A Manual for Working with People with Schizophrenia and their Families

COPSI

Community Care for People with Schizophrenia in India

The COPSI Manual: Manual for Working with People with Schizophrenia and their Families

ISBN No.: Applied For

First Edition: September 2012

Illustrations: Conrad Pinto
Covers & Book Design: Lester Fernandes
Printed by: Rama Harmalkar

Contact:

Sangath
Address: 841/1, Behind Electricity Dept.,
Alto Porvorim, Bardez, Goa - India 403 521.
E-mail: contactus@sangath.com
Phone no.: (91-832) 2414916; (91-832) 2417914
www.sangath.net

Introduction

Schizophrenia is a relatively uncommon but severe mental illness which can have negative consequences for the affected person, the family caring for the person and the larger community. The illness tends to affect young people and can sometimes continue for a long period of time. This often leads to many difficulties in the personal, social and economic roles of the individual and the family.

Adding to these problems is the issue of negative attitudes and discrimination which people with schizophrenia and their families face in their everyday lives, affecting their chances of leading a full and dignified life. A combination of these factors makes schizophrenia a challenging illness to deal with for everyone involved.

On the positive side, we now know that there are effective medical and non-medical treatments for schizophrenia which can improve the quality of the person's and family's lives. We also know that a combination of these treatments provided in a timely and convenient manner (like at home) works quite well. In countries like India, one of the biggest problems in providing these treatments is the lack of trained professionals who can actually deliver these treatments. This means that the majority of people with schizophrenia do not get these treatments, thus affecting their lives greatly.

The challenge is therefore to deliver the effective treatments - we know work well - to a larger proportion of persons with schizophrenia in the near future. One of the ways of doing this is by combining medical treatments (provided by Psychiatrists) with a range of simple and essential non medical treatments delivered by persons who do not need to have previous experience in mental health treatments, working as a team. Such a lay person can, with training, become a **Community Health Workers (CHW)**.

To be an effective CHW, you will need to acquire the set of essential theoretical and practical skills which the manual describes. The manual is organized as a series of modules that will provide these skills in a graded manner, combined with training exercises involving the group. The manual begins with a moving **First Person Account** of the impact of schizophrenia and the ways that close family and friends can help in the recovery process.

Module 1 introduces the essential concepts of schizophrenia starting with a description of normal brain functioning which is affected by the illness as well as the symptoms, disabilities and impact of the illness on the person and family.

Module 2 provides a broad overview of the essential treatments and counseling skills that are necessary for best results including medical treatments, individual and family treatments that you will be providing, understanding the issue of stigma and discrimination in detail and the necessity for networking with other social agencies.

Module 3 describes all the individual treatments you will be generally expected to provide in more detail: needs assessment, treatment planning, providing information about the illness, medicines, prevention of relapses, ways to improve overall health and well being, helping people continue with their treatments, manage discrimination, as well as details of the rehabilitation and social initiatives to improve the overall quality of life of the persons with schizophrenia and their family members.

Module 4 has an Appendix which shows the forms and tools used in the **Community Care for People with Schizophrenia in India (**COPSI) study. Obviously, not all of these need to be used in other settings; nonetheless, having these might be useful in thinking about documentation for other similar programs.

This manual has been written for CHW's who do not have any previous exposure to providing care for persons with schizophrenia or other mental illnesses. Accordingly, we have attempted to use non-technical language as much as possible to make it interesting and user friendly. This manual has been developed by revising the earlier, draft version used during the study to include some of the real life experiences of the people involved to provide you with a better understanding of the problems faced by people with schizophrenia in their daily lives. We would also welcome any suggestions to make the manual better and more user- friendly.

It is my pleasure to thank the contributors to this manual — Professor Graham Thornicroft, Dr. Mirja Koschorke, Dr. R. Thara, Dr. R. Padmavathy, Professor Mathew Varghese, Dr. Neerja Chowdhary, Professor YCR Janardhan Reddy, Mr Sujit John, Mrs Achira Chatterjee, Ms Madhumita Balaji, Mr K.K.Pratheesh, Mrs. Dakshin Lilly, Ms Smita Naik, Ms Jesina Pereira, Dr. Ana Eduardo, Dr. Monica Campos and Ms Beth Brennan for their specific contributions.

I am also extremely grateful to Ms Baljeet Ahluwalia for the inspiring first person account as well as to Mr. V.K Sathyendran for kindly agreeing to share his striking paintings for the manual. Finally, I am grateful to Sampada Prabhudessai for diligently keeping track of the many bits and pieces of the manual and putting it together.

I also wish to acknowledge the support of the Wellcome Trust, the UK medical charity which has funded the COPSI project. In addition, I would like to acknowledge the various institutions in India involved in the study for their fantastic support in developing the manual- the Schizophrenia Research Foundation (SCARF) at Chennai, Sangath at Goa, Parivartan and Nirmittee at Satara and the National Institute of mental Health and Neurosciences (NIMHANS) at Bangalore. I am also grateful to the Institute of Psychiatry (IoP) at the Kings' College, London and the London School of Hygiene and Tropical Medicine for their support during the process of developing the manual.

I am also grateful to all our collaborating psychiatrists -- T. C. Ramesh Kumar, R. Padmavati, R. Hegde, P. Pai Kakode, M. Chagas Silva, P. Castelino, H. Dabholkar, P. Dabholkar, A. Chavan and R. Deshpande who guided and supported the delivery of COPSI intervention across the sites.

Finally, I am very thankful to the fantastic team of lay community health workers across the study sites. Their experiences in delivering the intervention have been invaluable in revising the manual which is deeply appreciated.

I do hope this manual will be a valued resource for Community Health Workers during their training and in the course of work in programs providing community based services for people with schizophrenia in other programs and settings.

Dr. Sudipto Chatterjee, MD
Consultant Psychiatrist and
Trial Coordinator, COPSI

Table of Contents

FIRST PERSON ACCOUNT:

Baljeet Aljeet Ahluwalia

Schizophrenia! – The word fell like a bombshell on my already shattered universe. After almost two months of fighting demons and slashing my wrists to save the world from Osama Bin Laden, I was told that it was all a play of chemicals in my head.

Initially no one including me thought anything was wrong. But as my situation started to worsen, my ex-husbands' family were convinced that I was a victim of black magic. I was forcibly taken to a tantric who pronounced that someone was trying to destroy them through me. A story that took deep roots in my mind and I suspected everyone including my mother of subjecting me to black magic. After a single visit to the doctor I was left at my mother's place in my hometown.

For almost a week my mother didn't realize what was wrong with me. She thought that I was overreacting to a fight with my husband. She realized the gravity of the situation when one morning I attacked her physically. She managed to escape from me and summoned family friends who were also doctors. It was then that she realized that my condition was serious and I needed to be taken to a doctor. But I would hear none of it, convinced that she was conspiring to dump me in a mental asylum. Finally the daughter-in-law of the family friends, who is herself a doctor and also my close friend, convinced me to go to the doctor. It was he who pronounced that I had schizophrenia. Unfortunately, I perfectly understood the implications of schizophrenia.

So at the age of 30, I was without a family, without a career and without a stable mind. I lived in a constant daze caused by the thirty odd pills that I had to swallow daily and a heightened sense of panic, not knowing what would happen with the rest of my life. I was convinced that I would never recover. My mother on the other hand firmly believed otherwise. She kept repeating to me that I would be well again and would lead a normal life, though I chose not to believe her. My husband and his family on the other hand completely ignored me.

In spite of heavy medication, the hallucinations took some time to subside, a time which was hell for my mother. Apart from ministering to me as a patient, she also had to listen to my ranting about the end of the world and how I was responsible for it. She and my friend did their best to convince me that what I was experiencing was the result of my illness. My disturbed mind however only partly believed them.

During this hellish period as I struggled with the images and thoughts which played havoc with my mind, the other chief challenge was the execution of the activities of daily living. I couldn't perform the simplest of tasks, as I was unable to focus on my own actions. When I was served food, I had to concentrate on every bite I took. The very act of picking up a chapatti and putting it in my mouth took effort. If I managed to pick up a glass of water from the table, I would forget to put it back. Putting my feet in my slippers was a challenge by itself.

This is where my mother's strong horse-sense helped me. She taught me to concentrate on the present moment and stop thinking about everything else. She taught me that when I took up a glass of water I should focus on the glass and every sip I took. When I put my feet into my slippers I should concentrate on the shape of the slippers and the shape of my feet and then co-ordinate my actions. Slowly with medicines doing their work and following my mother's advice I managed to accomplish these simple tasks of everyday life.

Once the initial phase of the illness subsided and the hallucinations were completely under control, I was plagued by other worries. My husband had already told me that he wanted a divorce and though our marriage had been torrid since the beginning, I tried to dissuade him from his decision because I could see no future for myself. Up until then I had been an egotistic, independent individualist. But the dreaded disease and my fear of the future caused me to grovel for the survival of the relationship. I was disgusted with myself for the way I was throwing myself at him but at the same time I was convinced that I would not be able to live life on my own.

Here again my mother and Nalini stood by me and kept trying to tell me that I did not need a crutch to survive. My mother especially reminded me of the strong person that I had always been. She reminded me of all the accolades I had won in my student life both in studies and extracurricular activities. Nevertheless I was unable to recover from the shock of my husband ditching me at this crucial time.

In the meanwhile at the advice of the doctor and my friend I tried to involve myself in things to occupy my mind. But to my horror I found that I could not concentrate on watching T.V. or reading books. The images just went by on the screen and I could not even register them. The words that I read did not make sense to me. I was left with a void in my mind and my anxiety grew worse because I could only worry. Slowly that also passed and I could concentrate once more.

Up until my illness I had been an occasional smoker and sometimes chewed tobacco for the fun of it. But now my urge to consume tobacco became uncontrollable. This is what caused a major rift between me and my mother. She is a strong believer of Sikhism and considered tobacco consumption to be a major sin.

She on the other hand did not realize that at that time my tobacco consumption was of least importance as my entire entity had been thrown out of kilter. That is to say that she did not fully understand the implications of Schizophrenia and everyday there were ugly scenes between me and her.

At this time I also felt the need to talk to my friends and my only friend in my hometown was Nalini and there was a limit to the amount of time and energy that she could devote to me. The result was that I started calling everybody I knew on the planet on a daily basis resulting in huge phone bills, which infuriated my mother even more.

The other bone of contention between me and my mother was my practice of the healing system of Reiki. My mother was against my practicing any system other than Sikhism, whereas I do not believe in organized religion. I believe in one God and the non religious practice of meditation. But according to my mother, all my problems in life originated from my forsaking the practices of the religion I was born into.

On the other hand I had practiced Reiki healing on others and seen its positive effects. At this crucial time I took to Reiki and meditation and was greatly benefited in terms of recovery and improved concentration. But my mother considered it a useless thing.

So to get away from it all I took up a job earning Rs.2500/-. My job was to call up people at random and take appointments for the sales people to visit them personally. Here although I was diligent and made more than the requisite number of calls, there was no enthusiasm in my tone a fact which was pointed out to me every day. But I had completely forgotten to smile, leave alone laugh. Try as I might I couldn’t infuse enthusiasm in my calls. But working there for a few months gave me the confidence that I could go to Ahmedabad (a bigger city with better job options) and take up a better paying job. Also in Ahmedabad I would be away from the constant bickering that prevailed at home.

My mother would hear none of it because she was convinced that tobacco consumption would leave me unfit for any work and would lead me to further trouble. Try as I might I could not change her views on tobacco in spite of scientific explanations. But the constant arguments at home and the worries of the future made me determined.

My situation was quite hopeless; I was a simple graduate with no other degrees or diplomas under my belt. The only skill I had acquired was textile designing, which along with a natural flair for writing were the only things that I had going for me in a professional sense. But I found that I could do neither of them anymore.

To my dismay I had come up against a severe creative block. I would sit with pencil and paper for hours together and would not be able to create a single design concept. I could not put together a paragraph that could be considered creative. I cried bitterly as my two talents and passions seemed to be gone forever. I bid goodbye to my dream of becoming a designer or writer and looked at other professions.

With advice from friends I realized that the only thing left for me to do was to join the corporate field. Here too, I did not have any qualifications to speak of. I had not even begun my career where on the other hand my peers were in mid-management posts in good organizations. This meant that I had to start from scratch in a field which I did not like. On the basis of my communication skills the two fields open to me were customer relations and direct sales. I decided on the latter because it was the fastest moving profile in the corporate sector.

I was too proud to ask for help and approached an employment consultant. The first sales job that I got was with a Hindi newspaper. I thought it was an excellent opening as selling advertising space in a Hindi newspaper in Gujarat would be a challenge and would teach me the nitty-gritty of sales. It was a tough job and I was hell bent on proving *to* myself that I was capable of doing it. I worked 12 hour days, most of which were spent in the field on a scooter in the arid summers of Ahmedabad, with the temperature reaching 48 degrees on some days. I performed well through sheer hard work and was appreciated for it.

This was the time that I had my first relapse. As earlier I did not realize what was happening. My roommate at the hostel was terrified with the sudden change in me. I went with her to my Reiki teacher who recognized the relapse for what it was and gave my friend instructions to take me to the doctor. My relapse totally scared the wits out of me. I lost my job and the strength I had gained over the time after my recovery.

The two year period after my relapse was the worst in my life. After I lost my job with the newspaper I tried my hand at many jobs, but could not hold on to a single one. I would visit the doctor, take the prescription, and take medicines regularly for some time, then stop taking them. I could not tell my seniors at work what doctor I needed to visit and hence missed my appointments. I also failed to perform meditation and Reiki properly and regularly. Severe insomnia, volatile mood swings and lack of focus kept me on edge. I would start a job but within a month or two would go into a relapse and be forced to quit it. Even while I was working, my behavior was odd, drawing the open and at times cruel ridicule of the people around me. In fact this was the time when I realized how cruel human beings could be.

My friends were flummoxed at the sudden change in me. They could not draw the comparison between my earlier self and the mess I had become. None of them realized what my problem was, thinking that I was losing my cool because I was not prepared to face the travails of professional life. They tried their best to counsel me that I had to gear up and take control of my life. Everyone thought that I had somehow become emotionally and mentally weak in the face of adversity.

Try as I might I could not explain to them that I was facing a physiological problem and what was being construed as the weakness of my personality was actually an inability to properly treat and control a hormonal imbalance. I myself was unable to accept my inadequacy in the professional sphere because I was used to succeeding at whatever I undertook. The result was that I became a social recluse.

In spite of their exasperation, my friends stood by me in every way. I am grateful to them for this support because without their emotional anchor I would not have been able to survive that period. But enough was enough and after two months at the umpteenth job I finally gave up. Since the time I had my first attack I had been in touch with my school friend who was married in Kolkata. Both she and her husband had insisted from the beginning that I should go to Kolkata and take a long break with them.

Initially my mother didn’t let me go there because she was afraid to let me go and live with strangers for an indefinite period. Later I kept trying to settle in a job. But when I called my friend, she insisted that I drop everything and take the first train to Kolkata. In fact she sent me the ticket because I had no money on me.

I landed in Kolkata a total mess and spent the first few days crying my heart out. Luckily my friends’ husband was close friends with a psychologist so they understood the implications of what I was facing. Gradually with their care and counseling I regained my bearings. Finally at the end of two months I left Kolkata for Gujarat a totally new person. I had regained the confidence that I would be able to face life no matter what.

On the long train journey back from Kolkata I made up my mind about a few things. I would not miss my medicines no matter what and I would practice Reiki and meditation regularly. Since no one else could do anything for me except give me support I had to take the trouble of living my life myself.

In Ahmedabad I took up a job with a BPO because that was the upcoming thing. While in Ahmedabad I got through an interview for a BPO in Noida and decided to move because Delhi was a land of better opportunities and Ahmedabad had too many ugly memories. I landed in Delhi in the February of 2005, with just my luggage and the money to see me through a month. Within seven days I had hired a house with the help of colleagues.

During the first month of my job I had a relapse, but I controlled it by consulting my doctor in my hometown over the phone and adjusting my medicine dose accordingly. I slowly started taking interest in life again and made some wonderful friends who taught me that no place is strange if you have the right attitude.

While in Delhi I met a friend who is very deeply interested in Urdu poetry and is a very creative person although he is a doctor by profession. In spite of the fact that we lived in separate states and our friendship blossomed over the phone, we struck a very compatible chord. When he learned that I was suffering from a creative block, he took it upon himself to resolve it and guided me with creative exercises and counseling.

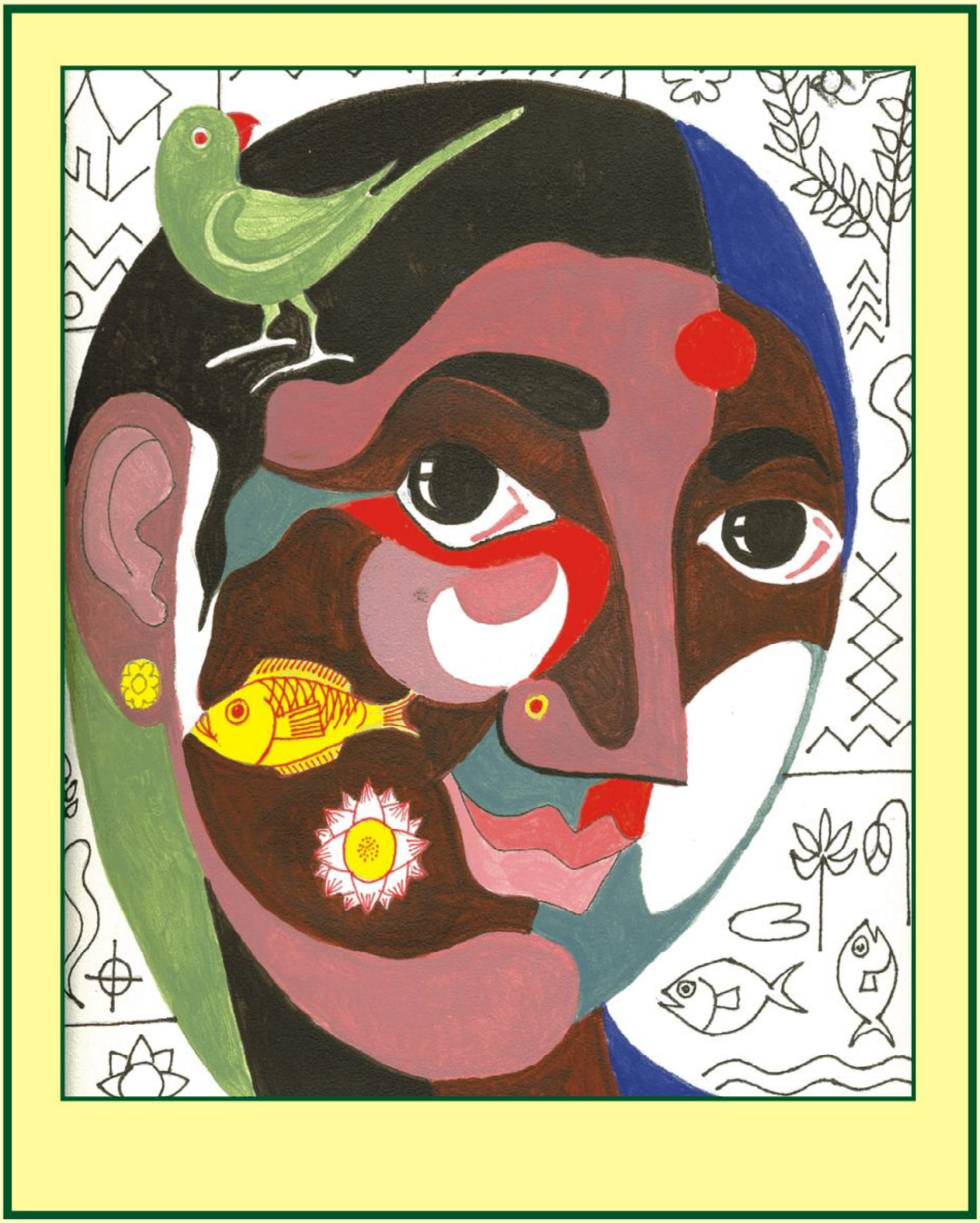
Slowly I started to sketch simple themes and put together a few words here and there, though my progress was hampered by the lack of time and energy. Now I am able to do full design concepts and am writing Urdu poetry. I am exploring avenues in the writing and designing field and am making slow but sure progress.

Now it has been more than seven years since my first attack and I am still plagued by mood swings and periods of insomnia, not to mention loneliness. But now I have started to treat my problem as any other chronic illness which requires regular supervision and medicine.

I have stopped feeling ashamed of being a psychiatric patient, though I have to hide the fact in professional circles where I would not be employed if I made my condition known. At the same time I feel the desire to reach out to other people who are suffering from the same illness and extend to them the emotional and mental support of a person who knows exactly where and how the shoe pinches.

The positive part of this ordeal had been my strong bonding with my friends who were already very close to me. At the same time my life with schizophrenia has taught me to be tolerant, a quality which I lacked earlier. Now I believe that if a person as strong as me could falter due to a problem, so can anyone else.

I am no more the perfectionist that I used to be and I am most considerate with myself where earlier I would drive myself into the ground to achieve that perfect result. I have also resolved my relationship with my mother, though I am unable to quit smoking yet. So life has come full circle and I am taking the responsibility of living it for myself as well as for those who helped to put me back on my feet.



MODULE 1

Introduction to Schizophrenia

CHAPTER 1.1

The human brain and behaviour

1.1.1 Introduction:

The word 'mental' is linked to the brain in our everyday language and understanding. Though the exact nature of the relationship between the brain and the mind is not clear, many years of scientific research have shown that the brain is responsible for all known mental functions like thinking and emotions, as well as the sense of being an individual person ('who I am').

Therefore, when we talk about mental illnesses we mean that these are related to problems in the brain. A good place to start is to understand the working of the human brain in some more detail so that we can appreciate the changes seen in mental illnesses.

1.1.2 How is the physical structure of the brain organized?

The overall brain weighs approximately 1.4 kilograms and is divided into two parts - the left and the right 'hemispheres' (refer to photographs at end of this chapter) that are connected together but have different specialized functions (see Box below).

Left Hemisphere
Communicates by using words, has highly developed verbalabilities and logical thinking.

Right Hemisphere
Communicates using images (pictures), has highly developed spatial abilities, is intuitive and imaginative, concerned with emotions and feelings.

Both hemispheres are interconnected and communicate, bringing together human abilities into a whole.

The human brain is a deeply wrinkled, jellylike mass made up of about 100 billion specialized nerve (neurons) and supporting cells, densely packed together in the small space of the head. The neurons are supported and kept in place with other cells (glia), are surrounded by a thick overall covering, and suspended in a fluid solution. The nerve cells develop early in the mother's womb and continue to change over time till they become set in a certain pattern in early adulthood. There are several kinds of nerve cells which have specific patterns in different areas of the brain, and are responsible for particular functions. As you can imagine, the brain requires a lot of energy to work properly (oxygen and glucose) which is supplied by blood vessels. (Refer end of the chapter 2.1 for photographs). By convention, the brain is divided into a number of different areas.

- The 'frontal' area or the front 1/3rd of the brain
- The upper side or the 'parietal' area
- The lower side or the 'temporal' area
- The back area of the brain or the 'occipital' area

The *frontal area* is the biggest part of the brain and is much bigger and complex in humans compared to even our nearest animal ancestors. This is where all inputs are 'brought together' and integrated, and is the place for all 'higher' mental functions like thinking, organizing things, planning and controlling impulses, allowing us to behave in a socially accepted manner.

The two *parietal lobes* are responsible for processing complex sensations like touch, shape and directions. The two *temporal lobes* process all things that we hear, and are very important for memory and learning. Both *occipital lobes* are responsible for processing sensations that come from seeing objects. (Ref. end of the chapter for Photographs). If we look from above ('top down') position, the brain can be divided into:

- The upper crust known as the 'cortex'
- The middle area known as the 'midbrain'
- The deepest part or the core of the brain, known as the 'reticular' area

The cortex is about 85% of the weight of the human brain and is responsible for most information processing. The midbrain contains many of the brain structures that are important for motivation, emotions, memories and movement. The reticular brain contains the centres that control vital body functions like breathing, digestion and the heart.

The brain is the single most complex organ that makes us human and sets us apart from other living beings in the world, giving people the capacity for art, language, moral judgments, and rational thought. It is also responsible for each individual's personality, memories, movements, and how we sense the world. As the central command, or control centre, it processes information from our bodies, operates our internal organs, registers what is happening around us, generates thoughts and emotions, stores and recalls memories, and controls our behaviours all at the same time without us being aware of it!

1.1.3 What does the brain do?

The brain performs an incredible number of tasks:

- It controls body temperature, blood pressure, heart rate and breathing and all vital body functions.
- It accepts information about the world around you from your various senses (eyes, ears, nose, etc.) and processes them.
- It handles physical activities like walking, talking, standing or sitting.
- It lets you think, dream, reason and experience emotions.

To understand the functioning of the brain, it is useful to think of something like a telephone network system. In the network, there are thousands of individual points with a physical instrument (telephone) that we use to talk or send messages. All these individual connections are linked together with telephone lines that are packed together into junction points- firstly in the local area and finally at a central point- the main telephone exchange. Once these signals are relayed to the central point, the message is sent to the receiver point using the same network.

Similarly, in the context of the human body, we know that there are nerves that are present in all our peripheral sense organs (skin, eyes, ears, tongue and nose) as well as in the inside of the body. These peripheral sense organs are antennas to the environment around and within us, and help record what is happening there continuously. Nerves relay the messages from their side to the spinal cord (the junction box in the local area) which in turn relays the information to the brain. Unlike the central point of a telephone network which can only relay the information, the brain is unique in being able to independently *process the information being fed in from the nerves*.

After this processing (which mostly happens without our realizing it), the brain then determines the most appropriate response and enables us to carry out the necessary actions. For example, when we touch a hot object, we instantly take our hand away. This response happens without any effort on our part but it hides the complexity of the events that lead to this action. The heat is sensed by the nerves in the skin which is relayed to a particular part of the brain. In this part of the brain, it is recognized as an unpleasant and threatening event, and the message to instantly withdraw the hand is relayed to the muscles.

As a general rule, the information from various senses are processed in specific areas of the brain. For example, visual images are processed in the back of the brain while sounds are processed in the temporal areas. Once synthesized at this level, the data is further processed to attach meaning or emotional significance, and certain behaviors are activated in response.

For example, when we have a 'good' meal that makes us happy, the taste of the food is fed back to the brain, given a positive emotional tone and we behave by having more than our usual amount and by complimenting the cook. Again, when we watch a movie that is 'nice', it is not only the images and sounds that make it nice. Rather, it is the emotional color given to the images and sounds that makes us happy and makes us recommend the film to our friends.

The brain is responsible for maintaining *the overall coordinated functioning of the various body organs* and our physical well being. It receives extensive information about the functioning of various organs and uses that information to keep things the same or make changes. For example, when we need more energy to run away from something, the brain responds by ensuring that the leg muscles receive more blood flow and oxygen. Every action that comes naturally to us (walking, talking, smiling, etc) and those that we have to learn (swimming, cycling, playing cricket, etc) are all linked to specific parts of the brain.

Another key function of the brain is to be able to *think and be self conscious* or aware of being a person. Thinking is the key ability that has enabled human beings to make extraordinary advances in arts, sciences, music and technology, and be the most successful species on earth. Being self conscious makes it possible for us to have a sense of continued identity as well as the wonderful ability to observe our own minds and record our thoughts and emotions! We know that consciousness is dependent on the overall functioning of the brain as states of consciousness can change depending on the brain functioning (while sleeping, becoming unconscious when medicines are given before a major operation, under the influence of drugs and alcohol, etc).

The human brain is also capable of *experiencing emotions* like happiness, sadness, anxiety and anger. Emotions add color and spice to our lives and strongly determine how we feel and behave. We now know that there are specific parts of the midbrain that are responsible for emotional feelings which can be lost or reduced when these parts of the brain are affected. Emotions involve a combination of mental and physical experiences. For example, when we are scared or anxious, our heart beats more quickly, breathing becomes more rapid and our hands shake. When we are angry, our body reacts by becoming more tense and ready for 'action'. Similarly, in the presence of someone we love, we tend to experience certain physical sensations. This link between the mental and physical experiences is the reason why we commonly locate emotions as coming from the heart.

The brain also enables us to *develop and maintain social interactions* with other people. This is an extremely important function that enables us to understand and communicate thoughts and feelings to others in a manner that both parties understand.

There are several complicated brain processes that contribute to our ability to understand social interactions. Firstly, we are able to guess quite accurately the mental state of someone we are communicating with, either while talking face to face or over the phone. This is done by the brain's ability to monitor speech, emotional tone and behavior of the person concerned. For example, if someone is speaking very loudly and quickly, using threatening hand gestures and is agitated, we can all accurately understand that the person is angry and upset about something. Similarly, we can accurately understand and respond to human faces in predictable ways across many cultures and societies- a smiling face of a known person makes us feel happy whereas the angry face of a grumpy teacher makes us feel scared and anxious. Finally, we seem to have a built-in ability to guess the minds of others and behave accordingly.

To summarize, *the human brain is designed to understand and respond to the external and internal (body) environment* on a continuous basis. This is possible through the smooth combination of highly organized mental functions like perceiving the environment, thinking, feeling emotions and being self conscious. This enables us to make sense of the environment and attach a meaning to it, which is both public (shared and understood by people around us) and personal. Each of these complex mental functions is itself a combination of many specific sub-functions. For example, mental processes like attention, concentration, memory and language skills are necessary to think properly.

While we know a fair bit about how the specific mental functions are organized and located in different areas of the brain, we are not clear about how all this is integrated to produce the overall experience of human existence.

1.1.4 How does the brain work?

To process a whole range of information and experiences, it is obvious that nerve cells must be able to communicate. Nerve cells typically lie close to one another and pass on information to each other through certain specific chemicals in the brain, and through small electric currents. These 'messenger' chemicals (neurotransmitters) and currents have been studied in great detail, and we have some idea of how they can influence mental functions and behavior. For example, a particular chemical called adrenaline can improve attention, concentration and overall alertness. Similarly, another chemical called dopamine is responsible for the sensation of happiness and well being. (Ref. End of the chapter for photographs)

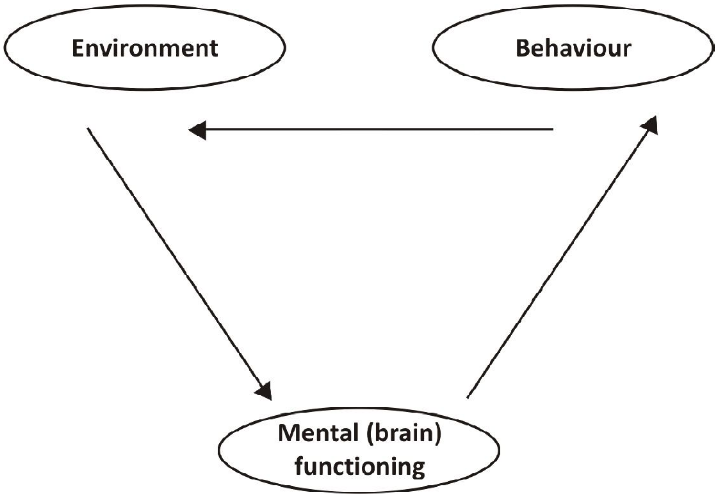
1.1.5 How are behaviour and brain related?

The particular way in which we interact with the environment is through a range of behaviours (actions which can be observed). Behaviours can be activated in response to both the internal and external environment. Internal body sensations are responsible for many of our routine behaviours that we do almost automatically. For example, when we are hungry, we sit down for a meal at home or, if working, go out to a hotel for lunch. When we experience a headache, we either rest or take a medicine to reduce the unpleasant sensation.

Our behaviours are also dependent on events in the external environment. In a relaxed and comfortable environment with friends, we are all likely to behave in a caring and warm manner, while we may react by becoming angry and irritated when faced with some difficulty at work.

We all understand that mental processes determine our behaviour. Since mental processes are not directly observable, *we use behaviours as indirect or proxy indicators of our mental functions.* Again, since we know that mental functions are closely related to many specific brain functions, we can say that the brain and our behaviours are intimately linked to one another. The relationship between the environment, mental (brain) functioning and behaviour is shown in Fig 1.1D below:

Figure 1.1D: The relationship of brain, behavior and environment



1.1.6 What is the relevance of this for understanding mental illnesses?

By the term mental illness we commonly refer to a person developing abnormal behaviors which we can link to disturbances in mental functions like thinking clearly, having a range of emotions and being able to manage normal social interactions. There are 3 key messages that are important for us to understand in relation to mental illnesses:

Firstly, we are now confident in saying that mental illnesses are due to specific abnormalities in the functioning of the brain. As our understanding of the way the brain works has become clearer, we are able to identify how problems in usual brain functioning can cause various mental illnesses. Just as we know that heart disease or diabetes is not because of evil spirits, we can now say that *mental illnesses are associated with brain malfunctioning.*

Secondly, we are now much more aware that the brain is very flexible, and is continuously interacting with and changing to respond to what is happening in the environment. Now we are able to better understand how a *stressful environment can alter brain chemistry and cause mental illnesses or make an existing illness worse.* The implication for treatment of mental illnesses is also very clear - management must include both medicines to correct brain dysfunctions, and address the problems in the environment for best outcomes.

Finally, the brain matures over time so that by adulthood the final structure of the brain is in place. This means that there are *critical periods in the brain development process* when it is very sensitive to the influence of the environment. It is becoming clearer that some mental illnesses are possibly due to delayed or abnormal maturation of the brain. The brain is unusually sensitive during childhood and adolescence, which are periods when there are many changes happening in the environment as well - physically, at home and outside.

Summary

- Severe mental disorders like schizophrenia are linked to problems in the functioning of the brain
- The human brain is an amazing organ that does an incredible number of things that make us human
- The different parts of the brain specialize in doing specific things like processing sensory information, thinking and physical actions
- Brain functioning, the environment around us and human behaviour are closely linked

Plate 1: The Human Brain

Plate 2: Nerve Cells

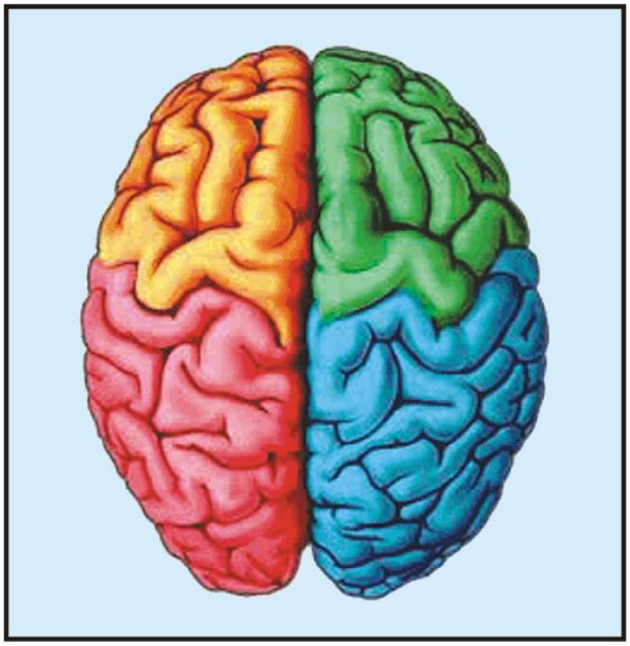


Plate 2: The Two Hemispheres of the Brain

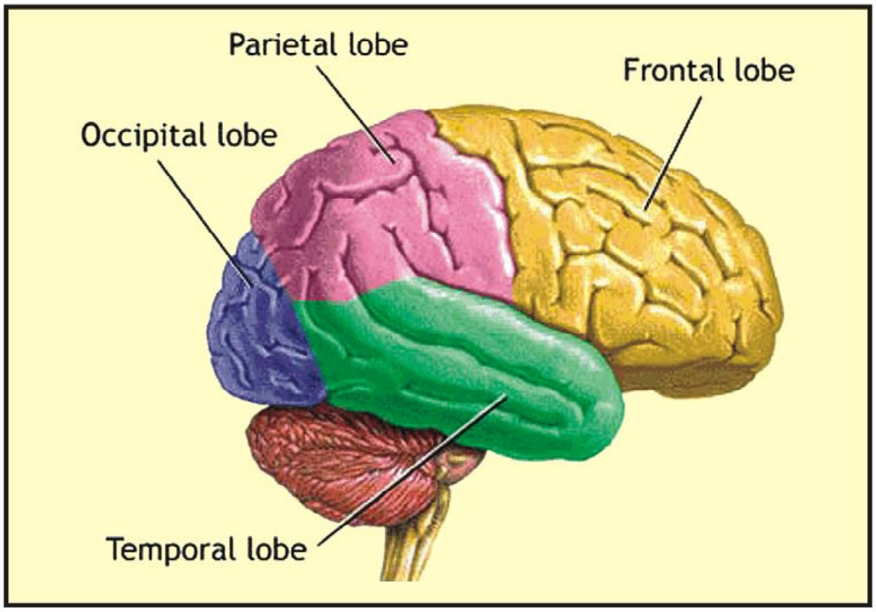


Plate 2: The Parts of the Brain

Plate 5: Nerve Cells

CHAPTER 1.2

What is schizophrenia?

1.2.1 History and meaning of the term schizophrenia:

Schizophrenia is the rather complicated name for an illness which has been recognized and described for a very long time. Some of the earliest descriptions are from the ancient Indian texts of medicine like the Charaka samita by Sushrut where it was classified as a disease ('unmada') due to constitutional changes related to certain 'doshas' created by imbalance of vital elements.

Till about a century ago, all persons with mental disturbances were described as a single category using terms like 'lunacy' and 'deviants'. The first large scale system of caring for people with severe mental illnesses was started in large and isolated institutions in nineteenth century England. The first such institutions were the 'poorhouses' where all people who were considered unfit to work were put together- these included people with serious mental illnesses, beggars, the homeless and destitute, and those considered 'morally weak'. These poorhouses led to the creation of large mental hospitals in Europe which were built to provide treatment only to those with serious mental illnesses. These hospitals (having a large number of people segregated there for the whole of their lives) were managed by specialist doctors who became known as Psychiatrists. The system of asylums was exported to most parts of the world during the colonial period. In India, the first such mental asylums were created by the British.

In the early twentieth century two famous Psychiatrists- Emil Kraepelin from Germany and Eugene Bleuler from Switzerland, provided the first systematic medical descriptions of the disease they named schizophrenia. The essential feature of the illness was described as due to a split (schizo in Latin) in the mind (phren in Latin) between actual reality and the individual's understanding of it.

However, the term schizophrenia is not just used in medical texts but is also part of our daily lives and conversation. In popular terms, schizophrenia represents somebody with a 'split mind' and has come to be used loosely to describe someone or something that is irrational and difficult to understand. It is also used in a negative sense ('schizo', 'psycho'), and implies that the person is not 'normal', and is unpredictable, dangerous, and deserves little respect.

1.2.2 What do we mean by the terms illness and disease?

When we are sick we experience symptoms - unpleasant experiences like fever, pain, lack of sleep or weakness. The combination of particular symptoms for a certain period of time and that cause difficulties in usual functioning defines any illness.

In medicine, particular symptoms are studied in detail to understand which part of the body they affect, how they produce undesirable changes in body functions, and how can they be confirmed by tests like X-rays and blood examination. Once a particular cause (bacterial infection, worm infection or change in blood pressure) is established for certain symptoms in a specific part of the body, we can make the diagnosis of a specific and unique *disease*.

1.2.3 What are common ways of understanding diseases?

Diseases are defined and understood according to a number of ways:

SYMPTOMS + TIME + FUNCTIONING DIFFICULTIES = ILLNESS
ILLNESS + IDENTIFIED CAUSE = DISEASE

- *The particular part of the body affected* like the lungs, heart or brain. For example, we often talk about diseases of the heart (blood pressure, heart attack), liver (jaundice, swelling of the abdomen) or diseases of the brain like stroke and mental disorders.

- Those that can be *communicated to others* (flu, malaria, loose motion, TB and HIV/AIDS), and those *that cannot be communicated* to others (anemia, high blood pressure, diabetes and mental disorders).

- Length of time that they are present in the person. A*cute* illnesses last for a short time (days- a few weeks)and *long-term or chronic illnesses* continue for a long time, such as cancer, diabetes, TB or HIV/AIDS.
- *Time that it develops in the person's life* - in childhood, adolescence, in adulthood or in old age. For example, we know that chicken pox, measles and asthma are common in young children, while heart disease and diabetes are most often seen in adults.

1.2.4 What kind of illness is schizophrenia?

Schizophrenia is usually a long term, infrequently seen mental illness identified by particular symptoms that usually starts in late adolescence or early adulthood due to problems in the functioning of the brain.

While we know some things about schizophrenia, we also do not know many things about the illness like the exact changes in the brain functions and why it develops in some people and not in others. In the last few years, there has been a great deal of interest in understanding the possible causes for schizophrenia. In the absence of a definite cause that can be identified by a particular test, Psychiatrists diagnose the illness through the clinical history which identifies the types and duration of the symptoms, the period of time they have been present for, and the problems faced by the person due to the symptoms. Since we do not know clearly enough the particular reasons that lead to the development of schizophrenia, there are also limitations in the treatments available. Due to these uncertainties, understanding and treating schizophrenia is a challenge.

SCHIZOPHRENIA:

• IS AN UNCOMMON LONG-TERM MENTAL ILLNESS

• DUE TO PROBLEMS IN BRAIN FUNCTIONING

• STARTS IN LATE ADOLESCENCE OR EARLY ADULTHOOD

1.2.5 What is the usual pattern of the illness?

Schizophrenia can be understood as having 3 stages: early, acute and chronic

The first stage is the slow and progressive changes in behavior over a period of time-usually from a few weeks to months. During this *early stage,* the illness develops slowly and the person experiences problems like withdrawing from people, losing interest and motivation in doing things like working or studying, change in their daily routine (staying up late, not taking care of clothes and hygiene as before), and becoming moody.

Most often family members and friends realize that something is definitely wrong when the person develops the more obvious symptoms of the illness, like markedly abnormal behavior and unusual experiences. This is called the *acute phase* of the illness and is characterized by symptoms that suggest a break with reality. For example, during this time, the person feels that there are people talking to him when no one is around, that neighbors are plotting to harm him by poisoning the food, that people can read their thoughts, or may be convinced that it is his duty to save the world from an alien plot to invade it. As you can understand, these symptoms are very distressing for the person who can become fearful, withdrawn and disorganized in their speech, thinking and behavior. Usually in this phase, the person is unable to sleep or eat properly, cannot carry out his daily functions and becomes anxious, restless and easily angry.

It is in the acute phase of the illness that the person with schizophrenia is taken by the family to the doctor. Depending on the severity of the problems, the doctor might decide to start treatment at home or admit the person in hospital for some time. With treatment, the symptoms of the acute phase become less prominent over weeks to months.

Some people have only one such acute episode followed by complete recovery. For many others, though, schizophrenia becomes a chronic illness over many years. During this time, the usual pattern is to have periods of wellness, when the person can have a relatively normal life, interrupted with return of the acute symptoms for some period of time.

For many people, the problems often continue for a long period unless specific treatments are used to help the person recover completely. The severity of the symptoms and the long-lasting, chronic pattern of the disease often cause a high degree of disability (Chapter1.6). Medications and other treatments for schizophrenia, when used regularly and as prescribed, can help reduce and control the distressing symptoms of the illness. However, some people are not greatly helped by available treatments or may prematurely discontinue treatment, mainly because of unpleasant side effects. Even when treatment is effective, persisting consequences of the illness, lost opportunities, stigma, mild symptoms, and medication side effects may be very troubling and distressing for the person with schizophrenia and their caregivers.

1.2.6 What are the symptoms of schizophrenia?

The symptoms of schizophrenia are described in detail in Chapter 1.4. Here we provide a brief description of the common symptoms seen in schizophrenia which can be divided into three groups:

1.2.6A) Positive symptoms:

These symptoms are rarely experienced by the general population, and refer to *experiences which are additional to normal experience*. They are not specific to schizophrenia and can occur in other serious mental illnesses as well. The most common positive symptoms are:

- Hallucinations
- Delusions

Hallucinations are unusual sensory experiences in the absence of an actual corresponding event in the real world. For example, people might report hearing a male voice talking to them by name and asking them to do something specific, when actually there is no such person around. In schizophrenia, hallucinations can take any sensory form – hearing things (the most common type), seeing things, having unusual sensations in the body, unusual smells or tastes.

Delusions are firmly held and obviously abnormal beliefs based on the person's altered way of interpreting the world. These beliefs and ideas are not shared by others (wife, children, friends, etc), who cannot understand why the person with schizophrenia insists in believing and acting in an obviously abnormal way. Delusions are formed when the person with schizophrenia has a changed perception of reality, and begins to attribute motives to things happening around him, which do not correspond at all to the way others see the world.

1.2.6B) Negative symptoms: These are symptoms that involve *loss of experiences that people normally have and take for granted*. In some cases, especially with hindsight, families may realize that their relative's behavior has been changing over a period of time in subtle ways. They may for instance have become slower to think, talk and move, and may have become indifferent to social contact. Their sleeping patterns may have changed, so that they prefer to remain up all night and sleep all day. Body language may also be affected. The overall result is a reduction of motivation, and the extent of this can vary from minor to severe. Negative symptoms are much less dramatic than the positive ones, but they tend to be more persistent, and more difficult to improve with treatment.

1.2.6C) Disorganization of thinking:

In schizophrenia, another set of common symptoms are related to difficulties in thinking as sharply and clearly as before. Many people with schizophrenia report that their concentration is poor, that they cannot remember things and have become absent minded, that they cannot follow conversation or read a book, nor remember details as before. This is particularly troublesome for people who are studying or working, as the lack of attention and concentration makes it very difficult for them to perform their work at an acceptable level.

As you can imagine, these difficulties impair the person's ability to perform household jobs like cooking, going to the shop and remembering to get the necessary things back, passing exams in spite of making an effort, or working in the office. Unfortunately, these symptoms tend to persist for long periods of time even when positive symptoms have been controlled. This can affect the overall quality of life of the person quite severely, unless specific steps are taken to manage them more effectively.

1.2.7 How is schizophrenia diagnosed?

Any illness, including mental illnesses like schizophrenia, is diagnosed on the basis of:

- the presence of particular symptoms over a certain period of time
- the impact of these problems on the person's life
- the distress caused by the problems

Once the doctor finds out these details, there are specific signs that are apparent on examination and may be backed up by investigations like blood tests. In mental illnesses, we are limited by the lack of blood tests or brain scans that can help to establish the diagnosis. Therefore, diagnosis of a particular mental illness depends on a detailed and systematic history of symptoms, followed by a *mental state examination.* This is an interview which specifically examines important mental functions like thinking, emotions, attention and concentration, symptoms like hallucinations, and what the person thinks about the problem. Similarly, schizophrenia is diagnosed after talking to the person and their family members about his experiences of the symptoms previously listed (especially positive symptoms), the overall progression of the illness, and the findings of the mental state examination.

As a CHW you will not be expected to make a diagnosis of schizophrenia. This is done by the Psychiatrist. However, it is important for you to be familiar with the main symptoms of the illness, as persons with schizophrenia and their families will want to know about them, and since you will need to tell them how to manage these problems better during your engagement with the family.

1.2.8 Some important facts about schizophrenia:

SCHIZOPHRENIA IS AN UNCOMMON ILLNESS.

Schizophrenia is an uncommon disease when compared to some others like TB or diabetes. It affects roughly 3-5/1000 in the population at any given point of time. Though the disease is found in all parts of the world, there are different rates of the disease within countries, for reasons that are not clear at this time. In India, for example, the rates of schizophrenia seem to be in the lower range, and people in rural areas have lower rates compared to people living in crowded big cities.

MEN WITH SCHIZOPHRENIA TEND TO HAVE WORSE OUTCOMES.

Although schizophrenia affects both men and women, the disorder often appears earlier in men, usually in the late teens or early twenties. Women are generally affected in their twenties to early thirties. Again, for reasons that we are not clear about, women with schizophrenia tend to have better outcomes in terms of recovery and persistence of symptoms.

PEOPLE WITH SCHIZOPHRENIA TEND TO DIE EARLIER.

One of the most consistent and troubling findings is that people who develop long-term or chronic schizophrenia tend to die earlier, when compared to other persons of their age and sex in their local population. There are two main reasons for this: high rates of suicide, and death due to poor physical health. One of the main aims of your work as a CHW is to try and provide support for improving physical health, and identifying and responding to suicidal risk.

MANY PEOPLE WITH SCHIZOPHRENIA RECOVER FROM THE ILLNESS.

Previously, it was thought that people with schizophrenia could not get better and recover from their illness. However, we now know that schizophrenia has many different long-term outcomes. Up to a third of all people with schizophrenia recover completely, and another third has acute symptoms at some points, followed by periods of stability. Only between 20-30% of people with schizophrenia have continuous symptoms and poor outcomes.

We also know that the severity of the problems in most people with schizophrenia becomes less over time. The first 2 years of the illness are the most difficult, with continuous symptoms, marked problems in functioning, and time spent in hospital. After 5 years, there is a general but slow improvement in the overall severity of the illness.

There are other possible factors that can help predict the course of the illness. As we have discussed earlier, women tend to do better than men. There is also strong evidence that developing the illness suddenly and being well adjusted before the illness started usually means that recovery is likely.

Unfortunately, in spite of knowing about these, we are not able to accurately predict the future behavior of the illness in particular individuals with schizophrenia. Nevertheless, having an optimistic outlook (‘recovery is possible’) is necessary and justified.

1.2.9 What causes schizophrenia?

In the last few years there has been a great deal of progress in our search for the causes of this illness. At present, we understand that there is no single cause for a person developing schizophrenia. Instead, and similar to other chronic diseases, it is likely that schizophrenia develops due to interactions between inherent biological problems of the individual and the environment, especially in early life and young adulthood.

The important point to understand is that most chronic diseases, including high blood pressure, diabetes, cancers and schizophrenia, develop when there is a particular interaction of inherited and environmental factors. We all know that diet rich in sugar and fats and low levels of exercise contribute to a person developing high blood pressure or diabetes. In countries where diets are rich in meat and fatty food, the rates of these diseases are high compared to places like Japan, where the diet is more balanced. Therefore, even if one had the inherent biological tendency to develop diabetes, living in Japan makes it less likely that diabetes will develop as the healthy diet reduces the risk. In schizophrenia, we are beginning to understand the nature of these interactions.

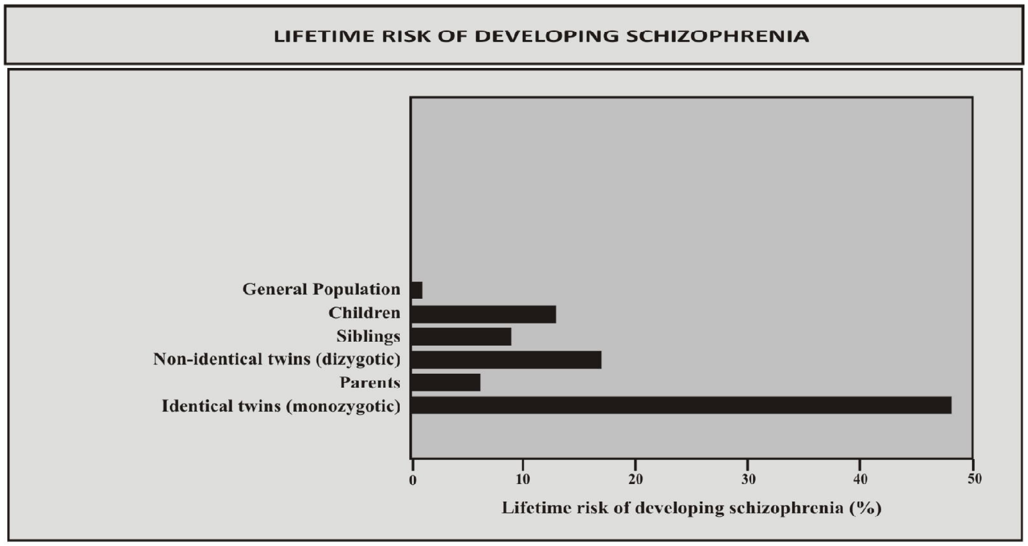
1.2.9 A) The inherited (genetic) reasons for developing schizophrenia:

Many diseases tend to occur in some families more than in others. The reason why certain families have an excess of a particular disease compared to the general population is because of their inherited genes. Genes are the basic building blocks of our body (including the brain) which are passed on by our parents, and are responsible for characteristics like the color of our hair, height, blood group and physical appearance. With recent advances in the understanding of how genes work and express themselves, we are able to identify why having certain genes puts people at a high risk for developing a particular illness. For example, we are now increasingly able to predict why people develop cancers, diabetes and heart disease based on whether they have a certain ‘high risk’ genetic profile.

There is clear proof that schizophrenia runs in families, and that the risk of developing schizophrenia increases as the degree of genetic material is shared. For example, the risk of developing schizophrenia is the highest in twins who share the same genetic material; the risk is progressively lower as the degree of shared genetic material gets lesser. This interesting relationship is shown in Figure 1.2A below.

However, in spite of a lot of effort, we cannot identify clearly which genes are actually responsible for the illness and whether a particular individual at risk will actually go on to develop the illness.

Fig 1.2A: Life Time Risk of Developing Schizophrenia



Lifetime risk of developing schizophrenia in relatives of schizophrenic individuals.

At this time we are able to identify some of the specific biological problems that are involved in the structure and function of the brain. One of the most well known abnormalities is in the chemical makeup of the brain, with some specific chemical messengers (neurotransmitters) being unbalanced. Also, the normal maturation of the brain is affected in people with schizophrenia due to the presence of abnormal genes.

However, we are yet to find a consistent abnormality (like high blood sugar in diabetes) which can be used as a reliable test to say that someone has schizophrenia.

1.2.9 B) The role of the environment:

We know that inherited genes play an important role. We also know that even with identical genetic material, the risk does not exceed 50-60%, meaning that the environment is equally important in a person developing the illness.

There are specific social and other environmental factors which increase the risk of a person developing schizophrenia. These include having problems at birth, living in deprived and poor areas of cities, being a migrant and living in a neighbourhood without much support and using cannabis (ganja/ bhang/ hash) repeatedly during adolescence and young adulthood.

1.2.10 The social consequences of schizophrenia:

Our early adulthood is a period in which very important life experiences happen. This is a crucial time of life when one completes his studies, starts working, and forms intimate relationships.

Schizophrenia most often develops during early adulthood, and can have a devastating impact on the person's life, as well as on the family. Due to the illness, many people with schizophrenia are not able to complete their studies, find employment or have intimate relationships. As a result, they become cut off from their friends and relatives, and become isolated and lonely. Young people with schizophrenia are often painfully aware that they are 'different', and can lose confidence and self belief. The terms 'madness' and 'mental illness' have very negative meanings in most societies, including in India. Very early in life we become used to the negative meanings of these words, fact that is reinforced by the frequent media comments about mentally ill people being 'funny' or 'dangerous'. As a result, people have negative attitudes towards those with serious mental illnesses, and do not treat them with respect. These social attitudes add to the existing problems and impair recovery.

Some people believe that 'mental imbalance' is caused by evil spirits and other supernatural forces. That is why many people with schizophrenia are often taken to places of traditional healing (temple, church, dargahs, etc.) before going to a doctor.

Due to the acute shortage of Psychiatrists in India and other low-income-countries only a limited number of people with schizophrenia have the chance to meet a Psychiatrist. The sum of the loss of earning potential with the costs of the treatment has a major impact on the finances of the family. Parents who are becoming older worry about the future of their son or daughter with schizophrenia after their passing away and caring for them becomes a burden and a reason for quarrels in the family.

Sometimes, overcoming social problems becomes a bigger barrier to recovery than the illness itself. Therefore, a broad range of medical and social treatments and support are necessary to improve the person's quality of life; CHWs, therefor should focus their attention on developing the capacity of the person with schizophrenia and their families to manage their social problems.

1.2.11 What are the special treatment needs for people with schizophrenia and their families?

Based on the understanding of schizophrenia, it is clear that treatments are necessary to manage the biological changes that lead to the symptoms, as well to help the person and the family cope with the challenging social consequences of the illness. As in many other chronic diseases, we cannot cure the illness completely, but there are several therapeutic options available to manage the illness. Like in most chronic diseases, we follow the principle that medicines need to be combined with changes in lifestyle, such as healthy diet, exercise or stress management. The management of schizophrenia can be challenging due to a number of reasons, which are detailed below.

- Before starting treatment we need to understand that people are all different in the way they cope with illness. Hence, *there is no one way of treating everyone with schizophrenia.* Instead, the general *principles of treatments need to be adapted to the particular situation of the person with schizophrenia and their families* in a thoughtful manner. In other words, we need to know the priorities of the person and his family members, and then work with them as partners to solve the problems.

- Besides the symptoms of the illness, people with schizophrenia have other problems such as difficulties in performing their social roles and feeling rejected by others. As you can understand, not all these problems can be sorted out by the use of medicines alone, so even when symptoms are well controlled, problems in other areas of their lives persist. In order to manage these problems and recover theirquality of life, there are various *effective treatments that are now available.*

- People with schizophrenia and their families may experience negative attitudes and discrimination in various social situations. For example, the person might find it hard to visit a friend, might feel that other people will laugh at him if he goes out, or might feel that people will not even consider a job application. This feeling of exclusion affects the confidence and self worth, and makes people believe that they cannot actually do anything successfully for themselves. It is vital to be aware of this problem when working with someone who has schizophrenia, and ensure that all your interactions are respectful, understanding and make the person feel valued. *Fighting discrimination and promoting the dignity of the individual is as important as controlling symptoms, and should be an essential component of the treatment.*

- *Recovery in schizophrenia is a long-term goal and a journey that has to be made.* There will be good and bad days in this journey, and it may be easy to get tired of fighting the illness and give up. Support and encouragement for the person, and getting the family to take a constructive role in this journey are important. We believe that it is unfair and difficult to expect that the person and the family will work towards recovery by themselves. This is why it is so important to have someone who can help and guide the person and the families managing the illness and the social problems.

- *As a CHW , you will play this crucial role and enable positive changes to be made in the persons' life by coordinating their overall treatment, helping them overcoming obstacles to recovery, and providing the means for real differences to be made.*

1.2.12 Why should CHWs work with people with schizophrenia and their families?

Although an uncommon illness, schizophrenia affects young people, often causing long-term problems and leading to several personal and social difficulties. While commoner health problems like malnutrition, mother and child health, and control of infectious diseases deserve more attention in low-income-countries, the fact is, that schizophrenia contributes very significantly to the national burden of illnesses in these countries. However, the care for people with schizophrenia has not received much interest, possibly due the pervasive discrimination associated with mental health. The situation is especially distressing since we do have effective treatments, but cannot deliver them in the context of resource limitations.

In a country like India, people with schizophrenia are often unable to get the necessary treatments. This is due to lack of easily available mental health specialists, the high costs of long-term care, and stigma related to the illness and to 'mental hospitals'. Even when people can access treatment, the focus is almost exclusively on the use of medicines. As a result of all these barriers and challenges, most people with schizophrenia do not receive the quality of care they need and deserve.

What can be done to provide quality care to more people with schizophrenia in countries like India?

- Provide the majority of the treatments in a convenient manner at home (community care)
- Provide a range of need-based effective treatments (medical, psychological and social) for best results
- Deliver treatments in a way that enhances the dignity and rights of persons
- Involve family and society in providing effective treatments, based on mutual trust and collaboration.

If we are to deliver care for people with schizophrenia according to the principles we just described, we need to rethink how and who can actually deliver the treatment package. The individual doctor cannot provide the whole range of necessary services, and non-medical treatments can be efficiently delivered by lay persons who need not have any previous experience or formal training in mental health care.

These additional non-medical treatments include home visits, providing information on how to manage the illness, supervising medication adherence, and improving social situation.

Community based mental health programs consist of a team that includes the treating doctor and CHWs. These are people like you, trained properly and given ongoing supervision from professionally trained mental health staff, like Psychiatrists. You are in the crucial and unique position of establishing the connection between the ill person, the family, and the doctors, while providing the much needed support.

THE IMPORTANCE OF YOUR WORK AS A COMMUNITY HEALTH WORKER (CHW) IS TO HELP PEOPLE WITH SCHIZOPHRENIA AND THEIR FAMILIES UNDERSTAND THE ILLNESS, AND PROVIDE THEM WITH A NUMBER OF METHODS TO DEAL BETTER WITH THE PROBLEMS.

Summary

- The term schizophrenia was first used more than a hundred years ago
- Schizophrenia is a relatively uncommon illness that usually starts in early adulthood and can be persistent for long periods
- Symptoms of schizophrenia can be broadly classified in 3 categories- ‘positive’, ‘negative’ and ‘problems with processing information’
- We know some important facts about the reasons for the many different course of schizophrenia
- We are beginning to understand in more detail the genetic and environmental reasons that are linked to schizophrenia
- People with schizophrenia and their families face many social difficulties in countries like India and have special needs
- Your work as a CHW is very important in meeting these needs and helping people with schizophrenia recover

CHAPTER 1.3

Why do some people develop schizophrenia?

1.3.1 Introduction:

In the previous chapter we learnt that schizophrenia is linked to both hereditary (genetic) factors and the environment. It has become increasingly clear that neither genes nor environment, by themselves, can explain the risk of developing schizophrenia. Rather, it is *the interaction of the genetic structure of a person and particular kinds of negative environmental events that make a person more likely to develop the illness.* The most useful and simple way to understand this interaction is the *stress- vulnerability model*. Before we discuss the model, let us familiarize ourselves with the two key words-*stress and vulnerability* that we will be using in this chapter.

1.3.2 What is vulnerability?

The word vulnerability describes a greater possibility of developing an illness at some time in a person's life compared to others. This can sometimes be due to the person having a specific genetic makeup that increases the risk of developing the disorder. For example, many disorders that lead to intellectual disability are caused by a single malfunctioning gene. Chronic disorders, like diabetes, high blood pressure and schizophrenia, are caused by a number of genes having small individual effects. At this time, we do not know for certain which genes contribute to the vulnerability of developing schizophrenia though there are many possibilities or 'candidate genes'.

Not everyone who has a genetic vulnerability will develop schizophrenia. This means that the environment is equally important in the development and outcome of schizophrenia. The word environment is broad terms that includes our family, friends, social circumstances and the place where we live, work and interact with others. Environment *exerts a negative effect on the vulnerable brain* through a mechanism called *'stress'*.

1.3.3 What is stress?

Over the last few years, the words stress and tension have become part of the common language. In general, stress is commonly understood in mechanical terms, and is often compared to having an excessive physical load being placed on a person. While some stress is bearable, beyond a certain threshold there is a 'breakdown' of the person's ability to deal with daily life. Stress can worsen or bring on health problems, create difficulties in close relationships, and have a negative influence on studies or work performance.

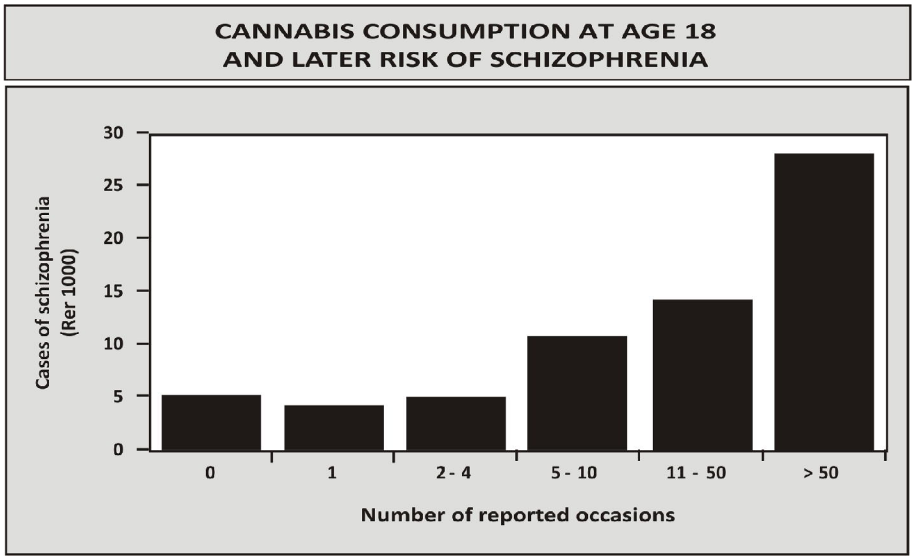
QUITE SIMPLY, STRESS CAN BE DEFINED AS ANY EVENT OR EXPERIENCE THAT DISTURBS THE BALANCE OR THE ABILITY OF THE PERSON TO FUNCTION SMOOTHLY.

In the context of schizophrenia, stress increases the possibility of individuals developing schizophrenia or experience a worsening of the existing illness. Some specific factors within the larger environment can increase the risk of developing schizophrenia; these particular factors are called 'risk factors'.

Risk factors for developing schizophrenia:

- Birth complications
- Mother developing influenza in the first 3 months of pregnancy
- Older father at the time of birth
- Living in cities
- Being a migrant and living in an area with few other migrants
- Smoking cannabis repeatedly during adolescence

Fig 1.3A: The Stress –Vulnerability Model of Schizophrenia:

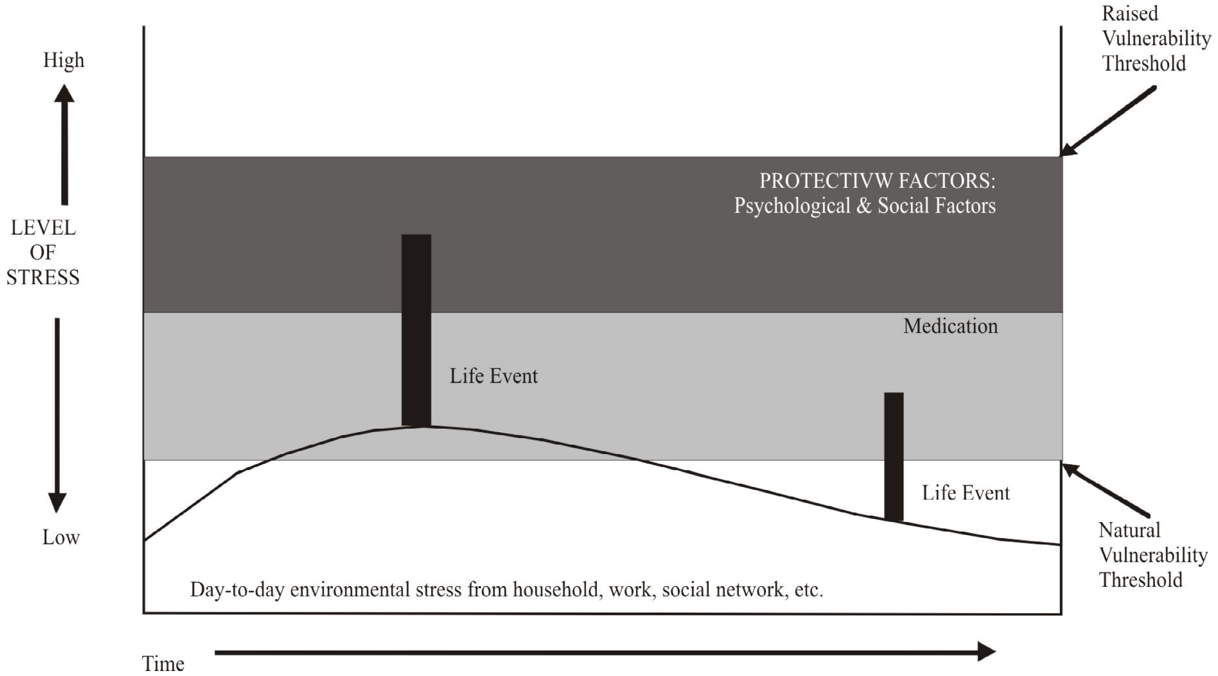


1.3.4 How do stress and vulnerability interact?

We are only beginning to understand the way in which something stressful in the environment influences the brain to react in a particular manner. In schizophrenia, the most common explanation is that stress changes the levels of certain chemicals in the brain (neurotransmitters). One such chemical is dopamine.

AS A NORMAL RESPONSE TO COPE WITH STRESS, DOPAMINE LEVELS INCREASE IN CERTAIN AREAS OF THE BRAIN.

Because of specific genetic vulnerability, people with schizophrenia are unusually sensitive to the effects of the increased dopamine. It is believed that the positive symptoms of schizophrenia are one of the consequences of this increased sensitivity.



1.3.5 How is the stress-vulnerability model useful for treatment?

The stress vulnerability model is a useful way to understand the nature of the illness- the beginning as well as the subsequent pattern of fluctuating symptoms. Very importantly, the model allows us to explain the nature of the illness to persons with schizophrenia and their families. It also helps understand the overall treatments necessary for schizophrenia.

Reduce biological vulnerability:
As in many other chronic medical conditions, there is no cure for the biological vulnerabilities in the brain of people with schizophrenia. However, medicines can reduce symptoms and the risk of relapse, as they do for other long-term diseases like diabetes and high blood pressure. Though the medicines we have at this point of time are not perfect, they are the most powerful way of reducing the biological vulnerability in schizophrenia, and their long-term use is essential.

Reduce stress in the person's environment:
Reducing the stress of the person with schizophrenia is a very important part of the treatment. While no one can avoid stress completely, improving family relationships, practicing stress management techniques regularly, exercising and working regularly (at home or outside) can help reduce the personal experience of stress. Similarly, helping the person cope with difficult symptoms can improve the person's ability to deal with stress.

While planning therapeutic interventions for people with schizophrenia and their families, the stress-vulnerability model is a useful starting point. Medicines by themselves play a limited role, and should be backed up by a range of simple and effective activities, as well as with the provision of support and hope.

These measures are usually not part of treatments in India, and you are the most important person to fill the gap. We expect that the package of medical, personal and social treatments that you will be trained to provide will improve the overall functioning of individuals with schizophrenia.

Summary

- Some people have an inherent vulnerability to develop schizophrenia due to their genetic makeup and some social risk factors
- Stress can increase the possibility of developing schizophrenia in those who are already vulnerable
- The stress- vulnerability model is useful for understanding, communicating and treating schizophrenia

CHAPTER 1.4

The symptoms of schizophrenia

1.4.1 Introduction:

You will be working with people with schizophrenia, who may be quite unwell and experiencing the acute phase of the illness. Hopefully, with your help, these symptoms will improve. In this section, we describe the different phases of the illness that you are likely to encounter in your work.

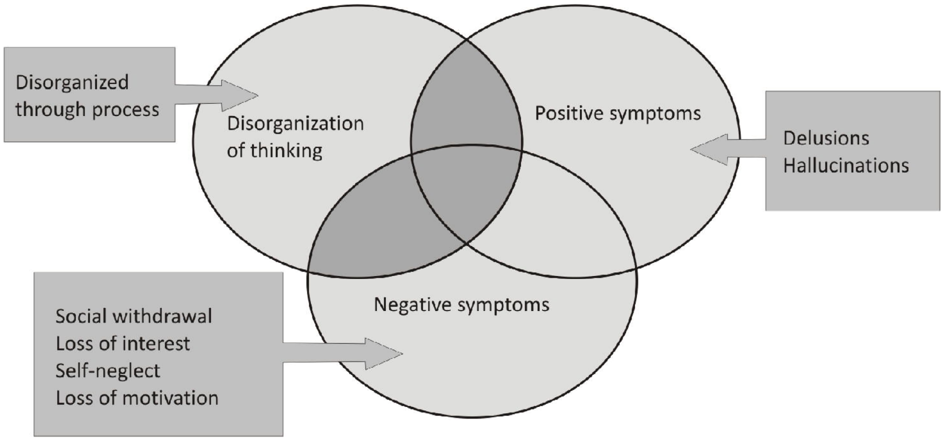
1.4.2 Symptoms in the acute phase:

As we said in Chapter 1.2, the symptoms of schizophrenia can be broadly divided in to 3 groups:

- 'Positive' symptoms
- 'Negative' symptoms
- Symptoms due to disorganized thinking

As shown in Fig 1.4A, people with schizophrenia usually experience a mixture of the three types of symptoms. In the acute phase, the predominant symptoms are the positive symptoms and disorganized thinking. These symptoms reflect the person's break with reality and their altered interpretations of the world. The world feels strange and unusual and everyday experiences take on a different meaning. Things may seem special, indicated by supernatural forces, or filled with religious significance.

Fig 1.4A: The Symptoms of Schizophrenia



1.4.2A) Positive symptoms:

'Positive' does not mean that the symptoms are good for the patient, but that they are beyond the usual range of experiences. However, it is not that they are unique to schizophrenia, and can also be seen in other mental illnesses, as well as in normal people under certain circumstances. An easy way to understand this is to think of situations where the 'mind plays tricks on you' and you hear something like a particular line of a song or wake up thinking that someone is calling you. However, in schizophrenia, these symptoms continue, gradually become more prominent and noticeable to others, distressing to the person, and disruptive to his usual life. Some of the positive symptoms are hallucinations and delusions.

> ***Delusions*** – We all believe things with great conviction and invest a lot of emotion into them. For example, some of us believe in some particular religion and the associated rituals, that good will overcome evil, that men are superior to women, that politicians are corrupt and inefficient, or that the mentally ill are violent and dangerous. Beliefs are based on our shared and personal experiences of the outside world. Accordingly, when circumstances change, our beliefs may change as well, for example, if we meet an honest politician or someone with schizophrenia who is mild mannered and polite. Delusions are beliefs with sense of ownership and emotional attachment.

DELUSIONS ARE 'ABNORMAL 'BELIEFS BASED ON UNIQUE ('FALSE') PERSONAL EXPERIENCES THAT NO ONE ELSE UNDERSTANDS OR AGREES WITH. THESE FALSE BELIEFS ARE STRONGLY HELD IN SPITE OF EVIDENCE SUGGESTING OTHERWISE, THEY WILL NOT BE SHAKEN BY ATTEMPTS TO REASON WITH THE PERSON.

Some of the common types of delusions seen in schizophrenia are:

- *Paranoid delusions*, or *delusions of persecution*: for example, believing that people are "out to get" you, are doing things to harm or hurt you, or trying to poison your food.

- *Delusions of reference:* when things in the environment seem to have a special meaning for you. For example. it may seem as if people are talking about you, or special personal messages are being communicated to you through the TV, radio, or other media.

- *Delusions of grandeur*: when you believe that you are very special or have special powers or abilities. An example of a grandiose delusion is thinking that you are the 'chosen' savior of the world.

- *Delusions that your thoughts are known to others*: feeling that others can read your mind or that your thoughts are being broadcast to the outside world against your wish.

Hallucinations – The world around us is full of experiences that we record through our five senses. These are somewhat like our antennas to the world. We hear, see, taste, smell and touch things around us. These sensations are fed in to our brain, which makes sense of the experience and gives it a particular meaning and emotional value. For example, when we hear good music or taste good food, our brain tells us that it is a good experience compared to hearing vehicle horns on the streets. We are also able to clearly understand that these experiences are happening 'outside' of us. Most of the time we take this ability of the brain for granted and are not even aware that an active process of integration is going on continuously where the brain is making 'sense' of the chaotic outside world.

Sometimes, in circumstances where the brain is confused or altered, like having high fever, using drugs or being half awake, we can have strange experiences as well. In schizophrenia, the part of the brain responsible for processing external experiences is affected, which leads to strange experiences where the person hears, sees, feels, smells or tastes things which are simply not there.

HALLUCINATIONS ARE ABNORMAL SENSATIONS IN THE ABSENCE OF AN EXTERNAL, CORRESPONDING EVENT, SO THE PERSON MAY HEAR, SEE, FEEL, SMELL OR TASTE THINGS THAT ARE NOT PRESENT.

Even though the experience is happening in the absence of an actual event, the brain tricks the person in to believing that what is being experienced is actually happening outside. To the person with schizophrenia, these experiences are as 'true' as your experience while reading this page.

In schizophrenia, the most common type of hallucination is the experience of hearing 'voices' when there are no people talking to the person in reality. The person may hear a single or many voices that may comment on his behavior, order him to do things, warn him of an approaching danger, or talk to each other about him.

Disorganized thought and speech- During the acute phase, another group of symptoms are caused by the disorganization or disruption of the brain's ability to think clearly and logically. If delusions are problems in 'what we think', disorganized thinking refers to problems in 'how we think'.

THOUGHT DISORGANIZATION REFERS TO PROBLEMS IN HOW WE THINK. THESE UNUSUAL THOUGHT PROCESSES ARE REFLECTED IN THE WAY WE SPEAK.

When thinking becomes disorganized, the person has difficulty organizing his thoughts or connecting them logically. Speech may become jumbled or hard to understand, as the person may jump from topic to topic in a haphazard manner. Sometimes, the person experiences 'thought blocking', where the person stops talking abruptly in the middle of a sentence. When asked why, the person may say that it felt as if the thought had been taken out of his head.

ONE OF THE MOST PECULIAR AND DIFFICULT SYMPTOMS OF SCHIZOPHRENIA IS THE *LACK OF AWARENESS* AND DENIAL OF HAVING AN ILLNESS, WHICH OFTEN LEADS TO TREATMENT REFUSAL.

Sometimes, the person understands that 'something is not right' and feels that the problem is due to black magic or other supernatural causes. Over time, many people start understanding that they might be having a problem that needs to be managed more actively.

1.4.3 Symptoms in the stable phase:

With - and, sometimes, without treatment - in most people with schizophrenia, the acute phase passes and the person enters a period of relative stability, with a reduction of positive symptoms. This does not always mean that the person has recovered; actually there are often a distinct set of symptoms that continue to be present. These symptoms are more subtle and difficult to understand and to manage, and can have a negative impact on the quality of the person's life.

1.4.3A) Negative Symptoms:

Negative symptoms refer to the loss or reduction of the person's emotional range, level of motivation, spontaneous conversation and a general loss of interest or spark in life. If these are not managed, the person becomes dull, does not want to take care of his personal hygiene as before, hardly talks to friends or family, spends a large part of time by himself, and generally does not seem to care about anything in particular. These negative symptoms are often misinterpreted as the person being deliberately lazy or not making an effort, which can make the family turn hostile towards the person. Some specific types of negative symptoms are described below.

- *Reduced quantity and quality of speech*- the person speaks less fluently and slowly; hardly makes spontaneous conversation and replies in monosyllables (yes, no).

- *Reduced emotional range*- the person hardly reacts emotionally to anything happening around him, does not laugh at funny things nor becomes sad as others. Instead, there is a general lack of facial expression and eye contact, and the person seems very distant from his immediate world.

- *Lack of motivation*- the person does not seem to be interested in doing anything and spends most of his time doing nothing useful. The progressive lack of interest might extend to personal appearance (shabby clothes, unshaved), hygiene standards (dirty nails, poor teeth), lack of hobbies and interests (watching TV, reading, listening to music) and day-to-day household duties like cooking and cleaning.

As you can imagine, these symptoms affect the basic identity of the person, and accepting this is the most difficult thing for families. The sense of loss and grief in seeing their active, friendly and caring relative become progressively withdrawn, emotionally disconnected and lost in his own world is hard to describe. The additional problem is that negative symptoms do not respond very well to current treatments and require more sustained efforts like rehabilitation.

1.4.3B) Difficulties in attention and concentration:

During the stable phase, another set of symptoms are related to significant problems in attention and concentration. As such, the person can have difficulty in understanding what is being said, becomes easily forgetful (such as having difficulty in remembering the sequence of doing everyday things, like putting masala and salt in the cooking), cannot concentrate on studying, reading a book or watching TV.

These problems mean that the person requires a lot of effort to do things that were almost effortless before, like writing a letter or negotiating prices at shops. Another negative effect of the lack of concentration is the impact on either returning, finding or sticking to a job.

Summary

- The symptoms of schizophrenia can be broadly classified in 3 groups-‘positive’, ‘negative’ and ‘problems with processing information’
- Positive symptoms include delusions, hallucinations and disorganized thinking and speech
- Positive symptoms are more evident in the acute phase of the illness
- Negative symptoms like lack of motivation, reduced emotional responses, limited speech and indifference to the environment are distressing and a challenge for treatment
- Difficulties with attention and concentration are also an important problem in the stable phase of the illness that affects work and social functioning

CHAPTER 1.5

The Course and Outcome of Schizophrenia

1.5.1 Introduction:

As we mentioned earlier, people with schizophrenia are all different individuals who are faced with specific life circumstances. Since any illness is greatly influenced by the individual vulnerabilities and the social context, there is also great variation in how schizophrenia unfolds over time. This is true also for other chronic illnesses like cancer and HIV/AIDS. In spite of this variation, it is useful to understand the broad patterns of an illness, and the associated individual factors, the treatments, and the social environment. This is done by studying groups of persons with schizophrenia over a period of time, and recording various aspects of their life and what happens to their illness. A group can be studied continuously for some years, although this requires a lot of money and resources. By now, we have a large amount of information about the patterns of schizophrenia in people from many parts of the world. Describing these patterns is the focus of this chapter.

1.5.2 What do we mean by the words course and outcome:

When we talk about the *course* of an illness, we refer to *the path or progression of a particular disease*- the improvements or worsening happening over a period of time. For example, we would like to know whether the illness is incurable (life-long) or if people affected by the illness recover. Again we would like to know whether the problems with the illness increase or decrease with time. In schizophrenia, we know that there is a gradual improvement in the overall illness for most people after the first 5 years.

We may also want to know how the group with the illness is doing at a specific point of time. *Outcome refers to this one time measure (as opposed to continuous observation) of all members of the group* in order to get a good idea of the overall function of the person at that point of time. In other words, it is a measure of the stage of the illness at a given point in time – 1, 2, 5, 10 years and so on.

Some other terms that you need to be familiar with are:

1. Remission- absence of symptoms for a period of at least 6 months
2. Relapse- reappearance of symptoms after a period of well being
3. Residual symptoms- continuing symptoms at a low intensity

The term "cure" is generally not used in the context of schizophrenia. When the person improves from the acute illness, his symptoms become less troublesome and he is able to function better. At this time, the person is said to be in a state of partial or complete *remission (absence of problems*). After being in a state of remission for at least a month, if there is a *reappearance of symptoms,* then it is termed a *relapse.* It will be necessary to examine the person with schizophreniacarefully during relapse and suggest changes in medication if necessary.

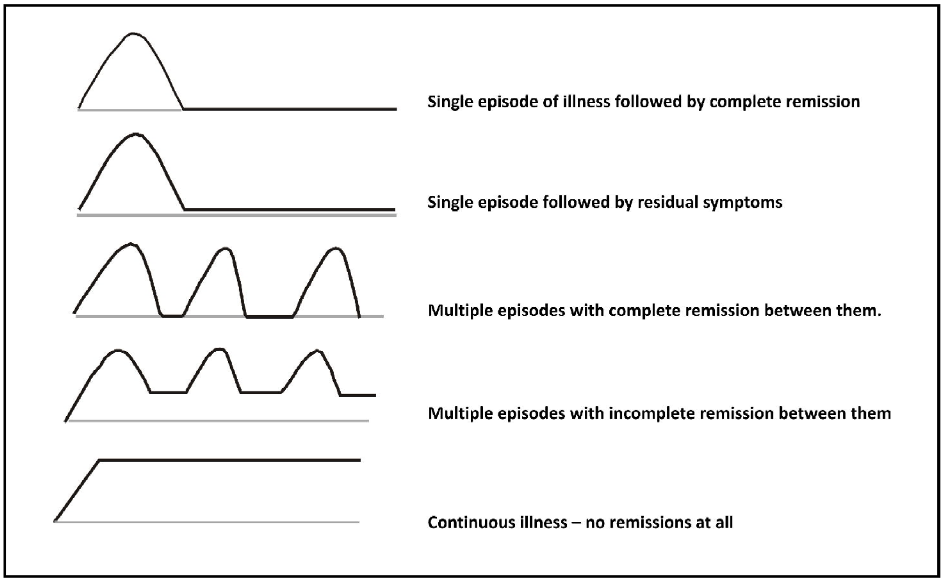
Some persons may continue to have few negative symptoms such as lack of motivation, slowing or under activity that can affect their functioning. This phase of the illness where the *low grade symptoms (residual symptoms)* and difficulties in personal, social and emotional life continue is called the residual stage.

1.5.3 What are the different types of course in schizophrenia?

The main types (patterns) of course seen in schizophrenia can be conveniently understood as:

1. Single episode of acute illness followed by complete remission
2. Single episode followed by residual symptoms
3. Multiple episodes with complete remission between them
4. Multiple episodes with incomplete remission between them
5. Continuous illness – no remissions at all.

The most common course of the illness is either Type 3 or 4.



1.5.4 Which outcomes are important for people with schizophrenia?

As a single measure is very unlikely to give an overall picture of the person's functioning, we measure several outcomes (the person's functioning at home, at work and his interactions with others) at different points of time for the same individual. In doing so, different results can be obtained over time. For example, at the time of starting treatment it is likely that the problems are very prominent, while with treatment and other support outcomes can be much better at 1 year.

As we mentioned, we usually measure a number of different dimensions of the person's current status, and then use them to understand whether outcomes are good or less than expected. The most common outcome measures are:

- *Clinical functioning*: this is measured by improvement/ persistence/ worsening of symptoms, the difficulties in performing expected roles, number of relapses, days spent in hospital, among others.
- *Social functioning:* ability to relate to others, act appropriately in social situations, etc.
- *Work performance*: work at paid jobs, housework, studying, and work in a special (sheltered) environment.
- *Quality of life*: what the person feels and expects about his own life.

Good outcome in one of these areas does not necessarily extend to the others. A person may not have any symptoms, but his social functioning can be affected resulting in inability to hold a job. It is also possible that people with hallucinations or delusions may be able to work well and keep their jobs.

1.5.5 Which factors determine outcomes?

Some of the common factors that are associated with **good outcomes** of persons with schizophrenia are:

- Female gender
- Sudden onset of the illness (absence of long early phase)
- Less negative symptoms and problems with thinking
- Good social and emotional adjustment before the illness
- Good family support and encouragement
- Treatment started as early as possible
- Continued treatment with medicines

Similarly, we are also aware of some factors that can predict **poor outcomes**. These are:

- Male gender
- Those who are unmarried or separated
- Earlier age of onset of illness
- A slow and gradual onset of illness
- Delayed start of treatment and early discontinuation of the treatment
- Poor social support and many experiences of discrimination
- Hostile family attitudes toward the person
- Use of alcohol and drugs of abuse like nicotine, cannabis, heroin, etc
- Poor physical and dental health

Summary

- The pattern or course of schizophrenia is very diverse; most often people have an up and down course of the illness
- Many people with schizophrenia also recover from the illness
- The important outcomes for people with schizophrenia are related to treatment, dealing with the social and economic consequences of the illness and better overall quality of life
- There are some factors that determine or good or poor outcomes in schizophrenia

CHAPTER 1.6

The disabilities caused by schizophrenia

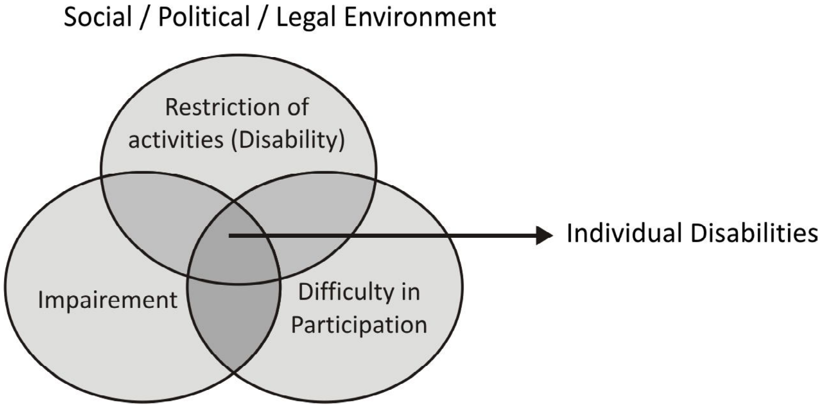
1.6.1 Introduction:

As you can imagine, the nature of the symptoms are such that they have a negative influence on the overall life of the individual. For example, individuals with schizophrenia often hear voices and talk back to them loudly. This is considered to be odd and inappropriate by others around him, and can have a very negative impact on the person's social interactions.

One of the major consequences of developing schizophrenia is the significant loss of the person's ability to 'be himself' and meet his expected personal, social and employment roles. Schizophrenia is a difficult illness to deal with because of the loss of potential. This loss of potential ability is one of the most important areas to respond to in the treatment of people with schizophrenia, and is the focus of this chapter.

1.6.2 Key concepts related to disability:

Before proceeding further, let us understand some of the terms we will be using in this chapter in more detail.



Body functioning refers to the ability of a person to perform certain tasks like walking, thinking, feeling or seeing and hearing clearly.

Impairment refers to problems in doing one or many of the body functions as before, and is therefore a reduction from previous levels. This may include difficulty in hearing properly or thinking as clearly as before.

A disability is the other word for describing *restriction of activity* that results from the impairment. For example, someone who has a fracture of the leg cannot walk (impairment) which prevents (restricts) him from doing his usual things like getting up from the bed, going to the toilet or going down the stairs to have breakfast. People with schizophrenia are often not able to go out of the house, to the market or to work, which restricts their usual activities.

As a result of the impairment or the disability, a person might have significant difficulties in participating in the whole of our usual life situations, like going for a vacation with a group of friends, taking part in festivals, attending marriages, voting for local elections, etc (*difficulty in participation*).

The experience of disability is very much a social experience and depends on the nature of the *environment and the individual*. In many countries, there have been a number of positive changes made to the lives of people with physical disabilities through social action and development of infrastructure. However people with schizophrenia have not been so fortunate. Public attitudes and reactions to schizophrenia are often in negative terms, and this affects the dignity and the rights of the individual.

Some people are naturally more positive and optimistic than others, which makes them deal better with difficulties in the long run.

1.6.3 Disabilities in people with schizophrenia:

Schizophrenia is usually associated with difficulties in role functioning. For example, a housewife may face problems in managing the finances of the house as before or difficulties in organizing the daily routine as smoothly. Similarly, students with schizophrenia often find it difficult to manage their studies and have poorer marks in examinations. Often, people with schizophrenia feel very bad about their inability to function as before.

A young woman with schizophrenia describes her situation:

> *"There are lot of differences with what I am now and what I was earlier. Earlier I was able to go out to work. But now I am unable to go out and have to stay at home. I feel why I am like this. Earlier I used to go and do the work but now that work has to be done at home. I feel very bad for this."*

Similarly, family members may not always understand why it is that the person with schizophrenia cannot do things quite in the same way as before their illness and may think, for example, that their family member is just being 'lazy' or negligent. This can lead to arguments at the home, as illustrated by the following statement by a woman with schizophrenia:

> *"Everyday there is confusion and arguments. (...) [My family members say] I don't do all the work, I cannot understand things correctly, then my brother shouts 'how is this bhakri [bread] made, do I have to eat this daily, no rice, bhakri is not cooked', my brother says this. Father says that the curry is spicy, or sometimes he says there is no salt added to the curry. Mother says I don't prepare bhakris well. Arguments start when I make mistakes while working."*

The overall life situation of the person with schizophrenia is the result of a number of factors that are actively interacting with each other. These include the particular impairment, the loss of usually expected activities (disability) and the restrictions in participating fully in public life. All of these are, in turn, influenced by social attitudes towards people with schizophrenia (which are usually negative) and the makeup of the individual.

When assessing disabilities of people with schizophrenia, it is important to remember that these are the result of an ongoing interaction of various personal, social, economic and cultural factors with the particular symptom(s). These are very closely linked so that changes in one area can produce changes in the others as well. For example, if the symptoms are controlled, there will be changes to the disabilities (reduction) and an improvement in person's ability to participate in his social life. Similarly, if an individual finds work, this could improve functioning in other areas as well.

The belief in your potential to make an overall positive change in the life of an individual through appropriate personal and social actions is an important philosophy while working with people with schizophrenia.

The power of this philosophy is illustrated, for example, in the following account by a person with schizophrenia who took part in the COPSI study and now fares much better at work and in other areas of his life:

> *"Earlier at the company, I was put down as lower, they felt I am low down, I could not do anything. Now the company people feel that I can do something. This is the experience. And they earlier used to treat me a bit lowly but now there is a change, they feel that I can do something in the future(...) [Now]I worked my way and got achievement (...) [It was possible because] I had created a confidence in me that I could complete this target for the company"*

1.6.4 The systematic assessment of disability in schizophrenia:

A systematic approach to assessing various dimensions of disability is important as it provides a good idea of the person's current level of functioning, the specific problem areas, and helps identify goals for treatment. The functioning of the affected person is checked by questioning family members, particularly those who live with the patient, and comparing changes in behaviour. The level of disability is assessed by asking if it is occasional (mild), quite often (moderate) or most of the time (severe).

The main areas which are assessed to identify disabilities are detailed below.

1.6.4 A) Self Care

Self-care refers to the attention someone pays to himself (personal care) and in the way he or she presents to others (self-presentation). This is a fundamental requirement in all our lives, and when it is compromised, difficulties in social relationships and at work can be expected.

1.6.4 B) Personal care

The quality of personal hygiene and bodily care need to be identified through:

- Completing morning ablutions
- Shaving
- Combing hair
- Keeping finger nails clean
- Taking bath regularly
- Serving food for themselves when hungry, eating at regular intervals and eating tidily.

1.6.4 C) Self-presentation

The quality of appearance is assessed by:

- Ability to choose clothing
- Washing and keeping clothes tidy.

1.6.4 D) Problems in social interactions

The quality, frequency and extent of contacts that the individual establishes with others should be assessed as follows.

- Ability to express mutual feelings of trust and emotional support
- Capacity to express ideas in a clear way when speaking to others
- Participation in social and community activities
- Ability to handle conflict.

1.6.4 E) Problems in family roles

The quality and quantity of the individual's involvement in family life can be evaluated through the participation in activities such as:

- Taking part in activities like watching TV together, playing games, going out, and helping in housekeeping
- Taking meals along with family members
- Taking part in discussions on family matters, helping in solving problems, and showing interest in the welfare of other members
- Doing all expected household tasks

1.6.4 F) Problems in marriage

The emotional quality of the relationship (as mainly expressed in mutual feelings of respect and trust) should be evaluated in terms of:

- Discussing day-to-day activities and problems with spouse
- Discussing personal problems with spouse
- Having an affectionate and mutually satisfying sexual relationship.

1.6.4 G) Problems in parenting

This concerns the relationship between the individual and his/her own children.

- Attending day-to-day needs such as feeding, changing clothes, putting them to sleep and dropping them to school
- Attending to the problems of the children
- Involvement in joint activities
- Interest in overall development of the child and in future related matters

1.6.4 H) Problems in working

Adaptability to rules and standard procedures regarding work may be assessed through:

- Punctuality in attending to work
- Good performance and interest in work
- Good relations with colleagues
- If unemployed, motivation in finding a job

At the end of the assessment, the areas of disability and the severity of the problems should become clear. As we said earlier, this assessment becomes the basis for planning further treatments that are matched to the particular difficulties in the person's life according to shared priorities.

Summary

- Schizophrenia is a highly disabling illness; disabilities in people with schizophrenia are influenced by the nature of impairments, restriction of activities and social barriers
- A systematic assessment of the disabilities of the person with schizophrenia is an essential part of planning treatment
- The assessment is focussed on three main areas- ability to care for self and manage daily activities, social problems and difficulties related to work
- The assessment will influence rehabilitation needs and activities to address specific disabilities

CHAPTER 1.7

The impact of schizophrenia on the family

1.7.1 Introduction:

In India, families represent the most important resource in the care of people with mental illness. Families are often involved in all aspects of the care of their ill member, such as in the supervision of the regular intake of medication. They also fulfill physical and emotional needs of patients. In every family, there is generally one key person (parent, spouse or child) who takes major responsibility for the patient; this person is called the **Primary Care Giver (PCG),** and obviously needs support from other family members. Certain socially embarrassing behaviors, such as talking and smiling to oneself, irritability and aggressiveness can all cause a lot of distress to the families. If the person with schizophrenia is not working, families often have to compensate for their deficiencies.

1.7.2 Common issues of concern among family members of persons with schizophrenia:

It is important to understand how families react to the illness and disability, and how their own lives are affected by this.

1.7.2 A) Coming to terms with the illness:

Not many families immediately know or accept the fact that their relative has a mental illness. At times, caregivers tend to believe that their loved one cannot suffer from mental illness. During the acute episode family members may be alarmed by what is happening. When the episode is over, everyone experiences a tremendous sense of relief, and may even believe that the symptomatic behavior will never return. Everyone involved wants to forget this painful time and focus on the future.

Families may also look for other answers, hoping that the symptoms were caused by some other physical problem or external stressors that can be removed. Another form of denial lies in the misconceptions surrounding psychiatric medications: a tendency to believe that these drugs would “damage the brain”, or that once treatment is initiated the person should be on medicines for their whole life.

Some family members understand the reality of the illness, while others in the same family may not. Those who accept the truth find that they must protect the ill person from those who do not, who instead blame and denigrate the ill person for unacceptable behavior and lack of achievement.

Obviously, this leads to tension within the family, isolation and loss of meaningful relationships with those who are not supportive of the ill person. And so disruptions in family relationships can be a consequence of schizophrenia.

1.7.2 B) Consequences of stigma and discrimination for families:

Even when families acknowledge mental illnesses, they may be reluctant to talk openly with others about their ill family member, because they fear other people’s reactions. After all, myths and misconceptions surround mental illness. Family members may become reluctant to invite anyone to the home or be anxious about leaving the ill person at home alone, as they may be concerned about disruptive behavior.

For example, the sister of a young man with schizophrenia pointed out that when a friend’s brother had cancer, all his friends were supportive and understanding. But, when she told a few close friends that her brother had paranoid schizophrenia, they said little and implied that something must be very wrong in her family to cause this illness. When others do not accept the reality of mental illness, families have little choice but to withdraw from previous relationships, both to protect themselves and their loved one.

In the following statement, a caregiver explains why she tends to avoid others and does not speak to them about her son’s illness.

> *“If people come to know they will completely fail him (...) meaning they will make him as if good for nothing.(...)They will say completely this like, mad like.(...) I don’t want people to know his defect, with treatment and all let him be alright. And if other people come to know then he will be of no value like because of this (...) in future his marriage time and all. And people make a big thing of small thing the way he is, that is why I don’t go to tell.”*

The issue of marriage is critically viewed when there is a family with a history of mental illness. In Indian communities, where most marriages continue to be alliances arranged by families, the existence of mental illness is often not mentioned before marriage. As a result, marital relations are beset with a sense of being cheated. When the woman is mentally affected, she might be sent back to her parental home. On the other hand, if the man is the person with schizophrenia, it is harder for the wife to leave him, for reasons of social pressures. Even if a woman with schizophrenia is accepted as a daughter-in-law, her in-laws may fear the criticism of others, as illustrated in the following statement:

In the following statement, a caregiver explains that she does not want others to know about her ill daughter-in-law's condition because she may get blamed for not having spotted the condition at the point of matchmaking and bringing an ill woman into the family. She further speaks about how she tries to minimize the chances of others finding out:

> *"I feel [I should not speak about the illness] because they will start speaking things that if she has mental illness then why did we bring her [into the family] as our daughter-in-law? (...) Relatives and neighbors should not know, she needs to behave properly. (...) I convince her and tell her how to behave, she doesn't realize, she speaks loudly or if she goes to attend any function, she hurries, I tell her not to do so, not to behave like that. (...) I make her sit beside me. I make her understand that she should do work which is told to her.(...) [When guests come,] I tell her not to come to the front often at that time, [to] stay in the kitchen and ask others to serve tea or breakfast for the guests"*

In many instances, some caregivers take difficult life decisions for themselves in order to take care of their relative. Sisters and brothers of persons with schizophrenia often decide not to ever marry so that they can take care of their sick relative.

In some instances, the caregivers' own marital prospects can get affected by the illness of a family member, as illustrated in the following quote by a male caregiver:

> *"My marriage got affected because of that [my brother's illness]. No one in this area knows about me but they know that I am from that family. We would go to see the girl for marriage. When they would try to enquire about me, they would mistake me for my brother (...). I would go personally and inform them but they would not accept that"*

Stigma also plays a major role in employment issues. It is seen that even when the person with schizophrenia is symptom free, employers can be reluctant to hire him/her. As a consequence, many a times, persons with schizophrenia do not inform the potential employer that he/she has a mental illness and is under treatment. The result of stigma in so many areas of daily life is that the family becomes more and more withdrawn and isolated from their social supports.

1.7.2 C) The burden of caring for a loved one with schizophrenia:

Families of persons with schizophrenia face many challenges. The concept of family burden illustrates the impact of mental illness on families.

Various aspects of impact on caregivers should be considered, including:

- The economic burden related to the support to the person with schizophreniaand the loss of productivity of the family unit.
- Emotional reactions to the patient's illness, such as guilt, feeling of loss, and fear about future.
- The stress of coping with disturbed behavior.
- Disruption of household routine.
- Problems of coping with social withdrawal or discomfited interpersonal behavior.
- Curtailment of social activities.

Objective burden includes the practical, day-to-day problems and issues related to having a family member with a mental illness, such as loss of income and disruption of household routines. Subjective burden includes the psychological and emotional impact of mental illness on family members, including feelings of grief and worry. Obviously such constant stress and concern can create serious family problems and life become unsettled and unpredictable. Family members may become angry and frustrated as they struggle to get back to a routine that previously they have taken for granted. Sometimes, families feel unable to cope with living with an ill person who must be constantly cared for, and often feel trapped, discouraged or exhausted by the stress of the daily struggle.

This sense of frustration and inability to make any change leads to the family 'giving up' or suffering emotional problems like depression and suicidal ideas.

Children of persons with schizophrenia may also experience stress in several areas. Issues such as not having a parent like other children, difficulties in bringing home friends, being teased by others because one parent is mentally ill are some of the issues. Many children are also aware of the genetic in heritability of the illness, which adds to their burden.

One caregiver described how she had to work harder because her daughter with schizophrenia was not doing her share of the work properly, which triggered uncomfortable observations by others:

> *"In the last one year, she [patient] has not done anything [housework]. I handle everything. People ask me the reason, I cannot tell them that my daughter is mentally sick, or she is haunted. I will generally tell them that she is ill and I am taking care of everything"*

1.7.2D) The economic impact of schizophrenia:

Another important aspect of schizophrenia is its economic impact which includes the costs directly linked to the treatment of the illness (like paying consultation fees, purchasing medicines, hospital admissions and travel costs) and the less easily measurable indirect ones (like loss of employment for the person with schizophrenia and the caregivers' potential for employment).

In India, most of the economic burden related to schizophrenia lies on the family. This includes, for instance, the fee paid to the treating doctor, the cost of medicines or of any clinical examinations, among others. Since schizophrenia is a long-term illness, the accumulated costs are quite high. For many people, especially those from poor economic backgrounds, this can become difficult to sustain and places a great strain on the entire family finances. Some persons with schizophrenia need someone in the family to care for them on a daily basis. This means that the possible income the care provider could have generated by working (if they did not have to provide care) is lost. Adding to this, the fact of having schizophrenia means that people may lose their jobs or not be able to get one. Both scenarios represent a big loss of potential income for the family, and are common examples of indirect costs of the illness.

A young caregiver describes the financial impact her mother's illness had on the family:

> *"We were very prosperous when my mother was normal. We never had any problems. My father was also well. My mother would manage everything including the finances. But when she became like this, our goal was to cure her. So we always thought about which temple we should take her to or which doctor should be consulted. We never cared for ourselves. We never cared for savings or any educational fees. In spite of it, we spent much on my mother. We went to temples, healers and spent money for her. Then we spent much on taking her to doctors. My father would avail a loan and would spend for her. We have gone to all temples and visited all doctors"*

The enormous financial burden faced by family members through the illness often leads to feelings of shame and guilt in the person with schizophrenia and can be a source of intra-familiar tension and uncomfortable reactions towards the ill family member.

In the statement below, a woman with schizophrenia reports how her brothers tease her for having brought poverty onto the family:

> *My brother says "your treatment is on, what should we do, we have become poor because of you. We would have built a nice big house, a bungalow to live in. If you weren't there we would have had our bungalow." Whenever he speaks to me he teases me like this. (...) I feel sad because I got this illness.*

As a consequence of the financial pressures, family members cannot afford to pay for the medication of their family member intermittently, or persons with schizophrenia feel guilty about asking for money for their medicines.

LACK OF MONEY TO CONTINUE TREATMENT IS ONE OF THE MOST IMPORTANT REASONS FOR PEOPLE STOPPING MEDICATION.

Summary

- People with schizophrenia and their family members face many social and economic difficulties
- In India, primary caregivers in the family are the key persons who care for their ill member and need to be supported
- Caring for a person with schizophrenia frequently places a heavy burden on family members
- Stigma and discrimination is frequently experienced by people with schizophrenia and their families
- There can be very negative impact on the financial status of the family die to the treatment costs in schizophrenia, especially for economically vulnerable families

MODULE 2

The Principles and Methods of Providing Care for People with Schizophrenia

CHAPTER 2.1

Overview of the individual treatments in schizophrenia

2.1.1 The philosophy of community interventions:

Community care interventions (collection of individual treatments) are designed to enable individuals and their family members to *develop a sense of control* over the illness. Like many other chronic diseases, schizophrenia cannot be completely cured with the treatments available now. However, there are a number of things that can be done to 'live positively with the illness' and actively manage problems in a manner that improves the overall quality of life. We expect to make a difference to the lives of individuals by collaboratively working together on individual treatments that will involve providing information, setting and working towards achieving mutually agreed goals. As a trained CHW, you play a crucial role in the success of these interventions.

One of the central beliefs of community interventions is that individuals with schizophrenia are able to manage their illness. The key idea of such interventions is to provide them with tools/skills and support them, while they test out the skills in their real lives. Providing hope, working in a mutually respectful manner, helping restore a sense of purpose, learning from failures, and attempting to generate an active sense of coping (as opposed to 'giving up') are the key objectives of the intervention.

The interventions are also geared towards 'making things happen', enabling individuals to get back to an adequate level of personal and social functioning, by working with the family and the local community.

THE CENTRAL IDEA IS TO *CREATE A POSITIVE, SUPPORTIVE AND ENABLING ENVIRONMENT* TO IMPROVE THE CHANCES OF THE INDIVIDUAL MAKING NOTICEABLE GAINS THAT IMPROVE QUALITY OF LIFE.

2.1.2 Guiding principles:

The previous chapters on the nature and consequences of schizophrenia make it clear that planning treatments for individuals and their families is a complex process. To develop a treatment plan, it is essential to have a systematic approach and this chapter describes the components of an effective treatment plan. Before going into the details of the areas which need to be included in the plans, it is important to remember a few important guiding principles:

- *Schizophrenia is a chronic disease*- Schizophrenia is a long-term illness, with periods of well-being and occasional relapse symptoms. The best treatments for this kind of diseases are a combination of medicines and efforts to manage the illness in a more effective manner ('not let the illness determine life completely') through psychological and social interventions.

- *The treatments are better understood through the stress-vulnerability model* - The implications of the stress-vulnerability model (Chapter 1.3) are clear when thinking about treatments for schizophrenia. Firstly, biological vulnerability to the illness can be reduced by the use of medicines. Secondly, reducing stress can improve the course of the illness. Finally, improving the social support available to the individual and the family provides additional protection against the ill effects of stress.

- *The framework of impairment, disability and activity restriction should be used to design interventions*- A clear understanding of the impairments, disabilities and activity restriction caused by the illness (Chapter 1.6) is a very useful way of determining the specific focus of the intervention. For example, positive symptoms (the impairment) cause odd and embarrassing behaviors and prevent the person from doing his expected functions at home and outside (disabilities), which is made worse by the discrimination he faces (activity restriction). All these areas need to be considered when designing treatments.

- *Matching treatments to needs*- As we have learnt, there is a great deal of variation between individuals and families in their particular needs to cope with the illness. Typically, needs depend on the stage of the illness (Chapter 1.5), the phases of treatment (Chapter 2.2), and the social situation of the individual and family. While there is a common framework to such interventions, their process and content need to be delivered in a relevant and acceptable manner to the individual and families. The key thing to avoid is to have the same package of treatments delivered to everyone, irrespective of their actual requirements.

- *Empowering the individual and family to deal with the illness*- Schizophrenia is a very distressing experience for the individual and the family, both due to the nature of the illness and because of the attitudes and discrimination they experience. The empowerment of the individual and the family is one of the most important goals of treatment planning. To achieve this, treatments have to be designed and delivered in a manner that is collaborative, respectful and takes into account the strengths of the individuals.

2.1.3 The specific treatment areas of interest in schizophrenia:

Keeping the above general principles in mind, the following areas need to be specifically evaluated when planning treatments for schizophrenia:

2.1.3 A) Symptom control:

The positive, negative and disorganization of thinking symptoms can be distressing, interfere with functioning, and damage the closeness and quality of relationships. Therefore, treatments to reduce and eliminate symptoms are an essential part of the treatment plans, as they improve the overall quality of life of the individual and the family. The most important methods of doing this are medicines (Chapter 2.2) and coping strategies to reduce the impact of persistent symptoms (Chapter 3.4 D).

2.1.3 B) Managing medicines appropriately:

Medicines will inevitably be a treatment for all individuals with schizophrenia. Medicines need to be taken every day in the doses prescribed by the doctor for relief of current symptoms and to reduce the possibility of relapses. These medicines also have side effects, which often make the individual discontinue the medication. As in any chronic disease, adherence to medicines can often be less than optimum, unless specific measures to increase adherence are implemented (Chapter 3.7). Similarly, assessing the benefits and side effects of the medicines should be an ongoing process and include the help of families, whenever possible.

2.1.3 C) Self care and living skills:

Most people manage to take care of themselves and go through the details of everyday life without much effort. However, this ability to manage the daily demands of life, which we take for granted, is often compromised in individuals with schizophrenia. Grooming, hygiene, money management, use of transportation, shopping, taking care of personal appearance and appropriate clothes, and taking care of health are some of the main areas of concern when assessing living skills. Helping the individual regain the ability to be independent and manage his life adequately is an important part of the overall treatment plans (Chapter 3.2.).

2.1.3 D) Improving role functioning:

The term role functioning refers to the ability to meet socially defined roles such as at school, at work, as a parent or a spouse. Difficulties in meeting the expected standards of these social roles, as understood by the local community, is one of the most important problems faced by individuals with schizophrenia. Therefore, understanding which areas of these roles the person is having problems with is vital while planning the treatment.

- Work: Most people with schizophrenia have problems in working at their expected level, and many find it impossible to get back to paid employment as a consequence of their illness (Chapter 3.8).

- Studies: Since schizophrenia starts in early adulthood, schooling or college studies may be interrupted, leaving the person with little prospect of finding suitable employment. Encouraging the person to resume studies in a graded manner is an important part of treatment planning.

- Parenting: For many people with schizophrenia, one of the most distressing parts of the illness is the loss of the ability to take care of their children. Some of these responsibilities are taken up by relatives, often making the individual feel devalued and worthless. Working with the family to encourage the individual's responsibilities is very important.

- Intimate relationships: The symptoms and disabilities often interfere with the quality of intimate relationships. Individuals with schizophrenia may require supervision, as they are unable to complete their household duties, and may become emotionally detached. A series of treatments can be planned to address and minimize specific problems, such as training for improving house management skills, reducing side effects of medicines, gradually improving concentration, communication and problem solving (Chapter 3.9).

2.1.3 E) Emotional well-being*:*

The quality of our lives is greatly influenced by the way we feel about ourselves, and our experiences of joy, happiness, sorrow, regret and fulfillment. Emotional well-being is also dependent on the physical and material circumstances of our life- whether we live in a reasonable house, whether we have reasonable money to manage our lives, whether we are working and have good social relationships within and outside the family. In people with schizophrenia, many of these basic requirements are greatly compromised.

People with schizophrenia are also likely to experience negative emotions like *depression, anxiety and anger*. Depression can have a devastating effect on the lives of people with schizophrenia by making them feel sad and miserable, reducing their motivation to work, take care of themselves or enjoy the company of others, and increases the risk of suicide. Detecting and treating depression is a priority in treatment planning.

Similarly, anxiety that leads to avoidance of social interactions is a frequent difficulty that individuals with schizophrenia experience. This could be because of their symptoms (delusions of being talked about, bad voices), their internal sense of shame, or as a response to previous experiences of discrimination.

Problems with excessive anger in schizophrenia are common because of the symptoms (suspiciousness, etc), the lack of meaningful activities, the frustration of being trapped by the illness, and the experiences of discrimination. Dealing with anger and aggression needs to be an important part of treatment planning (Chapter 3.5).

2.1.3 F) Social relationships*:*

One of the most common and distressing problem areas for people with schizophrenia is their social relationships within and outside their family. Often, close relationships in the family are characterized by high levels of conflict and disagreements. Similarly, one of the most common consequences of schizophrenia is the shrinking of the person's social networks. Improving family communication and providing skills to resolve conflicts (Chapter 3.6) need to be addressed while planning treatment.

2.1.3 G) Physical health:

People with schizophrenia have higher rates of medical problems, disabilities and death. Infrequent reporting of discomfort by the individual, the lack of concern when the person reports difficulties, smoking, weight gain, and poor oral health are some of the most important reasons for that. Thus, it is vital to assess physical health status of the individuals (Chapter 3.7) and suggest health promotion activities to improve overall physical health.

2.1.3 H) Facing up discrimination and negative attitudes:

People with schizophrenia and their families are often faced with experiences of discrimination and negative attitudes. This often leads to feelings of shame and guilt regarding the illness. Common responses are to deny the illness, avoid meeting doctors, and hide the ill person from social interactions. Discrimination can happen in obvious or subtle ways in the family, at work or in social situations. This is usually not talked about or 'hidden away', and assessing the nature and impact of discrimination is extremely important (Chapter 3.9).

2.1.3 I) Leisure and recreational activities:

We are happier when we have some time to pursue our hobbies and other personal recreational activities. Often, people with schizophrenia have a lack of interest on these activities, and end up sleeping excessively, eating more than usual, watching TV most of the time and isolating themselves from others. Gradually planning for leisure and recreational activities (reading newspaper, exercising, joining a club, taking up embroidery etc) is an important part of treatment planning, as these activities give a sense of purpose and make the individual happier.

2.1.3 J) Religion and spirituality:

For many people, religion and spirituality are an important part of everyday life. People with schizophrenia also have religious and spiritual needs which are often not met due to ongoing symptoms and activities' restriction. Making efforts to address these needs can be beneficial both in terms of accepting the illness and in improving social networks.

Not all of these areas will be of relevance to all the individuals that you will work with. This framework will allow you to systematically explore what should be the focus of the intervention at any point of your engagement.

Summary

- The COPSI intervention is designed to help people with schizophrenia, and their family members, work collaboratively with their treatment providers in managing the illness better
- There are some key guiding principles on which the individual treatments for the person with schizophrenia is based on
- There are specific treatment areas of interest in schizophrenia that include improving of personal, social, work and overall quality of life
- Assessment and understanding of these specific focus areas is important for the COPSI intervention

CHAPTER 2.2

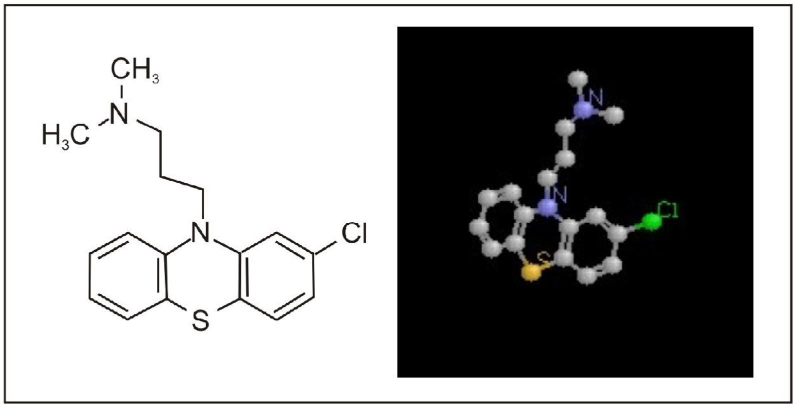
Drug treatment of schizophrenia

2.2.1 Introduction and types of medicines:

The discovery of chlorpromazine in the early 1950s was perhaps the most important contribution in the treatment of schizophrenia and other psychotic disorders. In 1952, it was demonstrated that chlorpromazine substantially reduced delusions, hallucinations and excitement in psychotic patients, reducing rates of hospitalization and improving discharges from psychiatric asylums. Since then, many other medicines with similar properties were introduced into the market.

Since these medicines reduce positive psychotic symptoms quite effectively, they are called *'antipsychotic medicines'*. Most of the medicines that are similar to chlorpromazine (haloperidol, trifluperazine, etc) have been in regular use from the 1970's and are called *first-generation or typical antipsychotics*.

Chlorpromazine



Another important step in the treatment of schizophrenia was the introduction of clozapine into the market in the 1990s. Clozapine is the prototype of *second-generation or atypical antipsychotic* drugs, which have less neurological side effects and are potentially beneficial in the treatment of negative and cognitive symptoms. Since 1994 several newer *second-generation* antipsychotics with similar therapeutic properties and side-effect profile have been introduced into the market. The common ones that you will encounter are risperidone, olanzapine, ziprasidone, quetiapine, aripiprazole and paliperidone. With the advent of second-generation antipsychotics, the use of older typical medicines has considerably declined. These newer medicines are effective, well tolerated, and cause minimal neurological side-effects. However, weight gain, abnormalities in the body fat profile, diabetes and heart problems are common and serious side effects. Unfortunately there is no ideal antipsychotic drug that can alleviate all the symptoms of schizophrenia without causing side effects.

2.2.2 How do antipsychotic medicines work?

Antipsychotic medicines are broadly classified into typical (first-generation, traditional, conventional) and newer (second-generation) groups. They are listed in Table 2.2.A with their brand names, and optimum and maintenance dose ranges. Antipsychotic medicines work in the brain. There they get attached to specific receptors of neurotransmitters (dopamine, serotonin), blocking their effects. Typical first-generation medicines have high dopamine receptor blockade properties, while the newer antipsychotic medicines block/modify both dopamine and serotonin receptors. Both are equally effective in the treatment of positive symptoms while the newer medicines are somewhat better than typical ones in their ability to improve negative and cognitive symptoms of schizophrenia. In addition, second-generation medicines are better tolerated and have a reduced risk of neurological and sexual side effects. The newer medicines are however associated with significant weight gain, risk for diabetes, abnormal fat levels and heart problems. Some antipsychotic medicines are available in an injectable forms and are listed in Table 2.2B.

2.2.3 Side effects of antipsychotic medicines:

Side effects of antipsychotic medicines can be divided into early (in the first few days of taking the medicines) and long term ones (after prolonged use). Table 2.2C provides a brief description of the common side effects and their management.

2.2.4 Phases of treatment in schizophrenia:

- *Acute phase:* This is the phase of active psychotic symptoms (delusions, hallucinations, disorganized speech and behavior) that requires immediate clinical attention. The symptoms may represent a first psychotic episode, a relapse, or an exacerbation of the illness.
- *Stabilization phase*: In this phase, that follows acute phase, symptoms are under control, though persons with schizophrenia are at risk of relapse. Treatment understandably, is an essential part of managing this period safely.
- *Maintenance phase:* While the illness is in remission the goal is to prevent relapse and improve functioning. Maintenance treatment may go on for years and may be even life-long, if the illness is chronic or is characterized by multiple relapses.

2.2.4 A) Treatment of acute episodes:

In this phase, goal is to control acute psychotic symptoms that require immediate clinical attention. There is often need to use an injectable antipsychotic to control agitation and excitement. Relatively high doses of the medicines may be used during this phase leading to many side-effects and challenges to adherence.

The choice of an antipsychotic drug largely depends upon the side-effect profile, affordability and the patients' symptoms. Usually first-generation antipsychotics are not the initial choice because of their poor tolerability and neurological side effects. Newer antipsychotic medicines are currently commoner choices, with risperidone and olanzapine being the most widely used ones.

2.2.4 B) Stabilization Phase:

In this phase, acute symptoms are under control with a stable dose of medication. It is generally recommended that the same medicine is continued for at least 6 months, with posterior attempts to gradually taper and stop it. However in many persons with schizophrenia, a longer duration of treatment may be required.

Table 2.2 A: Antipsychotic medicines available in India

Name of the drug	Brand names	Optimum dose/day	Maintenance dose/day
Older, first generation medicines			
Chlorpromazine	Largactil, Tranchlor	300-800mg	300-400mg
Haloperidol	Serenace, Senorm, Halopidol	10-20mg	5-10mg
Trifluoperazine	TFP, Eskazine	10-30mg	15-20mg
Fluphenazine *	Prolinate, Anatensol, Fludecan		
Fluphenthixol	Fluanxol	6-12mg	3-6mg
Zuclophenthixol*	Clopixol		
Amisulpiride	Sulpitac	300-600mg	300-400
Newer, second generation medicines			
Risperidone	Sizodon, Risnia, Rispond, Respidon	3-6mg	3-4mg
Olanzapine	Oleanz, Olanex, Zypine, Oliza, Olandus	10-20mg	10-15mg
Quetiapine	Quitipin, Quel	300-800mg	300-400mg
Ziprasidone	Zypsidon, Azona	80-160mg	80-120mg
Aripiprazole	Arpizol, Arip-MT	15-45mg	?
Clozapine	Sizopin, Syclop	200-800mg	200-300mg

* In India, available only as injection

Table 2.2 B: Injectable preparations of antipsychotic medicines

Name of the drug	Brands	Optimum dose/day
Haloperidol Acute preparation Depot preparation	Serenace, Senorm	5-10mg once or twice daily, IM/IV 50-200mg/month, deep IM
Chlorpromazine Acute preparation	Largactil	50mg once or twice daily, deep IM
Fluphenazine (long acting or depot)	Prolinate, Anatensol, Fludecan	25-50mg fortnightly, deep IM
Fluphenthixol (long acting or depot)	Fluanxol	20-80mg fortnightly, deep IM
Zuclophenthixol Acute preparation (aqueous)	Clopixol	50 mg once or twice daily, deep IM
Long acting or Depot preparation		200-400mg fortnightly, deep IM
Olanzapine Acute administration	Oleanz, Olandus	10-20mg once or twice daily IM
Risperidone (long acting or depot)	Risperdal Consta	25-50mg, fortnightly, deep IM

IM- intra muscular
IV- intra venous

Table 2.2. C: Side effects of antipsychotic medicines

Side-effects	Description	What can you advice
Acute neurological side effects:		
Akathisia (sense of restlessness)	*A personal sense of restlessness accompanied by observable movements* (fidgety movements of legs, rocking from foot to foot, pacing, inability to sit or stand still). Usually starts within few days to weeks of starting or raising the dose of medicines. Occurs in about a quarter of people using these medicines, usually within 10 days; common with typical medicines, risperidone and ziprasidone	Urgent review with treating doctor

Acute dystonias (severe muscle spasm)	*Abnormal positions or spasms of the muscles of the head, neck, limbs, or trunk.* Usually starts within few hours to days of starting or raising the dose of medicines Mostly within 3 days and occurs in about 10% of patients. Commonly associated with typical medicines	Urgent review with treating doctor
Drug-induced Parkinsonism	Shaking of hands (tremor), stiffness of muscles, slow movements ; may develops within a few days, usually within weeks of starting or raising the dose of medicines Occurs in about 20% of patients; typically seen with older typical medicines and higher doses of risperidone and ziprasidone	Urgent review with treating doctor
Other acute side effects:		
Excessive drowsiness or Sedation		Change in schedule of taking medicines in consultation with the Psychiatrist
Dryness of mouth		Keeping a clove or sugar free sweet in mouth
Excessive salivation		Use towel on pillow at night
Constipation		High fibre diet and liquids
Difficulty in passing urine		Consult doctor
Orthostatic hypotension	This refers to sudden drop of blood pressure after getting up from a sleeping or sitting position to standing; can lead to giddiness and falls which can be dangerous for the elderly	Advice person to get up gradually and move fingers and toes before getting up
Long term neurological problems:		
Tardive dyskinsia & dystonias	Involuntary and abnormal writhing movements of the tongue, jaw, or extremities. May also develop long term spasm of the head, neck, limbs, or trunk muscles. These are usually long-term complications of antipsychotic drug use. Usually develop after months and years of use. In elderly, they may develop earlier than usual. These movements are often socially embarrassing and a cause for distress. Occurs at an annual cumulative rate of 5% and eventually affects 20-35% of all persons on antipsychotic medicines. Usually associated with older medicines, although not unknown with newer newer medicines such as risperidone in higher doses	Review with treating doctor
Seizures or epileptic attacks	Seizures occur in about 1% of persons with schizophrenia receiving antipsychotic medicines. Up to 5-7% of persons with schizophrenia receiving clozapine at higher doses (above 500mg per day) may experience seizures.	Urgent review with treating doctor

Neuroleptic malignant syndrome (NMS)	A potentially fatal complication. Severe muscle rigidity, fever, confusion, excessive sweating and unstable blood pressure are the typical features of this syndrome .	Immediate hospitalization
Drug-induced Parkinsonism	Shaking of hands (tremor), stiffness of muscles, slow movements ; may develops within a few days, usually within weeks of starting or raising the dose of medicines Occurs in about 20% of patients; typically seen with older typical medicines and higher doses of risperidone and ziprasidone	Urgent review with treating doctor
Side effects on other body systems:		
Cardiac-side effects	Reports of sudden death are linked to antipsychotic medicines; special care with ziprasodone is necessary.	
Abnormal fat concentration in blood and weight gain	High levels of 'bad fats' in blood and obesity are common side-effects of newer medicines particularly olanzapine. This can lead to diabetes and high blood pressure as well	Regular exercise and attention to diet
Hormonal effects	Spontaneous milk secretion, enlargement of breasts, decreased libido, erectile dysfunction, and menstrual irregularities	Discuss with doctor about change in medicine
Skin	Blue-gray skin rash, sun-sensitive skin, particularly with chlorpromazine	Cover whole skin in the strong sun
Sexual side-effects	Impaired ejaculation, decreased libido, erectile dysfunction	Discuss with doctor
Gastrointestinal side-effects	Lack of appetite and gastritis	Discuss with doctor

2.2.4 C) Maintenance treatment

During the maintenance phase, persons with schizophrenia are usually in remission with minimal or absent psychotic symptoms. Nevertheless, drug treatment still plays an important role in preventing or at least delaying, a relapse and aids in overall recovery. Thus, persons with schizophrenia who continue on an antipsychotic medicine have much less chances of relapse than those who discontinue medication. It is well established now that even with the first episode of schizophrenia, persons with schizophrenia have 80% risk of at least one relapse over the next 5 years; stopping medications increases the risk by five fold. It is generally recommended that multi-episode persons with schizophrenia who have had multiple episodes of acute problems receive maintenance treatment for at least 5 years. For some persons with schizophrenia, indefinite or life-long treatment might be the best option. Usual maintenance doses for various drugs are given in Table 2.2A.

Non-adherence to medication is high with long-term maintenance treatment. Long-term side effects such as neurological problems and weight gain contribute to poor adherence. Engaging persons with schizophrenia and their family in treatment with periodic regular follow-ups, psychoeducation about illness course and treatment, and psychosocial treatments including rehabilitation may improve treatment adherence. In addition, use of long-acting depot antipsychotics (Table 2.2B) may also improve adherence

2.2.4 D) Route of administration

Most antipsychotics are administered orally in the form of tablets. Some antipsychotic drugs are available as injectable preparations for acute use and for maintenance treatment in the form of long-acting (depot) preparations. Depot preparations are especially useful in persons with schizophrenia in whom poor drug compliance is a major reason for relapses.

2.2.5 Antipsychotic drugs in special populations

2.2.5 A) Use in pregnancy

Although the risks to the foetus are statistically low, exposure to antipsychotic drugs during the first-trimester of pregnancy should still be avoided if the clinical condition of the person with schizophrenia permits. During the remainder of pregnancy, the lowest possible dose is desirable. The benefits and risks of antipsychotic medication should be carefully considered case by case. It is advisable to involve their mother with schizophrenia and the family in making decisions about the use of medications during pregnancy. Women with schizophrenia should be encouraged to plan their pregnancy and discuss with the treating doctor the risks and benefits of continued antipsychotic drug use. Antipsychotic drugs are expressed in breast milk, and caution in prescription is similarly advised during breastfeeding.

2.2.5 B) Use In the elderly

The elderly have decreased hepatic metabolism which makes them more prone to side effects. They seem particularly susceptible to tardive dyskinesia. Clinicians should start low dose and go slow. Risperidone is associated with higher risk for cardiovascular adverse events (stroke, transient ischemic attacks) in the elderly and this should be kept in mind.

Summary

- Antipsychotic drugs are the main stay of treatment in schizophrenia.
- In about 60% of persons with schizophrenia, there is significant reduction of symptoms, or remission.
- Typical antipsychotic drugs are associated with troublesome neurological side-effects, and may not be very effective in treating negative symptoms of schizophrenia.
- Atypical drugs have lesser propensity to cause neurological side effects and are well tolerated by most patients.
- Clozapine is used in persons with schizophrenia who do not respond well to other drugs, though its use should be carefully monitored.
- Engaging persons with schizophrenia and their families in the treatment process should help reduce poor treatment adherence.
- Depot preparations are useful in addressing poor treatment adherence.
- Although pharmacological approach is central to the treatment of schizophrenia, the role of psychosocial interventions in improving functional outcome cannot be underestimated.

CHAPTER 2.3

General principles of counseling and effective problem solving methods relevant to COPSI

2.3.1 Introduction:

An essential requirement for you as the Community Health Worker to help people with schizophrenia and their families is to establish rapport and build a relationship with them. Only then will the persons who you are working with be willing to confide in you and benefit from the process of counseling. Building a relationship requires certain skills and attributes which this chapter describes.

The general principles of counseling are discussed under the following headings:

- What is counseling?
- Self- awareness as a requirement for counseling
- Attributes of a good Counselor
- Basic counseling and interviewing skills

2.3.2 What is counseling?

Counseling is a 'talking' treatment that provides assistance and guidance in resolving personal, social or psychological problems and difficulties, by a trained person. It is an ongoing and dynamic process between you, the person with schizophrenia and key family members. The counseling process aims at making the person become more aware of him/her self, to accept his/her weaknesses, and to identify his/her strengths. Through counseling, the person gains a clearer picture of the problems facing him/her, the various options available to change the situation and deciding upon a suitable course of action. This enables the person to regain some control and mastery over his/her problems and feel that they are actively resolving problems.

Counseling **does not include**:

- Telling the person being counseled what to do
- Making decisions for the person being counseled
- Making personal judgments about the person being 'good' or 'bad'
- Blaming the person being counseled for problems or difficulty in changing
- Preaching or lecturing
- Making promises that you cannot keep
- Imposing your own beliefs on the person being counseled

2.3.2 A) Self awareness as a pre requisite to counseling

What is self awareness?

Self awareness is being aware of one's own attitudes, values and beliefs and how these have an effect on one's interactions with other people.

Why do you need to be self-aware to be a good counselor?

As a counselor self-awareness is important for a number of reasons:

- Self-awareness helps identify and learn about one's own values, beliefs and attitudes. This process helps one identify any stereotyped way of thinking, and also prejudices or biases that could influence how one treats the person being counseled. For e.g. the counselor may have a bias towards homosexuals or people of a particular religion and this could influence the counseling process if he/she is not aware of the bias.

- A counselor needs to make a clear distinction between him/herself and his/her person being counseled. Self-awareness helps differentiate between one's own thoughts, feelings and problems from those that belong to the person being counseled. Failure to do this can result in the counselor imposing a way of seeing things, or solutions that would work for him/her, rather than understanding how the person being counseled sees them and finding solutions that work for the person being counseled. For example, a counselor might think it unacceptable to live with a violent spouse and might impose this view on a woman who is in a violent relationship who may not be thinking along those lines.

- Being sensitive to personal emotional and physical reactions to what is happening in the counseling situation may also make the counselor more aware of things about him/herself that were not obvious and open up opportunities for personal growth and development.

- Making this separation or boundary between the counselor's thoughts, feelings or problems and those of the person being counseled is also an essential part of the counselor taking care of him/herself. He/she needs to make sure that this boundary remains clear. If it becomes hazy (finding it difficult to separate the issues of the person being counseled from his/her own, or being excessively preoccupied and concerned with the problems of the person being counseled) – it is a sign that he/she has taken on the person's problems as if they were his/her own. This can lead to emotional fatigue and high stress levels.

2.3.2 B) What are the characteristics of a good Counselor?

Counseling is a skill which can be learned by any person who has an interest in the subject and an open mind. Some of the most important requirements are to be:

A good listener: We are always 'hearing others out'. However, our listening process is selective and we often hear 'what we want to hear'. In counseling, one has to listen very carefully to the feelings being expressed by the person being counseled as well as to the words used to express the feelings with an open mind.

Be empathetic: Empathy is the ability to put one's self in the place of the person being counseled and feel what he or she could be feeling at the moment. The counselor then feels the frustration, anger, indifference, and the fears of the person being counseled. The process helps the counselor understand better the situation of the person being counseled. It is different from expressing sympathy or pity where the listener only expresses the fact that she feels bad for the person being counseled. This does not, in any way, make the person being counseled feel that she is being genuinely understood.

Ways to communicate empathy: Some ways to introduce expressions of empathy are below.
"You seem to feel…" ("you seem to feel discouraged")
"You seem to feel… but you also seem…." (when the person being counseled seems to have conflicting feelings)
"*It seems to me that you feel…"*
"It sounds as if…"
"You seem to be…"
"If I understood you correctly, you are feeling…"
"I wonder if you mean…"

Remember to:

- Link feelings to situation, context ("*you seem to feel…because…*")
- This linkage needs to be initially tentative and provisional - you can never be sure you are right, until you have checked with the person being counseled ("*from what you describe, it appears to me that you have decided to leave your job. Am I right*?")

Activities that can compromise empathy:

- Pretending to understand when you don't – rather ask for clarification.
- Not responding at all or giving a superficial response which gives the impression the person being counseled was not 'heard' or what she expressed was not worth responding to. For example: A lady expresses that she just lost her job and your response is '*How sad*"
- Giving a long response that says more about the counselor than the feelings of the person being counseled
- Just repeating word-for-word what the person being counseled said when expressing intense emotion
- Sympathizing e.g. *"I feel so bad for you, you are stuck at home since you have been ill"*
- Asking a question or giving advice instead of responding to a feeling expressed e.g. "*Don't cry, be strong. You have to look after your children now that your husband is no more*."
    - Using words like "*I understand*" in a superficial way
    - Sharing a personal experience that the counselor perceives as similar (but may not be)
    - Preaching or bringing in her personal moral bias ("*That's not the way to treat your partner*")
    - Interpretations that suggest personal judgments or blame ("*It seems you tend to lose your temper easily*")

Be non-judgmental: Hand in hand with empathy goes the ability to have a non-judgmental attitude. The counselor has to accept the person being counseled for who she is irrespective of her religion, caste, etc. Not only is the person being counseled entitled to her own views and feelings, but, even where these are contrary to those of the counselor, she does not judge the person being counseled negatively. If the counselor finds it difficult to maintain this attitude with a particular person being counseled, she should refer the person being counseled to another counselor. For e.g. a counselor who is uncomfortable in dealing with homosexuality, should be aware of this and discuss this with her supervisor.

Generate trust: The counselor has to make sure that she conveys to the person being counseled that whatever is spoken between them is confidential and that she would maintain the trust that the person being counseled has placed in her. If a need arises wherein the counselor feels that she has to reveal something spoken during the counseling session to a third person, for example, the Clinical Specialist, permission of the person being counseled has to be sought.

Be patient: Counseling requires patience. The person being counseled may take a lot of time to understand oneself and one's strengths. A person with schizophrenia counselor will often feel tempted to give advice but this does not serve the purpose of counseling.

Be observant: The counselor needs to be very observant not just about what the counselee says, but also the body language used. The person being counseled speaking with a smile on her face but with fists clenched or twisting her fingers vigorously, may indicate a build-up of tension which the counselor needs to observe.

Respect and acceptance: Always remember that the very basis of counseling is built on respect for the other individual, the kind of person she is, and accepting that people are capable of making their own decisions and managing their lives in general. Showing respect allows the counselor to create an atmosphere of acceptance where the counselee feels understood, cared for and respected, without having to meet any pre-conditions. This means accepting that the person being counseled has a right to think and feel differently from you.

To be an effective counselor you need to be:

- a good listener
- empathetic
- non-judgmental
- able to generate trust
- patient
- observant
- able to show respect and acceptance

2.3.3 Basic counseling and interviewing skills:

Encouraging people to talk about their problems without influencing them with one's own views is essential for conducting effective counseling and this requires some specific skills.

Attending behavior:

This is the most basic and yet a very important skill in counseling. The counselor should convey interest in what is being said and yet ensure that the counselee sticks to the point and minimizes needless talk. There are four critical dimensions to the attending behavior:

- Eye contact: Maintain eye contact with the person all the time.
- Attentive body language: Make encouraging gestures and express interest on your face. Sit facing the person being counseled with your arms opened out rather than folded against your chest. Do not keep checking your watch. Focus on listening to what the counselee is saying.
- Voice qualities: Keep your tone gentle, speak slowly, and clearly.
- Verbal tracking: Keep to the topic initiated by the person being counseled. If the person keeps on talking without keeping to the topic at hand, gently get the person to focus on the problem but do not start talking yourself.

Questioning Skills:

In the course of counseling one finds it necessary to employ questioning as part of getting the person to talk further. If the person is talkative it may not be necessary to ask many questions. However, if used effectively, questions can help to obtain a lot of relevant information. There are two types of questions:

- **Open-ended questions:** These are very useful in getting the person to talk. They are questions that cannot be answered in a few words or sentences. They encourage the person to talk and give maximum information. For example, "*Could you tell me more about that? / how did you feel when that happened?".*

- **Closed questions:** These are questions that can be answered in a few words, they help focus an interview and to bring out specifics. For example, "*Where do you live?*"

A general framework for collecting the required information in the first part of counseling would be the following:

- Who is the person being counseled? What are the key personal background factors? Who else is involved in the counselee's daily life?
- What is the problem? What are the specific details of the situation?
- When does the problem occur? What happens immediately before or after the situation?
- Where does the problem occur, in what environment and situation?
- Why does the problem occur? What triggers it? What makes it better? How does the person react? How does she or he feel about it?

When does questioning become a problem?

- Bombardment/grilling: Never ask too many questions; it can put people on the defensive. Too many questions can confuse a person.
- Questions as statements: For e.g. *'Don't you think it would be helpful if you found a job*?' - putting your own view ahead can put the person off.
- Why questions: Exercise caution when using "Why" questions - it can cause discomfort and sound threatening and judgmental. For e.g. *"Why did you not go to work?"*
  Keep the questions short and simple. Long questions can confuse the counselee

Observation Skills:

Another important skill that one needs in order to be a good counselor is to be observant. Observation requires focusing on the counselee's non-verbal behavior in three areas. These are:

- Eye-contact patterns:
  When a person breaks eye contact or shifts his gaze constantly, it could mean that he is distracted and you have to probe.

- Body language:
  Leaning forward can mean excitement about an idea. Leaning back and crossing arms could mean the person is closing off.

- Facial expressions:
  The furrowing of the brow, tightening or loosening of the lip, flushing and tearfulness can indicate tension.

Encouragers and paraphrases:
These are skills used to let the counselee know that the counselor has been listening to what he/she has been saying, has seen their point of view and feels the world to be as they experience it.

Encouragers are just words interspersed in between like "*um*", "*is it*" "*really*" "*ah ha*". These also include nodding your head, keeping your palms open and other friendly non-verbal gestures. Sometimes just the repetition of a keyword could become an encourager. This usually leads to the person giving further details about the same topic. These words and actions encourage the person to continue talking while letting him or her know that he is being heard. For e.g. to a counselee who says that her life is a mess the counselor says *"A mess?"* this encourages the counselee to elaborate what she means.

Paraphrases are the feedback given to the counselee by the counselor by shortening and clarifying the counselee's comments. Paraphrasing is not just parroting of words. It is done by repeating some of the counselors own words alongside some important words used by the counselee. Paraphrases help the process of counseling by:

- Clarifying for the counselee what he or she has said. For e.g. *"You appear to be saying...", "You sound like..."*
- Clarifying for the interviewer what the counselee has said - by feeding back what you have heard, you can check on the accuracy of your listening. For e.g. *"Did I get you correct?", "Am I hearing you correctly?"*
- Helping person being counseled to talk in more detail about issues of concern to him/her.
- Helping a talkative person being counseled stop repeating the same facts or story.

Noting and reflecting feelings:
This is a very useful skill that helps the counselee talk and make him feel understood. It helps in identifying and sorting out the counselee's feelings. The focus is on the emotions of the person being counseled and his/her subjective experiences in coping with the situation. To do this one needs to pay attention both to what is said, and what is not said. For example:

- Emotional words used by the counselee — "I was so angry that I felt like hitting him" to which one would respond with "You *must have been really angry".*
- Non-verbally expressed emotional words – for e.g. to a person biting her lips - "*You seem very anxious today*".

Emotions can be observed directly or drawn out through questions ("*How do you feel about that? Do you feel angry*?") and then, reflected back through the following steps:

i) Begin with words such as, "*you feel*" or "*sounds like you feel"* or "*could it be you feel*?" Use the counselee's name when possible.

ii) Feeling words may be added (sad, happy, glad, puzzled, uncertain, confused)

iii) The context may be added through a paraphrase or a repetition of key content *("looks like you feel happy about getting a job*").

iv) A present-tense reflection is more powerful than past or future tense. "*You feel happy right now"* rather than "*You felt".*

v) After identifying a feeling you can confirm this with the counselee to make sure you are correct in your understanding ("*Am I hearing you correctly*?")

You can sometimes gather specific information after reflection. For e.g. "*You seem angry with your father. Could you give me one example of a specific situation when you feel this anger?"*

Clarifying:

When the counselee talks of anything that is not clear or contradictory to what she said earlier, the counselor can clarify rather than draw her own conclusions. Sometimes when a counselee is anxious he or she can keep talking in an unfocused way or move from one topic to another. In such circumstances it is better to stop the person being counseled gently and clarify matters that have been left incomplete or unclear.

Identify the positive strengths of the person:

While using other counseling skills, one useful technique is to identify the positive assets or strengths of the person being counseled. This raises the self esteem of the counselee. Ways in which the counselor can use this skill:

- The counselor can begin the session by asking what has happened recently that the counselee feels good about.
- The counselor can use it to remind a counselee of something positive, for e.g. *"You say you are unhappy about your daughter-in law being rude to you. At the same time you also mentioned how you enjoy playing with your grandson. That must be making you feel happy."*
- If your counselee constantly repeats negative statements, these can be paraphrased and then followed by positive feedback. For e.g. *"Yes, being insulted by your daughter-in-law really hurts. At the same time, I see a number of positive points — you have a good sense of humor, you seem to have very caring neighbors, and your daughter too seems to care for you a lot."*

Basic counseling skills are:

- Attending behaviors -- eye contact, attentive body language, vocal qualities, verbal tracking
- Questioning skills
- Observation skills
- Encouragers and paraphrasing
- Noting and reflecting feelings
- Clarifying
- Focus on the positive assets of the person

2.3.4 Telephone counseling

Telephone counseling is the use of the telephone to provide counseling. It can include various aspects of clinical care including assessment, intervention and follow up. Some persons being counseled may find it difficult to meet you due to various difficulties — work hours, care responsibilities at home and their own health factors. In such instances, the telephone provides increased access to these people and enables the counselor to conduct assessments, provide education, counseling, follow-up services and reminders for missed appointments.

2.3.4A) Before initiating the call the following important points should be noted:

- Consent: During face-to-face meetings, assessment must be conducted to determine the person's willingness to be contacted at home and to participate in a telephone counseling session. The consent provided should be documented.
- Privacy and confidentiality: Should be assured and maintained at all times. This includes privacy for the counselee as well as for you. For e.g. if the person being counseled is not available when you call, it may be inappropriate to leave your name or information about yourself. This needs to be discussed with the counselee in advance. Also ensure that you are alone and unlikely to be disturbed when making the call.
- Be adequately prepared with the various points that you need to cover during the call.

2.3.4B) Initiating the call:

- Introduce yourself. Give the introduction enough time. Dont rush.
- Move smoothly from the introduction to the reason for your call.
- Remember this is most likely to be a new experience for the counselee, so encourage participation and make an effort to reassure hesitant speakers.

2.3.4 C) During the call:

- Be focused. Sit up straight in your chair and talk directly into the mouthpiece.
- Be courteous, pleasant and friendly.
- Speak as clearly as possible in a natural conversational manner. Your tone of voice, attentiveness and manner can make all the difference to the person's comfort during the call.
- Pay close attention to what the counselee is saying and how he/she is saying it. Listen for hesitation or pauses that may indicate uncertainty and may need you to probe or verify.
- Take it slowly. Give the counselee time to talk without interruption and without having to hurry.
- As a general principle, answer all the person's questions, complaints and objections politely. Remain respectful and maintain an even tone of voice.

2.3.4 D) Concluding the call:

Summarize all that has been discussed. Ask the person counselee if she has any questions or wants to add anything to the discussion. Make an appointment for the next call or clinic visit.

2.3.4 E) Record-keeping:

After the call is completed, it is necessary to record/document the interview in detail. Document the details of the call including the duration, content and your impressions of the person's current state and future intervention plan.

If the counselee is not available when you call, ask when you can call back. Also ask the name of the person who answers the phone and his/her relationship to the counselee (if possible). Leave a message and your telephone number. If no one answers the phone, call back at three different times of the day.

2.3.4 F) Be prepared to deal with problem situations which may arise:

- The counselee is rushed and "just wants to get this over with". Ask if there is a better time to call when the counselee is not busy. You may also convey to the person being counseled that you have set aside time to speak with her and are in no hurry so she can take her time in speaking to you.
- The counselee is overly chatty and gives an unduly long account of his/her problems. Interrupt her and try to get her to focus on important information. Ask direct/closed questions.
- The counselee is confused or unable to focus. Try and elicit information about health problems and suggest a convenient time for a home visit.
- The counselee is argumentative. Stay calm and do not engage in an argument. Repeat the reason for your call and if you sense the counselee continues to be argumentative, terminate the conversation gently.
- The counselee is distraught and emotional. Allow the counselee time to ventilate her feelings. Do not interrupt. Encourage her to express her feelings and provide a non-judgmental, supportive attitude. Encourage her to make a visit to the FPC.
- The counselee is suicidal. Assess the risk of suicide, ask her to come to the PHC as soon as possible, elicit help from a family member, work out a no-suicide agreement.

Summary

- ♦ Counselling is a two-way interaction between the counsellor and the counselee that provides assistance and guidance in resolving personal, social or psychological problems,
- ♦ To be a good counsellor you should be a good listener, empathetic, non-judgmental, observant, convey respect and acceptance and able to generate trust in the person being counselled.
- ♦ Basic counselling skills include attending behaviour, questioning skills, observation skills, use of encouragers and paraphrases, noting and reflecting feelings, clarifying and positive asset focus.

2.3.5 Problem solving:

In the COPSI intervention, problem-solving technique can be used to clarify the particular problems the person with schizophrenia or their family face and to improve their ability to deal with them (coping skills). Problem solving is something that we do anyway in everyday life; in problem solving as a skill, the intuitive method of problem solving is broken down into smaller steps and implemented deliberately.

Goals of problem-solving skills:

- To define the person's or the family's current problems clearly
- To help the person and the family identify the resources they possess for solving their difficulties
- To develop problem-solving technique that attempts to resolve problems in a structured way
- To enhance their sense of control over problems and improve their confidence in being able to deal with future problems.

Problem solving is not:

- Telling the person with schizophrenia and the family what their options are
- Telling what the good and bad points of the options are
- Choosing the option for the person with schizophrenia and the family
- Telling them what they must do
- Expecting the person and the family to have the skills and confidence to put the plan into action immediately

2.3.5A) What are the steps in problem solving?

Problem solving is a tool, a skill and a process. It is a tool because it can help you solve an immediate problem or to achieve a goal. It is a skill because once you have learnt it you can use it repeatedly, like the ability to ride a bicycle, add numbers or speak a language. It is also a process because it involves taking a number of steps.

There are **seven main steps** to follow when trying to solve a problem. These steps are as follows:

Define and Identify the problem: This first step is critical, you need to identify and name the problem so that you can help person and the family find an appropriate solution. It is essential for you and the family to clearly understand the problem so that all energies will be focused in the same direction. A good way to define the problem is to write down a short statement which summarizes the problem, and then write down where you want to be after the problem has been resolved. The objective is to get as much information about the problem as possible.
For e.g. 'What is the problem which is getting in the way of person with schizophrenia in achieving his goal?'

Analyze the problem: In this step of problem solving, questions should be asked and information gathered and sifted. Do not make the mistake of assuming you know what is causing the problem without an effort to fully investigate the problem you have defined. Try to view the problem from a variety of viewpoints.

Questions to Ask When Analyzing the Problem:

- What is the history of the problem? How long has it existed?
- How serious is the problem?
- What are the causes of the problem?
- What are the effects of the problem?
- What are the symptoms of the problem?
- What methods do the person and the family already have for dealing with the problem?
- What are the limitations of those methods?
- What obstacles keep the family from achieving the goal?

Set goals: Once you have thought about the problem from different angles you can identify your goals. What is it that you want to achieve? Sometimes you might get so frustrated by a problem that you forget to think about what you want. For example, you might become ill, struggle to complete a number of tasks on time and feel so unmotivated that you let due dates pass. It is important at this time to consider the question, 'What is my immediate goal?' Do you want to:

- improve your health?
- increase your time management skills?
- complete the work to the best of your ability?
- finish the tasks as soon as possible?

If you decide your goal is to improve your health that will lead to solutions which are different from those linked to the goal of completing your tasks as soon as possible. One goal may lead you to a doctor and/or to take leave of absence from your work place; the other goal may lead you to apply for extensions for your work. So working out your goals is a vital part of the problem solving process.

Look at Alternatives: When you have decided what your goal is you need to look for possible solutions. The more possible solutions you find the more likely it is that you will be able to discover an effective solution. You can *brain-storm* for ideas. The purpose of brain-storming is to collect together a list of possibilities. It does not matter whether the ideas are useful or practical or manageable: just write down the ideas as they come into your head. Some of the best solutions arise from creative thinking during brain-storming with people who are involved and sometimes with people 'outside' the problem.

Select a possible solution: From the list of possible solutions you can sort out which are most relevant to your situation and which are realistic and manageable. You can do this by predicting outcomes for possible solutions and also checking with other people what they think outcomes might be. When you have explored the consequences, you can use this information to identify the solution which is most relevant to you and is likely to have the best outcomes for your situation.

Implement a possible solution: Once you have selected a possible solution you are ready to put it into action. You will need to have energy and motivation to do this because implementing the solution may take some time and effort. (If the solution had been easy to find and do, you would have probably already done it.) You can prepare yourself to implement the solution by planning when and how you will do it, whether you talk with others about it, and what rewards you will give yourself when you have done it.

Evaluate: Just because you have worked your way through the problem solving process it does not mean that, by implementing the possible solution, you automatically solve your problem. So evaluating the effectiveness of your solution is very important. You can ask yourself (and others):

- 'How effective was that solution?'
- 'Did it achieve what I wanted?'
- What consequences did it have on my situation?'

If the solution was successful in helping you solve your problem and reach your goal, then you know that you have effectively solved your problem. If you feel dissatisfied with the result, then you can begin the steps again. Viewing problem solving as a cycle may help you recognize that problem solving is a way of searching for a solution which will lead to different possible solutions, which you can evaluate. If you have solved the problem you have found an effective solution. If you judge the problem has not been solved you can look for, and try, alternative possibilities by beginning the problem solving cycle again.

Summary

- Problem solving is a useful skill that can be learnt quite easily
- Problem solving involves following seven steps to help resolve problems
- The person with schizophrenia and families can also be taught the principles of problem solving as a way of dealing with future problems

CHAPTER 2.4

Family treatments in schizophrenia

2.4.1 What are Family Interventions?

As we have seen, the impact of schizophrenia on the family is severe and can be difficult to manage. In family interventions, a trained person (like you as a CHW) provides support to the affected individual and family members as a unit. You will work with the family while planning treatment and rehabilitation.

Family interventions provide better understanding of the illness and equip members to deal more effectively with its ups and downs. These interventions also help the family to contribute to the overall recovery of the person with schizophrenia, and improve the quality of their personal lives.

2.4.2 Why should we involve the family in the treatment of schizophrenia?

Family members and relatives are the main **caretakers** of a mentally ill member. While you or the Psychiatrist will meet the person with schizophrenia for an hour or so every 2-3 weeks, the family has to care for the person every day. The family also provides the emotional, social and financial support for their ill family member. Involving the family in treatment and minimizing the burden of each member is essential for recovery.

- The family may want to help in the treatment but may not know how to do so, feeling helpless. Providing the family with relevant information and involving them in the treatment plans, gives them a sense of control and a more positive mindset.
- To reassure the family of the person with schizophrenia that they are not to blame for the problems and reinforce their strength in coping with a number of problems.
- The presence of an affected member changes the family life’s routine. The family members will have extra household chores, as the affected member may be unable to contribute. Trying to keep the family life as normal as possible, while simultaneously trying to help the affected member may be **frustrating.**
- The family may find the affected member’s behavior embarrassing and awkward. They may avoid their normal socialization with others due to the **stigma** of having a mentally ill member.
- Family may be **angry** with the affected member, especially when they feel that he is ‘lazy or not making an effort to control his own behaviors. This is a situation that can have a negative impact on both the illness and family members.
- Families may experience severe **stress**, marital discord or depression associated with living with the person with schizophrenia.
- Family members become more involved or preoccupied with the affected member, and tend to withdraw from others, increasing family isolation. They have fewer people to turn to for emotional or practical support **(social support)**.

2.4.3 What does Family Intervention involve?

Family interventions are conducted with key members of the family and the ill relative as a unit.
You will be seeing the family over a period of time, through some or all of the following stages:

- During the acute phase of the illness
- When the affected member is **recovering and** no longer acutely symptomatic
- During follow-ups, when the affected member is **maintaining** treatment

As the persons with schizophrenia and families that you meet may be in different backgrounds and phases of the illness, they may have different **needs** and **expectations**. The needs of the family *per se* will differ from those of the affected members.

Here are some of the common needs and concerns of the families:

- Understanding the nature of the illness
- Coping better with the disturbing symptoms
- Managing adherence to medication
- Accessing assistance during times of crisis
- Having links with social agencies
- Dealing with stigma and discrimination
- Dealing with the economic impact of the illness on the family

2.4.4 How to conduct Family Interventions?

- Before approaching the affected member and the family, you should be aware of some clinical details about the affected member's illness.

- It is preferable to see the family privately in a separate room. If this is not possible, speak to the family in a place where there will be **minimum interference and distractions**.

- As a CHW, you will be seeing the family and the affected member together over a number of sessions. The duration of each should not exceed **45-60 minutes**.

- The frequency of these sessions should be weekly or fortnightly over a period of 6-10 weeks.

- During engagement, families often provide the information that you may have intended to assess in later sessions. Use this information as starting points for obtaining further details, or for discussion in your sessions. If the information provided is sufficient, do not ask questions that elicit the same information again.

- Some families tend to introduce new or old issues towards the end of the session. Reassure them that it is not possible to address all issues in one session, and that you will discuss them in forthcoming sessions. You should wind up each session by summarizing all that had been discussed and what the family plans to do between sessions.

- Focus on the **family's behavior with each other during and in between sessions**. This will help you assess whether the family is applying what has been discussed in the sessions. It may also reveal areas that need to be approached in future sessions.

- Across your sessions, try to maintain the **continuity** in the topics and areas that you are discussing with the family. Show the relationship between the skills that you are training them in and their problem areas. Link them so that the family is able to see the inter-relationships between for example, handling communication and emotions.

2.4.5 Overview of Family Interventions in the COPSI intervention:

- Initially you will need to **assess** the family to understand their knowledge of the illness, their needs, the approaches they have adopted to solve their problems, the effect of the illness on the affected member's functioning, etc. These will influence the content and focus of your future sessions.

- You will need to provide information to the family about the illness, medicines and other relevant aspects. This process is called '**Psychoeducation**' and has been shown to be a very effective way of improving the family's skills in dealing with their problems.

- Assist the family in identifying their problematic coping responses, which hinder the affected member's improvement and make the overall atmosphere of the house hard to deal with. You will assist the family in acquiring more effective methods of reducing stress and coping with difficult situations. These are some **basic interventions** that set the foundation for more specific tasks.

- The affected member and the family will face a number of obstacles when **coping with some of the specific difficulties** associated with schizophrenia. You can help family members to acquire, initiate and practice specific techniques to manage difficult problems, so that the family unit is empowered to deal with future problems in a more effective manner.

The exact manner of conducting these sessions and the sequence in which they are to be delivered in the intervention are discussed in Chapter 3. 5.

Summary

- The specific needs of family members in managing the problems related to schizophrenia are addressed through family specific treatments
- Family treatments in the COPSI intervention are designed to address the specific needs of the phases of the illness
- There is a specific method of conducting the family sessions
- The family treatments include assessment, provision of information, a set of need based basic interventions and specific methods of dealing with more complicated problems

CHAPTER 2.5

Overview of the nature & consequences of stigma & discrimination in relation to schizophrenia

2.5.1 Introduction

STIGMA ATTACHED TO MENTAL ILLNESS IS ONE OF THE MAIN OBSTACLES TO THE PROVISION OF MENTAL HEALTH CARE, AND A MAJOR BARRIER FOR RECOVERY.

Stigma marks not only those who are ill, but also their families, and, to a certain degree, mental health workers and institutions. The presence of stigma starts a vicious cycle that leads to discrimination in all aspects of life including work, relationships, and access to physical healthcare. It can reduce the effectiveness of treatment, and thereby lead to a reinforcement of the negative attitudes and discrimination.

In order to facilitate the recovery and rehabilitation of people suffering from schizophrenia, it is important to recognize the impact that stigma has on their lives, and help them and their families in coping with the consequences of stigma and in resisting discrimination. However, to overcome stigma, interventions are required on many levels, including the legal system, employers and the media. Mental health professionals, and you as a CHW, also have an important role in acting as models and advocating for the rights of the people you will be working with.

2.5.2 What is stigma?

Stigma can be seen to consist of three related problems:

• The problem of knowledge:	*Ignorance*
• The problem of attitudes:	*Prejudice*
• The problem of behaviour:	*Discrimination*

2.5.2 A Ignorance - the problem of knowledge:

Although there is a lot of information available in the public domain about mental illness, the level of accurate information is very low. The general public and even health professionals tend to hold a stereotyped image of people with schizophrenia. This image usually involves some or all of the following misconceptions:

- Nobody recovers from schizophrenia
- Schizophrenia is an untreatable disease
- People with schizophrenia are usually violent and dangerous
- People with schizophrenia are lazy and unreliable
- Schizophrenia is the result of a deliberate weakness or weak character
- Everything people with schizophrenia say is non-sense
- People with schizophrenia cannot reliably report the effect of treatment or other things that happen to them
- People with schizophrenia are completely unable to make decisions about their own lives
- Schizophrenia is the parents' fault

For example, people will often not know that when a person with schizophrenia behaves in a way others find difficult to accept, e.g. not concentrating on their work or talking in a strange way, this is often a consequence of the illness rather than willful 'bad behaviour'.

To illustrate this, the example below shows what a caregiver from Goa has heard other people say about his ill daughter. He also admits that he himself is not sure what exactly is happening to her.

> *She [PLS] is fine, nothing is wrong with her they say (...) She is doing this all purposely. They say this. (...) Even I don't know what is happening to her. I also don't know.*

Ignorance about mental illness needs to be addressed by conveying more factual knowledge to the general public, healthcare providers, people with schizophrenia and their families.

2.5.2 B Prejudice – the problem of attitudes:

Prejudice involves not just negative thoughts, but also emotions such as anxiety, anger, resentment, hostility, distaste or disgust. Although attitudes can be difficult to change, there is evidence that they can be influenced with targeted educational interventions, especially when these involve direct contact with people with mental illness. There is also emerging evidence that with certain advertising and promotional methods, attitudes can be changed on a societal level.

An example of the negative attitudes often held against people with mental illness is given in the following statement by a caregiver of a person with schizophrenia:

> *One fellow was there, he was little bit like that [mentally ill] (...) people would say: "why did his people [family] keep him home? (...) Should have put him in the mental hospital and all", like this they would say. So you come to know (...) that this person is not well like, not to be kept in the society like.*

2.5.2 C Discrimination – the problem of behaviour:

Discrimination, the behavioral consequence of stigma, adds to the disability of people with mental illness.

Many people with mental illness are subjected to systematic disadvantages in several areas of their lives. Discrimination can have devastating effects on personal relationships, parenting and childcare, education, training, work and housing. Often, persons with mental illness report that the effects of stigma and discrimination are even more difficult to bear than the illness itself.

People suffering from mental illness experience discrimination from a variety of sources, such as the general public, employers, government institutions, the media, etc., but also directly from known people, such as neighbors, friends, family members or healthcare staff.

For example, many people with mental illness describe that others avoid them or that they have lost their friends because of their illness. In the following example, a woman from Tamil Nadu describes how her own relatives stopped visiting her and talking to her after she got ill:

> *"Earlier they [relatives] would visit me. We would meet up and speak. They would also regularly visit me. Now that I have this illness, no one comes regularly to meet me. (...) Even if they come they will speak to them [other family members]; they will not speak to me. They will not speak to me."*

Other forms of discrimination reported commonly involve disrespectful behaviour, e.g., not being greeted or talked to respectfully, being ignored in conversations (even conversations with health professionals), not being offered a seat in a bus or not being involved in decisions at home. Many persons with mental illness also experience teasing, harrassing and negative comments from others.

For example, a woman from Satara explains:

> "*Sometimes people, maternal uncles and aunts, (...) neighbours sometimes, make fun of me. They say "She has become mad." Or they (...) purposely tell me that a guest is coming to our house [even if this is not true]. They cheat [me] and then they laugh at me when they see me doing some work in the house [to prepare for the guests]. [When this happens] I feel [I want] to go and quarrel with them and ask, "Why did you do so with me? Why do you cheat me? What have I done to you?"*

It is important to note that negative reactions like the ones described above are not only enacted by strangers, but also by family members within the home. Many people with schizophrenia describe experiencing critical comments, teasing and disrespectful behaviour from the people they live with. Sometimes, the person with the illness will be asked to hide when visitors come or will not be involved in decision-making. Occasionally, persons with schizophrenia are restricted from going out or talking to others, and in rare cases, they may be chained or tied to a tree.

Last but not least, people with mental illness often experience discrimination in important areas of their lives, e.g., work or marriage. In the following example, a woman with schizophrenia explains why she did not tell her employers about her illness:

> *P: They [my employers) might have removed me from job in one month only. (...)Who will employ a mental person? Who will want to ruin his business by employing a mental person?*

And in the following statement, a female caregiver describes how difficult it is to find a marital alliance for her daughter, because people perceive her to have a (mental health) problem:

> *My relatives brought a couple of alliances. They saw the girl and then said that they will check for name compatibility and come back. Then they will inform us that names don't match. What can I do? (...) When they saw the girl, they might have thought that she looks different and might have thought there should be some problem. But they are not openly revealing it. They quote name compatibility as a reason.*

2.5.3 Self-stigma:

In addition to the stigma and discrimination experienced by others, some people with mental illness accept the common prejudices held against them and lose self-esteem, resulting in self-stigmatization.

Many will also be very self-critical or feel they are responsible for having brought on their illness, e.g., calling themselves 'stubborn' or 'lazy' or speaking regretfully about their own 'incorrect' actions. These kinds of self-critical thoughts are sometimes reinforced by critical comments from family members.

Consequences of self-stigmatization include feelings of shame hopelessness, depression, a sense of being separate from society, and social withdrawal.

> *P. [My friends] don't say anything [about my illness] but they ask me why I always keep quiet.*
> *I. How do you feel when they ask you that?*
> *P. I feel ashamed [Putting his head down]*
> *I. What are you ashamed about?*
> *P. I feel as if something has happened to me (...) like I have become mental [Pause]*
> *I. Have they said you have become mental?*
> *P. No*

In addition, people with mental illness commonly expect to be treated in a discriminatory way by others, for example being teased, avoided or blamed. Many also anticipate negative treatment at work or in marriage, or fear that others will gossip or 'spread the news'. As a consequence, people with mental illness and their family members often try to hide the illness, are reluctant to seek help and avoid social interactions. People with mental illness may also avoid applying for work or taking up educational opportunities because of fears of being discriminated against..

The following examples illustrate the enormous effect these anticipated reactions often have on the lives of people with mental illness and their families.

A woman with schizophrenia describes how she avoids social functions because of fears that others would laugh at her and call her mad.

> *I myself am not willing to go [to social functions]. (...) people will call me mad or will laugh at me. They will tell each other 'she has this.... her mind is affected'. I feel like this. So I do not want to go anywhere and do not want to show my face to anyone. So nowadays I do not go anywhere.*

A man with schizophrenia explains what he fears would happen if others found out about his illness:

> *"I used to get scared that somebody might see me visiting a psychiatrist (...)If somebody sees me then they will pass the news that I am not well (...)my name will be spoilt (....my life will be full of changes...(...) Nobody will come close to me, everybody will avoid me (...) because this illness is like that. Everybody avoids those people having such type of illness"*

2.5.3 A Effect of stigma and discrimination on families:

It has been shown that stigma and discrimination may also seriously effect families of people suffering from mental illness.

Family members of people with schizophrenia often experience that other people pass critical comments or blame them for their family members illness. Sometimes, the whole family is avoided or treated with less respect. Family members may also fear negative consequences of the illness for other family members chances of getting married. Consequently, they will try to conceal the illness from others. Worry and feelings of grief or depression are common amongst caregivers.

In the following example, a male caregiver describes how the whole family home has been been labelled as a ‘mad house’ because of his brother’s illness:

> *“Others look at him [person with mental illness] with shame. They call him ‘loose’. When anyone asks for our address, people mention our house as ‘mad house’. They speak of our house as a ‘loose house’. They would identify me as the brother of a mad person. (...) No one knows me here. But everyone knows my brother. They would send people to our house taking him for identification”*

A young female caregiver from Tamil Nadu explains that she fears that her future in-laws would treat her badly if they knew about her mother’s illness:

> *“If they are getting me married and if the person who is marrying me feels that my mother [patient] is like this, I would feel bad (...) if they ill-treat me and dominate me.... I fear for that”*

2.5.3 B What can be done to reduce stigma and discrimination?

In order to overcome the stigma and discrimination associated with mental illness, action needs to happen at many levels and by many different people and institutions. This includes the legal system, the media, physical and mental healthcare providers, employers, educational institutions, social care, communities, and people who support a person with mental illness. There are also strategies that people with mental illness can take to protect themselves, as far as possible, against the effects of stigma, and resist discrimination. These strategies can be supported by mental health professionals.

2.5.4 Actions at the societal level:

Community bodies need to promote social inclusion of people with mental illness, address discrimination at the workplace and avoid misinformation about mental health issues.

- National and international governmental and legal bodies need to ensure that discrimination due to mental health problems is adequately targeted. This includes effective mental health and disability legislation that makes it illegal to discriminate against someone on the basis of a mental health problems and provisions to promote the social inclusion of people with mental health problems and to support those unable to work due to a mental health-related disablity.

- Education, Health and Police authorities need to provide interventions to increase integration with, and understanding of, people with mental illness to targeted groups such as schoolchildren, police and healthcare staff.

- Professional training and accreditation organizations need to ensure that mental health practitioners receive adequate training with regards to stigma and discrimination and are fully aware of the actual recovery rates in mental illness.
- Employers in the health and social care sector, when recruiting, need to make explicit that a history of mental illness is a valuable attribute for many roles.   Further, employers’ federations need to inform employers of their legal obligations under existing disability laws towards people with mental illnesses

- For some people with mental illness, allowance needs to be made at work for their personal requirements in parallel with the modifications made for people with physical disabilities. In practice this can include, for example, having a quieter work place with fewer distractions or providing a more gradual introduction phase for those who return to work after a prolonged absence. Mental health services need to work with employers and business confederations to ensure that reasonable accommodations and adjustments in the workplace are made for people with mental illness.

2.5.5 Actions to support people with mental illness and their families:

Empowerment has been described as the opposite of self-stigmatization. Therefore, it can be argued that the more people with mental illness are empowered to manage their own lives and live with their symptoms as best as possible, the more self-stigma and feelings of shame, low self-esteem and self-confidence are likely to be reduced.

Strategies that people with mental illness and their families can employ include:

- learning as much as possible about the condition itself
- weighing up whether to tell other people, who to tell and how
- eliminating reasons for discrimination, e.g. by trying advised treatments, modifying behavior, or changing clothing
- participating in care-related decisions
- taking up opportunities for social reintegration and rehabilitation
- getting involved in self-help groups, anti-stigma movements, etc

Mental health care providers and institutions have an important role in supporting people with mental illness and their families, in their efforts to cope with the consequences of stigma and to resist discrimination. Examples of actions to support people with mental illness and their families will therefore be provided in the following section.

2.5.6 What can mental health care providers do to reduce stigma and discrimination?

Mental health professionals are a source of support to people with mental illness, and take an important role as advocates for their rights. Though, some of the people that receive mental health services find it to be a mixed blessing, and sometimes damaging.

A main concern from reports of discrimination by service users is dehumanization. Core issues reported by persons with schizophrenia include being spoken to as if they were children, being excluded from important decisions, and the assumption that they are not responsible for their own lives. Further recurrent themes from the perspective of service users are being given insufficient information about their condition and treatment options, and feeling that behind many encounters with psychiatric staff is the usually unspoken threat of coercive treatment. The first and foremost concern for health care providers should be to take care, not to engage in discriminatory or patronizing behavior, and to provide a role model for contacts of the person with mental illness.

Secondly, staff can take an active role in empowering people with mental illness by providing accurate information about the condition and the treatments available, involving them in decision-making about their treatment as far as possible, helping them maintain self-esteem, offering preparation for and encouraging them to take up appropriate work opportunities, etc.

To summarize, actions that mental health care providers can take to reduce stigma and discrimination include:

- Actively providing factual information against popular myths about mental illness
- Having information packages for persons with schizophrenia and family members that explain causes, nature and treatments of different types of mental illness
- Developing and rehearsing with persons with schizophrenia accounts of mental illness experiences understandable to other people, discussing pros and cons of disclosing illness in certain situations
- Supporting people with mental illness to take their medication regularly
- Promoting participation of people with mental illness in decisions about treatment; developing and implementing the plan of treatment together as far as possible
- Making sure that patients' priorities are respected while planning treatments
- Working with families, learning from their experience, and providing them with practical and useful information
- Helping people with mental illness maintain and build self-esteem
- When interacting with people with mental illness and their families:
    - ♦ Avoiding negative statements such as 'You will never work again', or 'You must not expect to have children'
    - ♦ Avoiding 'totalizing' terms such as 'schizophrenic'
    - ♦ Not using pessimistic terms such as 'chronic schizophrenic'
- Encouraging service users to prepare for and take placements in appropriate work settings
- In society, acting as advocates and models of tolerance and acceptance of people with mental illness

Summary

Stigma consists of three related problems- ignorance, prejudice and discrimination. It adds significantly to the disability caused by mental illness and its effects are often perceived as even more burdensome than the primary condition itself. Stigma affects people with mental illness as well as their family members in many areas of their lives.

To tackle this complex issue, action needs to happen at many levels and by many different people and institutions. There are also strategies that people with mental illness and their families can employ. Health workers can support and empower people with mental illness in these actions by providing adequate information, helping them tackle self-stigma and low self-esteem, assisting them in their journey towards recovery and, importantly, by acting as advocates and models of tolerance and acceptance of people with mental illness.

CHAPTER 2.6

Overview of the need and benefits of community linkages for people with schizophrenia and their families

2.6.1 Introduction:

As we have described in the preceding chapters, schizophrenia can have a negative impact on the social functioning of the individual and the family. The gradual deterioration of social roles and functioning, and increasing isolation from mainstream community activities is due to a combination of symptoms, disabilities and discrimination. The gradual loss of meaningful social networks is one of the reasons for the poor outcomes seen in schizophrenia.

It is fairly obvious that repairing and restoring the loss of meaningful social and economic roles should be an important part of interventions, as these can have a very positive influence and improve the quality of life of the individual and the family.

2.6.2 Why should we make an effort to create linkages to community resources?

Schizophrenia has a profound impact on the social functioning of the individual and places a heavy burden of care on the family, restricting the family members' normal activities of recreation and leisure. This creates frustration and high stress in the whole family unit as members feel isolated and blamed for the illness. Anger and resentment for the overall situation is often taken out on the person with schizophrenia; in other words, families often become hostile and critical towards their ill family member. For the person with schizophrenia the increased stress arising from the tense family environment can often bring about a relapse of symptoms, or slow the process of recovery.

However, many of the solutions to the problem of being sidelined from social roles cannot be corrected by the individual and the family alone. It is necessary to look for ways to reconnect the individual to existing community resources that can provide support (matched to the needs of the person) to promote recovery.

The first reason for making an active effort to maximize the functioning of the family unit is to contribute to the overall clinical effectiveness of the treatment.

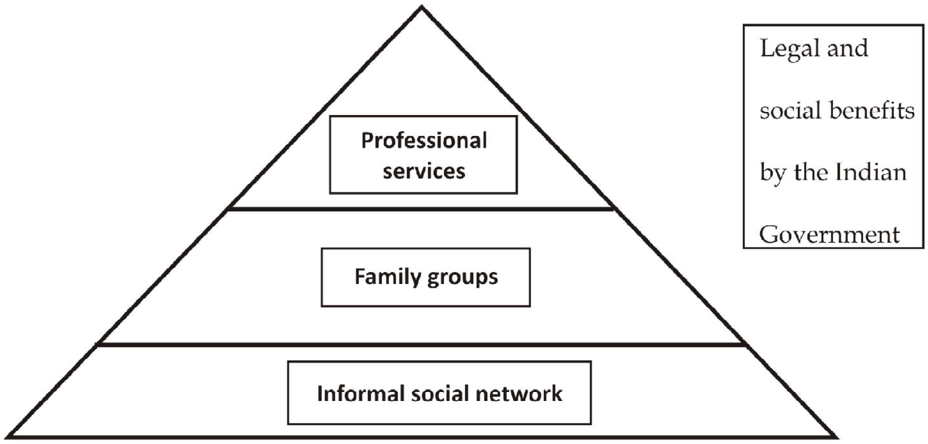
Secondly, when we talk about recovery and maintaining well-being as an important reason for interventions, we also have to take into account the overall social integration of the individual. Since recovery is very much a social concept, promoting better social and economic functioning with the support of community agencies beyond the treating team is vital. The important thing to remember is that stigma and discrimination often compromise the ability of the person with schizophrenia to make use of available resources. Hence, it is not enough to inform the individual and the family about the potential resources, and taking on an active role as an advocate for the person and ensuring that 'doors are opened' are essential elements of the intervention.

Thirdly, we know that the 'self- help' movements - wherein persons who face a common problem come together to solve problems as a group - can be very useful in improving the overall situation of the family unit. Many such groups have been formed in recent years to represent the views and strengths of the persons who are directly affected by the illness. Whatever the nature of the group and their stated goals, being a member of such a group can make one feel less lonely and isolated and provide practical and psychological support. These groups are also useful because they allow members to discuss commonly faced problems, and exchange information of how others have dealt with the issue. Again, group action can be more effective than individual action in trying to fight discrimination- the power of many being more than one. For all these reasons, CHWs should facilitate the availability of such self-help groups.

2.6.3 What are the various community resources available?

A convenient way of understanding the types of community resources available to people affected by schizophrenia is to imagine a pyramid (see Figure 1). At the bottom of the pyramid are the informal or routine social networks like the extended family, friends, neighbors, priests, colleagues at work, local politicians and elders in the community. This informal network is the richest source of support in all of our daily lives. For example, when we feel worried and stressed, this is the first place where we seek some advice or help. Similarly, informal networks absorb much of the pressures and frustrations of living with schizophrenia. However, as the illness becomes long standing and various disabilities accumulate, the informal network shrinks very quickly. Identifying the possible sources of support and encouraging family members to interact more widely is something that can be done relatively easily. Even small improvements in social networks through visiting relatives or attending a marriage can have a powerful impact on self-confidence of the person with schizophrenia. Like the ripples seen when we throw a stone in still waters, improvement in one such area can spread across other areas like self-care and improved conversation skills. As a CHW, you should stress the importance of reviving the previously existing social network, by providing encouragement and support.

Figure 2.6 A: Social networks and supports for people with schizophrenia.



The second source of support for individuals and families is to either establish or join an existing group of people who share the experience of schizophrenia. The groups can consist entirely of people having schizophrenia, only family members, mixture of both or having some mental health professionals also involved.

The least used form of social support is to avail of specialized, professional led services. These include private and paying residential houses in general community where people with schizophrenia can spend periods of time. These facilities are called ‘half-way homes’. On the other hand, many Non Governmental Organizations (NGO’s) are now providing some form of services in the community for rehabilitation and individual support.

Cutting across all these sections of potential support is the overall social and legal supports provided by governments. In recent years, the awareness that schizophrenia is a disabling condition and that people with schizophrenia need formal state support has grown. Under current laws, people with schizophrenia are entitled to various governmental benefits similar to those of people with physical disabilities. These can include free transportation in public transport, disability pensions, labor quotas, and access to special loans to promote small scale enterprises for sustainable livelihoods.

Summary:

Improving the overall quality of life of the person with schizophrenia and family members includes systematic efforts to connect with existing community resources in various sectors.

As a CHW you need to:

- explore the possible ways to improve social interactions of individuals and families
- support the family to deal with barriers and get the entitled benefits
- make concrete plans with the family to ‘make things happen’.

As you will see, these efforts can have great impact on the overall well being of the entire family.

Summary

- Social difficulties present major challenge in persons with schizophrenia and their families
- Community linkages to provide improved social interactions are an essential part of treatment planning
- Community resources- informal and formal, exist at various levels
- Improving the overall quality of life of the person with schizophrenia and family members includes systematic efforts to connect with existing community resources in various sectors for social and work related needs

MODULE 3

The Individual Components Of The CHWs' Intervention

CHAPTER 3.1

Therapeutic alliance - the foundation for working with the person with schizophrenia and the family

3.1.1 Introduction

The foundation on which any health intervention is based on is the quality of relationship with the person providing care. This is especially important when working with people with schizophrenia and their family who have special and complex needs. Studies have shown that individuals with schizophrenia who form good working relationships with their support workers are more likely to engage with interventions, adhere to the prescribed medication and have better outcomes than individuals who do not. As a CHW, one of the most important skills you will need in the course of your work is establishing and maintaining therapeutic alliance.

In this chapter, we seek to understand the nature and factors of this relationship. In this way, we can adopt methods to enhance this relationship and thus ensure optimum individual care.

3.1.2 What is therapeutic alliance or therapeutic relationship?

Therapeutic alliance is the relationship between a mental health care provider (like you as the CHW) and an individual, by which the care provider attempts to engage with and effect change in the individual. In the context of severe mental health illness, the therapeutic alliance is expanded to include the relationship with the family, since family members play an integral role in individual care. It consists of three main components:

- an agreement about the goals of treatment
- an agreement about the tasks necessary to accomplish these goals
- an emotional bond between the health worker and the individual with the illness/family

3.1.3 Why is the therapeutic alliance important?

The quality of the relationship between the treatment provider and the person(s) for whom the treatment is being provided plays a very important role in improving the overall outcomes. For example, a good relationship increases the adherence to medicines and overall engagement, since individuals who perceive that their health worker or doctor understands them and has their best interest in mind, are more likely to take their medicines and visit the doctor regularly. In addition, a good relationship with the family helps to provide support by letting them know that they are not alone in their task of caring for someone with a chronic illness. It also provides them with an outlet for their emotions, and instills hope that some things can get better.

3.1.4 Challenges in establishing a therapeutic alliance

Engaging family members and encouraging their participation in care can be a major challenge and needs to be individually tailored to each situation. For example, sometimes there is more than one person caring for the individual with schizophrenia. In such instances, it is important to collaborate with the individual in identifying the key members of the family support system and what role they may play in helping him manage his illness.

Another challenge in establishing an effective therapeutic alliance is the cognitive impairment and thought disorder that are part of schizophrenia. These symptoms can have a substantial impact on the individual’s ability to engage in a therapeutic alliance, and this may lead to non-adherence, which then further worsens these symptoms in a downward spiral. We will discuss below various strategies which can be employed to enhance the therapeutic alliance and hence treatment compliance.

3.1.5 Specific techniques to enhance the therapeutic alliance with the individual

As a starting point in establishing a therapeutic alliance, it is important to identify the goals that the individual has of his treatment program, and then define the tasks which need to be undertaken to achieve these goals. For example, if one of the goals that the individual wants to achieve is a relaxed state of mind, then the tasks which can be employed are listening to music, relaxation exercises or taking medicines. It is important to elicit the individual's agreement on goals and tasks, rather than to impose your own. The following specific strategies can be used:

- Solution focused interviewing: Solution focused questions help identify goals. Examples of solution focused questions are *"What would make this a helpful visit?"*, *"What would you like to see different after our meetings?"* Some possible goals may include improved relationships at home, ability to be more productive in the house, etc. Once the individual has identified these as things he wants, he will be more ready to work on achieving these goals, and will have a more positive attitude towards you. Once the alliance is established, it will be easier to help the individual address new goals and to even suggest some to him.

- In depth interviewing: Sometimes the individual has unhelpful behaviors such as substance abuse or not taking medicines. It is important, in such situations, to identify the reasons for the person behaving in that way, in spite of knowing the negative impact of the actions. For example, an individual may be using alcohol heavily. On asking him for the reasons for such heavy drinking which is affecting his health and well being, he may say this is due to frequent distressing quarrels at home. He can then be led to discuss effective ways of reducing the quarrels (instead of drinking to deal with the problem), thus identifying healthy goals and tasks.

- The medication interest model: It is important to listen to an individual's concerns about medication side effects and address these honestly rather than dismissing them. A particular interviewing strategy which is found to be effective in engaging individuals to take their medication is to ask them *"Is there anything your illness is keeping you from doing that you wish you could do again?"* This usually helps to identify useful motivators that lead to medication compliance.

It is important to remember when establishing a therapeutic alliance to never provide false hope or promise things you know cannot be realistically provided for. Also, the positive regard for the individual should not hinge solely on behaviors like medication compliance. Instead, you should empathize with the individual's distress and concerns and address them in a direct and honest manner. This usually is the starting point from where you can then guide the individual towards healthy and fruitful behaviors.

3.1.6 Specific strategies in building therapeutic alliance with families:

Although family psychoeducation is extremely important in the treatment of schizophrenia, it should be combined with the establishment of an effective therapeutic alliance. Some strategies to achieve this are elaborated below:

- Family members experience many fears and anxieties about their relative's illness and it is important to acknowledge these and normalize what they may be feeling. Techniques such a reflection *(e.g. "Sounds like you are feeling frustrated")* help the family members feel heard and understood. Normalizing statements can be used, such as *"Your anger with …… is normal in the present situation while you are coping with what you have to"*

- Relatives may have unrealistic expectations about the medicines completely curing the individual's long standing illness. This usually stems from lack of information about the illness and the role of medicines. Rather than making any assumptions, it is important to elicit what the family members know about the illness, and then provide them with appropriate information.

- Social stigma may result in families becoming isolated while they cope with the individual's illness. It is important to help families identify social supports and reestablish relationships that may have been disrupted by the illness.

- It is important to address safety concerns such as suicide and violence. The family members may be under extreme anxiety and fear if such a threat exists, and is important to provide them with practical strategies in the face of such threat. For example, devising an effective suicide prevention plan or strategies to protect themselves from a violent individual help them feel equipped to deal with these situations when they arise.

- Family members sometimes feel they are responsible for the individual's illness. It is important to convey to them that the illness is not the family's fault and provide them with information about the possible causes of schizophrenia.

- It is important to convey to the family the important role they play in the individual's treatment and how their inputs are invaluable to both the treatment team and the person with schizophrenia himself.

Conclusion

Establishing an effective therapeutic alliance with individuals and families requires a combination of effective communication strategies, as well as genuineness and empathy. This goes a long way in enhancing the quality of care provided to individuals with severe mental illness and increasing their opportunities for recovery.

Summary

- Having a good professional relationship or therapeutic alliance is the foundation on which the COPSI intervention is based on
- Sometimes, there are challenges in establishing a good therapeutic relationship with people with schizophrenia and their families; however, there are particular strategies that can be useful
- Effective communication, empathy and other basic counseling skills are important in developing a positive relationship

CHAPTER 3.2

Developing and updating treatment plans for the individual with schizophrenia and the family.

3.2.1 Introduction:

Developing a treatment plan for the individual with schizophrenia and his family is one of the most important activities that you will need to conduct as a CHW. The treatment plan is the method by which you can translate your skills into making a real difference in the individual and family's life. In other words, the treatment plan is the vehicle by which you deliver the intervention in a coordinated and systematic manner to maximize its benefits.

Each individual with schizophrenia and their family will have different treatment priorities at different periods of time. The treatment plan is the method of recording and then matching the treatments according to the requirements of the person. This means that the treatment plan will have to be updated on a regular basis to reflect the changing requirements of the individual and family.

As we will discuss a little later, the record of the treatment plan is the best method to monitor progress of the individual, and is a useful indicator of the overall quality of the intervention.

3.2.2 Why have systematic treatment plans?

- The process of developing a collaborative plan helps develop mutual trust and a strong therapeutic relationship
- Involving individuals and key family members in the management plan so that their priorities and concerns are addressed (collaborative, participatory care)
- Recognizing and reinforcing the strengths and resilience of individuals and their families
- Building upon effective strategies that individuals or families have used to address problems
- Introducing specific strategies, information and new ways of coping in an orderly sequence based on specific target problems
- Helps indicate the quality of the program and is used for supervision
- Method to bring the different members of the community team to think about the person collectively
- Evaluate and monitor progress of the treatments started on an ongoing basis.

The treatment plan is based on 2 important activities which are linked- the *need assessment* and the *individualized treatment plan.* In this section, we describe the process of conducting the needs assessment and the subsequent treatment plan which reflects the findings of the need assessment exercise.

3.2.3 Need assessment:

As the name indicates, need assessment is a method to understand and record the requirements of the individual with schizophrenia and the family. As you can imagine, people with schizophrenia will have a number of areas that need attention to maximize the possibility of recovery. These commonly include medicines, support, information and specific skills to enhance role functioning in problem areas. A well planned need assessment is based on a clear framework and is done in a particular manner which makes it likely that most areas which require attention are captured in the treatment plans.

3.2.3 a) The framework for need assessment:

The need assessment exercise can be clearly understood if we recall the disabilities caused by schizophrenia and the overview of the individual interventions. In Chapter 1.4, we discussed that schizophrenia causes specific *impairments* (hearing voices, lack of concentration, etc) that lead to difficulties in carrying out expected role functions optimally (*disability*), which is often worsened by the discrimination that the individual faces (*activity restriction*). The need assessment is based on a clear description of these particular problems; the Table 4.2A below illustrates this process with some common examples.

Table 3.2 A: The framework for needs assessment

Impairment (symptom)	***Disability (functioning)***	***Activity restriction (environment)***	***Identified need***
Hallucinations	Poor concentration	Unemployment	Need to control hallucination
Depressed mood	Cannot go out of the house	Social isolation	Need to control depression
Lack of motivation	Poor personal care	Loss of friends	Need to improve personal care

To ensure that we cover most of the areas which usually need further attention, we will base the need assessment on the areas identified and discussed in Chapter 2; these are listed below:
The need assessment section of the intervention record form (Appendix) reflects these broad areas which are specifically assessed for every individual with schizophrenia.

Needs of people with schizophrenia and their families:

- Symptom control
- Managing medication
- Self care and independent living
- Role functioning
- Emotional well being
- Social relationships
- Physical health
- Stigma and discrimination
- Leisure and recreational activities
- Religious and spiritual activities

3.2.3 b) How is the needs assessment done?

Need assessment is done through a process of discussion with the individual, the family and the treating team members. The inputs of all the major persons involved in the treatment are essential to arrive at the best possible overall picture of the requirements of the individual in the near future. It is quite possible that different people involved in this discussion will have different points of view about the immediate needs of the individual. For example, the individual might feel that getting employment is the most urgent need, while the parents feel that control of positive symptoms is the most important area of concern. The need assessment takes the viewpoint of the people involved into consideration and is then finalized by everyone agreeing on a limited number of areas to focus on, in a particular period of time.

Need assessment conducted in a collaborative manner is the direct and substantial way in which individuals and family members can contribute to determining the nature of treatments to be provided to them and as such contributes to the principles of empowerment and self management which are the foundations of your intervention.

During your intervention, individuals may be quite unwell and in the acute phase of treatment. The primary area of concern at this point is improving the acute symptoms as quickly as possible. The needs of the family are most often around managing the difficult behavioral symptoms (agitation, reduced sleep, lack of any routine, laughing or talking to self) and getting information about how to cope with them. The treating doctor will be understandably keen on using adequate doses of the medicines and might need to review the individual more frequently.

This is quite different from the situation 6 months later, when acute symptoms have been controlled and the focus is on improving the quality of the individual's life by improving relationships within the family, increasing the social network outside home, engaging in some work on a regular basis and wanting to attend college again.

Need assessment is therefore a flexible and dynamic process which depends on the overall clinical situation at the time it is done. It is very unlikely that the entire need assessment exercise can be conducted at one time. Therefore, it needs to be updated on a regular basis to reflect the changing nature of the individual's overall situation.

There are 3 other important issues when conducting the need assessment

- **Scoring of the need assessment form:**
  As you notice, in the needs assessment form, the right hand section deals with the result of your assessment, as you will need to arrive at one of the 3 possible conclusions; *no need, partial need or unmet need*. For example, an individual with schizophrenia may be able to manage money and use public transportation comfortably. In this case, he has no need for further help in these particular areas and this item is scored as no need. However, this individual may continue to have positive symptoms which are less intense than before but still troublesome. In this case, his need for symptom control has been partially met. On further discussion, it emerged that this individual has no friends, cannot work regularly, has no leisure activities and is mostly isolated at home. His needs for social relationships outside of home, work and leisure activities are unmet and therefore need specific attention.

- **Take into consideration local social and cultural norms while scoring:**
  Need assessment is conducted to look at the gaps in the individual's current levels of problems, in contrast to what would be expected of a 'normal' person of similar backgrounds. Therefore, it is very important to be aware of the common sense, local understanding of what it means to be 'normal' in that community. Often, there will be different expectations of what is considered normal for women and men in the same community. Similarly, not all things that are considered normal for a 45 year old married man with 2 children will be the same for another unmarried 21 year old male. When scoring the outcome of the assessment for each item, it is useful to keep the social and cultural concepts of normality in mind.

- **Having the same people involved in all assessments:**
  Since need assessment is dependent on the views of different people, it is important that reviews of the assessment are done with the same set of people who were involved in the initial assessment. Commonly, this would include parents, spouses, grown up children and other members of extended families who will be discussing their need perceptions with you. It is best that the same set of people is involved in all the discussions so that the basis for the assessments remains consistent.

3.2.3 c) When is the need assessment done?
The need assessment will be done when the person *enters the program*, and should be revised *every 3 months*.

Therefore, in the 12 months that you will be working with the individual and the family, there will be 4 assessments done. Remember that you do not have to do the whole of the assessment at each point and that there will be different needs at different points of time. For the ones that you have assessed previously, just update the scores at every review:

- has the need been met since it was identified- no need
- has the need been met somewhat- partial need
- has nothing changed and the unmet need continues to be the same- unmet need

3.2.4 Developing the individual treatment plans:

The treatment plan is the final result of the need assessment exercise and it matches the particular needs which require intervention. The treatment plan is the agreed upon guide for treatments to be delivered to the individual with schizophrenia and their family, in order to enable gradual recovery. The requirements of a good treatment plan in outlined in *Box 3.2 B* on the following page.

A good treatment plan:

- reflects the priority needs identified
- link to specific needs like control of psychotic symptoms, improving role functioning, independent living skills, increasing social networks etc.
- has strategies in the plan that are based on proof of effectiveness
- has a time bound review of the plans for positive or negative results
- includes the individual and the family as much as possible
- is clearly understood and agreed upon by the individual and the key family members
- guarantees that the same treating team will work with the family over the period of engagement

3.2.2 a) Treatment matching to identified needs

The key element of the treatment plan is the matching of the treatment to a specific problem area in a feasible and acceptable manner to achieve the best possible results.
A few examples of this exercise are provided in the Table 3.2 B below.

Table 3.2 B: Matching treatments to needs

Identified need	*Matched treatment*
Control of positive symptoms	Antipsychotic medications Adherence management Information about medicines and possible side effects Regular medical review
Poor physical health	Information about exercise, stopping smoking and diet provided Ensure medical and dental checkup Follow up on investigations Start treatments for health problems with physician
Poor relationship with family members	Information about illness Improving communication within family Problem solving to deal with difficult situations
Lack of employment	Improving personal care and grooming Social skills training Linkage with community organizations for local job opportunities Self employment schemes in local government Accessing disability linked employment opportunities

3.2.2 b) The components of the treatment plan:

The treatment plan is a precise statement of how the intervention is being delivered to each individual. While *treatment matching* is an important element of the plan, there are some additional tasks that need to be completed for a good treatment plan to emerge.

Since there are a number of players in providing the intervention, it is important to clearly specify in advance the *roles and responsibilities* of each member. For example, for controlling symptoms the doctor would take the lead in prescribing medicines, while you would need to provide information, initiate coping strategies and implement the adherence management plans.

The treatment plan also needs to include a brief description of the *process* by which the intervention is being provided. For example, the plan needs to specify *where* the treatment will be delivered (home or treatment center/hospital), the *method* of providing the treatment (in group, face to face contact, etc), *how often* it will be provided (once every 15 days) and the *people involved* (individual, parents, etc).

Finally, the plan also needs to specify the *frequency* at which it will be *reviewed* to understand if progress is being made. The reviews may need to be individually specified according to certain areas; e.g. adjusting the dose of medications may need more frequent reviews.

To summarize, the treatment plan is unique to each individual, based on an assessment of needs, has a clear method of matching treatments to needs, specifies the roles of the individuals involved and describes the actual process of delivering the treatment, the results of the treatment and the frequency of the review.

3.2.2 c) Content of the treatment plan:

Finally, we are in a position to design the treatment plan. The intervention record form may have the format shown below in Table 3.2C below.

Table 3.2 C: Example of individual treatment plan

Need	*Treatment*	*Who will deliver*	*Process*	*Results*	*Frequency of review*
Control of positive symptoms	Antipsychotic medicines	Treating doctor	Review face to face at hospital every 15 days with parent & CHW	Increased dose of antipsychotic has improved symptoms Side effects like stiffness and restlessness	Every 15 days
	Adherence management Information about medicines Side effect monitoring	CHW	Face to face meeting at home with parents and younger brother every 15 days	Family are more supportive & understanding of the individual & involved in adherence	Every month
Poor physical health	Information about exercise, stopping smoking & diet Ensure medical and dental checkup Follow up on investigations Start treatments for health problems with physician	Treating doctor and CHW	Face to face meeting with individual and family at hospital with CHW and doctor Referrals to appropriate medical specialists Referral to dentist	Individual has changed diet, is exercising regularly Has not met with the GP or the dentist	Every month
Unemployment	Improving personal care & grooming Social skills training Linkage with community organizations for local job opportunities Self employment schemes in local government Accessing disability linked employment opportunities	CHW	Skill training through meetings at home every 15 days Follow up enquiries about practicing of skills through weekly phone contact	Improved social skills-able to make good eye contact and maintain conversation Meeting with local government officials conducted and forms for self-employment filled	Every month

			Meeting with local government official to enquire about employment opportunities that can be availed		
Poor relationship with family members	Information about illness Improving communication within family Problem solving to deal with difficult situations	CHW	Face to face meeting with individual and family member at home once every 15 days Follow up enquiries about practicing of skills through weekly phone contact	Family interactions and overall atmosphere has improved Family are doing more things together like having dinner, going out for a movie Family members are feeling less stressed and angry-frequency of arguments have come down	Every month

3.2.2 d) Updating the treatment plan:

The initial treatment plan is a blueprint to start with the delivery of the intervention in an appropriate manner and needs to be updated at each of the scheduled reviews. For example, in the example provided in Table 4.2D, the individual has side effects due to the medicine, has not met the GP or the dentist, and has more work to do in applying for a job. These partially met or unmet needs are recorded and become the focus of the next period of treatment planning. An example of this is shown in Table 3.2D below.

Table 3.2 D: Updating the individual treatment plan

Review of needs	***Current problems***	***New treatment plans***	***Who will monitor***	***Next review***
Control of psychotic symptoms	Side effects affecting adherence	Reduce dose of medicine. Add new medicine to counter side effect	Treating doctor CHW	After 15 days
Physical health	Has not met GP or dentist	Find out reasons for this; Remove any systemic barriers to meeting; Personal referral letter to concerned physicians; Encourage the individual and the family; Reiterate need for physical health promotion	Treating doctor CHW	After I month

Employment	Has not submitted forms to local government office for self employment scheme under the Social Justice and Empowerment Ministry	Schedule home visit and accompany the individual to the block office to submit forms and meet the relevant official	CHW	After I month
Poor family relationship	Much improved overall	Reinforce communication and problem solving strategies	CHW	After I month

Summary

- Developing a systematic individual treatment plan is an essential part of the COPSI intervention
- Need assessment is the method through which the focus areas for the intervention is identified
- Need assessment is a collaborative process that allows the person and the family determine their treatment priorities
- Needs are then matched to particular treatments in the individualized intervention record form which forms the basis for the planned intervention delivery content and sequence
- Treatment plans need regular updating to ensure that current priorities are being addressed in the COPSI intervention

CHAPTER 3.3

The assessment and management of suicide risk in the COPSI intervention

3.3.1 The assessment of suicide risk in schizophrenia

Suicide is a major cause of death among persons with schizophrenia, with 5–13% of schizophrenia persons dying by suicide. Some new studies have now indicated that the risk might be lower than what was reported earlier. Overall, the risk of people with schizophrenia committing suicide is 10 times greater than the risk for the general population. Obviously, this is a matter of great concern and we want to make sure that we can detect someone at risk of attempting suicide and do something to manage the risk properly.

As a CHW, one of the key tasks would be the identification and assessment of the risk of suicide in the persons you will be seeing in the course of your work. This will help you plan interventions that can minimize the possibility of suicidal acts and save precious lives. In this chapter, we will learn about the method of carefully assessing the risk of suicide.

3.3.2 How do we define suicidal acts?

Completed suicide is defined as an act of knowingly harming oneself in a manner that results in death. The methods employed by people who complete suicide vary widely across the world and are dependent on local factors like the easy availability of guns, pesticides or cooking gas. However, drowning, hanging and ingestion of medicines are common methods seen in most areas of the world. Jumping into wells and consumption of pesticides are also commonly used methods to commit suicide.

Attempted suicide, in contrast, is an act of harming oneself that is not fatal. Suicide attempts are 10-20 times more common than completed suicide and are most common in young women. Any suicidal act poses a significantly increased risk of completed suicide during the person's lifetime, and should be taken very seriously when assessing risk.

3.3.3 The principles of Risk Assessment:

3.3.3 a) The importance of detection of suicide risk:

As a CHW working with persons with schizophrenia, you will be dealing with a high potential risk of suicide. **The assessment of suicidal risk, therefore, is an essential part of your work and must be integrated within the overall interventions.** As someone who will be working closely with the person with schizophrenia, you are in an important position to identify and manage this risk.

The most important thing to remember is to ask for the presence of suicidal ideas. It is a wrong idea that asking for suicidal ideas introduces the idea in the person's mind. On the contrary, asking whether the person has experienced suicidal ideas is the only way to identify risk and provide the necessary help to prevent suicidal acts.

Risk may alter over time. Therefore, frequent review may be necessary in the same person. Since this is a very private experience that the person may feel guilty or embarrassed about sharing, it is important to ask for the presence of suicidal ideas in a gentle and non-judgmental manner. **A good relationship with the person makes it easier to assess risk.**

Some of the ways that the question may be framed include:

- ***"Have you felt in the last few weeks that it would be better if you did not wake up in the mornings?"***
- ***"I can see that you are going through a very difficult period. In your situation, many people feel that carrying on with life is not worth it. Have you ever felt this way in the last few weeks?"***
- ***"Have you ever felt that that the problems in your life are too difficult to be solved and that you are better off dead?"***

3.3.3 b) Understanding factors contributing to risk of suicide in people with schizophrenia:

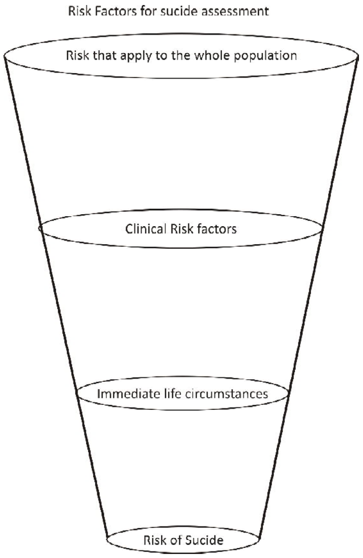
Risk factors for suicide can be understood as being multi- layered and in the form of a cone; at the top (broadest part) of the cone are the relatively broad, population based risk factors that are of limited help in assessing risk in the individual at one point in time (see Figure 2). As in a cone, the risk factors become 'narrower' and more useful in predicting risk; thus, clinical risk factors are more specific in assessing risk. In the same manner, the immediate risk factors are the 'closest' risk factors that are most sensitive to immediate risks:

- **Socio demographic risk factors:** These are chronic, relatively long-standing factors that apply to the whole of the population rather than just the individual. These factors are also hard to modify easily.

- **Clinical and treatment related risk factors**: These are the risks that are related to the clinical problems and treatment that the person presents with. Some of these risk factors can be modified and should, therefore, be part of the treatment plans.

- **Immediate risk factors**: These are the risks that are closely linked to the current social and psychological situation of the person and need immediate attention to reduce the risk of suicidal acts.

Figure 3.3A: Risk factors for suicide assessment



3.3.3 b i) Socio-demographic risk factors:

- *Age*: The risk of suicide is the greatest in young adults and in old age.
- *Sex:* Suicidal risk is higher in females but men make more violent and lethal attempts.
- *Socio-economic status:* Lower socio economic status has a strong relationship with suicide.
- *Marital status:* Single persons, persons who have recently lost their spouse or the recently separated are at a greater risk of suicide.
- *Employment:* Being unemployed or recently losing one's job is an very important risk factor

3.3.3 b ii) Clinical risk factors:

- *Presence of mental illness or chronic, serious physical illness:* Having any current or past mental or physical illness is one of the strongest predictors of suicide. Many people who commit suicide have diagnosable illnesses like schizophrenia. The treatment of the mental illness is one of the most important ways of reducing risks.
- *Family history of suicide:* This is another important risk factor since having a family member who has committed suicide increases the risk many times.
- *Previous history of suicide attempt:* The risk of completed suicide is 10 times greater in persons who have attempted suicide earlier.
- *Use of alcohol:* The current and past use of alcohol, commoner in men, is a very important predictor of suicidal risk.
- *Unsupportive family:* This is an understandable risk factor which is especially important to consider in young adults, women who have married recently and the elderly.
- *History of past or current abuse:* Physical and sexual abuse are very important risk factors. In our context, ongoing domestic violence from an alcoholic husband is a common and a serious risk factor that warrants immediate attention.

3.3.3 b iii) Immediate risks:

- *Ongoing and severe social stresses:* Social stresses where the person feels trapped (large debts), humiliated or loses status (sudden loss of employment) are often the immediate factor for attempting suicide.
- *Hopelessness:* The experience of hopelessness *('Nothing can be done to change my situation')* is the final common pathway to suicidal acts and is the single best predictor of risk in the immediate term.
- *Loss of interest:* Another important clue to the risk of immediate suicidal risk is when the person loses interest and withdraws from their usual social interactions with friends or family members or does not feel motivated to work as usual. In these circumstances, biological changes like diminished appetite and sleep are quite common and lead to the person dropping out of treatment as well.
- *Conveying the intention to attempt suicide:* Suicidal acts can be impulsive or planned in advance. In the case of planned suicide, very often, the person would have communicated their intent through clues like suddenly giving away personal possessions and drawing up a legal will
- Making attempts to get *access to means* of suicidal attempt like buying pesticides or stocking large amounts of medicines. This is an extremely serious situation that signals high suicidal risk and needs immediate interventions.

The *Checklist for assessment of suicide risk* (see Appendix) will help you summarize the degree of risk.

3.3.3 c) Protective factors that can reduce the risk of suicide:

The act of harming oneself is a very difficult decision to make since life is the most precious thing we possess. Most often, persons who attempt suicide are caught in two minds about the act till the last minute. This is partly due to protective factors in the person's life.

Protective factors refer to those reasons that minimize the risk of suicide and are therefore the opposite of risk factors. An understanding of these factors is essential in planning interventions for reducing the suicidal risk. In managing suicidal risk, we must try to increase the protective factors in the person's life.

Some of the more common protective factors are:

- *Social support* from family, friends and other significant relationships like children who offer support.

- *Religious and cultural beliefs* that consider suicide as morally wrong can be a very important factor preventing suicide.

- *Community involvement* and integration through employment and membership of groups can be powerful factors that reduce risks.

- *Access to help* like priests, counselors and telephone hotlines where the person can discuss her problems in a confidential manner.

- *The person's perception of the consequences* of the suicidal act and the possible repercussions on children and family are frequently important factors that hold the person back from committing suicide.

- *Individual personality differences* like an optimistic view of life, sense of control, positive coping styles and problem solving abilities are personal assets that can reduce the risk of suicide.

Table 3.3 A: Risk factors for suicide in schizophrenia:

Socio-demographic risk factors	Male
	Young (often under 30 years)
	Unmarried
	Unemployed/ Dependent or incapable of working
Clinical risk factors	Past and present history of depression
	History of suicide attempt(s)
	Substance abuse
	Deteriorating physical health
	Family history of suicide
	Long duration of illness with numerous exacerbation
	Gradual onset of illness
	Apparent improvement followed by a relapse or exacerbation
	Early onset of illness
	Good personal understanding of current situation
Treatment related risk factors	Side effects caused by medications like restlessness, muscle stiffness
	Prescription of a greater number of antipsychotic and antidepressant medicines
	Negative attitudes towards medication and reduced adherence with treatment
	Difficult relationship with staff (complaining about the treatment personnel and about their treatment in general)
	Immediately after admission
	Shortly after discharge from hospital
	Continued symptoms in spite of treatment
	Loss of faith in treatment
Social variables	Social isolation
	Family stress or instability
	Limited external support
	Recent loss or rejection
	Living alone

The most significant of these risks are presence of:

- co-occurring depression
- previous suicide attempts
- alcohol or other psychoactive drug misuse
- agitation or motor restlessness as a side effect of antipsychotic medicines
- poor treatment adherence
- recent experience of loss and rejection
- hopelessness about the future

3.3.3 d) If there is a history of suicide attempts then the following questions should be asked:

- When was the last time that you made an attempt to harm yourself?
- How many times have you tried to kill yourself?
- How did you try to kill yourself?
- Did you require medical treatment after this attempt?
- Were you hospitalized after this attempt?
- Did you want to die very strongly?
- Did you think you would die from what you had done?

On the information derived from the questions above the level of the desire to die (**intent),** the seriousness of the attempt **(lethality)** and the degree of prior planning **(premeditation)** of the suicide attempt are rated.

The intent or the desire to die is rated as:
(1) No intent or minimal intent, manipulative gesture
(2) Definite intent, but ambivalent
(3) Serious intent, expected to die
(4) No information, not sure

The lethality or the seriousness of the attempt is rated as:
(1) No danger (no effect, held pills in hand)
(2) Minimal (scratch on wrist)
(3) Mild (5-10 tablets of pain killers, mild gastritis)
(4) Moderate (briefly unconscious)
(5) Severe (cutting of wrists or throat)
(6) Extreme (respiratory arrest or prolonged coma)
(7) No information, not sure

The premeditation or advance planning is rated as:
(1) Impulsive (less than 1 hour forethought, used materials immediately at hand).
(2) Somewhat premeditated (had suicidal thoughts over hours or days prior to making the attempt).
(3) Thoroughly premeditated (continuous thoughts about suicide over weeks, months or longer prior to attempt).
(4) No information, not sure.

If all of it was high the greater is the risk for a repeated attempt.

3.3.4 Assessing the degree of risk in people with schizophrenia

Once you identify that the person has been experiencing suicidal ideas, it is essential to then make an estimate of the degree of the risk. It is possible that some persons may not feel comfortable about disclosing their suicidal ideas in the first meeting. In both scenarios, you need to be aware of identified risk factors for suicide and make an informed judgment about the possible risk involved that will guide your further interventions.

It is equally important to understand that the prediction of suicide is an imperfect science and that it is better to overestimate the risk rather than ignoring important clues. If the person does mention that she is experiencing suicidal ideas, it is very important that you are able to manage your personal anxiety (that is normal in these situations) and remain calm but emotionally supportive. Remember, you can always discuss such cases with your supervisors. An understanding of the risk and protective factors should enable you to make a judgment about the seriousness and immediacy of the risk (see box below). At this point, if you think the person you have just seen is at possible risk of attempting suicide, you should ask some specific questions that will confirm the degree of the risk. These include:

- Have you been having thoughts of harming or killing yourself?
- Have you made any plans for harming yourself?
- Have you been having these thoughts repeatedly and cannot distract yourself from them?
- Have you been feeling hopeless and that nothing can help you?
- Have you been thinking about what will happen to your family after you die?

At this point, taking into account your understanding of the balance between risk and protective factors and the frequency and type of suicidal thoughts, you will need to specify the degree of risk for that person. Based on the guidelines given in the box below, there are three possible categories of risk and you will need to choose the most appropriate one. When completing the risk assessment checklist, please remember that it is not a matter of ticking and simply counting the ticks to make a summary risk profile. Instead, as we had discussed earlier, not all the items on the checklist have the same specificity. Thus, the presence of any immediate risk factors gets higher value when compared to a socio-demographic risk factor like being a male.

3.3.4 a) Levels of risk of suicide risk:

- **No/Low risk:** Absent or very occasional, stray reports of passive suicidal ideas ('I am better off dead') which the person can forget easily and do other things. There are mild clinical problems, no immediate risks and adequate protective factors.

- **Moderate risk:** Persistent suicidal ideas with no concrete plans, moderate- severe clinical problems, one or more immediate risk factors and limited protective factors.

- **High risk:** Persistent suicidal ideas with definite plans, severe and multiple clinical risks, multiple immediate risks including severe hopelessness and limited protective factors.

Summary

- Assessment of suicide risk is an integral part of your role as CHW
- A good rapport with the person makes it easier to assess suicide risk
- It is important to understand the risk factors for suicide, which can be classified as socio-demographic, clinical and immediate risk factors.
- Protective factors that reduce the suicide risk must also be identified as they are important in planning risk management strategies
- Degree of suicide risk can be classified as low, moderate or high, depending on the balance of risk and protective factors, and the frequency and type of suicidal thoughts

3.3.5 Management of people with schizophrenia who are at risk of self harm:

3.3.5 a) Working with people who are experiencing suicidal ideas- general guidelines:

There are some general guidelines of how a health provider should approach a person who is experiencing some degree of suicidal risk.

- *Being non-judgmental*: Your personal attitudes towards suicide (sign of weakness, against religion, etc) should not be allowed to become part of the interaction. Suicidal ideas are not an expression of weakness, morally wrong or something to feel ashamed about. People experiencing suicidal thoughts are distressed by them and are told by close friends or family members that these are 'wrong'. Your role as a CHW is to accept the person's suicidal ideas and not reject or blame the person concerned. This does not mean that you agree with the person's decision to attempt suicide as a way of dealing with problems, but disagreement does not mean rejection. Calm and matter of fact acceptance of the situation is often what people with suicidal ideas need to discuss rational solutions, something that does not happen in other interactions.

- *Empathy- no blame*: In dealing with mental illnesses like schizophrenia, the best way of understanding the person is to try and see things from his or her perspective. This communicates to the person that you are respectful of his opinions and serves to improve the quality of the therapeutic alliance. Obviously, talking about private issues like suicidal ideas is easier and more effective when the alliance is strong and based on trust and mutual respect.

- *Collaborative problem solving*: One of the most effective methods of reducing the risk of suicide is to engage the person in solving problems that are contributing to the risk. For example, if the main reason for the suicidal ideas is continued auditory hallucinations commanding the person to harm himself ('*you are useless and should not live any more*'), possible actions can include an urgent visit to the doctor to discuss solutions and trying to distract from the voices by listening to music loudly.
  The very fact of engagement in such process is important in providing a sense of hope and control over the problems to the person in reducing risk.

- *Keeping in touch*: Another general guideline is to ensure that you will have further contact with the person with the suicidal ideas at an appropriate date and time. This provides a sense of continuity and an assurance to the person that his problems are being seriously addressed.

- *Management needs to be matched to the degree of risk*: This simply means that there is no uniform method of providing support to a person experiencing increased risk of suicide, and that treatments need to be individualized to the needs and particular situation. For example, it is obvious that persons with a higher degree of risk will require more intensive services when compared to someone with a low risk.

3.3.5 b) Details of risk management methods:

- A *positive and trusting therapeutic alliance* is crucial to encourage the person with schizophrenia to discuss his feelings and concerns in a supportive and confidential manner. Investing and promoting a positive relationship from the very beginning is something you need to be conscious about all the time, especially when assessing and managing risk.

- *Provision of hope*: In the short term, this is probably the most important goal when managing suicidal risk. The idea is to encourage the person to find a way to overcome hopelessness by reminding him that things *will* improve with some joint effort.

- *Ensuring safety by reducing access to means*: This is an essential element of the management of suicide risk. The risk of suicide can obviously be decreased somewhat if access to means of self harm (pesticides, alcohol, gas cylinders, long ropes, knives) is restricted or banned for the person. This also means that the family has to be told about the risks, the need for removing access to means and of continued observation. Informing about the risk needs to be discussed specifically with the person with schizophrenia before • actually meeting the family. In some situations, the person may not agree for you to inform and involve the family. Getting the balance between the rights of the individual to not let the family know and the need to protect and save a life by disclosing the risk to the family is a difficult situation and you need to get some immediate guidance from your supervisors about the most acceptable course of action.

- *Enhancing protective factors*: This is an obvious strategy to counter the risk factors as we have discussed earlier. Some examples include reminding the person about support from family and friends, and asking him to pray more frequently as a means of calming himself down when feeling very vulnerable. Sometimes it is also useful for the person to make an effort to meet up with close friends or family members to have some respite from the thoughts of self harm.

- The *systematic detection by the CHW of common problems that increase suicide risk* is also essential for risk management. Screening for positive symptoms, depression, alcohol use, side effects like restlessness, hopelessness and any immediate social difficulties is recommended as a matter of routine. This exercise has some inherent value as well, since it provides a clearer understanding of the reasons for the current risk situation and reassures the family and the individual that there is a well thought out plan for the management of the risk. This belief can be a powerful way of reducing risk in the short term.

- Have a *clear management plan with specific timelines for ongoing review of risk:* Having a clear plan which involves key people, each with clear roles and responsibilities, is a simple and effective way of getting the individual, key family members, you and other close friends or priest involved and in pooling the available support effectively. Facilitating the plan, getting everyone to agree and then making it work is a necessary component of your suicide management responsibilities. Also, this is something that you need to review with your supervisors as detailed below.

- *Increasing the frequency of contact* including phone contacts: Most often, and especially when the risk is moderate- severe, increasing the frequency of contact between you and the family will be a requirement. The frequency and details of the temporary increase in contacts need to be discussed and cleared by the treating psychiatrist, as will be the decision to get back to the usual frequency of planned sessions.

- *When in doubt, discuss with supervisor*: This is something you need to remember at all times- consult your immediate supervisors (Intervention Facilitators/ Coordinators) and, if necessary, the psychiatrist. Please do not feel that you need to be able to resolve frequently complicated scenarios all by yourself; the supervision arrangements are in place for this very reason. In addition, all persons with schizophrenia in your caseload who have been rated as having any suicidal risk need to be reviewed during team supervision without fail.

- *Documentation*: Documenting the risk rating, the follow up action that you have undertaken, the plans for managing the risk and the details of the supervision inputs is a necessary part of the whole process of managing risks. The documentation will be guided by your supervisors initially till you are clear about the procedures and expected standards. While documenting the process, please remember that this will be read by other collaborators who will not have any direct idea of the person. Communicating the essential details of the process of risk management clearly and in sufficient detail is a skill that you will need to acquire.

- *Taking care of yourself*: Unfortunately, this is often not given the importance that it deserves- dealing with people who are suicidal is a stressful and demanding activity and it is natural to feel emotionally exhausted. Usually this happens when the risk is high or when you feel completely responsible for the person and overdo things as a consequence.

  There is nothing unusual for this to happen to you- anyone who has worked with people who are at risk have gone through the same experience at some point. The important thing is to have support systems in place that you can access if feeling stressed. In the first instance, your supervisor and peers will be able to support you and deal with any difficult emotional issues in complete confidence. If necessary, other staff members can be asked to help as well. The key thing is to recognize and ask for help without feeling ‘weak’ or inadequate.

3.3.6 Things to do for suicide risk management:

To do list for low risk rating:

- Ensure treatment plan is appropriate
- Enhance protective factors
- Continue agreed frequency of contact
- Ensure follow up and clinical review
- Reassess risk every three months

To do list for moderate risk rating:

- Discuss and agree on safety plans (means, observation)
- Discuss with **Intervention Coordinator** supervisor and organize clinical review with **treating Psychiatrist** as soon as possible
- Enhance protective factors
- Meet immediate social problems in a planned manner
- Ensure adequate treatment and adherence
- Ensure follow up and increase frequency of contact
- Reassess risk at every visit till risk reduces
- Document actions taken carefully in intervention record form

To do list for high risk rating:

- **Discuss with Intervention Facilitator/ Coordinator and treating Psychiatrist immediately and follow suggested management plans in person**
- Schizophreniatreatment may be required in the short term for safety- provide family with details and referral
- Discuss with family and ensure safety; ensure continuous observation
- Assertive and frequent follow up and ongoing risk reassessment
- Document actions taken carefully in intervention record form

Summary

- People with schizophrenia have a higher risk of attempting and completing suicide; suicide prevention is therefore one of the most important elements of the COPSI intervention
- Suicide risk is best understood as interplay between risk and protective factors
- Suicide risk can be systematically assessed and divided in low, moderate or high risk categories
- There are some general principles of ensuring the safety of the person at risk of suicide and specific actions you need to consider in people with schizophrenia
- In the COPSI intervention, there are specific protocols for responding to degrees of suicide risk

CHAPTER 3.4

Individual treatments for people with schizophrenia in COPSI

Chapter 3.4 A Information about the illness for the individual with schizophrenia and family members

3.4 A i) Why is providing information about schizophrenia important?

- Information enables the individual with schizophrenia and the family members understand the fact that the problems facing them are caused by a specific illness. This gives a rational explanation for the problems and gives a sense of control for everyone concerned- that schizophrenia is a chronic medical condition which can be managed
- Providing a framework for the problems being encountered and generate a sense of optimism and hope that it is possible to 'live life with the illness' similar to many people with heart problems or diabetes
- Enables the individual and the family become partners in managing the illness rather than being passive recipients of advice and medicines. This, in turn, can have a positive impact on the confidence and well being of people concerned as they feel that their views are being heard
- Emphasizes that the person with schizophrenia and the family members have an active and important role to play in managing the illness and improving their overall quality of life
- Information is a way of ensuring that the person with schizophrenia and the family are empowered to deal with the illness after the intervention ends

3.4 A ii) What are the key methods of improving uptake of the information provided?

Providing information by itself is ineffective in making real changes to a person's life. Information should be provided in a way that makes it more likely to be actually used. In persons with schizophrenia the challenge is bigger since the symptoms of the illness can make the effective exchange of information more difficult. The strategies that can help improve the effectiveness of the messages are described below and apply to many of the sections of this chapter.

Educational Strategies:

An important goal of your intervention is to provide basic information about the nature of mental illness, the principles of treatment and strategies for preventing relapses and coping with symptoms. In order to be effective in teaching basic information, and to ensure that people understand its relevance in their own lives, several educational techniques are useful.

First, education must be *interactive* and involve all parties to be effective. People learn information by actively processing it in a discussion with someone else. Interactive learning involves frequently pausing when presenting information to get the person's reaction and perspective, talking about what the information means, and clarifying any questions that may arise.

Also, an interactive teaching style conveys to the person that he or she has important contributions to make to the learning process, and that the practitioner is interested in what he or she has to say. In order for the practitioner to know whether he or she is successful in transferring the information successfully, frequent checks must be made to evaluate the person's understanding of information.

This is best done by asking the person to summarize the information provided in their own language rather than asking Yes or No questions, such as, *"Did you understand?"* Hearing the person explain his or her understanding of basic concepts enables the CHW to know what areas have been understood and what areas need clarification. It is also helpful to ask *"Is there anything that you disagree with?"* when reviewing information in an educational handout.

When information is presented, it should be *broken down into small bits* to make it as easy to understand as possible. Some mental illnesses cause impairment in cognitive functioning, which can result in a slower rate of processing information. By presenting small amounts of information at a time, and frequently pausing to check understanding, everyone can learn the information at their own pace.

Homework assignments are an important way of improving the effectiveness of the information being provided. As so, homework assignment for the person with schizophrenia and family members is strongly recommended at various stages of the intervention.

Finally, when providing information to anyone it can be helpful to adopt their language whenever possible in order to facilitate communication. Individuals have their own ways of understanding their experiences, thinking about their lives, and looking into the future. The more the practitioner can "*speak the same language*," the easier it will be to make a connection and avoid unnecessary misunderstandings.

Strategies to improve the motivation to use information in daily life:

Strategies to generate and maintain motivation for change address the fundamental question of why a person should be interested in learning the information and skills that are part of the intervention. Developing motivation to learn information and skills is critical for improving the uptake of the information.

Motivational strategies involve helping people see how learning information and skills will help them achieve short and long-term goals that are personally important. Since each person with schizophrenia is a unique individual, selecting and working towards a *personally meaningful goal* is important.
For example, some people might identify the reduction of distress due to symptoms and symptom relapses as being important, while others may have goals like improving relationships, finding work or other meaningful activity.

Another important way of keeping up motivation is to *set small, achievable goals* in the initial period when the person is trying out the new information or skills. This will ensure that the person gains in confidence while attempting to solve other problems. Motivation is difficult to sustain if people perceive their goals to be distant and difficult to achieve. Defining initial goals realistically around problems that are likely to produce short term results is very important if motivation is to be created and maintained.

Finally, to help people sustain their motivation, you *need to convey your own confidence and belief* that the person can accomplish goals and promote optimism, self-confidence, and self-efficacy through a strong therapeutic relationship.

Developing motivation for learning the information and skills is an ongoing and collaborative process that occurs throughout the duration of your involvement. Motivation can change over time and often needs to be rechecked and encouraged by praise and by reminding the person about the changes made in his or her life by using the information appropriately.

3.4 A iii) Strategies to promote effective behaviors:

There are some simple and important methods to help the individual with schizophrenia and the family achieves consistent results while attempting to deal with problems identified as being important. These include:

- *Reinforcement*
- *Shaping*
- *Modeling*
- *Practice and role plays*
- *Homework assignments*

Each of these approaches is briefly described below:

Reinforcement:

Reinforcement refers to systematically linking positive or negative consequences to the behavior. This is something we do normally in everyday life as well For example, we give the child who does something well a prize and we smile when someone is being friendly to us to encourage them. Other examples of positive reinforcement include having a special dish at a meal, money, a hug, praise and going to the movie. Reinforcements can be especially important to encourage and help people learn information and skills during the sessions.

First, the CHW should use positive reinforcement in the form of praise, smiles, interest, and enthusiasm (called reinforcers) during the session. Secondly, the CHW needs to get families to provide reinforcements

(such as praise, cooking something that the person likes, letting him or her buy a small article of interest, etc) that are explicitly linked to desired changes in behavior in everyday life.
This will encourage the person with schizophrenia to change and maintain the positive behavior quickly and lessen friction and stress in the family unit.

Shaping:
Shaping refers to moving towards a desired goal like employment or increased social interaction with friends, in small steps at a time. The expression “Rome wasn’t built in a day” summarizes the concept of shaping. Similar to Rome, the information and skills taught in the sessions take time to learn, with each person learning at his or her pace. As people work on learning complex skills, such as identifying their early warning signs of relapse and developing a relapse prevention plan, it is important for the practitioner to recognize the steps taken along the way and to provide ample positive feedback and encouragement. Even when the pace of learning is quite slow and each step forward is small, practitioners can acknowledge these gains pointing them out, praising efforts, and letting people know they are making progress.

Modeling:
One of the most powerful methods for teaching someone a skill is to demonstrate it for him or her. *Modeling* refers to the demonstration of skills for the purposes of teaching. When modeling a new skill, it is useful for the CHW to first describe the nature of the skill and then to explain that the skill will be demonstrated to show how it works. Modeling can be used to demonstrate a wide range of different skills, including those used in social settings as well as those used alone. For example, the person might want to work on the skill of starting a conversation. The CHW then demonstrates how he or she might start a conversation with someone in the bank or shop or how to try starting a conversation with a relative at the next family function.

Practice and role play:
In order to learn any new skill like cycling, cooking or maintaining eye contact while speaking, they need to be practiced, both in the sessions and outside of the sessions. Practice helps people become more familiar with a new skill, identifies obstacles to using the skill outside of teaching sessions, and provides opportunities for feedback from the practitioner and others. It is only by practicing skills outside of the sessions that people can improve their ability to manage their symptoms and make steps towards recovery.

Practice of skills in sessions is especially effective when it is combined with modeling by the practitioner. One of the best methods to help people practice a new skill is for the practitioner to set up a role play (for example: how to buy 3 items and complete the financial transactions in a neighborhood shop) that will allow the person to try using the skill in a real life situation.

Homework assignments:
Homework assignments are an important method for helping people practice skills on their own. Specific assignments to practice skills are helpful soon after a skill has been taught. The person should be familiar with the skill and have some specific plans for when and where to practice it. It is important that the person is involved in planning the homework assignment and to have confidence that he or she will be able to perform the skill successfully. Practicing within the session is one strategy for building up confidence about using a skill outside of the session.

In the session following a homework assignment to practice a skill like talking to the neighbor about the weather, the CHW should follow up to find out how it went. When the exercise worked as planned, the CHW should reinforce it through praise. When a problem was encountered in using the skill, the practitioner can explore what went wrong, make and practice necessary modifications, and develop another homework assignment to practice the skill. With sufficient practice, people can learn new skills to the point where they become automatic and they can be used with little or no forethought.

3.4 A iv) Specific goals of providing information to individuals and their families:
The more people with schizophrenia and their families understand the basic facts about the illness, the better equipped they are to speak for themselves and to take an active role in their treatment and recovery. This section provides the opportunity to answer some of the common questions people have about mental illness:

- What is the nature of the illness?
- What are the symptoms?
- What are the treatments?
- How common is it?
- What does the future hold?

Main reasons for providing the information to individuals and their families:

- Provide a message of optimism about the future.
- Assure people that having mental illness is nobody's fault.
- Provide the message that involvement in treatment and overall management of the illness is essential for recovering
- Introduce people to the need for continued treatment
- Introduce the stress-vulnerability model.

3.4 A v) Number, pacing structure and useful strategies for sessions:

Within each session, most people find that covering one or two topics and completing a questionnaire is a comfortable amount. Information about the illness is provided to families as one of the first things to be done in the intervention. Involving the individual with schizophrenia in these initial sessions needs to be an individual decision taken by the treating Psychiatrist; in general the recommendation is to provide information to individuals when their acute symptoms are reasonably controlled. Before providing the information, you need to do some homework:

- Complete the family assessment of knowledge interview to establish their current understanding
- Review what you will talk about and make an advance plan for the session
- Discuss with your supervisor about your plans and get feedback
- Incorporate the feedback in your session plans and finally
- CONDUCT THE SESSION

Structure of Sessions:

- Informal socializing and identification of any major problems- 5 minutes
- Review the previous session- 2-5 minutes
- Discuss the homework from the previous session. Praise all efforts and problem-solve obstacles to completing homework- 5 minutes
- Complete the planned, interactive information session- 30 minutes
- Summarize the content of the session and clarify any doubts- 5 minutes
- Set the agenda for the current session- 2-5 minutes
- Agree on homework to be completed before the next session- 5 minutes
- Agree on time and date of next meeting

Strategies to be used in each session:

Motivational strategies:

- For each major topic covered in the handout, help the person to identify at least one way that information about that topic might be helpful. For example, in the section "What are the symptoms of schizophrenia?" you might ask a general question, such as "How could it be helpful to you to learn how to recognize symptoms?"

- Show an appreciation for the person's experience and knowledge. Show the person that you appreciate his or her comments and clarifications. This makes the therapeutic relationship collaborative, reinforcing and motivating.

Educational strategies:

Educational strategies for this module focus on ensuring that people understand basic information about their disorder. The best learning will take place when people can relate this information to their own personal experiences. The following strategies are useful for this section:

- Review the contents of the handout by summarizing

- Pause at the end of each section to check for understanding and to learn more about the person's point-of-view.
- Allow plenty of time for questions and interaction.
- Break down the content into manageable "pieces."

Homework:
For homework, you could ask the person to summarize the contents of the session after reading the handout and discussing any doubts in the first part of the next session. Also remember to:

- Follow up on the homework by asking how it went; praise completion and if any effort was made to complete the assignment
- If people do not complete the homework, you can gently ask what got in the way. You can role play ways of overcoming obstacles to completing the homework.

3.4 A vi) Introducing the stress vulnerability concept:

The other specific component of the information sessions is to introduce the concept of the 'stress vulnerability model' and orient the persons receiving the information about the utility of the idea for further work.

The specific goals of the session are:
- Explain how stress and biological vulnerability play a role in causing symptoms
- Understand the importance of the environment in shaping the course of the illness
- Convey the message that treatment can help people reduce their symptoms and achieve their goals.
- Help people become familiar with different treatment options

Number, structure and useful strategies for sessions:

The Stress-Vulnerability Model and Treatment Strategies section can usually be covered as the last section of the overall information sessions.

Structure of Sessions:

- Informal socializing and identification of any major problems- 5 minutes
- Review the previous session- 2-5 minutes
- Discuss the homework from the previous session. Praise all efforts and problem-solve obstacles to completing homework- 5 minutes
- Complete the planned, interactive information session- 30 minutes
- Summarize the content of the session and clarify any doubts- 5 minutes
- Set the agenda for the current session- 2-5 minutes
- Agree on homework to be completed before the next session- 5 minutes
- Agree on time and date of next meeting

Useful strategies to be used in the session:

Motivational strategies:
Motivational strategies in this module focus on helping people see how treatment can improve their lives. The two major questions to keep in mind are:
"How can treatment decrease symptoms and distress for the person?"
"How could treatment help the person to accomplish his or her personal goals?"

Educational strategies:
Educational strategies for this module focus on helping people understand the stress-vulnerability model. According to the stress-vulnerability model, effective treatments must address both stress factors and biological factors.

It is helpful to relate the information in the handout to the person's own situation. For example, learning more about the stress-vulnerability model might help someone recognize that stress contributed to an increase in symptoms or a hospitalization in the past.

- Review the contents of the handout in an interactive manner
- Pause at the end of each topic to check for understanding and to learn more about the person's point-of-view.
- Allow plenty of time for questions and interaction
- Break down the content into manageable *'pieces'*

Homework:

For homework, you could ask the person to summarize the contents of the session after reading the handout and discussing any doubts in the first part of the next session. Also remember to:

- Follow up on the homework by asking how it went; praise completion and if any effort was made to complete the assignment
- If people do not complete the homework, you can gently ask what got in the way. You can role play ways of overcoming problems in completing the homework

Chapter 3.4 B Providing information about medicines in COPSI

3.4 B i) Why is providing information important?

- Ensures that the person with schizophrenia and important family members understand that taking prescribed medicines regularly will control symptoms and reduce the risk of relapse.
- Ensures that the person and the family have an adequate understanding of the benefits and side effects of the prescribed medicines.
- Describe side effects while stressing that problems need to be resolved in discussion with the doctor and not by stopping the medicine.
- Ensure that the person understands how and when to take the medicines.
- Discuss methods of maximizing adherence to the medicines.
- Establish collaborative supervision of adherence involving identified family member(s)

3.4 B ii) Information needs to be provided according to the phase of treatment:

As we have discussed before, there are 3 phases of treatment involving the persons with schizophrenia that you will work with. In the *acute phase,* the treatment is used to control prominent symptoms so that the person is able to function reasonably. During this time, medicines will be used in sufficient doses to control the symptoms rapidly. As a consequence, the possibility of side effects is also higher which might be upsetting for the person. During this time, it is also important to understand that the person with schizophrenia will be having ongoing positive and thinking disorganization symptoms, and it is best to minimize the information while focusing on support and encouragement to continue. Explaining the benefits and side effects as well as the need for adherence to the family is the most important goal of education at this time.

As the person improves and enters the *stabilization phase* of treatment, most of the positive symptoms would have been controlled and the person's thinking is also much clearer. During this time, detailed information about the necessity, benefits and side effects of medicines need to be provided in an interactive manner with the ultimate goal of improving adherence.

In the *maintenance phase* of treatment, the person is possibly on lower doses of medicines and is relatively symptom free. This is the time for gradual recovery to happen and efforts need to be made to consolidate the information provided, ensuring that the benefits of adherence are clearly understood. This is also the time to revise the relapse prevention exercise (see Chapter 4.4C) and provide information to the person and the family about how to manage any emerging symptoms.

3.4 B iii) How should information be provided?

As we have stressed earlier, the key to providing information that is likely to be effective is to *engage* the person and the family in a therapeutic relationship that is collaborative, respectful and matched to felt needs. The more *interactive and participatory* the method of sharing information is made to be, the greater is the impact of the information. For example, getting the person and the family to complete a side effect checklist, a simple rating scale of the effectiveness of the medicines and a list of the medicines being currently used may be useful strategies to enlist their support more actively (see Appendix). Similarly, before providing information, understanding the *attitudes* of the person with schizophrenia and their family about medicines (e.g. 'medicines are addictive', 'taking medicines will make me weak', etc) is important, so that the new information being provided is more acceptable. Finally, to improve the effectiveness of the information, you will need to use the handout (see below) and other visual prompts like flip charts.

3.4 B iv) What information needs to be provided?

- What are the medicines being used for- method of improving chances of recovery
- How do they work- reduce vulnerability using the stress vulnerability model
- How does taking medicines help- symptom reduction and relapse prevention
- What are the names, the actual medicine and the dose of the drugs that have been prescribed?
- What are common side effects of these medicines?
- What needs to be done to manage side effects?
- The importance of taking medicines as prescribed (adherence)
- Managing the logistics of continuing the medicines (e.g. medical reviews, having enough stocks, etc)
- Monitoring the effectiveness of the medicines

The specific details of the information to be provided will obviously depend on the medicines being used for the individual and the route of delivery.

The 2 most important goals of the exercise are to provide effective information to the individual and the family to enable them to participate in managing the treatment and to promote adherence.

Chapter 3.4 C Relapse Prevention

3.4. C. 1 What is a relapse and how does it happen?

As we have seen earlier, most commonly, people with schizophrenia have an 'up and down course of the illness- i.e. sometimes they feel well and have no symptoms, while at other times they experience a return of symptoms or a worsening of previously mild problems. In technical terms, *the return of symptoms to an extent that is problematic and distressing for the person is known as a relapse.*

Different people experience relapses due to particular reasons and the time taken to experience an obvious relapse also varies a lot. In general terms, most relapses develop gradually over a longer period of time- typically over a few weeks, but some people experience a relapse very quickly- in a matter of days. During the time before the relapse, there are initial and often minor changes in behavior, mood and thinking which are called *'early warning signs'*. These warning signs are often unique to each person and the person with schizophrenia and family members can often identify them since they have seen this happen a few times. These early signs of a relapse are important to recognize and respond to, since this can be a time when something can be done to stop the person from suffering the serious consequences of a relapse.

3.4 C. 2 What are the consequences of a relapse?

For many people who suffer a relapse, a period in hospital stay becomes necessary to control the troublesome symptoms. For some people, the time spent in hospital can be a few days, while for others it may take much longer to be discharged from hospital. Even after returning from hospital, it takes a few weeks or months for the person to return to the previous state of functioning. Some people can experience a high degree of suicidal risk during this period due to constant, 'nasty voices' or depression while others can become very suspicious and frightened. This is also the time when some people become irritated and easily angry; rarely, there can be a risk of harm from the person to others in the family or community. A relapse is also accompanied by a sense of failure ('having it in spite of trying so hard to do things to stop these from happening in my life') and can add to the experience of discrimination from immediate family members and the wider social network. As you can understand, having a serious relapse is a setback for everyone concerned and preventing this from happening is one of the most important goals of the community health worker´s intervention.

3.4 C. 3 What is relapse prevention?

Relapse prevention is a convenient way to describe a systematic method of enabling the person with schizophrenia and the key family members to recognize the early signs of a relapse and putting in place a plan to deal with the situation. Relapse prevention is a collaborative effort involving you as the CHW, the person with schizophrenia and the family. Using the stress vulnerability model of schizophrenia as a guiding framework, we can understand that the key elements of the relapse management plan will be efforts to decrease stress and protect against the biological vulnerability.

In the next section we discuss how we can recognize that a relapse is likely to happen, the possible ways to respond to the situation, as well as the actual process of developing a relapse prevention management plan. Relapse prevention is not going to be always successful in avoiding a relapse. *The aim of relapse prevention is to prevent a relapse from happening (if possible), minimize the severity of the relapse so that the time to recovery is shortened and, even if hospitalization becomes necessary, to reduce the number of days spent there.*

3.4 C.4 What are early warning signs of a relapse?

As we have discussed earlier, the most important way in which a possible relapse can be identified is through early signs that ‘something is not right’. Clinical experience and research has identified that the most common early warning signs are:

Tension and nervousness:

These are some of the most common signs that there is something going wrong. Many people with schizophrenia report feeling anxious, nervous or tense about small things that they would not worry about earlier, As a result, people feel worried, frequently walk around the house excessively, and are unable to rest by sitting in one place for long.

Sleep disturbances:

Before a relapse, most people with schizophrenia experience changes in their sleeping habits- they either have difficulty in sleeping or start sleeping excessively. Changes in the person’s usual sleeping pattern are one of the most consistent and important of the early warning signs, and can be recognized easily.

Feeling sad, miserable and angry:

Many people who experience relapses describe feeling consistently sad and miserable for the period of time that precedes the relapse. This can lead the person feeling hopeless and having suicidal ideas. Family member will also be able to notice the changes- the person is talking less, does not want to meet anyone, hardly smiles, looks worried and is often tearful. An increase in the symptoms of depression is again a consistent and reliable early sign of relapse.

Becoming isolated from others:

Many people with schizophrenia will become less interested in talking to people and withdrawn before a relapse. This is often noticed first by family members, as the person becomes quieter, spends more time inside the room, does not meet guests or talk to friends, and avoids going out of the house. There can be many reasons for the social isolation. Some people feel tense and anxious if they have to talk to someone, while others can start feeling suspicious of people and decide the best way to deal with it is by reducing social interactions.

Difficulty in concentration:

Another common early warning sign is a decrease in the ability to concentrate and pay attention to something for a period of time. This leads to difficulty in following a conversation, reading the newspaper and remembering the details, cooking a meal, remembering to get things back from a shop or watching TV. As a result of this problem, the person can often lose track of what she is saying or may respond inappropriately, can forget to put salt in the food, can have difficulty in handling money or can start asking family members to repeat what they have said and become generally forgetful. More serious consequences of this problem may arise, like forgetting to put the cooking gas off or leaving a cigarette burning on the bed leading to a fire hazard.

Reducing or stopping medicines:

Quite commonly, the person with schizophrenia experiencing the early signs of a relapse can be unaware of it or deny that anything is wrong at all. Due to the lack of awareness or active denial, the person can often decide to reduce or stop the usual medicine(s), refuse to meet the doctor and may not want to meet you as well. Stopping treatments is often the crucial step that determines whether the person will progress to a relapse or not.

Change in appetite:

Often, a relapse is preceded by changes in the person's eating habits. Most commonly, there is loss of appetite and a general reluctance to eat. Whether this can be a result of excessive smoking or tea consumption, most people have a general reduction in the desire to eat at all. This can sometimes lead to a noticeable loss of weight and to a general sense of tiredness and lack of energy. Less commonly, people may start having a lot of food several times a day, particularly sweets and food rich in fats.

Early warning signs in people who continue to have symptoms most of the time:

Some people with schizophrenia will experience continuous symptoms in spite of doing everything as suggested by the treating doctor, including taking medicines regularly. Most commonly, they continue to hear voices but are able to deal with them and get on with life. Others may have a degree of suspiciousness or feel that people are talking about them, but are nevertheless able to control these thoughts and function quite well. For such persons, a relapse occurs when the intensity and frequency of the symptoms increases to an extent that it becomes obvious to others and interferes with the person's life significantly.

Unique signs of relapse:

Quite often, family members will be able to describe particular signs of a relapse that are unique to the individual and tend to occur only in such situations. This can include dressing only in particular colors, having an unusual haircut, start collecting particular things (like newspaper cuttings) or drawing strange pictures. These unique behaviors are often the most reliable method of predicting a relapse, so it is useful to discuss with the family in some detail whether they have observed odd behaviors consistently before a period of worsening of the illness.

3.4 C. 5 What the effective ways of responding to early warning signs of a relapse?

Information exchange with individual and family:

The first and most important component of the relapse management strategies is to exchange information about the nature and problems of relapse with the person and the family. This has to be done collaboratively and all parties should be encouraged to draw upon their previous experience to understand the importance of relapse prevention. While discussing the principles and need for relapse prevention, it is useful to take the most recent period of hospitalization or crisis caused by the relapse. The nature of symptoms that became prominent in the relapse phase, the early warning signs and the consequences of the relapse can be then discussed in an understandable context.

Following this sensitization, it is important to stress that the next step is to work collaboratively to decide on a relapse prevention plan.

Family meeting to discuss the situation:

Family members who live with the person on a daily basis will be the key allies in identification of early warning signs and responding to it appropriately. There should be a clear agreement with that the person himself or the key family member(s), who notices any problem, can convene a meeting. During this discussion, the concerns are talked about openly and, wherever possible, a plan of action is mutually agreed on. This process is enables everyone, including the person with schizophrenia, to participate as equals in trying to solve a problematic situation. This participatory process also helps the person with schizophrenia and family members take on responsibility for managing the illness more effectively and improve their sense of control over a difficult illness. It also allows the family to be clear about their preferences for the management of the relapse, which can be discussed with you and the treating psychiatrist in order to arrive at a consensus.

Adherence review:

As we have noted earlier, non adherence with medication (partial or total) is often the 'last straw' in precipitating a relapse. Therefore, reviewing the status of adherence is a very important part of the intervention to understand the reason for changes in behavior, mood or thinking seen in the early part of the relapse. This has to be discussed openly with the person to get his feedback about adherence.

If there are differences of opinion about the extent of adherence between the family members and the person, or if there is clear evidence that the person has stopped taking the prescribed dose of the medicine, it is best to ensure that the person gets back on the most recent dosage of medicines prescribed by the treating psychiatrist as soon as possible. At this point, it is very important to understand the person's reasons for stopping the medicine (denial of problem, side effects, cannot remember to take them due to poor concentration, etc) and respond to the concerns in a supportive manner.

Clinical review:
Most often, once the early warning signs have been noted, there will be a need for an urgent clinical review with the treating Psychiatrist to review the situation and decide on further treatment plans. At this point, you need to facilitate the clinical review by informing the psychiatrist and setting up a meeting date as soon as possible. You need to inform the family and the person about the date and time of the review, and underline the need to attend the meeting. To make sure the family can make the trip to the hospital, please check if there are any major barriers to accessing the treatment facility; if you feel that the risk of not attending this meeting is high, you might need to accompany the person to the hospital. Finally, you will need to clarify if everyone has understood the advice and monitor the ongoing situation closely through frequent phone contacts or home visits.

Reduce stress:
As we have repeatedly highlighted, excessive stress can lead to a flaring up of the symptoms of the illness. In addition, people with schizophrenia tend to be highly sensitive to the effects of stressful situations like arguments, criticism and sudden changes in life circumstances. As such, measures to reduce stress are a critical part of an effective relapse prevention plan. The first thing to do is to identify any obvious stressful situation that the person has been experiencing recently; some of the common stressful situations are highlighted in Box 1 below.

3.4C.1: Common stressful situations for people with schizophrenia

- Recent life event like getting or losing job, illness, death in the family
- Any sudden and significant change in routine or living arrangement
- Any significant argument or inter personal conflict
- Any problem in relationships with parents/ spouse/ close friend
- Any change in the family situation like family member falling ill, going away on a holiday or relatives come visiting - which changes the responsibilities of the person

Once the source of the stress has been identified, the person with schizophrenia, the family and you need to sit together and discuss the best ways to reduce the stress. There are two basic ways of doing this. One can try and solve the problem that is causing the stress or one can cope with the stress better, especially in situations where the source of the stress is not easy to resolve (e.g. the loss of job or loved ones). Depending on the situation, reducing stress can involve steps like taking a break from work or resolve an ongoing family conflict urgently. Other common ways of managing stress (see chapter on stress management) need to be actively and frequently encouraged, supported and reinforced by the family and you, till the situation gets better.

Alcohol/drug use:
In many instances, the period before the actual relapse is characterized by an increased use of alcohol or other substances, including nicotine and caffeine. Most of these interact with the same chemicals in the brain that are responsible for the symptoms of schizophrenia (like dopamine) in producing their relaxing effects or the high. As a result of these chemical changes, the brain becomes more vulnerable to a relapse. Reducing and, if possible, stopping the use of these drugs can make an obvious difference to the outcome of the relapse. The family and you can help the person with schizophrenia who is using alcohol, for example, by removing any bottles from the house, providing less money to buy it and by reinforcing any steps taken by him to reduce alcohol use. As the CHW, your role is very important in these situations, as sometimes you will be the best person to negotiate changes in the use of substances, by using your skills of improving the motivation to make a positive life change.

Ongoing monitoring of situation:
Once early warning signs have been detected and a plan has been addressed, it is important that the signs (e.g. decreased sleep, excessive anger, stopping medicines, suspiciousness, etc) are monitored closely till there is a clear improvement. The useful questions to consider during the monitoring process include:

- Is the particular warning sign(s) any better?
- Has it become worse?
- Are there new signs that are noticed?
- Is it possible to care for the person at home?

If the signs are resolved and the person is able to get back to his previous level of functioning, a relapse has been successfully averted. However, if there is no improvement and the clinical situation has become worse, it is time to consider whether additional measures are necessary, such as another clinical review or a short period of hospital stay.

3.4 C.6 Formulating a relapse management plan:

Coming up with a particular relapse management plan which specifies how the person with schizophrenia, family members and you will respond in case of early warning signs is the end product of the relapse management strategy. Being prepared in advance about ways to deal with the warning signs makes it more likely that, when it happens, there will be a clear plan of action which will help everyone deal with the relapse quickly and effectively rather than being caught by surprise. In this section, we describe the process of developing such a plan in more detail.

Decide in advance who participates in the family meeting:

This is a crucial first step as it must include the person with schizophrenia as well as other key family members who the person trusts and is comfortable with. Most commonly parents, spouses and in some cases adult children or more distant relatives will be included in the group which should be small (between 3-5 people).

Usually, the person(s) actually living with the person with schizophrenia will be the first to spot the changes in behavior and they need to contact whoever else is part of the group for an urgent meeting.

Discuss past relapses and identify early warning signs:

Based on the collective experience of the group, it is useful to identify in advance the early warning signs that are particular to the individual and have been noticed in previous relapses. To help this discussion, you would need to sit with the group and go through a structured early warning signs checklist (see Appendix) to identify those that are of relevance to the particular person with schizophrenia. The selected 3-5 signs that are identified are then noted in the plan and it is agreed that these will be monitored on an ongoing basis.

Discuss and identify past stressful experiences:

The family group should also be able to discuss and identify the stressful experiences that have led to relapses in the past. For example, it may emerge that whenever the person has an argument at work, he becomes very upset about it, thinks that he has been humiliated and this leads to lack of sleep and other warning signs. For other persons, taking on a new responsibility at home or at work can be a source of stress. Whatever the source of the stress, it is very useful to know it in advance so that action can be taken to either avoid it or cope better with the particular stress.

Putting the plan together:

After the group members are identified, are clear about the early signs of a relapse and about the stressful situations which place the person at a high risk, everything is in place for the development of a plan. While the individual elements of the plan are based on the unique experiences of the person with schizophrenia and his particular social context, for most families it is useful to include some or most of these elements:

- Initial meeting after someone in the group notices the warning sign(s)
- Review adherence and correct any partial or total non adherence as soon as possible
- Activate or intensify the stress management activities that have been useful before
- If using alcohol or drugs, plan to reduce or stop
- Plan for an early clinical review with the treating psychiatrist
- Identify other social support and practical support from relatives, friends and other community agencies
- Clearly plan your involvement and responsibilities as the support community worker
- Monitor the situation closely till one's problem is resolved

Once the plan has been discussed and agreed upon by the person with schizophrenia and the family members, it is useful to give a copy of it to all parties concerned so that there is no disagreement or confusion at the time of the relapse. This is best done with the help of the relapse management plan format (see Appendix).

This plan will only work if everyone knows the steps involved and is aware of their individual responsibilities. It is a good idea to review the plan every 6 months, to ensure that everyone involved remembers the issues clearly and any fresh updates can be made. Relapse prevention is a simple, yet powerful, method to decrease the chance of a relapse needing high intensity care at the hospital. This will allow the person with schizophrenia and their family enjoys the benefits that come with long term stability, and allows everyone to focus on their personal and shared goals.

Chapter 3.4 D Dealing With Distressing Symptoms

3.4 D.1 Introduction:

With treatment, most people with schizophrenia will be able to have adequate control over their symptoms and to live in their homes. However, for some people symptoms of the illness persist in spite of taking their medicines. As you can imagine, these persistent symptoms make things difficult for the person and their families, as they are distressing and disabling. In this section we describe ways in which you can make a difference in this situation, by working collaboratively with the person and key family members, doing things to *manage* these symptoms better and minimizing their impact.

3.4 D. 2 Dealing with positive symptoms:

As you will recall, positive symptoms refer to the unusual experiences of people with schizophrenia- specifically hallucinations, delusions and difficulty in organizing their thoughts (Chapter 1.4). These symptoms may be mild or severe, occasional or persistent and can make the person unhappy or, in some cases, can be comfortable and a positive experience. There are many individual differences in the way people will react to these symptoms, and it is important to understand the *feeling* or emotions that are linked to the symptoms. Most people will be upset by the symptoms and want to do things to manage them better. Another issue has to do with the *motivation* that the person has in turning the symptoms less problematic. There are a set of simple things that can be helpful but need to be done systematically, regularly and over a period of time. To maintain positive behavior changes, it is essential to encourage and support the efforts made by the person- something we have stressed while discussing adherence with treatments and other health promotion efforts.

It is important to understand that the stress- vulnerability model (Chapter 1.3) is a useful way to understand the possible reasons for any continuing symptoms. For example, when symptoms are continuing, it is important for the treating doctor to use medicines in higher doses or change them, as a way to reduce vulnerability. When such changes are being tried, providing information and encouraging adherence are related activities that are as important as the medicine changes. Similarly, stress can play an important role in maintaining symptoms, and ways to reduce stress are important general measures that can help. In this section, we describe the specific methods to manage the positive symptoms.

Hallucinations:

The three broad methods to reduce the impact of continued hallucinations (most frequently known as ‘voices’) involve changing levels of physical activity, using specific behaviors to deal with symptoms, or using new ways of thinking about the symptom.

Changing level of activity:

Changing the level of activity, either by reducing or by increasing certain behaviors, is a simple and effective method of dealing with the distress of symptoms.

- Relaxation
- Taking a walk
- Exercising
- Keeping busy through work like cooking or washing

Specific behaviors:

Very often, doing some specific things can be an effective way of reducing the distress associated to symptoms. Common to all of these activities is the fact that they *distract* the person's attention to the symptoms by getting involved in doing something else that is pleasurable.

- Talking to family members or friends
- Playing some game- badminton, chess, carom
- Listening to music, specially through earphones
- Singing or humming to music
- Watching TV
- Reading a newspaper or magazine, solving a puzzle

New ways of thinking about the symptom:

- Shifting attention- thinking about something pleasant like visualizing a peaceful scene, solving a puzzle, listening to music, etc
- Adaptive coping strategies like positive self talk- 'Take it easy', 'I can handle this'
- Ignoring the symptom as much as possible
- Problem solving-'What can I do to make this better?'

Delusions:

By the nature of the problem, persisting delusions are more difficult to manage, as they seem very real to the person and become a part of the person's life. Delusions are caused by the unusual meaning given to things or events in the environment by the person with schizophrenia. Like all of us, people with schizophrenia also look for a likely explanation to understand the unusual things happening to them, and then hold on to beliefs that are hard to appreciate. Generally, it is not useful to question the reality of the person's belief, except in some circumstances when the person is able to understand the false nature of the beliefs. Attempts to argue and debate the reason for the person having such a belief most often leads to arguments and further distress to all concerned.

The most useful strategy is to have a discussion with the person about the delusion, the distress and the impact of the belief on the person's life. While not confirming the belief as being true, it is better to politely disagree with the content of the belief while making sure that the person feels emotionally secure to talk about the symptom. For some people, it may be possible to use problem solving to look at alternative ways of coping with the beliefs, like distraction and shifting attention.

Unhelpful coping strategies:

- Angrily ordering the voices to go away
- Sleeping excessively
- Avoiding social contact by gradually withdrawing from interactions
- Use of alcohol or drugs
- Stopping medicines as *'They are anyway not working'*

Helping the person to develop and use these strategies:

Developing alternative and personally effective strategies to cope with the difficult psychotic symptoms has to be a gradual process. The process can be easier by enforcing the strategies described below.

- Choose one specific symptom to work on: Choosing a single symptom (like a single male voice saying nasty things) usually makes it more likely that effective coping strategies can be found.
- Do some homework: This includes getting a detailed description of the symptom, the frequency of the symptom, how it affects the person and trying to identify any particular situations or circumstances that make it worse (having a quarrel with parents, going out to the market) or that make it better. The more complete this information is, the greater the likelihood that effective strategies can be found.
- Select a coping strategy after discussion with family and the person with schizophrenia. This could involve listening to music with earplugs, cooking a dish or talking to some family member about football.
- Practice the strategy a few times to test whether it is consistently feasible and try to find out situations where they are not possible.
- Plan and implement the strategy in daily life: This is the most important part and will need to be encouraged and monitored closely by the person and the others involved. A record of the use and effectiveness of each strategy can be a useful way to motivate the person to continue.

- Evaluate how successful the strategy is: This can be done on a weekly basis, as a joint exercise between the person and the family. Any problems can be identified during this discussion and changes in strategy need to be discussed for further rectification.

3.4 D.3 Dealing with negative symptoms:

As we have described in Chapter 1.4, negative symptoms are the absence of doing, thinking or feeling the way people without the illness do. For example, people with schizophrenia often do not laugh at something that others find funny, do not talk much, do not like to interact with other people and have few activities that they do regularly. Negative symptoms are often hard to deal with for the family, and many persons with these symptoms are criticized for being lazy or worse.

These are the lasting 'defects' or damage due to the illness, and can persist for many years.
However, it is important to understand that negative symptoms can be also caused by depression and/or medicine side effects, so it is useful to ask the doctor to rule these out before starting to reduce the impact of these distressing symptoms.

The most problematic symptoms are due to the lack of interest and motivation in doing things, and the lack of feeling or emotion to what is happening around them. The first step is for the family members to understand that this is not under the person's control and is a core symptom of the illness. This information leads to the family having realistic expectations and sympathy for the person, rather than blaming him/her for not doing things as before. Some useful strategies for making things happen include:

- Having a regular and realistic routine for the person with schizophrenia (activity scheduling): Left to themselves, people with lack of motivation will not do much. The important thing is to have a routine of simple activities that engage the person in some work for a part of his time. It is really important that the family is supportive of the initial efforts and reinforces attempts made by the person, while having realistic expectations.

- Schedule some enjoyable activities together with the rest of the family. This can include going out for a movie, watching a performance or sitting down with the family to watch a TV program that everyone enjoys. In addition, it is important that the person comes along for some social occasions, like visiting relatives, participating in festivals, or going to the church or temples.

- Identify previous recreational activities: These could include activities that the person used to enjoy before developing schizophrenia, such as having a chat with friends, having a hobby or being involved in a sport.. It may be worthwhile to consider if the person is interested in doing some of these activities in a step wise manner to improve his sense of enjoyment.

- Focus on the future: Sometimes people with schizophrenia are painfully aware of how they have changed or how their social world has become restricted. As a result, they become demoralized and discouraged, while thinking they are 'failures', and do not have the motivation to try and make a difference. It is useful for the person and the family to focus on the future with hope and plans to improve things gradually, rediscovering the spark in life.

3. 4 D. 4 Dealing with difficulties in organizing thinking:

Most people with schizophrenia experience some difficulties in organizing their thinking. These problems tend to appear early in the course of the illness and persist for long periods of time. Some of these like having difficulties in paying attention and concentrating may be obvious. Other problems like having difficulty in solving problems are often more difficult to understand. These thinking difficulties may lead to work and social difficulties. It is important to specifically address these persisting thinking difficulties routinely.

Attention and concentration problems-

- Remove distractions: Since people with schizophrenia have difficulty in paying attention to a specific thing in the environment and they get distracted easily, it is useful to think of ways to minimize distractions, like reduce noise and background conversation, when possible.

- Having regular breaks while doing something: People with schizophrenia benefit from taking breaks between tasks that require concentration. While this is true for all of us, people with schizophrenia need to take small breaks at more frequent intervals to help them refocus their attention.

- Gradually increasing the period of concentration: This is done by the process of shaping i.e. gradually extending the period of concentration required by adding new tasks. For example, the person with schizophrenia could be encouraged to read both the main page as well as the sports page of the newspaper and have a conversation with a family member about the main events.

- Tasks to improve attention: Activities like painting, knitting, solving a puzzle or playing a game of cards can be used to improve attention and concentration of people with schizophrenia while being fun.

Slow speed of doing things-

- Be patient: The key thing to remember is that difficulties in completing tasks are due to problems in thinking and that the person must be given enough time to complete a task.

- Repeated practice: This ensures that particular tasks are practiced till the point that they become automatic. This could include having a bath properly, making tea or cooking a dish for lunch.

Poor memory-

- Using reminders: These memory 'aids' are useful to remind the person that certain tasks are to be completed on a particular date. For example, if the person is supposed to pay the telephone bill, the date can be circled boldly in a calendar that the person can see clearly. Similarly, having a written list of things to be bought from the grocery shop can be useful in remembering the items to be purchased.

- Having a daily routine: This allows things to be done as a habit and without having to think about them individually. Helping the person organize a place to keep money, keys or medicines can be built into the routine till they become a habit.

- Practice till activities become a habit.

CHAPTER 3.5

Delivering the family treatment in the COPSI intervention

3.5.1 Introduction:

In this section, we describe how you are actually expected to deliver the family intervention. As we have mentioned earlier, involving the family in the intervention is essential to the improvement of the person with schizophrenia.

As you will see, some of the details of the intervention have been covered in other sections of the manual. In such cases, we will refer you to the appropriate section for detailed discussions,

3.5.2 Sequence of the family intervention:

Ideally, the family intervention should follow this order:

- Assessment and engagement
- Providing focused information about the illness (psychoeducation)
- Conducting a routine set of basic treatments
- Helping in the assessment and management of difficult problems
- Follow up

However, you may not always be able to follow this order with all the families and you may need to be flexible in delivering the sessions according to the family's needs and expectations.

3.5.3 Content of the intervention:

3.5.3A) Engaging the family:

How can you promote engagement?

- You will need to be familiar with some of the details of the affected member's illness and some aspects of the overall family situation before meeting the family, by carefully going through the information provided in a specific form and by interacting with the treating Psychiatrist. This helps families understand that you have done your homework before meeting them and are serious about the engagement.

- For the intervention to be effective, you need the **trust and confidence** of the family. This is achieved over a number of sessions by **paying attention** and **listening carefully** to their concerns, showing **empathy,** and **understanding** the family's problems.

- The family knows the person and their problems better than you do. Respect their knowledge and their suggestions as equal partners as collaboration is best achieved when the power equations between you and the family are balanced. Avoid using technical terms as far as possible; use simple and clear language.

- There is usually one member who makes most of the family´s decisions; though, some families may not have any particular member fulfilling this role. The 'leader' initiates and guides the members in implementing decisions and therefore plays a vital role in making things happen in the family. Having the leader endorse the intervention is very useful as the intervention may prove more effective if you **work with or through the leader.**

- Provide opportunities for all key family members to **express their worries and concerns** about the affected member's illness. Allow them to speak about how they feel about the affected member, as family members feel relieved after disclosing these preoccupations. This will strengthen the bond between you and the family. You do not need to **agree** with them and should not be **judgmental**. You also do not need to provide **quick solutions or suggestions** to their problems; just the fact of sympathetic and attentive listening is a powerful way of relieving distress in the family members.

- Family size and composition differs widely. Though ideally you should engage with all family members, this is often not possible due to other commitments. However, working with **the main caregivers** (parents, spouse, brother or sisters) who actually spend more time with the individual is essential.

- Make sure that you spend the time with the family most effectively. This means you need to have completed the necessary documentation and discussions in supervisory meetings in order to have clear plans and focus. Please remember to discuss all issues in a **systematic and thorough manner**. Refer to previous discussions that you have had with them and when they appear uncertain or reluctant to try a new task, **reassure** them.

- Observe **the way the family members interact** with each other over sessions, before forming an impression of their communication skills or problem solving abilities. This will provide you with time to decide how much input you may need to invest in that particular family.

- Family members tend to disagree on how to settle family problems. Listen to what **all** the members have to say before guiding them in how to resolve the issue. You must **remain neutral and not take sides** with any member, as this can adversely affect how the rest of the members perceive you in their future interactions.
  Do not disagree or contradict the caregiver's approach or opinion on how to solve their problems with the affected member in the affected member's presence. This will adversely affect the relationship between the caregiver & the affected member, as well between the caregiver & you.

- As mentioned in the previous chapter, you need to **be flexible** in your approach with the family. The family may come to you with different needs from what you may have planned to address in that session. Find out if there is a crisis that needs to be addressed immediately or whether it should be approached in later sessions. At times, a problem may be solved only when other smaller problems are previously resolved. For example, if the family wants the affected member to be employed, this can be achieved only if he is able to pay attention, motivated to work and if symptoms improve.

- Look for the **positive assets and strengths** of the family and highlight them to the family. This increases their *confidence and sense of improvement*.

- If the family does not acknowledge any positive changes, **do not argue** and attempt to prove therapeutic efficacy as the family will respond by showing you how you are wrong. Instead, you should repeat that changes are slow. Try to understand why the family is reluctant to admit that change has occurred.

- Some families may not take you as seriously as they should, or you may find yourself having to comply with many of their wishes and get a sense of not being in control of the sessions. You should make it clear to the family that there are certain **expectations** that you have of them concerning the sessions. Families will need to understand that it is necessary to participate in the sessions to improve their overall well being and need to be motivated. The family should not intrude on your personal life by visiting you at your home. Provide a contact number for the family to use during a crisis only.

What are possible strategies for families that are difficult to engage with?

- Request that you are introduced to the family in the presence of your supervisor and if necessary, the treating psychiatrist who can reassure the family about your involvement.

- You should have some ready and convincing reasons for wanting to work with the family. *"I would like to see how you are managing now that ____ will be returning home soon"* or *"I want to find out how things are at the moment and see if I can help you with any problems that may come up"*.

- At times, you may meet only one member of the family. Once this contact has been made, you should make it clear that you would like to meet all those who have reasonable contact with the affected member, such as those who live in the same house, parents or spouses.

- Sometimes, in the acute phases of the illness, the affected member may not be in a position to engage due to ongoing symptoms. In this scenario, it is best to engage with the primary caregivers first. This observation is based on the fact that the benefits of family intervention is best achieved when the person with schizophrenia has some control over the symptoms and can attend to the discussions adequately.

- At times, we run the risk that the sessions become a forum for the family to complain about the person's shortcomings. You must make it clear to everyone in the group that criticism has to be constructive in nature.

- Despite all efforts, there are some families where only a few members will engage. It is still important to work with whosoever will attend, as they may be able to persuade other members to join in; continue to ask if absent members would like to join.

What are the essential skills for engagement?

- *Listening attentively or active listening:*
  Accurate and active listening is important for developing an effective working relationship, helping the family members to talk and to experience and express their feelings. As described in Chapter 2.1, you will need to use good counseling practices of active listening:

a) *Leaning forward slightly*: This indicates your involvement and encourages people in the group speak.

b) *Maintaining good eye contact*: Good eye contact allows you to see the facial expressions that the family members are making. Avoid staring, as family members may feel uncomfortable. Looking down or away too often may indicate tension and boredom.

c) *Appropriate facial expression*: A friendly, relaxed facial expression, including a smile, usually demonstrates interest. Your facial expression needs to show that you are tuned to their verbal and bodily messages.

d) *Relaxed body posture*: A relaxed body posture, without slumping or slouching, contributes to conveying the message that you are receptive. A stiff body posture or fidgeting may indicate tension.

- *Having and showing empathy:*
  This involves communicating through your talk and body language that you have understood the crux of the family member's thoughts, emotions and distress. Good empathic responding indicates a basic acceptance of the family members as people. It avoids sending out discouraging messages to the family that stop their flow of talk and emotions. Good empathic responses are made in easily comprehensible language. They provide an opportunity for the next statement to be a continuation of the family's original train of thoughts.

- *Reflecting content to ensure that both you and the family are clear about what is being discussed:*
  The literal meaning of what the family member said is mirrored or restated in slightly different form. You should use simple and direct language and avoid psychological jargon.

- *Reflecting feelings:*
  This involves identifying the family member's feelings correctly and then correctly expressing their level of intensity. You will need to use your judgement in choosing how much of the family member's feelings you want to reflect, as this depends on whether and to what degree the family member acknowledges their feelings. Sometimes, the family member may both smile and clench their fists at the same time. You will need to decode this mixed message.

- *Silence*
  If you speak too much, this acts as a barrier to family members talking. Keeping silent gives them space and encouragement to get more deeply in touch with their thoughts and feelings. Whether a long silence is appropriate depends on what the family member has been saying and their body messages during the silence. A silent family member can mean any of the following:

  - The family member is generally uncommunicative
  - They need time to sort out their feelings
  - They are afraid to disclose more
  - They have come to the end of a thought or theme.

Maintaining the family in treatment:

Once the family attends the first session, the main task is to continue to engage with them over the following period of the intervention. You need to be aware that there can be several barriers for the long term engagement of the family if:

a) The family has had **unpleasant experiences** with treatments in the past and is skeptical about the present offer of help.

b) The family has different or **unrealistic expectations** of the intervention.

c) The family has been coping for a number of years and is **pessimistic** about the future or members have resigned themselves that nothing can be done.

d) The family members feel **they are to be blamed** for the illness and are worried that your intervention will reinforce this message.

e) They fear that any change will make the situation **worse**, and therefore, the current status with all its problems is better.

f) The **timing and place** of the sessions are realistic and convenient for the family.

If the member's reluctance to engage is not tackled, the family will not accept the intervention no matter how skilled you are,. Hence, it is extremely important to determine the families 'past experiences with professional help, as well as their expectations and reluctance on the present therapy. You will have to try to infuse **hope** and convey what can be **realistically expected** from your intervention. Conveying the message that this type of family intervention has been shown to **prevent relapse** and that change will be **slow and gradual** is a strategy that can be used for this purpose.

There are however some families who appear resistant to the intervention. These families may have certain characteristics such as being defiant, argumentative, thwart attempts to improve their circumstances, or deny factors associated with the illness. These families should be **referred** to the supervisor for further interventions.

After engaging the family, you should:

1. Have formed a working relationship with the family or engaged the family.
2. Have been able to ensure that the family will continue with the intervention.
3. Identify reasons for family not wanting to engage and have a plan to overcome this.

3.5.3 B) The family assessment:

3.5.3B.i) Guidelines for assessment:

- Knowledge of the affected member's **past and present symptoms** (content of their delusions, nature of hallucinations, behaviors related to these symptoms as well as negative symptoms) in some detail is necessary to conduct a good assessment.

- Prior understanding of the **family's attitudes and beliefs about the illness** in general and the symptoms of the affected member in particular will help to foster an interactive mode of information presentation for the psychoeducation sessions.

- You should speak to the whole family together, preferably in the absence of the affected member. You should address the question to the family as a whole and then ask each of the family members for their **individual opinion**.

- Although your primary objective is to assess the family, be prepared to answer the family's questions. It is unlikely that you will be able to gather all the details of your assessment without the family questioning you about the illness. Judge whether it is appropriate to answer every question now or some of them later, as planned.

3.5.3 B.ii) Key domains of assessment:

Knowledge about illness:

- To begin with, ask the family as to whether they think something is wrong with the affected family member or not. Almost all family members should agree that something is wrong.

- If so, ask them what do they think that is wrong with him/her? The responses to this could vary depending on whether this is the first episode of the affected member or whether the affected member has had numerous episodes in the past. If it is the first episode, the family may or may not report any of the psychiatric symptoms, i.e., they may be unable to say that the affected member has "hallucinations" or "delusions". They will instead report the "effect or influence" of hallucinations or delusions on the affected member's behavior. Thus, they may reply that the affected member has odd behaviors such as laughing and talking to himself, saying odd things that do not make sense, not doing well in work or school, withdrawing from social contacts with others, etc.

- Ask the family what illness the affected member has. The family members may not have been told the diagnosis, or if they have, they may not understand the details fully. If they do not know the diagnosis, you should provide them information about schizophrenia. Judge how much to tell them at this point. You could give them some information on the course, causes and prognosis of the illness.

- If the family member's do know what the diagnosis is, then ask each family member to tell you what he or she thinks schizophrenia means. This will allow you to assess what the family knows or thinks about schizophrenia, and it will also reveal some of their fears and misconceptions about the illness.

- Ask the family members what they think about the symptoms of schizophrenia. Family members may give you answers which indicate that they know the behavioral repercussions of the illness. Some family members may also mention other behaviors which are not a part of the illness but that the affected member does of his own volition. Assess whether the family is able to differentiate between actual symptoms and willful behaviors.

- Ask the family what they know about available treatment options for schizophrenia. Some families may be aware of medications alone and not of other therapies or places that offer vocational rehabilitation.

- Find out from the family about their knowledge about medications. Do they know why medicines are given for? What is the relationship between the medications and the symptoms? What are the side effects of the medication?

- Ask the family what they think about the course and outcome of the illness. Most families expect the illness to be cured with medication. They do not usually expect the affected member to take medication for several years or while asymptomatic. They may not be aware that the affected member may not fully recover from an episode or that there may be many episodes.

- Finally, enquire as to what they think about the causes of the illness. Most family members will not consider structural or chemical changes as being primarily responsible for the illness. They may wonder if they are responsible for the affected member's illness in some way because of their behavior (bad parenting or unhappy marriage) and therefore feel guilty, angry or responsible. Some family members may think that "black magic" or "evil spirits" cause it. Parents may wonder if it has been inherited and may blame the other spouse which may have a relative with a psychiatric illness.

3.5.3 B. iii) Burden of caring:

- These questions are more relevant for families who are living with an affected member for a number of years, than for those living with a first episode affected member. Assess the objective burden of the family by asking the family members to describe the consequences of living with a person with schizophrenia. Ask them to describe the differences that they now observe in their family´s life, how it has affected them financially, in terms of their physical well being, leisure time, social supports from others, etc.

- To ascertain the subjective burden, ask each family member to describe how they feel emotionally about having a relative with schizophrenia, how they feel when they are around that person, and their future expectations for the relative. Some common responses of the family are frustration (since the affected member is unable to communicate clearly with them or for being "lazy"), anger (at the affected member for having the illness or the restrictions that it has imposed on them), sadness (as the affected member may be unable to fulfill expectations of a bright career), hopelessness and pessimism.

3.5.3 B.iv) Needs of the family:

Refer to Chapter 4.2 for details on need assessment

- You may have already formed an impression of what the family wants from you while engaging them and enquiring about their perceived burdens. If not, ask the family members what they expect to receive from you. Ask them about the specific problems they would like to solve in the next few weeks-months.

- The families may also come to you with their own needs. Some families may expect you to provide information about the illness. They will want to know about the treatment, the cause of the illness, the prognosis and chances of recovery. They may also want to know about the effectiveness of different treatments like homeopathy, ayurveda, etc.

- The family may ask you for advice on how to keep the affected member clean and tidy. The affected member may be unable to care for himself and may need family supervision.

- They may ask you about how to get the affected member employed meaningfully or in some appropriate activity. They could ask you about the availability of day-centers or vocational training.

- If the affected member is violent or harms himself, the family may need help to handle this.

- Before the illness the affected member may have been contributing towards the daily household work or looking after children. The family may not be able to cope after the illness. Though, not all families find this problematic.

- If the affected member is married, the spouse may have an unsatisfactory relationship with the affected member, as sexual problems are common. Unmarried affected members may feel lonely, and they have additional difficulties in maintaining close relationships and in finding a partner.

- You can raise some of these concerns in future sessions, preferably during the problem solving skills sessions, as some may not be an immediate priority in the management of the affected member.

3.5.3 B. v) Social supports:

- Most families of people with schizophrenia gradually become isolated from their families and friends. Ask each of the family members what they do to distract themselves from the problems of living with the affected member. Do they have contacts outside of the family with whom they can spend time outside of working hours? Does the family approach anyone outside the immediate family during a crisis?

- If not, what are the difficulties experienced by the family in doing so? Are these contacts able to provide support? What kind of support do they provide? Do they offer to supervise the affected member while the family goes out? Do they offer financial support? Do they advise the family in what they should do? Do they listen to the problems of the family and provide them emotional support?

- Does the affected member have any contacts outside of the family as well? Do these contacts visit the affected member during or after acute episodes? How do they help the affected member?

3.5.3 B. vi) Family responses:

Ask the family members how they feel about their relative having schizophrenia.

- They may *deny* or have difficulties accepting that the relative has schizophrenia. This is a response commonly seen when the family first receives the diagnosis of schizophrenia. They may not fully accept it later either.

- They may get *angry* that the affected member has the illness. They may feel envious of others. They may think “why did this happen to me”. They make promises to cure the illness, such as “I promise to pray every day if he is cured of this illness.”

- They may feel *depressed* when they are unable to cope. The financial burdens, the affected member’s inability to work, stigma, between others, all contribute to this feeling.

♣ They continue to *hope for* a cure, the discovery of new medication that will improve the symptoms. This helps them to cope during their suffering.

After assessing the family, you should:

1. Have a good estimate of the understanding and knowledge the family has about the illness
2. Be able to evaluate the objective and subjective burden experienced by the family members
3. Determine the primary needs of the family
4. Determine whether the family has and makes use of social supports
5. Know the attitudes of the key family members towards the person with schizophrenia

3.5.4 Family psychoeducation in COPSI:

3.5.4 A) What is psychoeducation?

Psychoeducation is a simple and effective treatment where you will provide essential, scientifically valid information and advice about various aspects of the illness to empower the family to manage the illness better. The ultimate purpose of psychoeducation is to encourage the family and the person with schizophrenia take active steps towards recovery and live with the illness in a more positive manner.

Sessions: The number of sessions you will consider for conducting the family psychoeducation process should be tailored to the individual affected member’s symptoms and circumstances, such as the causes, symptoms and prognosis of schizophrenia, as well as the treatment and management. In general, between 2-4 sessions are necessary for the initial psychoeducation component spread over 1-2 months during the initial engagement phase of the intervention.

However, it is very important to understand that psychoeducation is a continuous process and continues till the termination of the intervention; the contents of the psychoeducation change with the progress of the intervention.

For example, in the stabilization and the maintenance phases, there will be continued discussions on emerging needs like control of difficult symptoms, participating in rehabilitation efforts, addressing stigma and discrimination, relapse prevention and other relevant issues on an individual basis.

3.5.4 B) Who should be included in the group?

- If there are many relatives, you should assess each relative's knowledge in individual sessions and then present the information to the family collectively. You may decide whether to include the affected member in the family sessions. Otherwise, the affected member can have a separate information session.

- Seeing the family in the absence of the affected member may be preferable in the initial, acute phase as the relatives may want to ask questions about the affected member, and feel uncomfortable asking them in his presence. If the affected member is actively symptomatic, he may also disrupt the session by being unable to concentrate, showing inappropriate emotions or their speech may be disturbed, etc.

3.5.4 C) Useful strategies while providing psychoeducation:

- The family's view of the affected member's condition may not change immediately in response to the psychoeducation, but will gradually change over time.

- Allow them time to **ask questions** and pause after each theme.

- You may need to **encourage** some families to ask questions or voice their disagreements with the information provided.

- Be prepared to **discuss and clarify** the information with the family.

- Avoid **over-loading** the family with too much information or medical jargon.

- Avoid using **remote and theoretical explanations** to explain concepts that are difficult to understand. Use examples from the history of the affected member.

- **Listen** and understand the family's view of the illness.

- Be **sensitive** to the distress experience of the family members, such as when the affected member is violent, suspicious or has delusions that the spouse is unfaithful, etc. Be alert to this and address it in future sessions.

- If you do not know the answers to their questions, admit **uncertainty**. Assure them that you will provide the information in the next session and do so after talking to your supervisors.

3.5.4 D) Some issues of interest during providing the psychoeducation sessions:

The term schizophrenia:

- Some families may feel afraid or distressed when they hear that the affected member has 'schizophrenia'. It is important that they are aware of the diagnosis. If not, they may assume other causes to be responsible for the affected member's behaviour and treat the affected member the way they think is more suitable.
- Another drawback of not knowing the diagnosis is that the family may think the affected member has more control over his or her symptoms than he or she actually has. They may then conclude that medication is unnecessary and even harmful. They may also doubt whether the affected member is pretending to have an illness.
- Terms like schizophrenia & psychosis may be confusing for families. Clarify their doubts. They may feel uncomfortable using the term 'schizophrenia' with their friends or relatives, as they may feel stigmatized. They can use terms (such as 'breakdown') which they are comfortable with to describe the illness to others.
- Some families associate schizophrenia with violence. When the affected member is not violent, they may not then accept the diagnosis. They may be afraid that the affected member may become violent later. You will need to clarify such fears and doubts by stating that not all persons with schizophrenia become violent. Most are shy and fearful.

Understanding the symptoms of schizophrenia:

- Use examples from the affected member's behavior to educate the family about their symptoms.

- You may notice that families often find it difficult to focus on the symptoms of schizophrenia. They usually tend to talk about specific experiences of the illness.

- Inform the family that each affected member has a different symptom pattern. The affected member can have different symptoms at different phases of the illness. This is important, as family members may not pay attention to you when you speak of symptoms that the affected member does not have.

- Emphasize that the affected member's positive symptoms cannot be easily understood. They are thoughts, ideas, and voices that go in inside the affected member's head. The family can see their indirect effects through the affected member's behavior.

- Emphasize that the symptoms are real to the affected member. Thus, the affected member cannot control them. They will neither be able to resist answering the voices they hear, nor can they be dissuaded from their fears. They are not doing it on purpose.

- Emphasize that negative symptoms (like lethargy, absence of emotion, amotivation) cannot be easily overcome by the affected member.

- Ensure that the family does not form the impression that all the problems are outside the affected member's control. They will otherwise be over protective and feel guilty if the affected member makes demands on them.

Discussing the causes of schizophrenia

- Families usually have their own theories, such as why the illness may have occurred. These are problematic only when the family acts upon such beliefs as the sole cause of the illness. For example, if they think the affected member is too sensitive or imaginative, they may then try to talk the affected member out of delusional ideas or protect them from stress.

- Family members may think they caused or could have prevented the illness in some way, especially if an incident precipitated the illness. Such theories make the relatives guilty and depressed. They may blame it on a failure in the affected member's exams or a love affair, bad parenting, or superstitious beliefs.

- You may need to answer doubts such as whether the affected member will be able to have children, and if they will inherit the illness. You can answer such questions by telling the families that the children will not inherit the illness. They may or may not however, inherit the tendency to develop the illness. If they do, then some develop the illness with exposure to stress.

Issues related to medication:

- Discuss with the family and emphasize the need for regular treatment as prescribed instead of an erratic treatment.

- Emphasize that medication will need to be taken for a long period of one to two years or even indefinitely. The duration of the treatment depends on the recovery and not on the duration of the illness before the treatment.

- Some families may feel that the medications are like "sleeping tablets" and are addictive if used for a long time. They may then decide that the affected member should learn to cope without the medication. Clarify that this is not so and that the medications reduce the positive symptoms.

- Discuss with the family and emphasize the need for continuing the medication even when the affected member appears better. The medications control the symptoms. Inform them that the underlying problem will still be present. By continuing the medication, they can prevent symptoms from recurring.

- Should the family ask, you should be able to explain how the medications work. Explain that schizophrenia develops from a malfunctioning of chemicals in the brain. The medication works by compensating for this malfunction. This usually involves restoring a chemical imbalance. The result of this will be fewer hallucinations and delusions.

- Discuss and explain the common, unwanted side effects of medication. Reassure them that by changing/ reducing medication or by adding other medications it can be eliminated.

- If family members enquire about the use of Electroconvulsive therapy (ECT), say that you do not have the technical knowledge to give any opinion and that the family needs to speak to the treating Psychiatrist.

Course and prognosis:

- Most families expect the affected member to be cured-that is, to not have any more episodes. They may assume that the affected member does not require further treatment and that the illness will not recur. Discuss remissions and relapses in schizophrenia and the need for longer treatment duration.

- Inform them that there are good chances that the affected member can recover from an episode and have a near normal life. Reassure them that they may recover up to 60-70% with medicines and other treatments. This statement should be made depending on the individual course of the illness and in consultation with the treating Psychiatrist to ensure similar messages are being conveyed to the family.

- For chronic affected members, your discussions should focus on reduction of symptoms and improvement of the affected member's ability to live independently. Discuss rehabilitation programs and family support to help the affected member return to a normal life.

- Inform the family that there are possibilities of the affected member having future episodes of schizophrenia. This statement helps the family to continue the medication for long periods and prevents them from being disappointed when the affected member has a relapse.

    - Allow them time to **ask questions** and pause after each theme.

    - You may need to **encourage** some families to ask questions or voice their disagreements with the information provided.

    - Be prepared to **discuss and clarify** the information with the family.

    - Avoid **over-loading** the family with too much information or medical jargon.

    - Avoid using **remote and theoretical explanations** to explain concepts that are difficult to understand. Use examples from the history of the affected member.

    - **Listen** and understand the family's view of the illness.

    - Be **sensitive** to the distress experience of the family members, such as when the affected member is violent, suspicious or has delusions that the spouse is unfaithful, etc. Be alert to this and address it in future sessions.

    - If you do not know the answers to their questions, admit **uncertainty**. Assure them that you will provide the information in the next session and do so after talking to your supervisors.

3.5.4 D) Some issues of interest during providing the psychoeducation sessions:

The term schizophrenia:

- Some families may feel afraid or distressed when they hear that the affected member has 'schizophrenia'. It is important that they are aware of the diagnosis. If not, they may assume other causes to be responsible for the affected member's behaviour and treat the affected member the way they think is more suitable.

- Another drawback of not knowing the diagnosis is that the family may think the affected member has more control over his or her symptoms than he or she actually has. They may then conclude that medication is unnecessary and even harmful. They may also doubt whether the affected member is pretending to have an illness.

- Terms like schizophrenia and psychosis may be confusing for families. Clarify their doubts. They may feel uncomfortable using the term ‘schizophrenia’ with their friends or relatives, as they may feel stigmatized. They can use terms (such as ‘breakdown’) which they are comfortable with to describe the illness to others.

- Some families associate schizophrenia with violence. When the affected member is not violent, they may not then accept the diagnosis. They may be afraid that the affected member may become violent later. You will need to clarify such fears and doubts by stating that not all persons with schizophrenia become violent. Most are shy and fearful.

Understanding the symptoms of schizophrenia:

- Use examples from the affected member’s behavior to educate the family about their symptoms.

- You may notice that families often find it difficult to focus on the symptoms of schizophrenia. They usually tend to talk about specific experiences of the illness.

- Inform the family that each affected member has a different symptom pattern. The affected member can have different symptoms at different phases of the illness. This is important, as family members may not pay attention to you when you speak of symptoms that the affected member does not have.

- Emphasize that the affected member’s positive symptoms cannot be easily understood. They are thoughts, ideas, and voices that go in inside the affected member’s head. The family can see their indirect effects through the affected member’s behavior.

- Emphasize that the symptoms are real to the affected member. Thus, the affected member cannot control them. They will neither be able to resist answering the voices they hear, nor can they be dissuaded from their fears. They are not doing it on purpose.

- Emphasize that negative symptoms (like lethargy, absence of emotion, amotivation) cannot be easily overcome by the affected member.

- Ensure that the family does not form the impression that all the problems are outside the affected member’s control. They will otherwise be over protective and feel guilty if the affected member makes demands on them.

Discussing the causes of schizophrenia

- Families usually have their own theories, such as why the illness may have occurred. These are problematic only when the family acts upon such beliefs as the sole cause of the illness. For example, if they think the affected member is too sensitive or imaginative, they may then try to talk the affected member out of delusional ideas or protect them from stress.

- Family members may think they caused or could have prevented the illness in some way, especially if an incident precipitated the illness. Such theories make the relatives guilty and depressed. They may blame it on a failure in the affected member’s exams or a love affair, bad parenting, or superstitious beliefs.

- You may need to answer doubts such as whether the affected member will be able to have children, and if they will inherit the illness. You can answer such questions by telling the families that the children will not inherit the illness. They may or may not however, inherit the tendency to develop the illness. If they do, then some develop the illness with exposure to stress.

Issues related to medication:

- Discuss with the family and emphasize the need for regular treatment as prescribed instead of an erratic treatment.

- Emphasize that medication will need to be taken for a long period of one to two years or even indefinitely. The duration of the treatment depends on the recovery and not on the duration of the illness before the treatment.

- Some families may feel that the medications are like “sleeping tablets” and are addictive if used for a long time. They may then decide that the affected member should learn to cope without the medication. Clarify that this is not so and that the medications reduce the positive symptoms.

- Discuss with the family and emphasize the need for continuing the medication even when the affected member appears better. The medications control the symptoms. Inform them that the underlying problem will still be present. By continuing the medication, they can prevent symptoms from recurring.

- Should the family ask, you should be able to explain how the medications work. Explain that schizophrenia develops from a malfunctioning of chemicals in the brain. The medication works by compensating for this malfunction. This usually involves restoring a chemical imbalance. The result of this will be fewer hallucinations and delusions.

- Discuss and explain the common, unwanted side effects of medication. Reassure them that by changing/ reducing medication or by adding other medications it can be eliminated.

- If family members enquire about the use of Electroconvulsive therapy (ECT), say that you do not have the technical knowledge to give any opinion and that the family needs to speak to the treating Psychiatrist.

Course and prognosis:

- Most families expect the affected member to be cured-that is, to not have any more episodes. They may assume that the affected member does not require further treatment and that the illness will not recur. Discuss remissions and relapses in schizophrenia and the need for longer treatment duration.

- Inform them that there are good chances that the affected member can recover from an episode and have a near normal life. Reassure them that they may recover up to 60-70% with medicines and other treatments. This statement should be made depending on the individual course of the illness and in consultation with the treating psychiatrist to ensure similar messages are being conveyed to the family.

- For chronic affected members, your discussions should focus on reduction of symptoms and improvement of the affected member’s ability to live independently. Discuss rehabilitation programs and family support to help the affected member return to a normal life.

- Inform the family that there are possibilities of the affected member having future episodes of schizophrenia. This statement helps the family to continue the medication for long periods and prevents them from being disappointed when the affected member has a relapse.

After your session, you should be able to achieve the following:

- Impart information on the facts of schizophrenia
- Clarify the doubts, misconceptions the family may have had regarding the illness
- Reassure the family that there is hope for the affected member to get better
- Motivate the family to comply with medication as prescribed.
- Engage and maintain the family in treatment

3.5.5 The basic interventions with families in COPSI:

3.5.5 A) Guidelines for basic interventions:

- Inform the family members that the suggestions you provide will not have an **immediate effect**. It will take time and will be a difficult process for the family.

- Should family members be discouraged at the slow rate of improvement and wish to discontinue, emphasize the importance of the intervention in **preventing future episodes** and in maintaining the affected member's improvement.

- Reinforce that the family can influence the **course** of the affected member's illness. The goal of the family members must be for the affected member to return to **as normal as possible functioning**. Point out that there are many reasons for optimism regarding improvement, whereas they follow the plans jointly formulated.

- Help the family to identify unhelpful ways that they may have begun to use in their interactions with the affected member. To do so, use examples that you have obtained from the family or that you have observed during the assessment sessions. Some of the areas that you should highlight are given below (Refer Identifying Inappropriate Responses of the Family).

- Point out to the families that although they may consider their responses to be normal and appropriate, they are not and are **unlikely to be successful** in the long run.

- Be **empathic** or the family will feel you are unappreciative of the efforts they have made to try to cope. They may then be unreceptive to trying new ways of coping.

3.5.5 B) Specific actions of the basic set of interventions:

Adherence with medication:

- Prepare the family for the possibility of the affected member discontinuing the medication when they feel better or to stop side effects. If medicines are stopped, things might continue as they are or actually improve for a while. However, we know that 80% of people who stop medicines prematurely will have a serious relapse in the next 12 months.

Normalize the family routine:

- Discuss with the family the disadvantages of turning the affected member the **center of their lives**. Tell them that since schizophrenia is a long-term illness, they may become too stressed to be able to look after the affected member. They may also develop problems of their own. This could result in the affected member feeling guilty and responsible. The affected member could then perceive himself as a burden to his family.
- As far as possible, encourage them to resume the **daily routines** that were present **before the illness.** If there were no routines or they appear disruptive, help them make a daily routine, which should also include time for leisure, celebration of festivals, birthdays, etc.
- Advise them to attend to the **needs** of other family members. They should not always support the affected member when he is unreasonable and be stricter with other members of the family.

Have appropriate expectations:

- The affected member is often expected to revert to their former **roles** and behaviors soon after hospitalization. The family feels disappointed when the affected member is unable to do so. Discuss and encourage them to have **realistic expectations** of what the affected member can do.
- The family should be encouraged to view the affected member as having a **serious physical illness**, which requires a long time for resting.
- Once the affected member's symptoms are stable, some affected members c**an be inactive, sleep mo**re and appear not motivated. They may also be restless and unable to perform small tasks. Reassure the families that these belong to the normal course of the illness. Discourage them from viewing the affected member as "lazy."

- Encourage them to **compare** the affected member's current behavior with that of how it was a month or more ago. This allows the family members to recognize the positive changes that have occurred and to have expectations that are more appropriate.

Set limits:

Suggest to the family that because the affected member is ill, the family does not need to/ should do whatever the affected member asks. Instead, they should set limits on the unacceptable behaviors by:

- Help them to specifically identify **what behaviors they will and will not tolerate**. Help them to decide which behaviors are **intolerable** (violent and bizarre) and which are irritating (based on a consensus). When the behavior occurs, they must immediately set limits not to let develop a pattern of behaviors. For example, if the affected member hits a family member, they should try to stop them from doing so each time. Instruct them not to tolerate the behavior for some time and then later try to stop the affected member.

- Advise them to **avoid discussing** with the affected member the reasons for setting the limit or how they feel about it. Train them to only state that the behavior is unacceptable, without explaining why.

- Advise the family to **be specific in their requests and to use specific reminders** when they want the affected member to do a task. Advise them against, for example, expecting the affected member to do household chores unless they have been specifically told what to do and how often to do so. The affected member may forget and need reminders.

- Help the family to identify **which reinforcers are most effective**. They can identify material reinforcers (such as money, food, etc) and activity reinforcers (for example, if the affected member does the chores they are allowed to watch TV or may be taken for an outing).

- Assist them in identifying a variety of reinforcers so that the affected member is not bored. Initially **material or activity reinforcers** should be used with social reinforcers (smiling, praise, patting them). Later the material reinforcers should be reduced but the social ones continued.

- When the affected member behaves well, instruct them to praise the behaviours immediately. This will **positively reinforce** that behaviour. They should state which behaviour they are praising or reinforcing. This will help the affected member to link the positive reinforcement with the behaviour.

- Demonstrate to them how they can **simplify tasks** for the affected member by breaking it up into a number of small steps. The affected member should be reinforced when the first step is completed. They can then provide a clue as to what the next step is and reinforce it when performed. This should be done for every step until the task is completed.

- As the affected member may be unable to perform the task correctly by the first time, the behaviour will have to be **shaped** to resemble the task more accurately. Instruct the family to reinforce those responses that approximate the desired behaviour and ignore those unlike the desired response.

- When the affected member behaves in an undesirable way, the **social reinforcements are stopped**. The affected member should be taken away from the others for a short period and returned when desirable behaviours are shown. For example, when the affected member disturbs others by shouting, then he should be taken to another room and not spoken to until he stops it. The material and activity reinforcers that they usually receive should be removed.

- Irrespective of the affected member's age, **limits should be set.** Discuss with the family the necessity for the affected member to behave in an age-appropriate manner and encourage them to modify their expectations of the affected member's behaviour. For example, an adult should not have tantrums.

- Discuss with the family the necessity for insisting on the **affected member complying with their limit setting**. However they should not set limits when they are unable to enforce them.

- Point out to the family that they will probably be unsuccessful the first few times they attempt to set limits. It may take a number of weeks. Encourage them **not** to **give up trying**.

- Discuss with them the improbability of solving all their problems at once.

- Advice the family to select one or two issues which they wish to focus on. They should ignore the others until they are successful in solving the selected ones.

- Instruct the family that they must, however, not ignore behaviors such as suicidal threats, violence or other psychotic behaviors. The approach to be adopted for these problems are addressed in the chapter "**Addressing and Handling Difficult Problems"**

Reduce stress:
Remind them that the affected member has a lower tolerance for stress; use the stress-vulnerability model here for explanation.

- Instruct the family to reduce fights, conflicts, rejection and nagging behaviours.

- Discuss with them how being over enthusiastic, showing extreme concern and encouragement can be upsetting for the affected member, and discourage them from doing so.

- Advice them that should the affected member wish to withdraw and be alone, the family should allow it.

- To avoid the affected member withdrawing completely, discuss with them opportunities or activities to offer the affected member to engage in, such as going out. Prepare them to accept the possibility that the affected member will refuse.

Simplify communication:

- Affected members often do not respond immediately when they are spoken to. There may be a pause or a delay before they communicate. Advise the family members to **avoid speaking on the affected member's behalf** when this occurs. Advise them to **wait for the affected member to respond**. Remind them that the affected member can contribute to the conversation.

- Advise them to avoid the tendency to **assume** what other members are thinking about, want or need, even before they say so. Encourage them to speak only for themselves. Advise them to accept what other members say even if they do not agree with it.

- Advise family members against talking about **complex and emotional topics** in the presence of the affected members, especially during times of crisis. They should also avoid detailed conversations, which the affected member will find confusing.

- At times when the meaning behind the affected members communication cannot be easily understood, family members try to discover the hidden meaning in it. Discuss with them the advantages of instead **asking the affected member to speak more clearly**. Be empathic with the family's frustrations in dealing with these odd conversations.

- Encourage them to be **appreciative of the affected member's positive behaviors,** and to encourage the affected member when having difficulties.

- **Generalized comments** should be avoided. For example, if an affected member does something inappropriate, they should not make comments such as "He is useless" or "She can never do anything right" or other similar comments.

- Advice them to **avoid vague, unclear or ambiguous statements,** as these are difficult for the affected member to interpret.

Strengthening social networks:

- Sometimes family members adopt the attitude that they should not trouble others with their problems. They may also worry about the reactions of others. Discuss with the family the benefits of discussing their problems with others like relatives, friends, neighbours, religious or social organizations, as it will help in reducing their distress. It also helps them to generate new and better solutions to their problems and prevents them from using the same unsuccessful tactics in solving it.

- Use the reasons stated in the introduction chapter *(Why involve the Family? Point # 13)* when discussing with them about the need for improving their social contacts. Point out that they will not be able to care for the affected member for a long time unless they look after themselves as well.

3.5.5 C) Identifying unhelpful coping strategies used by the family:

- Overadapting and normalizing the situation: Family members usually adapt their routine to include the affected member's behaviors. This is usually a slow and gradual process of adaptation that helps the affected member to maintain a role in the family. Sometimes the affected member may be unable to perform the tasks due to the illness, and family members may find it difficult to adjust. You should be able to get this information from the "coping" part of the assessment.

- Making sense of the unusual: Family members tend to convince the affected member that their unusual ideas and beliefs are untrue and try to persuade him to behave in a more acceptable manner. Though, the affected member does not control his symptoms, and this kind of confrontation can lead to arguments and angry responses from both sides. You should be able to get this information by asking the family what they say to the affected member when he is symptomatic.

- Making sense out of nonsensical communication: Even though it becomes apparent that the affected member does not make sense, some family members may still try to understand the meaning of its often bizarre and nonsensical statements. They may try to determine the essence of the message or may look for something realistic in the affected member´s speech.

- Ignoring: Family members sometimes hope that the affected member will gradually stop behaving the way they do. At times, they ignore the illness symptoms, deny its significance, or try not to think about it. This is ineffective when the symptoms are extreme.

- Providing constant supervision: Family members are unable to predict the affected member's behaviors. So, they tend to constantly supervise the affected member's behavior, which gives them some kind of control over the situation and sense of protection.. However, it is difficult for the family to maintain this constant supervision for a long time.

- Reducing their own activities: The family members gradually begin to plan their routines and activities to care for the affected member. This may involve actually looking after the affected member and supervising him so that he does not harm himself or others. Family members become exhausted and eventually use even their spare or free time to do the minimum necessary house work.

- Ignoring the needs of other family members: Caring for the affected member becomes a full time job. The emotional needs of the other members become secondary or the caregivers may not have enough time and energy to look after the others. This results in others feeling uncared for or neglected, and family relationships deteriorate.

At the end of the basic family psychoeducation, you should have helped:

- empower the family with better coping strategies

- provide advice to the family on their role in preventing future episodes through compliance with medication, revising their expectations, simplifying their communication, reducing stress and identifying early warning signs

- assist the family on how to normalize their family routines, how to set limits and selectively ignore the affected member's behaviors

- help the family to identify inappropriate means of responding to the affected member, so that they can recognize and modify them

3.5.5 D) Assessing and handling difficult problems:

- In your first session, as well as in other sessions, you would have obtained information on the family's *approach* to problems, the *coping ability* of the affected member and the family, their *success* or failures in solving problems. These will mostly be unsuccessful or successful for a short period.

- With the help of specific examples and this information, point out to the family the approach they adopted and their success in the short- term as well as the long term.

- Inform the family of the strengths you have identified in them. These can be abilities, interests and resources available to the affected member as well as the family members. Family members can include other strengths that you may not know about. Relate how these can be used to help obtain the desired outcomes or goals.

- Family members often compare the affected member's previous functioning with their current level. They may not consider skills and abilities that the affected member previously had to be present still. They may feel some skills (like driving a car, etc) are not worth mentioning.

- If the affected member is unable to suggest any interests, ask the affected member to describe what he used to enjoy doing. This can be added to the list of strengths or positives.

3.5.6 Guidelines for management of some specific problems commonly faced by the family:

3.5.6 A) What to do in a crisis?

The family will be unable to reason with acute psychosis. Advise the family members to:

- Not express irritation or anger. They should attempt to keep their emotions under control.
- They should decrease other distractions (TV, radio) immediately.
- Advise the family to calmly ask anyone (friends, guests) who is present to leave.
- They should speak quietly, firmly and with simplicity to the affected member.
- They should express understanding for what the affected member is experiencing.

3.5.6 B) What to do when the ill family member is violent?

The family can first identify the precipitating behaviors and events. Encourage the family to use problem solving steps. Encourage them to suggest methods of dealing with a potential violent behavior. Some possible solutions are:

- Asking the affected member to go to another room or asking the involved family member to go to another part of the house or to leave the house.

- The family can also contact the **police** and explain what they are experiencing. They can seek their help to obtain treatment, to control the violent behavior or admission.

- They could contact the treating **doctor** and ask for advice.

- Inform them that they can also write to the **magistrate** for admitting the affected member.

They can also suggest preventive measures, such as keeping knives and other objects away from the reach of the affected member.

3.5.6 C) How does one deal with the issue of sexuality?

Some families may refuse to talk about sexuality. It may be felt to be too painful, culturally unacceptable or inappropriate, and problems will be denied. It is not necessary to insist that a family faces these issues. If it is an area where the family identifies problems, then you should facilitate solutions.

Parents may find it difficult to cope with the fact that the affected member is likely to have sexual needs and may choose partners who the family members may not approve of or welcome. These partners could be other affected members. They may also have casual sexual contacts. Risks such as AIDS, pregnancy are understandable fears in the caregivers. You should:

- Aim for a realistic and frank **discussion** of sexual needs in adult affected members. This is not an issue for all affected members.

- Sexuality needs privacy and acceptance by the rest of the family- ways of achieving this may have to be discussed. The family's **fears** of risk of pregnancy and diseases have to be discussed openly. Clarify whether affected member has taken responsibility for himself or herself. Look at the likelihood of various negative outcomes-the family's worst fears may not be realistic.

- Encourage the family to openly discuss their worries of pregnancy-whether the baby will inherit the illness, whether the affected member will be able to look after the baby or whether the affected member should have the baby at all. Encourage the family to discuss the options and come to some agreement.

3.5.6 D) Marital issues/ Separation / Divorce:

Your focus is to help the couple to cope more effectively with the illness and their relationship. Clarify repeatedly of your commitment, support and positive intent. Ask for periodic feedback to insure that no misunderstanding or alienation has occurred.

Avoid

♣ Taking sides with one of the partners
♣ assuming the role of the adversary or champion of either partner

Marital problems:

1. Explore & understand reasons for strain in the relationship due to the impact of the illness, like changes in roles & responsibilities, social & economic problems and the absence of a confiding partner in the marriage.

2. The discrepancies between the affected member's past and present functioning may be significant. Help the couple reset realistic and achievable priorities before beginning to explore and eventually assume redefined roles.

3. Consider **role reversal** of conventional roles. The wife may go out to work while the husband cares for the home, children, or both. If this is not possible for a male affected member, negotiate carrying out tasks such as mending or fixing things, which represent a valued contribution.

4. For a female affected member undertaking a conventional role, help may be needed in improving skills such as shopping, budgeting and cooking. Distinguish between lack of opportunity to exercise a skill and basic lack of the necessary skill.

5. The healthy spouse should be encouraged to **reward** the affected member with praise for successfully completing small tasks.

6. As the affected member improves, aim for a more **balanced relationship** with the affected member being given greater responsibilities. This should be accomplished in such a way that it does not allow for the affected member's role to dominate either spouse's view of the affected member or the marriage.

7. Encourage the spouse to find a person of the same sex from his/her social network in whom he/she can confide in.

8. Suggest better **communication skills,** such as initially encouraging the affected member to make more sense, reinforcing clarity and limiting bizarre communications. Later help them to make their needs better known to each other, and to translate their complaints and concerns into measurable and achievable goals.

9. Re-establish a **warm relationship** by using the following three strategies:

    a) Ask each partner to say something positive about the affected member. If they complain and cannot think of anything positive currently, ask them to remember a positive aspect of the affected member in the past.

    b) Ask each partner to say something they would like the affected member to do for them, and negotiate for this to be carried out. Ensure that the task is within the affected member's capabilities.

    c) Find something that the partners would enjoy doing together outside the home, and set them the task of trying it. If they complain there is nothing at present that they enjoy doing together, then get them to review the history of their relationship to find a suitable activity.

10. Avoid emotionally charged issues to reduce the risk of overwhelming the ability of the couple to cope.

11. If necessary, arrange for a review of the medications with the treating Psychiatrist to ascertain effect on sexual desire and functioning. A spouse may interpret a reduction in their partner's sexual interest and activity as a sign of loss of love and affection. It is important therefore to give an alternative explanation.

12. Make up for the loss of sexual relationship by using other ways of expressing affection like hugging.

Separation:
Despite your best efforts, the partners may remain irreconcilable. Under these circumstances, you should help them to separate in a manner as constructive as possible.

- Assess how serious and soon it may occur.

- Discuss the pros and cons of such a decision, as the desire to leave may be related to a temporary sense of frustration or a need for a time out rather than a genuine wish to terminate the relationship. If so, then focus on finding ways to increase support for the spouse.

- Assist the spouse to express guilt about deserting the affected member and explore anxieties about possible disastrous outcomes such as suicide or destitution.

- Negotiate short term treatment contracts to include:
    a) Establishing a time schedule that helps to ease the abruptness of this change.
    b) Help each partner to better understand the reasons for the dissolution of the marriage.
    c) Help each spouse to plan for the separation-possible sources of emotional and practical support for the affected member need to be identified and brought in so that they are not left completely isolated.
    d) Establish ways of coping before the associated stress and pain occurs.

- If there are children in the household, their welfare must also be considered.

Divorce:

- Help them to separate with minimum of stress and chaos.
- Avoid judging the behaviour of the departing spouse. Leaving someone who has a mental illness is difficult.
- Assist the spouse to express their ambivalence guilt and anxiety.
- Do not implicitly or explicitly suggest to either spouse that there is a right or wrong way to behave under these circumstances.

- Facilitate whatever decisions either spouse feels must be made.

3.5.7 Termination of the intervention:

The intervention will have to end. The family will have to be told clearly ahead of time of the leaving date so that specific activities can be conducted in preparation.

Carefully plan the transfer of care arrangements with the treating Psychiatrist and the family so that there is no gap in the care arrangements after termination. This will be conducted in the group supervisory meetings where you will be expected to provide a summary of the process and details of the intervention, identify changes and possible challenges for further recovery. It is ideal if you can organize a joint meeting with the family and the Psychiatrist and discuss the details of the handover clearly.

Review the changes that have occurred as a result of the intervention with the family using the various sections of the Intervention Record Form (need assessment, adherence, suicide risk, positive behavior change, etc).Identify the positive changes in their attitudes, behavior, and communication with the affected member. Highlight their ability to resolve problems. Identify the positive changes in the affected member's activity levels, his independence in doing tasks related to his personal care and household chores.

Review and reinforce adherence management, relapse prevention, health promotion and gains through rehabilitation sections of the intervention.

Identify specific goals for the family and the person with schizophrenia to work towards in the next 12 months. This gives a sense of purpose and direction for the family to move towards instead of facing an uncertain future.

You should prepare the family for the **recurrence of old problems** and/or the appearance of new ones as being part of the nature of schizophrenia. The family should try to solve these problems as they did during the intervention. They should contact the treating Psychiatrist when they are unable to cope.

The family may feel angry or upset when you terminate the intervention. They may feel that they need your continuous support to care for the affected member. Reassure the family by giving specific examples of how they have learnt to solve and handle their problems during the intervention. Encourage the family to be **independent** and confident to deal with any issue.

Reinforce the need to strengthen social networks by continuing to make active attempts to interact outside of the home setting. Review the specific techniques used for improving social and personal care skills necessary for quality social interactions.

Reinforce the need for gradually improving work functioning either at home or outside, and maintaining the skills necessary for negotiating money transactions, using public transport and appropriate social interactions.

Review the change in attitudes in the family and outside towards the person with schizophrenia in the last months and explore the family's understanding of the changes. At this time, reinforce the need for the person with schizophrenia to be treated as an equal citizen, and empower the family to fight discrimination by increasing their literacy of the relevant legal and social benefits.

There may be rare occasions where the family expresses that they wish to stop receiving the intervention. This may leave you shocked, angry or feeling rejected and inadequate. You could handle it by:

- First determine the type of termination being considered. The affected member and the family may decide to stop the family intervention but the affected member may wish to continue the medication. This provides a link with the family and allows for continued monitoring of the affected member. It might also lead to an opportunity for restarting the family intervention later.
- Do not attempt to **prove** to the family the value of your work together, as this will lead to confrontations and arguments.
- **Accept** what the family says.
- If possible, try to find out what the problem is. If it is something specific, then you may be able to change your approach or deal with the problem.
- If the family is uncooperative, you should try to arrange a final session in order to say goodbye and to do some work on leaving. Arrange this session after a few weeks so that the family has time to calm down.
- Review the progress that has been made and rehearse coping strategies for any emergencies with the family. Tell the family that you can be contacted (by leaving a telephone number) even if they reject it.
- Stress that although termination has occurred, you will remain available to the affected member and the family should the need arise. Inform them that you would like to see them again should they change their mind, and wish them well for the future.
- You can also telephone them after a few weeks to see how they are managing. The family will realize that you are willing to be involved and are still concerned.

Summary

- ♦ Families of persons with schizophrenia are our most important partners; Interventions specifically focused on caregivers and other family members is, therefore, an essential element of the COPSI intervention
- ♦ The intervention follows a particular sequence- from assessment to termination and comprises a basic package for all families in the intervention
- ♦ The basic package comprises of provision of information and skills to manage daily problems
- ♦ In addition, there are sometimes more complicated problems that require attention for the person with schizophrenia to recover in a supportive family setting

CHAPTER 3.6

Adherence management in COPSI

3.6.1 Introduction:

Long standing or chronic diseases need treatments ranging from months to years for the best results. This is true for infectious diseases such as HIV/AIDS and TB, or non-infectious diseases like schizophrenia, heart disease, diabetes and asthma. This applies both to medicines that need to be taken on a daily basis, as well as to specific lifestyle changes that the individual needs to commit to and continue with. For example, the treatment of heart diseases involves regular exercise, stopping smoking and excessive alcohol use, modifications of diet to decrease fat and salt intake, as well as medicines that need to be taken 2-3 times per day. As discussed earlier, in schizophrenia the treatments that produce the greatest benefits, like antipsychotic medicines, need to be continued for long periods for the individual to recover and maintain improvement.

While there are effective treatments available for most chronic diseases, *the single, greatest challenge facing health providers worldwide is to get individuals to continue with their recommended treatments for the required periods of time.* If you consider that taking treatment is a challenge even when it needs to be taken only for a few days, (like antibiotics for chest infections) where many individuals start to miss the doses of medicines once the acute symptoms start to improve, then you can imagine how great a challenge this is for chronic diseases. It is obvious that even the best treatments will be of limited benefit if the individual is not following through with the necessary requirements and is, in technical terms, non-adherent with treatments.

3.6.2 How do we define adherence?

Adherence can be understood as ‘the act or quality of sticking (adhering) to something’. *Adherence is that part of treatment which describes the individual’s ability to follow a treatment plan, take medications at prescribed times and frequencies, and sustain positive lifestyle changes that correspond to the advice of the treatment provider.*

However, scientific research shows that only a small proportion of those who are adherent with treatment do it completely and perfectly. Most people, within those who are considered adherent with treatment, do have times when they deviate from their recommended treatments by choice (during religious ceremonies, when staying overnight in relative’s house) or because of forgetting. In other words, partial adherence with chronic treatment requirements is the most common pattern seen. The question of how much of deviation from treatment recommendations is needed to consider a person as being non adherent is not clear; for the purpose of intervention we will define adherence as continuing with treatments as recommended for at least 6 of the 12 months.

3.6.3 How do we define non adherence:

Non adherence with treatments can happen in many ways. Non adherence can be complete or partial when the individual takes the treatment only for a certain proportion of the time. Some individuals may refuse to take the treatment from the very beginning, while others may start taking the treatment and become non adherent over a period of time. For our purpose, we will consider non- adherence with treatment under the following heads:

- *Treatment refusers*- These are people who do not take any of their prescribed treatments from the very beginning and are intentionally non adherent.

- *Treatment acceptors who become non adherent*: These are people who initially start with the treatment but later discontinue it due to reasons like troublesome side effects, the cost of the medicine or non availability of the medicine. Within this group, there will be people who stop completely (becoming intentional treatment refusers) and those who stop for a specified period before they can be supported to start treatment again (unintentional non adherence).

The most important thing to remember for you is that adherence is a dynamic and changing part of the intervention that must be monitored closely and addressed to prevent people lapsing into non adherence on a long term basis.

3.6.4 The extent and health consequences of non adherence in schizophrenia:

In the context of schizophrenia, non adherence with treatment is both very common and has serious consequences. Between 40 to75% of people with schizophrenia starting treatment become non adherent within the first few months of treatment. High rates of non adherence persist even where resources provided to care for the individual with schizophrenia are quite extensive. In low-income countries, most individuals with schizophrenia do not get treated in the first place. Of those who are starting on treatment, the very limited findings suggest that 30-40% of individuals became non adherent with treatment within 12 months.

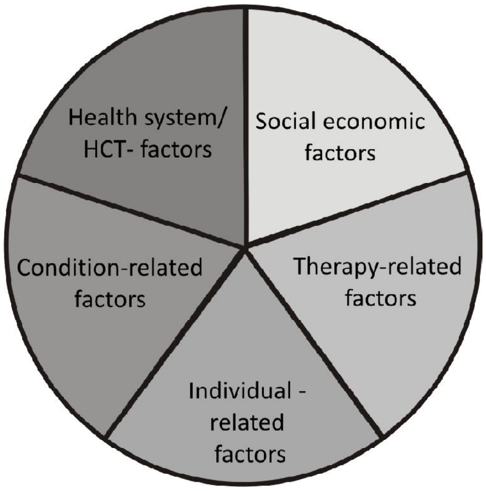
There is consistent proof that non adherence leads to poor long term outcomes in schizophrenia. Of those persons with schizophrenia who are non adherent, between 60-80% will have a major relapse of symptoms within the next 6-12 months. This is accompanied by a number of personal (symptoms, distress) and social (conflicts at home or at work, loss of income and loss of status) problems that have a negative impact on the overall life of the individual. There is also a large economic cost to the family and the health system for non adherence, since the relapse of symptoms means more intensive treatments at a hospital, as well as indirect costs to the family like travel, having to care for their ill relative and the loss of daily wages involved in caring.

Given these facts, adherence management is one of the most important and essential components of the overall package of interventions.

3.6.5 Understanding the reasons for non adherence in persons with schizophrenia:

Non adherence in schizophrenia, like in other chronic diseases, is usually due to a number of reasons which operate together to produce the observable fact of the individual not taking the recommended treatment. A systematic understanding of the overall context in which non adherence happens is very important for any plans to improve adherence. The broad reasons influencing adherence are given in Fig 1 below and can be summarized as:

- Individual factors
- Illness related factors
- Treatment related factors
- Relationship between the individual and the care provider
- Systemic factors and socio-economic factors



3.6.5 A) Individual factors:

Socio- demographic profile

In general, socio-demographic factors such as gender, ethnicity, age, employment, income, education and literacy have a limited predictive ability in determining whether the individual will be adherent or not. In the case of schizophrenia, some social factors like poverty, lack of formal education, unemployment, lack of support from family and not having a stable house to stay in are related to poorer adherence and need to be addressed in the management strategies for improving adherence.

Psychosocial factors

A number of psychosocial factors are more reliable in predicting adherence behavior in comparison to the very general demographic details. These include:

- In any chronic illness like schizophrenia, individuals and family members may understand the possible reasons for the illness in ways that are very different from the 'scientific facts'. For example, many individuals and families believe that schizophrenia is due to supernatural causes like being the victim of witchcraft, which is quite different from the perspective of being a chronic, medical disease due to problems in the brain. Medicines may be then seen as a necessary resource for quick relief from troublesome symptoms like sleeplessness and agitation, but not something that should be continued for long.

  Understanding the explanations for the illness that the individual and the family have is essential to plan an adherence management strategy that is based on the middle ground of the common and scientific views on schizophrenia. Discountingthe family understanding as being 'unscientific' and providing a detailed explanation of the brain dysfunction to a skeptical audience does little to promote adherence. Adherence is better in situations where the individual and the health provider's understanding of the illness match reasonably well, so that the treatment recommendations are seen as being acceptable, understandable and manageable to everybody involved.

- The individual's information and understanding of the medication regimen and a good understanding of the relationship between non-adherence and poor outcomes is an important element of improving adherence. Some individuals feel very strongly about 'mind control though chemicals' and may wish to stop medicines to demonstrate that treatment is not really necessary. On the other hand, the individual's belief and confidence in treatments provided as being useful and effective usually promotes adherence.

- Stigma or the feeling of shame in having a mental illness that requires regular treatment can be a powerful reason for individuals with schizophrenia refusing to take the prescribed medicines. However, stopping medicines usually results in a relapse of the illness which then further reinforces the stigma, making this a negative, downhill cycle. These feelings of shame and stigma of being 'inferior' in some way and the harmful consequences of stopping medicines as a response need to be actively discussed and managed for adequate adherence.

- Having good social supports like an understanding family who encourage the individual to adhere with treatment recommendations is a very important element of improving adherence in your intervention. Many individuals will be living with their families who are the most important caregivers on a daily basis. It is essential to develop a close collaborative relationship with the family, provide them with information and actively involve them in adherence management plans. This is possibly, the single most important element of any adherence management plan in our social context.

3.6.5 B) Illness characteristics:

Sometimes the disease itself can be a risk factor for non adherence. This is especially true for schizophrenia for a number of important reasons. Many individuals with schizophrenia will experience psychotic symptoms and other alterations in their perception of everyday life. This can affect their judgment and ability to make a reasonable choice about the potential benefits of the treatment. For example, during periods of being unwell, the individual might feel that the medicines are being used to poison him as part of an elaborate plot and might refuse to take the most appropriate medicines.

Some individuals might have predominant symptoms of lack of motivation, poor social skills, lack of drive in achieving things and very limited spontaneous conversation (negative symptoms) which makes it difficult to maintain adherence. Another common concern in improving adherence in schizophrenia is the lack of awareness of the presence of an illness that requires treatment (lack of insight). This makes it difficult for the individual to understand the possible benefits of treatment, which is considered to be irrelevant since the individual feels there is no problem in the first place! Also, the poor concentration and memory problems that many individuals experience can lead to forgetting to take medicines on a regular basis. Similarly, ongoing use of alcohol and drugs and the presence of other psychological problems like depression generally predict poor adherence to treatments.

As you can understand, schizophrenia, by the unique nature of the illness, presents a big challenge in improving rates of adherence. This is why your intervention should have a specific emphasis and strategies to improve adherence.

3.6.5 C Treatment related factors:

Simple dosage pattern improves adherence

In chronic diseases, frequently the treatment regimen consists of many pills per day, with multiple dosing throughout the day and specific food and fluid related instructions. These are often difficult to follow for individuals and contribute to poor adherence. In general, the more complex the treatment requirements become, the lower is the adherence. Importantly, in schizophrenia, one of the more effective ways to improve adherence has been to have a simple, once daily dosage pattern which is easier to understand, remember and follow.

Side effects lead to more non adherence

Another very important reason for non adherence is the experience of side effects of the treatment. For example, in the treatment of schizophrenia, antipsychotic medications may have unpleasant immediate and longer term side effects. It is obvious that if individuals experience these side effects, they tend to stop treatment or take it irregularly; in both scenarios, the recovery from the symptoms of the illness is delayed. However, providing information about the benefits and common side effects can help individuals feel more in control of their treatment. Responding to concerns about side effects and helping individuals understand the benefits of the medicines is an essential element of adherence management for people with schizophrenia.

The individual - provider relationship:

As you might expect, the quality of the individual –provider relationship plays an important role in determining adherence. Trust and confidence in providers has been found to influence adherence positively in all settings. The importance of a positive relationship between the individual, family and the members of the treating team cannot be exaggerated as this is possibly the single most important factor that predicts long term adherence. As a result, you should be making a lot of effort to develop the skills necessary to have a trusting and respectful professional relationship with the individual and family.

3.6.5 D Systemic and social factors:

Where and how treatment is provided matters

It is important to remember that the setting in which treatments are being delivered are important in determining adherence. For example, many facilities have stigma attached to the treating centre as well as the treatment being provided. This is especially true if the centre is part of an established mental hospital; many individuals do not attend these clinics even when required due to the stigma attached to the consultation in an ‘asylum’. In your intervention, this factor is minimized by providing most of the services at home and by fostering a needs based and collaborative approach to treatment.

Again, the physical infrastructure and the attitude of the treatment staff at the clinics have an important relationship to adherence. If individuals go to the treatment facility and feel that the staff is rude or uncaring, it is more likely that they would not return for continuing their treatment. On the other hand, having sympathetic staff, provision of basic physical amenities like clean toilets, drinking water and privacy during physical examinations or consultation sessions, provides encouragement for the individual to come back on a regular basis.

Another factor that can have a bearing on adherence is the assured availability of the treatment and staff. For example, if individuals attend the treatment centre to find that the doctor or their medicines are not regularly available, they are likely to stop treatment. Finally, treatment facilities that are easily accessible (i.e. individuals do not have to travel long distances to reach them) are strongly associated with better adherence.

Social barriers to adherence need to be addressed

There can be a number of social barriers to adherence which need to be addressed if individuals are to continue with their medicines. These include the barriers to equal care to women with schizophrenia due to gender discrimination, the inability of the individual and the family to return for treatment due to their poverty and the inability to meet treatment expenses, the lack of confidence in negotiating the treatment pathway due to ‘backward’ social position and, very importantly, the stigma and discrimination of schizophrenia which make families hide the illness and not seek treatment till there is a crisis.

These social barriers can have a very powerful influence in predicting adherence. One the most important way in which we can address these social concerns is through your work with the family where collaborative efforts are made to find solutions to those potentially modifiable factors through systemic efforts.

3.6.6 What are the general principles of improving adherence?

The first and important message is that *there is no one, simple method to improve adherence in chronic diseases like schizophrenia.* Secondly, improving adherence requires a combination of methods like individual and family education, reminders through letters, phone calls or home visits, the use of aids to improve adherence and incentives for sticking to the treatment.

Thirdly, there cannot be a single method of improving adherence in all individuals, as they are all unique in their social and personal circumstances and beliefs. Adherence management strategies need to be matched to the needs and circumstances of that particular individual- one method will not fit all. Finally, since non-adherence cannot be 'cured' or solved, adherence management is always an ongoing and essential part of the intervention.

Through research, we now have some idea of the general principles that health programs need to adopt to improve adherence in designing an appropriate adherence management strategy. The most important ones are described below and are illustrated by the following examples:

- Making treatments ***accessible*** by addressing the systemic and social barriers to adherence. For e.g., distance from the treating centers is often an important reason for individuals to become non- adherent; you as CHW will deliver most of the intervention at home and will assist the family in making the necessary visit to the treating facility as required. In addition, you will be able to respond to any problems with treatment more promptly than the doctors in the clinics. Reducing this time lag for action is the main function of making accessible care available.

- Ensuring that the treatments provided are ***equitable,*** i.e. the same quality of treatment is available to all persons irrespective of their gender, economic status and social standing. In other words, there is no discrimination in the time, energy and quality of the treatments provided for those who are socially more vulnerable. As a CHW, you should ensure that women, socially isolated families and those with pressing economic problems are given adequate attention, as this will help minimize some of the most important social challenges to adherence management.

- In schizophrenia, there are special challenges in making treatments ***acceptable*** to individuals and their families. However, helping individuals to understand the benefits of the treatment and to follow the recommendations can be challenging. In general, having a simple treatment schedule, monitoring and avoiding side effects and helping the individual understand the positive changes from using medicines are useful ways to improve adherence rates.

- In schizophrenia, one of the commonest reasons for non adherence is the high, ongoing cost of treatment. Usually most of the costs are borne by families- these include the cost of the medicine, the travel expenses to the treatment centre and the loss of daily wages involved. Making the treatment ***affordable*** for the family is essential for adequate adherence. To reduce the indirect costs of treatment, we would encourage the CHW to provide the backup support to enable less frequent clinical reviews at the treating centre, accessing medications for 2-3 months at a time and a proxy family member picking up the medicines in case of the individual being assessed as 'stable' by the CHW.

- Finally, the treatments that are being provided need to be ***effective*** and produce the desired effects, like reduction of psychotic symptoms, to encourage the individual to continue to use them on a regular basis.

3.6.7 The adherence management strategies:

Overall framework:

The framework for adherence management is described in Table 4.6A below. For this, we have brought together the dimensions that influence adherence together with the principles of a proactive adherence program. This table, or matrix, enables us to understand the interactive (adherence domain´ treatment delivery principle) relationship of the components of the adherence management package logically.

Table 3.6A): Adherence managem

	Individual and family factors	Treatment related factors	Therapeutic relationship factors	Environmental and social factors
Accessible	Community based care including crisis home delivery of medicines Use of telephone for communication between treating team and individual	Ensure uninterrupted availability of prescribed treatments at the facility Community health worker and treating team provide regular, predictable and easy access to appropriate care Treating team is easily contactable (phone, visit) during crisis Reminders and support to attend scheduled appointments for medical reviews	Supportive and sympathetic therapeutic alliance	Address social and practical difficulties of families or individuals in attending treatment facility
Equitable	Community based care which is provided to everyone as clinically needed	Medicines are provided at no charge to those who need it the most. Longer duration of medication supplies to minimize travel and other costs for those who are poor		Identify inequity and risk through adherence and social difficulties checklists Addresses some of the modifiable social factors that contribute to inequity like gender, poverty, stigma and discrimination
Acceptable	Common understanding of the problem and benefits of treatment between individuals and treatment team Information about the medicine, side effects, management of side effects, self monitoring and reinforcement to improve understanding of the management of medicines successfully Family provided with information and	Simple to follow regime- once a day or depot injections Appropriate adherence aids Encouraged to discuss benefits and concerns with medicines during clinical reviews with doctor		Community health worker will assess and address the social needs of the families through networking with existing community agencies Support the individual and family in overcoming discrimination at home and outside through targeted approaches.

	Collaborative relationship for monitoring adherence developed			
Affordable	Community health worker provides most of the individual and family interventions at home	Longer duration of medication supplies at clinical reviews CHW will respond to needs of individuals who cannot attend scheduled clinical reviews by arranging for medicines to be dropped at homeTelephonic clinical reviews by treating team when possible and appropriate to minimize need for travel to facilities		
Effective	Treatments provided have a sound scientific evidence	Treatments structured according to the convenience and needs of individuals and families		Produce improvement in overall quality of life

3.6.8 The components of adherence management packag

3.6.8 A) Creating favorable conditions for adherence:

This involves a combination of methods to create the best possible environment in which adherence can be managed. There are a set of clearly identified methods by which a positive adherence atmosphere can be created, such as systemic efforts to understand the perspective of the individual and their family, providing information about the treatment in a balanced and hopeful manner, actively involving the family and identifying and addressing the main barriers to treatment.

This set of strategies to improve adherence comprises the first part of the adherence management package.

The individual components are described briefly below:

- Understanding the adherence related beliefs and possible systemic/ social barriers of the individual and the family, using a consistent format
- Completing the checklists for identifying risks to adherence and social difficulties that have an impact on accessing care (see Appendix)
- Providing information about medications to improve assessment of benefits and side effects in an informed manner (see section on antipsychotic medications)
- Responding promptly to concerns about side effects of the medicines (see section on antipsychotic medicines)
- Having a strong therapeutic relationship with members of the community team, so that any concerns and problems can be discussed in a supportive manner
- Maximizing family support and encouragement through information sharing and setting up monitoring mechanisms collaboratively
- Reducing the impact of modifiable health system and social barriers through referral to social agencies and by advocating for the needs of the individual in the community team
- Ensure continuity of care and reviews through clinical team processes

3.6.8 B) Specific adherence management procedures:

- *Build medication in to the daily routine of the individual:*
  This involves making a link between taking the medicine and some daily, routine activity that the individual engages in. Examples of this include having the medicines side by side when having meals, brushing teeth, watching TV or after a bath. These are things that we all do routinely without thinking about them and associating the act of taking the medicine with any of them decreases the chances of forgetting. For some individuals with schizophrenia, there may not be a stable routine; in these circumstances, it is better to chart the actual activities undertaken by the individual at home for a week and then discuss the activity with which medicines can be combined.

- *Using incentives and providing positive feedback:*
  People with schizophrenia have difficulty with motivation and self regulation of behaviors as part of their illness, which can come in the way of long term learning. Everybody needs acknowledgement and positive feedback from people we value when we are trying to maintain a new and useful behavior. People with schizophrenia are no exception to this and, in fact, require frequent and consistent feedback and appreciation from family members, you and doctors for continuing to take their medicine. In the initial phases, it might be useful to reward the individual taking his medication with concrete signs of appreciation (cooking his favorite dish or buying something cheap that the individual appreciates) making the direct association of this with the fact that the individual has been taking the prescribed medicines.

- *Using adherence aids:*
  During the project, we will provide individuals who are forgetful about taking the medicine with aids to adherence. This will include pill boxes where the medicines that need to be taken are put in the space(s) for the day, like the morning and evening doses. One advantage of this method is that if there are different medicines to be taken, they are all together in one space. Another advantage is that it is easier to estimate the degree of adherence by simply looking at the pill box.

- *Use of depot injections or syrups:*
  Sometimes, the treating doctor may choose to discuss the option of using injections every 15 days or so for individuals who are high risk of non adherence, for those who have very rapid and severe relapses, or in a situation where other adherence management techniques involving oral medicines have not worked. There are obvious advantages to this method as it means that the need to take the antipsychotic medicine is not a daily source of friction. On the other hand, these injections cause side effects, which mean that other tablets may have to be taken daily to prevent this from happening. The individual may also feel angry about having to take the injection. While the decision to use the injection is made between the doctor and the individual, your role will be to encourage the individual to continue, point out the benefits, and being especially careful about side effect management. Another method of using medicines is through syrups that are like water and can therefore be mixed with food or drinks without the person being aware. Obviously, this is a tricky situation as it violates the central principle of the individual's view being taken into consideration while choosing the medicine. This method will be used in exceptional circumstances by the doctor, when he is convinced that there are very good reasons for breaching this trust in the larger interest of protecting the individual from suffering a serious relapse. Your role in this scenario is to keep the individual engaged without disclosing the use of the syrup, and encourage him to start on the tablets or injection as soon as possible.

- *Keep the schedule of taking medicines simple:*
  One of the most consistent factors that contribute to non adherence is when the schedule of taking the medicines is complicated (multiple doses and tablets). The treating doctor will attempt to make the taking of medicine as simple as possible (like one single night time dose), but this is not always possible. In the event that the individual feels that the schedule is too complicated to remember, encourage him to speak to the doctor about this issue in the clinical review. You could also bring this up for discussion within the team and get some changes made to the schedule with the treating doctor's permission.

- *Home delivery of medicines:*
  This is one of the most difficult decisions to make. While this is obviously useful to ensure that the individual has access to medicines regularly, the problem is that once started, there is every possibility that the family and the individual expect *this to happen* in the long term and become dependent on this practice. Therefore,

we recommend that the decision to supply medicines at home is used selectively after the team discussion, and when no other viable option can be thought of. If started, it is best to negotiate with the family and the individual beforehand that it is a time limited activity to tide over a crisis (accompanying relative too ill to attend, severe financial problems with no money for bus fares to come to the clinic etc) and that it cannot be continued in the long term.

3.6.8 C) Individual interventions:

Improving adherence in people with schizophrenia requires ongoing inputs. The most important individual focused interventions that promote adherence are:

- Positive and strong therapeutic alliance with you and the treating Psychiatrist.
- Enabling relationship where the individual feels free to discuss concerns without feeling rejected
- Continued encouragement and highlighting the gains made in the individual's life and the role of adherence in this improvement.
- Being sensitive to side effects and responding to the concerns of the individual in a timely manner
- Using problem solving and motivational enhancing techniques to discuss and resolve concerns about medicines and need for continuing in spite of feeling better

3.6.8 D) Family based interventions:

The individual's immediate family is your most important partner in helping him initiate and continue medicines and other lifestyle changes. Involving the key caregivers is both natural and necessary if adherence is to be maintained and monitored on an ongoing basis. It is important to understand the family member's viewpoint and attitudes towards medicines, and provide them with adequate information on the benefits and side effects of medicines so that they can make informed decisions. I many scenarios, some members of the extended family (uncles, aunts, cousins, etc) may have a significant role to play in promoting adherence, and contacting them may be a good strategy to enlist support. The important ingredients to improve the family's participation in adherence management are:

- Positive and strong therapeutic alliance with you and the treating Psychiatrist.
- Adequate information sharing to enable the family to understand the importance of adherence in the recovery of their relative.
- Encouragement and positive reinforcement as discussed above.
- Discussing the social concerns that may affect adherence and making collaborative attempts to solve them.
- Enabling the family to improve their skills in dealing amicably with situations where the family members and the individual have different views on adherence.

3.6.8 E) Mobilizing community resources to promote adherence:

Sometimes, it may be possible to use existing community resources effectively in managing non adherence. For example, if the individual or the family has a serious social concern, like poverty, coming in the way of adherence, it may be useful to look at appropriate governmental schemes for assistance. This could include disability benefits and the small loans for setting up businesses available to persons with disability which could be tied to maintaining adherence and staying well. Similarly, it may be possible to get a trusted community member, like the parish priest or village elder, to have a discussion with the individual and reinforce the need for adherence. One of the most effective ways of improving adherence is to have other persons with schizophrenia spend some time with the individual and discuss the benefits of adherence and its importance in getting and staying better so that the overall quality of the person's life can improve.

3.6.9 How should adherence management be delivered in the COPSI intervention:

Adherence management is an essential component of the overall intervention for all individuals; however, the details and content of the package will depend on two factors:

- The point of time when the individual is seen and his or her needs and
- The individual's previous and current adherence behavior.

Table 3.6B : The delivery of the COPSI adherence management component of the CCBC intervention:

Intervention	How delivered	Who delivers	When is it delivered
Information	Oral information during information sharing and through handouts	Treating doctor / CHW	At entry During follow up visits
Adherence aids		CHW	If felt necessary by the treating team
Side effect monitoring	Oral information and handouts. Clear management plans if side effects are noted- who to contact, what is the expected action	Treating doctor / CHW	At entry During follow up visits
Ensuring timely supplies	Ensure individuals have adequate medicines at the time of pick up. Family to inform when medicines are running out before scheduled consultation with doctor. Home delivery in exceptional circumstances	CHW	At every clinical review
Behavioral strategies for improving adherence	Through actual demonstration with families and individuals	CHW	During intensive engagement phase
Collaborative adherence management	Clear plans and roles about monitoring adherence	CHW	At entry and during each follow up visit
Enlisting family support	At entry and during each follow up visit	CHW	At entry and during each follow up visit

3.6.10 Things to do for non adherence:

Intentional non adherence (treatment refusal):

Establish rapport with the individual on issues where there is no disagreement (like having daily routine activities, healthy living, going back to meet the doctor to discuss medication related concerns, etc); schedule weekly visit with mutual consent and clear instructions for the family and the individual to contact in case of new problems. During this time, also complete a baseline assessment of symptoms, current functioning and suicidal risk.

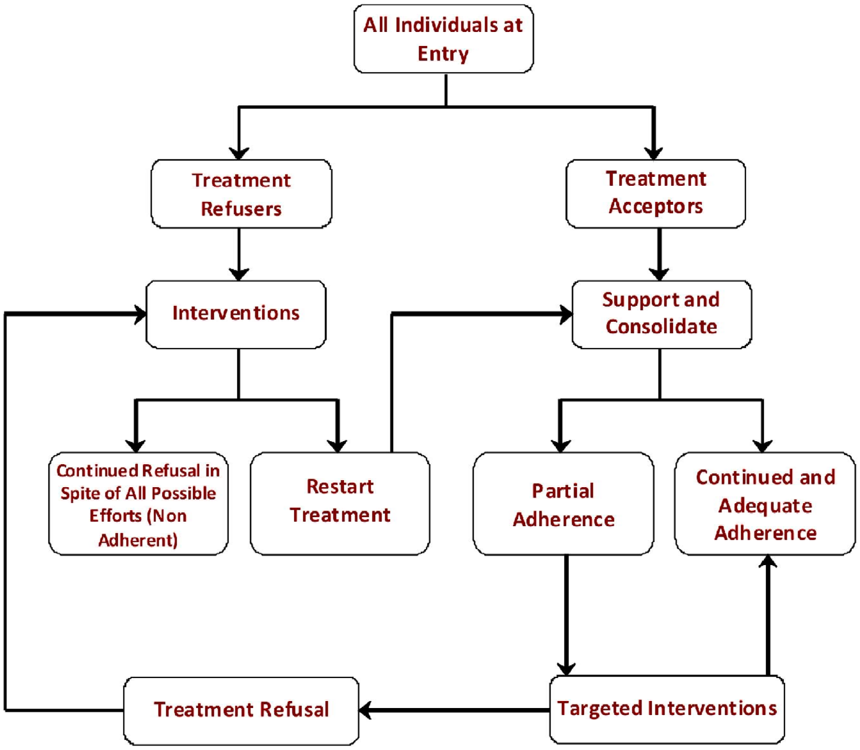
Maintain engagement by reinforcing positive changes made and discuss the nature of illness using the stress-vulnerability model, using the handouts in a neutral manner. Subsequently, discuss reason for not wanting to start on medicines and use motivational analysis and interview to assess readiness for accepting treatment (see section on motivational interviewing skills). Review relapse prevention action plan with family with clear understanding of what needs to be done if symptoms or risk escalates.

Discuss in team meetings the current situation arising from refusal, and agree on treatment plans in consultation with the treating Psychiatrist. Update the family about the outcomes of this discussion, and invite them to meet with the Psychiatrist in your company for discussion regarding the pros and cons of treatment. If at any time during this process there is clear indication of a crisis situation where the individual's safety is compromised, discuss with family and treatment team about the response to be activated (immediate consultation at hospital, involuntary treatment through the Police and a Magistrate, etc).

Unintentional non adherence (those who miss treatment):

For those who miss treatment, it is less complicated to resolve the problems that have led to non adherence. Usually, these are related to social and systemic problems like having missed an appointment for a clinical review, not having the money to come to the hospital or having forgotten the medicine while attending family functions like weddings. Any non adherence needs to be responded to immediately, and the individual and family are often the best agency to help in these circumstances. If there are obvious solutions to the problem that has caused the non adherence, both family members and the individual resolve them and get back to the medicine routine. If there are problems that cannot be sorted out by the family, you need to have a joint meeting and use problem solving techniques to identify, evaluate and agree on a plan to overcome the problem.

3.6.11 The COPSI adherence management flowchart:



Summary

- Many people with schizophrenia do not take their medicines as prescribed; this usually leads to negative events like a relapse of symptoms
- There are a number of reasons why people with schizophrenia do not take their prescribed medicines
- Managing adherence is an essential part of the COPSI intervention and is carried out throughout the duration of the intervention in many ways within a defined framework
- There are many specific strategies that are useful in promoting adherence being used in COPSI
- There are specific methods for managing non adherence in the COPSI intervention

CHAPTER 3.7

Health promotion in people with schizophrenia

3.7 A Improving physical health in people with schizophrenia

3.7 A.1 Introduction

As we have discussed before, people suffering from schizophrenia are at greater risk of physical illness and premature death when compared to the general population. Sixty percent of these premature deaths are caused by schizophrenia-related physical illness. There are many reasons for the poor physical health of people with schizophrenia. Unhealthy lifestyle choices such as poor diet, tobacco smoking and substance abuse are common among this group. These, in turn, produce increased rates of heart disease, diabetes and obesity. Antipsychotic drug-induced weight gain and other medication side effects also contribute to physical health problems. It is also important to note that social and economic consequences experienced by people with schizophrenia, such as family instability, unemployment, poverty and lack of quality healthcare contribute to the excess physical health problems in this group of people. Physical health problems and their possible solutions, therefore, need to be understood within the framework of biological and psychosocial factors.

3.7 A. 2 What are the common physical health problems of people with schizophrenia?

Health promotion through education and behavioral modifications of healthy lifestyle behaviors are essential elements of community care interventions. In this chapter, we address the most important physical health problems seen in people with schizophrenia and explain why these physical ailments occur. We suggest recommendations to minimize these health risks and to improve their overall physical health.

Weight Gain and Obesity

Weight gain and obesity are due to excessive and unhealthy stores of fat that accumulate in the body posing potential and serious health risks to an individual. People with schizophrenia have been noted to have high rates of obesity. Poor diet, limited physical exercise, tobacco smoking, substance abuse and the use of particular types of medicines are common reasons for this problem.

The most reliable way to screen for and measure body fat is defined by the Body Mass Index. This simple calculation which you can complete easily is to divide a person's weight by their height. Thus, BMI = weight (kg) / [height (cm/ 100)]^2. (Since height is commonly measured in centimeters, divide height in centimeters by 100 to get height in meters.) For adults 20 years of age or older, a BMI between 18.5 and 22.9 is considered to be healthy while a value of 23-29 indicates that a person is overweight. A BMI value below 18.5 is considered to be underweight. Obesity is the most serious form of excess weight and is defined by a BMI score of 30 or greater.

Normal weight BMI values among Asians differ from those of Western countries due having moderately more body fat and less muscle proportion.

Because of this, the World Health Organization has adjusted the normal weight BMI value for Asian populations and suggests that BMI values should be less than 23.

The following example calculates the BMI of a healthy adult person:

Weight = 61kg
Height = 1.65m (or 165cm/100 = 1.65m)

BMI = 64/ $(1.65)^2$ = 22.4

It is also important to monitor the waist circumference in addition to calculating BMI values. Just because a BMI value is considered in the "normal" range doesn't mean an individual is free from obesity-related disease risk. In fact, BMI calculations do not take into account fat accumulated around the waist (a strong predictor of obesity and many other health risks). Waist circumference measures should not exceed 80 cm for females or 90 cm for males.

We now have consistent scientific data that antipsychotic drugs contribute to weight gain, with some medicines being more likely to increase weight than others. The reasons for this are not quite clear. However, it is believed that the interaction between medications and neurotransmitter receptors alters eating behaviors by increasing appetite and reducing feelings of being full (satiety).

The table 3.7A.1: The association of weight gain with particular medicines:

Marked weight gain	***Moderate weight gain***	***Slight weight gain***	***No weight change***
Clozapine Olanzapine Quetiapine Chlorpromazine Trifluoperazine	Risperidone	Amisulpride Haloperidol Fluphenazine Flupenthixol	Ziprasidone **Aripiprazole - no data available*

The health consequences of weight gain, commonly due to a combination of factors, are very serious. The most important thing for you to remember is that this leads to a much higher risk of developing heart disease, high blood pressure (hypertension), diabetes and stroke. For example, due to the high rates of obesity, hypertension, tobacco smoking and diabetes, people with schizophrenia are 12 times more likely of getting heart disease than those of the general population.

Most of the information about weight gain in people with schizophrenia has been collected in Western countries, and it is not clear how this affects people with schizophrenia in other societies. Irrespective of the extent of the problem, this is a common and serious health problem that you need to be aware of.

Cardiovascular Disease

Cardiovascular disease (CVD) is a broad term used to describe diseases that affect the heart and the blood vessels (arteries and veins) of the body. CVD includes coronary heart disease (CHD), cerebrovascular disease (e.g., stroke), and hypertension (high blood pressure). CHD is a disease where there is a blockage (i.e. a build-up of fatty material) in the blood vessels that transport blood and oxygen to the heart. If the blood is unable to reach the heart, the result is a heart attack or a stroke.

Scientific evidence highlights a strong positive association between CVD and people diagnosed with schizophrenia. Several risk factors for CVD such as obesity (high fat/low fiber diet), limited physical exercise and tobacco smoking are common lifestyle behaviors among this population which significantly increase their overall health risk. Not only do people with schizophrenia have higher rates of CVD, they also have limited access to quality screening and treatment.

Summary

- CHD is the leading cause of mortality among this population.
- Compared to 10% of deaths by suicide, CHD accounts for 70% of deaths in individuals with schizophrenia.
- People in India are more likely to develop heart diseases than in Western countries due to their physical makeup; the increased risk is superimposed on top of the already higher risk in the general population.

Diabetes

Diabetes refers to a common disease caused by an excess of blood sugar levels. Some people develop the disease early in their life (Type I) but by far the commonest form is type II diabetes that usually effects older and overweight populations. Diabetes affects the way your body makes or uses insulin. Insulin is required to transport glucose (e.g. blood sugar) into cells, where it is used for energy. If glucose cannot get to the cells, the body cannot use it for fuel.

Type II diabetes rates are double among people with schizophrenia when compared to the general population, and contribute to their increased morbidity and mortality rates. Obesity (poor diet and sedentary lifestyle) is the primary risk factor for type II diabetes. However, antipsychotic medications, due to their induced weight gain, have been shown to increase the risk of developing this disease. Diabetes has very serious consequences like kidney failure, CVD, blindness, lack of blood supply to the limbs leading to infections and gangrene, sexual problems, and the lack of sensation in various parts of the body which increases the chance of accidental injury. Overall, diabetes reduces quality and length of life.

Summary

- People in India are more likely to develop diabetes than in Western countries due to their physical makeup; the increased risk is superimposed on top of the already higher risk in the general population.
- Due to early onset among people with schizophrenia (< 45 years old), diabetes increases the risk of chronic physical illness.

Smoking

Tobacco smoking is one of the leading causes of preventable deaths and chronic diseases, such as cardiovascular disease and cancer. People with schizophrenia have a higher prevalence of tobacco smoking compared to those of the general population and even to those suffering from other psychiatric illnesses. There are varied hypotheses as to why smoking rates are so high among this population. One suggestion is that people with schizophrenia use smoking as a mean of “self-medication”. The nicotine is said to increase levels of certain brain chemicals like dopamine, which reduce the impact of positive and negative symptoms of schizophrenia. Nicotine has also been shown to improve mental functions like attention and concentration and help individuals with schizophrenia to “relax” and calm down.

Conversely, however, the tar in cigarettes cause a faster than normal metabolism of the antipsychotic medicines. This means that a person with schizophrenia who smokes will break down the same amount of medicine much faster than someone who does not smoke, and may therefore require higher doses of medication. The increased dosage increases the chances of experiencing more severe medication side effects, such as tremors, when compared to non-smokers with schizophrenia.

Summary

- People with schizophrenia typically begin smoking earlier in life, are less likely to quit, and have a higher chance of death due to tobacco-related disease than the general population.
- Genetic and environmental factors also strongly link nicotine dependence and schizophrenia.

Substance Abuse

According to the Diagnostic and Statistics Manual for Mental Disorders (DSM-IV), substance abuse is defined as the persistence of alcohol and/or drug use despite problems (absence from work, family conflict, legal consequences, etc.) related to the use of the substance. Between 40-50% of people with schizophrenia struggle, or have struggled at some point in their lives, with a substance abuse disorder. Among the many problems that coexist with schizophrenia, substance abuse is by far the most common. Alcohol and drug abuse in people suffering from schizophrenia have serious social, legal and physical consequences which include suicide, violence, depression, homelessness and incarceration.

The cause of the high rates of substance abuse in this population is still unclear. However, there are several explanations like, for instance, self-medication relieves anxiety and increases motivation, energy and social interaction. Also, the use of alcohol and drugs helps to cope with the symptoms of schizophrenia including both positive and negative symptoms, depression and the side effects of antipsychotic medications.

Summary

- Alcohol is the most commonly abused substance, followed by marijuana, among people with schizophrenia.
- 47% of people with schizophrenia report a lifetime prevalence of a substance abuse disorder.
- Young males have the highest prevalence of substance abuse disorder in this population.
- Genetic susceptibility may also be a cause for substance abuse disorder.

Reproductive Health Complications

Another very important, but often neglected health concern in people with schizophrenia regards their reproductive and sexual health. The main reason for this is the use of antipsychotic medicines which increase the level of prolactin, a hormone called that regulates many reproductive functions.

Several physical health problems, such as sexual problems, irregularities in the menstrual period (commonly reduced and irregular flow), infertility and bone mineral loss are associated with increased prolactin levels, in both men and women.

Sexual dysfunction is very common among people with schizophrenia, but it is more prevalent when antipsychotic medicines are being used. Antipsychotic-induced high prolactin levels is considered one of many explanations causing sexual dysfunction. Symptoms of sexual dysfunction include decreased libido, impotence and inability to achieve arousal.

Menstrual abnormalities are also widespread among women taking antipsychotic medications. Both amenorrhea (the absence of menstrual periods) and oligomenorrhea (infrequent menstrual periods) can occur in women on antipsychotics regardless of the presence of high prolactin levels.

Antipsychotic medicines can be classified in two categories, depending on how they affect prolactin levels: “prolactin-raising” or “prolactin sparing/neutral”.

Table 3.7A.2: Risk of developing raised prolactin with antipsychotics:

Frequently causes side effects	*Sometimes causes side effects*	*Mild/occasional side effects*	*No side effects*
Haloperidol Risperidone	Thioridazine	Ziprasidone	Clozapine Quetiapin Olanzapine Aripiprazole

Osteoporosis

A reduction in bone mineral density (BMD), or osteoporosis, causes bones to become frail, weak and prone to fracture. Because bones become more brittle in the presence of osteoporosis, fractures can occur during simple, everyday movements without a traumatic event or fall. The pain and discomfort from fractures may prevent an individual from leading an active life.

Osteoporosis is highly prevalent among individuals suffering from schizophrenia for a wide range of reasons: prolactin-raising antipsychotic medications, excessive smoking, nutrient-deficient diet and limited exercise.

Table 3.7 A. 3: Risk factors for developing osteoporosis

Factors due to schizophrenic illness	Factors due to antipsychotic medications	Other factors that influence risk of bone fracture
Nutrient deficiencies (lack of calcium, vitamin D) Poor diet Limited weight-lifting exercises Smoking (direct harmful effect on cells that form the bone)	High prolactin level Lower estrogen levels	Sedation Dizziness and falls Post-menopausal period

Summary

- The enlargement of the male breast tissue due to hormone changes and the abnormal secretion of milk from the breasts occurring in both genders are both potential health and socially embarrassing concerns of antipsychotic drug therapy.

- Sexual dysfunction is ranked one of the highest discomforting side effects of antipsychotic use by people with schizophrenia and creates a challenging obstacle to maintain medication adherence.

3.7 A. 3 Recommendations for improved physical health and well being

As mentioned before, people with schizophrenia have morbidity (ongoing health problems that compromise a person's life) and mortality rates much higher than the expected for the general population. A combination of lifestyle and social factors, effects of antipsychotic treatment and the illness itself are responsible for the high rates of poor physical health. Given the high rate of preventable premature deaths, it is important that health promotional programs, that provide care via lifestyle and risk factor modification, are available and accessible to this population.

Sustaining Medication Adherence

Medication adherence is extremely important for people with schizophrenia. However, adherence is a serious challenge in treating people with schizophrenia given the cognitive difficulties, lack of insight and poor motivation among this group. Adherence management not only leads to improved symptom control, but it also adds insight to the individual to continue following the medication schedule. Several feasible and acceptable strategies are suggested to retain adherence and avoid relapse. Medication calendars or pill boxes, behavioral tailoring (couple mealtime with taking medication) and long-acting antipsychotic injectibles (as available) are mechanisms which have proven to be successful among this population.

Implementing a Healthy Diet

As we have mentioned in the section on diet, a diet rich in fruits and vegetables, whole grains, high fiber and low fat foods, and essential vitamins and minerals is important in managing weight and improving overall health. A few recommendations to improve diet and treat and prevent weight gain are listed below. However, please refer to the “Dietary Recommendations” section of this manual.

The following recommendations help to prevent weight gain and maintain a healthy weight:

- Regular assessment of BMI, waist circumference, blood pressure, blood sugar and fat levels.
- Dietary education.
- Diet consisting of low fat, high fiber foods, fruit and vegetables, and proper vitamin and nutrient intake.
- Sustained counseling promoting healthy food choices, appropriate portion sizes and exercise regimens.
- Switch antipsychotic medication to one with less tendency to cause for weight gain.
- Medicines to reduce fat (this is something that the doctor will prescribe, when needed).
- Food sampling, cooking classes, temporary distribution of healthy foods (fruits, vegetables, whole grains, etc.).

The individual should also be encouraged to maintain a healthy weight by regular weight monitoring (home scale), food intake (portion sizes) and diet choices (fruits, vegetables, whole grains).

Increasing physical activity

It is evident from various research studies that there is a strong correlation between an active lifestyle and good physical health. Although only a few studies have investigated the association of physical exercise and the overall health of people with schizophrenia, they have a found that physical activity reduces depression and anxiety, the positive and negative symptoms of schizophrenia and BMI. It has been reported that group-facilitated, facility-based exercise programs increase social functioning and participation. Walking has been noted as the primary form of exercise but yoga has also provided similar benefits.

Weight loss interventions have been proven successful recently when coupled with smoking cessation programs. It is assumed that those people who are willing to modify smoking behaviors will be also open to adopting an exercise routine.

With that, physical exercise outreach programs should be combined with individual’s treatment as usual, and should include physical activities such as walking groups, yoga classes, and/or simple exercises performed in groups.

Stopping tobacco use

As mentioned above, tobacco smoking is far more prevalent among people with schizophrenia compared to those of the general population. It is important to continue to convey the dangers of tobacco abuse and help people with schizophrenia to stop smoking. Methods of tobacco cessation will be suggested under the supervision of the treating doctor. However, mechanisms such as nicotine replacement therapy (gum, patch, inhaler, etc.) and pharmacotherapy have been proven effective despite the low first-time and long-term quit rates in people with schizophrenia.

Motivation counseling and support groups have also been successful in reducing tobacco smoking rates among this population. Based in this empirical evidence we will implement similar treatment methods in our community intervention.

Controlling Substance Abuse

It is challenging to provide appropriate treatment services for those individuals with dual-diagnosis: people suffering from schizophrenia and a substance abuse disorder. Typically, treatments catered primarily for substance abuse disorders are too severe and intense because of the emotional fragility of this population. Often, individuals with schizophrenia are frequently shifted between two different treatment programs (often referred to “ping pong” treatment”): one for mental illness and the other for addiction. The unsuitability of these two types of treatments could potentially exacerbate the individual’s symptoms and trigger a psychotic episode and/or relapse. It is important that we develop “hybrid” treatment programs that cater to both illnesses. Community-based intervention programs should include substance abuse treatment as part of the individual’s standard of care treatment. Such mechanisms of treatment include sustained individual therapy and addiction support groups, both of which should be flexible in the treatment criteria (i.e. allow multiple quit attempts, etc.).

Managing High Prolactin Level-related Concerns
As noted above, there is a range of reproductive and sexual problems related to the increased levels of prolactin caused by medicines. This leads to a range of health problems, sexual problems and can be a source of social embarrassment. This means that the benefits of the medicines need to be balanced with the risk of causing an increase in prolactin levels and the consequent health problems. This is primarily done by the treating doctor. Your role is to be aware of such problems, ask for them and bring them to the notice of the doctor, who can then suggest ways to manage them.

Table 3.7A.4: Summary points:

Main health problem	Reasons for the health problem	Recommended actions	Challenges to making the changes	Solutions
Weight Gain/ obesity	-High fat/high carbohydrate diet -Low rates of exercise -Antipsychotic medication -induced weight gain -Lack of proper diet education -Poor exercise knowledge -Nutrient-deficient diet	-Introduce healthy diet high in fruits, vegetables, whole grains, healthy fats and protein -Increase essential vitamin and mineral intake -Increase physical exercise -Reduce smoking/ substance abuse rates	-Poor motivation -Lack of insight -Cognitive difficulties -Inadequate availability of physical health programs/ education -Economic constraints -Social exclusion and stigma -Lack of family support	Community Care Intervention which includes:- Structured physical exercise -Psychoeducation -Family -integrated treatment -Psychotherapy -Diet/nutrient education -Medication adherence -Support groups
Cardiovascular disease	-High fat diet -Increased smoking rates -No or limited exercise -Poor access to quality screening and health care	-Reduce unhealthy fats in diet -Increase whole grains, fruits and vegetables in diet -Increase physical activity -Decrease tobacco smoking rates -Improve access to and quality of screening and health care		
Type II diabetes	-Obesity/weight gain -Low protein/low fiber intake -High fat/high lipid profile -Sedentary lifestyle -High blood sugar (high sugar intake) -Hypertension -Stress	-Introduce healthy diet (decrease high fat/high sugar intake) -Increase physical activity		

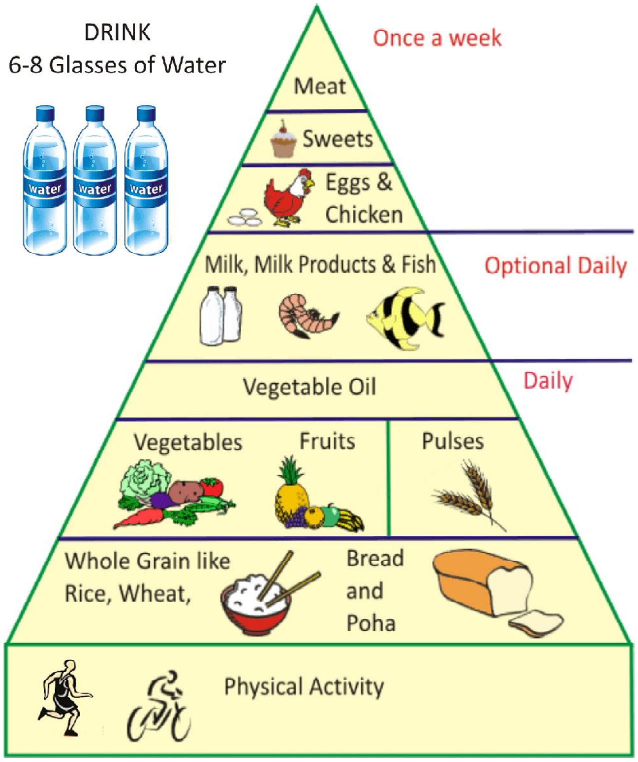
Smoking	-Additive nature of nicotine -Self-medication -Reduction of positive & negative symptoms -Relaxing/calming effect -Improved concentration	-Introduce nicotine replacement therapy -Motivational interviewing/ individual counseling -Support groups -Pharmacotherapy	-Highly additive agent -Lack of insight -Poor motivation -Persistent schizophrenia-related symptoms -Lack of knowledge of tobacco-related illness -Feelings of helplessness and hopelessness -Limited availability of treatment programs -Low quit rates	Community Care Intervention which includes: -Nicotine replacement therapy -Addiction support groups -Psychotherapy -Psychoeducation -Pharmacotherapy
Substance Abuse	-Additive nature of alcohol -Self-medication -Reduction of positive & negative symptoms -Relaxing/calming effect -Increased social interaction -Coping mechanism for depression and other symptoms	- Psychotherapy -Support groups - Pharmacotherapy	-Highly additive agent -Lack of insight -Poor motivation -Persistent schizophrenia-related symptoms -Lack of knowledge of alcohol-related illness -Feelings of helplessness and hopelessness -Poor availability of treatment programs	
Hyperprolactinaemia leading to: *Sexual dysfunction* *Menstrual irregularities* *Infertility*	-Antipsychotic-induced prolactin production	-Switch to different (prolactin-sparing) antipsychotic	-Risk of relapse -Risk of medication non-adherence (if drug being switched from was depot) -Potential ineffectiveness of new drug	-Assess risk-benefit ratio of switching from prolactin-raising to prolactin-sparing antipsychotic
Osteoporosis	-Sedentary lifestyle-High rates of smoking-Prolactin-raising antipsychotics-Nutrient deficient diet	-Increase calcium and vitamin D intake -Introduce weight-bearing exercises -Reduce tobacco smoking -Switch to prolactin-sparing antipsychotic	Poor motivation Low smoking quit rates	-Provide education on weight-lifting exercises -Provide information about foods and sources of vitamin D and calcium -Explain potential side effects of prolactin-raising antipsychotics

Chapter 3.7 B Dietary Recommendations for people with Schizophrenia

3.7 B.1 Introduction to section

People with schizophrenia are more likely to experience several physical health problems compared to the general population; in particular, individuals are at an increased risk of developing heart diseases, high blood pressure and diabetes and are prone to excessive weight gain *(See section on physical health).* For chronic diseases like schizophrenia (and the physical health conditions that occur along with it), there is substantial scientific evidence to support the inclusion of diet and other lifestyle factors in overall treatment. Diet recommendations are an important component of the health promotion package. In this chapter, we will cover the following: what a healthy diet is, why a healthy diet is important for schizophrenia, what the ingredients and proportions of a healthy diet are and what dietary changes need to be implemented and continued for long term benefits.

3.7 B.2 What is a healthy diet?



The figure above shows the constituents of a healthy diet; food categories to be consumed at larger quantities are towards the bottom of the pyramid, and taper off as one moves up the pyramid. This means that carbohydrates (such as whole grains, rice, bread etc) need to be consumed in the largest quantity. These are responsible for providing energy, and are responsible for growth and development of the body. Closely following are vegetables (such as green vegetables, orange vegetables, beans etc), fruits, and nuts, which contain protein, vitamins and minerals that are particularly responsible for metabolic functions. Vegetable, fish, or cooking oils come next, and should be consumed every day. Milk, eggs, fish and milk products, rich in protein should be consumed in smaller quantities when compared to the others, and eggs and chicken less so. It is sufficient if sweets and meat, food rich in fat, are consumed once or twice a week. Adequate water (around 6-8 glasses) intake and making an effort to exercise daily are essential for maintaining a good health.

3.7 B.3 What is the relationship between diet and schizophrenia?

People with schizophrenia often have certain health, metabolic and lifestyle problems that are caused by and affect their food intake. In general, people with schizophrenia tend to eat poorly and inappropriately, consume high amounts of unhealthy food (like fried snacks) and low amounts of healthy foods like fibers and fruits, Caffeine intake through tea, coffee and cold drinks is also high and people with schizophrenia tend to smoke more than the general population.

The physical health of people with schizophrenia is often affected due to a combination of factors like a poor diet, smoking and use of antipsychotic medication. This predisposes them to have serious physical health problems such as cardiovascular diseases, obesity or high blood pressure *(see physical health section);* conditions that often lead to early mortality in this population.

3.7 B.4 What are the common dietary problems seen in schizophrenia?

People with schizophrenia have nutrient deficiencies and low levels of fatty acids. The nature and impact of these problems are described in the sections below.

3.7 B.4 i) Nutrient deficiency:

What are nutrients? Nutrients (vitamins and minerals) are essential for the growth and development of the body, and for the healthy maintenance of the cells, tissues, and organs. They help utilizing the energy provided by food, and processing other food components such as proteins, carbohydrates, and fats.

Table 4.8B.1 shows the main vitamins, their functions, and their sources.

Type	Benefits	Sources
Vitamin A	Prevents eye problems, promotes a healthy immune system, helps the growth and development of cells, and keeps skin healthy.	Milk, eggs, green vegetables (such as carrots, sweet potatoes, pumpkin, and kale), and orange fruits such as apricots, peaches, papayas, and mangos.
Vitamin C	Forms collagen, a tissue that helps to hold cells together. It is essential for healthy bones, teeth, gums, and blood vessels. It helps the body absorb iron and calcium, aids in wound healing, and contributes to brain function.	Red and green capsicum, tomatoes, spinach, and juices made from guava, grapefruit, and orange.
Vitamin D	Strengthens bones	Egg yolks, fish oils, and milk
Vitamin E	Helps protect cells from damage and builds red blood cells.	Vegetable oils, nuts, and green leafy vegetables, wheat germ, and whole grains
Vitamin B12	Helps to make red blood cells, and is important for nerve cell function.	Fish, red meat such as poultry, milk, cheese, eggs, breakfast cereals.
Vitamin B6	Is important for normal brain and nerve function. It also helps the body break down proteins and make red blood cells.	Potatoes, bananas, beans, seeds, nuts, red meat, poultry, fish, eggs, spinach, and cereals.
Thiamin (also called Vitamin B1	Helps the body convert carbohydrates into energy and is necessary for the heart, muscles, and nervous system to function properly.	Fortified breads, cereals, and pasta; meat and fish; dried beans, soy foods, and peas; and whole grains like wheat germ.
Niacin (also called Vitamin B3	Helps the body turn food into energy. It helps maintain healthy skin and is important for nerve function.	Red meat, poultry, fish, hot and cold cereals, and peanuts.
Riboflavin (also called Vitamin B2	Is essential for turning carbohydrates into energy and producing red blood cells. It is also important for vision.	Meat, eggs, legumes (like peas and lentils), nuts, dairy products, green leafy vegetables and cereals.
Folate (also known as vitamin B9, folic acid, or folacin)	Helps the body make red blood cells. It is also needed to make DNA.	Dried beans and other legumes, green leafy vegetables, oranges and other citrus fruits, and poultry, bread, noodles, and cereals.

Table 3.8 B.2: The main minerals, their functions, and their sources

Type	Benefits	Sources
Calcium	Builds strong bones and teeth	Milk and dairy products such as yogurt, cheese, and cottage cheese, and dark green leafy vegetables, orange juice and soy milk
Iron	Helps red blood cells carry oxygen	Shellfish, poultry, lentils, beans and soy foods, green leafy vegetables, and raisins. Some flours, cereals, and grain products are also fortified with iron.
Magnesium	Helps muscles and nerves function, steadies the heart rhythm, and keeps bones strong. It also helps the body create energy and make proteins.	Whole grains and whole-grain breads, nuts and seeds, green leafy vegetables, potatoes, beans, bananas, prawns, and chocolate
Phosphorus	Helps form healthy bones and teeth. It also helps the body make energy.	Phosphorus is found in most foods, but the best sources are dairy foods, meat, and fish.
Potassium	Helps with muscle and nervous system function, and maintains the balance of water in the blood and body tissues.	Potassium is found in potatoes (with skins), green leafy vegetables, citrus fruits, bananas, dried fruits, and legumes such as peas.
Zinc	Is important for normal growth, sexual development, strong immunity, and wound healing.	Poultry, oysters and other seafood, nuts, dried beans, soy foods, milk and other dairy products, whole grains, and cereals.

What is malnutrition? Malnutrition is a physical condition that occurs when a person is not getting enough nutrients, or is not eating enough food. The condition may result from an inadequate or unbalanced diet, digestive or absorption difficulties (such as high rates of metabolism that reduce nutrient levels), or other medical conditions.

How does nutrient deficiency affect schizophrenia? Nutrient deficiencies and subsequent malnourishment are risks for developing schizophrenia. Lack of fibers and vitamins content, especially vitamin C, is associated with hallucinations and poor social functioning. Insufficient quantities of folic acid and vitamin B12 also have similar effects, and in addition to these, also result in mood disturbances Vitamin B6 deficiency is associated with arthritis, skin problems, indigestion, irritability, amnesia and mood disturbances.

Nutrient deficiencies can also result *from* schizophrenia. Lifestyle factors such as smoking, alcohol consumption, or the use of anti-psychotic medications often interfere with the absorption of vitamins. People with schizophrenia are also likely to be under nourished due to their tendency towards apathy and withdrawal; they tend to neglect personal hygiene, diet and daily routine and self care. Some individuals are also neglected by their caregivers.

How can nutrients be increased in diet? People can consume foods like fresh fruits and vegetables, whole grains, dairy products, low fat meat and fish to increase their intake of nutrients. Food such as vegetable pizzas, pastas or sandwiches and baked potatoes are nutritious choices too.

What if the person is vegetarian? If a person is vegetarian, he/she need to make sure they get the vitamins and minerals that are usually found only in meats (such as zinc and iron). Taking dried beans, seeds, nuts, and leafy green vegetables may be useful. In order to get Vitamin B12 (not found in plant foods) it is best to take eggs, milk and breakfast cereals. Vegans (vegetarians who do not consume any dairy or animal product) may need to take vitamin supplements, and may need to consult their nutritionist or doctor about what supplements are best for them.

3.7 B.4 ii) Low levels of fatty acids:

What are fatty acids? Fatty acids are chemicals derived from food that are used to regulate a wide range of bodily functions, including blood pressure, blood clotting, and immunity. They are used as fuel for the functioning of organs and muscles of the body, cellular growth and repair, and energy supply.

What are the functions of fatty acids? Fatty acids can be monounsaturated, polyunsaturated, or saturated. Monounsaturated and polyunsaturated fats are believed to be "healthy" fats that provide energy without raising cholesterol levels. However, saturated fats have proven to raise cholesterol levels and have been linked to increased rates of heart disease, stroke and death. Essential fatty acids (EFAs) are one type of polyunsaturated fatty acids that regulate healthy fat levels, blood clotting and blood pressure, and help to control inflammation in the event of injury or infection.

What are the sources of fatty acids? Monounsaturated fats are found in natural foods such as nuts and avocados, and are the main components of tea, seed oil and olive oil (oleic acid). Canola oil contains 57%–60% of monounsaturated fat, olive oil, about 75%, and tea seed oil over 80%. Other sources include ground nut oil, peanut oil, flaxseed oil, sesame oil, corn oil, whole grain wheat, cereal, oatmeal, and sunflower oil.

Fatty acids and schizophrenia: Imbalances in fatty acids (EFA's in particular) are risk factors for the development of symptoms of schizophrenia, especially negative symptoms such as catatonia and apathy. They are also related to the severity of the illness and to antisocial behavior. This is because people with schizophrenia have enzymes that break down fatty acids at a very fast rate, as a result of which the levels of fatty acids are low. Low levels are also the result of hormonal imbalances, changes in cell membrane structures and nutrient deficiencies.

3.7 B.5 Is there a need for diet change?

As seen from above, several factors related to diet (food intake, nutrient deficiencies, lifestyle etc) are both potential risk factors for the development of schizophrenia, and outcomes of the disease. These factors have an impact on the individual's physical health and play an important role in influencing symptoms. This argues for a comprehensive treatment strategy that provides advice about diet, physical activity, and regulates use of external risk factors like smoking and drinking alcohol.

Research studies show that diet changes have resulted in, or have the potential to result in, positive effects in this population. Countries with low fat in diet and unsaturated fatty acids are likely to show better outcomes in schizophrenia. There is evidence that avoiding refined sugars and carbohydrates and using more vitamins can prevent physical illness conditions such as diabetes and heart diseases and also improve symptoms. Intake of vitamins (especially vitamin C, A B12, B3 and E) helps in reducing adrenalin levels and in decreasing frequency of anxiety and hallucinations. Studies have also shown that increased intake of Omega6, Omega3, and Eicosapentaenoic acid (EPA) (types of fatty acids) leads to reduced schizophrenic symptoms and prevents cardiovascular problems. Some studies even show that a gluten withdrawal from daily diet can reduce symptoms and lead to discharges from hospitals.

In this section, we concentrate on the dietary advice that we will be providing individuals and their families and discuss ways in which these can be initiated and continued.

3.7 B.6 What are the diet recommendations?

Do's

Eat	*Such as*	*Dose*	*How often*	*Why*
Fish	*Mackerel, sardines, fresh tuna, salmon or trout*	*800-1000mg*	*Three times a week*	*Contains fatty acids, niacin, zinc*
Fruits	*Oranges, lemon*	*1000mg*	*Everyday, twice a day*	*Contains vitamin C & B*
Vegetables	*Leafy green vegetables, beans, lentils*	*300-400mg*	*Everyday, once a day*	*Contains vitamin all B, vitamin E*
Nuts and seeds	*Flax seeds, pumpkin seeds, rapeseed, canola, peanuts*	*250-500 mg*	*Three or four times a week*	*Contains fatty acids, zinc, vitamin , niacin*
Fish oil	*Primose oil, starflower oil, menhadden oil and linseed oil*	*1000mg*	*Everyday, once a day*	*Contains fatty acids and vitamins*

DONTS:

Have less	*Why?*
Cigarettes, alcohol, caffeine	*Are stimulants that lower vitamin C levels and prevent digestion and absorption of nutrients*
Chocolate, sugar	*Are rich in saturated fat, and increase risks of heart problems*
Sweet potato, rice, white flour and white pasta	*Contains carbohydrates, difficult to digest*
Meat and eggs	*Rich in protein; difficult to digest*

Chapter 3.7 C Stress management in schizophrenia

3.7 C. 1 Introduction:

The stress-vulnerability model of schizophrenia (Chapter 1) suggests that stress is one of the factors which determine the severity and course of the illness. Learning to manage stress is critical for promoting the recovery and well-being of the individual. Stress management techniques can lessen the severity of schizophrenia, reduce overall anxiety and delay relapse. Hence, stress management is an important component in the care package for people with schizophrenia.

3.7 C. 2: Identify the sources of Stress:

People differ markedly with regard to what they find stressful. Also, stress can have a wide range of effects on people, including changes in the body, mood, thinking and behavior. Stressors are divided into two broad categories: Life events and Ongoing stressors. It is important to identify what it stressful in the person's life in order to cope effectively.

3.7 C. 3: Life Events:

Although each person is unique in how he/she perceives stress, there are certain types of experiences that most people find stressful. These are called life events (e.g. starting a new job, moving house, experiencing a death in the family). Even life events that are a source of happiness could be stressful (e.g. having a baby, getting married, etc). **Recognizing that a life event is likely to be stressful can prepare the person with schizophrenia to find ways to best deal with such a situation and cope more effectively.**

3.7 C. 4: Ongoing Stressors:

In addition to stressful life events, most people are faced with ongoing stressors ('hassles') like financial difficulties, conflicts with family members, poor living conditions and medical problems. **Understanding how the person with schizophrenia responds to stress will help him/her to recognize when he/she is under stress and to take action to reduce its effects.**

Summary

- Stress management techniques can lessen the severity of schizophrenia, reduce overall anxiety and delay relapse.
- To cope effectively with stress it is important to first identify and recognize what is stressful in the person's life, and then find ways of coping with the stressor/s.

3.7 C. 5 Managing stress:

Many people react to stress in ways that make it worse (yelling, blaming others, withdrawing). However, there are more effective options which either eliminate the stressor or minimize its negative effects, or both. Some of these techniques are described below:

3.7 C. 6: Reducing the sources of stress:

These techniques try to reduce the stress by addressing the cause of the problem.

3.7 C. 6 A: Avoid or modify situations that have caused stress in the past:

If a situation was stressful before, it is likely to cause problems for the person when he/she encounters the situation again. These situations can be avoided if possible (e.g. a person finds it difficult to attend a wedding, he/she can avoid going to the ceremony) or modify the situation (meet the bride and groom at another convenient time).

3.7 C. 6 B: Set reasonable expectations:

Setting realistic goals can reduce stress. People with schizophrenia tend to benefit from moderate, but not excessive structure .Stress is also minimized if the person can find the right balance of stimulation and have realistic expectations.

3.7 C. 6 C: Schedule meaningful activities:

Having activities that a person enjoys makes a significant difference in reducing stress. For some people, their work is meaningful and enjoyable. Other people look to volunteering, hobbies, music, sports or art for meaning and enjoyment. It all depends on what the individual finds most meaningful.

3.7 C. 6 D: Maintain a healthy lifestyle:

Eating right, avoiding alcohol or drug use and getting enough sleep can help buffer the effects of stress to an extent. Scheduling regular exercises improves the general sense of well-being.

3.7 C. 6 E: Schedule regular leisure activities:

Planning leisure activities (those that a person finds relaxing and enjoyable) on a regular basis prevents stress from “accumulating”. It also gives the person something to look forward to. Sometimes, the negative symptoms of schizophrenia make it difficult for the person to think of pleasurable activities. It is important for the person’s family support member, peer or health counselor to review the pastimes the person enjoyed before the illness and schedule them at regular intervals.

3.7 C.6 F: Avoid being hard on the person:

It is important not be critical of the person with schizophrenia and for the person not to be self-critical. Credit must be given to the person for the little tasks that he/she performs, and positive changes (however little) must be acknowledged. It can be helpful to identify some positive features about the person and remind him/her of these features when her/she is feeling negatively about himself/herself.

3.7 C.7 Coping with Stress:

4.7 C.7 A: Unhelpful coping strategies

- Smoking
- Excessive use of alcohol
- Denial of problems
- Unnecessary use of drugs
- Taking it out on others
- Overactivity and being excessively busy
- Withdrawal and social isolation
- General rather than selected avoidance of problems

3.7 C. 7 B: Helpful coping strategies:

Communicating directly about stress

Letting the person talk about his/her feelings often provides some immediate relief and can keep stress from building up. **If the person with schizophrenia can tell you or a relative when he/she is feeling stressed, the early warning signs of relapse can be recognized**.

Holding a family problem solving discussion:
If just talking to the person with the illness is not found to be effective discuss the situation with the patients' family members and try and resolve/find possible solutions to the problem causing the stress.

Using Relaxation Techniques:
The person with the illness can be taught specific relaxation techniques which help in reducing the effects of stress. Theses relaxation techniques are most effective when practiced regularly, such as once a day. You will help the person with schizophreniato learn the techniques through verbal instructions and by demonstrating how it is practiced. Three types of relaxation techniques are described below:

- Relaxed Breathing
- Muscle relaxation
- Imagining a peaceful scene

Using positive self-talk:
Encourage the person with schizophreniato replace negative, self-defeating talk (e.g. "this is awful") with more positive self-talk that includes a coping orientation (e.g." this is a challenge but I can handle it", "I am going to do the best I can", etc). Also, the person with schizophreniacan be helped by suggesting different ways of thinking about a stressful situation.

Maintaining a sense of humor:
Many people with schizophrenia have a good sense of humor and respond well when they look at a lighter side of a stressful situation rather than being totally overwhelmed by it. A humorous movie or book can sometimes take a person's mind off stress.

Using religion or other spiritual inspiration:
For many people religion gives comfort and direction to their lives. These beliefs can help people cope with stress arising from difficult circumstances. For some people, prayer or other religious activities (attending services at a church, temple, mosque, and gurudwara) may substantially reduce stress. Also, religious organizations can be a source of social support which can reduce feelings of isolation and stress.

Exercising regularly:
Almost any type of physical activity has a positive effect on reducing stress, lifting mood and improving sleep patterns. The exercise must be done regularly, at least three times a week. Some persons with schizophrenia may find talking a walk or taking a bicycle ride relaxing, while others may prefer swimming, or running useful.

Keeping a journal:
Some persons with schizophrenia enjoy writing and maintaining a journal helps them to express their thoughts and feelings and relieve some stress. Some people also like to use their journal for writing poetry, drawing or writing song lyrics.

Creating artwork/ viewing art or creating music/listening to music:
Some people find it relaxing when they engage in creative pursuits themselves or when they visit an art gallery or listen to music. It may help the person to take up a hobby or revive one that he/she used to enjoy earlier.

Making a plan to increase the coping strategies:
Review the effectiveness of the coping strategies used by the person with schizophrenia from time to time and develop a plan for trying out one or two new coping methods. Any method will need to be used for a certain amount of time to be effective, as so the techniques must be chosen, modified or discarded cautiously.

Summary

Persons with schizophrenia can learn three kinds of palliative coping techniques to deal with psychotic and other symptoms:

- cognitive control (e.g. reappraisal, self-instruction, acceptance, manipulation of attention);
- behavioral control or the generation and implementation of action alternatives (e.g. increased or decreased activity, diversion, withdrawal from stimulation, altered arousal);
- social support recruitment.

They can be helped to identify their usual coping techniques, modify and extend them. Health workers can encourage persons with schizophrenia to practice these by imagining they have a particular symptom and then implementing an identified coping strategy. Such rehearsal of coping skills may facilitate their successful transfer to everyday settings.

3.7 C. 8: The Relationship between Stress and Anger:

People with anger control problems frequently experience difficulty in coping with stress. This is because the inability to cope with interpersonal conflicts, negative thoughts, day to day pressures and anxieties are common causes of both anger and stress. High levels of stress increase tension and frustration and therefore the likelihood of feeling angry and behaving aggressively. Similarly, failure to control anger can have an impact on the person's capacity to deal with different problems and interpersonal relationships.

3.7 C. 9: Anger and Aggression:

A common definition of aggression is any form of behavior directed towards the goal of harming or injuring another living being or object. A common definition of *anger* is that it is an emotional state experienced as the impulse to behave in order to protect, defend or attack in response to a threat or a challenge

3.7 C. 10 Response to Anger:

A. THE PHYSIOLOGICAL RESPONSE

The function of this response is to prime the individual for action. The release of adrenaline provides the body with the necessary energy. This biological response is an evolutionary adaptation, commonly known as the 'fight or flight' response

B. THE SOCIAL RESPONSE

The function of this response is culturally defined. It is also determined by an individual's social and interpersonal environment. For example, individuals who have grown up in the context of gangs and street violence, where aggression is expected and rewarded, are more likely to use aggression habitually. Those who have grown up in the context of solving problems through talking and negotiation are more likely to resolve conflicts verbally.

The following are common social functions of anger leading to aggression:

- establishing status within a group (for example, 'Top dog');
- group identification ('One of the lads');
- validation of valued roles ('Protect your own');
- need to control the social environment ('Attack is the best form of defence').

The social response is a product of a person's thoughts which are influenced by:

- perceptions- the individual's specific and personal view of a situation;
- prejudices- biased views about certain groups or types of individuals (for example, people with short hair are aggressive);
- attitudes- general views held by all of us, and influenced by past and present events and experiences;
- beliefs- opinions which develop over time and underpin an individual's ideas about themselves and the world around them.

C. THE PSYCHOLOGICAL RESPONSE:
The psychological function of anger is often ‘self-serving; that is, it helps to reinforce thoughts and feelings about a situation to confirm that what a person thinks and feels is right. Anger can also serve the function of self-protection, for example from vulnerability: “People cannot use me/ laugh at me/ hurt me if they are afraid of me.” Often, the psychological function of anger is erroneous because one’s thoughts are distorted or negative. Negative thoughts, such as “I feel a fool”, can lead to negative feelings, such as embarrassment. These can reinforce and escalate one another, leading to a vicious circle.

An assimilation of the three responses, physiological, social and psychological, leads to the individual’s behavioral response, which is either *adaptive* (maintaining control) or *maladaptive* (losing control). *Adaptive* responses might include assertiveness, problem solving, reducing of physiological arousal, negotiation, agreement or tactical withdrawal. *Maladaptive* responses might include physical assault, verbal abuse, manipulative behavior, indirect aggression (such as spreading malicious rumors), and buildup of resentment (sulking), non-tactical withdrawal or suppression.

Any response results in an outcome. An *adaptive* response is likely to result in positive outcome, while a *maladaptive* response is likely to result in a negative outcome. *Positive* outcomes might include increased self-esteem, reduced stress, improved confidence, improved relationships or increased likelihood of future anger control success. *Negative* outcomes might include increased likelihood of physical complaints (for example, ulcers, high blood pressure), reduced self-esteem, breakdown of relationships, reduced intimacy, isolation and rejection, increased likelihood of deterioration in general coping ability, psychological distress (such as anxiety and depression) or reinforcement of negative perceptions.

3.7 C. 11 THE TEN PRINCIPLES OF ANGER CONTROL

1. **Aggression is a learnt behavior which can be changed.** Motivation and commitment to change are essential to successful anger control. As a person develops and matures, learns different ways of behaving which are influenced by others. Some people may learn to be aggressive. However, behavior can be changed and one can be taught to use alternative, non-aggressive behaviors.

2. **The beliefs that a person develops influence the way he understands people and situations.** Knowing how beliefs affect a person and his behavior adversely can help a person to challenge his views. Holding irrational beliefs can lead to irrational behavior. For example, believing that life should always be fair inevitably leads to disappointment and frustration, and can ultimately result in a person taking frustrations out on others.

3. **Awareness and understanding of what a person thinks affects the way the person behaves.** This increases a person’s ability to control himself. Helping a person recognize his thoughts and feelings and the impact they have, is one of the first steps to controlling a person’s behavior.

4. **What you feel affects the way you think and behave.** Positive and negative feelings are common to everybody. Some persons with schizophrenia may experience negative feelings such as jealousy or hatred more intensely than others, and this can become overwhelming. The person can learn to recognize the self-defeating nature of these powerful emotions, and other ways of reducing their impact can help the person to control his behavior.

5. **Anger has a physiological component.** Increased awareness of this physical response can be used as an early warning sign to help the person calm down by using coping strategies to reduce the response. Symptoms such as increased heart rate and tense muscles can be alleviated through techniques such as relaxation.

6. **Aggression almost always results in negative consequences for the person and others.** Helping the person with schizophrenia to know the negative short and long-term consequences of aggression will make it easier to understand that it is always better to control anger. It must be reinforced to the person with schizophrenia that controlling aggressive impulses results in better relationships, increased self-esteem and more positive consequences in general.

7. **Identification of all the specific factors which are likely to make a person aggressive helps him to anticipate and cope with them as they arise.**

Sometimes factors such as negative life experiences can color the way that a person views the world, and make him particularly sensitive.

8. **Loss of control is usually a result of a build up of small irritants that have not been dealt with.** Situational pressures (such as financial worries), internal pressures (such as high expectations of a person from himself) and interpersonal difficulties (such as relationship problems) can work together to create an aggressive reaction that is out of proportion to the actual situation. Sometimes the final trigger or 'last straw' can be a relatively minor incident.

9. **An imbalance of chores and pleasures in a person's general lifestyle increases the likelihood of your behaving aggressively.** Too much work, few rewarding activities, self-neglect and continuing relationship difficulties are common factors associated with an unbalanced lifestyle and can lead to a tendency to react negatively to situations. Helping a person with schizophrenia create a healthy, balanced lifestyle and looking after himself and his needs will make life more pleasurable and rewarding.

10. **Anger can be a positive and empowering emotion if used constructively.**
    Anger is a normal emotional response which every person experiences from time to time. The goal of effective anger control is not to eliminate anger altogether, but to learn to channel it into productive, not destructive behaviors.

3.7 C. 12 Stages of Anger Management:

Anger management can be divided into three stages –

1. Managing anger before it even shows up
2. Managing anger when a person is angry
3. Managing anger after the person is angry

Managing Anger before it Ever Appears

Persons with schizophrenia can be taught to manage anger before it manages them. This is the '*prevention is better than cure'* approach. This is actually the only effective technique for anger management. This involves two steps:

A. Understanding the root cause of anger in general and anger patterns in particular.
B. It also involves **having a self-structure that is non-conducive to anger or stress**. This is done by continuous practice of some relaxation techniques such as somatic relaxation (like progressive muscular relaxation) and psychological relaxation (like yoga and meditation). It also involves developing and putting effective coping strategies in place.
C. Preventive Techniques:

- Practicing relaxation, meditation, or stress releasing or dissolving techniques.
- Being optimistic, positive, and having hope.
- Living in the present (here and now) as far as possible.
- Being aware of oneself and one´s anger patterns. Find the cause of your anger – it will be fear, lust or attachment.
- Develop self-confidence in the patient.
- Accepting himself as he is, with his limitations and strengths.
- Learning to forgive himself.
- Learns to guard against being hypersensitive.
- Finding coping strategies that work for the person.

What to do when the person is Angry

There are no fool-proof techniques available for anger management at this stage. This is the most difficult stage to manage because the person must learn to manage himself. The person with schizophrenia can try one or more of the following:

- Withdrawing from the situation to avoid irreparable or irreversible damage to self, others, relationships, and the environment.
- Recognizing that he is angry, and just stop doing what he has been doing (walking around or sitting calmly for a few minutes).
- Releasing the stress (stored due to anger) in a way in which there is least possible harm to self, others, and the environment (e.g. punching a pillow).

- Breathing deeply, inhaling deeply and holding for a second or two. Then exhaling deeply. Repeating this a few times.
- If possible getting involved in some creative work that can pacify him.
- If possible, diverting his attention to something else that can relax him, like humorous films, calming music, watering his garden, going to the beach or park.

Getting into the company of loved ones and speaking to them, if possible. If he has a love for children, their presence may pacify him, and even pets can sometimes pacify him.

- Learning to laugh it out, if possible, by perceiving things in a humorous way.
- Perceiving it creatively and constructively and take it as an opportunity to know himself, his anger patterns and the situation or other people involved.

After the Anger Incident

This stage involves two things:

A. Analyzing and Finding Out the Root Cause

The person will need to analyze calmly what caused him to be angry, and how he behaved in the situation that caused him anger. This will help the person to gain some insight into his fears and anxieties. Also, the person may be able to think of the damages and losses caused to himself, others and the environment due to his anger. This awareness may help the person to think of other ways to deal with the same situation without losing control.

B. Repairing and Restoring

- The person may need to practice relaxation, meditation or any releasing technique so that all the pent up stress energy is either released or dissolved without disturbing himself, others or the environment.
- Also, the person may need to apologize to others if it is appropriate. Also, he may need to reach out to the persons affected by his temper.
- If the person has disturbed the environment by throwing or destroying something, he must take time to reinstate them as far as possible.

Summary

- ♦ Failure to control anger can have an impact on the person's capacity to deal with different problems and interpersonal relationships.
- ♦ Anger has a physiological, social and psychological response.
- ♦ Anger control is based on a person's awareness of these responses.
- ♦ There are different stages at which anger can be controlled

CHAPTER 3.8

Rehabilitation to improve the quality of life of the person with schizopherenia and their family members

3.8.1 Introduction

Being a part of society, enjoying good family relations, a healthy lifestyle, or having a satisfying job are what most people aspire to. Unfortunately, due to the illness and disabilities, people with schizophrenia lose many of the essential life roles that normally provide self-esteem and meaning. People with schizophrenia have the same life aspirations as others in their society or culture. They want to be respected as individuals and lead a life as normal as possible through:

- an adequate education and a meaningful work career,
- satisfying social and intimate relationships, and
- participation in community life with full human rights.

Most persons suffering from an illness like schizophrenia require rehabilitation or support to help deal with the impact of the illness on their lives. Psychosocial rehabilitation is a term used to describe treatments that aim to restore the patient's ability to function independently in the community. It not only includes the medical and psychosocial treatment but also include ways to improve social interactions, to promote independent living, and to encourage vocational performance.

The goal of psychiatric rehabilitation is to help people with these disabling disorders develop the emotional, social and intellectual skills needed to live, learn and work in their homes and community. Within this overall philosophy, rehabilitation for people with schizophrenia comprises **two sets of intervention strategies**. The first strategy is **individual-centered** and aims at developing the person's skills in interacting with the environment. The second strategy is directed towards identifying and developing the **environmental resources** to maximize their functioning in the community. Most people with schizophrenia will need a combination of both these components for achieving full potential.

Rehabilitation involves closing the gap between the individual's current skills and those needed for improved functioning. Since people with schizophrenia will have different levels of disability, different problems and different social situations, rehabilitation efforts have to be specific to the needs of the individual. While designing the best possible rehabilitation efforts, it is important to make the individual treatments relevant, realistic and objective to make them effective. A systematic and collaborative approach to assess the person's situation and needs will contribute to a more effective rehabilitation and make the journey towards recovery easier.

3.8.2 Essential principles of rehabilitation:

The following elements are essential for the implementation of rehabilitation strategies for people with schizophrenia:

- **Strategies must be tailored to the individual and family needs**. The delivery of psychosocial rehabilitation program must be very flexible and driven by individual needs and priorities. Sometimes, there are different needs of individual and family members- this must be accounted for in the planning of the psychosocial rehabilitation program

- **Restoration of hope:** This is central to the whole process of rehabilitation. Engagement in planning rehabilitation is undertaken on the shared belief in the potential to change, even in the most difficult circumstances.

- **Improve on existing strengths and abilities:** Every individual with schizophrenia has some strengths and positive abilities; these need to be actively sought out and built upon to facilitate rehabilitation.

- **Plans should be context specific:** Strengths and abilities must be assessed in relation to a specific social environment. For example, the rehabilitation needs of a person with schizophrenia will be quite different in urban and rural areas as well as their expected gender based roles. Thus, skills must also be taught in relation to the environment in which they will be used.

- **Environmental supports:** Modifying the environment and building external supports are as equally important as skill teaching. This includes social and environmental change (changing attitudes, rights, laws, etc).

- **Collaborative approach:** This is a central principle which aims to respect individuals with schizophrenia and their family members and make them central partners in the planning and execution of rehabilitation efforts.

- **Balance skill development and support:** A person can only concentrate on improving/learning 1-2 skills at a time. Supports must be provided in any other deficit areas to enable the person to function until they master the current skills and can move on to learning or improving 1 or 2 more skills. Therefore, skills and supports are always in balance with one another.

3.8.3 What are the individual components of rehabilitation in the COPSI intervention?

Based on the feedback from people with schizophrenia and their caregivers before the COPSI intervention was finalized, in COPSI, we will focus rehabilitation efforts on:

- Skills training to improve self care and in essential activities of daily living like toileting, having a bath, brushing teeth, basic hygiene techniques (such as or washing clothes and menstrual hygiene in women) and in managing essential activities of daily living (contributing to household work, independent use of transport and basic money management).
- Improving social skills (eye contact, engaging and maintaining a conversation) to enhance social interactions within and outside home
- Improving skills for resuming work in the appropriate social and gender context.

All of these take time and efforts on the part of the person with schizophrenia, family caregivers and, most importantly, on your enthusiasm and commitment. In this chapter, we will discuss the practical measures that you need to implement to make gradual improvements in these focus areas that are of most concern to people with schizophrenia and their families. The particular methods needed in the rehabilitation process are relatively straightforward- describe the problem in detail, determine the strategy for making changes, demonstrate it, and practice it till it becomes a habit. However, for some focus areas like managing one's money, maintaining employment, coping with psychotic symptoms, and participating in basic conversation, this is neither quick nor easy.

3.8.4 The process of rehabilitation:

Psychiatric rehabilitation is based on the assumption that adequate role functioning is the result of three factors:

- The extent and nature of the impairments that limit the individual's current functioning like current symptoms and cognitive functioning

- The extent and nature of the disabilities in the personal, social and work related functioning and how they contrast with the expected social norms

- The immediate environment in which the individual lives, which may be either responsive or indifferent to the individual's attempts to function.

The interaction among these three factors defines the process, form and content of psychiatric rehabilitation's assessment and intervention procedures. The rehabilitation process begins with a systematic understanding and documentation of the individual's medium and long term goals for improved role functioning.

3.8.4 A) The initial assessment:

This includes a good understanding of the person's past and current functioning and the potential resources, in the family and outside, which can be utilized to make gradual changes. These will include:

- Personal details like age, educational status, details of key caregivers and work history. All of these will be known to you by the time you are planning the assessment.
- The important clinical information needed to plan rehabilitation include the duration and course of the illness, current symptoms cognitive functioning/problems, current treatment and adherence to treatments; again, all of these will be well known to you.
- Understanding the needs of the person for planning the specific activities related to rehabilitation. This has already been discussed in earlier Chapter 4.2 in detail.
- Assessment of the social supports available to the person within (like spouse, children) and outside (like relatives, close family friends); this will enable you to determine who can be partners for implementing changes.
- Possible barriers and challenges that can compromise rehabilitation efforts like having an uncooperative spouse, severe poverty, inadequate social support, severe discrimination within and outside the home; many of these will be evident to you before you initiate planning for rehabilitation.

Much of this information specific to determining the rehabilitation strategy for the person with schizophrenia will arise out of interviewing the individual and the primary care givers to find out:

- Details of the daily routine of the individual's household and the participation of the person with schizophrenia in this routine. This will give an overall idea about the level of functioning of the person, as well the requirements of the household.
- Primary caregiver's perceptions of priority areas for intervention; this will help to assess the needs and expectations of the caregivers and enlist their support for the process.
- Assess the motivation of the person to overcome their disability, as well as the presence of environmental barriers. The specific areas of interest include the individual's description of their personal daily routine as well as household activities, things that the person enjoys doing, and the identification of those areas where the individual acknowledges that he/she may need help.

3.8.4 B) Planning for change collaboratively:

There needs to be a strong emphasis that a joint effort between caregivers training professionals and the disabled individual is essential to ensure success. A specific strategy of training has to be discussed with the individual and the caregiver. The tasks and responsibilities of the natural caregivers needs to be listed and should include providing regular feedback, supervising transfer of skills, creating a supportive environment in which the disabled individual can practice the skills learned in the training program. Caregivers need to be informed that skill learning may be slow and that expectations of change need to be realistic.

The individual, the family and the community treatment team will review the results of the pre intervention assessment and formulate the **incremental, short-term goals** towards achieving the individual's medium and long-term goals. They will collaboratively design a rehabilitation plan that specifies the strategies needed for each incremental goal. Specific strategies should include a flexible combination of teaching behavioral skills that comprise improved functioning of the individual, and increasing the environmental support.

3.8.4 C) Implementing the plans:

The next and most important step is to actually implement the plans in real life. Most times, with your active encouragement, the choice of the correct reinforcement strategies and participation of the family members, changes are easy to observe.

Sometimes, however, this can be challenging for the person with schizophrenia, key family members and you as the best made plans can run into difficulties. Sticking to plans and orienting everyone about the small, step wise progress made is essential to keep up the motivation for change.

3.8.4 D) Evaluation of achieved results*:*

Once the strategies have been implemented, the individual's functioning is periodically assessed and compared to the identified goals. These comparisons will tell you about the progress made and highlight potential areas for new or modified actions.

3.8.5 Specific Behavior Techniques and approaches that are useful in rehabilitation:

A variety of behavioral and specific techniques are needed to conduct the training sessions. The text box below, gives a list of techniques that could be used. These are similar to the methods described in Chapter 4.4 and you should refer back for a more detailed explanation. However, it is important to remember that innovations, improvisations and flexibility in approaches will be required at times.

Useful methods of promoting change
- Interactive Discussion
- Role Play
- Home Work Assignment
- Verbal and Non-verbal reinforcement

3.8.6 The specific focus areas for rehabilitation in the COPSI intervention:

3.8.6 A) Improving self care:

Cleaning teeth:

The person with schizophrenia may or may not be cleaning their teeth daily. This leads to poor dental and oral hygiene. Most often, this involves brushing with toothpaste, but families can also be using other means like tooth powders that need to be rubbed.

- Explain the need for cleaning teeth regularly (health and social benefits) and find the right strategy to implement the plan. Most commonly, this will involve a key family member (spouse, parent) supervise the person or do it together.

- In some people with schizophrenia who are quite disorganized, you may need to break the task into small steps- pick up the toothbrush, then the toothpaste, apply the paste on the brush, place the toothbrush in the mouth and brush the teeth in a uniform 'up and down' manner for few minutes before rinsing two to three times. This can be followed by demonstrating how to clean the tongue, to wash the face using soap and then dry with a cloth.

Having a bath:

- The family may be concerned about the inadequate/irregular personal bathing habits of the person with schizophrenia. First, establish the frequency of having a bath that is acceptable to everyone. As in the previous example, the idea is to help break down the individual tasks that go into having a bath and building gradually on these till the process of having a bath is resolved. For example, the person needs to take clean clothes to change into and a towel into the bathroom, collect sufficient water in a bucket at the required temperature and then (using a mug) pour the water over all parts of the body. When the body is thoroughly wet, the person applies soap all over the body, wash it off, use the towel before putting on fresh clothes. It should not take more than 10-15 minutes to bathe every day. The family members and the person should also decide on the frequency of trimming, washing and oiling hair as locally relevant and keeping it free of lice and dandruff. In the case of women, this will include brushing and braiding their hair and tie it in the style they are comfortable with.

Grooming:

- *Nails:* The person with schizophrenia should be encouraged to have short and clean nails on fingers and toes for health and social reasons. Determine the preferred method in the family to trim nails; if a nail clipper is being used, you can demonstrate how it works. The family should then supervise the first few attempts by the person to ensure that he/she cuts it safely and neatly.

- *Shaving:* You may need to ask some other male person in the house to demonstrate the steps involved in shaving. This will require using the shaving scream to lather, the right angle at which to hold the shaver and how to shave and then wash and wipe the face afterwards.

Toilet and menstrual hygiene:

- This is a sensitive issue and you must be careful when you discuss this topic so as not to offend the affected member or the family. The affected member should be encouraged to have clean and regular toilet habits and encourage the thorough cleaning of hands after using the toilet. For women, you may also need to discuss how to maintain hygiene during menstruation.

- You may need to discuss with the affected member about the consequences of poor hygiene. You will need to discuss with the affected member to choose from the various options of materials available for this purpose and how they are to be used. Also discuss disposal and washing of soiled clothes.

Dressing and taking care of clothes:

- Discuss the improvements necessary in dressing appropriately for health and social reasons. The person with schizophrenia needs to follow local norms of dressing (for example, women might be expected to wear saris, salwar kamiz or skirts depending on their social and religious identity), wear clean clothes and undergarments that are appropriate for the weather. In addition, washing and keeping their clothes in order is another useful skill that the person with schizophrenia sometimes needs to do regularly. As in all other areas of rehabilitation, these need to be built progressively and with lots of positive reinforcements in the form of encouragement from the family and small material rewards.

Healthy eating habits:

- Wash hands (with soap) before eating and arranging the plate, glass of water and other utensils necessary for eating on the table or on the ground.

- Serve adequate amount of food at a time and eat it with fingers without spilling.

- After finishing, wash hands, rinse mouth and then dry face and hands.

- Wash the plate and glass after eating.

- Clean the table after eating with the family demonstrating their preferred method

3.8.6 B) Having a schedule for daily activities:

One of the most important areas identified by families is the need for the person with schizophrenia to have a daily schedule of activities that require little or no supervision. This can be one of the most distressing problems faced by families where the person with schizophrenia is seen as being ‘lazy’ and spending the day doing nothing in particular. This can be addressed by collaboratively constructing a schedule of daily activities. An activity schedule involves the affected member ‘doing’ something i.e. being participative, involved and productive. It should be a **combination of work, rest, leisure, self-care and sleep**.

It is important for the person with schizophrenia to follow an activity schedule for the following reasons:

- Keep the person **engaged** in useful tasks
- Improve **memory, attention, concentration and judgmental abilities**
- **Distract** from troublesome symptoms like hallucinations and delusions.
- **Develop problem-solving abilities**
- Improve his **self-confidence**

While considering rehabilitation geared towards improving independent ADL skills some of the things you need to keep in mind are:

When planning the activities that the person is expected to do you affected member should:

- Offer choices of specific activities the individual would like to do in the course of the day
- Ensure that there is a high probability of **success** by using a graded approach
- Give careful **instructions** on how to do the task; enlist the support of the key family members
- Ensure that the person has the **capacity** to do the task
- **Encourage and compliment** the person consistently upon trying to do things on the schedule
- Look at difficulties and suggest alternative strategies
- Encourage the person to develop a personal stake in the process

The following is an example of an activity schedule. You can form similar activity schedules for the person you are working with after considering his age, sex and needs. Key caregivers are required to be involved and encourage the person stick to the schedule as far as possible.

7:00 am: Wake up, brush teeth, attend to toilet, brush hair
7:15 am: Tidy bed, exercise
7:30 am: Have a bath
7:45 am: Say prayers
8:15 am: Eat breakfast
8:30 am: Wash plate and glass, tidy table
8:45 am: Read newspaper, grocery shopping
9:45 am: Rest or tea/coffee break
10:00 am: Wash clothes
10:30 am: Household activities like cooking, tidying rooms, and folding clothes
11:30 am: Go out to post office and bank
12:30 pm: Lunch
12:45 pm: Wash plate, glass and tidy table
13:00 pm: Rest
15:00 pm: Stitching on sewing machine
16:00 pm: Tea and converse with family members
17:00 pm: Go for an evening walk
17:30 pm: Free time
19:30 pm: Household tasks like helping in the cooking or other activities
20:30 pm: Eat dinner
20:45 pm: Wash plate and glass and tidy table
21:00 pm: Watch TV
22:00 pm: Sleep

3.8.6 C) Other essential skills for independent living:

Household tasks:

- The family should encourage the person to tidy the bed, fold the blanket, straighten the bed sheets and pillows upon getting up from sleep.
- The family should encourage the affected member to change and wash the bedclothes as often as they usually do.
- The family should encourage the affected member to keep his room neat and clean. He should be encouraged to pick up fallen items and replace them. He should clean the floor if something has been spilt. Family members should demonstrate how this should be done.
- The affected member can dust their room at least every alternate day. He should sweep and mop the room every day. Family members can demonstrate these tasks to the affected member.
- Encourage the person to participate in other household tasks like helping in kitchen tasks like cleaning and cutting vegetables, helping set the table with plates, glasses, and the food containers and dispose the garbage in the dust bin.

Managing money:

- The family may need to reorient the person with schizophrenia to recognize the various denominations for both coins and notes.

- Family members should encourage the person to purchase things required for the family by initially giving the exact amount to be spent. Later, the person should be encouraged to pay the appropriate amount, collect the correct balance and return home with the items.

Using public transport:

Going out on the streets and using public transport can be a major problem for many persons with schizophrenia. This particular skill requires considerable planning and support and can be implemented when the person and caregivers are ready and have the time on hand.

- The person with schizophrenia needs to have the house address and a contact phone number in a card, in case there is a problem.
- The caregiver should orient the person to the landmarks and way to the bus stop/ train station.
- The person should be told the specific numbers that will carry him to the destination and be shown the place where the bus/train will stop.
- Clearly noting the bus route and number, before boarding the bus; if in doubt, clarify with the bus conductor before boarding.
- Ensuring that he/she have adequate money before boarding the bus, present the money to the conductor, and clearly state their destination.
- Retain the ticket until the end of the journey.

3.8.6 D) Social Skills Training:

Social skills are specific behaviors people use (like looking at the other person, smiling or making some conversation) when interacting with others that enable individuals to be effective at achieving their personal goals. Having a casual conversation, making friends, expressing feelings, or obtaining something from other person are all situations that require the use of social skills.

Why are social skills important?

People with schizophrenia usually experience problems in their relationships with others, including treatment providers, family members, and other people in the community. These problems result in difficulties in community adjustment and in a diminished quality of life. For many persons with schizophrenia, poor social functioning is related to inadequate social skills. For example, people may have difficulty starting a conversation, speak in a low monotone voice, or fail to establish eye contact. Helping the person you are working with improve their social skills can enhance their social functioning in the community.

Reasons for using social skills training in schizophrenia:

There are several reasons for stressing on social skills related rehabilitation in COPSI. For example, social skills and social competence can be viewed as protective factors in the vulnerability- stress model of schizophrenia. Strengthening the social skills and competences of individuals with schizophrenia can reduce and compensate for the negative effects of cognitive deficits, neurobiological vulnerability, stressful events and social maladjustment. Coping skills and social competences confer not only protection against stress-induced relapse, but also resilience, interpersonal supports, social affiliation, and improved quality of life. When individuals have been equipped with skills to deal with stressful life events and daily hassles, they are more proficient in solving problems and challenges that arise in their lives. As a result, stressors are less likely to trigger symptom relapse or exacerbations. Moreover, the protective effects of social skills training also help individuals stabilize their illnesses, improve adherence to medication and psychosocial treatment, and promote progress toward recovery.

Though there are different methods of conducting social skills training for persons with schizophrenia, there are some common **basic principles**:

- *Problem identification* is made in collaboration with the person in terms of obstacles (barriers to the individual's personal goals) in his/ her current life.

- *Goal Setting* this requires detailed descriptions of what communication skills are to be learned (learning to ask for the time), with whom they to be used (from a passerby), where (on the street) and in which situations (not having a watch).

- Through *role- plays or behavioral rehearsal*, demonstrate the speaking (verbal) and behavior (nonverbal) skills required for successful social interaction in the identified situation.

- *Positive & corrective feedback* to praise and improve the quality of the behaviors exhibited in the role play.

- *Social modeling* is provided with the CHW demonstrating the desired interpersonal behaviors in a form that can be learned by the observing individual.

- *Behavior practice* by the individual is repeated until the communication reaches a level of quality tantamount to success in the real life situation.

- *Positive social reinforcement* like praise, smiles and encouragement, is given contingent on those behavioral skills that showed improvement.

- *Home work assignments* are given to motivate the individual to implement the communication in real-life situations

- *Positive reinforcement & problem solving* is provided based on the individual's experience of using the skills.

Important components of Social skill training:

Skills to express something:

- Verbal skills- the structure, content and amount of words said
- Behaviors related to speaking- the characteristics of the voice during the speech i.e., volume, pace, intonation and pitch
- Non-verbal behaviors - facial expression, eye contact, body posture and maintaining an appropriate distance between people during interaction.

Skills necessary to maintain social interactions:

- Receptive behaviors- Attention to what the other person is saying, recognition of emotions expressed by another person
- Interactive behaviors- responding in conversation at the right time, taking turns to talk
- Being aware of the social context- knowledge of social norms and expected ways of behaving

Specific steps in social skill training:

- Step 1: To help the person understand why it is important to learn the skill.
- Step 2: To demonstrate (model) the skill in a role play.
- Step 3: To engage the person in a role play scenario.
- Step 4: To provide feedback and specific suggestions for improvement.
- Step 5: To encourage the person to practice the new skills.

Type of skills which you can implement:

A wide variety of skills can be taught, depending on the person's needs. Some of the most common skills include:

General purpose social skills:

- Listening attentively and responding to people appropriately
- Expressing positive or unpleasant feelings to others
- Expressing feelings clearly
- Making requests
- Expressing thoughts and ideas
- Eating together in an orderly manner
- Sharing physical amenities, like bathroom, in a considerate manner

- Appreciating others’ need for privacy
- Helping others within and outside the house

Specific skills like:
Conversation skills:
- Starting, entering, maintaining and ending a conversation
- Negotiation skills
- Dealing with stressful situation
- Expressing differing view points
- Accepting constructive criticism gracefully
- Apologizing when required

Assertiveness skills:
- Making requests
- Refusing requests
- Making complaints
- Expressing angry/unpleasant feelings
- Asking for information
- Explaining one’s position

Friendship skills:
- Initiating friendship
- Giving compliments
- Accepting compliments
- Identifying and sharing common interests

Skills to remain healthy:
- Making appointments with the treating team
- Asking questions about medication and related issues
- Seeking clarifications regarding self improvement (smoking, diet, lifestyle)

Job related skills:
- Job interview
- Conveying one’s interest, abilities, motivation
- Handling criticism from superiors/coworkers (constructive/unhealthy)
- Adjustment in interpersonal situations at the work place

Example of Social Skill Training:

While medication plays an essential role in controlling the symptoms of schizophrenia, the disabilities associated with the condition have a profound impact on cognitive and social functioning as well as physical health, creating a barrier to reintegration. The CHW’s can play a major role in reducing the impact of these factors through assertive monitoring of physical health, and referral to psychosocial rehabilitation and other community support services. Timely intervention and ongoing support can make the difference between isolation and relapse, and being able to re-establish a meaningful life as part of the community.

Specific skill/ task: Giving a compliment to your friend

Explain the importance of giving compliments:

Giving specific compliments is a good way to express positive feelings. Compliments are usually given about something that can be seen, such as an article of clothing, a haircut, or a pair of shoes. Giving and receiving compliments make people feel good about themselves.

Explain the smaller steps involved in the action:

1. Look at the person in the eye
2. Use a positive tone and smile while speaking
3. Be specific about what it is that you like

Possible scenarios while role playing:

Meeting a friend who is wearing an attractive new pair of shoes
Liking someone's shirt or Churidar

This is a good skill to review frequently. People usually enjoy it, and the exercise can be a welcome break from more difficult skills.

3.8.6 E) Getting the person with schizophrenia back in work:

As we have described earlier, schizophrenia can have a very negative impact on the person's ability to work. Getting the person back at doing some work, either inside or outside home, is a very important overall goal of rehabilitation as it improves the person's sense of achievement and self confidence. In addition to the fact that the person is contributing to the family in some productive manner, (either by earning money directly or by contributing to work inside the house thus enabling someone else to earn) it also promotes the participation of the person in society and can significantly improve the overall quality of life.

Importance of work in rehabilitation:

- Reduces symptoms, helps distract the person's attention from troublesome symptoms
- Reduces isolation
- Improves the person's level of functioning
- Adds to self-esteem and builds up confidence as the person feels useful and valued
- Reduces financial burden of care on the family as the person becomes a contributing member
- Relieves family or caregivers of the constant need to supervise the ill person
- Can reduce the extent of criticism, over-involvement and hostility from the family members towards the patient
- Work can contribute to increase the social support for the individual - colleagues, employer, others

Of course, like any rehabilitation effort, work related rehabilitation **runs parallel** to other aspects, like pharmacological management, medication compliance, individual and family counseling, and strengthening the social support of the person and family.

Stages in planning work related rehabilitation:

- Assessment of vocational skills
- Adjustment to work (prevocational skills)
- Job skills training
- Sheltered employment
- Transitional employment
- Finding a job
- Job maintenance / retention

Assessment which includes:

- Illness-related aspects
- Current level of the individual´s functioning and disability caused by the illness
- “readiness to work”
- Illness-related deficits such as poor motivation, social skill deficits, cognitive deficits
- Assets - positive aspects in the individual and the family that we can strengthen
- Individual and family expectations about outcome of the vocational rehab process

Basic skills:

Before the person is ready to resume work, certain aspects like adequate symptom control, appropriate dressing, punctuality and social skills to deal with demands of being in a job need to be addressed. The emphasis is not on the acquisition of specific or work skills but on the ability of the individual to manage the work environment, get along with co-workers, report for work on time and adjust to the discipline of the work milieu. Most work therapy programs focus primarily on this step of work adjustment, which is commonly referred to as work habit skills. This process of getting the person to work is obviously critical for the success of the employment plans.

Vocational skills:

This step involves the learning of skills for specific jobs or preparing the person for a specialized trade- the skills required to be ‘job ready’ for entering and persisting in some financially gainful activity. These skills can be taught informally or in vocational centers run by a number of government and private organizations. Referral to vocational training facilities is often not enough in itself; it is necessary for caregivers and CHW’s to accompany the person and smooth out adjustment problems.

Placement:

In determining what kind of specific work the person might be best suited for, it is useful to consider factors like the nature of the job, location of the work site, timings, duration of breaks, probable stresses while on the job, number of co-workers, etc. These factors play a role in determining whether the client is comfortable with the job. Also remember that:

- Regular ongoing contact with the person is necessary to handle any stresses or adjustment problems that might emerge, especially initially.
- The attitude of the employers and co-workers needs to be looked into and modified to make the work place more supportive to the client
- The work environment must not be too stressful, nor should it be under-stimulating
- Be alert about discrimination or exploitation by the employers and address these

Job retention:

This is the final stage in the process. Helping the person retain the job skills and supporting them to continue in a job successfully can often pose a major challenge. Here again, regular but less frequent contact with the person is essential.

It is not necessary for all individuals to progress through all the steps that have been described above. Some individuals can skip few of the intermediate steps if they had possessed good work skills before the illness began. On the other hand, if the disabilities are very severe, regular employment in a sheltered setting may represent the optimal vocational potential.

Employment opportunities for people with schizophrenia:

Getting people back to work at home or outside should be seen as a series of proactive measures that enable individuals to function to their optimal capacity and not just for the sake of it. This redefinition of work therapy from passive ‘make work’ approach to an active collaborative approach has resulted in more options to consider. Some of the possible work opportunities include:

- Competitive / normal employment
- Self-employment- small business
- Sheltered employment / production workshops- usually function with assistance from social welfare agencies
- Home-based work- tailoring, weaving, basket making etc
- Social cooperatives comprising people with schizophrenia who pool their resources to provide services like cleaning, catering etc

The two main methods of job placement are the:

1) Train and place approach:

"Train and place" approaches have been the mainstay of work related rehabilitation for over three decades. This is best understood as a step wise approach that was described earlier.

2) Place and train approaches:

Exposing individuals to the realities of the market place or training center, and giving them on the spot training is the philosophy of this approach. In contrast to the more gradual train and place approach, the advantage of this approach is the real life setting. This allows individuals to acquire the appropriate skills in real life settings and also gives employers an opportunity to identify the abilities of the individuals instead of focusing on the disabilities. Obviously, during this process, active and specific support needs to be made available to the person to help them adjust and cope with the demands of work.

Summary

- Schizophrenia leads to disabilities in many life domains that need rehabilitation for optimum recovery in many people with schizophrenia
- Most people will require a combination of individual and environmental efforts for best results
- There is a sequence of planning rehabilitation efforts based on key principles that is followed in the COPSI intervention
- In the COPSI intervention rehabilitation efforts, specific attention will be placed on self care, activities of daily living skills, social and vocational skills
- There are a number of strategies and methods that are useful in making changes in each of these areas

CHAPTER 3.9

Enhancing the social recovery of people with schizophrenia by addressing environmental barriers

3.9.1 Introduction:

The COPSI intervention is guided by the principle of enhancing the process of recovery for the person with schizophrenia and to enable him/her to participate as fully as possible in the mainstream of life. This is a gradual process. It starts with the person with schizophrenia and their families receiving a combination of specific treatments like medicines, overall health promotion and rehabilitation to improve personal care and social skills etc to help manage their illness better. This is an important necessity for the person to return to previous roles or find new things to do. Recovery of social roles and functions is linked to improvement in overall control of the illness to an extent.

However, there are many other challenges that a person with schizophrenia and their family members have to face when attempting to normalize their social and economic activities. In Chapter 1.6, we highlighted that the functioning of someone with schizophrenia (as in persons with other disabilities) is influenced by a dynamic interaction of impairments, restriction in activities and difficulties in participation due to social barriers. Often, even when symptoms (impairments) and disabilities in social functioning are improved, the social barriers can be very difficult to change. This can lead to a feeling of frustration and 'giving up' in the person with schizophrenia and their family members.

Having more 'friendly' social conditions for people with schizophrenia to be reintegrated back in their community roles has been very hard to achieve in spite of many efforts and binding legal obligations. One of the most important reasons for this lack of success is the high levels of stigma and subsequent discrimination that affects the prospects of work, relationships and the family's social status. Another important reason is that family members and persons with schizophrenia have little support in dealing with the problems due to a sense of shame and guilt leading to progressive social isolation.

Efforts to change these social barriers can be thought of at two levels:

- *Efforts that are targeted at the entire community:* These include community awareness campaigns to reduce stigma, legal challenges to discrimination in the workplace due to having schizophrenia, improving access to special employment opportunities in the government sector, providing information to sections of the community like the media, police and judiciary about the facts of schizophrenia etc.

- *Actions at individual and group levels with the persons with schizophrenia and their families*: these include strategies to manage stigma and discrimination, facilitating the formation of group of people affected by schizophrenia as a forum for support, improving employment opportunities through innovative schemes etc.

As a rule, efforts directed at the whole of the community are difficult to organize, implement and evaluate effectively in a short time frame and are therefore not part of the time limited COPSI intervention.

Instead, we have chosen to implement 2 specific sets of individual and family activities to facilitate social recovery- **actions to cope with stigma and discrimination and self help initiatives**. Both of these are described in more detail in the rest of the chapter.

3.9.2 Addressing Stigma in COPSI:

As you will recall, stigma, prejudice and actual experiences of facing discrimination are both common and distressing for people with schizophrenia and their families. As a consequence, many people with schizophrenia start to believe that they are actually incapable of getting back to life and work as before. This erodes the person's self belief and confidence and can lead to a sense of having 'given up' and accepting that things will not improve.

The following statement provides an example of how this experienced by a person with schizophrenia:

> *"I feel dejected, less confident.... [my] confidence [hope] seems to be lost.... [I feel] that there is nothing in my life.... this illness will continue forever...(...) [In the past I used to] feel that why should I worry if it is getting cured by medicines.... then at another moment I feel that once I am labelled [shikkaa] like this, then who will call me good or normal.... They will say that I have become mad. (....) [I used to feel that] all things will be good after my marriage.... I never dreamt of such illness in my life and that this will happen with my marriage (...) [that] I [will] have to search hard for a job (...) I have never thought of this (...) It is my illness [that has caused these changes]"*

Living with stigma and discrimination is a very important barrier to recovery as social roles and reintegration become harder to achieve. This is common for all disabilities but particularly severe for schizophrenia as it overlaps with the popular understanding of 'madness'. Even though this is such an important problem, till recently there has not been much attention paid to this aspect in delivering interventions in countries like India. As a result, there is not a lot of experience in designing local treatments to address stigma and discrimination that could be incorporated in COPSI as a ready made package (unlike say medical treatments, rehabilitation, etc).

In developing the strategies for addressing stigma in COPSI, we started with asking persons with schizophrenia (both in Goa and in Chennai) and their caregivers their lived experiences of stigma and discrimination prior to carrying out the study. The overall experience of being stigmatized and discriminated against is composed of many related concepts like negative views of the possibility of recovery, low self confidence, a sense of shame and embarrassment or a perceived need to conceal the illness and discrimination outside (and sometimes inside) the home. Based on this understanding, and recommendations from the current evidence base of effective interventions to address stigma and discrimination, we have tried to match the components of the intervention that can be useful in addressing specific aspects of the stigma experience in Table 4.9A below:

Table 3.9 A: The experience of stigma and strategies to address them in COPSI:

Particular aspect of Stigma Experience	Narratives from formative IDI's	Recommended strategies
Negative views of outcome and lack of belief in the possibility of recovery	*"I am mad and I will remain like this in the future" (Person with schizophrenia)*	*Psycho-education with the person with schizophrenia and Caregivers:* • Provide accurate information and hope about course of illness and recovery and about what persons with schizophrenia can do themselves to ensure optimal outcomes • Emphasize possibility of positive outcomes, that 'people with schizophrenia can and do lead meaningful and productive lives'. • Convey a hopeful notion of recovery which is appropriateto the specific situation of the person with schizophrenia. • Provide examples/ case stories of people with positive outcomes • Emphasize positive effects treatment can have
Misinformation and negative views of illness	*"I don't know whether he will get it again in the future. (...). If he had been injured, he can be cured within a week or within one month. I don't know whether this will be cured. I don't know what to do."*	*In psycho-education with the person with schizophrenia and Caregivers:* • Provide accurate information on nature of Illness • Address myths about the illness- e.g. that it is due to past misdeeds or 'karma'

	(Caregiver) *“I feel [I don’t want to tell others] because [my] condition was very silly (...) some psychiatric condition was there” (Person with schizophrenia)*	• Emphasize that this is an ‘illness that anyone can get’, that it is ‘nobody’s fault’
Low self-esteem and self confidence	*“My self esteem has gone low. I feel I don’t have any good qualities and all.” (Person with schizophrenia)*	• Address low self-esteem by identifying qualities and strengths and building them up further • Rehabilitation to improve and networking on things the person with schizophrenia wants to focus on
Sense of Embarrassment	*“I feel he is not normal like other children he doesn’t socialize doesn’t speak well. That is what I feel embarrassed about. “ (Caregiver)*	• Psycho-education for Caregivers (understanding and accepting some difficulties as part of the illness) • Support groups for Caregivers and Person with schizophrenias (sharing of experiences and mutual support) • Social Skills Training for Person with schizophrenia
Concealing the Illness • Not knowing what to say	*“I didn’t tell them, I just told them that my ... like I had bad fever and all so I didn’t tell them the thing which actually happened [...] because I myself don’t know properly what happened to me.” (Person with schizophrenia)*	• Psycho-education (understanding of condition, possible causes and triggers) • Role plays: practice what and how to explain to others about the illness
Concealing the Illness • Anticipated Discrimination	*“If they come to know they will just laughing at me may be, may be, start having a different behaviours with me, may be.” (Person with schizophrenia)*	• Explore (where appropriate) what is likely to happen if illness is disclosed to selected people • Explore advantages and disadvantages of disclosing (aspects of) illness to specific persons (e.g. distinguish between cohabiting family (helpful if they understand) and family living elsewhere (who the close family may not want to tell) • Role plays of disclosing to persons the person with schizophrenia/caregiver would like to disclose to
Concealing the Illness • Impact on Marital Prospects	*“Because it affects badly afterwards...now if you ask me why... it is because when the time comes for marriage people inquire...how is the girl...so that time it affects” (Caregiver)*	
Concealing the Illness • Fear of Disclosure to People at Work	*“I never did reimbursement because [...] when we forward the bills they go to our office...so those who are interested can find out what’s wrong with her...So because of that I never claimed the bills.” (Caregiver)*	

Concealing the Illness • Trying to Conceal despite most people knowing	*“Actually we don’t want anybody to know about my son’s illness but at the same time we can’t hide because in village everything is closely connected” (Caregiver)*	• Explore advantages and disadvantages of concealing the illness (as above) • Work towards acceptance of illness within the family (as above, distinguishing between cohabiting family and other family as appropriate)
Concealing the Illness • Avoiding social contact for fear of disclosure	Examples brought up by caregivers in the Chennai	• Support initiatives for persons with schizophrenias and families • Explore advantages and disadvantages of concealing the illness (as above)
Fear of Disclosure through home visits by CHW’s or researchers	*“When you come and somebody finds you there on the road and you ask “Where is advocate V’s house?” and if they say “Who are you?’ say I am “X”, if they say “Why are you going there?” [...] just keep it a secret. If anybody asks say “I have some work with him he is a lawyer” (Caregiver)*	• Offer to hold sessions in a neutral place nearby if the person with schizophrenia or family wishes this • Reach an agreement with the family at the first visit about how to deal with neighbors asking; ensure this is dealt with consistently by different team members visiting the home
Negative treatment and discrimination from people outside the family • verbal abuse, mocking, not being let in the house, being treated differently at college/ school or at work	*[About the neighbors] “They don’t even allow me to enter their house.” (Person with schizophrenia)*	• Discuss stigma and discrimination as something that happens to many people with similar problems • Discuss ways of coping with discrimination from others; feed back useful strategies that have been reported by other person with schizophrenias or families • Think through and practice ways of responding to negative comments from others • Motivate person and family to join support group
Negative Treatment and Discrimination from People within the home	A small number of participants reported not getting basic amenities or not being let into their own house	• In psychoeducation with caregivers, provide realistic information about potential for improvement with adequate treatment • Work towards acceptance within the family • Encourage resumption of some household work at the earliest to convince caregivers about the utility of the person • In a sensitive way, explore reasons for negative behaviour from within the family/ household (e.g. teasing, critical comments) & discuss practical solutions

3.9.3 The role of the CHW in improving coping with stigma:

As the CHW, you will play a vital role in implementing the planned set of activities to address the often hidden issue of discrimination. There are some *general principles of engagement* which will greatly improve the possibility of you enabling the person with schizophrenia deal with stigma and discrimination in a more meaningful manner. These include:

- Respect for the person with schizophrenia as a core value of the community team
- The person (and not the illness) is the centre of your attention at all times
- Never use stigmatising words like 'mental' or 'madness' while communicating with the person and care givers; use non stigmatizing words like problems, illness
- Ensure the priorities of the person with schizophrenia is respected and they have a say in decisions concerning them
- Act as role models and through your example, demonstrate the benefit of positive interaction with the person with schizophrenia

In addition to these general principles, there are some specific actions we will be conducting in the COPSI intervention actively to address stigma related issues. Some of these were detailed in Table 1; as you can see, these consist of delivering the other components of the COPSI intervention and some specific stigma focused actions. We believe that many components of the overall intervention are indirectly useful in reducing stigma for reasons outlined in Table 4.9B below and are, therefore, essential actions to address stigma. For example, many of the treatments like rehabilitation to improve personal care and social skills may help remove 'markers' (visible symptoms and side effects) of the illness making social recovery more likely.

Table 3.9 B: Possible usefulness of COPSI intervention components in reducing stigma:

Intervention Components	Possible Mechanisms of Stigma Reduction	What should you do to maximize effect
Therapeutic alliance	Disclosure and discussion of otherwise distressing private experience-'ventilation' and relief that someone understands and cares for person	Develop and maintain trusting, positive and confidential professional relationship at all times 'Walk the talk'- show through your actions that you genuinely respect and care for the person
Adherence Management	Reduces likelihood of stigmatising experiences by contributing to overall recovery	Support person with schizophrenia in taking medication regularly
Psycho-education for person with schizophrenia and Caregivers	• Increasing knowledge of illness for enhancing sense of control • Addressing internalized stigmatizing beliefs, negative views of the illness, feelings of shame and self-blame • Empowering participants and caregivers to respond to prejudices or comments from others	Emphasize possibility of positive outcomes Address negative views/ myths about illness Explain causes of illness 'Nobody is to blame.' Help family accept some difficulties as part of the illness Provide accurate information on recovery Provide factual information and address 'myths' about the illness
Self help initiatives	• Improving social interaction • Sharing successful strategies of coping with stigma and discrimination	Strongly encourage participation in self help initiatives Facilitate access to such activities

Rehabilitation	• Improving personal care (facilitating interaction with others) • Better social skills • Improved social interactions • Specific retraining for improving job prospects • Becoming useful and taking on additional responsibilities at home • Increasing Self-esteem	Focus on identification and remediation of disabilities
Referral to community agencies	• Improve ability to interact socially • Confidence in negotiating for needs	Look for agencies that can meet specific needs for social and work related recovery Facilitate access to identified agencies

In addition, there are some *specific activities* that you need to initiate during the intervention which can have a beneficial effect on helping the person cope with stigma and discrimination.

At the very beginning of your engagement, you will have some idea about the priority given by the person and caregivers to the issue of stigma. This should be further clarified during the initial needs assessment you will conduct. You will then need to explain to the person and caregivers that there are some general measures to manage the problems related to stigma (as in Tables 4.9A and 4.9B) which need to be followed through. The specific actions to deal with stigma with the person with schizophrenia is best done when symptoms are stabilized and there has been some progress in improving the social and work related functioning of the person. In other words, stigma related activities are best initiated in Phase 2 and continued with till the end of the intervention. One of the most important intervention components in terms of reducing stigma experience is the introduction of specific psychoeducation activities around this theme:

- Actively discussing myths about the illness that the family themselves, neighbors/ other family members may hold, and providing information to counter these; this could lead into a role play of how to discuss the illness with a relative etc.
- Assessing the presence of ‘internalized’ stigma where the person with schizophrenia feels that she deserves to be treated badly; this can be discussed when you have a good therapeutic alliance and strategies to counter this belief and testing them out in real life situations should be part of the psychoeducation process
- Discussing the pros and cons of concealment and disclosure of the illness in certain situations, like at work, before marriage etc

The specific methods of equipping the person and the family deal with stigma include role play around specific situations (disclosure etc) and problem solving conducted in a supportive atmosphere. Your overall approach and the timing of introducing the more specific actions will need to be discussed with your supervisors and the treating Psychiatrist as closely as possible.

3.9.4 Self Help initiatives in COPSI:

Self help initiatives is the broad term to describe a scenario where people joined by a common health or social interest (dealing with severe mental disorders, alcohol, other disabilities, HIV/ AIDS, mothers of young children or as a way to improve access to loans) come together to help each other out. Most commonly, this involves the formation of a self help group (SHG) but there can be other self- help methods like having a person with the same problems visiting as a ‘peer support’ person.

There has been a lot of interest in recent years in the idea of SHGs for a range of community development and health programs for a number of reasons. Firstly, SHGs are an important way to mobilize people around a particularly pressing social concern within the local community effectively. Secondly, SHGs are seen as an effective way of formalizing what is often an existing, informal network of people with common problems in a more organized manner for greater overall impact. Thirdly, SHGs are often a mechanism for persons from disadvantaged sections of the community participate democratically within a common purpose group without being discriminated against. Fourthly, SHGs are a mechanism for people involved in a program to come together, define their needs and get their voices heard in the planning and implementation of activities that involve them.

Finally, and most importantly, SHGs have been demonstrated to be effective in improving the ability of people to manage social and health problems in many sectors like micro-finance, social forestry, women's' health and disabilities.

Self help initiatives in mental health have a long history, especially involving families and people with severe mental disorders like schizophrenia. Though the self help movement originated in the West, they have now become a common component of community mental health initiatives in many parts of the world, including in India. These groups and other initiatives like peer support have been shown to be effective in promoting recovery in people with schizophrenia; in view of this strong evidence that self help initiatives should be an important component of an effective intervention, we have decided to include this in the COPSI intervention as well.

In formal terms, an SHG can be defined as a group of individuals living with similar problems who meet for the purpose of providing support and information to each other through mutual problem solving and pooling of resources. SHGs can be of 2 types:

Transactional SHGs: These include groups that are involved in a formal process of transaction of money or goods within the members to help improve their overall socio economic status. A good example of this is the micro-credit SHG's which focus on financial transactions (like providing loans to members with low interest) or management of natural resources (like forest products or water). These transactions are the focus of the group and are generally part of poverty reduction and livelihoods initiatives.

Interactional SHGs: These are groups where the focus of activities is the interaction that happens between members on an issue of common interest. Self help groups for people with mental disorders is a good example of this type of a group where people come together, provide mutual support and are thus encouraged to make positive changes in their lives. Interactional SHGs use the common pool of experience that people have (in say living with schizophrenia) as the focus of the meeting rather than dealing with material transactions. The planned SHGs in COPSI will be interactional groups of people who share a common desire to overcome the problems associated with severe mental illness and increase their level of wellbeing.

Why are SH initiatives helpful for people affected by schizophrenia?

There are many reasons why self help initiatives can be useful for people affected by and living with schizophrenia. Some of these include:

- Overcoming the sense of being alone and not having people who can understand what the individual or family members go through in coming to terms with schizophrenia
- Sense of relief that group members can discuss about their fears and concerns in a supportive atmosphere without felling embarrassed or ashamed
- Learning from each others experience in dealing with specific problems like managing medications, anger, lack of personal care and relapses and applying these new strategies in their lives
- Emotional support from other members of the group which can reduce the burden of caring and in dealing with the sense of loss and grief that accompanies a family member developing schizophrenia
- Help reduce feelings of internalized stigma and improve the confidence to disclose problems to other people through sharing of common experiences
- Use the social contacts of the group to organize work for recovering persons with schizophrenia
- By being a forum where members can form social relationships, enjoy each other's company and plan recreational activities that provide a break from everyday lives

3.9.5 Details of the self help initiatives in the COPSI intervention:

What are the types of self help initiatives in COPSI?
In the COPSI intervention, there are 2 different types of self- help initiatives that we are planning to implement:

In Chennai, we will attempt to get family members and persons with schizophrenia who have recovered as volunteers (peer support person) who can provide support to designated families receiving the intervention.

In Goa and Satara, we plan to form SHGs during the course of the intervention and make all efforts to ensure that they continue to function even after the trial period is over.

When and how do we invite people to enroll in the self help initiatives?
In either case, we will ask you to motivate the person with schizophrenia and the care givers to enroll in the local SHG or meet with the peer support persons in the second phase of the intervention. This is to ensure that there has been enough time for you to have developed a good rapport with the family and for the prominent symptoms to have been reduced to an extent that will allow the person with schizophrenia to participate meaningfully. As you are engaged in working with 3-5 families, you will need to prepare them by:

- Explaining to them the purpose of the meetings (self help, support, learning from each other etc)
- Explaining the basic rules that need to be followed by all members:
- Confidentiality: No member will discuss the contents of the interview with non members informally
- Punctuality: The group will function on the basis of all members being present for the meeting in time. If, for some reason, they are either unable to attend or are late for the meeting, this has to be communicated to the group earlier
- All participants need to be treated with respect:

Violations to the guidelines can be dealt with in various ways. Less serious ones can be raised in a general way, not by confronting a specific member, but by reminding all members of the guideline and asking for a recommitment to it. More serious violations can be dealt with by having specific members meet separately with group leaders. Only in the most extreme situations should a member be confronted in front of other group members.

Explaining the details of the meetings:

- How often will they be held
- Where will the meeting be held
- Who are the others likely to participate

While introducing the idea of participation in a SHG, you could say something like:
''We are planning to start a self help group in your locality which will allow you to meet with people having similar problems as you are experiencing. This will give you opportunity to express your difficulties, ***gain*** *support by sharing personal experiences and will help to learn different coping strategies. Will you be interested to be a part of the group?*''

Who will be invited to join the SHGs?
In the planned COPSI SHG's, we intend to invite the primary care givers and other interested family members of people with schizophrenia receiving the intervention to participate. The person with schizophrenia is also welcome to join in the group at a time when they are ready and willing to commit themselves. However, the group will exclude children below the age of 16 from participating as this has been shown to be unhelpful in most other groups.

What is the ideal size of the group?
Ideally, most SHGs are composed of 5-10 members. This is a general rule of the thumb figure; smaller groups are not very interactive and big ones are difficult to manage and coordinate. In other words, we will invite 5-10 caregivers (caregivers like parents are considered as one entity) to participate in the group. Remember that in the program, persons with schizophrenia will be recruited in the intervention over a period of time (9 months). This means that you may need to start the group with around 3-5 families and keep it 'open' i.e. allow other participants who will join later to come in over time. This is something that you will need to explain to initial group members and prepare them to receive the new members cordially and make them feel at home.

Organizing group meetings:

Choosing a place:

Group meetings are best held in common, public venues like community meeting places provided by the government (panchayat hall) or private agencies (Rotary or Lions Club halls, temple or church halls, etc). While it may be possible for the SHG to meet in a member's house (especially with small groups), this needs to be discussed and agreed upon by the group to prevent any future misunderstandings. Whatever the venue, the key things to keep in mind when choosing a place are:

- Make sure that the venue is of a reasonable size to accommodate the group members
- Must have basic facilities like lighting, fans, toilets and drinking water
- There are adequate seating arrangements (chairs, mattresses) that can be organized in a circle
- The place is located in a convenient place that can be reached easily by members using public transport; this is an essential requirement as a place that is far from bus stops will compromise attendance
- That the meeting place is close to group member's homes and does not involve a lot of traveling time. This is another essential requirement for a stable group
- That there is clear understanding of the composition and purpose of the group meetings with the providers of the space before the meetings are actually started

Choosing a meeting place is often a good starting point for the group members to start talking to each other. This often helps bond the group together as the task involves giving suggestion, negotiating and accepting the group decision. All of these are important tasks of the groups in the future as well.

How often will the meetings be held?

For interactional SHGs like the one we are proposing, the recommendation is for the group to meet every 15 days. Transactional groups like micro-credit SHGs usually meet more frequently but this is unnecessary and too disruptive for other groups. Please remember that the group members are already coping with a lot of things and the group meetings will put an additional strain on their time and expense. It has been repeatedly shown that members will attend the meetings regularly if it does not strain their time and finances (traveling expenses, having to take time off work etc) too much.

The details of how often the group meetings will be held will also need to be discussed with the group members early on and a consensus decision needs to made; once decided on, members have to agree to come regularly for the meetings.

When should the meetings be held?

One of the main challenges of starting a group is to find a time that is convenient for all members to attend. This is an important issue for you to resolve as democratically as possible and the group needs to decide in it's first couple of meetings about the time (morning, afternoon or evenings) that is suitable. It also helps if a particular day of the week (say second and last Saturday of every month) is agreed upon as this helps people both remember the meeting and also make the necessary arrangements (household work, child care, etc) in advance to attend the meeting.

How long should the meetings be for?

As a rule, meetings should not exceed a maximum of 90 minutes. From our personal experiences, we know that maintaining attention and focus for more than an hour and a half at the most is difficult and the same applies for group members as well. Also, long meetings mean that members will have to spend greater periods of time (travel and meeting time) than is convenient.

Getting the group to work together:

Any group is a collection of individuals having unique personalities, social status, educational background, religious affiliation and unique past experiences. All these individuals come together united by a common reason (supporting people living with schizophrenia) and interact with each other to meet certain common requirements. However, it is impossible to separate one's personal and social background and ways of interacting from the collective group experience. It is inevitable that the COPSI SHGs will be influenced by the same factors that influence all such groups- social power structures (rich versus poor, dominant versus minority group membership), gender roles (women expected to be quiet and in agreement with what men decide on), trust and belief in each other, credibility (members are seen by each other as doing what they say) and practical utility in meeting needs (reduced stress, increased social networks, improved skills in handling non adherence etc).

Managing a group so that the focus on the primary agenda (in COPSI, support for persons living with schizophrenia) is maintained needs active work and a lot of attention, especially in the initial period. Successful groups have some common features:

- *Well defined purpose*: Groups that have a clear, shared agenda and purpose are more likely to be meaningful for the participants and be more effective

- *Formal engagement*: Groups that treat the meetings seriously by having them regularly, having an agreed agenda for every meeting, keeping records of the discussion, circulating them to members and following up on plans made collectively are useful methods of making members feel that they are part of a worthwhile exercise

- *Autonomy in deciding agenda*: Managing a group is somewhat like bringing up children- at first the child needs a lot of care and attention but over time becomes an individual who decides on things more independently. Successful groups also need time to come together and mature and be able to decide on their own agenda and future purpose. This is not something that happens automatically. Initially, group members will take time to open up and be comfortable in participating in the group interactions. Making sure that everyone is treated with respect, that everyone is given the opportunity to contribute and that no one person dominates the group are some of the important principles that will help groups mature and become responsible for their collective future

- *Working in a democratic manner*: Group members have to ensure that it is open and democratic in it's functioning. All members should have an equal say (irrespective of social background), proceedings need to be conducted in a transparent manner, activities should involve all members equally and that majority group decisions should be binding on all member are some of the key ways of making the groups more inclusive

- *Good leadership*: Every successful group needs to have good leadership from the very beginning. Initially, for the first 2-3 meetings, it is necessary that you provide leadership for the group by facilitating meetings, encouraging members to attend, ensuring that the place for the meeting is booked in advance, getting the group to 'warm up' and start interacting, keeping notes and setting the agenda for each meeting. During this time, you also need to actively look for people in the group who can take on some of these activities and pass on responsibilities to the group members as soon as possible. For example, you could identify someone who can record the discussions of the meeting and get them typed before the next meeting date. Someone else can take the responsibility of making reservations for the hall or getting a cup of tea and snacks organized. At some point, the group will need to elect a leader who will conduct proceedings in an orderly manner according to the agenda; leadership is best rotated within members of the group

- *Well defined conflict resolution mechanism*: It is inevitable that there will be differences of opinion and conflicts between members of the SHG as in any other group institution like the family or the workplace. Having a clear way of discussing and resolving these conflicts within the group is an important requirement for a successful group. The exact method of doing so will need to be discussed and agreed upon by the members; as the CHW, you will need to make this happen in a positive manner

- *Continuous development*: Groups flourish when they become a way of new learning in a positive atmosphere. Creating this atmosphere needs active planning in partnership with the members. Group members can think of inviting people for talks on themes of interest to them, making a visit to another SHG with similar agenda, can learn about basic group management principles and can ask for help in specific activities they might be planning (for example, an art exhibition organized by the group, highlighting human rights issues in the media etc)

- *Awareness of group processes*: Successful groups have inbuilt methods of reflecting on the direction that their group is taking and what are the possible reasons for this. For instance, some groups maybe very dependent on the CHW for everything and do not meet if you are absent for some reason. This needs to be discussed in the group after you have had a chance to discuss the issue with your supervisor

As you can imagine, translating the principles of successful groups in the COPSI SHGs will require a lot of attention and supervision to make you comfortable in the role of the facilitator. There is some inherent uncertainty about predicting whether a group will be successful and maintain itself once the active support from the COPSI team comes to an end. Group processes also need time to work; it is also hard to predict if the time available in the COPSI program is adequate for the groups to become independent of the support from program staff like the CHW. However, being aware of these principles and making active efforts to build them into the way you organize them will certainly be useful in trying to achieve the goal of having a successful group in place.

One of the ways to help you meet the challenge of organizing the SHGs is the close supervision that will be available to you. The Intervention Coordinator and Intervention Facilitators will be providing you with support and supervision during the process both by observing some sessions and giving you the opportunity to reflect on the meeting during team meetings so that you can get suggestions and feedback from your peers and supervisors.

Structure and content of meetings:

In an open group, there has to be a mix of some activities that are common (so that new members joining the group do not feel left out) and some that are based on the previous discussions of the group. Keeping this balance intact is also an important role for you while thinking about the way in which you want the group to conduct the meetings and what needs to be discussed. The COPSI intervention is for a limited period of time and you need to be aware that a specific goal is to enable the groups to continue meeting after the intervention has come to an end. There are also some guidelines and activities that we can learn from many other groups that have met for similar reasons in India and other parts of the world.

In Table 3.9C below we present a general framework that can be used as a general plan at various points of the group meetings.

Table 3.9 C: General guideline for organizing SHG meetings:

Step	*Time*
1. Informal socializing (greeting & welcoming members) and signing of attendance register	5 minutes
2. Introduction of all members present at initial meeting and when new members join	5 minutes
3. Review and agree on minutes of previous meeting and agenda for current meeting	5 minutes
4. Discuss the specific items on the agenda for the meeting	30 minutes
5. Tea break	5 minutes
6. Specific problems of members are discussed by the group (1-2 persons)	15 minutes
7. Any administrative issues	5 minutes
8. Agree on any assignments to be completed by members before the next session	1-2 minutes
9. Summarize discussions of the meeting	5 minutes
10. Set agenda and confirm date/time for next session	3-5 minutes

Please remember that the structure suggested is just a general guide and should be made more specific and adapted for use according to the demands of the situation.

In many situations, groups are formed of say family members to specifically deliver a particular treatment like family therapy either by professionals or by family members themselves. These groups have a structured agenda and meet for a specified number of times and are easier to define. In COPSI, however, the SHG's are an additional method of improving the overall effectiveness of the intervention and are not formed for the purpose of delivering any particular treatment (like adherence management or rehabilitation). The specific treatments are delivered to the individual person with schizophrenia and care givers in a carefully matched manner and need not be replicated in the group meetings. Of course, if group members feel that some specific issue needs to be discussed, there should be opportunities to do so with the permission of other group members.

The primary purposes of the self help groups are to:

- Enable members to improve their skills at managing the illness through sharing of collective experiences
- Help each other through difficult times by providing practical and emotional support
- Develop the capacity of the group to use problem solving skills to discuss their concerns and arrive at solutions
- Develop an independent identity and purpose so that the group continues to function after the program is over

These goals are much more difficult to define in very specific terms. Broadly, however, you can think of the group developing in separate phases like we have outlined for the intervention. The groups will start functioning around month 5 from the start date of the intervention and will continue till the end of the intervention for a total of about 16 months. The initial, *high engagement phase* will last for the first 3- 4 months of the formation of the group. During this time, as the person coordinating the process, you will need to play a very active role in getting the group to meet regularly, help with demonstrating the way it should be structured, enable participants to become confident in participating freely and lead the discussions. During this time, we expect to conduct around 6 meetings.

Once the group has begun to meet regularly and the participants are clear about the purpose of the group and have experienced some benefits, it is time to move on to the *consolidation phase*. During this phase, we intend to conduct around 12-15 meetings over 9 months. This is the time to enable the group to become progressively more independent of the CHW, develop their own agendas, programs, leadership structures and conduct regular meetings in a participatory manner. This process of 'letting go' needs to be managed carefully- doing it too slowly (for example, due to the CHW being too 'controlling') or too quickly can be disruptive for the group and you will need plenty of guidance during this time.

The last 3 months is time to plan for an *independent identity* of the group and is best utilized to plan for developing their longer term identity and specific programs. During this time, you will need to facilitate this process by actively bringing the issue to the notice of the group, discuss with them what additional training or help needs to be done to make the group more confident (like networking with similar groups in other parts of the State or country) and setting up a future course of action after you leave (like registering the group formally as an independent organization to advocate for the rights of people with severe mental disorders, help in finding jobs or setting up small businesses for people with schizophrenia who are well etc).

This overall guideline will help you and your supervisors think of the specific contents of the group meetings depending on the stage at which the group is at any point of time.

How many meetings should members attend for best results?

This is a hard question to answer as we simply do not know if there is a minimum number of meetings individual group members need to attend to experience benefits in their personal lives. However, drawing on previous experiences, we feel that a minimum of 10 sessions would be necessary for any long lasting benefits to be apparent in the levels of burden experienced by caregivers or improved social functioning in persons with schizophrenia.

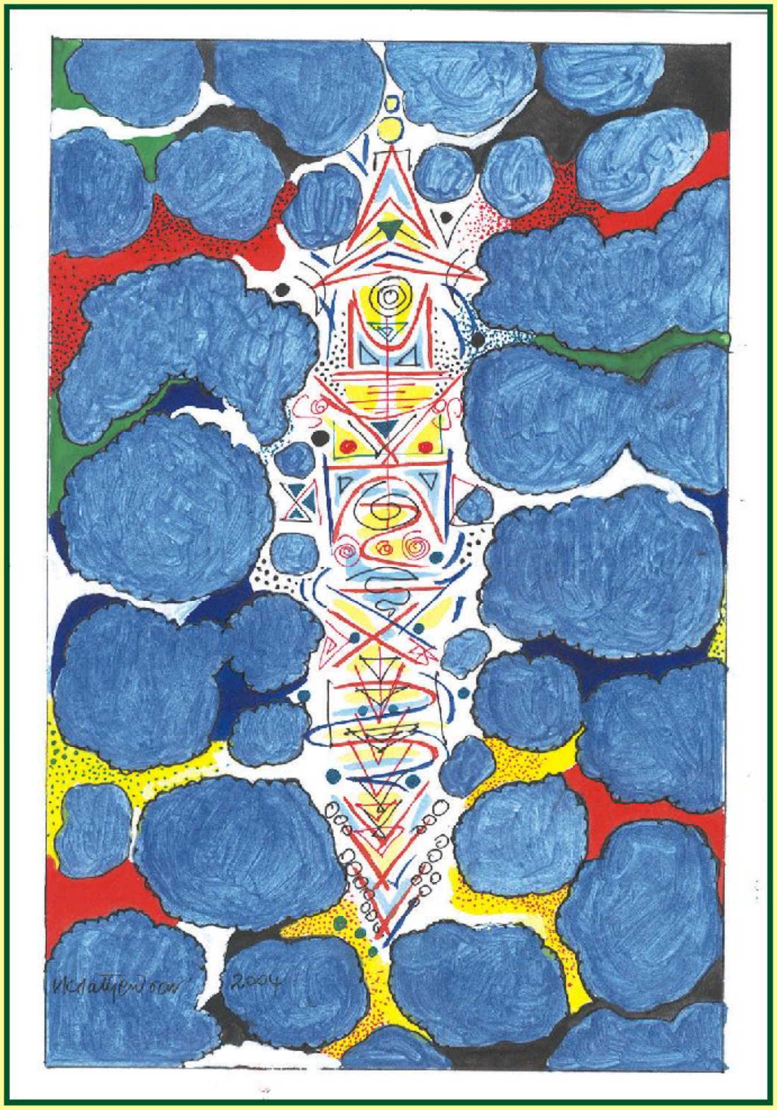
Sustainability of the SHGs:

This refers to the planning and efforts to ensure that the SHG's survive and thrive even after the COPSI program comes to an end. While there are specific things which help groups become self sustaining, this is not easy to achieve; in many instances, SHGs are so dependent on the program that they collapse after the direct support from the program comes to an end.

Sustainability is something that needs to be kept in mind from the very beginning of the process of forming the group and not something that is thought of at the last minute. Groups will take time to mature and take responsibility for their functioning. Getting members to understand that self help is an independent and powerful way of coping with schizophrenia (that can be used by a well organized group) is one of the best ways to ensure that the SHG continues. The experience of benefiting from a relatively simple way of mutually discussing problems from a common viewpoint is what motivates group members to stick together to use their collective strengths in the long term. In addition, guiding the group in becoming a semi-formal entity in the medium term, setting up good practices to ensure that group processes are transparent and building the capacity of the group through targeted training (in maintaining records, handling financial transactions, interacting with professional groups or the media etc) will improve the chances of the SHG becoming able to function and evolve successfully in the longer term.

Summary

- People with schizophrenia and their family members need support to overcome the social challenges they face; efforts can be directed at individuals or on a larger frame
- Stigma and discrimination is a significant challenge which is explicitly recognized in the COPSI intervention
- The specific strategies to combat stigma in COPSI are based on actual feedback from people with schizophrenia and their family members
- The CHW has a central role in helping people deal with stigma in an empathic and effective manner
- Self help groups and other initiatives are another useful method of helping people overcome social problems of isolation and lack of support and an essential part of the intervention
- The methods and content of self help group meetings is also clearly defined in the COPSI intervention


2004

MODULE 4

Appendix

Appendix 4.1: Initial Contact Form

Date: ___________________

1. Introduction to patient and caregivers	Yes ☐ No ☐
2. Defining role using hand out	Yes ☐ No ☐
3. Duration of engagement in the programme	Yes ☐ No ☐
4. Convenient day and time for CHW's subsequent visits	
5. Who is/are the primary caregiver(s) and relationship to patient	
6. Any immediate family need	
7. Next follow up appointment	Date: Time:
Any other remarks	

Appendix 4.2: Home assessment Form

Date: _______________

	Description
1. Persons living at home Who is living at the home? What is their relationship to the patient? Please describe	
2. Size and type of home Please describe the home including the number of rooms. Does the patient have a private room?	
3. Environment at home (calm, peaceful, noisy etc)	
4. Where is the most suitable place to hold the intervention sessions? Inside the house (which room?), outside the house (where?)	

Appendix 4.3: Needs Assessment Form

☐ **Baseline** ☐ **Review 1** ☐ **Review 2** ☐ **Review 3** ☐ **Review 4**

Date: ____________________

Description of needs	**Met need** (Tick)	**Unmet need** (Tick)	**Partially met need** (Tick)	**Comments**
1. Managing Symptoms				
Positive symptoms				
Negative symptoms				
Cognitive symptoms				
2. Emotional Well-Being				
Meaningful activities				
Managing negative emotions (depression, anxiety and anger)				
3. Role Functioning				
Work or school				
Parenting				
Spouse				
Home related activities				
4. Social Relationships				
Friends				
Family members				

Description of needs	**Met need** (Tick)	**Unmet need** (Tick)	**Partially met need** (Tick)	**Comments**
Co-workers				
Marital relationship				
5. Leisure Activities				
Hobbies				
Sports				
Playing music or creating artwork				
Listening to music or looking at artwork				
Creative writing				
Reading for pleasure				
6. Self-Care & Other				
Living Skills				
Grooming / hygiene				
Money management				
Use of transportation				
Shopping / food prep				
Cleaning and caring for clothes				
Personal safety				

Description of needs	Met need	Unmet need	Partially met need	Comments
7. Physical Health				
Health checkups				
Regular dental care				
Eating nutritiously				
Stopping tobacco use				
Avoiding alcohol use				
Managing other diseases				
8. Spiritual Needs				
Involvement in religious activities				
Experiencing nature				
Meditation / yoga				
9. Stigma				
Concern about disclosure				
Discrimination from others				
Low self- esteem/ Shame				
Negative views of illness/recovery				
10. Any other Needs				

Appendix 4.4 : Individual Service Plan Form

☐ Baseline ☐ Review 1 ☐ Review 2 ☐ Review 3 ☐ Review 4

Date: ____________________ Next Review date: __________________

Identified unmet need	Tick if yes	What are the necessary inputs	How will the inputs be delivered
Managing Symptoms:	☐		
Suicide Risk:	☐		
Medication Adherence:	☐		
Medication Side Effects:	☐		
Emotional Well-Being:	☐		
Role Functioning:	☐		

Identified unmet need	**Tick if yes**	**What are the necessary inputs**	**How will the input be delivered**
Social Relationships:	☐		
Other Social Difficulties:	☐		
Leisure Activities:	☐		
Role Functioning:	☐		
Self-Care and Other Living Skills:	☐		
Physical Health:	☐		
Spiritual Needs:	☐		

Identified unmet need	Tick if yes	What are the necessary inputs	How will the input be delivered
Dealing with Stigma:	☐		
Self help group:	☐		
Any Other:	☐		

Appendix 4.5 : Contact Summary

Phase (1, 2, 3)	Date of contact	Time spent with contact person	Time spent to travel to meet the contact person	Mode of transport *	Cost of Travel	Type of Contact**	Contact Person(s)***	What were the specific activities conducted****

This sheet is to be filled for every contact with the Family/Patient
*Codes for *, **, ***, **** are listed overleaf*

***Codes for mode of transport**

A. Project vehicle
B. Public transport (Bus)
C. Walking
D. Other

**** Codes for type of contact:**

E. Face to face at home
F. Face to face at hospital
G. Telephone contact
H. Letters sent
I. Others

***** Codes for contact person:**

A. Patient
B. Primary caregivers
C. Other family members
D. Other community members
E. Others

****** Codes for specific activities:**

A. Establishing therapeutic alliance
B. Conducting needs assessment
C. Organizing medical review
D. Adherence management
E. Psychoeducation with patient
F. Psychoeducation with family
G. Health promotion
H. Rehabilitation
I. Linkage to other community resources
J. Stigma management
K. Self Help Group
L. Any other

Appendix 4.6 : Checklist for assessing non-adherence

☐ **Baseline** ☐ **Review 1** ☐ **Review 2** ☐ **Review 3** ☐ **Review 4**

Date: ____________________

1. Socio- demographic factors:

Female gender
Poverty in family
Illiterate
Unemployment
☐ Distance
☐ Single

2. Psychosocial factors:

☐ Different explanations for illness
☐ Lack of information about illness and need for adherence
☐ Stigma related to taking treatment
☐ Poor family support

3. Illness related factors:

☐ Lack of understanding (insight) of the need for treatment
☐ Positive symptoms (delusion of being poisoned through medicines)
☐ Negative symptoms
☐ Poor attention/ concentration
☐ Depression
☐ Alcohol/ drug use

4. Treatment related factors:

☐ Complicated dosage schedule
☐ Side effects
☐ High cost of treatment
☐ Poor therapeutic alliance

5. Systemic and social factors:

☐ Stigma related to treatment centre
☐ Negative attitudes of treatment providers
☐ Erratic supply of medicines

6. Summary risk of non adherence:

☐ High *(factors from 3 or more domains*)
☐ Moderate *(factors from 2 domains)*
☐ Low *(only socio-demographic risks)*

Describe the Action Taken:

Appendix 4.7 : Symptom Profile checklist

☐ Baseline ☐ Review 1 ☐ Review 2 ☐ Review 3 ☐ Review 4

Date: ____________

The first two columns are to completed by the CHW before the 3 month review; the third column is completed at the 3 month review with the intervention coordinator and Psychiatrist (taking into account strategies identified in earlier reviews)

Symptom (tick as appropriate)	**Comments** (provide details for symptoms identified)	**Strategies for Symptom Management** (complete after discussion with intervention coordinator)
Behavioural changes: ☐ Lack of personal care ☐ Wandering ☐ Anger and aggression ☐ Excessive/ very reduced activity ☐ Other (Please specify): ____________		
Changes in biological functions: ☐ Sleep- reduced or excessive ☐ Appetite-reduced or excessive ☐ Menstrual cycle- regular or irregular ☐ Sexual functions- lack of desire, erectile problems, painful sex etc.		

Symptom (tick as appropriate)	**Comments** (provide details for symptoms identified)	**Strategies for Symptom Management** (complete after discussion with intervention coordinator)
Changes in mood: ☐ Sad and unhappy most of the time ☐ Angry and irritable most of the time ☐ Very happy and cheerful most of the time without obvious reason ☐ Dull and not interested ☐ Anxious and fearful most of the time		
Abnormal Thinking: ☐ Talking about plans or conspiracy to harm him/her ☐ People talking about him/her behind his back ☐ Convinced about his superior abilities ☐ Feeling hopeless and worthless ☐ Worried excessively about something going wrong ☐ Other________________________ ________________________		
Having unusual experiences: ☐ Seeing things others cannot ☐ Hearing things others cannot ☐ Smelling/ tasting something others cannot		

Symptom (tick as appropriate)	**Comments** (provide details for symptoms identified)	**Strategies for Symptom Management** (complete after discussion with intervention coordinator)
☐ **Suicidal thoughts or plans**		
What does the patient think is the problem: ☐ Does not have any problem ☐ Thinks he/she has a problem but does not know what it is ☐ Thinks that there is a supernatural cause of the illness ☐ Thinks that there is something wrong with the brain/ mind ☐ Not sure		

Any Other comments

Appendix 4.8 : Medication Side Effects Checklist

☐ **Baseline** ☐ **Review 1** ☐ **Review 2** ☐ **Review 3** ☐ **Review 4**

Date: ___________________

Side effect	**Not Present** (Please tick)	**Occasionally present** (Please tick)	**Definitely present most of the time**(Please tick)
* Sedation			
* Muscular stiffness			
* Tremor			
* Restlessness, feeling jumpy			
* Sensitivity to sun			
* Increased salivation (drooling)			
* Abnormal movements			
* Dizziness			
* Nausea, vomiting			
* Constipation			
* Irregular menstruation			
* Sleep disturbed			
* Fatigue			
* Breast enlargement in men and leakage of milk in women			
* Headache			
* Weight gain			
* Blurred vision			
* Sexual difficulties			
* Difficulty in passing urine			
* Any other side effects			

Advice given:

Appendix 4.9 : Follow up form

Session Number: ________ **Date:** __________________

(Please mention not applicable (n/a) where ever necessary)

1. Session conducted at	☐ Home ☐ Other community site_________________
2. Who were present for session	☐ Patient ☐ Family ☐ Others____________________________
3. Review of previous session (including homework) Adequate understanding of issues discussed in previous session	
4. Social difficulties (Brief details)	
5. Suicide risk assessment Action Taken: (Please specify)	
6. Status of adherence with medicines (Since last visit) Any adherence management strategies delivered: (Please specify)	Medication (Name) Dose missed (Number) General Medicine 1. ______________ ______________ ______________ 2. ______________ ______________ ______________ 3. ______________ ______________ ______________ 4. ______________ ______________ ______________ 5. ______________ ______________ ______________ 6. ______________ ______________ ______________ 7. ______________ ______________ ______________ 8. ______________ ______________ ______________ 9. ______________ ______________ ______________ 10. ______________ ______________ ______________
7. Side effects of medicine assessment completed Action Taken: (Please specify)	☐ Yes ☐ No
8. Overall clinical status Action taken: (Please specify)	☐ Better ☐ No Change ☐ Worsen

9. Have there been any changes to the medicines since the last visit	☐ Yes ☐ No If yes, specify the new medication doses below: Date:
10. Psychoeducation Describe Briefly	☐ Patient ☐ Caregiver ☐ Any other family member attended
11. General health promotional advice provided	☐ Regular meals ☐ Regular sleeping pattern ☐ Avoid alcohol/ tobacco ☐ Maintain personal cleanliness ☐ Regular check up (periodical check up)
12. Rehabilitation Describe Briefly	☐ ADL ☐ Social skill ☐ Vocation rehabilitation ☐ SHG
13. Improving social welfare and employment Describe Briefly	☐ Govt./Non Benefits ☐ Referrals to other Org.
14. Stigma Identified issues Action taken:	
15. Homework assignment Brief details of homework tasks	
16. Tasks for next session identified Brief details of activities for next session	
17.Next date for consultation with Psychiatrist	
18. Follow up appt date	
Any additional remarks:	

Appendix 4.10 : Early Warning Signs of Relapse Checklist

Date:__________________

Early warning signs	**Experienced in the past** (Tick if yes)	**If yes, Describe**
1. Rapid changes in mood.	☐	
2. Unusually high levels of energy (cannot stop).	☐	
3. Unusually low energy level (cannot get started).	☐	
4. No interest in doing things.	☐	
5. No interest in taking care of personal appearance	☐	
6. Feeling hopeless about the future.	☐	
7. Having trouble concentrating and remembering things	☐	
8. Thoughts are coming too fast (racing).	☐	
9. Cannot understand what is going on.	☐	
10. Religious rituals and thoughts are suddenly more intense.	☐	
11. Feeling afraid that something bad was going to happen.	☐	
12. Having trouble sleeping.	☐	

13. Feeling sad and unhappy most of the time.	☐	
14. Worrying about physical health excessively.	☐	
15. Feeling tensed and nervous.	☐	
16. Getting easily angry at little things.	☐	
17. Having trouble sitting still; having to keep moving	☐	
18. Having trouble remembering things.	☐	
19. Eating less than usual.	☐	
20. Hearing voices or seeing things that others didn't hear or see.	☐	
21. Thinking that people are talking about him/her or staring unnecessarily.	☐	

Appendix 4.11 : Checklist for Social Difficulties

Date: (dd/mm/yy)					
Social Difficulties	◆ **Baseline**	◆ **Before Review 1**	◆ **Before Review 2**	◆ **Before Review 3**	◆ **Before Review 4**
Financial difficulties	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Domestic Violence	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Unemployment	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Legal disputes	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Interpersonal conflicts	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Illness in family/ disability	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Substance abuse	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Parenting issues	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bereavement	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Social isolation	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Others	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐

Describe Social Difficulties identified in the table below

Social Difficulty	Brief Description	Action taken	Outcome
			n/a

Appendix 4.12 : Checklist for Suicide Risk Assessment

♦ **Baseline** ♦ **Review 1** ♦ **Review 2** ♦ **Review 3** ♦ **Review 4**

Date: ___________________

Demographic risks:

☐ Male
☐ Young adult
☐ Poverty
☐ Lack of social support
☐ Unemployed
☐ Single or separated

Clinical risks:

☐ Persistent, 'commanding' hallucinations
☐ Depression
☐ Previous suicide attempt
☐ Family history of suicide
☐ Misuse of alcohol or other drinks
☐ Physical illness and disability
☐ Long duration of symptoms
☐ Clear awareness of personal loss due to illness
☐ Side effects of medicines
☐ Not taking medicines/ not wanting to engage
☐ Immediately before or after admission

Immediate risks:

☐ Persistent, 'commanding' hallucinations
☐ Ongoing severe social difficulty/ problems seem unsolvable to patient
☐ Hopelessness
☐ Loss of interest
☐ Communication of desire to end life
☐ Active plan to commit suicide and access to means

Summary risk: (remember immediate risks> clinical risk> demographic risk)

☐ No risk / Low risk
☐ Moderate risk
☐ High risk

Action Taken: (Describe)

Degree of risk

♣ **Absent / Low** – Very occasional thoughts / passive ideas prevailing, no concrete plans, social support, stable life circumstances.

♣ **Moderate** – Persistent ideas, moderate – severe clinical problems, limited protective factors, 1 or more immediate risks.

♣ **Severe / High** – active plan, severe / multiple clinical risks, multiple current problems, severe hopelessness, limited protective factors.

1. Plan of action for moderate risk rating:

- Discuss and agree on safety plans (means, observation)
- Discuss with supervisor and organize clinical review
- Enhance protective factors
- Meet immediate social problems in a planned manner
- Ensure adequate treatment and adherence
- Ensure follow up and increase frequency of contact
- Reassess risk during every visit

2. Plan of action for for high risk rating:

- Discuss with treating Psychiatrist immediately and follow suggested management plans.
- Inpatient treatment maybe required in the short term for safety - provide family with details and referral.
- Discuss with family and ensure safety; ensure continuous observation, assertive and frequent follow up and ongoing risk reassessment.

Appendix 4.13: Discharge Form:

Date: ____________________

Completed by: ____________________ Checked by: ______________________

1. Key needs identified at Baseline:

2. Summary of intervention delivered including challenges faced:

3. Progress Achieved:

4. Ongoing Unmet Needs:

a)	Suicide risk	♦ Yes ☐	♦ No ☐
b)	Social difficulties	♦ Yes ☐	♦ No ☐
c)	Non adherence	♦ Yes ☐	♦ No ☐
d)	Managing Symptoms	♦ Yes ☐	♦ No ☐
e)	Side effect	♦ Yes ☐	♦ No ☐
f)	Any other	♦ Yes ☐	♦ No ☐

If yes, please describe:

5. Plans for the future:

a) Overall Plan:

b) Relapse Management Plan:

c) Adherence Management Plan:

6. Key persons involved in Future Plan and their Roles:

Remarks:

NOTES

"I am an ex-student of the College of Arts & Crafts, Chennai. At the 3rd year I was given Applied Arts as my main subject. But I was interested in portrait painting. I was good in Applied Art also.

So after college, for about 3 years, I worked in advertising agencies. Then I quit the advertising agencies as I wanted to do paintings.

Then the sickness struck me.

Now about my paintings. My paintings are modern and very different from the way of realistic thinking."

V.K Sathyendran

Artist of the cover and inside paintings

The COPSI study was a collaborative project between a number of institutions in India and the UK.

The study was conducted by a consortium of NGO's in India : The Schizophrenia Research Foundation (SCARF) at Chennai, Sangath in Goa and Parivartan and Nirmittee at Satara.

Our institutional partners were the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore, India, the London School of Hygiene and Tropical Medicine and the Institute of Psychiatry, Kings' College, London.

Supported by wellcome trust