. The baseline included of 82 (50 males and 32 females) participants with schizophrenia. Their (patients) ages ranged from 17 years to 62 years with the mean age of 37.5 (SD=10.2). So, forty-one (41) patients were the experimental group who interviewed and also received intervention , and the remaining forty-one(41) were only interviewed at the baseline. After nine months, follow-up was done, and it included fifty-seven (36 males and 21 females) participants who were followed up at their homes. Thirty-one (31) were the experimental group and twenty-six (26) were the control group. Their ages ranged from 20 years to 62 years with the mean age 39.3 (SD=12.6). At follow-up, the questionnaire was going along with the Brief Psychiatric Rating Scale for both groups. The results showed that most of the patients were compliant to their medications however, with no significant differences because of the small sample that represented the population. For instance, not all patients were available at the follow-up session and there were other factors that could harm the effectiveness of research. The research concludes that psycho-education in South Africa can promise to improve health for the individuals only if the psychiatrists continue to educate patients to be effective on their treatment; and it can provide a concrete approach to the development of social and coping skills of the patients and their families.

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Chapter One

1. Introduction

This chapter consists of: (1) definition of schizophrenia, (2) aetiology and course of schizophrenia, (3) positive and negative symptoms of this illness, (4) forms of schizophrenia, (5) diagnosis, (6) prevalence, and (7) intervention with schizophrenic patients and their family members.

1.1. Definition

Schizophrenia is a disease with protean manifestations, including auditory and sometimes visual hallucinations, delusions, impairment in simple perceptual tasks, and evidence of impairment in information processing and the gating of sensory information. Secondary impairment in social skills which can interfere with the patient's ability to maintain employment may lead to homelessness and extreme social isolation, even from the patient's family (Adler & Griffith, 1991). Zubin and Spring (1977) view schizophrenia as a permanent condition leading to chronic deterioration or unremitting impairment. However, Tarrier, Yusupoff, Kinney, McCarthy, Gledhill, Haddock and Morris (1998) argue that schizophrenia remains a debilitating disorder despite the development of drug treatments. Many patients continue to experience persistent positive psychotic symptoms, hallucinations, delusions, which are disabling and distressing.

Schizophrenic disorders are a group of illnesses characterized by various combinations of neuropsychiatric symptoms. Modern diagnostic classifications also include criteria related to duration of symptoms, declines in functioning, and an absence of comorbid neurological disease. Problems with attention and memory may be prominent in psychoses: for example, some patients have difficulties with novel tasks that require flexibility and planning. The positive symptoms of schizophrenia include hallucinations, delusions, and disorganized communication. The negative symptoms of schizophrenia include blunted affect and poor motivation (McGrath &

Eemerson, 1999).

Schizophrenia is also considered as a chronic disabling illness without any known cure to date. It requires, in its management, a broad spectrum of interventions that include psychopharmacological, psychosocial as well as an array of housing and social support. The introduction, more than four decades ago, of the first antipsychotic medication, chlorpromazine, has profoundly changed the management of schizophrenia and allowed for care to shift from the hospital to the community. With the subsequent development of a wide array of antipsychotic medications, the pharmacological approach has become the cornerstone of clinical management. However, the increased awareness of their limited usefulness has challenged the unrivalled role of these medications in treating the broader spectrum of psychotic symptoms as well as the wide range of their side effects, which can frequently impact on the functional status and quality of life of individuals suffering from schizophrenia (Awad & Voruganti, 1999).

Schizophrenia is a clinical syndrome, not a discrete disease; the most common psychotic disorder; a major public health problem. Usually, the onset is in adolescence or late adolescence (Shaffer & Krug, 1996). However, Verga, Macciardi, Cohen, Pedrini and Smeraldi (1997) see schizophrenia as a severe mental disorder associated with disturbances of thought, affect, volition, and behaviour that are characterized by highly variable age of onset and different degrees of functioning and intellectual deterioration.

Kaplan and Sadock (1998) propose that Bleuler coined the term schizophrenia and that he chose it to express the presence of schisms between thought, emotion, and behaviour in patients with the disorders. This psychiatrist defined dementia praecox nearly a century ago in terms of a deteriorating curse leading to dementia. Several modern long-term studies of schizophrenia converge on an even more optimistic view. At least half of the schizophrenic patients in several cohorts demonstrate significant improvement or recovery over the long-term; most of the others stabilize rather than deteriorate. The natural history of schizophrenia for patients results in a remission of psychotic symptoms, some capacity for independent living, and varying degree of social and occupational recovery (Drake & Sederer, 1986).

Andreasen and Flaum (1991) argued that the specific symptoms have varied widely

over time and across cultures, as has the diagnostic and prognostic importance placed on the symptoms. The historical concepts of what constitutes the characteristic symptoms of schizophrenia are reviewed in the context of the development of Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

Schröder, Niethammer, Geider, Reitz, Binkert, Jauss and Sauer (1992) argue that previous studies have shown that minor neurological abnormalities-also called neurological soft signs (NSS) are more frequent in schizophrenics than in non-psychiatric controls. It is generally agreed that NSS mainly reflect areas of integrative sensory function, motor coordination and sequencing of complex motor acts. The significance of these signs, however are largely unknown despite increased scientific efforts in recent years. Some of the available studies seem to suggest that NSS represent characteristics of the illness, based on finding NSS in untreated and non-psychotic relatives of schizophrenics. In contrast, other studies have presented some evidence, which may indicate that the impairment is tied to fluctuations in the clinical state.

Symptoms are characterised most usefully as positive or negative, although the traditional diagnostic subcategories (hebephrenic, paranoid, catatonic, and simple) have mixtures of both aetiological and prognostic importance. These are essentially disordered versions of the normal brain functions of thinking, perceiving, formation of ideas, and sense of self. Patients with thought disorder may present with complaints of poor concentration or of their mind being blocked or emptied (thought block): a patient stopping in a perplexed fashion while in mid-speech and the interviewer having difficulty in following the speech are typical signs (Turner, 1997).

The Department of Health (1985) indicated that each patient is an individual, but there are certain things that happen to almost every patient at some stage of his/her illness. Disturbances of thinking are very common. As the patient may say things that are not expected, or understandable, s/he may talk a lot or lose the thread of what he is saying. This kind of behaviour can make communication very difficult. At times a person suffering from schizophrenia may perceive things around him/her in an odd way, as s/he may hear noises or voices and sometimes see things that are not there. These voices can say unpleasant things and the person may talk to or shout back at them.

Rarely, there may be times when the patient threatens to smash things or harm someone but more often s/he is shy and withdrawn. He cannot help all this because his/her usual feelings have been swamped by the illness and from time to time he may realize just how much he has changed and how different his life has become- this end up making him miserable and desperate.

1.2. Aetiology and course of schizophrenia

Evidence for genetic cause grows stronger: up to 50% of identical (monozygotic) twins will share a diagnosis compared with about 15% of non-identical (dizygotic) twins. The strength of genetic factors varies across families, but some 10% of patients' first degree relatives (parents, siblings, and children) will also be schizophrenic, as will 50% of the children of two schizophrenic parents (Turner, 1997).

Shields (1977) proposed that being the identical twin of a schizophrenic is the best single predictor of schizophrenia, but such twins are hardly appropriate subjects for prospective high-risk studies. Some monozygotic co-twins of schizophrenics will already be affected when the case is discovered. Furthermore, some pairs may be discordant because the illness in the proband was a symptomatic schizophrenia.

The offspring of two schizophrenic parents also incur risk of developing schizophrenia-usually taken to be around 40% which place them, like monozygotic co-twins, within the high risk range of 25% or over, using the term in the sense in which it is generally employed by geneticists when speaking of recurrence risk in genetic disease (Shields, 1977).

The great majority of the high-risk studies that have burgeoned recently examine children with one schizophrenic parent, since they are more accessible. On average the children have only a moderately high-risk of around 10% and become affected if they live long enough. Up till recently, the range varied from 7% to 17% in different studies, and the risk depended to some extent on the type of schizophrenia in the proband and the characteristics of the spouse (Shields, 1977).

According to Kates and Craven (1998), schizophrenia is a cyclical illness with acute episodes characterized by abnormalities in thought, perception, and behaviour. Between

such episodes, many individuals with the illness will continue to experience residual deficits or symptoms that can impair their day-to-day functioning, community involvement, self-care, and the capacity to form and maintain relationships.

Although it is seen as a mental disorder, this disease has to be defined by symptomatology because there is currently no laboratory test for the condition. It may well cover a diversity of conditions with differing aetiologies. Whatever the biological basis for the condition is, patients are very sensitive to environmental stress; both acute and long-term. While maintenance with anti-psychotic drugs reduces the relapse rate, this gives only partial protection against stress. Helping patient and family to cope better with the everyday problems of living with schizophrenia confers additional benefit over and above drug treatment (Jenkins & Field, 1996).

Although schizophrenia categorised to mental illnesses, is somewhat differently used by different clinicians, there are systematic differences between schools of psychiatry, between countries and between continents. Schizophrenia is to be regarded as an illness affecting the mind and the personality of the patient in a way that is seldom completely resolved. After an attack of the illness, there is nearly always some degree of permanent change of personality, even though there may be complete restitution of apparent mental health and social capacity. If a single illness continues for a longer time, the probability of personality change and the degree of such change, if it occurs, will be greater (Slater & Cowie, 1971).

Illnesses of this kind may at times be imperceptible at the onset and insidious in development, but more usually, they occur in one or more acute attacks of relatively severe illness with florid symptomatology. The symptoms of the acute illness are in many ways characteristic of focal disturbances of central nervous function occurring in a setting of general lucidity, hallucinations (especially in the auditory field), passivity of feelings, primary delusional experiences, and rather typical forms of thought disorder (Slater & Cowie, 1971).

Premorbid abnormalities of speech and behaviour may be present during childhood. The role of obstetric complications and viral infection in utero remain unproved. Enlarged ventricles and abnormalities of the temporal lobes are not uncommon findings computed

tomography of the brain. Thus, a picture is emerging of a genetic brain disorder, enhanced or brought out by subtle forms of environmental damage (Turner, 1997).

1.3 Positive and negative symptoms of schizophrenia

1.3.1 Hallucinations: These are false perceptions in any of the senses: a patient experiences a seemingly real voice or smell, for example, although nothing actually occurred. The hallmark of schizophrenia is that patients experience voices talking about them as third person (auditory hallucinations), but second person command voices also occur, as do olfactory, tactile, and visual hallucinations (Turner, 1997).

1.3.2 Delusions: These are false beliefs held with absolute certainty, dominating the patient's mind, and untenable in terms of the sociocultural background. Delusions often derive from attempts to make sense of other symptoms such as the experience of passivity (sensing that someone or something is controlling your body, emotions, or thoughts). Typical experiences are of thoughts being taken or sucked out of your head (a patient insisted that his/her mother was stealing his /her brain or inserted into your mind or of your thoughts being known to others (respectively termed thought withdrawal, thought insertion, and thought broadcast). Cult beliefs in telepathy and mind control may relate to partial forms of these experiences (Turner, 1997).

Negative symptoms involve loss of personal abilities such as initiative, interest in others, and the sense of enjoyment (anhedonia). Blunted or fatuous emotion (flat affect), limited speech and much time spent doing nothing are typical behaviour (Turner, 1997).

1.4 Forms of schizophrenia

Paranoid schizophrenia, the increasingly common form, is dominated by florid, positive symptoms, especially delusions, which may build up into a complex conspiracy theory that seems initially quite credible. In contrast, those presenting only with negative symptoms are described as having simple schizophrenia, while hebephrenia is a mix of negative and positive symptoms with insidious onset in adolescence (Turner, 1997).

The early age of schizophrenic illness can vary considerably. Atypical presentation is a family's concern that a personality has changed or an insistence that a son must be on drugs. A decline in personal hygiene, loss of jobs and friends for no clear reason, and depressive symptoms mixed with a degree of ill-defined perplexity are common. About one in ten sufferers commit suicide, usually as younger patients. It is relatively rare for a sufferer to assault others (Turner, 1997).

1.5. Prevalence

According to Torrey (1987), geographical comparisons of the prevalence of schizophrenia have been of interest to mental health specialists for well over a century. Emil Kraepelin voyaged to Singapore and Java in 1904, and he specifically looked for cases of dementia praecox, and concluded that in all civilized nations the disease comes under observation in approximately the same forms and everywhere it accounts for the greatest number of the permanent inhabitants of institutions.

As a major mental disorder, it has shown a relatively high incidence in South Africa, including the Northern Province. There is an important area of study in spite of problems of over-diagnosis in South Africa, and broader debates over definition and diagnostic criteria. Several authors have argued about the consideration of black patients' experience in South Africa that they are distorted by the way culture is construct by psychiatric researchers and clinicians (Lund & Swartz, 1998).

According to estimates made by the black Central Statistical Services (Bester, Weich & Gagiano, 1991) black aged population would increase by 129% from 1980 to the year 2000. This development would place a much higher demand on health services. To be able to cope with this increasing demand it would be of the utmost importance to do careful and economical health care planning based on scientific data. According to researchers very little psychiatric data is available on elderly blacks in South Africa. According to previous studies in Central Africa and other Third World countries, the prevalence of psychiatric disorders is the same as in the western world. However, one can currently only speculate about the actual situation in South Africa (Bester, Weich & Gagiano, 1991).

International studies estimate that between 17% and 24% of the general population suffer from psychiatric disorders. In a review of 24 epidemiological studies conducted in clinic and community adult samples in Africa since the late 1960s, it is found that the median figure for community studies was within this range. These disorders may not be severe in terms of symptomatology, but may be distressing, disruptive and costly to the individual, the community and health services. Mental disorder, especially among formerly disenfranchised South Africans, has been argued by some to be more prevalent than elsewhere, and apartheid has been portrayed as psychiatrically pathogenic. However, no broad age-range community studies have been conducted in South Africa since 1968 (Rumble, Swartz, Parry & Zwarenstein, 1996).

Recently, South African health policy makers have committed themselves to improve community health, including mental health, and to integrate mental health care into primary care. Health services in South Africa have been grossly inadequate; with access in rural areas being a particular problem. In order to plan mental health care in the mental health field, there is a need for research on the prevalence and nature of mental health problems in the general population, on associated socio demographic variables and on attitudes towards, and usage patterns of, formal and informal services (Rumble, Swartz, Parry & Zwarenstein, 1996).

Turner (1997) proposes that schizophrenia is a relatively common form of psychotic disorder (severe mental illness). Its lifetime prevalence is 1%, its annual incidence is about 10-15 per 100000, and the average general practitioner cares for 10-20 schizophrenic patients depending on the location and social surroundings of the practice. It is a syndrome with various presentations and variable, often relapsing, long- term course. Although schizophrenia is publicly misconceived as a split personality, the diagnosis has good reliability, even across ages and cultures, though there is no biochemical marker. Onset before the age of 30 is the norm, with men tending to present some four years younger than women. Clues as to aetiology are tantalizing, and management remains endearingly clinical.

Kates and Craven (1998) caution that schizophrenia has a relatively high prevalence (1%), although the incidence of new cases is only 1 per 4000 people per year. In other words, a primary care provider may have as many as 20 individuals with schizophrenia in his

or her practice but will only see a first episode case less than once a year. Jenkins and Field (1996) narrowly define schizophrenia as the illness that has a relatively constant incidence across the world affecting about 1 in 100 people.

Besides the possible impact of such side-effects, it is recognized that there are other factors, which can also negatively impact on quality of life: The illness itself, with its wide-range of symptoms, can have a profound impact on thinking, cognition, communication, behaviour and that it can often lead to long-term deficit symptoms. Similarly, a host of social and life-related issues can further compromise quality of life, which include poverty, lack of resources, social isolation, homelessness, criminalisation and stigma (Awad & Voruganti, 1999).

Frangou and Byrne (2000) proposed that the lifetime prevalence of schizophrenia is about 1 %, but the associated social disability and cost are disproportionately large. According to the World Health Organization (WHO), schizophrenia is among the leading cause of disability worldwide. Representative measures have estimated the annual cost of schizophrenia in England to be, \$2.6bn and in Canada to be \$2.35bn (1.06bn). A growing body of evidence suggests that the early stages of schizophrenia are critical in forming and predicting the course and outcome of the disorder. Accordingly, clinical and research interest is now focused on the early stages of the illness because early detection and treatment may result in a better prognosis and functional outcome.

The first episode of schizophrenia typically occurs in the late teenage years or the early 20s. However, the illness can remain undetected for about 2-3 years after the onset of early diagnosable symptoms. Early recognition is hindered by the insidious nature of the onset of schizophrenia, which occurs against a background of premorbid problems of language, cognitive ability, and behaviour. Frequently, neurotic features (social anxiety, panic attacks, obsessional ideas), antisocial behaviour, or substance misuse dominate the clinical picture and obscure the underlying psychosis. Functional deficits such as emotional flattening, social withdrawal, and lack of motivation and pleasure are usually prominent. The most common reported psychotic features are auditory hallucinations and delusions (Frangou & Byrne, 2000).

Once schizophrenia is diagnosed, the primary aim of treatment is to bring about rapid remission of the acute psychotic episode using the most effective and tolerated drugs. A number of randomised clinical trials and cohort studies have suggested that patients are more responsive to treatment during their first episode regardless of the anti-psychotic drug used but are more sensitive to extra-pyramidal side effects, such as acute dystonia and parkinsonism. In this respect, treatment strategies that minimize the risk of side effects, such as the use of low dose typical neuroleptics or atypical anti-psychotic drugs, may be a rational choice for the first episode (Frangou & Byrne, 2000).

1.6 Intervention

This section consists of: (1) psychiatric services, (2) the effects of cultural differences and politics among South African psychiatric hospitals (3), medication and, (4) psycho education.

1.6.1 Psychiatric services

Mental health care in South Africa is faced with numerous challenges. These include the spiralling costs of care, the need for accessible mental health services; the need, in turn, for epidemiological research which clarifies costing and accessibility; deinstitutionalisation and the management of patients in community settings; and the development of prevention mental health care services. More broadly, there is a need to adapt and supply nosological systems developed in the west, such as the DSM-IV, to the specific needs of South Africans (Lund & Swartz, 1998).

These issues are crystallized in the experience of black psychiatric patients. An understanding of the experience and explanatory models of black psychiatric patients can inform epidemiological research. It enables mental health planners to assess the most appropriate form of community based mental health care (whether preventive or curative), based on a clearer understanding of needs. It also enables researchers and clinicians to understand the way in which western psychiatric constructions of psychopathology are reconstructed in our context. Psychiatric patients internalise and integrate psychiatric constructions in an attempt to make sense of their experience. The distortions of imported

psychiatric constructions, as well as the construction of culture by psychiatric research and clinician practice, can all be more clearly understood by investigating the way in which psychiatric patients understand and experience their condition (Lund & Swartz, 1998).

1.6.2 The effects of cultural differences and politics on black patients in South African psychiatric hospitals

The concept of culture in mental health field as used in South Africa was anything but ideological and neutral. Cultural differences were used to legitimise shameful apartheid practices. Within the mental health field, inadequate and discriminatory services were justified with recourse to the idea that different cultures had different needs in the mental field. Psychological suffering as a response to iniquitous social and economic condition was often seen by mental health researchers as a primarily a problem of cultural adjustment (Swartz, 1996).

The consideration of black patients' experience in South Africa has been distorted by the way in which culture has been constructed by psychiatric researchers and clinicians.

Some researchers (Bürmann, 1977, 1984; Cheetham & Griffiths, 1980; Cheetham & Rwadkowski, 1980; Fischer, 1962; Hillis, Koch & Joy, 1989; Hickson & Christie, 1989 cited in Lund & Swartz, 1998) have been criticized for reifying scientific western and holistic African culture as observable forms of social division within which they are located. For example, specifically in Xhosa people's experience of schizophrenia is described as *thwasa*, *phambana* and *amafufunyana*, using an idiographic analysis of interviews with a diviner's consultees. Lund and Swartz, 1998) proposed studies that showed a typical cluster of identifiable symptoms attached to *amafufunyana* as a form of spirit possession primarily due to sorcery/witchcraft. A mixture of soil and ants from a graveyard is used to make a harmful concoction, which can be placed in the path of the victim.

In a Zulu tradition, schizophrenia is seen as *indiki* and *amafufunyane*. Concomitant with increasing modernization, there is increasing demand of indigenous African peoples for modern Western medicine in general and psychiatrics in particular. It has often been noted that traditional Zulu views of illness and health are vastly different from those of modern

Western medicine. Despite increasing acceptance of modern Western medicine, traditional Zulu beliefs and practices are widely held, particularly in rural settings. This is particularly understandable owing to the individual and social homeostatic effects of these beliefs and practices over generations (Edwards, et al., 1983).

Researchers such as Murdock et al have developed a comprehensive classification of theories of schizophrenia in underdeveloped societies throughout the world. These researchers also developed three major explanations of supernatural causation: animistic, magical, and mystical. As this can attack a person irrespective of age, gender and so on, Zulu tradition ascribe the disorder to the behaviour of some personalized supernatural agent, such as a spirit or gods, for example, *abaphansi basifulathele*- means the withdrawal of protection of the ancestral shades, mostly caused by disharmony within the home; *ukulahla amasiko*- failure to perform necessary rituals, such as sacrifices to the shades; *ukuthwasa*- a creative illness following by the ancestral shades to become a diviner.

Northern Sotho and Zulu traditions are just the same as they focus this illness on the African perspective such as ancestral or witchcraft through or by an enemy. These theories form the cornerstone of African cosmological, religions, social, and moral worldviews of good and evil, health and sickness. So, African religion embodies the essence of all religions in its reverence for elder kinsmen, both living and dead (Edwards et al, 1983).

Swartz's (1991) view on the question of the political organization of health and mental health care in South Africa has attracted considerable attention in recent years. South African research in this area has tended to focus on macro social questions, the central one being that of the distribution of health and mental health resources in the apartheid state. Central though macro social studies are (particularly so in South Africa), the issues they raise beg the question of how the power relationships they have identified can be observed within the clinical setting itself. How do clinicians, patients, and other players in the health care arena respond to, reproduce, question or even sabotage and undermine the pattern of unequal social relations into which they are inserted? That South African health and mental services are racist at the structural levels has been well established.

Lund (1991) cited in Lund and Swartz (1998) view on one of the most depressing features of work in a modern psychiatric hospital anywhere in the world is what is known as

the revolving door-the phenomenon of patients' repeated readmissions to hospital. No one who has worked in psychiatric hospital can be unaware of stories of how this pattern has on occasion been broken-through the discovery of an underlying physical disease, through re-labelling of the patient into a new diagnostic category, or through some other imaginative restructuring of treatment.

1.6.3 Medication

Over the past few years, several new generations of antipsychotics have been introduced: Risperidone, Olanzapine, Seroquel and the list are quickly expanding further to include Ziprasidone and a few others in the future. Similarly, clozapine, for which there is well-documented evidence, related to its superiority in treatment resistance, new and conventional antipsychotic medications are generally comparable in terms of their efficacy (Awad & Voruganti, 1999).

Eckman, et al (1992) argue that the public health problems posed by schizophrenia, as well as the personal misery experienced by patients and their families are amplified by the revolving door, a pattern of multiple rehospitalisations and homelessness, which is so often the consequence of patients failing to adhere to their treatment regimens. Despite more than a quarter century of research evidence for the efficacy of maintenance neuroleptic therapy in reducing relapse rates for patients with chronic schizophrenia, reliable compliance with medication is more the exception than the rule.

Consistent with the current emphasis on promoting patients' understanding of their illness and cooperation with their treatment, skill training has emerged in recent years as an effective technique for psychiatric rehabilitation. As a psychosocial adjunct to anti-psychotic drug therapy, training schizophrenic patients in social and independent living skills through individual, group and family interventions has yielded improvements in social functioning, reductions in relapse rates, and superior cost-effectiveness. If skill training is to be effective in teaching patients how to be more responsible and reliable consumers of treatment, the training procedures must be designed to overcome or compensate for the enduring cognitive and information processing deficits commonly found in schizophrenia

1.6.4 Psycho- education

In examining models of psycho education, Anderson, Reiss and Hogarty (1986) advocate the family education model as the most effective psychosocial approach for helping person with schizophrenic disorders. This model stems from the theory that schizophrenia is biological in origin and refutes the notion that disturbed family relationships and deviant communications are the primary etiological agents for schizophrenia. It is recommended that families who care for schizophrenic relatives receive psychosocial interventions emphasizing health education and family stress management. Educational components that address specific information about schizophrenia, relapse, and caregiver contributions are seen as core elements.

Hornung, et al (1996) see the only means of providing schizophrenic patients with satisfactory, comprehensive relapse prevention through multidimensional therapy as comprising not only drug therapy but also environmental and social therapy as well as psychotherapeutic approach that is constituted by what is known as psycho-educational measures which are aimed at providing schizophrenic patients with a reduce risk of relapse. These have resulted from work with families of schizophrenic patients in which the emotional family atmosphere is relaxed by integrating and informing relatives, resulting in a reduced relapse rate. There is no uniform psycho-educational procedure in the treatment of schizophrenic patients. According to a more broadly valid definition, its components in general are provision of educational information and various methods based mainly on interventions.

Ó Shea, Bicknell and Wheatley (1991) postulate that psycho-education programmes are structured, didactic approaches to helping relatives adapt effectively to chronic conditions that involve emotional and behavioural impairment and have a known or suspected physical aetiology. The decision to employ a psycho-education program with a specific group of patients and/or families typically stems from three sometimes controversial and somewhat incompatible assumptions: (1) the family environment is not responsible for the genesis of the focal disturbances, (2) characteristics of the family may influence, positively or negatively, the level of severity of the disturbances, level of adjustment, and/or

the quality of life of the patient and family, (3) the family is a resource rather than an impediment to effective treatment, management, and adaptation to the illness.

As the name implies, psycho-education programmes usually emphasize one or more of the following: (a) education regarding the manifestations, causes, and /or contributing factors, aspects of psychological responses, treatment, and related services for the conditions; (b) information and skill training in how to effectively manage the demands of the illness and cope with illness related- stress; and (c) providing expert or peer-mediated social and emotional support to patients and families. With respect to schizophrenia in particular, a decade of research has shown that psycho education program combined with appropriate maintenance anti-psychotic medication substantially reduce relapse rates compared to other social treatment lacking a family-focused component.

Miller, et al (1994) caution that psycho-educational programmes for mentally ill persons and their families have gained considerable recognition as models of treatment within the managed care arena. Psycho-educational programmes are defined as time-limited, closed groups, conducted by health professionals for the purpose of educating and providing support to its lay membership. The continuity care that psycho educational programmes provide for patients and their families has been the focus of several clinical studies. However, there is no clear indication that all psycho-educational programmes should focus on similar outcomes. It may well be more useful and appropriate to focus on the specific outcomes unique to specific disorders and/or disabilities.

Hogarty (1993) proposes that the hope for a treatment for schizophrenia that reduce the frequency and severity of relapse is being realized through an approach that combines a reduction in levels of stress in the intervention and home environment with the thoughtful application of neuroleptic medication. Rarely can a schizophrenic patient be maintained in stable life-style without the use of anti-psychotic drugs, and it is known that psycho-education enhances maintenance of drug treatment as well.

1.7 An overall aims and objectives of the study

1.7.1 Aims of the study

- * To strengthen families to be long-term care givers
- * To assess whether psycho education can lead to compliance

1.7.2 Objectives of the study

- * To help the relatives as well as the patients to appreciate what risks they themselves or other family members have to develop the condition.
- * To improve knowledge and the quality of life to both the schizophrenic patients and their relatives.
- * To improve concrete strategies for coping with psychotic crises.
- * To prevent schizophrenic relapses.
- * To increase awareness of early signs of impending relapses.
- * To improve co-determined management of neuroleptic medication.

The efficacy of the psycho educational training for schizophrenic patients is investigated within the framework of a controlled prospective intervention study. The main scope of the study is whether psycho education alone could lead to compliance within 9 months follow-up. Studied patients are randomly assigned either to one of the treatment conditions or to the control group.

Chapter two

2. Literature review

Different researchers have different opinions about the psycho-education for the schizophrenic patients, how they can manage to live with their illness and their quality of life; factors that can destruct their living skill such as, substance use; education provided to patients; how their care givers were unable to manage with patients' illness and behaviour; the support that families got from the professional in order to cope with their living; and so on.

2.1 Educational programme for Schizophrenic Patient at Cornell Medical Centre- West Chester

Gallagher and Nazarian (1995) presented a preliminary report of an innovative psycho-educational programme developed originally for long-term inpatient and day hospital schizophrenic patients, although it has now been modified for shorter treatment as well. Patients receive an ongoing series of didactic lectures and simultaneous individualized follow-up coaching sessions on dealing with their disorder. The sessions are focused especially on:(1) how the illness characteristically affect their understanding of themselves, their thinking patterns, their social relationships, and their ways of dealing with their emotions; and (2) the coping skills and other strategies they can use in each of these key problem areas.

The Educational Programme for Schizophrenic Patient is an explicitly broad-based program in its intent to address the wide array of emotional, behavioural, cognitive, and social difficulties characteristically found over and over again in our average schizophrenic or schizoaffective patient. It can also be individually tailored, depending on the specific needs, conflicts, and deficits of particular patients (Gallagher & Nazarian, 1995).

2.2 Psycho-educational model for managed care

Miller, et al (1994) say the level and intensity of psycho-educational programmes, geared to managed care, need to be especially sensitive to the patients its serves. High intensity programmes have been known to precipitate an early relapse for some anxious, withdrawn, low-insight, or disorganized patients, assigned to a post-hospitalisation clinic. Similarly, intense and over-stimulating outpatient programmes have produced an increased incidence of relapse symptoms in some patients. Psycho-educational programmes geared to the needs of patients stressed early inclusion into the therapeutic process.

Every effort should be made to address the crucial issues of client responsibility, understanding one's own illness, developing methods of addressing the illness, realizing the variety of community resources available and developing an early treatment phase in which the patient can develop confidence and draw support from a health care service delivery system.

The psycho-educational component should include conjoint sessions with patients and family members or significant others. The purpose of such sessions is to provide a structured place for family or significant others to share observations, issues, concern, and are a part of the managed care system. The family component can also provide a continuing education module for understanding schizophrenia and identifying early signs of relapse. Emphasis on communication skills, the family's identification of early signs of relapse, and discussing problems of mutual concern, can be beneficial treatment components in the management of most disorders (Miller, et al., 1994).

2.3 Advantages of psycho-education in managed care

There are several clear advantages to using a psycho-educational model within a managed care system. First, it is a service model that is widely accepted in the professional literature. Second, it serves as a mental health service delivery system in the mental health consumer market. Third, the information imparted empowers the patients and their families to assist in the management of the illness. Fourth, it serves as a preventative approach and addresses the

specific issues of relapse prevention Fifth, the model places fewer demands upon limited professional time and, therefore, provides an opportunity to serve a large number of patients. Sixth, it encourages the multi-disciplinary brokering of services in a managed care setting (Marder et al, 1991).

2.4 Educating schizophrenic patients about drug treatment and its compliance

Macpherson, Jerrom and Hughes (1996) argue that to educate patients about drug treatment is to provide information, increasing understanding among patients, and encouraging health-promoting behaviour. The approach has generated research attention particularly through family intervention programmes in schizophrenia, but there is a relative dearth of studies of patient education aimed at the individual sufferer, and little research evidence regarding the extent of patient education in routine clinical work. Benson (1984) cited in Macpherson, et al (1996) found that only one third of North Carolina psychiatrists routinely supplied information about a major anti-psychotic side effect (such as jaundice). There is a disparity between reported communication by psychiatrists and actual understanding in patients, and a process of selective transmission/assimilation of information is suggested. Poor understanding of medication in the long-term population was associated with cognitive impairment.

Empirical studies of patients education in schizophrenia have varied widely in methodology from a single informed consent procedure to prolonged training in medication management skills; most studies employing a single instruction session and didactic lecturing led to significant knowledge gain, the clinical relevance of which has been questioned. Impaired educability has been associated with more severe schizophrenic symptoms, presence of tardive dyskinesia, cognitive impairment and negative attitudes to treatment. Education also improved compliance and reduced negative symptoms(Macpherson, Jerrom & Hughes, 1996).

Hogan, Awad and Eastwood (1983) assert that a clear communication to the schizophrenic patients on the purpose of a drug, its expected effects, the nature of the regimen, and the right and wrong time for discontinuation, are intrinsic to sound

pharmacotherapy. Such practices may be useful in securing improved compliance from those patients who, for reasons of lack of comprehensive or mistrust of the physician may falter in taking their pills. There is still a larger number of patients whose persistent protestations about their medication, based on vague complaints of not feeling like themselves, or of being in some manner limited in their functioning, present the greatest difficulties in long-term drug management

Educating patients about drug therapy is becoming increasingly important in health care. In psychiatry, patient education has centred on issues of compliance and informed consent. Many studies have evaluated the effect of providing information about drug compliance. Providing both verbal and written information about a prescribed drug has been found to be most effective in improving compliance among patients, including depressed outpatients. However, when providing drug information to psychiatric patients, it is unclear how much emphasis should be placed on side effects because psychiatric patients may have a greater tendency to be anxious (Brown, Wright & Christensen, 1987).

2.5 Cost of schizophrenia

Davies & Drummond (1994) and Haddad and Knapp (2000) reveal that the costs to society of schizophrenia include the direct costs of treatment and care, the indirect costs of lost productivity due to unemployment, impaired work performance, premature mortality and family burden; and the economic costs apart, schizophrenia is associated with considerable intangible costs in terms of pain and suffering due to reductions in the quality of life, so all these could outweigh the direct costs.

In the study that was conducted in UK, estimates of both costs were published in 1990. These included the total annual and lifetime cost of the disease for the UK, using 1987 unit cost or price data that have been updated to 1990/1 (Davies & Drummond, 1994).

Haddad and Knapp (2000) caution that although much of the discussion was related to the full range of serious mental illness, the primary focus was schizophrenia, the associated cost of which were wide ranging and high. Not only are there costs to the NHS but also, other public sector agencies are regularly involved such as housing, social services

and criminal justice; as are the voluntary and private sectors.

The high and enduring costs of schizophrenia have attracted growing attention from policy-makers; care professionals and others. Evaluations have been commissioned to discover whether costs can be reduced or contained while maintaining or improving patient and other outcomes. Although there are still comparatively few completed economic evaluations of schizophrenia treatments, they nevertheless often numerous pointers to cost-effectiveness improvement. That is, there are proven ways to use existing resources to greater effect (Haddad & Knapp, 2000).

Haddad and Knapp (2000) propose two issues, which emerge from the costs of this illness. Firstly, care of schizophrenia can be worryingly fragmented due to the involvement of multiple agencies and professionals, each with their own objectives, constraints, performance requirements and values. Secondly, there are major inequalities in services and in the needs of population. These factors are seen as contributing to variations in standards of care and clinical problems, hampering the pursuit of greater effectiveness and cost effectiveness. Combining the average cost of treating a person with schizophrenia with estimates of the prevalence of the disease provides a useful indication of the overall costs to the health service in one year. However, decision-makers also require information on how these costs are distributed between people with differing severities of the disease. For this, an estimate of costs based on various outcomes of schizophrenia is required.

2.6 Interventions with families of schizophrenics can reduce relapse rates

Schizophrenia follows a relapsing course for life in most sufferers. In one study almost 80% of patients relapsed repeatedly, and at five years half showed persistent handicap. Relapse takes on patients and their families and imposes a financial burden on hospital and community services. Some of the patients relapse while taking maintenance medication, and this stimulated a search for other contributory factors, which has now led to an emerging consensus (Davies, 1994).

The chance of relapse in patients with schizophrenia living at home depends heavily on the emotional environment provided by the family. The concept of expressed emotion

has evolved as an index of the quality of this environment. Expressed emotion covers many of the emotional responses by a key relative, usually the spouse or parent, towards the patient.

Antipsychotic medications have been repeatedly shown to be effective for the treatment of acute psychosis and the prevention of relapse for persons suffering from schizophrenia. Novel antipsychotics with fewer neuromotoric side effects are a clear therapeutic advancement. However, with the exception of Clozapine for treatment-resistant psychosis, the newer agents have not been clearly shown to have clinical advantages in other domains of outcome, such as social adjustment and obtaining competitive employment (Bustillo, et al., 2001).

Thus, the majority of persons with schizophrenia, even those who benefit from medication, continue to have disabling residual symptoms and impaired social functioning and will most likely experience a relapse despite medication adherence. Hence, it is necessary to integrate empirically validated psychosocial treatments into the standard of care for this population (Bustillo, et al., 2001).

A general rise in public interest in health and in desire for knowledge about illness has coincided with increased recognition of the importance of social factors in the course of schizophrenia and with the beginning of prophylactic psychosocial interventions to try to reduce relapse rates. An integral part of the intervention process has been a knowledge or information component, by which patients are provided with information about the diagnosis, symptomatology, aetiology, treatment, and course of schizophrenia, and this might be integrated more easily into clinical practice (TARRIER & BARROWCLOUGH, 1986).

However, this necessitates further investigation into how information about schizophrenia might best be presented to relatives and patients, and what effect this information has on them. However, relatives are often not actively supported in this work, and may even be blamed for the illness itself. How information about the nature, course, treatment, and management of schizophrenia could assist relatives to help to rehabilitate the patients needs to be examined (TARRIER & BARROWCLOUGH, 1986).

2.7 Burdens experienced by families of schizophrenic people

There is some evidence that instrumental and affective professional support can reduce burden. Consistent with the coping framework, family members' responses to the stress of care giving, and certainty of social and personal resources might explain variation in the burden experience. One potential social resource is support from nurses and other mental health professionals. Families report needs for instrumental professional support, such as information about their relative's illness and practical techniques for dealing with aberrant, sometimes threatening behaviours. They also seek affective support, particularly empathy and respect for their concerns and opinions regarding their relatives' ongoing rehabilitation (Reinhard, 1994).

Family members who provide care to mentally ill relatives bear a significant burden and often feel helpless in dealing with the problems associated with severe and persistent mental illness. Many families report frustrating attempts to receive support from mental health professionals to help them cope with these burdens, instead of feeling blamed and excluded from the treatment process. Yet, families continue to seek help in managing their demanding role, and some experts claim that support from professionals can reduce family members' sense of burden and feeling of helplessness (Reinhard, 1994).

Since families commonly report that the relative's disturbing behaviours create a chaotic environment, professional support is needed to acquire the information and skills necessary to alter the environment. Instrumental support, such as guiding families on techniques for setting limits on relatives' demands, can enhance feelings of competence and a sense of control. Affective support, such as positive reinforcement for effective problem solving, can bolster caregivers' confidence that there are pragmatic actions that they can implement to manage their situations. Though caregivers cannot control their relative's mental illness, they can manage their response to it (Reinhard, 1994).

Biegel, et al (1994) found that chronic mental illness affects not only the patient but also the entire family system. Normal patterns of family interaction are disrupted, and reassignments in tasks and roles assumed by particular family members may occur. As with other chronic illnesses, schizophrenia is often stressful on caregivers. Studies over the past

decades have provided consistent evidence that family caregivers of persons with chronic mental illness suffer from a number of significant stresses and moderately high levels of burden. Relatives of persons with mental illness shoulder significant care giving responsibilities, often with inadequate assistance from mental health and human services agencies.

A number of researchers believe that deinstitutionalisation has led to a greater strain on families today because many patients who would have been hospitalised in the past are now treated in community based programmes. Family strain increase because patients may not follow through and utilize community services, or needed resources such as housing or job training may be unavailable in the community. In addition, because length of hospitalisation has decreased, many patients are returning to communities and to their families with severe emotional problems. Even though studies indicate that families exhibit high tolerance toward family members with mental illness, often it is at considerable cost to the family. Because of the chronic nature of mental illness, the burden on families can continue with varying levels of intensity for long periods of time (Biegel et al, 1994).

The burdens of care giving are multiple and pervasive, often contributing to feelings of guilt, resentment, worry, and grief. Significant issues and problems facing caregivers of persons with mental illness cited in the research and practice literature include: managing their relatives' symptomatology and behaviour; isolation of caregivers due in part to the stigma of mental illness; interference with personal needs of family members; inability of the patient to carry out the tasks of daily living; improper use of medication; and perceptions of mental health professionals as not being helpful and blaming families as a causal agent of the patient's disease (Biegel, et al., 1994).

Although there is general agreement in the literature that family caregivers of persons with mental illness, like caregivers of person with other chronic illnesses, experience significant level of burden, there remain many significant gaps in our knowledge. Overall, the extant research on families of persons with mental illness has a number of significant limitations (Biegel et al, 1994).

Mueser, et al (1996) state that mental health professional has become increasingly aware of the burden on relatives of caring for a psychiatric patient and of the importance of

helping families improve their ability to cope. Despite recognition of the distress that relative experience, the specific determinants of family burden are not well understood. Understanding which symptoms are most problematic may be critical to helping families cope more effectively with mental illness. Most research on family burden and psychiatric disorders has focused on the relatives of patients with schizophrenia, with minimal attention given to other severe psychiatric disorders. Evaluating the differences in problems experienced by relatives of patients with schizophrenia will inform professional about which problem areas are most common for each diagnosis.

The most common pattern of discharge following inpatient treatment for illness exacerbations is the return of psychiatric patients from a public psychiatric hospital to board-and-care facilities, group homes, or co-residence with parents or other relatives. Several studies of family care giving have shown high levels of burden among those families who reside with their ill relative. Nearly half of households surveyed had experienced such co-residence. While co-residence is acceptable within the large community and provides satisfactions as well as frustrations, sharing the household with an offspring limited in coping ability, such as those with episodic or persisted psychiatric illness, often requires resumption of the active parenting role that parents prefer to have transitioned out of (Cook, et al., 1997).

The family's ability to work together to resolve problems posed by the illness and care giving demands also is essential in coping effectively with the challenge of caring for a troubled family member. Although care giving provides enhanced mastery and resilience at both personal and family levels of analysis, caregivers are able to express their feelings of frustration and distress (Cook, et al.1997).

With an accelerating pace of deinstitutionalisation and the discharge of approximately 65% of hospitalised patients to their families, the issue of family burden is receiving increasing notice in the literature. Descriptions of the impact of severe and chronic mental illness on patients' family are derived from family members and reports of concerned psychiatrists. The terms objective and subjective family burden have been used to distinguish, respectively, between the reality demands of living with mental illness and family members' personal suffering as a result of the illness. Examples of objective burden are the patients' dependency and inability to fulfil expected social role functions; financial

costs of the illness, which may impoverish the family, disruption of household routines; deprivation of needs of other family members, including younger siblings and children; adverse relations with neighbours and an uncomprehending and rarely sympathetic external world; diminishing social support system; and converse need to curtail social activities as a function of diminished energy resources and stigmatisation of both patient and family (Lefley, 1987).

For subjective burden, it includes the following: grief and empathic reactions to the pain of loved ones who are often fearful of symptom recurrence and capable of mourning their own mental and physical health; inability to make or fulfil personal plans and worries about the patient's future (Lefley, 1987).

An important element in alleviating burden is the capability of the mental health system of offering timely and effective treatment and of supporting families in their care giving efforts. Research indicates, however, that although families continue to look to provide for help, professional support and interventions are viewed as inadequate. This, of course, may be a misperception of bewildered and frustrated people with little knowledge of the complexity of the illness/disorders and with unrealistic expectations of cure (Lefley, 1987).

There is general agreement that it is helpful to diagnose and treat mental illness using the family as the unit of observation, description, conceptualisation and treatment. Nor is there any doubt that families with mentally ill members, especially schizophrenic patient, show profound dysfunction in a variety of ways. These include: deviant communication patterns, deficits in interrelatedness, inadequate ego differentiation, unresolved grief reactions, internal and external boundary disturbances, shared denial of obvious family problems and the presence of high level of anxiety, and what has been termed pseudomutuality. However, there is significant disagreement about the precise nature of the relationship between the thoughts, feelings, and behavioural interactions among family members (Hunter, Hoffnung & Ferholt, 1988).

Families withdraw their support out of frustration, guilt, and anger; or they withdraw their relative from treatment. In addition, patients learn to blame their families for the illness. Alienating the patient's family can have tragic consequences. Although

dysfunctional patients tend to reside in dysfunctional families, there is no evidence for the leap from association to causation. The belief that families cause schizophrenia may represent another clinical myth. On the other hand, living with a schizophrenic person can cause enormous stress for a family (Drake & Sederer, 1986).

2.8 Supportive educational interventions

Patients with schizophrenia and their caregivers should expect support and have a right to be well informed about the illness. Support involves helping everyone to come to terms with a potentially stigmatising and disabling major mental illness, and practical day-to-day assistance with additional challenges that result from having a person with a major illness in the family. Patient education can take a variety of forms depending upon the abilities and interest of the patient and their family; for example, the education may take place in small groups or individual discussion (Adams, Wilson & Bagnall, 2000).

Tessler, et al (1984) propose that community supportive systems have emerged as a new conceptual mode to improve the quality of life of chronically mentally ill persons in community settings. As adapted by the community support programme (CSP) of the National Institute of Mental Health, the model specifies various essential components for comprehensive care, extending beyond the boundaries of the mental.

2.9 Concept of quality of life in schizophrenia

Although interest in the concept of quality of life in schizophrenia has its roots in the early 1960s, as an extension of the increasing concerns about the unsatisfactory life conditions of the chronically mentally ill in the community, these interests were, unfortunately, not adequately sustained over the next two decades except some serious contributions by new researchers. As quality of life has emerged over the last two decades as the new image of modern medicine, viewed from a psychosocial perspective, a number of medical specialists have successfully embraced the concepts; cancer, arthritis and others. Unfortunately, renewed interest in quality of life in psychiatry has lagged behind other medical specialists.

In a previous review, researchers examined several factors, which may have contributed to the early lack of interest in quality of life studies in schizophrenia. Among the factors that have impeded research are: lack of agreement on a definition of what constitutes quality of life in schizophrenia. As schizophrenic patients often experience disturbed thinking and communications, there have been concerns about the reliability of patients' self reports; particularly the subjective judgment is a key element of quality of life estimation (Malm et al, 1981; Lehman et al, 1982; Lehman, 1983 cited in Awad & Vorugranti, 1999).

In addition, the lack of adequate appropriate conceptual models for the population as well as the phase of the illness and the impact of its pharmacological treatment, has also contributed to the slow progress in the field. As most persons with schizophrenia are treated with medications nowadays, there exists a need for conceptual models that can not only incorporate the impact of the illness or the psycho-social conditions, but are also capable of reflecting the impact of medications, positively or negatively, on quality of life (Awad & Vorugranti, 1999).

2.9.1 Quality of life for the schizophrenic patients

Addington-Hall and Kalra (2001) propose that one of the reasons behind the rapid development of quality of life measures in health care has been the growing recognition of the importance of understanding the impact of health care interventions on patients' lives rather than just on their bodies. This is particularly important for patients with chronic, disabling, or life threatening diseases who live without expectation for cure and have conditions that are likely to have an impact on their physical, psychological and social well-being.

Health professionals frequently make quality of life judgments when making decisions about the care of disabled patients and their view on expected quality of life is often the key factor in determining whether effective treatment for a life threatening condition will be given or withdrawn. Professionals' perceptions may however, be at odds with those held by their patients. It is therefore important to ask patients to assess their own quality of life by using one of a growing number of reliable and valid measures.

Choosing an appropriate measure and using it in clinical practice can be problematic. Deciding to use a measure, however, presupposes that patients are able to assess their own quality of life and complete a quality of life measure. Some patients in some conditions are unable to do this because of cognitive impairments, communication deficits, severe distress caused by their symptoms, or because the quality of life measure is too burdensome physically or emotionally. These may be precisely the patients for whom information on quality of life is most needed to inform clinical decision-making (Addington-Hall & Karla, 2001).

2.9.2 Physicians and nurses as raters of patients' quality of life

Historically, it has most often been the physician who has provided assessments of patients' health status and quality of life. Thus, for example, in clinical trials, physicians are asked routinely to rate the performance status of their patients and the side effects of treatment. More recently, physician-based rating procedures have been developed that are intended to address a broader set of quality of life issues, including psychological and social well-being (Sprangers & Aaronson, 1992).

The available evidence suggested that the ability of physicians and nurses to rate accurately their patients' quality of life is limited. For example, studies of performance status measures have documented relatively wide variability in physicians' and nurses' scores, and only low to moderate levels of inter-observer agreement. The degree of agreement between performance status and quality of life ratings provided by physicians and those provided by patients ranges from low or moderate to relatively high (Sprangers & Aaronson, 1992).

2.9.3 Significant others as raters of patients' quality of life

Spangers and Aaronson (1992) also propose that relatively little attention has been paid in the literature to the potential role of significant others as rates of patients' quality of life. While recent studies have explored the psychosocial impact of schizophrenia on both

patients and their family members, such studies have not addressed the more specific questions of whether family members can provide valid and reliable estimates of patients' health status or quality of life.

Studies assessing patients' performance status and quality of life that reported low to moderate levels of agreements as well as relatively high levels of agreement between the ratings provided by patients and their proxies. The majority of the studies suggest that relatives, like health care providers, tend to underrate the patients' performance status and quality of life. Significant others' ratings have also been found to diverge from those of patients in the areas of pain, health and psychoneurotic complaints, depression, and patients' psychosocial adjustment to schizophrenia (Spangers & Aaronson, 1992).

2.9.4 Factors contributing to recent prominence of the concept of quality of life

Although interest in quality of life studies has come relatively late to the psychiatric field, several factors have recently contributed to enhance clinical and societal interest in the concept of chronic illnesses, such as schizophrenia, which has replaced acute life-threatening illness of the past. Schizophrenia as an illness without any known cure so far, exacts a major cost on society besides the personal suffering of those afflicted with the illness and the impact of their families. The direct and indirect costs of the illness include the frequent need for hospitalisation, the indefinite demands for psychiatric and medical care, the cost of medications, particularly the high cost of the new generation anti-psychotics and several indirect costs related to loss of productivity as well as demands on their families with the indefinite need for social support, housing, etc (Awad & Vorugranti, 1999).

With the economic constraints and efforts to contain health care costs, more attention has focused on quality of life as an outcome measure for comparison of therapies and programs as well as for resources allocation (Awad and Vorugranti, 1999). With the recent rise in consumerism, there has been increased pressure on clinicians not only for participation in the clinical decision making process but also in setting clear expectations of better therapies consistent with the present societal value for money. In addition, with the increased shift in medical practice from prolonging life to improved quality of life and the

increased emphasis on evidence-based medicine, the concept of quality of life has become a new image of medicine viewed from a bio-psychosocial perspective (Awad & Vorugranti, 1999).

The recent introduction of new anti-psychotic medications with high acquisition costs has led drug regulatory agencies as well as formulary and drug benefit plans to require data about quality of life and pharmacoconomics. Although the cost of medication in the management of schizophrenia is generally small, representing no more than 3 to 5% of the total direct cost, the recent rise in the cost of new anti-psychotics has generated a good deal of pressure in mental health budgets. Compared with the cost of medications used in other medical illnesses such as cancer, cardiovascular, AIDS etc., the cost of new anti-psychotic in schizophrenia is still very small. The major problem lies with the traditionally low budgets for psychiatric illness that were historically based, in part, on relatively inexpensive medications among other factors (Awad & Vorugranti, 1999).

2.10 Social and historical forces impacting people with schizophrenia and their families

In the second half of the 20th century, Cook et al. (1997) did a study in the United Kingdom showing a significant improvement in psychotropic medication for schizophrenia, depression, and bipolar mood disorders, along with shifts in financial reimbursement policies for care, enabled many persons to reside outside of education. Deinstitutionalisation led to the movement; beginning in the 1950s and 1960s, of large cohorts of inpatients from state facilities to a community-based system of mental health care that was under funded, under-monitored, and largely ineffective. A continuing emphasis on community care has involved periodic modification of this system despite its patchwork quality and vulnerability to political and economic manipulation

Due to a paucity of housing options and lack of residential services designed to establish and maintain independent community living, many former inpatients returned home to live with families or in board and care facilities. Recently, introduction of managed care into the public mental health arena has created additional uncertainty and instability for

patients and their families by erecting barriers that prevent access to appropriate levels of care (Cook et al, 1997).

In the early 1970s, supplemental security income (SSI) benefits were extended to adults with mental illness and broadened further in 1991 to include benefits for emotionally disturbed people. As a result, the SSI system grew to include increasingly large waves of disability income recipients with severe and persistent forms of mental illness (Cook et al, 1997).

2.11 A persistent problem that need a concerted and long-term response

Fryers, et al (1998) argued about a few surprise that mental health problems are common in people in prison, especially those on remand. But in the light of the longstanding policy consensus that people with severe mental illness should be cared for in health and social services, the results of a recent national survey of mental disorders in prisons are still a shocking indication of inappropriate and inadequate psychiatric care on a huge scale.

The survey that is funded by the Department of Health was based on semi structured clinical interviews and the office carries out the latest in the important series of studies of psychiatric epidemiology in Great Britain for National Statistics. Its most dramatic finding is the high rate functional psychosis: 7% of sentenced men, 10% of men on remand, and 14% of women in both categories were assessed as having a psychotic illness within the past year. People with a dual diagnosis of mental illness and substance abuse pose a special problem as a current concern in the United State (Fryers, et al. in print).

In 1996, Farrar from the National Health Services (NHS) Executive could write that government policy had been consistent in 1983-1995 in advocating that mentally ill offenders should be cared for in health and social systems and not the criminal justice system. Many people are diverted from prison into psychiatric care, and in spite of some initial growth of court diversion schemes and transfers of mentally disordered prisoners to hospital, the number of the prisons are still substantial. Five years after the Health of the National strategy made mental illness a key area and drew specific attention to the needs of mentally ill offenders there is little evidence that government policy is offering the

fundamental changes required (Fryers, et al., (1998).

The policy implications are important and far-reaching. Firstly secure hospital accommodation is already inadequate and under pressure. Uncertainty surrounds the future of the high security special hospitals, and any reduction or reconfiguration to them would shift patients into the NHS (Fryers, et al., 1998).

Secondly, there are many hundreds of men and women remanded in prison for a long time; many are suffering from longstanding mental disorder, current mental illness, or both. For them, effective treatment is an issue of basic human rights; as the need to continue speeding up the criminal justice process itself (Fryers, et al., 1998).

An effective service combining individual care and policy protection must be a flexible 24-hour service. If this means something more assertive the aftercare and more paternalistic than current practice, so be it, but community care programs for those patients must recognize their peculiar lifestyles. Out of prison many are essentially homeless, with limited, not very supportive, social networks, often close to alcohol and drug cultures. There is a need to find some way of mobilizing individual continuing care packages which will address both their mental health and social problems and reduce the risk of their re-offending (Fryers, et al., 1998).

2.12 Beyond behaviour change and risk reduction: mind and mood matters

When behavioural issues are considered within mainstream medical care, it is usually within the context of trying to change unhealthy behaviours that contribute to disease and disability. Patients are encouraged to stop smoking, curtail alcohol consumption, take their medications, practice safe sex, and so on. This focus on behaviour change and risk reduction makes sense because all these lifestyle factors, and others, have been associated with health outcomes. However, the link between changes in health behaviours and improvement in health status, especially with regard to chronic disease is not as clear as generally believed (Sobel, 1995).

The impact on health status of shared determinants such as social support, socio-economic status, and personality disposition may influence health through mechanisms other

than the usual behavioural risk factors. When other factors such as beliefs, attitudes, and emotions are considered, they are often viewed as determinants of health behaviour, which in turn influence health. However, such beliefs may themselves have direct effects on physiological system independent of their effects on health behaviour (Sobel, 1995).

Chapter Three

3. Research methodology

3.1 Sample

The study included two phases: phase1, the baseline, consisted of 82 (50 males and 32 females) chronic schizophrenic outpatients on the baseline study at Mankweng Hospital in the Northern Province. Their ages ranged from 17 years to 62 years with the mean age of 37.5 (SD= 10.2). Their level of education ranged from non-education to tertiary education, and their marital status ranged from single to widow. Forty-one patients constituted the experimental group and the other forty-one constituted the control group. The experimental group received psycho-education, while the control group did not. Phase 2, the follow-up, consisted of 57 (36 males and 21 females) chronic outpatients. Their ages ranged from 20 years to 62 years with the mean age of 39.3 (SD= 12.6). Their level of education ranged from no education to tertiary education, and their marital status ranged from single to widow. Included will be a diagnosis of schizophrenia according to the new Diagnostic and Statistic Manual of Mental Disorders (DSM-IV) that requires one month of acute criterion symptom. However, DSM-IV requires a total duration of 6 months, at least one month of active symptoms and at most 5 months of negative and attenuated positive symptoms.

The DSM-IV criteria contain two positive symptoms (hallucinations and delusions) and one negative symptom group (affective flattening, alogia, avolition). Finally, DSM-IV excludes schizophrenia in the presence of manic or depressive moods that are substantially longer in duration than the psychotic symptoms (Warner & de Girolamo, 1995).

An examination schedule

All patients were examined at the beginning of the therapy and also after nine months follow-up. Information on previous medication and medication management was obtained in a structured interview (Medication Questionnaire)(Hornung, et al., 1992), see appendix. This questionnaire

consisted of 18 items concerning information about medication, medication behaviour, medication management and subjective statements about neuroleptics and overall treatment. Other question items were on a preform, which allowed the indication of categorized answers. Primary evaluation was focused on the following items designed to cover satisfaction with knowledge about medication and confidence in coping with future medication self-management. Examples of the questions were as follows: Are you content with knowledge about your medication? (Item6). Do you believe that you are capable of modifying on your own the dose of your neuroleptics within certain limits following your actual need? (Item9). Patients could answer in three categories: yes, no, or I don't know.

Procedure

Permission to do the study was obtained from the ethics committee, University of the North, the Department of Health and Welfare of the Limpopo Province and the superintendent of Mankweng Hospital gave the researcher allowance of administering the questionnaire within the institution. Verbal consent was obtained from participants. Questionnaires, which were used to interview them, were translated from German language to English and then to Northern Sotho. They were also back translated according to standard scientific procedures.

Forty-one consecutive schizophrenic outpatients fulfilling the study criteria were selected as the experimental group at Mankweng Hospital in the first three weeks and another forty-one consecutive schizophrenic outpatients were selected as the control group in the last three weeks at the same hospital. Each of the selected patients was approached in the waiting room before or after being seen by the psychiatrist, and was informed that the researcher was a student from the University of the North who wanted to provide the patient with information on their illness.

Although the control group did not receive intervention, for them an assessment was done by interview administered. Psycho-educational intervention was conducted with schizophrenic patients of the experimental group (one session, 60 minutes) and the relatives that accompany their patients if there were any (one session, 60 minutes).

During the course of 60 minutes, intervention covered eight broad areas:

understanding schizophrenia, problem-solving skills, social relationship skills, emotional skills, medication management, and patient education on schizophrenia, communication skills and effective living skills. Intervention was conducted irrespective of race and no patient lost interest because of language difficulties, and no termination of intervention was expected for this reason. Details of the psycho-educational programme are illustrated in the appendix.

Before the follow-up, the researcher was trained to use Brief Psychiatric Rating Scale by a psychiatrist from the Child and Family Unit, Mankweng Hospital. Home visit was done through follow-up after 9 months and the same questionnaire (like the one that was used on the baseline study) along with Brief Psychiatric Rating Scale was used.

If the patient was not found the first time, the researcher made another visit for the second time and third time, if all the visits were made without finding the patient, the researcher stopped the visits. Some patients were not found because of false physical addresses; others were not found because their relatives took them to the neighbouring provinces. The whereabouts of some could not be traced by their parents/relatives; and one woman was married to someone in another area.

Data analysis

Correlational and descriptive statistics using the SPSS was used in this study. In this study, the researcher wanted to see whether there is a relationship between two variables, which are psycho education as independent variable, and compliance as the dependent variable. Within these variables, the researcher also wanted to see whether psycho-education led to compliance among the schizophrenic patients.

Chi-square was used by doing cross tabulating for both groups (experimental and control) in order to assess patients on their satisfaction of using medication, compliance on their medications the way they are described to them, regularity and the dates of taking their tablets/injection. T-test was also used to see how the patients differ through social functioning by rating their mental health in general by using /BPRS (Overall &Gorham, 1962).

Chapter four

4. Results

Out of the eighty-two participants only sixty-three were available at the follow-up. Those had been diagnosed to be schizophrenics from between two (2) to nine (9) years. Out of these sixty-three participants, six had terminated on their medication

The results are divided into: (1) drugs used at baseline study, (2) drugs used at follow-up for both experimental and control groups, (3) medication required at baseline and at follow-up, (4) medication compliance at baseline and at follow-up, (5) satisfaction with medication self-management at baseline and at follow-up, (6) brief psychiatric scale score and social functioning at follow-up, (7) the side effects that burden the patients at follow-up, (8) negative effects due to long intake of medication at follow-up, (9) attitudes of relatives towards medication at baseline and at follow-up, and (10) relationship of patients with their doctors at baseline and at follow-up.

4.1. Drugs used at the baseline study and drugs used at follow-up for both experimental and control groups

Various kinds of drugs such as Leponex, Disipal, Melleril, Modicate, and Serenace and others were used in the form of tablets and injection and their quantity also differed based on the patients' stage of schizophrenia. All the mentioned drugs were used on a daily basis by the patients, although injection was used monthly.

In terms of drugs used, on the follow-up, it was found that Modicate (43.8%) was used by high percentage of patients of both groups (experimental and control) for their illness, followed by Leponex (26.3%); a drug like Leponex was only used if the patients were not responding to other medications (see Table1).

Table1: Drugs used at the baseline study and drugs used at follow-up

Drug used	Baseline				Follow-up			
	Dose (mg)	Exp (n=41)	Con (n=41)	Total (n=82)	Dose (mg)	Exp (n=31)	Con (n=26)	Total (n=57)
Leponex	25	1(0.2%)		1 (0.1%)	25	4 (12.9%)	11(42.3%)	15 (26.3%)
	50		3 (0.7%)	3 (0.3%)	50	4 (12.9%)	2 (0.7%)	6 (10.5%)
	75		1 (0.2%)	1 (0.1%)	75	1 (0.3%)		1 (0.1%)
	100		1 (0.2%)	1 (0.1%)	100	6 (19.3%)		6 (10.5%)
	150	3(0.7%)		3 (0.2%)	150	1 (0.3%)		1 (0.1%)
	250	1 (0.2%)		1 (0.1%)				
	300	1 (0.2%)		1 (0.1%)				
Melleril	3	1(0.2%)	1 (0.2%)	2 (0.2%)	25	1 (0.3%)		1 (0.1%)
	5	1(0.2%)	1(0.2%)	2 (0.2%)	50	1 (0.3%)	1 (0.3%)	2 (0.3%)
	10		1(0.2%)	1 (0.1%)	75	1 (0.3%)		1 (0.1%)
	15	2 (0.4%)	2(0.4%)	4 (0.4%)	100	1 (0.3%)		1 (0.1%)
Disipal	25	1 (0.2%)	1 (0.2%)	2 (0.2%)	25	2 (0.4%)	2 (0.7%)	4 (0.7%)
	75	1 (0.2%)	2 (0.4%)	3 (0.3%)	75	2 (0.6%)	3 (11.5%)	5 (0.8%)
Modicate	13		1(0.2%)	1 (0.12%)	25	7 (22.5%)	18 (69.2%)	25 (43.8%)
	25	7 (17%)	4 (0.9%)	11 (13.4%)	37.5	1 (0.3%)	10 (38.4%)	11 (19.2%)
	37.5	3(0.7%)	1(0.2%)	4 (0.4%)	50	14 (45.1%)	4 (15.3%)	18 (31.5%)
	50	1 (0.2%)		1 (0.1%)	75	1 (0.3%)		1 (0.1%)
Serenance	75		1(0.2%)	1 (0.1%)	3	1 (0.3%)		1 (0.1%)
	200	1 (0.2%)		1 (0.1%)	5	1 (0.3%)		1 (0.1%)
					10	1 (0.3%)		1 (0.1%)
					13	1 (0.3%)		1 (0.1%)
					50	1 (0.3%)	1 (0.3%)	2 (0.3%)

4.2 Perception of medication required at baseline and at follow-up

On the baseline study, 82 (41 of the experimental and 41 of the control groups) patients reported that they required medication for their illness, and on the follow-up 57 (31 of the experimental and 26 of the control groups) patients reported that they were using medications as prescribed for their mental illness, however, 6 were terminated to take their medications. Chi-square is used at the baseline and at follow-up to see the significant difference between two groups (see Table 2).

Table 2: Perception about medication taking at baseline and at follow-up

Baseline					Follow-up			
Medication required	Experimental group	Control group	χ^2	p	Experimental group	Control group	χ^2	p
No			.000	ns		5 (15.6%)	0.43	ns
Yes	41 (100%)	41 (100%)			31 (100%)	26 (81.3%)		
Don't know						1 (3.1%)		
Total	41 (100%)	41 (100%)			31(100%)	32 (100%)		

4.3 Medication compliance at baseline study and at follow-up

On the baseline study for the experimental group, 41 patients showed medication compliance; for the control group; 41 patients also showed medication compliance, while at the follow-up 31 patients of the experimental group and 26 patients showed medication compliance as well. Overall the percentage for the control group decreased because six patients terminated on their medication, and the experimental group remained the same on medication compliance at the end of the programme. Chi-square analysis is used and there is no significant difference between two groups (see Table 3).

Table 3: Compliance at baseline and at follow-up

Baseline					Follow-up			
Medication compliance	Experimental group	Control group	χ^2	p	Experimental group	Control group	χ^2	p
	41 (100%)	41 (100%)	.000	ns	31 (100%)	26 (81.3%)	.44	ns

4.4 Subjective rating of level of information and satisfaction for medication self-management at baseline and at follow-up

On the baseline study, the control groups consist of 41 patients who were satisfied with their medication self-management. However, in the experimental group, 41 patients were also satisfied with their medication.

On the follow-up, patients reported less percentage of medication satisfaction in the experimental group. However, there is no statistically significant difference between the groups, (see Table 4).

Table4: Patients with confidence in medication self-management at baseline and at follow-up

Baseline					Follow-up			
Yes	Experimental group	Control group	χ^2	p	Experimental group	Control group	χ^2	p
	41 (100%)	41 (100%)	.000	ns	29 (93.5%)	26(81.2%)	.44	ns

With an almost identical baseline situation, at the end of the training period all patients of two groups did not feel capable of dosing their medication themselves within certain limits and following their actual need on their own.

4.5 Brief Psychiatric Rating Scale score (Overall & Gorham, 1962)

At baseline, the BPRS was not used for both groups, however at follow-up, the scale was used to see the psychopathological between groups at follow-up. Frequencies were used to see the mean and standard deviation of the groups as well as T-test to see if the significant differences because mean and standard deviation of both group were likely to the same (see Table 5).

Table 5: Brief Psychiatric Rating Scale score at follow-up

Follow-up			
Experimental group (n=31)	Control group (n=26)		
Mean (SD)	Mean (SD)	Value t	p
2.5 (.74)	2.7 (.63)	1.2	ns

4.6 Side effects that burdened patients at follow-up

The total percentages of the major extra pyramidal side effects that are caused by medications on the experimental group and control group was muscle stiffness (77.4%), followed by restless feet (74.2%), followed by dizziness (72.6%), followed by visual disturbances (66.1%), followed by shaking (64.5%), followed by reduced salivation (56.5%) followed by involuntary muscles movement (46.8%), followed by stomach trouble (41.9%) and so on. The above were the most side effects that deteriorate patients' life as they complained about them. T-tests cannot be computed because the standard deviations of both groups are 0 (see Table 6).

Table 6: The most side effects that burden patients at follow-up

Side effect	Experimental group	Mean (SD)	Control group	Mean (SD)	Total
Increased tiredness	6 (9.7%)	.90 (1.1)	10 (16.1%)	1.1 (1.1)	16 (25.8%)
Sleeping disorder	8 (12.9%)	1.9 (1.1)	15 (24.2%)	2.1 (1.0)	23 (37.1%)
Stomach trouble	11 (17.7%)	9.7E-02 (.54)	15 (24.2%)	.24 (.7)	26 (41.9%)
Nausea/vomiting	12 (19.4%)	.2 (.7)	9 (14.5%)	.4 (.9)	21 (33.9%)
Constipation	7 (11.3%)	3.2E-02 (.9)	9 (14.5%)	.1 (.4)	16 (25.8%)
Diarrhoea	9 (14.5%)	.0 (.0)	13 (21%)	3.9E-02 (.2)	22 (35.5%)
Dryness of mouth	5 (8.1%)	.5 (1.0)	10 (16.1%)	.5 (1.0)	15 (24.2%)
Increased salivation	15 (24.2%)	.4 (.9)	20 (32.3%)	.7 (1.0)	35 (56.5%)
Dizziness	27 (43.5%)	1.5 (1.0)	18 (29%)	1.7 (.9)	45 (72.6%)
Visual disturbances	20 (32.2%)	.6 (1.0)	21 (33.9%)	.6 (1.0)	41 (66.1/5)
Restless feet	25 (40.3%)	1.8 (1.0)	21 (33.5%)	1.6 (1.0)	46 (74.2)
Involuntary muscles movement	13 (21%)	1.4 (1.0)	16 (25.8%)	1.6 (1.0)	29 (46.8%)
Muscle stiffness	28 (45.2%)	1.6 (1.1)	20 (32.3%)	1.7 (.8)	48 (77.4%)
Shaking	23 (37.1%)	1.4 (1.0)	17(27.4%)		40 (64.5%)
Retardation of movement	2 (3.2%)	.6 (1.0)	8 (12.9%)	.5 (.9)	10 (16.1%)

4.7 Negative side effects due to long intake of medication at follow-up

On the follow-up study, 30 participants (96.8%) of the experimental group reported that they were not afraid of any negative side-effects and only one (3.2%) of the experimental group said s/he had negative side-effects about their illness, whereas 26 participants (8.13%) of the control group said that they were not afraid while six had terminated on their medication.

4.8 Attitudes of relatives towards their patients' illness and medication at follow-up

On the follow-up study, 28 (90.3%) relatives of the patients on the experimental group reported positive attitudes about their patients' illness and medication they were taking and 29 (90.6%) relatives of the control group also showed positive attitudes about the illness and medication of their patients. Two (6.3%) relatives of the control group and 1 (3.2%) relative of the patients in the experimental group had no idea of what the illness meant and the importance of medication.

The relatives were informed about the illness first time they took the patients to the hospital for admission, and the patients reported that they got 100% courage of taking medication from their relatives/spouses.

4.9 Relationship between patients and doctors at baseline and at follow-up

With doctor-patient relationship, on the baseline, 12 patients of the experimental group reported not good relationship with their doctors whereas 28 patients of the same group reported a good relationship. In the control group, 5 patients reported bad relationship whereas, 35 patients of the same group reported a good relationship with their doctors. On the follow-up, the patients from the experimental group had 31 good relations, and of the control group 26 also reported good relationship. Although the patients reported good relationship with the doctors, this meant that they felt warmth from them (doctors) and that is why they showed compliance towards their medication. This means that patients were

considerably using their medications the way they were told, (see Table 7).

Table 7: Doctor-patient relationship at baseline and at follow-up

Doctor-Patient relationship	Baseline			Follow-up		
	Count	Experimental group	Control group	Count	Experimental group	Control group
	No	12 (30%)	5 (12.5%)	No		
Yes	28 (70%)	35 (87.5%)	Yes	31(100%)	26 (81.2%)	
Total		40 (100%)	40 (100%)		31 (100%)	26 (81.2%)

Chapter Five

5. Discussion

Antipsychotic medications that were used by the patients differed and their mechanism differed according to them. Patients reported that Clozapine was useful for them, as it controlled salivation on them and Modicate reduced side effects, seemingly, they saw other medications as also being useful to them.

Neuroleptic medications are effective for both the treatment of acute schizophrenic psychosis and the prevention of relapse in schizophrenic patients who have recovered from psychosis. However, these drugs have a number of important limitations; they have a number of serious adverse effects; and they are limited in what they can do (Marder, et al., 1991).

Drugs are divided into two groups: atypical and typical antipsychotic drugs and their mechanism are not the same. The use of neuroleptic drugs in the lowest possible affection doses is recommended for minimizing the risk of side effects, and there are no definitive treatments.

The use of neuroleptics in the medically ill schizophrenic patient needs to be approached judiciously, since neuroleptics can interact with other medications and exacerbate the patient's medical symptoms (Adler & Griffith, 1991).

Carpenter and Buchanan (1994) argued that many antipsychotic drugs are now in use, differing from one another in their side effects and dosage requirements but similar in their mode of action and efficacy. These drugs are used in three ways: to manage acute psychosis by gradually reducing hallucinations and delusions, even more gradually reducing thought disturbances, and improving a broad range of symptoms including withdrawal and apathy; as maintenance therapy to control symptoms; and as long-term prophylactic treatment to prevent relapses. These benefits are dramatic in the short term, and the effectiveness of the drugs is maintained over a period of years. The feasibility of outpatient care depends on effective drug therapy.

Awad and Voruganti (1999) revealed that generally, there is agreement that the new generation of antipsychotics, compared with conventional antipsychotics, possesses a much better side effects profile and is better tolerated by patients. Obviously, they (patients) are not completely

free of side effects and they may have brought a spectrum of other side effects that were not frequently associated with the conventional antipsychotics. Yet, overall, they are much better tolerated. Although claims have often been made about their superior efficacy, except Clozapine, the evidence of superior efficacy over conventional antipsychotics continues to be inconclusive. Similarly, their efficacy in improving neurocognitive deficits continues to require more conclusive evidence.

Reductions in dose of neuroleptic, and change of agent have shown some benefit in ameliorating akathisia. Anticipation, early detection, and prompt attention are all necessary to minimize the negative effects of akathisia (Drake & Sederer, 1986).

Neuroleptics are not equivalent in their side effects. Generally, when compared to atypical antipsychotic drugs, the typical compounds like Melleril, Serenace, Fluphenazine and others have less sedation, fewer anticholinergic effects, and fewer cardiovascular effects, but at a cost of producing more acute extra pyramidal side effects. The choice of which neuroleptic to use is generally made by considering which particular constellation of side effects would be least harmful or most beneficial to a given patient.

Psycho-educational intervention will act as a useful tool towards schizophrenic patients and their family members, only if psychiatrists continue to provide it and encourage patients take medications as prescribed and follow-up treatment, and the patients who were found at follow-up showed compliance on their medication. Although there were no significant differences between these groups, it is because of the small sample that represented the population, for instance, the patients that were terminated on their medications, others were visited to the nearby provinces, others (especially women) were married to other areas and the stigma that the patients got within their societies end up causing them to leave their family members without telling them (family members) where they (patients) are going.

In general, the psychiatric services need to promote compliance among the patients and their relatives by continuing interventions in order to improve their quality of life; the families could get courage of coping with their patients. Davies (1994) proposed that interventions share several elements: a positive approach to the family, in which the needs of the relatives are acknowledged and respected; education about the disorder, emphasizing that the family is not its cause; support for firm

structure and boundaries within the family; practical help with coping strategies and clear communication; a behavioural approach to setting boundaries and attaining goals, and cognitive restructuring to enable the relatives to make sense of the patient's behaviour in terms of the illness. These interventions are usually performed in the patient's home by two therapists working together, for a period of six to twelve months.

Although families followed the western tradition, not all but at least some family members believed much in the traditional approach. They (family members) reported schizophrenia as a disease that is caused by witchcraft because of various reasons, they also correspond medications with traditional herbs as they believe that if the two types of treatment were used simultaneously, may be the patients would be recover. Since the 1970s at least there have been many calls in South Africa for the recognition of the mental health role of indigenous healers. There has been a great deal written about indigenous healing in South Africa over the past decades. One notable change in the literature of this area has been the increasing concern with witchcraft-related murders and abuse, which have been apparently been on the increase in South Africa (Swartz, 1996).

McFarlane, et al (1995) argued that at 12 and 24 months after initiation of treatment, the treating psychiatrist assessed medication compliance during the previous 6 months based on all available source of information. Compliance was reported on a six-point scale, and it was measured globally as a percentage of the total prescribed drug dosage actually taken. Thus, a 50% rating could reflect any pattern of compliance that led to consumption of 50% of the total prescribed dosage.

Historically, group therapy with schizophrenic patients focussed on coping with symptoms, education and/or interpersonal therapies, leaving medication issues relegated to individual psychiatrist visit. The separation of medical and non-medical issues might be effective if the healer/doctor work with schizophrenic patients for many years, although the trend today is toward integrating the two, (Miller & Mason, 1998).

Supportive groups that respect the biological aspects of the disease as well as the intrapsychic effects of the illness work towards the goal of fostering compliance with treatment which includes medication and decrease isolation, (Miller, et al., 1998).

Although the families of schizophrenic patients expected strong support from others such as pastors, mental health staff, and lay persons. These families also expected treatment that is respectful

and sometimes they need encouragement by making them to consider their own needs and to enhance the quality of their own lives. In supportive relationship, the supporters might be always with them, and to be helpful in whatever way they can. The supporters would reflect empathy for the painful dilemma the families face, and offer reassurance and hope and the acknowledgment of the belief in each person's strength and competence in surmounting the present crisis (Hatfield, 1988).

In addition to examining the support needs of caregivers in different living situations, researchers should explore differences according to kinship relationships. Finally, the relationships among professional support, personal control, burden, and the well-being may change significantly during the course of the illness. Future studies are needed to explore families' changing needs and readiness for specific support as they strive to cope with the challenges of caring for their mentally ill members.

McGorry (1995) viewed that providing patients with access to information about their illness has become relatively commonplace in general medical practice. The underlying assumptions are that such information would improve the patients' sense of mastery and control, and would thus improve outcome.

Patients guaranteed their satisfaction on medications they were taking, knowing their medication and were able to remember the dates of following up the treatment. This showed the great responsibility for taking their treatment and if the psychiatrist prescribed different medication, they were not satisfied, as they usually wanted to take the same medications.

The ultimate question in the management of schizophrenia with the new antipsychotic medications is whether patients are more satisfied with their treatment. Recently, a conceptual model for satisfaction with medication was proposed. The model is clinically intuitive, based not only on clinical experience, but also draws on available research findings. As major determinants of satisfaction on medication, three factors are identified: clinical symptoms and their severity, subjective tolerability of medication including side effects and subjective quality of life. Other important factors that can have second order impact on subjective satisfaction include stigma, self-concept and insight. These factors are integrated in a circular model that emphasizes their interconnectedness as well as their potential to influence each other. Any change in its components

whether improvement or deterioration, can influence the level of satisfaction (Awad & Voruganti, 1999).

There were great differences for the patients before and after taking medications. Their behavioural and social functioning with family members, friends and others was completely changed as they showed great relationship with other people (such as doctors) whether they knew them or not. Others showed commitment within the society, such as being involved in the community matters, taking part in the community gatherings (funerals), and attending social functions (parties, soccer fun and so on). After using the treatment, mental patients showed much concern with the community involvement.

Family members showed long-term caregivers an understanding of the illness of their patients as they realized that mental illness is long-life illness, its cause is unclear and has no cure.

Hatfield (1988) proposed that families of the mentally ill must necessarily prepare themselves for the long-term caregivers, a virtual career in mental illness. For the sake of efficiency, they must acquire background knowledge and general problem-solving skills so that they can cope with their problems independently and for an indefinite future. Although there are now many programmes across the United States that use educational approaches to families, no data are yet available on their long-term effectiveness

In conclusion, psycho education in South Africa can hold the promise of improving health of schizophrenic patients as well as their relatives only if the intervention continue to be provided by the psychiatrists. For the patient, the psycho educational phase of treatment can provide a concrete approach to the development of social and coping skills. The involvement of family and significant others allows an opportunity for them to discuss and deal with the issues and problems that they may experience from their patients. Psycho education is also valuable in that mental health professionals can monitor signs, symptoms, and progress of mental illness in patients.

Subjective tolerability, improved side effects profile and achievement of greater satisfaction with treatment, are all important benefits; however, the key issue is whether all these improved aspects can translate into better compliance with medications, improved quality of life, and better functional status.

Future studies are also needed to take into account the multi-dimensional nature of caregiver burden. In order to understand the concept of burden and the variables associated with higher levels of burden, it is necessary to separately examine the components as well as the overall dimensions of caregiver burden. Further research is needed to continue to refine this concept. Additionally, future studies with caregivers of schizophrenic patients should examine long-term outcomes of care giving, such as its effects on the caregivers' physical and mental status.

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Appendix 1

The psycho educational program that should be given to schizophrenic patients and their family members (Gallegher & Nazarian 1995; Miller, Shurling, Carter, Johnson & Eggerth 1994)

1. Understanding schizophrenia

- (a) An overview of the illness and one's ability to cope with it.
- (b) The need for realistic optimism and appreciation of one's capacity to progress.
- (c) How to think about and cope with symptoms (hallucinations, delusions etc).
- (d) Role of medications: benefits/ risks, crucial, but not a cure.
- (e) Dealing with the stigma and loss of self-esteem from having the illness.
- (f) Coping with demoralization.

2. Problem-solving skills

- (a) Use of the " wise mind" concept.
- (b) Acknowledging one's thoughts/feelings (observing and describing skills).
- (c) Participation needs and knowing each other.
- (d) Non-judgmental-ness.
- (e) Mindfulness.
- (f) Commitment of "effectiveness" in one's life.

3. Social relationship skills

- (a) Need for relationship: "No man is an island", danger of isolation.
- (b) Setting objectives for dealing with others, appropriate goal setting.
- (c) Modelling and role-playing social interaction.
- (d) Getting ones needs met: assertiveness training.
- (e) How to have conversation and develop friendships.

- (f) Different types of relationships with different people: the need to make distinctions.
- (g) Keep one's self-esteem in relationships, avoiding unhealthy extremes.

4. *Emotional skills*

- (a) Need to respect one's emotions as important and meaningful.
- (b) Danger of self-condemnation for feelings (feelings as opposed to behaviour).
- (c) Need for self-nurturance and seeking emotional support from others.
- (d) How to deal with panic and anxiety in general: stress management.
- (e) The pros and cons of anger.
- (f) Other problematic emotions (e.g., shame, guilty, depression, demoralization).
- (g) Self- image problems.

5. *Medication management*

- (a) Reduce vulnerability to stimulation.
- (b) Information of drug mechanisms action, main effects, and side effects of anti-psychotic medication should be given.
- (c) Weight the pros and cons of medication.
- (d) Discuss questions and concern regarding medications with their physicians.

6. *Patient education on schizophrenia*

- (a) How to reduce tension and to change attitudes about the illness.
- (b) Information regarding the onset, course, diagnosis, symptomatology, treatment and prognosis of schizophrenia.
- (c) Patients are typically encouraged to actively participate by asking question, expressing their feelings and sharing their own experiences.
- (d) Address specific myths and misconceptions about patient illness.

7. *Communication skills*

- (a) Decrease the likelihood of symptom exacerbation by teaching patients more effective specific skills taught in communication training involve the expression of feelings making in a positive, direct request, expressing unpleasant feelings, constructive manner, attentive listening, and problem-solving.
- (b) Shaping better family communication through the use of instruction, modelling, coaching, and social reinforcement and performance feedback.

8. *Effective living skills*

- (a) Caring for oneself and managing one's own lifestyle.
- (b) Maintaining a balanced family lifestyle, planning enjoyable family activities, identifying and using social support networks and anticipating some stress frustration.
- (c) Addressing the danger of increasing family conflict and criticism, use clear and simple communication.

Appendix 2

QUESTIONNAIRE MEDICATION

Biographic

(a) Age: -----

(b) Initial onset of illness: -----

(c) No. Of hospitalization: -----

(d) Medical compliance: -----

Group: -----Patient No: ----- Date: -----

Currently: in hospital: in day-clinic: as outpatient:

In the case of questions with a number of supplied answers please ask the patient which of the answers are applicable.

1

1.1 Which neuroleptics (incl. depot) were prescribed to you for your illness in the past year during your treatment as outpatient or day-care/night-care patient?

(if trade name is not known, please write code 26)

Medical preparation	A	B	C	D	E
(a) Trade name					
(b) <u>Maximum</u> dosage (Codify: CPZ equivalents) Unknown (U)					
(c) Longest uninterrupted period of medicinal intake (as out patient, in day-care/ night-care)					
less than 1 month (1)					
1-6 months (2)					
6-12 months (3)					
more than 1 year (4)					
unknown					

--	--	--	--	--	--

1.2 Which medication (see 1.1) is currently prescribed to you in which dosage and frequency? (mg/day; ml/week)? (If patient is in hospital: write down last prescription as out patient)
(Codify: CPZ-equivalent as well as frequently of intake according to code)

Medication Daily Frequency of Code
dosage intake

A			1/day = (1) 1*2/weekly = (5)
B			2/day = (2) 1*3/weekly = (6)
C			3/day = (3) 1* 4/weekly =(7)
D			1/week = (4) other (8 =uncoded text)
E			

1.3 Apart from the neuroleptics are you taking additional psychopharmacological drugs? Which?

	No	Yes
Anti-Depressants	[]	[]
Anti-Parkinson drugs	[]	[]
Other	[]	[]

2

2.1 Has the neuroleptic prescription changed during the past year as outpatient?

No (0)

Yes as follow:

	Neuroleptic				
	A	B	C	D	E
Dosage increased					
Dosage reduced					
Discontinuation of medication					
Medication newly prescribed					

What was the main reason for the most recent change in prescription as indicated above? [the above table (2.1) fill in your answer according to the following code]

Improved condition.....= (1)

Deteriorated condition.....= (2)

Side effects.....= (3)

Medical advice.....= (4)

Own suggestion.....= (5)

Other.....= (6)

Unknown.....= (7)

3.

3.1 In your opinion do you require medication for your illness?

No (0)

Yes (1)

I don't know (2)

If "yes":

Which medication do you need?

Exactly those that I get (1)

Others (2)

I don't know (3)

How many medical preparations do you need?

As many as I am currently getting (1)

More than I am currently getting (2)

Less than I am currently getting (3)

Varying (sometimes more, sometimes less) (4)

I don't know (5)

4

4.1 Which positive experiences with your current medical preparation(s) are especially important to you?

(Examine the following statements. More than one statement is possible)

As a result of the medical preparation(s) I am taking currently	No	Yes
The symptoms of the illness are decreasing (1)		
Relapses are prevented (2)		
I can think clearer (3)		
My mood is improving (4)		
I am becoming more balanced (5)		
I am getting less anxious (6)		
I am able to relate better with other people (7)		
I can sleep better (8)		
I feel healthier (9)		

4.2 Which of the following possible side effects have you had during the past year or are you having now as a result of your current medication? (Definition: now means last week)

Possible side effects	None	Last year	Last year and now	Now new
Increased tiredness (1)				
Sleeping disorders (2)				
Increased in appetite (3)				
Sexual disturbances (4)				
Stomach trouble (5)				
Nausea / vomiting (6)				
Constipation (7)				
Diarrhoea (8)				
Dryness of mouth (9)				
Increased salivation (10)				
Dizziness (11)				
Palpitations (12)				
Micturition disturbances (13)				
Increased perspiration (14)				
Visual disturbances (15)				
Restless feet (16)				
Involuntary muscle movement (17)				
Muscle stiffness (18)				
Shaking (19)				
Ataxy (20)				
Damaged blood cells (21)				
Retardation of movement (22)				
Weight gain (23)				
Other (24 = uncoded text)				

4.3 Which of the side effects do you find particularly burdening? (name more than 4 side effects in reducing order)

1. 2. 3. 4.

4.4 Are you afraid of negative effects due to prolonged intake of medication?

No (0)

Yes (1), namely the following:

I don't know (2)

4.5 All in all, how do you assess the individual medical preparations (as listed above)?

Medical Preparation	A	B	C	D	E
Has helped me very much (2)					
Has helped me to a certain extent (2)					
Has helped me a little (3)					
Has not helped me (4)					
Has rather harmed me (5)					
I cannot judge (6)					

5

5.1 Do you unsolicitedly inform your doctor about the side effects you are experiencing?

No (0)

Yes, about all occurring side effects (1)

Yes, but only the most stressful side effects (2)

Yes, but only if I cannot solve the problem in any other way (3)

5.2 In your opinion to what extent does your doctor take your experience with the medication and your expectations of the medication into consideration (e.g. in the choice and dosage of the medication)?

Not at all (0)

Insufficiently (1)

Sufficiently (2)

As much as possible (3)

I cannot judge (4)

6

6.1 Are you satisfied with your knowledge about your medication?

No (0) Yes (1) I don't know (2)

7. How regularly do you really take your present medicine, or how regularly do you really get the depot injections?

(Codify: 100 = no deviation from prescription

90 = 10% deviation

80 = 20% deviation

A: _____

D: _____

B: _____

E: _____

C: _____

7.1 Do you find it difficult to take medication regularly, as prescribed?

No (0) Yes (1), because: _____

7.2 Do you find it difficult to adhere regularly to the dates of the depot injections?

No (0) Yes (1), because: _____

8.

8.1 Did you during the past year at one time increase or reduce the dosage or go off the medication A to E independently (i.e. on your own accord)? If so, what was the longest period of time?

(Write the code in the table. The whole period of time is codified, while the respective change was kept constant).

(Definition: reduction = to reduce the daily dosage or to interrupt taking medication on a regular basis for a short time, or to shift depot on a regular basis).

To go off medication = not taking tablets, or omitting depot once.

	A	B	C	D	E
Increased (1)					
Reduced (2)					
Discontinued (3)					

Never = (0)	Up to 2 weeks = (4)
1 day = (1)	Up to 1 month = (5)
2-3 days = (2)	Longer = (6)
4-7 days = (3)	Unknown = (7)

8.2 How do you subsequently change the dosage of your medication?

Fill in according to code.

	A	B	C	D	E
After increase					
After reduction					
After discontinuation					

Code

Independent unchanged continuation of dosage	= (0)
Independent (continued or renewed) increase	= (1)
Independent (continued or renewed) reduction	= (2)
Independent discontinuation	= (3)
<hr/>	
After consulting doctor unchanged continuation	= (4)
After consulting doctor (continued or renewed) increase	= (5)
After consulting doctor (continued or renewed) reduction	= (6)
After consulting doctor discontinuation	= (7)

8.2.1 Why did you increase the dosage independently?

(More than one answer possible)

(This refers to the most recent increase)

	No	Yes
- because I noticed (early) symptoms of the illness	<input type="checkbox"/>	<input type="checkbox"/>
- because I found myself in a stressful situation	<input type="checkbox"/>	<input type="checkbox"/>
- because at the outset I wanted to make sure that a relapse would not occur	<input type="checkbox"/>	<input type="checkbox"/>
- because others (e.g. relatives) advised me to do so	<input type="checkbox"/>	<input type="checkbox"/>
- unknown	<input type="checkbox"/>	<input type="checkbox"/>
-other reasons: _____		

8.2.2 What did you experience after increasing the dosage independently?

	No	Yes
-My condition did not change	<input type="checkbox"/>	<input type="checkbox"/>
-(Early) symptoms of illness diminished	<input type="checkbox"/>	<input type="checkbox"/>
-I felt safer that a relapse would not occur	<input type="checkbox"/>	<input type="checkbox"/>
-My condition continued to deteriorate	<input type="checkbox"/>	<input type="checkbox"/>
-Side effects appeared or were aggravated	<input type="checkbox"/>	<input type="checkbox"/>
-Unknown	<input type="checkbox"/>	<input type="checkbox"/>
-Other experiences: _____		

8.3

8.3.1 Why did you reduce the dosage on your own accord or discontinue the depot injections?

(More than one answer is possible)

(This refers to the most recent change)

	No	Yes
- because I did not feel ill (any longer)	<input type="checkbox"/>	<input type="checkbox"/>
- because I did not feel any improvement	<input type="checkbox"/>	<input type="checkbox"/>
- because the side effects impaired my every-day life	<input type="checkbox"/>	<input type="checkbox"/>
- because I was afraid of becoming dependent of the medication	<input type="checkbox"/>	<input type="checkbox"/>
- because others were not to know that I am under medication	<input type="checkbox"/>	<input type="checkbox"/>
- because it became burdensome to adhere to the prescribed taking of the medication or to adhere to the dates of the injections	<input type="checkbox"/>	<input type="checkbox"/>
- because I was no longer in the position to adhere to the prescription of the medication as a result of a relapse of my illness	<input type="checkbox"/>	<input type="checkbox"/>
- unknown	<input type="checkbox"/>	<input type="checkbox"/>
- other reasons: _____		

8.3.2 What did you experience after you had the dosage on your own accord, or when you discontinued the medication or depot-injections?

(More than one answer is possible)

Subsequently the following occurred (immediately or with delay)...

	No	Yes
- side effects decreased or disappeared	<input type="checkbox"/>	<input type="checkbox"/>
- (early) symptoms of the illness appeared	<input type="checkbox"/>	<input type="checkbox"/>
- hospitalisation due to a relapse	<input type="checkbox"/>	<input type="checkbox"/>
- my condition did not change	<input type="checkbox"/>	<input type="checkbox"/>
- unknown	<input type="checkbox"/>	<input type="checkbox"/>
- other experience:	<input type="checkbox"/>	<input type="checkbox"/>

How do you overall experience with determining the dosage of your medication on your own accord?

Dosage	Predominantly positive (1)	Predominantly negative (2)	I cannot judge (3)
Increased			
Reduced			
Interrupted			

9

9.1 Would you have the confidence in future to determine the dosage of your medication according to your needs (within certain limits)?

No (0)

Yes (1)

I am not sure (2)

10

10.1 In your opinion what is the attitude of your relatives (people close to you) towards your medication?

(This refers to the person closest to you)

My relatives (people close to me)...

	No	Yes
- disapprove of me taking the medication	<input type="checkbox"/>	<input type="checkbox"/>
- are indifferent towards my medication	<input type="checkbox"/>	<input type="checkbox"/>
- see to it that I take the medication or get the depot-injection regularly	<input type="checkbox"/>	<input type="checkbox"/>
- allot the medication to me regularly	<input type="checkbox"/>	<input type="checkbox"/>
- have a positive attitude to my medication	<input type="checkbox"/>	<input type="checkbox"/>
- I don't know	<input type="checkbox"/>	<input type="checkbox"/>
- no comment, because there is no person close to me	<input type="checkbox"/>	<input type="checkbox"/>
- other: _____		

10.2 Do you think that your relatives (people close to you) are informed adequately about your medication?

No	(0)
Yes	(1)
I cannot judge	(2)
No comment, because there is no person close to me	(3)

11.1 Co-determination of Medication

During the past year did you yourself determine the quantity of your medication and/ or the dosage of your injection within the limits that had been discussed with your doctor?

Over which entire period of time did you do this?

Add up the number of days or the time intervals between the injections on which variations occurred during the course of the year.

	A	B	C	D	E
Increase					
Reduction					

Code

- Never = (0)
- Up to 1 week = (1)
- Up to 2 weeks = (2)
- Up to 1 month = (3)
- Up to 6 months = (4)
- Up to 1 year = (5)

11.2 Consequently on how many days/ over how many weeks at the longest without interruption?

11.3 In the case of

11.2.2 In the case of **depot** administering

Oral administering:

- | | | | |
|---------------|--------------------------|----------------|--------------------------|
| Up to 7 days | <input type="checkbox"/> | up to 4 weeks | <input type="checkbox"/> |
| Up to 14 days | <input type="checkbox"/> | up to 3 months | <input type="checkbox"/> |
| Up to 30 days | <input type="checkbox"/> | up to 6 months | <input type="checkbox"/> |
| Over 30 days | <input type="checkbox"/> | longer | <input type="checkbox"/> |

12. Qualitative Description

Which top limits and bottom limits had been agreed upon, which top limits and bottom limits did you actually adhere to, and which of the medical preparations possibly remained unchanged?
Also indicate when you exceeded the limits or fell below the limits.

Neuroleptis	constant	top limits and bottom limits					
		(mg per day or ml per week)					
		as agreed upon			as carried out		
		from	until		from	until	
A:.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
B:.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
C:.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
D:.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

13. Reasons

13.1 State the reasons for increasing your neuroleptics within these agreements. Codify the most common reason with 1, the least common reason with 4.

If “never”, codify 0

Consequently, did you have the desired result?

Mark with a cross.

	Order of sequence	Desired Result	
		without	with
In order to let (early) symptoms disappear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In order to cope with a stressful situation better (prophylaxis of early symptoms)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Without a definite reason, because I wanted to feel more secure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For a different reason (uncoded text)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13.2. Why did you reduce the original dosage within these fixed limits?

In doing so, did you predominantly get the results you desired?

Codify the most frequent reason with 1, the least frequent reason with 3.

If “never”, codify 0.

	Order of sequence	Desired Result	
		without	with
In order to let possible Side effects disappear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Because I was symptom free for a fairly long period of time and Could reduce the dosage without My condition deteriorating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For a different reason (uncoded text)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. During the past year did you consult your doctor about a possible change of the prescription of your medication?

	No	Yes
Prior to an increase	<input type="checkbox"/>	<input type="checkbox"/>
Prior to a reduction	<input type="checkbox"/>	<input type="checkbox"/>
Prior to discontinuation	<input type="checkbox"/>	<input type="checkbox"/>

15. Summarised assessment

Codify in the sequence of time the first occurrence with 1, the last occurrence with 15, and when “never”, codify 0.

During the past year the dosage of this male/ female patient was at least once with one of his/ her neuroleptics

	increased	reduced	discontinued
On patient’s own initiative (without prior consultation with the doctor) (1)			
On patient’s own initiative. <u>Subsequently</u> consent was obtained from the doctor (2)			
With consent from the doctor within certain limits (3)			
With consent without adhering to the limits (4)			
After consultation with the doctor who had issued a new prescription (5)			

16. Through your present medication do you currently feel impaired?

	No	Yes
In your mood	<input type="checkbox"/>	<input type="checkbox"/>
In your drive	<input type="checkbox"/>	<input type="checkbox"/>

17. Have you during the past year discussed your ideas and wishes pertaining to medication with your doctor more frequently than previously?

No (0)
Yes (1)

18. Do you regard your current relationship with your doctor better than a year ago?

No (0)

Yes (1)

Appendix 3

POSITIVE AND NEGATIVE SYNDROME SCALE AND BRIEF PSYCHIATRIC RATING SCALE

Olanzapine versus Lithium in Relapse Prevention in Bipolar Disorder

Positive and Negative Syndrome Scale (PANSS) and Brief Psychiatric Rating Scale (BARS)

The PANSS is a rating scale used to assess the positive symptoms, negative symptoms, and general psycho pathology specifically associated with schizophrenia. The scale consist of 30 items. Each item is rated on a scale from 1 (symptom not present) to 7 (symptoms extremely severe). The sum of the 30 items is defined as the PANSS total score and range from 30 to 210. The PANSS positive score (item 1 to 7) and PANSS negative score (items 8 to 14) contain seven items of the 30 PANSS items, and the scores range from 7 to 49. The PANSS general psycho pathology score (items 15 to 30) includes 16 of the 30 PANSS items, and the score range from 16 to 112.

The BARS, extracted from the PANSS, consists of 16 items (PANSS items 2 to 9 and 15 to 24). Each item is rated on a scale from 1 (symptom not present) to 7 (symptom extremely severe).

1. Delusions: Beliefs, which are unfounded, unrealistic, and idiosyncratic.

Basis of rating: thought content expressed in the interview and its influence on social relations and behaviour as reported by primary care worker or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionable pathology may be at the upper extreme of normal limits. |
| 3. Mild | Presence of one or two delusions, which are vague, uncrystallized, and not tenaciously held. Delusions do not interfere with thinking, social relations, or behaviour. |
| 4. Moderate | Presence of either a kaleidoscopic array of poorly formed, unstable delusions or of a few well-formed delusions that occasionally interfere with thinking, social relations, or behaviour. |

- 5. Moderately severe Presence of numerous well- formed delusions that are tenaciously held and occasionally interfere with thinking, social relations, or behaviour.
- 6. Severe Presence of a stable set of delusions which are crystallized, possibly systematized, tenaciously held, and clearly interfere with thinking, social relations, or behaviour.
- 7. Extreme Presence of a stable set of delusions which are either highly systematized or very numerous, and which dominate major facets of the patient's life. This frequently results in inappropriate and irresponsible action, which may even jeopardize the safety of the patient or others.

2. Conceptual disorganization: Disorganized process of thinking characterized by disruption of goal-directed sequencing, e.g., circumstantially, tangentially, loose associations, non sequiturs, gross illegality, or thought block.. Basis of rating: cognitive verbal processes observed during the course of interview

- 1. Absent Definition does not apply.
- 2. Minimal Questionable pathology may be at the upper extreme of normal limits.
- 3. Mild Thinking is circumstantial, tangential, or paralogical. There is some difficulty in directing thoughts toward a goal, and some loosening of associations may be evidenced under pressure.
- 4. Moderate Able to focus thoughts when communications are brief and structured, but becomes loose or irrelevant when dealing with more complex communications or when under minimal pressure.
- 5. Moderately severe Generally has difficulty in organizing thought, as evidence by frequent irrelevancies, disconnectedness, or loosening of associations even when not under pressure.
- 6. Severe Thinking seriously detailed and internally inconsistent, resulting in gross irrelevancies and disruption of thought processes, which occur almost constantly.
- 7. Extreme Thoughts are disrupted to the point where the patient is incoherent. There

is marked loosening of associations, which results in total failure of communication, e.g., “word salad” or mutism.

3. Hallucinatory behaviour: Verbal report or behaviour indicating perceptions, which are not generated by external stimuli. These may occur in the auditory, visual, olfactory, or somatic realms. Basis for rating: verbal report and physical manifestations during the course of interview as well as report of behaviour by primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionable pathology may be at the upper extreme of normal limits. |
| 3. Mild | One or two clearly formed but infrequent hallucinations, or else a number of vague abnormal perceptions, which do not result in distortions of thinking or behaviour. |
| 4. Moderate | Hallucinations occur frequently but not continuously, and the patient’s thinking and behaviour are affected only to a minor extent . |
| 5. Moderately severe | Hallucinations are frequent, may involve more than on a sensory modality, and tend to distort thinking and/or disrupt behaviour. Patient may have delusional interpretation of these experiences and respond to them emotionally and, on occasion, verbally as well. |
| 6. Severe | Hallucinations are present almost continuously, causing major disruption of thinking and behaviour. Patient treats these as real perceptions, and functioning is impeded by frequent emotional and verbal responses to them. |
| 7. Extreme | Patient is almost totally preoccupied with hallucinations, which virtually dominate thinking and behaviour. Hallucinations are provided a rigid delusional interpretation and provoke verbal and behavioural responses, including obedience to command hallucinations. |

4. Excitement: Hyperactivity as reflected in accelerated motor behaviour, heightened responsivity to stimuli, hyper vigilance, or excessive mood lability

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| 1. Absent | Definition does not apply. |
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| 2. Minimal | Questionable pathology may be at the upper extreme of normal limits. |
| 3. Mild | Tend to be slightly agitated, hyper vigilant, or mildly over aroused throughout the interview, but without distinct episodes of excitement or marked mood lability. Speech may be slightly pressured. |
| 4. Moderate | Agitation or over arousal is clearly evident throughout the interview, affecting speech and general mobility, or episodic outbursts occur sporadically. |
| 5. Moderately severe | Significant hyperactivity or frequent outbursts of motor activity are observed, making it difficult for the patient to sit still for longer than several minutes at any given time. |
| 6. Severe | Marked excitement dominates the interview, delimits attention, and to some extent affects personal functions such as eating and sleeping. |
| 7. Extreme | Marked excitement seriously interferes in eating and sleeping makes interpersonal interactions virtually impossible. Acceleration of speech and motor activity may result in incoherence and exhaustion. |

5. Grandiosity: Exaggerated self-opinion and unrealistic convictions of superiority, including delusions of extraordinary abilities, wealth, knowledge, fame, power, and moral righteousness. Basis for rating: thought content expressed in the interview and its influence on behaviour as reported by primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionable pathology may be at the upper extreme of normal limits. |
| 3. Mild | Some expansiveness of boastfulness is evident, but without clear-cut grandiose delusions. |
| 4. Moderate | Feels distinctly and unrealistically superior to others. Some poorly formed delusions about special status of abilities may be present but are not acted upon. |
| 5. Moderately severe | Clear-cut delusions concerning remarkable abilities , status, or power are expressed and influence attitude but not behaviour. |

- 6. Severe Clear-cut delusions of remarkable superiority involving more than one parameter(wealth, knowledge, fame, etc.) are expressed, notably influence interactions, and may be acted upon.
- 7. Extreme Thinking, interactions, and behaviour are dominated by multiple delusions of amazing ability, wealth, knowledge, fame, power, and/or moral stature, which may take on a bizarre quality.

6. Suspiciousness: Unrealistic or exaggerated ideas of persecution, as reflected in guardedness, a distrustful attitude, suspicious hyper vigilance, or frank delusions that others mean one harm. Basis for rating: thought content expressed in the interview and its influence on behaviour as reported by primary care workers or family.

- 1. Absent Definition does not apply.
- 2. Minimal Questionable pathology may be at the upper extreme of normal limits.
- 3. Mild Present a guarded or even openly distrustful attitude, but thoughts interactions, and behaviour are minimally affected.
- 4. Moderate Distrustfulness is clearly evident and intrudes on the interview and/or behaviour, but there is no evidence of persecutory delusions, but these do not seem to affect the patient's attitude or interpersonal relations.
- 5. Moderately severe Patient shows marked distrustfulness, leading to major disruption of interpersonal relations, or else there are clear-cut persecutory delusions that have limited impact on interpersonal relations and behaviour.
- 6. Severe Clear-cut pervasive delusions of persecution which may be systematized and significantly interfere in interpersonal relations.
- 7. Extreme A network of systematized persecutory delusions dominates the patients thinking, social relations, and behaviour.

7. Hostility: Verbal and nonverbal expressions of anger and resentment, including sarcasm, passive-aggressive behaviour, verbal abuse and assaultiveness. Basis for rating: interpersonal behaviour observed during the interview and reports by primary care workers or family.

1. Absent Definition does not apply.
2. Minimal Questionable pathology may be at the upper extreme of normal limits.
3. Mild Indirect or restrained communication of anger, such as sarcasm, disrespect, hostile expressions, and occasional irritability.
4. Moderate Presents an evenly hostile attitude, showing frequent irritability and direct expression of anger or resentment.
5. Moderately severe Patient is highly irritable and occasionally verbally abusive or threatening
6. Severe Uncooperativeness and verbal abuse or threats notably influence the interview and seriously impact upon social relations. Patient may be violent and destructive but is not physically assaultive toward others
7. Extreme Marked anger results in extreme uncooperativeness, precluding other interactions, or in episode (s) of physical assault toward others.

8. Blunted affect: Diminished emotional responsiveness as characterized by reduction in facial expression, modulation of feelings, and communicative. Basis for rating: observation of physical manifestations of affective tone and emotional responsiveness during the course of interview.

1. Absent Definition does not apply.
2. Minimal Questionable pathology may be at the upper extreme of normal limits.
3. Mild Changes in facial expression and communicative gestures seem to be stilted, forced, artificial, of lacking in modulation.
4. Moderate Reduced range of facial expression and few expressive gestures result in a dull appearance.
5. Moderately severe Affect is generally “flat”, with only occasional changes in facial expression and a paucity of communicative gestures.
6. Severe Marked flatness and deficiency of emotions exhibited most of the time.

There may be unmodulated extreme affective discharges, such as excitement, rage, or inappropriate uncontrolled laughter.

7. Extreme Changes in facial expression and evidence of communicative gestures are virtually absent. Patient seems constantly to show a barren or “wooden” expression.

9. Emotional withdrawal: Lack of interest in, involvement with, and affective commitment to life's event. Basis for rating: reports of functioning from primary care workers of family and observation of interpersonal behaviour during the course of interview.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Usually lacks initiative and occasionally may show deficient interest in surrounding events.
4. Moderate Patient is generally distanced emotionally from the milieu and its challenges but, with encouragement, can be engaged.
5. Moderately severe Patient is clearly detached emotionally from persons and events in the milieu, resisting all efforts at engagement. Patient appears distant, docile, and purposeless but can be involved in communication at least briefly and tends to personal needs, sometimes with assistance.
6. Severe Marked deficiency of interest and emotionally commitment results in limited conservation with others and frequent neglect of personal functions, for which the patient require supervision.
7. Extreme Patient is almost totally withdrawn, uncommunicative and neglect of personal needs as a result of profound lack of interest and emotional commitment.

10. Poor rapport: Lack of interpersonal empathy, openness in conversation, and sense of closeness, interest, or involvement with the interviewer. This is evidenced by interpersonal distancing and reduced verbal and nonverbal communication. Basis for rating: interpersonal behaviour during the course of interview.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Conversation is characterised by a stilted, strained, or artificial tone. It may lack emotional depth or trend to remain on an impersonal intellectual plane.
4. Moderate Patient is typically aloof, with interpersonal distance quite evident. Patient may answer questions mechanically, act bored, or express disinterest.
5. Moderately severe Disinvolvement is obvious and clear impedes the productivity of the interview. Patient may tend to avoid eye or face contact.
6. Severe Patient is highly indifferent, with marked interpersonal distance. Answers are perfunctory, and there is little nonverbal evidence of involvement. Eye and face contact are frequently avoided.
7. Extreme Patient is totally uninvolved with the interviewer. Patient is appears to be completely indifferent and consistently avoid verbal and nonverbal interactions during he interview.

11. Passive/apathetic social withdrawal: Diminished interest and initiative in social interactions due o passivity, apathy, anergy , or abolition. This lead o reduced interpersonal involvements and neglect activities of daily living. Basis for rating: reports on social behaviour from primary care workers or family

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.

3. Mild Shows occasional interest in social activities but poor initiative. Usually engages with others only when approached first by them.
4. Moderate Passively goes along with most social activities but in a disinterested or mechanical way. Tends to recede into background.
5. Moderately severe Passively participates in only a minority of activities and shows virtually no interest or initiative. Generally spend little time with others.
6. Severe Tends to be apathetic and isolated, participating very rarely in social activities and occasionally neglecting personal needs. Has very few spontaneous social activities.
7. Extreme Profoundly apathetic, socially isolated, and personally neglectful.

12. Difficulty in abstract thinking: Impairment in the use of abstract symbolic mode of thinking, as evidenced by difficulty in classification, forming generalizations, and processing beyond concrete or egocentric thinking in problem solving tasks. Basis for rating: responses to questions on similarities and proverb interpretation, and use of concrete versus abstract mode during the course of the interview.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Tends to give literal or personalized interpretations to the more difficult proverbs and may have some problems with concepts that are fairly abstract or remotely related.
4. Moderate Often utilizes a concrete mode. Has difficulty with most proverbs and some categories. Tends to be distracted by functional aspects and salient features.
5. Moderately severe Deals primarily in a concrete mode, exhibiting difficulty with most proverbs and many categories.
6. Severe Unable to grasp the abstract meaning of any proverbs or figurative expressions and can formulate classifications for only the most simple of

similarities. Thinking is either vacuous or locked into functional aspects, salient features, and idiosyncratic interpretations.

7. Extreme Can use only concrete modes of thinking. Shows no comprehension of proverbs, common metaphors or similes, and simple categories. Even salient and functional attributes do not serve as a basis for classification. This rating may apply to those who cannot interact even minimally with the examiner due to marked cognitive impairment.

13. Lack of spontaneity of flow of conversation: Reduction in the normal flow of communication associated with apathy, abolition, defensiveness, or cognitive deficit. This is manifested by diminished fluidity and productivity of the verbal- interactional process. Basis for rating: cognitive verbal processes observed during the course of interview.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Conversation shows little initiative. Patient's answers tend to be brief and unabolished, requiring direct and leading questions by the interviewer. |
| 4. Moderate | Conversation lacks free flow and appears uneven or halting. Leading questions are frequently needed to elicit adequate responses and proceed with conversation. |
| 5. Moderately severe | Patient shows a marked lack of spontaneity and openness, replying to the interviewer's questions with only one or two sentences. |
| 6. Severe | Patient's responses are limited mainly to a few words or short phrases intended to avoid or curtail communication (e.g. "I don't know", "I am not liberty to say"). Conversation is seriously impaired as a result, and the interviewer is highly unproductive. |
| 7. Extreme | Verbal output is restricted to at most an occasional utterance, making conversation impossible. |

14. Stereotyped thinking: Decreased fluidity spontaneity, and flexibility of thinking as evidence in rigid, repetitious, or barren thought content. Basis for rating: cognitive- verbal processes observed during the course of interview.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Some rigid shown in attitudes or beliefs. Patient may refuse to consider alternative positions of have difficulty in shifting from one idea to another. |
| 4. Moderate | Conversation revolves around a recurrent theme resulting in difficulty in shifting to a new topic. |
| 5. Moderately severe | Thinking is rigid and repetitious to the point that despite the interviewer's efforts conversation is limited to only two or three dominating topics. |
| 6. Severe | Uncontrolled repetition of demands, statements, ideas, or questions which severely impairs conversation. |
| 7. Extreme | Thinking, behaviour, and conversation are dominated by constant repetition of fixed ideas or limited phrases leading to gross rigidity inappropriateness and restrictiveness of patient's communication. |

15. Somatic concern: Physical complaints of beliefs about bodily illness or malfunctions. This may range from a vague sense of ill being to clear-cut delusions of catastrophic physical disease. Basis for rating thought content expressed in the interview.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Distinctly concerned about health of somatic issues as evidence by occasional questions and desire for reassurance |
| 4. Moderate | Complaints about poor health or bodily malfunction, but there is no delusional conviction, and over-concern can be allayed by reassurance. |
| 5. Moderately severe | Patient express numerous or frequent complaints about physical |

illness or bodily malfunction or else patient reveals one or two clear-cut delusions involving these themes but is not preoccupied by them.

- 6. Severe Patient is preoccupied by one or a few clear-cut delusions about physical disease or organic malfunction, but affect is not fully immersed in these themes, and thoughts can be diverted by the interviewer with some effort.
- 7. Extreme Numerous and frequently reported somatic delusions or only a few somatic delusions of a catastrophic nature which totally dominate the patient's affect and thinking.

16. Anxiety: Subjective experience of nervous, worry, apprehension, or restlessness ranging from excessive concern about the present or future to feelings of panic. Basis for rating: verbal report during the course of interview and corresponding physical manifestations.

- 1. Absent Definition does not apply.
- 2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
- 3. Mild Express some worry, over-concern, or subjective restlessness, but no somatic and behavioural consequences are reported or evidence.
- 4. Moderate Patient reports distinct symptoms of nervousness, which are reflected in mild physical manifestations such as fine hand tremor and excessive perspiration.
- 5. Moderately severe Patient reports serious problems of anxiety, which have significant physical and behavioural consequences such as marked tension, poor concentration, palpitation, or impaired sleep.
- 6. Severe Subjective state of almost constant fear associated with phobias marked restlessness or numerous somatic manifestations.
- 7. Extreme Patient's life is seriously disrupted by anxiety which is present almost constantly and at times reaches panic proportion or is manifested in actual panic attacks.

17. Guilt feelings: Sense of remorse or self-blame for real or imagined misdeeds in the past.

Basis for rating: verbal report of guilt feelings during the course of interview and the influence on attitudes and thoughts.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Questioning elicits a vague sense of guilt or self-blame for a minor incident, but the patient clearly is not overly concerned.
4. Moderate Patient expresses distinct concern over his or her responsibility for a real incident in his or her life but is not preoccupied with it, and attitude and behaviour are essentially unaffected.
5. Moderately severe Patient express a strong sense of guilt associated with self-deprecation or the belief that s/he deserves punishment. The guilt feelings may have a delusional basis, may be volunteered spontaneously, may be a source of preoccupied and/or depressed mood, and cannot be allayed readily by the interviewer.
6. Severe Strong ideas of guilt take on a delusional quality and lead to an attitude of hopelessness or worthlessness. The patient believes s/he should receive harsh sanctions for the misdeeds and may even regard his or her current life situation as such punishment.
7. Extreme Patient's life is dominated by unshakable delusions of guilt for which s/he feels deserving of drastic punishment such as life imprisonment, torture, or death. There may be associated suicidal thoughts or attribution of others' problems to one's own past.

18. Tension: Overt physical manifestations of fear, anxiety, and agitation such as stiffness, tremor, profuse sweating and restlessness. Basis for rating: verbal report attesting to anxiety and, thereupon, the severity of physical manifestations of tension observed during the interview.

1. Absent Definition does not apply.

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| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Posture and movements indicate slight apprehensiveness such as minor rigidity, occasional restlessness, shifting of position of the rapid hand tremor. |
| 4. Moderate | A clear nervous appearance emerges from various manifestations such as fidgety behaviour, obvious hand tremor, excessive perspiration or nervous mannerisms. |
| 5. Moderately severe | Pronounced tension is evidenced by numerous manifestations such as nervous shaking profuse sweating and restlessness, but conduct in the interview is not significantly affected |
| 6. Severe | Pronounced tension to the point that interpersonal interactions are disrupted. The patient for example may be constantly fidgeting, unable to sit still for long or show hyperventilation. |
| 7. Extreme | Marked tension is manifested by signs of panic or gross motor acceleration such as rapid restless, pacing and inability to remain seated for longer than a minute which makes sustained conversation. |

19. Mannerisms and posturing: Unnatural movements or posture as characterized by an awkward, stilted, disorganized or bizarre appearance. Basis for rating: observation of physical manifestations during the course of interview as well as reports from primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Slightly awkwardness in |
| 4. Moderate | Movements are notably awkward or disjointed, or an unnatural posture is maintained for brief periods. |
| 5. Moderately severe | Occasional bizarre rituals or contorted posture are observed, or an abnormal position is sustained for extended periods. |

- 6. Severe Frequent repetition of bizarre rituals, mannerisms, or stereotyped movements, or a contorted posture is sustained for extended periods.
- 7. Extreme Functioning is seriously impaired by virtually constant involvement in ritualistic, manneristic, or stereotyped movements or by a unnatural fixed posture which is sustained most of the time.

20. Depression: Feelings of sadness, discouragement, helplessness, and pessimism.

Basis for rating: verbal report of depressed mood during the course of interview and its observed influence on attitude and behaviour as reported by primary care worker or family.

- 1. Absent Definition does not apply.
- 2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
- 3. Mild Express some sadness or discouragement only on questioning, but there is no evidence of depression in general attitude or demeanour.
- 4. Moderate Distinct feelings of sadness of hopelessness which may be spontaneously divulged, but depressed mood has no impact on behaviour or social functioning and the patient usually can be cheered up.
- 5. Moderately severe Distinct mood is associated with obvious sadness, pessimism, loss of social interest, psychomotor retardation, and some interference in appetite and sleep. The patient cannot be easily cheered up.
- 6. Severe Markedly depressed mood is associated with sustained feelings of misery, occasional crying, hopelessness, and worthlessness. In addition, there is major interference in appetite and/or sleep as well as normal motor and social functions with possible signs of self-neglect.
- 7. Extreme Depressive feelings seriously interfere in most major functions. The manifestations include frequent crying, pronounced somatic symptoms, impaired concentration, psychomotor retardation, social disinterest, self-neglect, possible depressive or nihilistic delusions, and/or possible suicidal thoughts or actions.

21. Motor retardation: Reduction in motor activity as reflected in slowing or lessening of movements and speech, diminished responsiveness to stimuli and reduced body tone.

Basis for rating: Manifestations during the course of interview as well as reports by primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Slightly but noticeable diminution in rate of movements and speech.
Patient may be somewhat under productive in conversation and gestures. |
| 4. Moderate | Patient is clearly slow in movements, and speech may be characterized by poor productivity including long response latency, extended pause, or slow pace. |
| 5. Moderately severe | A marked reduction in motor activity renders communication highly unproductive or delimits functioning in social and occupational situations. Patient can usually be found sitting or lying down. |
| 6. Severe | Movements are extremely slow, resulting in a minimum of activity and speech. Essentially the day is spent sitting idly or lying down. |
| 7. Extreme | Patient is almost completely immobile and virtually unresponsive to external stimuli. |

22. Uncooperativeness: Active refusal to comply with the will of significant others including the interviewer, hospital staff, or family, which may be associated with distrust, defensiveness, stubbornness, negativism, rejection of authority, hostility, or belligerence.

Basis for rating: interpersonal behaviour observed during the course of interview as well as reports by primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Complies with an attitude of resentment, impatience sarcasm may inoffensively object to sensitive during the course of interview. |

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| 4. Moderate | Occasional outright refusal to comply with normal social demands such as making own bed, attending schedule programs etc. The patient may project a hostile, defensive or negative attitude but usually can be worked with. |
| 5. Moderately severe | Patient frequent is in complaint with the demands of his or her milieu and may be characterized by others as an “outcast” or having a “serious attitude problem”. Uncooperativeness is reflected in obvious defensiveness or irritability with the interviewer and possible unwillingness to address many questions. |
| 6. Severe | Patient is highly uncooperative, negativism, and possibly also belligerent. Refuses to comply with most social demands and may be unwilling to initiate or conclude the full interview. |
| 7. Extreme | Active resistance seriously impacts in virtually all-major areas of functioning. Patient may refuse to join in any social activities, tend to personal hygiene converse with family or staff, and participate even briefly in an interview. |

23. Unusual thought content: Thinking characterized by strange, fantastic, or bizarre ideas ranging from these which are remote or atypical to these which are distorted, illegal, and patently absurd. Basis for rating: thought content expressed during the course of interview

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Thought content is somewhat peculiar or idiosyncratic, or familiar ideas are framed in an odd context. |
| 4. Moderate | Ideas are frequently distorted and occasionally seem quite bizarre. |
| 5. Moderately severe | Patient expresses many strange and fantastic thought (e.g. being the adopted son of a king, being an escape from death row) or some which are patently absurd (e.g. having hundred of children, receiving radio messages from outer space through a tooth filling). |

6. Severe Patient expresses many illogical or absurd ideas or some which have a distinctly bizarre quality (e.g. having three heads, being a visitor from another planet).

7. Extreme Thinking is replete with absurd bizarre and grotesque ideas.

24. Disorientation: Lack of awareness of one's relationship to the milieu including persons, place, and time which may be due to confusion or withdrawal. Basis for rating: responses to questions on orientation.

1. Absent Definition does not apply.

2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.

3. Mild General orientation is adequate but there is some difficulty with specifics. For example, patient knows his or her location but not the street address, knows hospital staff names but not their functions, knows the month but confuses the day of the week with an adjacent day or else in the date by more than two days. There may be narrowing of interest evidenced by familiarity with the immediate but not extended milieu, such as ability to identify staff but not the Mayor, Governor, or President.

4. Moderate Only partial success in recognizing persons, places, and time. For example, patient knows s/he is in a hospital but not its name; knows the name of his or her city but not the borough or district; knows the name of his primary therapist but not many direct care workers; knows the year and season but not sure of the month.

5. Moderately severe Considerable failure in recognizing persons, places, and time. Patient has only a vague notion of where s/he is and seems unfamiliar with most people in his or her milieu. S/he may identify the year correctly or nearly so but not know the current month, day of the week, or even the season.

6. Severe Marked failure in recognizing persons, places, and time. For example, patient has no knowledge of his or her whereabouts, confuses the date by

more than one year; can name only one or two individuals in his or her current life.

7. Extreme Patient appears completely disoriented with regard to persons, place, and time. There is gross confusion or total ignorance about one's location, the current year, and even the most familiar people such as parents, friends, and primary therapist.

25. Poor attention: Failure in focussed alertness manifested by poor concentration, distractibility from internal and external stimuli, and difficulty in harnessing, sustaining, or shifting focus to new stimuli. Basis for rating: manifestations during the course of interview.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Limited concentration evidenced by occasional vulnerability to distraction or faltering attention toward the end of the interview.
4. Moderate Conservation is affected by the tendency to be easily distracted, difficulty in long sustaining concentration on a given topic, or problems in shifting attention to new topic.
5. Moderately severe Conservation is seriously hampered by poor conservation, distractibility, and difficulty in shifting focus appropriately.
6. Severe Patient's attention can be harnessed for only brief moments or with great effort, due to marked distraction by internal or external stimuli.
7. Extreme Attention is disrupted that even brief conservation is not possible.

26. Lack of judgment and insight: Impaired awareness or understanding of one's own psychiatric condition and life situation. This is evidenced by failure to recognize past or present psychiatric illness or symptoms, denial of need for psychiatric hospitalisation or treatment decisions characterized by poor anticipation of consequences and unrealistic short-term and long-range planning. Basis for rating: thought content expresses during the course of interview.

1. Absent Definition does not apply.

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| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Recognizes having psychiatric disorder but clearly underestimates its seriousness, the implications for treatment, or the importance of taking measures to avoid relapse. Future planning may be poorly conceived. |
| 4. Moderate | Patient shows only a vague or shallow recognition of illness. There may be fluctuations in acknowledgment of being ill or little awareness of major symptoms which are present, such as delusions, disorganized thinking, suspiciousness, and social withdraw. The patient may rationalize the need for treatment in terms of its relieving lesser symptoms, such as anxiety, tension, and sleep difficulty. |
| 5. Moderately severe | Acknowledges past but not present psychiatric disorder. If challenged, the patient may concede the presence of some unrelated or insignificant symptoms, which tend to be explained away by gross misinterpretation or delusional thinking. The need for psychiatric treatment similarly goes unrecognised. |
| 6 Severe | Patient denies ever having had a psychiatric disorder. S/he disavows the presence of any psychiatric symptoms in the past or present, and though complaint, denies the need for treatment and hospitalisation. |
| 7. Extreme | Empathic denial of past and present psychiatric illness. Current hospitalisation and treatment are given a delusional interpretation (e.g. punishment for misdeeds, as persecution by tormentors, etc) and the patient may thus refuse to cooperate with therapies, medication, or other aspects of treatment. |

27. Disturbance of volition: Disturbance in the wilful initiation, sustenance, and control of one's thoughts, behaviour, movements and speech. Basis for rating: thought content and behaviour manifested in the course of the interview.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |

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| 3. Mild | There is evidence of some indecisiveness in conservation and thinking, which may impede verbal and cognitive processes to a minor extent. |
| 4. Moderate | Patient is often ambivalent and shows clear difficulty in reaching decisions. Conservation may be marred by alteration in thinking and in consequences verbal and cognitive functioning are clearly impaired. |
| 5. Moderately severe | Disturbance of volition interferes in thinking as well as behaviour. Patient shows pronounced indecision that impedes the initiation and continuation of social and motor activities, and which also may be evidenced in halting speech. |
| 6. Severe | Disturbance of volition interferes in the execution of simple, automatic motor functions, such as dressing and grooming, and markedly affects speech. |
| 7. Extreme | Almost complete failure of volition is manifested by gross inhibition of movement and speech, resulting in immobility and/or mutism. |

28. Poor impulse control: Disordered regulation and control of action on inner urges, resulting in sudden, unmodulated arbitrary, or misdirected discharge of tension and emotions without concern about consequences. Basis for rating: behaviour during the course of interview and reported by primary care workers or family.

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| 1. Absent | Definition does not apply. |
| 2. Minimal | Questionnaire pathology may be at the upper extreme of normal limits. |
| 3. Mild | Patient tends to be easily angered and frustrated when facing stress or denied gratification but rarely acts on impulse. |
| 4. Moderate | Patient gets angered and verbally abusive with minimal provocation may be occasionally threatening, destructive, or have one or two episodes involving physical confrontation or a minor brawl. |
| 5. Moderately severe | Patient exhibits repeated impulsive episodes involving verbal abuse, destruction of property, or physical threats. There may be one or |

two episodes involving serious assault for which the patient requires isolation, physical restraint, or sedation.

- 6. Severe Patient frequently in impulsively aggressive, threatening, demanding, and destructive without any apparent consideration of consequences. S/he shows assaultive behaviour and may also be sexually offensive and possibly respond behaviourally to hallucinatory commands.
- 7. Extreme Patient exhibits homicidal attacks, sexual assaults, repeated brutality, or self-destructive behaviour. Requires constant direct supervision or external constraints because of inability to control dangerous impulses.

29. Preoccupation: Absorption with internally generated thoughts and feelings and with autistic experiences to the detriment of reality orientation and adaptive behaviour.

Basis for rating: interpersonal behaviour observed during the course of interview.

- 1. Absent Definition does not apply.
- 2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
- 3. Mild Excessive involvement with personal needs or problems such that conversation veers back to egocentric themes and there is diminished concern exhibited toward others.
- 4. Moderate Patient occasionally appears self-absorbed as if daydreaming or involved with internal experiences which interferes with communication to a minor extent
- 5. Moderately severe Patient often appears to be engaged in autistic experiences as evidenced by behaviours that significantly intrude on social and communication functions such as the presence of a vacant stare, muttering, or talking to oneself, or involvement with stereotyped motor patterns.
- 6. Severe Marked preoccupation with autistic experiences which seriously delimits concentration, inability to converse, and orientation to the milieu. The patient frequently may be observed smiling, laughing, muttering, talking, or

shouting to him/herself.

7. Extreme Gross absorption with autistic experiences, which profoundly affects all major realms of behaviour. The patient constantly may be responding verbally and behaviourally to hallucinations and show little awareness of other people or the external milieu.

30. Active social avoidance: Diminished social involvement associated with unwarranted fear, hostility, or distrust. Basis for rating: reports of social functioning by primary care workers or family.

1. Absent Definition does not apply.
2. Minimal Questionnaire pathology may be at the upper extreme of normal limits.
3. Mild Patient seems ill at ease in the presence of others and prefers to spend time alone, although s/he participates in all social functions when required.
4. Moderate Patient grudgingly attends all or most social activities but may need to be persuaded or may terminate prematurely on account of anxiety, suspiciousness, or hostility.
5. Moderately severe Patient fearfully or angrily keeps away from many social interactions despite others' efforts to engage him. S/he tends to spend unstructured time alone.
6. Severe Patient participates in very few social activities because of fear, hostility, or distrust. When approached, the patient shows a strong tendency to break off interaction, and generally s/he appears to isolate him/herself from others.
7. Extreme Patient cannot be engaged in social activities because of pronounced fears, hostility, or persecutory delusions. To the extent possible, s/he avoids all interactions and remains isolated from others.